

Exploring the outcomes of engagement  
with arts-based learning for adults with  
learning disabilities: A participatory action  
research project

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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## Dedication

This thesis is dedicated in loving memory of Sam Waterman – a beautiful daughter, wonderful friend, and amazing researcher.

## Acknowledgements

I would like to start by thanking my fantastic supervisors Professor Karen Burland and Dr Freya Bailes. Their consistent guidance, support and reassurance throughout this process has been invaluable and I feel very fortunate to have had such kind, dedicated and inspiring supervisors.

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## Abstract

This research aims to explore the arts-based learning experiences of adults with learning disabilities. A range of environmental, social, and institutional barriers can reduce access to lifelong learning for this community. Inclusive approaches to learning, including arts-based activities, may reduce barriers to learning opportunities. However, the arts-based learning experiences of adults with learning disabilities are relatively unexplored. This project seeks to explore the creative learning experiences of adults with learning disabilities and in doing so, identify the outcomes of engaging with such learning in adulthood for this community.

The present research utilises a Participatory Action Research (PAR) approach. Seven adults with learning disabilities who attend Purple Patch Arts (a Yorkshire-based charity providing creative lifelong learning experiences for adults with learning disabilities/autistic people) were recruited and trained as co-researchers for this project. Now known as the Purple Research Group (PRG), co-researchers were actively involved in the design, implementation and dissemination of the research.

This thesis outlines three themed cycles of research, which were chosen in collaboration with the PRG: 'People', 'Arts and Variety', and 'Accessibility and Support'. Each theme employs a range of arts-based, co-produced and adapted research methods to explore the PRG's experiences of arts-based learning at Purple Patch Arts. Data were analysed utilising an adapted approach to thematic analysis. The findings demonstrate the wide-ranging outcomes of engagement with arts-based learning for adults with learning disabilities and the underlying mechanisms that support these outcomes. These include: the creation of a safe space, freedom within structure, supporting learners to reach their maximum effort, valuing participant voice and varied approaches to learning. The PRG's and the university researcher's reflections concerning their engagement in the project are also presented to demonstrate the outcomes of involvement in PAR for researchers with and without learning disabilities. Suggestions for future research in this field, alongside practical recommendations for participatory researchers, inclusive learning organisations and the research sector, are proposed.

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## Abbreviations

C1	Cycle one (People)
C2	Cycle two (Arts and Variety)
C3	Cycle three (Accessibility and Support)
CoP	Community/Communities of Practice
LLL	Lifelong Learning
HE	Higher Education
OS	Office Staff
PA	Programme Assistant
PAR	Participatory Action Research
PL	Programme Leader
PPA	Purple Patch Arts
PRG	Purple Research Group
PS	Programme Support
RQ	Research Question
UR	University Researcher

# 1 Introduction

## 1.1 Purpose of the research

Lifelong learning (LLL) is considered to be a key goal of education (Demiral, 2009). Despite this, adults with learning disabilities may face a multitude of barriers when attempting to access opportunities for learning in adulthood (Beart et al., 2001). Inclusive approaches to learning, which often utilise creative arts-based methods, may support adults with learning disabilities' engagement with learning opportunities. However, little is known about the experiences of adults with learning disabilities who engage with arts-based learning, and therefore the components and outcomes of these inclusive learning environments. Adults with learning disabilities are often excluded from doing research, and therefore research concerning this community may not accurately represent their interests and views (Nind, 2008).

The broad purpose of this project is to understand the outcomes of participation in inclusive creative learning experiences, within the context of the Purple Patch Arts Lifelong Learning Programme. By working collaboratively with participants who attend Purple Patch Arts, this project seeks to use a participatory action research (PAR) approach to understand the experiences of PPA participants. The process and participatory approach to research in the present study was therefore considered to be equally important as understanding the outcomes of arts-based learning for adults with learning disabilities.

## 1.2 Introduction to Purple Patch Arts

Purple Patch Arts (PPA) are a Yorkshire-based charity that aim to provide inclusive creative learning experiences for adults with learning disabilities, autistic people and adults with complex needs. Through their 'Purple Patch approach', which consists of a combination of creative arts-based methods including music, drama, visual arts, movement and sensory activities, PPA aim to improve the lives of participants by supporting them to access inclusive learning opportunities and experiences. This is largely achieved through the LLL programme, which was established in 2008 and takes place across 13 groups in Yorkshire. Each group, which consists of approximately 15 participants and three staff members (a programme leader, programme artist and programme support), meets once a week at a community venue from 10am-3pm. The LLL programmes address a new topic of learning each week, covering areas from personal development and life skills, to history, literature, science and the arts. These weekly sessions also feed into the overall theme for the year, which guides the learning content. For example, the theme for 2020/21 was 'Mystery'. Topics covered

within this year included 'mysteries of transport', 'the mysteries of communication' and 'mysterious fictional characters'.

Programme staff are provided with a 'scheme of work' for each term, detailing the information about the individual topic for the session and providing potential activities. However, each session is adapted by programme staff to meet the needs and preferences of their group. Therefore, no two PPA programmes are identical on any given week. However, all PPA sessions always begin with a warm-up, which consists of movement, signing and singing to a musical medley relating to the yearly theme. After the warm-up, the PPA day is split into three one-hour sessions, with regular breaks built into the day to allow for socialising and refreshments. The day ends with a cool-down (using the same principles as the warm-up) to bring the programme to a close.

PPA's approach to learning includes five learning/teaching styles which are incorporated into each session. These are: group activity (any activity considered to be collaborative); multi-sensory activity (activities which focus on sight, sound, touch, taste and smell), game-based learning (making a game of out of key learning points; Pho & Dinscore, 2015), physical experience (including movement, mirroring and somatic activities); and imaginative discovery (creative responses to a theme, question or stimulus). Learning at PPA is not intended to lead to a specific qualification and is therefore encouraged but not expected. However, participants set individualised goals, which are tracked throughout the year. Goals ranged from learning about a particular topic (e.g. "I want to learn more about penguins"), engaging with a particular activity (e.g. "I want to dance more") or developing a particular skill or attribute (e.g. "I want to feel more confident"). Progress towards goals is mapped throughout the year and participants are celebrated when they reached their desired goal.

Alongside the LLL programme, PPA deliver a range of additional projects which aim to support people with learning disabilities. They also have a keen interest in capturing the voices of participants through inclusive approaches to evaluation. This interest resulted in their recruitment as a partner in the present study. Throughout this thesis, PPA is used as a shorthand to refer to the PPA LLL programme.

### 1.3 A note on language

In inclusive research concerning and/or involving disabled people, language is particularly important to ensure that a) everyone is being represented in a way that they feel comfortable with and b) particularly in participatory projects, it is clear which roles were fulfilled by the various stakeholders included in the project.



Three key stakeholders were involved in this project: the university researcher (UR; the author of this thesis), PPA (the community partner in the project) and co-researchers (a group of adults with learning disabilities who all attend PPA and were recruited and trained as researchers specifically for this project). The terms UR and co-researchers were chosen to distinguish between these individuals for the purpose of reporting in this thesis. The label 'co-researchers' also recognises the role of these individuals as researchers and equal contributors in this project. While attempts have been made to avoid traditional hierarchical language such as 'principal investigator', it is possible that the term UR may also have hierarchical connotations. However, due to the requirements of the thesis, it was important to distinguish what the UR and co-researchers were responsible for. This is an example of when the nature of doctoral study directly contradicts with the goals of PAR. This and other examples of the tensions between doctoral research and PAR will be considered in chapter ten.

Language concerning the identities of co-researchers in particular must also be clarified. All co-researchers in this project identified as having a learning disability, therefore co-researchers are described as 'adults with learning disabilities', when this is relevant. Co-researchers were not asked to disclose any medical diagnoses, but nonetheless, many members of the group discussed their varied diagnoses with the UR. Several co-researchers identified as autistic. This is representative of participants across PPA programmes, of whom approximately 50% are autistic. Despite the range of diagnoses and identities reported by co-researchers, this thesis will largely draw on research concerning adults with learning disabilities, since it would be impossible to include literature spanning all of the potential diagnoses of PPA participants. Similarly, literature concerning some diagnoses/identities (e.g. autism) would not be relevant to all of the co-researchers involved in the project. It is important to note that using the label 'learning disabilities' is not intended to generalise the experiences of participants with additional diagnoses. The UR recognises that, for example, autistic people may not identify as having a learning disability and vice versa. To ensure that co-researchers were represented in a way that they felt comfortable with, the UR took their lead when making decisions around language. Since co-researchers used the term learning disabilities to describe themselves throughout the project, this term has been adopted throughout the thesis.

There has been some debate as to the best way to refer to disabled people. Some researchers have argued that person-first language (i.e. person with a learning disability), is most appropriate as it places the emphasis on the individual, rather than their diagnosis (Blaska, 1993). However, more recently there has been a move towards identity first

language when referring to adults with learning disabilities. Despite this, co-researchers used person-first language when referring to themselves and other adults with learning disabilities throughout the project. Therefore, in line with using language which was preferred by the co-researchers in the present study, this thesis refers to 'adults with learning disabilities' as opposed to 'learning-disabled adults'.

It is worth noting that some of the language included in this thesis (e.g. in references to previous literature) may be outdated and therefore considered to be offensive to adults with learning disabilities. In lieu of ignoring the existence of this literature and the important insights it provides regarding the misconceptions, ableism and discrimination experienced by adults with learning disabilities, this literature has been included when relevant. However, the UR does not condone the use of ableist language. Additionally, since some literature included in this thesis is from outside of the UK, the term 'intellectual disabilities' may be used in place of 'learning disabilities' (which is more commonly used in the UK). These terms are otherwise used interchangeably. Finally, in some parts of this thesis, co-researchers used the label of 'learning difficulties' synonymously with 'learning disabilities'. While co-researchers may identify as having learning difficulties, this term encompasses a range of different diagnoses, including dyslexia, dyspraxia and ADHD. A definition of learning disabilities is provided in section 2.1.1.

#### 1.4 Thesis structure and content

This thesis is structured around three themed cycles of research, which were identified by co-researchers as key aspects of their experiences at PPA, and therefore of inclusive creative learning. These cycles of research are reported in chapters four, five and six. All remaining chapters concern the project as a whole. The structure of this thesis is as follows:

Chapter two is a literature review, which begins by introducing definitions of learning disabilities and the Social Model of Disability. This is followed by an exploration of literature relating to learning in adulthood and LLL for adults with learning disabilities, which evaluates the opportunities and challenges of accessing learning opportunities for adults with learning disabilities. Inclusive, creative and social approaches, which may facilitate learning experiences for adults with learning disabilities are then explored. Finally, the literature review considers inclusive approaches to researching the experiences of adults with learning disabilities. Within this section, the opportunities and challenges of participatory action research (PAR) are considered. On the basis of this literature review, four key research problems are identified, and overarching aims for the project are outlined.

Chapter three introduces the methodological approach employed throughout the project. The application of the principles of PAR to the present study, in particular to the 'pre-planning' stage of the project, are outlined. Additionally, the process of setting up a PAR project, recruitment of co-researchers (the Purple Research Group; PRG), the development of accessible resources for this project and the process of selecting research themes are outlined.

Chapters four, five and six address the three cycles of research undertaken by the PRG. Chapter four (cycle one; C1) concerns the PRG's experiences of people at PPA, and the impact of social relationships on inclusive learning experiences. Chapter five (cycle two; C2) explores the PRG's experience of the arts and variety at PPA, including the role of arts-based activities within inclusive learning programmes. Chapter six (cycle three; C3) considers the role of accessibility and support at PPA, including aspects of access which may impact co-researchers' experiences of learning. Each chapter concludes with recommendations that emerged from each cycle. However, distinct conclusions from these cycles will not be discussed here, since conclusions are drawn from across all three cycles of research and presented in chapters eight and eleven.

Chapter seven discusses the process of ending a PAR project, including the ethical challenges associated with ending PAR and the approach taken within the present study to mitigate these challenges. This chapter draws on wider literature to contextualise the decisions that were made concerning the ending of this project.

Chapter eight outlines the five overarching outcomes of engagement with PPA, which were present across all three cycles of research. Additionally, this chapter discusses the five underlying mechanisms, which supported these outcomes for co-researchers.

Chapter nine considers the outcomes of engagement with PAR for co-researchers, including their experiences of being a researcher, development of skills as a result of their involvement in the research and development of researcher identities. This chapter concludes with a case study of Ella's personal research journey.

Chapter ten discusses the UR's reflections on PAR as a non-disabled researcher, including the various roles of a participatory researcher working with co-researchers with learning disabilities. These roles are used as lenses through which to examine the opportunities and challenges of PAR within the context of the present study.

Finally, chapter eleven offers conclusions relating to the three aims set out in chapter two. Conclusions relating to inclusive learning experiences for adults with learning disabilities and the PAR approach employed in this study are shared, limitations of the study are discussed and recommendations for future research are presented.

## 2 Literature Review

### 2.1 Introduction to learning disabilities

The following sections will provide a definition of learning disabilities. In keeping with the participatory approach of this project, the definitions provided are based on the writings and experiences of people with learning disabilities and the organisations that support them. While a medical definition may be useful in order to understand the characteristics of a particular diagnosis, the present study considers adults with learning disabilities to be the experts in relation to their own experience of these diagnoses, and therefore the best placed to define them. However, there is very little literature produced directly by people with learning disabilities concerning their experiences of learning disabilities. This may be due to the restrictive formats of academic literature, which largely require written publications, something which adults with learning disabilities may find challenging (Mencap, n.d). There are, however, a limited number of resources which have been produced in collaboration with adults with learning disabilities, which will be included in the definition below, alongside the writings of organisations who aim to support people with learning disabilities

#### 2.1.1 Learning disabilities

Approximately 1.5 million people in the UK have a learning disability (Mencap, n.d). This equates to 2.16% of adults in the UK. The definition of a learning disability produced by Mencap (n.d), a charity for people with learning disabilities, states:

A learning disability is a reduced intellectual ability and difficulty with everyday activities [...] which affects someone for their whole life. People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people

The experiences of individuals with a learning disability vary considerably. Mencap have collaborated with adults with learning disabilities to produce videos which explain their personal experience of having a learning disability. In their video titled 'What is a Learning Disability', one adult states, "Learning disability means that people will find it hard to be able to learn things first time and they need time [...] to understand things" (Mencap, 2019a). A second adult adds "learning disability is a lifelong condition [...] but it does not mean that we cannot work just as well as anybody else" (Mencap, 2019a).

Despite this, Adults with learning disabilities may face a number of societal challenges. People with learning disabilities often face social stigma and may feel socially excluded (Scior & Werner, 2015). Additionally, adults with learning disabilities may have lower self-esteem and self-efficacy beliefs than other adults (Harrison, 2003). Common

barriers, such as finances, communication and support may prevent people with learning disabilities from accessing activities and opportunities that are commonly associated with the development of friendships and improved quality of life (Wilson et al., 2017). Indeed, research suggests that over half of disabled people report feeling lonely, rising to 77% for adults age 18-34 (Sense, 2017). People with learning disabilities may therefore need support to access everyday activities and experiences, which positively impact their lives.

### 2.1.2 Social Model of Disability

It is important to note that definitions and perceptions of disability in this project are influenced by the model of disability adopted within the research. The present study aligns with the Social Model of Disability, which was developed as an alternative to the Medical Model of Disability in the late 1970s and 80s (Oliver & Sapey, 1983). The Medical Model of Disability proposes that disability is as a result of an individual's 'deficits', which must be addressed so that the individual can function 'normally' in society (Marks, 1997). In contrast, the Social Model of Disability proposes that disability is a social construct, caused by society's failure to reduce the barriers faced by individuals with an impairment (Oliver & Sapey, 1983). The Medical Model of Disability therefore places the responsibility for inclusion on the disabled person, whereas the Social Model of Disability proposes that is society's responsibility to reduce the barriers faced by disabled people.

A common example which illustrates the difference between these key models of disability is that of a wheelchair user encountering a flight of stairs while trying to access a building. The Medical Model of Disability proposes that it is in the individual's impairment which means they are not able to access the building by using the stairs. In contrast, the Social Model of Disability places the responsibility on society to provide accessible methods of accessing the building (e.g. by providing a ramp).

Physical/environmental barriers (such as inaccessible places, spaces and transport) are perhaps one of the most obvious barriers to disabled people's inclusion in wider society. Additional barriers include attitudinal barriers, such as discrimination and bias (Nario-Redmond et al., 2019), economic and cultural barriers (Oliver, 2004), barriers to communication (Chew et al., 2009) and organisational barriers (e.g. disabling policies and practices; Ahmad, 2012). Perhaps most relevant to the present study are the barriers faced by disabled people when accessing learning opportunities, particularly in adulthood. The following section will provide an overview the key barriers to learning faced by adults with learning disabilities.

### 2.1.3 Barriers to learning

Access to education is considered to be a right of disabled people (United Nations, 2016).

While most adults have access to some form of learning opportunity, this is not always the case for adults with learning disabilities (Nind, 2007). A range of barriers may prevent adults with learning disabilities from accessing learning experiences (see table 1).

*Table 1: Barriers to learning faced by adults with learning disabilities*

Types of barrier to learning	Impact of this barrier on people with learning disabilities
Physical/environmental barriers	A lack of physical access or accessible transport may prevent adults with learning disabilities' engagement with learning (Copestake et al., 2014). The Department of Health and Social Care (2001) notes that access to transport may support adults with learning disabilities to access a wider range of leisure opportunities and opportunities for education and LLL (p. 78).
Financial barriers	Financial barriers may restrict co-researchers' access to learning opportunities due to the cost of engagement with learning programmes, transport and support (Copestake et al., 2014)
Organisational/institutional barriers	Inflexible approaches to learning within organisations and learning institutions may reduce opportunities for learning for adults with learning disabilities (Ahmad, 2012; Mittler, 2012). For example, inflexible learning organisations may deliver learning via formats, styles and resources that are inaccessible to people with learning disabilities. Additionally, inflexible timings for learning may also become a barrier, and people with learning disabilities may need additional time to access learning opportunities (Ahmad, 2012).
Attitudinal barriers	Attitudinal barriers may reduce opportunities for learning for adults with learning disabilities. People with learning disabilities may have their capabilities underestimated and may therefore not receive adequate support or encouragement to access learning (Ahmad, 2012). Learners with learning disabilities may also feel discouraged or underestimate their own capabilities through self-stigma (Ali et al., 2012)
Lack of support	Adults with learning disabilities may require support to access learning opportunities. A lack of support available for adults with learning disabilities may therefore hinder adults with learning disabilities' engagement with learning (Jordan et al., 2022)
Communication	Adults with learning disabilities may find it challenging to communicate their needs and preferences to others (Chew et al., 2009), particularly if those supporting them are unaware of how they can adapt their communication to support the learner (Mencap, n.d). Therefore, communication may be a barrier to engaging with learning experiences and asking for support when needed.
Exclusion from adult learning environments	Adults with learning disabilities may have limited opportunities for learning due to challenges in accessing and participating in environments where learning in adulthood usually takes place, such as higher education institutions and employment (Björnsdóttir & Traustadóttir, 2010). For example, the workplace is acknowledged as a place where learning opportunities are commonly accessed (e.g. through professional development and training; Demirel, 2009). However, only 4.8% of adults with learning disabilities in England are in paid employment (NHS Digital, 2022). Therefore, a lack of access to learning environments may exclude adults with learning disabilities from learning opportunities.

Past negative experiences	Previous negative experiences with inaccessible educational environments may result in anxiety around learning, poor self-esteem and self-stigma, thus becoming a barrier to learning in adulthood (Ali et al., 2015).
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The importance of learning in adulthood has been emphasised in previous research, which identifies a range of benefits, including: fostering a sense of identity (Hammond, 2004), positive impact on wellbeing and sense of self (Manninen et al., 2014), and increased social connections (Schuller, 2017). With over 1.5 million people diagnosed with a learning disability in the UK (Mencap, n.d) it is vital for these individuals to have access to inclusive opportunities for learning. Inclusive learning attempts to remove barriers faced by adults with learning disabilities when accessing education. The following sections will discuss literature investigating inclusive learning and the educational approaches which seek to remove barriers to learning for adults with learning disabilities.

## 2.2 Inclusive approaches to learning

In line with the Social Model of Disability, inclusive learning proposes that it is society's responsibility to ensure that learning is accessible and inclusive. Responsibility for inclusive learning therefore lies with educators, facilitators and the education system as a whole (Tomlinson, 1997). However, there are multiple understandings of what is meant by the term 'inclusive learning', and therefore what constitutes inclusive learning (Nind, 2014a). Variations in the ways in which these terms are considered are impacted by a range of factors, including: geographical location and cultural differences concerning the ways in which disability and inclusion are conceived (Ainscow & César, 2006; Rodríguez Herrero et al., 2020), the site of learning (e.g. within a classroom), and the specific communities that learning aims to include (e.g. a focus on inclusive learning for all marginalised communities and/or specific communities such as disabled people; Mittler, 2012). The present study aligns with disability oriented inclusive learning, which aims to promote the active participation of disabled learners through "socially just" approaches to education and the removal of barriers experienced by disabled people (Nind, 2014b, p.525). Disability oriented inclusive learning is therefore not only about making adaptations to pre-existing environments to support diverse learners, but is also concerned with transforming the approaches, perceptions, values and ethics that underpin learning.

### 2.2.1 Learning in childhood versus adulthood

Previous literature concerning inclusive learning opportunities for people with learning disabilities has commonly focused on formal education settings, such as inclusive learning



within schools, and therefore mainly concerns children (Mittler, 2012; McLeskey & Waldron, 2011; Nind, 2014b; Slee, 2011). This literature provides an indication of the components and key considerations of inclusive learning environments, including the importance of the approach of the teacher/facilitator (McLeskey & Waldron, 2011) the size of the group (with smaller group sizes best suited to more inclusive learning environments: Iverson et al., 2005) and issues of exclusion (Slee, 2019). However, there is very little comparable research concerning adults with learning disabilities.

It is commonly recognised that adults and children approach learning differently (Collins, 2004). 'Andragogy' or 'Adult Learning Theory' was proposed by Knowles (1984) as an alternative to pedagogy. Andragogy suggests that adult learners have distinct characteristics from child learners in relation to their motivations, experiences and learning preferences. In particular, Knowles (1984) suggests that adult learners are self-directed, draw on their previous lived experiences, and are motivated to learn by practical and applicable learning experiences. Adult learners may therefore be more interested in understanding why something is being learned than children (Collins, 2004). Additionally, Knowles (1984) suggests that involving adult learners in the design of learning experiences is a key principle of andragogy.

Rodríguez Herrero et al. (2020) note, "the concept of inclusion does not only apply to compulsory education" (p.377). Given the differences between learning in adulthood versus childhood, previous literature exploring inclusive learning environments may not accurately represent the experiences and needs of adults with learning disabilities. Research regarding the inclusive learning experiences of adult learners is therefore crucial in order to fully understand their experiences, and the outcomes of learning for this community. The smaller number of studies exploring inclusive learning environments for adults may be due to limited learning opportunities available to this population, as a consequence of the barriers to learning discussed in section 2.1.3 and the focus on learning in childhood discussed above. Nonetheless, a small number of studies have investigated the development of learning opportunities for adults with learning disabilities. These are mainly concerned with developing a specific (often practical) skillset with learners, such as the improvement of travel skills to support engagement with leisure activities and employment (Brown et al., 2011) and to reduce anxiety relating to nurses (Nash-patel., 2022).

Previous research has also investigated opportunities for inclusive learning programmes within Higher Education (HE). Björnsdóttir (2017) reflected on the process of establishing a two-year part-time programme at the University of Iceland, which aimed to develop employability skills for people with learning disabilities interested in working in

schools or in roles relating to self-advocacy. An inclusive environment was facilitated through a flexible, collaborative and adaptable approach to learning, which involved learners, academics and faculty staff. Additionally, a more recent account by Rodríguez Herrero et al. (2020) outlines the *Promotor Programme* at Universidad Autónoma de Madrid; a two-year programme which aims to support the personal development and employability skills of adults with learning disabilities. Focus groups with four first-year students revealed that engagement with the *Promotor Programme* supported their professional development, increased self-esteem and social inclusion (Rodríguez Herrero et al., 2020). Courses within HE settings are traditionally inaccessible to adults with learning disabilities due to the required qualifications to attend. These programmes therefore demonstrate the potential for inaccessible environments and experiences to be adapted so that they are accessible to adults with learning disabilities. However, inclusive learning in HE environments often focuses on employability skills. While employment may be a key goal of learning for some adults with learning disabilities, employment may not be a goal and/or a possibility for some adults with learning disabilities. Further research concerning the impact of learning programmes which focus on the development of a broad skillset/knowledge across a range of areas would therefore be beneficial.

Moreover, inclusive learning experiences for adults with learning disabilities are often short-term opportunities (Björnsdóttir, 2016; Brown et al., 2011; Nash-patel., 2022; Rodríguez Herrero et al., 2020). The temporary nature of courses which aim to develop employability skills may be appropriate, since the long-term goal of these learning opportunities is to support learners to access employment. However, it is important to consider how the longevity of inclusive learning opportunities may impact the experiences of learners. Decisions concerning the length of learning programmes are often imposed by organisations or HE institutions and little is known about the experiences of adults with learning disabilities who are forced to cease their engagement with learning due to time-restricted opportunities. The long-term inclusive learning experiences of adults with learning disabilities, and the long-term outcomes of inclusive learning in adulthood, therefore remain relatively unexplored.

In contrast to time-restricted opportunities for learning, LLL aims to support individuals to “continue to develop their knowledge, skills, and attitudes throughout their lifetime” (Lifelong Learning Project, 1978, p.1). The premise behind LLL is that learning is not only restricted to childhood and/or to formal educational settings, but rather takes place across an individual’s life through a variety of formal, vocational and social learning opportunities (Billett, 2010; Field & Leicester, 2003). Previous research has identified a range of positive outcomes of LLL, including improved self-esteem, self-efficacy and sense of

purpose (Hammond, 2004), an increase in social connections and community engagement (Laal & Salamati, 2012) and overall improved quality of life (Preston & Hammond, 2003; Hammond, 2004). LLL may therefore be particularly beneficial for adults with learning disabilities to support their personal development and inclusion in the local community. The role of LLL in the lives of adults with learning disabilities specifically will now be discussed.

### 2.2.2 Lifelong learning for adults with learning disabilities

Despite the fact that LLL is included in Article 24 of the Convention on the Rights of Persons with Disabilities (United Nations, 2016), the challenges faced by individuals with learning disabilities mean that they may not be able to access the same learning opportunities as other adults. To ensure that adults with learning disabilities have the opportunity for LLL, and the positive outcomes associated with this, programmes which are specifically designed to provide learning opportunities for adults with learning disabilities may be particularly beneficial, and in some cases, may be one of the few learning opportunities accessible to these individuals.

With these challenges in mind, it is important to consider the elements of successful LLL for people with learning disabilities. In her paper concerning LLL for people with profound and multiple learning difficulties, Nind (2007) suggests that the principles of LLL for these individuals may not be so different to those of LLL for any other individual. The principles of effective LLL, as outlined by Collins et al. (2010) are: start with the learner (e.g. through learner-led teaching), foster good communication, develop motivation for learning, support emotional engagement with learning and develop good working relationships. While many of these principles overlap with Knowles' (1984) Adult Learning Theory, a key distinction between the principles of Andragogy and LLL for adults with learning disabilities appears to be the emphasis on LLL as a social endeavour, which requires the development of trusting relationships between the facilitator and the learner (Collins et al., 2010). It may therefore be particularly important to consider the impact of the learning community on the inclusive learning experiences of adults with learning disabilities.

Additionally, the methods and mediums used in learning activities for adults with learning disabilities may require some adaptation. Traditional methods of teaching usually require the learner to have skills in reading and writing (Harrison, 2003). However, as adults with learning disabilities may find these skills challenging (Abedin, 2010), inclusive LLL learning for people with learning disabilities may require a variety of educational approaches and the use of alternative mediums, such as creative and arts-based approaches to support diverse learners. The following sections will introduce inclusive approaches to learning, with a

particular focus on social and creative approaches to learning, such as Communities of Practice, Active Learning and Arts-based learning.

### 2.2.3 Communities of Practice

The concept of Communities of Practice (CoP) was first developed by Lave and Wenger (1999) to describe context-specific, interactive and socially co-constructed learning. Wenger-Trayner and Wenger-Trayner define CoP as “groups of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly” (2015, p.2). This approach to creating and sharing knowledge has been applied to a range of contexts, but perhaps most commonly to learning within organisations and corporate settings (Roberts, 2006; Wenger et al., 2002). While CoP develop naturally and therefore cannot be specifically ‘created’, they may be cultivated through the design of environments where collaborative approaches to learning can thrive (Wenger et al., 2002). CoP are commonly recognised to consist of three key elements: Domain, Community and Practice.

- (1) Domain** - Refers to a shared area of interest, which guides community members’ learning and skill development. Membership to a CoP therefore implies a “commitment to the domain, and therefore a shared competence” (Wenger-Trayner & Wenger-Trayner, 2015, p.1) relating to a specific topic, area, problem or identity.
- (2) Community** – Individuals self-identify as members of the community based on their interest in the domain, described above (Wenger et al., 2002). Members of the community collaborate, encourage and support each other, co-produce and share learning, experiences and ideas. Relationships developed within CoP, which support peer learning opportunities, foster a sense of belonging to the CoP through regular interactions with each other (Wenger, 2011).
- (3) Practice** – Refers to the practical and applied nature of learning within CoP. Communities develop shared resources, tools, methods, experiences and stories within the domain, which contribute to the co-creation of sustained knowledge (Wenger, 1999). Members of a CoP may therefore be considered as practitioners (Wenger, 2011).

Since much of the literature concerning CoP is concerned with organisational and corporate environments (Roberts, 2006; Wenger et al., 2002), where adults with learning disabilities are commonly excluded, there is limited research concerning CoP involving adults with learning

disabilities. Additionally, previous research which has investigated CoP within inclusive education has recruited staff members, teachers and/or parents, as opposed to directly involving learners with learning disabilities (Cress, 2008, Mortier, 2020). There is therefore limited research which captures the voices of CoP involving adults with learning disabilities.

Features of CoP outlined above overlap with the principles of inclusive learning. For instance, CoP may reduce barriers to learning by providing a culture of support, developing relationships and the varied approaches to practice within the domain. However, it is important to consider how CoP may be experienced by communities who may have previously been labelled by society as incompetent in relation to learning. In particular, adults with learning disabilities may have previously been excluded from CoP due to socially defined competence. Further research is needed to explore the potential for CoP to facilitate inclusive learning experiences for adults with learning disabilities.

#### 2.2.4 Active learning approaches

Active learning is an educational approach which proposes that individuals learn better when they are actively involved in co-creating knowledge and the learning experience, as opposed to passive approaches to learning (Petress, 2008). Learners are therefore encouraged to actively participate in meaningful activities, including group discussions, problem-solving and hands-on/interactive activities (e.g. experiments, role playing and experiential activities). Collaboration with other learners also contributes to a more enhanced, social learning experience (Prince, 2004). Previous research suggests that active learning may be more likely to promote LLL, and support engagement with learning content (Stefanou et al., 2012). Active learning is often considered in relation to learning in the classroom/lecture theatre (Prince, 2013). However, the principles of active learning also apply to learning in adulthood. As Collins (2004) notes in relation to Adult Learning Theory, “the learner should be actively involved in learning” (p.1483). Figure 1 outlines active learning techniques arranged according to their complexity and required time-commitment.

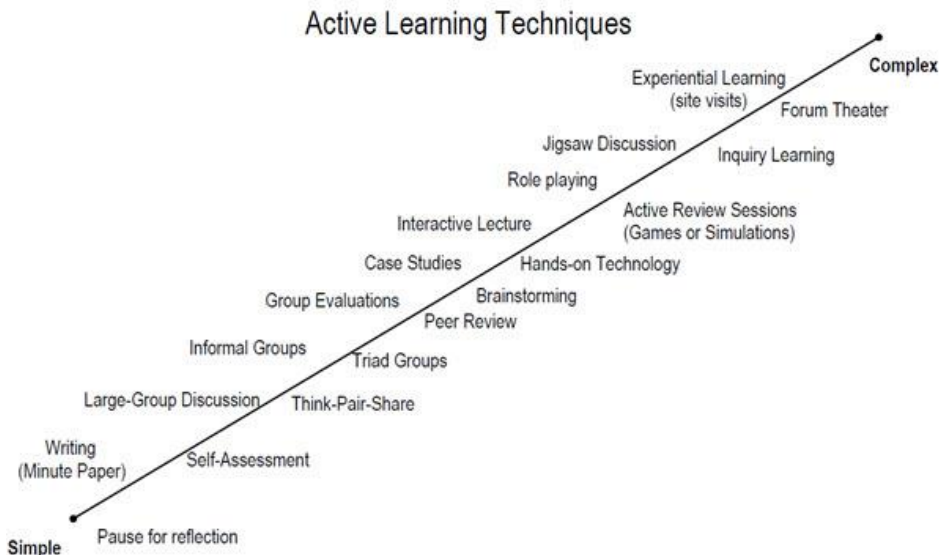


Figure 1: Active Learning Techniques (O'Neal & Pinder-Grover, 2016)

There is limited literature concerning the impact of active learning techniques on the learning experiences of adults with learning disabilities. However, 'complex' active learning techniques (see figure 1) may be considered as more inclusive and accessible to adults with learning disabilities, since they integrate multiple, flexible approaches to learning and do not rely on skills such as writing and verbal communication, which adults with learning disabilities may find challenging (Abedin, 2010). This is not to say that 'simple' techniques do not have a place in inclusive learning environments. However, these learning techniques may require adaptation in order to reduce barriers relating to inflexible learning formats and styles (for example by utilising arts-based approaches, as discussed in section 2.2.5.1, or by using multiple methods of communication). In particular, research concerning experiential learning, role-playing and game-based learning suggests that these active learning techniques may reduce barriers to learning for adults with learning disabilities. Table 2 briefly introduces each of these learning techniques in turn and considers their application with learners with learning disabilities.

Table 2: Complex Active Learning techniques and their application with adults with learning disabilities

Active learning technique	Description of technique	Application with adults with learning disabilities
Experiential Learning	Experiential learning theory suggests that the best way to learn is through direct experience (Kolb, 1984). Kolb's (1984) cycle of experiential learning proposes four stages to learning: (1) "concrete experience", through engagement with real-world experiences; (2) "reflective observation", whereby the learner reflects on these experiences; (3) "abstract conceptualization", whereby learners form new ideas based on these experiences and reflections and (4) "active experimentation".	Experiential learning may provide opportunities for people with learning disabilities to learn to navigate the challenges of practical life skills and social interactions, through applied experiences and reflection on these scenarios. Brown et al. (2011) developed an experience-based learning programme for adults with learning disabilities designed to support the development of travel skills. This learning programme utilised game-based learning to support participants to learn new travel routes, and therefore increase access to activities and opportunities for LLL. Similarly, replicating real-world environments through virtual experiential learning has been used to support the development of practical skills (e.g. grocery shopping and road safety) with adults with learning disabilities (De Oliveira Malaquias & Malaquis 2016; Standen & Brown, 2005; Standen et al., 2001)
Role playing	Role playing is an active learning technique which allows learners to simulate real-world scenarios and social interactions (Abdoola et al., 2017). Learners may take on a specific role or act out a particular situation within in a safe environment (McGahee et al., 2021). Role playing may therefore support the development of communication skills, understanding of real-world scenarios and of others' point of view (Chan, 2012).	Role playing may provide opportunities for adults with learning disabilities to practice skills and experiences within a safe environment. McGahee et al. (2021) developed role-playing activities designed to provide opportunities for students to discuss their accommodation options, resulting in the development of self-advocacy skills. Additionally, Lancia (2021) suggests that role-playing exercises may support the development of social skills in adults who find social situations challenging.

Game-based learning	Game-based learning (also referred to as gamification or 'serious games') is an active learning technique which refers to the incorporation of game mechanics into learning activities, to enhance engagement with learning content (Pho & Dinscore, 2015). Examples of game-based learning activities include quizzes (Down, 2008), digital games (Stančin et al., 2020) and role playing (Corti, 2006).	Game-based learning may support adults with learning disabilities' engagement with and motivation for learning (Standen et al., 2005), alongside improving retention of information/ the development of skills (Brown et al., 2013). Learning is supported via immediate feedback to learners, which may be used to check understanding of content (Boyle et al., 2016). Game-based learning may also be considered to be a flexible and inclusive approach since games can be repeated multiple times (Corti, 2006) and can be experienced at the learner's own pace (Boyle et al., 2016).
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#### 2.2.4.1 Thematic learning

The active learning techniques discussed above are often considered within the context of traditional learning environments (such as school or HE settings) and therefore often relate to the learning of individual subjects. However, this fails to recognise approaches to learning which are not subject-specific, and which instead combine multiple disciplines and activities through 'theme-based/thematic learning'. Thematic learning focuses on exploring themes or topics (e.g. ocean life) as opposed to learning based on a singular subject (e.g. Science or English). This approach to learning therefore supports learners to make connections between different types of knowledge by drawing on multiple disciplines and varied activities, which support learners' collaboration, communication and creativity skills (Ye & Xu, 2023).

Thematic learning may facilitate inclusive learning by supporting engagement with complex topics, by using a range of hands-on activities and subjects to support learners to explore a theme in different ways and from different perspectives (Broadhead, 2001). In particular, sensory and arts-based activities combined with thematic learning may provide a range of accessible and creative approaches to learning, which supports diverse learners to engage with a range of topics (Corradi et al., 2022). Arts-based learning will now be introduced followed by a discussion about the arts-based learning experiences of adults with learning disabilities.



### 2.2.5 Creative experiences of adults with Learning Disabilities

Previous research exploring the impact of the arts in the lives of people with learning disabilities has done so largely through the lens of arts-based interventions, which aim to address the symptoms and challenges experienced by individuals with these diagnoses. Common arts-based therapies employed with people with learning disabilities include music therapy (Pavlicevic et al., 2014; Warner, 2005), drama therapy (Jennings et al., 2005) and art therapy (Freilich & Shechtman, 2010; Hackett et al., 2017). Studies such as these suggest that therapeutic engagement with the arts can have positive outcomes for participants, particularly in areas that many individuals with learning disabilities may find challenging, such as communication, social interaction and the development of social relationships (Freilich & Shechtman, 2010), and developing confidence and self-esteem (Pavlicevic et al., 2014). These studies position the arts in the lives of adults with learning disabilities as a medium through which the 'deficits' of disabled people may be addressed. However, in line with the Social Model of Disability, the arts may also be used to adapt pre-existing opportunities for self-development and personal growth (such as LLL opportunities) so that they are accessible to adults with learning disabilities.

Despite utilising many of the art forms listed above, and often having similar goals to that of arts-based therapies, creative arts programmes have received significantly less research attention. Whilst arts-based therapies may be considered to focus on the process of engagement with the arts, creative arts programmes tend to be concerned with the outcomes produced by participants (Hall, 2012). Hall (2012) states that this focus on the outcomes of participation can be especially valuable for people with learning disabilities, who may not ordinarily be valued for the things they produce/create.

Clover (2000) suggests that community-based arts programmes could be considered to be 'therapeutic' due to the positive outcomes associated with participation. Previous research suggests that participation in creative arts organisations can provide opportunities for emotional expression, connection with others and a sense of belonging (Hall, 2012). Similarly, when discussing the outcomes of a community-based arts programme, Richards et al. (2019) state that participants with learning disabilities used the arts to express thoughts and feelings as well as to respond to the world round them. Finally, in a report for Arts Council England, Jermyn (2004) reports that socially excluded individuals participating in arts organisations may benefit from increased self-esteem and confidence, improved mental and physical wellbeing, a greater sense of control and ownership, and skills development, including creative and arts-based skills as well as skills for employment. These studies demonstrate the potential for arts organisations to provide participants with opportunities

for inclusive learning and personal development. Creative arts education programmes may therefore be especially important for adults with learning disabilities who may struggle to access other opportunities for inclusive learning in adulthood (Beart et al., 2001). The opportunity for the arts to support inclusive learning will now be discussed.

#### 2.2.5.1 Arts-based learning

Kerka (2002) states “art may be the means or a goal in itself” (p.3). In other words, learning may take place in the arts, (i.e., the development of skills relating to a specific art-form), or through the arts, whereby the arts act as a medium through which learning, new experiences and the development of skills across a wide range of topics may take place. Additionally, creative and arts-based activities may support the development of core creativity skills, such as “open-mindedness, imagination, problem-solving and curiosity” (Education Scotland, 2013, p.5). The development of specific skills in arts-based subjects can be beneficial for adults with learning disabilities and is indeed a key aim for many organisations in the UK. However, the present study focuses primarily on the opportunity for the arts to mediate learning in a variety of areas and to support the overall personal development of adults with learning disabilities.

Adult educators have utilised a range of artistic mediums, including music, drama, dance, poetry, theatre, photography and visual arts, as a useful medium for learning due to their adaptable and accessible nature (Clover, 2000; Rose, 1997). In particular, creative arts activities may provide people with learning disabilities with flexible ways to learn that do not rely on traditionally ‘academic’ skills such as reading and writing, thus playing to the strengths of the learner. Arts-based learning may therefore support varied learning outcomes (Abedin, 2010), such as: enhanced social experiences and improved interactions with others (Ho, 2010; Jindal-Snape & Vettraino, 2007), opportunities for expression and critical reflection (Brigham, 2011) and improved motivation for learning (Abedin, 2010). Previous research suggests that the arts may facilitate more interactive learning environments, which encourage learners to develop their analytical and interpretive skills (Chadwick & Stannett, 2000). Additionally, arts-based learning often results in the production of something (i.e., the artistic creations of learners). This can be shared with others, thus providing a platform for socially excluded individuals to “articulate their world view” and share their experiences and knowledge with others (Rose, 1997, p.3). For this reason, arts education programmes have also been used as a form of self-advocacy, whereby participants challenge common assumptions associated with learning disabilities through the arts, thus becoming educators in their own right (Hall, 2012; Richards et al., 2019).

There are, however, several limitations to previous research exploring these creative learning experiences. Firstly, like literature concerning inclusive learning, the majority of research exploring the outcomes of arts education has involved children and young people (Abedin, 2010; Burton et al., 2000; Mason et al., 2004; Sahasrabudhe, 2006) and therefore tends to focus on arts-based learning in formal environments, such as the classroom (Burton et al., 2000; Hutchens & Pankratz, 2000; Sahasrabudhe, 2006). The arts-based experiences of adult learners, in particular adults with learning disabilities, have received significantly less research attention. Further research which captures the experiences of adults with learning disabilities who attend creative arts education programmes is therefore required to ensure that programmes are meeting the needs of the individuals who attend them.

Additionally, the majority of research exploring the outcomes of participation in the arts appears to be almost exclusively positive. Despite this, disabled adults have been found to be less involved with the arts (DCMS, 2018) and may face numerous barriers to participation in arts-based learning programmes, including transport, cost and physical and emotional accessibility (Gratton, 2019; Mencap, n.d). Evaluations of arts-based learning programmes, which actively involve adults with learning disabilities have been recommended as a way to address these challenges and gain meaningful feedback, which captures both positive experiences and outcomes, as well as areas for improvement (Gratton, 2019).

However, research exploring the outcomes of arts-based learning for people with learning disabilities is rarely led by or informed by people with learning disabilities (Abedin, 2010; Sjöqvist et al, 2021). Research investigating the impact of creative and inclusive learning experiences may therefore not be in the best interests of this population, since it is ordinarily designed, owned and implemented by non-disabled researchers, with limited experience of the challenges faced by adults with learning disabilities. Inclusive research exploring the impact of arts-based learning experiences for adults with learning disabilities may therefore help to ensure that research is a) asking questions which are important to and for the benefit of people with learning disabilities, b) accurately capturing the views and learning experiences of these individuals, and c) providing further insight into the outcomes of these learning experiences in the lives of adults with learning disabilities and the mechanisms which support effective inclusive LLL.

The following section introduces inclusive approaches to research, including Participatory Action Research (the chosen approach for the present study), which advocate for the direct inclusion of people with learning disabilities in all stages of research.

### 2.3 Inclusive approaches to research and evaluation

Inclusive research is an overarching term which encompasses “a range of research approaches that traditionally have been termed ‘participatory’, ‘action’ or ‘emancipatory’” (Johnson & Walmsley, 2003, p.10). Typically, the term ‘inclusive research’ is associated with learning disability research (Nind, 2014a), however, it may also be used with any individual or community who “may otherwise be seen as subjects” of research (Johnson & Walmsley, 2003, p.10). The main aim of inclusive research approaches is to re-distribute the balance of power, so that rather than being considered as subjects *on* which to conduct research, people with learning disabilities are actively involved in all aspects of the research process (Walmsley, 2004). Johnson and Walmsley (2003, p.64) provide a useful account of the core values of inclusive research approaches in relation to research with people with learning disabilities:

- The research problem must be one that is owned (not necessarily initiated) by disabled people
- It should further the interest of disabled people; non-disabled people should be on the side of people with learning disabilities
- It should be collaborative – people with learning disabilities should be involved in the process of doing the research
- People with learning disabilities should be able to exert some control over process and outcomes
- The research question, process and reports must be accessible to people with learning disabilities

Nind (2014a) expands these criteria further by suggesting that research approaches that are encompassed by the label of inclusive research “reflect a particular turn towards the democratization of the research process” (p.1). Indeed, Smith et al. (2022) suggest that inclusive approaches to research are based on key principles of shared power, respect, flexibility, trust, relationships and mutual respect.

Inclusive research emerged in the late 20<sup>th</sup> century and has been closely linked to the Social Model of Disability. Inclusive research follows similar principles to the Social Model of Disability, by arguing that research should be conducted in collaboration with disabled people, to ensure that their views and experiences are considered when shaping society. A key goal of inclusive research is therefore to facilitate an inclusive and adaptable research process, which addresses the needs of disabled people (Walmsley, 2004).

Inclusive research has been described and implemented in various ways since its emergence. The language used to describe inclusive research approaches in particular, is often used interchangeably. For example, the terms ‘participatory’, ‘participatory action’, and ‘emancipatory’ are often confused and used in place of one another (Aldridge, 2016). This can result in difficulties defining and differentiating inclusive research approaches, particularly for researchers who hope to conduct inclusive research. While inclusive approaches have key elements in common (see Johnson & Walmsley, 2003) each approach differs slightly in its application, including the level of inclusion, who ‘owns’ the research and the research design itself. Figure two demonstrates the differences between three inclusive research approaches identified by Swartz and Nyamnjoh (2018, p.4). Participatory and emancipatory research are commonly used in research with people with learning disabilities but have some key differences. The central aim of Participatory Research (PR) is to promote inclusion and capture the ‘voices’ and experiences of participants (Aldridge, 2016). This is achieved through a collaborative ‘alliance’ between the participant (e.g. people with learning disabilities) and the researcher (Chappell, 2000). Participants are often recruited as co-researchers and work together with the researcher to address a research problem which affects disabled people (Cocks & Cockram, 1995).

On the other hand, emancipatory research puts disabled people firmly in control of “the process and the resources” as researchers in their own right (Johnson & Walmsley, 2003, p.63). Disabled scholars have argued that research concerning disabled people should be initiated and under the control of disabled people, to ensure that it is truly in their best interests (Oliver, 1992). Researchers utilising an emancipatory approach must therefore relinquish control of the research and ensure the research process and design is under the complete control of disabled people (Swartz & Nyamnjoh, 2018). For this reason, emancipatory research has been closely linked to the Social Model of Disability and the disabled people’s movement (Johnson & Walmsley, 2003).

The language used to describe the roles of the individuals involved in inclusive research approaches also differs considerably. For example, individuals recruited as collaborators have been referred to in research as ‘participants’ (Wang & Pies, 2004), ‘experts’ (Knox et al., 2000) and ‘co-researchers’ (McFerren & Hunt, 2008). The language used to describe particular roles in the research is important, as it plays a role in telling the reader how much control an individual has (Walmsley, 2004). As academic language is inherently hierarchical (e.g. the ‘researcher’ has more power than the ‘participant’) it is important to pay attention to the titles we allocate to individuals in research and to ensure that these accurately represent their role in the research.

Variable	Interactive	Participatory	Emancipatory
Knowledge	A commitment to <i>applied</i> knowledge and the <i>co-construction</i> of knowledge		
Learning	A commitment to <i>mutual and sustainable learning</i> , self-reflection and the <i>empowerment</i> of research participants		
Inclusion and power	<i>Slight</i> inclusion; <i>shared power on researcher's terms</i>	<i>Modest</i> inclusion; <i>shared power</i>	<i>Complete</i> inclusion (or partnership on participants' terms); researcher <i>relinquishes power</i>
Research agenda	Research agenda is <i>predetermined</i>	Research agenda is developed through <i>consultation</i>	Participants <i>choose</i> research <i>agenda</i> , enlist services of researcher
Research design	Research is <i>already designed</i> when research commences	<i>Joint</i> planning of design	Design is <i>initiated</i> by participants
Dissemination	Dissemination is decided <i>by researcher</i>	Dissemination is a <i>shared</i> responsibility	<i>Participants decide</i> what is done with the research findings.
Authorship	<i>Retained</i> authorship	<i>Joint</i> authorship	<i>Relinquished</i> authorship
Ownership	Research is <i>mine</i>	Research is <i>ours</i>	Research is <i>theirs</i>

Figure 2. "Comparing and contrasting interactive, participatory and emancipatory approaches" (Swartz & Nyamnjoh, 2018, p.4)

### 2.3.1 Levels of participation

Alongside variations in language, perceptions of what constitutes 'inclusive research' differ widely and are frequently disputed amongst researchers (Nind, 2014a). This has resulted in a variety of approaches to the implementation of inclusive research, including variation in the level and type of collaboration with marginalised communities. One of the earliest models of citizen participation is Arnstein's ladder of participation (1969; see figure 3). This model proposes eight approaches to citizen participation in social programmes, with each approach (or the extent of participation) represented by a step on a ladder (from the lowest level of participation at the bottom of the ladder, to the highest at the top). Arnstein (1969) argues that an awareness of these levels of participation allows for a greater understanding of the demand for citizen participation in social programmes. However, some have argued that the model does not provide sufficient information about these approaches in practice (Collins & Ison, 2006). Additionally, the model does not specify any particular population with which these approaches have/can be used.

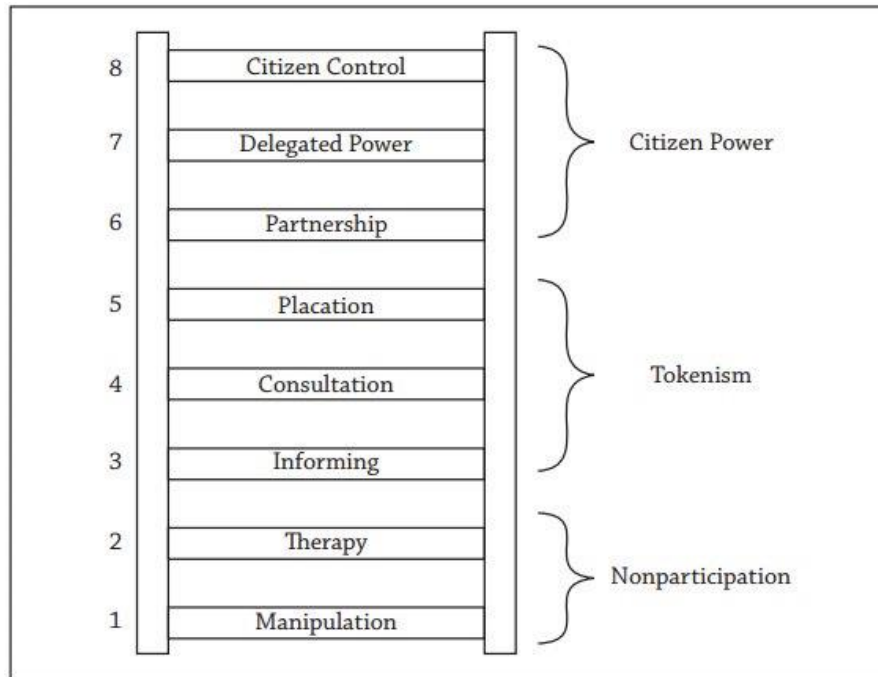


Figure 3. Arnstein's ladder of participation (1969)

Through a detailed review of inclusive research literature, Bigby and Frawley (2015) identified three approaches to inclusion in research, specifically for projects involving people with learning disabilities. These approaches are advisory, leading and controlling and collaborative group (see figure 4). Despite all being labelled as inclusive research, these approaches differ quite substantially in the level and type of involvement from the population concerned, demonstrating the various roles that individuals with learning disabilities (and non-disabled researchers) may fulfil within an inclusive research project. It is also worth considering that the definition of 'inclusive research' may differ depending on the individual's role. A non-

disabled researcher's perception of inclusive research may differ quite considerably to that of a disabled researcher.

	<i>Advisory</i>	<i>Leading and controlling (people led)</i>	<i>Collaborative group</i>
Paradigm to which most suited	Positivist or social constructionist	Emancipatory disability, participatory/ advocacy	Positivist or social constructionist, participatory
Characteristics of those included	People with intellectual disability experienced in either the particular issue or as self-advocates	Individuals with intellectual disability or organizations of people with intellectual disability who identify the research issue as relevant to their life experiences or the collective group	People with intellectual disability who have lived experience of the particular research area
Extent of inclusion	Overarching research priorities, or part of whole of a specific project	Whole project – research group supported by allies	Whole project – part of a groups comprising people with and without intellectual disability
Role of people with intellectual disability in initiation of inclusion	Reactive involvement, initiated by government, academics or organizations	Ideally but not always proactive and initiated by people with intellectual disability	Proactive involvement sole or joint initiation
Leadership	Government, organization or academic	People with intellectual disability	Academic
Control	Government, organization or academic	People with intellectual disability	Dispersed among group members
Purpose/ beneficiaries of inclusion	Government, organization or academic	People with intellectual disability, individually or collectively	Shared and distinctive purposes between academics and people with intellectual disability
Aim of research endeavour	Priorities for funding or new knowledge for social change	Advocacy/immediate social change	New knowledge for social change
Common methods	Group-based consultation, trial of questions, review of materials	Participatory action research, surveys, interviews, workshops	Adapted methods such as collective interviews, focus groups, iterative analysis

Figure 4. "Broad approaches to inclusion of people with intellectual disability in research" (Bigby & Frawley, 2015, p.5)

There may be several reasons for the lack of consistency surrounding how researchers label, describe and implement inclusive research approaches. Firstly, as Walmsley (2004, p.69) states, "there is no one right way to approach inclusive research. Adjustments are needed according to the topic, the methodology and the skills of those involved". The adaptive nature of these approaches may result in a 'blurring' of the boundaries between different approaches, depending on the researcher's experience and the nature of the research itself (Nind, 2014a). This results in a lack consistency in the way in which vulnerable people are involved in inclusive research (Walmsley, 2004). Additionally, there is a lack of clarity in the reporting of inclusive research. Many researchers have commented on the exclusion of important information in inclusive research papers, including a lack of detail about who did what and how (Bailey et al., 2015; Liddiard et al., 2018; Walmsley, 2004). The lack of explicit information concerning the roles, relationships, skills and resources required to carry out inclusive research poses challenges for researchers who hope to employ inclusive research approaches, particularly those who are new to these approaches. While inclusive research is intended to be adaptable, greater detail is needed in the reporting of these projects in order to share best practice and encourage the inclusion of individuals with



learning disabilities in research. With this in mind, the present study seeks to provide an in-depth account of the process of setting up, designing and implementing an inclusive research project, starting with a detailed introduction to participatory action research (PAR); the inclusive approach chosen for this project.

### 2.3.2 Participatory Action Research

Participatory action research (PAR; sometimes referred to as participatory or action research) is an inclusive approach to qualitative enquiry, which emphasises the importance of real action and social change, through collaboration with a community that has identified a common need/and or problem (Selener, 1992). Stalker (1998) suggests that PAR challenges the narrative of the researcher as an expert and people with learning disabilities as the object on which research is undertaken. Indeed Wright (2021) states that those with lived experience are the most knowledgeable and therefore in the best position to tackle social injustice and work towards meaningful solutions. In PAR, members of the community are therefore recruited as co-researchers and actively involved in all stages of the research, including research question design, data collection, analysis and research dissemination (Gratton, 2019). The focus of PAR on action/social change aims to directly address systemic injustices (such as the lack of LLL opportunities for adults with learning disabilities) that are identified by the community (Selener, 1992). For this reason, PAR approaches are commonly linked with self-advocacy organisations and disabled people's organisations, whose goal is to influence local and national change to improve the quality of life of disabled people (see for example, the work of Mencap, My Life My Choice and LD England).

Alongside the focus on social change, the structure of PAR is one of the key features that distinguishes it from other inclusive research approaches. PAR is based on a cyclical process of planning, action and review (Kindon et al., 2007). In the planning phase the researcher works together with a particular community and/or population to establish aims and questions (Kelly, 2005). The action phase attempts to create social change by working towards these goals. Finally, the review phase establishes whether this action has been successful in addressing the needs of the community and reflects on the process so far (Kelly, 2005). This process repeats as many times as necessary.

A growing body of literature utilises PAR approaches to collaborate with adults with learning disabilities (e.g. Garcia-Iriarte et al., 2009; De Castro et al., 2023; Pettican et al., 2023; Rickson et al., 2014). These studies have demonstrated the potential for adults with learning disabilities to fill the role of co-researchers and to actively influence the design, delivery and dissemination of research. PAR has been used in a number of different contexts and settings, most notably in the fields of health (Kelly, 2005; McFerren & Hunt,

2008), education (Dymond, 2001; Seale, et al., 2014) and social science (Bennett & Brunner, 2020). There are fewer examples where PAR have been applied in arts research involving disabled people. The majority of these studies concern arts-based therapies, where participatory and PAR approaches have been used to explore the outcomes of arts interventions (e.g. McFerren et al., 2016; Rickson et al., 2014; Warner, 2005). The use of PAR approaches in this field may be due to the collaborative nature of arts therapies, which lend themselves to a collaborative research approach. Despite the smaller number of PAR projects in the arts, researchers have argued that the adaptable and flexible nature of the arts and PAR makes them well-suited (co-researchers with varied needs can be supported to access both the arts and PAR; Clover, 2000; Nind, 2008).

#### 2.3.2.1 Opportunities and challenges of PAR

The opportunities associated with PAR are commonly recognised in wider literature. PAR challenges traditional hierarchies and power imbalances that are often present in research, through the involvement of communities who are ordinarily excluded from research (Pettican, 2022; Smith, 2022). By collaborating with experts by experience (such as adults with learning disabilities) research is considered to be more meaningful, impactful and representative of the voices of adults with learning disabilities (Wright, 2021). Since a key feature of PAR is social change, PAR also presents an opportunity to facilitate long-term local and national change, which benefits the community involved in the research.

Alongside the benefits of gaining meaningful feedback from participants, research suggests that directly involving adults with learning disabilities in the process of research can be a learning/personal development opportunity in itself (Mittler, 2012; Nind, 2014b; White & Morgan, 2012). Billett (2010) states that informal LLL occurs when our roles change. In becoming direct contributors to research, and researchers in their own right, adults with learning disabilities occupy a different role in life, allowing for the development of research-specific skills (e.g. in data collection and analysis) as well as personal and professional development (Nind, 2014b). Reflecting on her experiences as a researcher with a learning disability, White states “what we got from doing this research is confidence, getting more skills [...] learning so many different things and getting a lot more knowledge” (White and Morgan, 2012, p.103). It seems, therefore, that the direct involvement of people with learning disabilities in the evaluation of creative inclusive education programmes may inadvertently provide a learning opportunity in itself (for adults with learning disabilities, but perhaps also for university researchers, as they learn to collaborate with members of the community).

However, there are numerous challenges to PAR approaches. Firstly, people with learning disabilities have been historically marginalised and had their voices excluded from conversations which concern them (Oliver & Sapey, 1983). This community have therefore been excluded from actively contributing to research historically. Despite the growing body of literature which collaborates with adults with learning disabilities to explore their experiences, research processes and practices remain largely inaccessible to adults with learning disabilities and may therefore require adaptation. Due to the requirements of flexibility, adaptation and collaboration, PAR is often a time-consuming approach (Cook, 2012).

Working in collaboration with communities who are considered to be vulnerable may also present challenges. Ethical considerations in PAR (such as issues around informed consent, confidentiality and balancing power) must be carefully considered to ensure a balance between the empowerment and protection of co-researchers. A full exploration of the ethical considerations examined in the present study are included in section 3.1.6. Additionally, accessing communities who are ordinarily excluded from research may be challenging. Community organizations are often the gatekeepers of marginalized communities and may therefore make important decisions concerning who participates in research (Williams, 2019). Williams (2019) notes that this may be problematic, as organisations may withhold invitations to engage with research, without consulting the community. However, groups supporting adults with learning disabilities also hold valuable community-specific knowledge, which is crucial for meaningful research collaborations. Research based on partnerships between community groups and URs may therefore form the basis of effective PAR projects.

Previous research concerning how to implement PAR projects with adults with learning disabilities provides useful guidance on how to address some of these challenges, while enhancing the opportunities of PAR (Nind, 2017; Nind, 2014b; Northway, 2000b). Reflections on PAR projects which highlight the experiences of co-researchers with learning disabilities may therefore be particularly important when considering best practice in relation to PAR (Beighton et al., 2017; St John et al., 2018; White & Morgan, 2012). Alongside academic literature, 'toolkits' developed from PAR projects within community settings highlight key learnings from inclusive research within a range of contexts (NIHR, 2022; Pain et al., 2019). However, there are few toolkits which specifically focus on/include reference to PAR with adults with learning disabilities. Additionally, as previously noted, guidance regarding the implementations of PAR often lacks transparency regarding the roles and

responsibilities of those involved in PAR, and how specifically methods and processes were adapted to meet the needs of co-researchers (Smith et al., 2022).

To facilitate the active involvement of co-researchers with diverse needs, PAR may utilise inclusive, adaptable and creative methods. Previous PAR projects have used methods such as interviews (Rickson et al., 2014), focus groups (De Castro et al., 2023; Puyalto et al., 2016), research journals (Rickson et al., 2014), and arts-based methods (Aldridge, 2007; Liddiard et al., 2018; Rickson et al., 2014). While a goal of PAR in this context is that the research process should be accessible to adults with learning disabilities, utilising a participatory approach to research does not in itself guarantee that the research is accessible or inclusive. Indeed, many traditional research processes, methods and outputs are inaccessible to adults with learning disabilities, and require adaptation in order for co-researchers with learning disabilities to fully engage with them. One way that PAR projects have adapted research methods to be more accessible to individuals with diverse needs is by utilising creative, arts-based methods (Aldridge, 2007; Liddiard et al., 2018; Rickson et al., 2014). The following sections will consider creative methodologies and their use within PAR with adults with learning disabilities.

### 2.3.2.2 Creative methodologies

Arts-based methods have been described as "any social research or human inquiry that adapts the tenets of the creative arts as a part of the methodology [...] the arts may be used during data collection, analysis, interpretation and/or dissemination" (Jones & Leavy, 2014, pp.1-2). Arts-based methods are frequently used to support adults with learning disabilities to engage with research and/or to share their views on a range of topics (Rickson et al., 2014). Research utilising arts-based methods frequently combines multiple methods, including a combination of arts-based and traditional qualitative methods, such as interviews, focus groups and questionnaires. For example, Richards et al. (2019) used arts, photography, poetry, drama, film making and sculpture to challenge negative perceptions of adults with disabilities. Additionally, Rickson et al. (2014) combined focus groups, interviews, video diaries, song writing and research diaries<sup>1</sup> to explore the experiences of young people with learning disabilities who attended a music therapy programme. The present study draws on a range of arts-based, qualitative and adapted methods to increase the accessibility and inclusivity of the research process. The following sections will briefly introduce three

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<sup>1</sup> While research diaries are not specifically an arts-based method, they provide an opportunity to utilise many of the methods discussed above (e.g. by providing a space for photography, drawing, storytelling, poetry and other visual arts), while providing a space for reflections on the research process.

examples of creative methodologies which have been used in research with people with learning disabilities and that have influenced the approach in the present study.

#### 2.3.2.2.1 Photovoice

Photovoice is a participatory research strategy which uses photography to access people's individual worlds, by providing participants with cameras to capture key moments in their daily lives (Wang & Burris, 1994). Wang (1999, pp.187-189) identifies nine steps for utilising this visual method:

1. Select a target audience
2. Recruit participants
3. Educate participants about the photovoice method
4. Gain informed consent
5. Brainstorm the project focus with participants
6. Distribute cameras
7. Provide time for participants to take photographs
8. Meet with participants to talk about their pictures
9. Plan how to share this information with the target audience

While discussions based on these photos can provide further context about participants' experiences, this method does not rely on verbal communication, as participants are able to show rather than tell their experiences (Aldridge, 2007). Although traditionally used in healthcare settings, this approach has now been used to explore the experiences of people with learning disabilities in number of different contexts, including the experiences of mothers with learning disabilities (Booth & Booth, 2003) and the experiences of adults with learning disabilities who attend a respite programme in Australia (Seed, 2016). While this approach specifically uses photography, the same concept could be applied to other forms of art, such as drawings (e.g. Rickson et al., 2014) and film making (Hakak & Holmes, 2017)

#### 2.3.2.2.2 Draw, write, tell

Draw, write, tell is a participatory research method which asks participants to draw pictures and write words in response to a theme or particular question (Angell et al., 2015). Draw, write, tell is traditionally used to gain an insight into the lives and experiences of young children, for whom writing and/or verbal communication may be challenging (Angell et al., 2015). This method appears to be particularly useful when the topic area is sensitive and may be difficult to verbalise (e.g. the experiences of orphans: Ogina & Nieuwenhuis, 2010). At the

time of writing, there are limited examples of the application of this technique in research with people with learning disabilities. However, as people with learning disabilities may find written and verbal communication challenging (Mencap, n.d), draw, write, tell may provide a more accessible method of sharing their experiences with an interviewer. Although not described as draw, write, tell, Rickson et al (2014) incorporated a similar technique into their exploration of the experiences of young people with learning disabilities attending a music therapy programme. Young peoples' drawings in response to the project's research questions (what is good, bad, hard and easy about coming to music?) provided an insight into their experiences and aided communication between the young people and the music therapists. This demonstrates the potential for drawing-based methods to provide an insight into the subjective experiences of people with learning disabilities, particularly for those who communicate non-verbally.

#### 2.3.2.2.3 Storytelling

Storytelling and life stories have previously been used with adults with learning disabilities to capture their experiences (Atkinson, 2004; Atkinson & Walmsley, 1999; Booth & Booth, 1996). Atkinson (2004) describes life stories as a process whereby people "recall, recount and review their lives" (p.699). For this reason, this method had also been viewed as a form of self-advocacy and is often designed to challenge assumptions surrounding disabled people (Nind, 2008). Nind (2008) acknowledges the challenges with communication in storytelling methods. However, as with any textual information, there are ways to adapt narrative methods so that they are more accessible. For example, by utilising pictures and symbols (such as the Picture Exchange Communication system) and by using simplified language.

An example of an adaptable narrative method is story completion. This qualitative method aims to capture rich data from participants in response to a hypothetical situation (Braun et al., 2019). Participants are provided with a brief 'story stem' (the opening lines of a story) and are asked to complete the story. Due to the hypothetical nature of the stories, this method is suited for exploring participants' perceptions of sensitive topics (e.g. where participants may not feel comfortable directly revealing their own experiences). Completed stories may also be used as the basis for a semi structured interview on the same topic (see Gravett, 2019). Story stems may also be accompanied by pictures and/or symbols to improve the accessibility of this method.

## 2.4 The research problem(s)

The literature review above has introduced the community that this project aims to collaborate with and the barriers that adults with learning disabilities face when accessing opportunities for LLL. Literature relating to inclusive approaches to learning demonstrate a range of approaches and learning techniques, which may facilitate access to learning experiences for adults with learning disabilities. However, several problems relating to the learning experiences of adults with learning disabilities remain. The present study seeks to address these four key research problems:

Problem one: Despite the fact that LLL is a key goal of the education system (Demirel, 2009) and a human right (United Nations, 2016), adults with learning disabilities have access to fewer opportunities for learning than their non-disabled peers and often face a multitude of barriers when attempting to access LLL opportunities. Inclusive approaches to learning seek to remove barriers to learning, while supporting a range of positive outcomes for people with learning disabilities. However, research concerning inclusive learning experiences are child-centric, as there is limited literature concerning the learning experiences of adults with learning disabilities (i.e., beyond the formal education system). Further investigation of the inclusive learning experiences of adults with learning disabilities and the impact of these experiences in their lives is needed in order to a) identify ways of removing barriers to learning for this community, b) consider what constitutes best practice in relation to LLL for adults with learning disabilities and c) facilitate additional inclusive and accessible learning opportunities for adults with learning disabilities, to support their quality of life.

Problem two: Relating to problem one, there is limited research which explores the arts-based learning experiences of adults with learning disabilities, including the outcomes of engagement with arts-based learning programmes. While previous literature suggests that the arts may support inclusive learning (Corradi et al., 2022), previous literature exploring the impact of the arts in the lives of disabled people often focuses on therapeutic interventions as opposed to arts-based learning. Research focusing on arts-based interventions makes a valuable contribution to our understanding of the potential for the arts to support various aspects of an individual's life. However, research exploring the impact of arts-based learning is needed to support our understanding of how the arts may be used to facilitate inclusive LLL opportunities for adults with learning disabilities. Additionally, it is crucial for LLL programmes such as PPA to have a clear understanding of the impact of their services so that a) they can ensure that programmes meet the needs of their service users and b) the

outcomes of engagement with the programme can be evidenced to funders to support their continued operation.

Problem three: People with learning disabilities have historically had their voices excluded from conversations which concern them (Nind, 2011; Oliver & Sapey, 1983), thus contributing to the social exclusion of disabled people. While research involving people with learning disabilities has continued to grow, adults with learning disabilities are often excluded from *doing* research (Nind, 2008; Lester & Nusbaum, 2018). Additional research which actively collaborates with adults with learning disabilities as co-researchers is therefore required to ensure that research is furthering the interests of and accurately representing the experiences of adults with learning disabilities.

Problem four: Despite the growing body of literature which seeks to involve adults with learning disabilities in research (Di Lorito et al., 2018; Smith et al., 2022; St John et al., 2018; Pettican et al., 2022), there is a lack of transparent reporting of *how* this is achieved (Liddiard et al., 2018). Additionally, details concerning key stages of the research process, including analysis and the dissemination of research are often omitted. Researchers and organisations supporting adults with learning disabilities (such as PPA) who hope to actively involve participants in inclusive approaches to research and evaluation, may therefore feel unsure as to where to start.

This project sought to address the issues relating to the inaccessibility of learning opportunities for adults with learning disabilities (as described above), utilising a PAR approach. The aims of the study are described below.

#### 2.4.1 Aims of this project

Through exploration of previous literature and the identification of the four key problems outlined above, the following overarching aims of the project were established:

Aim one: To identify the outcomes of participation in the PPA LLL programme

Aim two: To work collaboratively with adults with learning disabilities, utilising a PAR approach, to explore and capture their experiences of inclusive arts-based learning

Aim three: To explore the outcomes of engagement in PAR from the perspective of co-researchers and the non-disabled researcher

In keeping with the PAR approach in this project, the specific research questions, methodologies and direction of the study were decided collaboratively with co-researchers.



Details for each cycle of the project are outlined in the planning and action sections of chapters four, five and six.

### 3 Methodology

In line with the goals of PAR outlined above, each cycle in the present study had its own research questions, methods and approach to analyses, which were decided collaboratively with co-researchers. This methodology section therefore introduces the overarching methodological approach to this project. Firstly, the process of setting up this PAR project (the 'pre-planning stage'<sup>2</sup>) is outlined, followed by the recruitment of co-researchers and the overall approach to analysis. This section draws on wider literature to highlight the key considerations and questions when establishing a PAR project and to contextualise the decisions that were made within the project. While the present study sought to identify the outcomes of engagement with arts-based learning for adults with learning disabilities, the process of how co-researchers were involved in the research through PAR was considered to be an equally important aspect of the present study. Due to the lack of transparency and detail in previous research concerning the process of setting up a PAR project, the methodology section of this thesis is deliberately detailed.

#### 3.1 Setting up a PAR project

In line with aim two of this project (to work collaboratively with adults with learning disabilities, utilising a PAR approach to explore and capture their experiences of inclusive arts-based learning), the first stage of this study was to establish a PAR approach to the research. Researchers have often discussed the lack of transparency in the recording of PAR projects involving disabled people (Liddiard et al., 2018; Walmsley, 2004). As such, there is limited guidance available regarding how to set up a PAR project with adults with learning disabilities.

When considering how to set up the present study, the UR drew from varied resources. Firstly, Kelly (2005) provides a useful overview of the steps required to set up a PAR project in the context of healthcare. While some of the steps outlined in Kelly's report are not directly relevant to the present study, they nonetheless provide a useful framework for setting up a PAR project. Additionally, in their book 'The Action Research Dissertation' Herr and Anderson (2005) stipulate that there is no right way to approach an action research project. Nevertheless, they provide guidelines as to how to approach action/participatory

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<sup>2</sup> Throughout this document the process of setting up the project will be referred to as the 'pre-planning' stage. This stage of the project included any activities which occurred prior to cycle one of the project, when co-researchers became equal partners in the project and therefore influenced the design and dissemination of the research. This terminology was chosen in order to distinguish this stage of the research from the 'planning' stages, which occurred at the beginning of each cycle of research (described in section 3.4.6).

research from start to finish, including practical examples from previous projects which provide the reader with a toolkit of ideas and approaches to apply to their own research. PAR toolkits (such as Pain et al., 2019) also provide a useful overview of the key stages and questions when establishing a PAR project (such as who, what, where, when and how PAR should be established). Finally, the UR observed the writings of other PAR researchers within the arts (e.g. Hense, 2015; McFerren & Hunt, 2008; Rickson et al., 2014) paying particular attention to the process of setting up PAR projects within this field.

Based on these resources, the UR identified five key phases of the 'pre-planning' stage of the project, which required attention when setting up the project: Identifying a problem; finding a community partner; resources and logistics; formalising the relationship with the community partner and ethics. For the purpose of this thesis, these components will be discussed in the rough order in which they took place. However, it is worth noting that these components were not necessarily considered in the order they are listed, nor were they addressed in a strictly linear fashion. Setting up a PAR project is notoriously messy, and as such, the process of setting up this project involved a lot of 'to and fro', with each component impacting its counterparts (Cook, 2009). Additionally, the Covid-19 pandemic (discussed in section 3.1.5) required the UR to revisit these phases multiple times to adapt the project to operate during the national lockdown.

### 3.1.1 Identifying a problem

A common question in PAR research is, should a community approach the researcher with a problem, or is it possible for a researcher to identify a problem and subsequently approach a community? While it may not be necessary for PAR to be initiated by the community, the problems identified by the researcher should be confirmed by the community (Johnson & Walmsley, 2003). This can be challenging, particularly when working with vulnerable populations, who may be difficult to access. One method of confirming problems is therefore to observe the issues that have already been highlighted in previous literature by a community and/or community representative.

Four key research problems were identified through the literature review for this project (see section 2.4). The present study sought to address these problems by working in partnership with PPA (a charity providing creative learning experiences for adults with learning disabilities) and PPA participants. These problems were initially confirmed by PPA staff (including the CEO and programmes manager), who had already expressed an interest in capturing the experiences of their service users through meaningful feedback of PPA. In this instance, the steps of identifying a problem and finding a community partner took place almost simultaneously.

Having identified these problems and confirmed them with community representatives, three overarching aims were established (see section 2.1). These aims were developed to establish broader goals for the project and to meet the requirements of the initial ethical review (which required the inclusion of project aims/research questions). However, the specific research questions for each cycle and decisions concerning the direction of the research were made during the planning stage of each cycle, in collaboration with PPA participants who were recruited and trained as co-researchers.

### 3.1.2 Finding a community partner

Community partners can play an important role in PAR projects, particularly when working with communities who are considered to be vulnerable. Community organisations may act as gatekeepers to research and therefore have the power to grant or deny access to community members (Emmel et al., 2007; Williams, 2019). Additionally, community partners can provide expertise in relation to the specific community, particularly when the researcher is an 'outsider' (i.e. not a member of the target community; Herr & Anderson, 2005). PPA were already known to the UR as they had previously approached the university with an interest in working with a doctoral researcher to evaluate their programme by capturing the participant voice. They therefore seemed to be an ideal partner for the project.

Hamberger and Ambuel (2000) state that establishing a partnership with a community partner involves "a complex process of negotiating philosophical, professional, personal and cultural differences" (p.269). They also make a number of recommendations for researchers collaborating with community partners, including to discuss the scope and limitations of the project and its outcomes early on, to identify common goals and design the project to be mutually beneficial. Following the advice of Hamberger and Ambuel's (2000) recommendations, the first step in establishing the partnership with PPA was to arrange an initial meeting. The aim of this meeting was to ensure that the aims of the project aligned with those of PPA and to agree on mutually acceptable goals. The UR also used this meeting as a chance to introduce PPA to the concept of PAR as a research approach. Initially PPA were unsure of this proposed approach, mainly due to concerns around how any data collected from this project would be received by funders:

The majority of the discussion centred around PAR, which \*staff member\* was understandably not familiar with. It became clear to me during the meeting that the kind of evaluation PPA were expecting might come out of this project is not what I was offering. It was clear from PPA's questions that funding bodies have traditionally asked for full programme evaluations based on statistics and therefore this is what PPA felt they wanted/needed. [...] One of the biggest realisations I had in this meeting is the very different positions that we are approaching this project from (UR - diary reflections after initial meeting with PPA)

This demonstrates the importance of acknowledging the different perspectives with which different stakeholders (including community organisations, researchers and adults with learning disabilities) may approach a project. Having honest conversations with PPA early on in the project (e.g. to explain that this project would not result in a traditional evaluation of the PPA, but rather, provide the opportunity for in-depth collaborative exploration of participants' experiences at PPA) allowed us to discuss our expectations and priorities in the project and to establish mutually agreeable goals:

After a discussion about participatory approaches to research and the opportunity for PPA attendees to be researchers and evaluate their own experiences, \*staff member\* was full of encouragement and seemed eager to continue conversations and collaborate on the project (UR - diary reflections after initial meeting with PPA)

Shortly after this initial meeting, PPA agreed to collaborate on the research. Naturally, PPA's main questions towards the beginning of the project revolved around the practicalities of how the project would work, including logistical and practical considerations relating to the delivery of the research. The following sections discuss the logistics considered when setting up the project and the resources required to support this.

### 3.1.3 Logistics and resources

An important aspect of setting up a PAR project is to consider the logistics involved with the project and the resources required. Due to the different perspectives and experiences with which the UR and PPA approached this project, a 'logistics' meeting was organised to consider the practicalities of the project. Kelly (2005) states that it is first useful to consider pre-existing resources at a PAR project's disposal. In line with this, some logistical decisions, such as the consideration of where and when research meetings would take place, were initially agreed upon by considering where PPA and the UR already had access to. Research meetings were planned to occur once a month, at either the PPA office, or at the University of Leeds, depending on the needs and preferences of participating co-researchers. Research sessions were planned to take place on a day which did not clash with PPA programmes attended by co-researchers, to ensure that their involvement with the project did not impact their ability to attend PPA. Additional logistics which were considered included<sup>3</sup>:

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<sup>3</sup> The Covid-19 pandemic resulted in a complete overhaul of these considerations, alongside the design of the project itself. These logistical considerations have been included here to demonstrate the practical aspects of a PAR project that may need to be considered by the UR and partner organisations. However, they have not been fully explained, as some (e.g. travel) were no longer relevant to the present study after it moved online. This further demonstrates the non-linearity of the process of

- Recruitment - How would co-researchers be recruited? What resources would be required for this? Do resources explaining the research process to adults with learning disabilities exist or do they need to be created?
- Travel – How would co-researchers travel to and from research sessions? Would travel expenses be provided, and if so, by whom?
- Research session resources – What resources would be required to run research sessions and who would provide these? (e.g. arts resources)
- Support within research sessions – would PPA provide support in research sessions or would this be provided by the UR alone? Would co-researchers be required to provide their own support? (when applicable)
- Contact – how would the UR contact co-researchers? Would contact concerning the research occur through PPA or directly from the UR?

Negotiating the logistics of this project involved a series of meetings between the UR and PPA. In particular, PPA were involved with the process of checking resources developed by the UR to ensure that these were accessible to PPA participants. Negotiating the logistical and practical considerations in the project also supported the formalisation of the relationship between the UR and PPA, which is discussed further below.

#### 3.1.4 Formalising relationship with community partner

Formalising the relationship with a community partner is an important component of PAR (Smith et al., 2022). Community partners can provide valuable expertise and knowledge, which can support the process of PAR (Pettican et al., 2022). The development and formalization of the relationships between the UR and PPA was therefore crucial for successful collaboration. In the present study, this process involved the negotiation of specific aspects of the collaborative relationship and of the project itself. Through regular meetings with PPA, the terms of access to participants and to PPA programmes were agreed. For example, it was agreed that the UR would be able to recruit PPA participants and attend PPA programmes, but that research sessions should take place outside of the programmes. Additionally, roles, responsibilities and expectations of PPA staff, the UR, co-researchers and parents/support workers were discussed and agreed upon. Lenette et al. (2019) highlight the

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setting up this PAR, as having addressed many of the questions outlines above, the Covid-19 pandemic forced the UR and PPA to reconsider many aspects of their collaborative relationship and the logistics involved with running the project. Section 3.1.5 explores the impact of the Covid-19 pandemic on this project, and the logistical considerations of setting up an online PAR project further.

importance of all stakeholders understanding the research goals and a shared vision in order to facilitate ethical participatory research. It was therefore important to ensure that everyone involved in the project understood the project, their role within it and what they were responsible for.

PPA agreed to:

- Have regular meetings with the UR and provide general support throughout the project
- Provide support and guidance on the accessibility of resources produced for the project, to ensure they were pitched correctly for the individuals involved
- Support the recruitment of co-researchers by circulating the recruitment materials described in section 3.3
- Be present for research meetings to support the UR when required (it is worth noting at this stage that this did not occur due to the Covid-19 pandemic, the impact of which will be discussed further below)
- Have responsibility for the welfare of co-researchers (e.g. by responding to safeguarding/welfare concerns raised by the UR, when applicable)

The UR agreed to:

- Organise regular meetings with PPA throughout the project to update them on the progress of the research
- Share the research questions and methodologies chosen by the group, particularly if this involved the recruitment of other PPA participants
- Report any welfare or safeguarding concerns to PPA's safeguarding officer
- Share the results/recommendations from the project with PPA

PPA representatives (namely the CEO and programmes manager) were involved at all stages of the project setup, which allowed the UR to gain regular feedback from them about the project. In their guide to community collaboration, Hamberger and Ambuel (2000) state that gaining feedback is an important part of the collaborative process, as it allows the researcher to gain a "real world perspective" (p.266). Involving PPA staff in decision-making surrounding the project, such as the creation of recruitment and research training materials, firmly established the relationship as collaborative early on and demonstrated that the UR was receptive to their ideas and suggestions.

Perhaps the most important element of any community partnership is trust and

knowing the community (Pinto et al., 2008). Building trust is a continuous process and was therefore ongoing in the present study. However, one way the UR began to establish trust was by visiting PPA programmes. These programme visits were important as they allowed the UR to experience PPA firsthand and to gain a better understanding of the structure of PPA programmes. Hamberger and Ambuel (2000) state “Spending time in the actual community setting in roles other than that of researcher [...] provides a visibility that fosters ongoing professional relationships” (p.267). This was certainly the case for the present study, as these visits provided an opportunity for the UR to meet and interact with participants, staff and parents/support workers, and begin building relationships with these individuals. The development of trust also allowed for open and honest discussions, including addressing potentially uncomfortable topics, such as conflict of interest. When collaborating with any organisation there is always a risk of conflict of interest. As the present study involved inviting PPA participants to share their experiences, it was possible that co-researchers may reveal aspects of their involvement in PPA that they deemed to be negative or requiring improvement. Discussing this with PPA staff early on resulted in an open conversation about their expectations of the findings of this project, including how they would feel about and/or react to negative findings. It was reassuring to hear that PPA were open to recommendations for improvement and honest feedback. Recommendations that co-researchers shared with PPA at each stage of the project are included as the final section of each cycle of research in this document (sections 4.4, 5.4 and 6.4).

### 3.1.5 The Impact of Covid-19

On the 23<sup>rd</sup> March 2020, roughly five months into the pre-planning stage of the project, the UK entered a period of national lockdown due to the Covid-19 pandemic. This resulted in the temporary closure of PPA programmes (which were moved online). As with many research projects during this time period, the pandemic had a significant impact on the research and required the project to be re-designed to operate under the new restrictions (Mikulak, et al., 2023). The UR revisited several of the steps involved with setting up a PAR project outlined above. In particular, the pandemic presented new logistical challenges, such as when and how to run research sessions using an online platform. Additionally, new resources were required for the project to run online, such as digital recruitment resources, which explained research and the role of co-researchers in the project. This presented a number of challenges to the accessibility of the project, since activities were now required to be accessible while operating online.



However, some of the logistical problems that were originally considered, such as space for research sessions and transport to and from sessions were no longer applicable, since the project was moved online. The online setting of the project therefore also removed some barriers to participation in the research. Section 3.3 introduces the online recruitment and research training materials produced for the project. Furthermore, section 3.4 outlines the overall procedure for the research, including how the project operated during the national lockdown.

### 3.1.6 Ethics

As the co-researchers in the present study were considered to be vulnerable, a full ethical review was required (appendix A). In the first instance, an ethical review was conducted based on the original pre-Covid-19 project design. This version of the project revolved around in-person meetings, with research activities undertaken at the PPA office and the University of Leeds. However, once it became clear that Covid-19 restrictions would render this first version of the project impossible, an ethical amendment outlining the current version of project was submitted and approved (ethics reference: FAHC19-078). This initial review and amendment covered setting up the project, recruitment and the planning stage of cycle one. A unique aspect of PAR is that an ethical review is required in order to access and recruit vulnerable people. However, this review did not include specific details about the study, including research questions and data collection methods, as these are decided in collaboration with co-researchers. As Northway (2000a) notes, ethics within PAR projects is therefore an ongoing process. This was certainly true for the present study, which required two additional ethical amendments for subsequent cycles of the project as decisions were collaboratively made about each cycle. Ethical amendments (when required) were submitted after the planning stage of each cycle and included the co-researchers' chosen research questions and methods. However, after discussions with the ethics committee it was agreed that, since the co-researchers were researchers in their own right, collaborative decisions concerning the design of future cycles that only involved co-researchers (i.e., did not recruit other PPA participants) would not require an ethical amendment.

Due to the collaborative nature of PAR, there are a number of 'usual' ethical procedures which are challenged in this project. For example, anonymity and confidentiality are traditional hallmarks for good ethical research. However, in PAR it is important to consider the ethical implications of not acknowledging co-researchers' contributions, versus protecting the identity of vulnerable people. In the present study, co-researchers were informed that their identity would be protected, unless they request to be named in the thesis. Given that in good academic practice it is important to acknowledge those who have

contributed to a piece of work, co-researchers are fully within their right to request to be named in the project. PAR is therefore slightly unusual, in that individuals who would ordinarily be automatically treated anonymously are given a choice as to whether or not they wish to remain anonymous or be credited for their contributions. In the present study, co-researchers were provided with an information sheet during cycle three (see appendix B), which explained their options concerning being named in research outputs and the implications of this. Co-researchers were given the choice of whether to be acknowledged by their real name, to be acknowledged using a pseudonym, or to remain anonymous. All co-researchers opted to be acknowledged using their real name in this thesis, and in all other research outputs. Despite this, some details provided by co-researchers, such as locations, people and organisations have been anonymised to retain their privacy. Data that has been anonymised are included in asterisks and replaced with a description of the content (e.g. if co-researchers shared their home address during a quoted passage, this is depicted as \*home address\*). Similarly, figures showing co-researchers' social media handles/profile pictures have been edited to cover this information to retain their privacy online. Additionally, all co-researchers were asked to 'check' their research work from each cycle of research and decide whether or not they wanted it to be included in the thesis. Therefore, all work created by co-researchers included in this thesis is done so with permission from the co-researcher.

The process of gaining informed consent when working with people with learning disabilities is also a contentious issue. In some studies which involve vulnerable populations, informed consent is provided by the individual alone (Rickson et al., 2014; White & Morgan, 2012) whereas in others it is also provided by a legal guardian or carer (Cameron & Murphy, 2007). While a key ethical consideration in the present study was ensuring that co-researchers were both able to fully understand their involvement in research and able to provide informed consent, an equally important ethical consideration was respecting the co-researchers' right to provide informed consent for themselves, as they are of the legal age to do so. Indeed, the Mental Capacity Act (2005) states that people with learning disabilities should be able to provide consent for themselves, providing they understand the implications of their involvement in research. In the present study participants were encouraged to ask for support from a parent/support worker to provide consent, if needed. However, consent was only required from the individual. Previous research has suggested that to support the process of providing consent, information should be provided in multiple formats, information sheets and consent forms should be adapted and additional time for gaining consent should be considered (Cameron & Murphy, 2007). In line with this, the present study developed accessible resources, using multiple methods of communication, which explained

the research process, to ensure that co-researchers understood what would be involved (see section 3.3). Additionally, an accessible information video (appendix C) and online consent form (appendix E) were created utilising easy read language and pictures/symbols, to ensure that the process of giving consent was as accessible as possible.

Several ethical considerations specific to a PAR approach were also reviewed. Particular attention was paid to the distribution of power in the research. Although PAR specifically aims to re-distribute power, the UR is still usually in a position of power, as an individual with skills and experience of research. The present study addressed this by teaching co-researchers the skills they required to do research, through the research taster videos, as well as activities and discussions throughout the cycles. By providing co-researchers with these skills and experiences, the present study aimed to gradually redistribute power to co-researchers, as they became less dependent on the UR to conduct research and make decisions. Support and representation are further important considerations. Walmsley (2004) states “There is no question that most people with learning difficulties need support to lead fulfilling lives, including participation in research” (p.32). An ethical challenge in PAR research is therefore to find ways to support co-researchers, while as much as possible, re-distributing the balance of power so that they are representing themselves, rather than being represented by non-disabled people (e.g. the UR or parents). In the present study, accessible resources (e.g. interactive videos) were created to support the co-researchers’ participation in the project, while encouraging them to undertake activities and make decisions independently.

Since research sessions were re-planned to take place online, the presence of PPA staff in online meetings and the impact their presence may have on the project was reconsidered. The opportunities of having staff present in online sessions included additional support provision for co-researchers from individuals who were familiar with them and their needs and preferences. Additionally, since the UR was unknown to the co-researchers, having a trusted individual and a ‘familiar face’ present may support engagement with the research. This was particularly important as many adults with learning disabilities have had negative experiences with, often unfamiliar, non-disabled people (Scior and Werner, 2015) and may therefore feel nervous when meeting new non-disabled people. However, the challenges of including staff in research meetings included the time commitment involved with their attendance, alongside the potential that the presence of staff may influence what co-researchers chose to share about their experiences. Discussing these opportunities and challenges early on meant that the UR and PPA staff were able to establish boundaries that protected and supported co-researchers while reducing any influence that PPA may have on

co-researchers. It was decided the PPA staff would attend specifically designed 'feedback' sessions during each cycle, so that co-researchers had opportunities to share their research and recommendations. Co-researchers were introduced to the UR via one-to-one meetings (discussed further in section 3.4.2) and were given the option for a PPA staff member to attend this meeting. PPA staff were not included as members of the Facebook group created for this project to retain the privacy of both PPA staff and co-researchers.

While this project aimed to involve adults with learning disabilities in all aspects of the study, including decisions around data collection methods, analysis and dissemination, there were inevitably points in the project where the UR was responsible for representing co-researchers (e.g. when writing up the thesis). The nature of doctoral research in particular presented a number of challenges in retaining a participatory approach, particularly during the concluding stages of the project, where co-researchers were not afforded the same level of control in the project (see chapter 7). It is also important to consider that different stages of participatory research may highlight different ethical considerations. For example, the dissemination stage of research may highlight conflicts between the goals of PAR (namely that research outputs should be accessible co-researchers) and the inaccessibility of traditional research outputs. Yassi et al. (2016) suggest that taking preliminary results back to participants for feedback is good practice to avoid misrepresentation, particularly during the write-up phase, where co-researchers may not be actively involved in the project. Previous research with adults with learning disabilities has approached this by creating easy read stories about an individual's experiences and presenting it to co-researchers to check it is in line with their perception of their own experiences (Rickson et al., 2014). In the present study, the UR adopted this process of receiving feedback from co-researchers, to ensure that co-researchers' experiences and opinions were accurately represented. However, the ethical issue of the thesis as an inaccessible output still remained. This was addressed in cycle three of the project, where co-researchers suggested the creation of an accessible output in the form of a research comic (see section 6.3.3.4).

The nature of participatory research means that ethical considerations such as respect, inclusion and collaboration with the community are core values which underpin the research process. However, ethical inquiry is an ongoing process and requires constant consideration. Since each cycle of research involved different questions, approaches and topics, ethical considerations outlined in this section were re-visited regularly. Additionally, PAR researchers may need to reconsider the ethical considerations of the project as co-researchers become more experienced in research. For example, as co-researchers begin to adopt the identity of a researcher, the UR may need to reconsider the distribution of power

and control to reflect this, particularly with regards to decision making around the research process

### 3.2 The Purple Research Group

A total of nine co-researchers were initially recruited for the present study (4 male, 5 female). Two co-researchers left the project in the first few weeks of cycle one due to reasons relating to the pandemic. This resulted in a team of seven co-researchers (3 male, 4 female). The small sample size in the present study was chosen to enable to collection of in-depth information, while catering to the individual needs of co-researchers and ensuring everyone's view were heard. Previous literature has commented on a lack of transparency when it comes to documenting the process of setting up a PAR project (Liddiard et al., 2018; Smith et al., 2022) and as such, there is limited written guidelines as to the 'ideal' number of co-researchers. However, previous PAR projects have recruited a similar number of participants (e.g. Hense, 2015: 11 participants, Pettican et al., 2022: 7 participants). All co-researchers were adults over the age of 18 ( $X=33.25$ ;  $SD=11.10$ ) who attended PPA. Four of the thirteen PPA programme locations were represented by co-researchers. All co-researchers identified as having a learning disability. Co-researchers also shared a range of additional diagnoses with the UR. However, co-researchers were not specifically asked to disclose any information regarding their diagnosis/diagnoses. This is in line with PPA's approach, whereby participants are not required to report their diagnoses unless it is crucial for the organisation to be aware of (i.e., for health and safety). Instead, co-researchers were asked throughout the project about their access needs in relation to different activities (for example, Tracey asked for research documents to be printed in larger text). Two co-researchers were accompanied to virtual research sessions by a carer/parent who supported their involvement in the project. These individuals were also able to provide the carer/parent perspective in the project and became valued members of the research team. The research team therefore consisted of seven disabled co-researchers, two carers and the UR. The name 'Purple Research Group' was suggested by a co-researcher at the beginning of the project to represent the research team ("[it] is a great name. I came up with it!" – Tracey, C2). Throughout this thesis, the group will therefore be referred to as the Purple Research Group (henceforth PRG) or 'co-researchers' when being discussed collectively.

### 3.3 Recruitment Materials

#### 3.3.1 Research taster videos

Strnadová et al. (2016) state that in order for people with learning disabilities to fulfil the role of a researcher, they first need to have a good understanding of research processes and methodologies. However, there are limited previous examples of research training for adults with learning disabilities, particularly for online use. Two research training programmes designed specifically for adults with learning disabilities have previously been developed by the University of Limerick (Salmon & Carey, 2013) and St George's University London (Tuffrey-Wijne et al., 2020). Both of these training programmes were delivered in person over the course of 11 weeks and 8 weeks respectively. These research training programmes covered topics such as: What is research and why do we do it?; introductions to methods, such as questionnaires and interviews; data analysis and ethics. Many PAR projects involving people with learning disabilities report that research skills were developed throughout the project, with learning about research incorporated within the project itself (c.f Burke et al., 2003; De Castro et al., 2023; White & Morgan, 2012). However, these studies often include limited specific information about how co-researchers with learning disabilities learned about research. There is therefore limited available guidance when developing research training for co-researchers with learning disabilities.

In the present study, five interactive animated videos, presented as 'chapters' in a research story were developed<sup>4</sup>. The videos follow the story of an adult with a learning disability, as she becomes a researcher and works through the research process. Videos were chosen as the basis of these recruitment materials as they utilise multiple methods of communication (including images, animations, audio and written text) and were therefore considered to be a more accessible way to communicate information. Additionally, since the Covid-19 pandemic resulted in a series of national lockdowns, it was not possible for research training to be delivered in-person. Videos were therefore produced to share important information with prospective co-researchers concerning research and the role of a researcher, while maintaining the potential for interactivity. Additionally, as co-researchers completed these videos before deciding whether to participate in the project, research taster videos were crucial to ensure that co-researchers had the information they needed to make an informed decision about their participation in the study.

A challenge of producing research training for co-researchers is not knowing which methods and analytical techniques would be utilised. Additionally, research taster videos

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<sup>4</sup> More information about the research training videos is available upon request. Please send your request to [mlkirby@hotmail.co.uk](mailto:mlkirby@hotmail.co.uk)

were designed with the time constraints of doctoral research in mind. The research training videos therefore aimed to provide a general introduction to research and research skills, rather than a comprehensive training programme for co-researchers. In line with previous research regarding the development of research training for adults with learning disabilities (Salmon & Carey, 2013; Tuffrey-Wijne et al., 2020), videos addressed questions such as: what is research? Who does research? and what research is for? Key ethical concepts in research such as consent and withdrawal were also introduced. Each video 'chapter' tackled a different stage of research, including developing research questions, collecting data, analysing data and sharing results. Previous research training for adults with learning disabilities has also provided practical opportunities for co-researchers to develop their research skills (Butler et al., 2012; Tuffrey-Wijne et al., 2020; White & Morgan, 2012). Throughout the research taster videos co-researchers were invited to complete arts-based and practical research activities, which included opportunities to practice collecting data (through completing a research journal and conducting practice interviews). These activities were designed to provide participants with a taster of what being a researcher is like. Activities included in these videos were designed to a) be in line with the style of activities usually undertaken at PPA, b) be completed in the home with potentially limited resources, and c) effectively communicate important aspects of the research process (e.g. consent, data collection and analysis). Co-researchers' understanding of key research concepts were tested through a research quiz, as well as scenario-based activities where co-researchers were asked to choose what they would do next. These activities were designed to encourage co-researchers to engage with important concepts, such as consent. The information videos were created using the website PowToon and were subsequently downloaded and displayed on the Purple Patch Research webpage (a dedicated page for this project). Research training continued throughout the project, as co-researchers encountered new stages of research, methods and analytical approaches. Therefore, while the research training videos provided co-researchers with an overview of the research process, much of their learning about research was acquired through practical experience during the project, as described in each cycle of research in this thesis.

### 3.3.2 Information video

An animated information video was created in place of a traditional information sheet (appendix C). The purpose of the information video was to provide participants with logistical and practical information about the project and what it involved, in a fun and accessible way, that could be accessed from their homes. The information video was created using the website PowToon and was subsequently downloaded and displayed on the Purple Patch

research page.

### 3.3.3 Information sheet

An information booklet (see appendix D) was created and distributed to parents of potential participants via email (on request). The purpose of the information booklet was to inform parents of the aims of the research and provide further information about what the study would involve, so they were able to discuss the project with their son/daughter.

### 3.3.4 Consent video

An animated consent video guide (appendix C) was created to support participants to complete the consent form. The video addressed what consent is and why it is important, as well as practical guidance to assist co-researchers to complete the consent form, including screenshots of each page, with example responses. The consent video was created using the website PowToon. The video was subsequently downloaded and displayed on the Purple Patch research page for potential co-researchers to access.

### 3.3.5 Consent form

An online consent form was created using Online Surveys (appendix E). An online form was used as participants were not able to complete a consent form in person, due to PPA programmes closing during the pandemic. The consent form collected demographic and contact information and asked co-researchers to indicate whether they agreed with seven written statements. As all participants were over the age of 18, consent was only required from the individual. However, participants were encouraged to ask for support from a parent/guardian to complete the consent form, if required. Additionally, the form was written in an easy read format and included pictures and symbols to ensure it was as accessible as possible. The form was opened on 10/07/2020 and remained open until 20/10/2020.

## 3.4 Procedure (pre-cycle planning)

### 3.4.1 Recruitment

PPA fulfilled the role of a gatekeeper in order to recruit co-researchers. PPA participants were first informed about the project through a phone call from PPA staff in May 2020. This initial phone call was designed to inform participants about the project, to answer any questions they had and to identify any potential barriers to participation so that suitable adaptations could be made to the project. Initial barriers identified included issues with accessing appropriate devices (e.g. laptop or tablet). For one participant the lack of a device initially



prevented their participation, however, they were eventually able to source a laptop with the help of PPA and joined the project at a later date. An interesting outcome of moving the project online was the reduction of other barriers, including transport and financial barriers. Indeed, if the project had run in person as intended, many of the co-researchers recruited for the present study would not have been able to participate due to the logistics of commuting to meetings at the PPA office in Leeds. This suggests that online methods may be beneficial for reducing common barriers to research faced by adults with learning disabilities.

Participants who expressed an interest in the project during this first phone call received a follow-up phone call from PPA staff in July, inviting them to watch and complete the activities in the research taster videos to help them to decide if they would like to participate in the project (see 3.3.1). The research taster videos were also circulated on PPA's social media platforms. Participants who were interested in becoming a co-researcher in the present study were invited to watch an information video to learn more about the project. This video was designed to be an accessible variation of a traditional information sheet. Having watched the video, participants were invited to complete the online consent form, using the consent video as a guide to help them, if required.

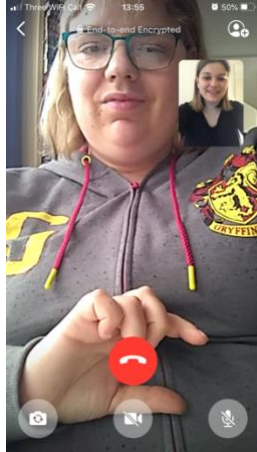
#### 3.4.2 One-to-one meetings



One-to-one preliminary meetings were arranged with all co-researchers who consented to participate in the project during August 2020. Six meetings were conducted using Zoom, and one meeting was conducted over the phone. The aim of these meetings was to get to know each co-researcher, including their interests, experiences of research and any personal or communicative needs the UR needed to be aware of. Understanding the co-researchers' needs and interests was crucial to designing initial activities which were accessible and fun. For example, the initial meeting with John shared that he found typing challenging due to limited movement in his hands. The UR was therefore able to arrange phone calls with John to discuss the research when needed. Additionally, one-to-one meetings revealed co-researchers had a broad range of arts-based interests. This led to the decision to provide different methods of accessing the same activity (e.g. the PPA Worlds activity described in section 3.4.7 was provided as both a visual arts-based activity and a story writing activity). The UR also encouraged co-researchers to ask any initial questions they had about the research and co-researchers were informed about the next steps in the project. Namely, that they would be invited to join a Facebook group where they could introduce themselves to other co-researchers, and that following this they would be contacted regarding the first research activity, which would help the group to choose their research themes for the year. The UR also used these meetings as an opportunity to find out how each individual felt about



being a researcher, including how confident they felt about undertaking research, why they had decided to sign up for the project, and any skills that they were hoping to learn/improve through the research process. The UR took notes about the content of each meeting, and took a photograph of each co-researcher indicating how confident they felt about undertaking research on a virtual scale. This exercise was intended to be an accessible baseline measure of the individuals' confidence, prior to undertaking any research. Co-researchers who indicated they were at the top of this virtual scale (held their hand high in the air) felt confident about undertaking research, and those who indicated they were at the bottom of the scale (held their hand lower) felt less confident about undertaking research. The researcher also confirmed how confident each individual felt verbally and/or by providing options to non-verbal co-researchers. Consent was obtained from each individual at the start of the meeting and prior to taking the photograph.


Table 3 details the range of skills co-researchers reported they hoped to improve through participation in this project, how confident they reported feeling about undertaking the research (including a photograph demonstrating this, if consent has been provided), and the reasons they provided for signing up to the project.

Table 3: Co-researchers' motivations for participation in the project and their self-confidence in conducting research

Co-researcher	Reason(s) for signing up	Skills to improve	Confidence in conducting research	Photograph indicating confidence
Tracey	<ul style="list-style-type: none"> <li>To use their experience to help and share ideas</li> </ul>	<ul style="list-style-type: none"> <li>Improve writing</li> <li>Helping others</li> <li>Knowledge of the research/publishing process</li> </ul>	Low	 <p>A screenshot of a video call interface. The main video shows a woman with glasses and a grey hoodie with a yellow logo. A smaller inset video shows another person. The interface includes a red hang-up button at the bottom center and icons for camera, mute, and video off at the bottom. The top of the screen shows 'Hand-to-hand Encrypted' and a battery icon.</p>
John	<ul style="list-style-type: none"> <li>"If I can help I will, I like to talk – with lockdown, it's good to talk to someone outside of your environment"</li> <li>Has shared his experiences as part of other research projects</li> </ul>	<ul style="list-style-type: none"> <li>Learning how to publish</li> </ul>	Medium	<p>One-to-one meeting was undertaken on the phone therefore it was not possible to capture a photograph of John's research confidence.</p>

Ella	<ul style="list-style-type: none"> <li>• “I’m interested about Purple Patch”</li> <li>• Wants to share the experience of PPA with other people</li> </ul>	<ul style="list-style-type: none"> <li>• Confidence skills</li> <li>• Speech</li> <li>• Cutting (using scissors)</li> </ul>	Medium	
Leanne	<ul style="list-style-type: none"> <li>• “Give me something to do until we’re back to normal”</li> </ul>	<ul style="list-style-type: none"> <li>• None stated</li> </ul>	Medium	

Liam	<ul style="list-style-type: none"> <li>• “I want to share what I know about PPA to a load of different people”</li> <li>• Experience in leaderships roles in other organisations (e.g. membership of boards)</li> </ul>	<ul style="list-style-type: none"> <li>• How to collaborate and bring research together</li> </ul>	Medium	
Charlie	<ul style="list-style-type: none"> <li>• Likes being around new people</li> </ul>	None stated	Medium	

Sam	<ul style="list-style-type: none"><li>• Likes talking to people, looking for things and finding things out</li></ul>	<ul style="list-style-type: none"><li>• Helping other people</li><li>• Helping to organise things</li></ul>	Just above the medium	
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### 3.4.3 PRG Facebook group

A Facebook group was set up for co-researchers to join in August 2020. Previous PAR projects have utilised online platforms, including Facebook, to connect disabled co-researchers and provide a space for discussion, decision making and sharing experiences (Liddiard et al., 2018). The PRG Facebook group formed the basis of our virtual research community, connecting all seven co-researchers, the UR and invited parents and carers. Upon the creation of the PRG Facebook group, co-researchers were asked to co-create group guidelines for the page and for the project as a whole to ensure everyone felt comfortable and safe. These were:

- Be kind to each other
- Be supportive and encourage each other
- Listen to each other
- Work as a team
- Give each other a chance to speak

Throughout the project, co-researchers were encouraged to interact, share their ideas, make decisions together and share their work in this virtual space. Co-researchers also used the Facebook group to share news and achievements, new ideas for the research, and to support each other's work (see figures 5, 6 and 7). The interactive features of Facebook groups (such as polls, reactions, emojis and gifs) were also used as an accessible tool to gain co-researchers' perspectives on a topic and to obtain co-researchers' availability for research sessions. The group was also used by the UR to share important information, such as links to research meetings and important dates.

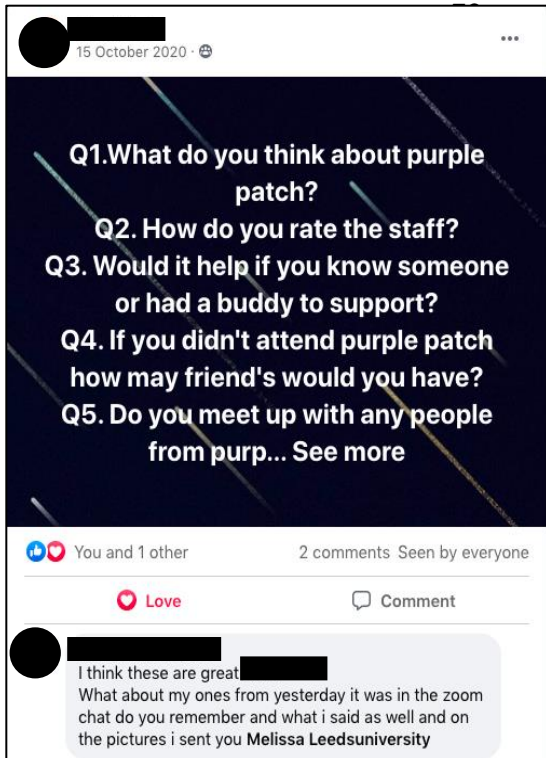


Figure 5: A co-researcher shares their ideas for research questions in cycle one



Figure 6: Co-researchers show their support for a researcher's work

The Facebook group served as a useful log of the activities and decisions that were made throughout the project, as well as capturing the progress made by researchers as they became more confident using online platforms. For example, one researcher who had previously communicated exclusively through her parent/carer's Facebook account began to post independently and interact with others in the group. This was noted by the researcher's



parent, as can be seen in figure 7.

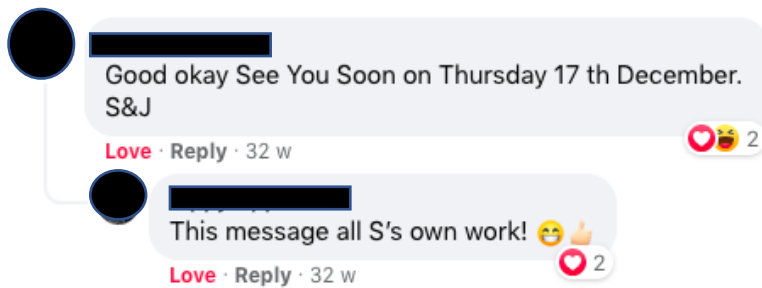


Figure 7: Sam posts independently on the Facebook group for the first time

#### 3.4.4 Research meetings

All research meetings for the present study took place online due to COVID-19 pandemic. Accessibility was a key consideration when setting up online research sessions. Allam et al. (2021) note the risks of digital exclusion associated with online methods. While online research sessions were unavoidable, it was important to select the right platform. Through consultation with PPA, Zoom was chosen as the most appropriate platform for research meetings. A key reason for this was that Zoom was used as the platform for PPA programmes throughout the pandemic, and co-researchers therefore already had some experience with Zoom. Previous research suggests that Zoom is an accessible platform for online collaboration (Daniels et al., 2019) and was therefore a common platform for PAR during the Covid-19 pandemic (De Castro et al., 2023; Pettican et al., 2023).

To support digital inclusion, PPA provided practical and logistical support to ensure co-researchers were able to access research sessions (e.g. by providing iPads to individuals who did not have access to a device and by coaching co-researchers through the process of accessing Zoom over the phone). The 'personal meeting room' on the UR's university Zoom account was used for the duration of the project. In line with previous PAR conducted on Zoom by De Castro et al. (2023), co-researchers were supported to access the virtual space, by ensuring the virtual room was accessible via the same link each week and did not require a password to enter. For safeguarding purposes and to ensure that the virtual room was only accessed by those within the research team, co-researchers entered a virtual waiting room before being manually added into the meeting room by the UR.

Co-researchers attended research meetings in two smaller groups of approximately two-four co-researchers, according to their availability. Smaller Zoom groups enabled all co-researchers to contribute to meetings, discuss topics with each other and for the UR to support individual co-researchers to undertake activities when needed. Research sessions

took place every other week and mostly lasted for one hour, with the occasional longer meeting during the data collection stages (up to a maximum of two hours). In-between meetings, co-researchers often opted to complete additional research tasks (e.g. writing stories about the research theme), as well as sharing their work on the Facebook group, and interacting with each other online. However, not all co-researchers engaged with research activities outside of meetings. It was therefore important that key research activities took place during the project's official meetings, where the UR could support them. A range of accessible resources were also provided to/developed for the group to aid their involvement in the project. These will now be introduced in turn.

#### 3.4.4.1 Research packs

All co-researchers received a research pack, which was posted to their preferred address. The pack included a research journal, which was intended for co-researchers to document their experiences of the project, complete activities in and make notes from meetings, should they wish to. Research journals were A4 and contained blank pages to ensure that co-researchers were able to write, draw or stick things in, depending on their preferences. Using blank journals meant that co-researchers were not limited by lined pages, which imply that writing is essential. The research packs also included some essential stationary items, such as pens, pencils, erasers and highlighters and a plastic folder to keep work together. Each co-researcher was also provided with a lanyard for them to wear during group calls/meetings, which distinguished them as a researcher. These lanyards were intended to help the group to feel unified in their new role as researchers, particularly as meetings were not able to take place in person.

#### 3.4.4.2 Easy read literature

Throughout the project the PRG were presented with easy read versions of relevant literature to support their understanding of different topics, contextualise their ideas and support them to make decisions concerning research questions and methodologies (see example in appendix F). Easy read or easy-to-read materials adapt information using simplified language, images, symbols, colours and layout to make it easier to read and understand (Nomura, 2010). Easy read documents have previously been used to support adults with learning disabilities' understanding of important topics, such as sex education (Garbutt et al., 2010), what to do if you have coronavirus (Mencap, 2022) and building the right support (NHS England, 2015).

In the present study, easy read versions of key literature were created by the UR. This was necessary as very little published literature is accessible to adults with learning disabilities, thus excluding them from engaging with previous research that is relevant to the project. The UR used their previous experience of creating easy read documents in previous research and through their role as a support worker to re-format journal articles which were relevant to the present study. The UR also utilised guidance provided by CHANGE (2016) concerning how to produce easy read documents. The UR first familiarised themselves with relevant previous literature, before noting down the most important points concerning the research aims, methods and findings. These points were presented in simplified language alongside a corresponding image which sought to capture the content of the text. Co-researchers were often asked to provide feedback on resources and information, to ensure that these materials were accessible to them, and to other adults with learning disabilities. These adapted research papers therefore became an important resource and were used to support the planning stage of each cycle of research in the project.

#### 3.4.5 Communicating ideas and preferences

Throughout the research, members of the PRG used multiple methods of communication to share their views and opinions. Six co-researchers predominantly communicated verbally, with support from alternative methods of communication, such as: signing (Makaton and British Sign Language), symbols, gestures (e.g. thumbs up/down), typing in the chat/on the Facebook group, emojis and videos. Sam was supported to communicate in research sessions by her parent/carer, Janine, who became a core member of the research group. Additionally, Charlie predominantly communicated via eye gaze, with support from his support worker Jo. Eye gaze is a form of non-verbal communication which involves using eye movements to communicate. Those who use eye-gaze may also use a device such as a tablet, which supports the user to make choices and share their views by controlling a mouse with their eye movements (Najafi, 2008). Co-researchers were asked how they prefer to communicate and share their ideas during their initial one-to-one sessions. This was to ensure that the UR was sharing information in ways that were accessible and engaging for all members of the group.

The UR also utilised tools on Zoom such as the screensharing, the whiteboard and the chat function, to facilitate multiple methods of communication with co-researchers. For example, the UR shared documents and images via Zoom (such as easy read literature or co-researchers' artwork) so that all co-researchers could engage with and respond to these documents simultaneously. Similar tools have been used in previous online PAR with adults

with learning disabilities on Zoom to facilitate interaction and communication (De Castro et al., 2023)

As much as possible, co-researchers were asked, and encouraged to ask, open-ended questions to ensure there were opportunities for them to openly share their views and opinions. For example, during each cycle, co-researchers were asked ‘what would you like to find out about people/arts and variety/accessibility and support at Purple Patch?’. Open-ended questions such as these supported the group to share their interests without influence from the UR. However, depending on the topic being discussed, the UR also provided options for co-researchers to choose between, to support the group to make decisions concerning the direction of the research. This was particularly important during the early stages of the project when co-researchers were less familiar with research processes, methodologies and practices.

While choosing from a list of options may be considered as a less flexible way for co-researchers to share their personal views, the PRG considered pre-determined options as a more accessible way to support adults with learning disabilities to share their preferences. Here Leanne suggests using options as part of a self-reflective questionnaire about accessibility at PPA in cycle three:

UR: do you think, should we ask on the questionnaire how people get there?

Leanne: yeah

UR: so, how do you get there... okay and then, what kinds of things about transport...

Leanne: we could do some options: a car, bus or a taxi

#### 3.4.6 Cycles of research

PAR consists of three key phases of planning, action and review. In the present study, these phases are present across the project as a whole, and within each ‘cycle’ of research (see figure 8). The present study consisted of three main cycles, each corresponding to a chosen theme (discussed further in section 3.4.7). The number of cycles in a PAR project varies and is usually flexible depending on the needs and goals of the project (Kelly, 2005). In the present study cycles of research were mapped to the three terms at PPA, to provide a clear structure for co-researchers. Each cycle therefore lasted between 11-13 weeks. In keeping with previous research which outlines the framework of PAR (Kelly, 2005; Pettican, 2022), each cycle in the project consisted of a planning, action and review phase. However, as Garcia-Iriarte et al. (2009, p.14) note, these phases “flow into each other and generate a cyclical process of praxis (action and reflection)”. Within the context of the present study, each stage involved the following:

**Planning:** Looking at previous literature linked to the theme (presented in an easy read format), choosing research questions, choosing appropriate methods

**Action:** Completing an ethical review (when required), collecting data based on the chosen methods, group discussions about the theme, and (from cycle 2 onwards) implementation of feedback/recommendations with PPA (e.g. feedback meetings with PPA staff)

**Review:** Data analysis and discussion about findings, reflection on next steps for the research (e.g. what have we found out? What is still unknown?). Feedback and recommendations made by the group for PPA and/or other organisations are fed back and/or implemented to improve or enhance their services.

A timeline presented in easy read format outlining the dates of each cycle and the stages of the research was provided to co-researchers. However, as will be discussed later in this thesis, activities often took longer than anticipated.

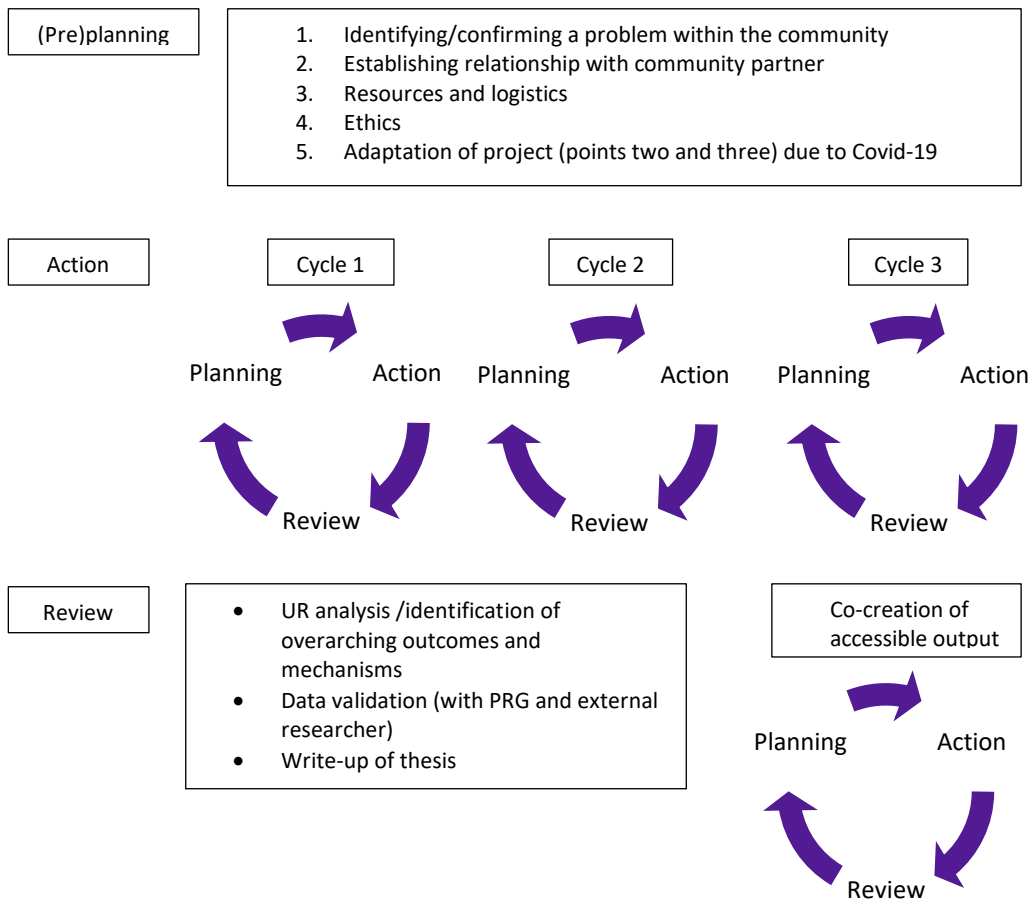


Figure 8: Outline of the structure of the project

### 3.4.7 Selecting research themes

In this project, each 'cycle' was assigned a theme. The decision to theme cycles was made for several reasons. Firstly, because the aims for this project were broad, having a theme for each cycle allowed the group to narrow down which specific area of their experience they were most interested in and ensured that research meetings and activities were organised and focused. Additionally, the idea of 'themes' mimics the structure of PPA, which has a theme for the year, and subsequent themes for each week of the programme. Co-researchers stated that they enjoyed having a theme to work to ("I think having a theme is good" – John, C1), and so it was decided that the research would be organised into three cycles, each with its own theme.

The next stage of the project was to select the themes. To do this, co-researchers were invited to complete an activity which was designed to aid reflection on the different components of their PPA experience. This activity ('Purple Patch Worlds') combined elements of creative methods, such as draw, write tell, and storytelling. For this activity researchers were asked to imagine that PPA was its own world, and consider what that world felt like, looked like, and sounded like, as well who would be there, and what kinds of things they would be able to do there. Co-researchers were given the choice of physically creating their world using arts and crafts materials or writing a story about their PPA world. These options were provided to allow researchers to select their preferred art form, as well as to account for variations in writing ability. An interactive video was created using Powtoon showing the UR creating her own PPA world as an example. Co-researchers were also given a list of prompts to help them, and those who chose to write a story were given the following story stem: "Once upon a time there was a mysterious world called Purple Patch, home to the purple people. The purple people had many adventures, and this is their story..."

Five co-researchers completed this activity. One co-researcher opted to create a PPA world (see figure 9), and four co-researchers chose to write a story (see appendix G). This was a little unexpected, as since many members of the PRG found writing challenging, the UR anticipated that most of the group would opt to do the activity that required the least writing. This was an early example within the project of the PRG challenging misconceptions surrounding people with learning disabilities, and their desire to participate in tasks which may challenge them. This example also served as important learning for the UR regarding the importance of reflecting on one's own assumptions in research concerning disabled people, to avoid unintendedly limiting co-researchers' experiences.



Figure 9: Charlie's Purple Patch Arts world

The content of the co-researchers' worlds were varied, and each co-researcher approached the activity slightly differently. A similarity across the responses to this activity was that co-researchers viewed their Purple Patch worlds through the lens of the Covid-19 pandemic. As a result, many co-researchers commented on the impact of the pandemic on their attendance at Purple Patch, and cited aspects of the experience that they missed, including seeing friends and family ("I miss seeing everybody in person" - Ella) not being able to leave their homes and their feelings around forced periods of quarantine ("In March a big purple virus called Covid-19 arrived, which makes you sad and miserable and stay at home" - Leanne) and attending PPA in person ("my world would be virus-free and it would also be able to travel [where we] would like to go" - John).

Analyses of these Purple Patch worlds were conducted by the PRG across two meetings. Co-researchers were shown each other's responses to the task and asked to identify aspects of each other's worlds that they felt were most important or interesting. This analytical technique is similar to those used in previous PAR projects (e.g. Stevenson, 2014). In Stevenson's (2014) work, co-researchers were asked to highlight or underline parts of an interview transcript which they deemed to be important or interesting. This was followed up by a group discussion about their analyses. Due to Covid-19 restrictions it was not possible for co-researchers to meet and physically annotate each other's work. Instead, the things that co-researchers found most important/interesting from each other's work were discussed as a group via Zoom, and responses were logged in a world cloud using Menti Meter. Figure 10 shows the word cloud that was produced from these meetings. Larger words were

mentioned by multiple people (e.g. 'friends' was mentioned by five co-researchers). Co-researchers were supported to identify three research themes for the group, using the word cloud to guide them. A discussion about potential themes was initiated on the Facebook group, with co-researchers commenting their suggestions. Three overarching themes were identified, and each assigned to a cycle:

- Cycle one: People (Social Connections). This theme was based around exploring social connections at PPA, and encompasses co-researchers' discussions about friends, family, staff and helping others at PPA. This theme also explored how social connections at PPA impacted the co-researchers' social experiences outside of the programme.
- Cycle two: Arts and variety (Programme Content). This theme was based around the programme content at PPA. In particular this theme addressed the co-researchers' discussions regarding the 'variety' of the programme content at PPA, including the variety of art forms used, activities, and the different views and strengths of participants.
- Cycle three: Accessibility and Support (Programme Accessibility). This final theme explored accessibility and support at Purple Patch, and the aspects of the programme that contribute to creating an accessible learning environment.



Figure 10: Word cloud produced by the PRG



### 3.5 Analysis

#### 3.5.1 Types of data

As with many PAR projects, the present study utilised a range of methods (including self-report, online, qualitative and creative methods) resulting in the collection/creation of a broad range of data. The main types of data included in the present study are<sup>5</sup>:

- Transcripts of research sessions and final interviews
- Poems and stories written by the PRG in response to a predetermined theme and/or question
- Questionnaire responses from the PRG
- Visual data created in response to a predetermined theme and/or question, including artistic responses, drawings and photographs
- Data from digital interactions with co-researchers, such as posts and comments from the PRG Facebook group, and transcripts of voice notes

Data were collected to support the PRG's understanding and reflections of their experiences of arts-based learning at PPA. Transcripts of research sessions therefore provided a valuable insight into the co-researchers' experiences and perspectives and were also used to inform understanding of other data types. For example, since data were usually collected and/or created during these research sessions, transcripts provided contextual information, which aided the analysis of visual and arts-based data in particular. However, transcripts of research sessions also provided a detailed overview of the co-researchers' engagement with the project, including the decision-making processes, how data were collected and analysed throughout the study, and the co-researchers' reflections on their experiences as researchers. Previous literature has commented on the lack of transparency in PAR projects, particularly in relation to the roles of co-researchers (including what co-researchers did and how they did it; Smith et al., 2022). As the present study also aims to explore and share the co-researchers' experiences of PAR, transcripts which captured the process of designing and delivering research collaboratively with adults with learning disabilities were also considered as data in themselves. Therefore, due to the breadth of materials and 'types' of data in the present study, the approach to analysis of these data depended on the data type, when and how the data were collected, and the research question being addressed. Approaches to

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<sup>5</sup> Examples of these data are included throughout this thesis. Additional examples are available on request.

analysis will be discussed further in the following section.

### 3.5.2 Approaches to analysis

Two broad approaches to analysis can be observed in this project. The first, collaborative analysis, refers to analyses completed collectively by the PRG (i.e., those included in cycles one, two and three). The second approach is UR analysis. This analysis was completed independently by the UR after all cycles of research were complete. The following sections provide additional information about each approach to analysis, the types of data that were analysed via each approach, and the specific analytical techniques utilised (including who did what, and any adaptations that were made to these techniques for the purpose of this project).

#### 3.5.2.1 Collaborative analysis

In keeping with the participatory nature of this project, co-researchers analysed the data collected in each cycle of research jointly in a process of 'collaborative analysis'. This involved utilising adaptive approaches to data analysis to ensure that all members of the group could contribute to this important stage of the project. People with learning disabilities are often excluded from the data analysis stage of research (Rickson et al., 2014; Stevenson, 2014). As such, there is a lack of guidance available for involving people with learning disabilities in the data analysis stage. The present study therefore drew influence from the small number of PAR projects where adults with learning disabilities were actively involved in collaborative analysis.

Previous examples of adaptive analytical techniques in PAR projects include asking co-researchers to highlight or underline parts of an interview transcript which they deemed to be important or interesting (Stevenson, 2014). In Stevenson's (2014) research, co-researchers were also encouraged to make notes about why they had highlighted particular words or phrases. This was followed up by a group discussion about their analyses. Another way in which previous research has adapted an analytical approach to suit the needs of individuals with learning disabilities is by asking co-researchers to search for textual data which fits pre-determined themes. Rickson et al. (2014) asked co-researchers to cut up entries from their own and others' research diaries and sort these entries into pre-themed cardboard boxes, which represented what was 'good', 'bad', 'hard' and 'easy' about attending the music therapy group they were evaluating. Co-researchers were then supported to look at the contents of each box and sort these entries into further subthemes. Similarly, to Rickson et al.'s approach, Williams (1999) supported co-researchers to analyse

interview transcripts based on predetermined themes. Themes were assigned to individual co-researchers who were responsible for cutting and pasting quotations from interview transcripts into theme 'sections'. Williams (1999) describes this approach as adaptive thematic content analysis.

An example of an analytical approach which has been used in PAR projects with non-textual data is photo elicitation. This technique is usually undertaken as part of photovoice, a method whereby co-researchers take photographs which capture their experiences, usually in line with a particular theme (Aldridge, 2007). Photo elicitation techniques involve interviewing the participant about the content of their photographs, thus gaining an insight into their individual worlds (Aldridge, 2007). Participants may also undertake sorting activities with their photographs, for example by organising photographs into particular themes or identifying photographs which are their favourite/most important to them (Aldridge, 2007; Booth & Booth, 2003). This type of analysis also has the potential to be applied to other forms of art, such as drawings and paintings (e.g. the analyses of drawn diary entries in Rickson et al., 2014).

The present study utilised an adaptive form of thematic analysis to collaboratively explore the data across all three cycles of research. This qualitative analytical approach, based on the principles of thematic analysis (Braun & Clarke, 2006), involves generating codes and themes at different levels of abstraction, in an accessible way which does not rely on prior knowledge of analytical techniques. Data analysed in this way included artwork, stories, poems and posters produced in research sessions alongside interviews with co-researchers. For the members of the PRG, the present study was their first experience of undertaking research, and therefore of being involved in the analysis of data. In the present study, explaining the process of analysis and the steps involved was a lengthy process, and co-researchers initially found the idea of picking out recurring and/or important themes in the data challenging. For example, initially the group approached the task by listing every feature on a piece of work, rather than searching for recurring interesting ideas. For the first cycle of analysis there was therefore a process of trial and error, with the UR providing guidance to co-researchers on what to look for in the data, and how to identify important features. For example, by asking co-researchers to consider what the most important feature of a poster, sentence or story was or by asking them to sum up their work in just a few words.

Despite this, co-researchers provided insightful and unique perspectives on the data and identified themes. The PRG conducted their analyses in two groups over several weeks in each cycle. Analysis sessions were undertaken solely online in cycles one and two, and online and in person in cycle three. The specific techniques utilised to support adaptive analysis will

be described in further detail in the analysis section of each cycle. However, table 4 provides an overview of the collaborative analytical process undertaken in each cycle, alongside the perceived level of involvement from co-researchers, based on Bigby and Frawley's (2015) approaches to the inclusion of people with learning disabilities in research. As co-researchers gained more experience and therefore confidence with analysis, the group took more ownership over the process and their level of participation therefore increased.

*Table 4: Analytical process and level of involvement from co-researchers in the analysis stage of each cycle of the project*

	Analytical process	Level of participation based on Bigby and Frawley's (2015) approaches to inclusion
Cycle 1 Analysis	<ul style="list-style-type: none"> <li>• Co-researchers identified important/interesting aspects of each other's work, which led to the identification of initial codes. The UR wrote these down on post-it notes.</li> <li>• The UR organised these codes into themes.</li> <li>• Co-researchers 'checked' themes by cutting and organising their work into four categories.</li> </ul>	Advisory
Cycle 2 Analysis	<ul style="list-style-type: none"> <li>• Co-researchers identified important/interesting aspects of each other's work, which led to the identification of initial codes. The UR wrote these down on post-it notes.</li> <li>• Co-researchers organised these codes into themes in online research sessions, with support from the UR</li> <li>• Co-researchers named and wrote descriptions of the groups.</li> </ul>	Collaborative group
Cycle 3 Analysis	<ul style="list-style-type: none"> <li>• Co-researchers identified important/interesting aspects of each other work, which led to the identification of initial codes</li> <li>• Co-researchers organised these codes into themes (with minimal support from UR)</li> <li>• Co-researchers mapped themes out physically using a large piece of paper to indicate relationships between ideas</li> <li>• Co-researchers discussed these themes at a higher level of abstraction, making attempts to understand the underlying relationships, feelings, experiences and processes which informed their interpretation of the data</li> </ul>	Leading and controlling

### 3.5.2.2 University Researcher analysis

The second approach to analysis in the present study was UR analysis. Participatory approaches to research should aim to involve disabled people in all stages of the research (Johnson & Walmsley, 2003). However, as Nind (2008) notes, co-researchers are often excluded from data analysis in participatory projects. Atkinson (2004) suggests that in order for adults with learning disabilities to be actively involved in analysis, time, space, support and practice are all required. In the present study, the time constraints of doctoral research

meant that co-researchers were not able to revisit all of the data produced in the present study. For example, while the PRG were actively involved in the analysis of all data produced within research sessions, transcripts of the research sessions themselves were not analysed by the group. It was, however, important for these transcripts to be analysed, as they included important discussions which contextualised the co-researchers' experiences at PPA, alongside insights into the process of conducting research (as discussed in section 3.5.1).

Due to the time constraints of the project (and time-consuming nature of PAR; Byrne et al., 2009; Cook, 2012) the PRG chose to focus their research on three themes. These themes were selected as the PRG considered them to be the most important aspects of their experiences at PPA. However, during the year-long period of data collection, the PRG discussed a much wider range of experiences, outcomes and characteristics of PPA than those the group chose to focus on. While these additional aspects were not directly investigated during one of the three cycles of research, they nonetheless impacted the PRG's experiences of inclusive arts-based learning at PPA. Additionally, transcripts of research meetings provided important insights into the process of designing and delivering PAR with adults with learning disabilities. Therefore, analysis of research sessions by the UR was included in order to ensure that the co-researchers' varied experiences (both at PPA and of PAR) were represented. This was a conflicting decision, as the present study attempted to actively involve co-researchers at all stages of the study, including data analysis. This is one of several examples where the requirements of the thesis and/or of doctoral research directly conflicted with the values of participatory research, forcing the UR to make decisions which felt uncomfortable and at odds with the aims of the project (discussed further in section 10.1.1).

The UR conducted two thematic analyses of these transcripts, following the principles of Braun and Clarke (2006). It was important to keep the analyses undertaken by the PRG intact to avoid re-analysing data and undermining the PRG's involvement in the project. Therefore, only data that had not previously been analysed through the process of collaborative analysis outlined above was included in the UR's analyses.

The first thematic analysis conducted by the UR sought to address research aim one, by identifying the outcomes of participation in PPA that had not previously been identified by the PRG through collaborative analysis. All transcripts from across the three cycles of research (57 transcripts in total) were included in this analysis. These included transcripts of research sessions and final interviews conducted in cycle three. After a process of familiarisation with the data, transcripts were analysed for recurring ideas relating to the outcomes of engagement with PPA. Initial codes were used to identify recurring ideas in the

data. At this stage, any codes that had been previously identified by the PRG were excluded from the analysis to avoid re-analysing previously coded content. Remaining codes were collated into themes and reviewed against the data set. In some instances, newly identified themes were closely related to pre-existing themes identified through the PRG's collaborative analysis and were therefore included as part of these themes. For example, the UR's analysis resulted in the identification of a group of codes relating to ownership and pride of creative outputs. These codes were closely related to the theme 'Being (and sharing) you', which was identified by the PRG through collaborative analysis in cycle two. The theme 'ownership and achievement' was therefore included as an additional sub-theme of the theme 'Being (and sharing) you' (C2). Where codes were not included as part of pre-existing themes, related codes were grouped together to form new themes. These themes were then compared to the original data set to ensure they accurately represented the data. New themes generated through this approach included 'Learning with, from and through the arts' (C2) and 'Whose responsibility is accessibility?' (C3), which was included as part of the reflections and recommendations section in cycle three.

The combined analyses of the UR and the PRG from all three cycles of research resulted in the formulation of 5 top-level categories concerning the overarching outcomes of engagement with the PPA for co-researchers (discussed in chapter 8). Finally, top-level themes were integrated to formulate a substantive theory, which extends beyond identifying the outcomes of participation in the PPA programme, to identifying the underlying mechanisms that support these outcomes. These 5 mechanisms are discussed further in section 8.1.

It was important for analyses undertaken by the UR to be validated by the PRG, to ensure they accurately represented their experiences. This was achieved by presenting the results of the analysis back to the group in an accessible/creative format. The metaphor of a 'Purple Patch Potion' was used to share the combined results of analyses conducted by the UR, alongside analyses conducted collaboratively by the group in cycles one, two and three (see chapter 8 for further discussion about the PPA Potion). The potion's 'ingredients' included the themes generated from the three cycles of research, alongside the mechanisms identified by the UR through their independent analyses. Combining these 'ingredients' provides an impression of the co-researchers' experiences at PPA. The overarching outcomes of engagement with the PPA were described as the 'effects of taking the potion'. This symbolised that the co-researchers' experiences relating to 'People', 'Arts and Variety' and 'Accessibility and Support' at PPA interact with the underlying mechanisms within the programme, resulting in outcomes across five key areas. The UR created a visual

representation of the 'Purple Patch Potion', which included symbols and simplified text, using Canva. An image of this visual aid was shared with the co-researchers with the PRG Facebook group. Co-researchers were asked to share their feedback on how accurately the potion depicted their experiences, to ensure the codes and themes identified accurately reflected their experiences at PPA. Co-researchers provided positive feedback regarding the validity of this conceptualisation of their experiences through 'reactions' (e.g. thumbs up and love heart reactions), Facebook comments (see figure 11) and during a group discussion on Zoom during the concluding stage of the project (see section 7.2.2.1)

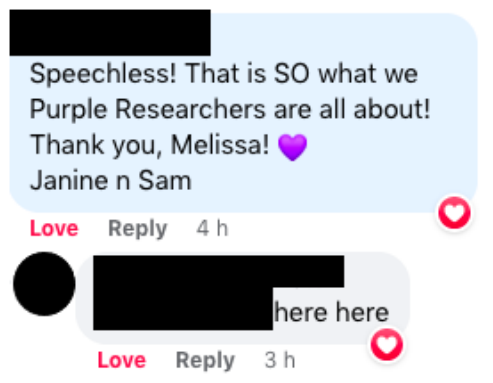


Figure 11: Screenshots of co-researchers' reactions to the 'Purple Patch Potion'

The second thematic analysis conducted by the UR sought to address research aim three, by identifying the outcomes of engagement in PAR from the perspective of co-researchers. Co-researchers shared their reflections on their involvement in the project in all three cycles of research. Since data relating to this aim had not previously been analysed by the group, all transcripts of research sessions were included in this analysis, alongside data from digital interactions with co-researchers (e.g. Tracey's reflections on being a researcher, which were sent via a voice note) and transcripts of the PRG's final interviews from cycle three. Following the same process of thematic analysis outlined above, five top-level themes relating to the co-researchers' experiences as researchers were identified. As with the previous analysis, results were shared with the PRG to assess the extent to which the identified themes represented the co-researchers' experiences of PAR. Co-researchers confirmed that the themes identified by the UR accurately represented their experiences during a group session in the concluding phase of the project.

### 3.5.3 Data validation

The nature of PAR meant that some data were validated by the PRG through the process of collaborative research. For example, since data validation was built into the collaborative analysis process (see section 3.5.3), data collected by the group in cycles one, two and three of the research were not validated by an external researcher. Additionally, analyses conducted by the UR and PRG, which identified the overall outcomes of engagement in the PPA programme, alongside the underlying mechanisms that contributed to these outcomes were validated by the PRG via engagement with the 'Purple Patch Potion' described above.

To avoid undermining the work of the of the PRG, only data that had not previously been analysed by the group were selected for data validation with an external researcher. Data which met these criteria concerned the PRG's experiences as co-researchers in the project. While the PRG were involved in checking the themes identified by the UR to ensure they accurately represented their experiences as co-researchers, they were not involved in the analyses of these data due to the time constraints of the project.

Co-researchers discussed their engagement with PAR and the outcomes of their engagement in the research throughout the project. These reflections were therefore intertwined with data relating to other research questions. Consequently, it was not possible to extract these data pertaining to outcomes of engagement with PAR for data validation. Instead, a sample selection of transcripts from cycle three of the project, which focused on the PRG's reflections on being a researcher were shared with an external researcher who was not associated with the project. These extracts included the co-researchers' final interview transcripts and in-person research day transcript, which included a session reflecting on the PRG's role in the project.

The external researcher conducted their own independent analysis of the sample data, following the principles of thematic analysis outlined by Braun and Clarke (2006). The UR and external researcher compared their respective analyses of the data, which confirmed that most codes identified by the external researcher matched those identified by the UR. Where the external researcher had not identified codes, these were discussed, and the external researcher agreed that they accurately reflected the data. Discrepancies in coding were often due to the external researcher not having access to data from across the study, and therefore only having a snapshot of the co-researchers' experiences from the final stages of the project.

An interesting outcome of the data validation process was the identification of codes specifically relating to my role in the project. In particular, the external researcher's perception of my relationship of the PRG was considered as an important theme. While I had



considered the importance of the UR in PAR (in particular their approach to research, values and experiences) I had neglected to consider my personal impact on the project and in particular, on the relationships developed with the PRG. The external researcher's reflections on the data considered the relationship they observed between the UR and co-researchers as a central theme:

Much of the coding focused on factors external to the researcher co-researcher relationship. However, there are clear instances where the lead researcher's (MK) specific place within the research was drawn into focus. Here the narrative focuses on the way that co-researchers uniquely trusted MK and that their ongoing engagement with research activity depended upon the presence of this trustworthy relationship. In this respect the lead researcher themselves appeared central to these codes emerging from the interview transcripts.

It is therefore clear that my personal role in the project had a greater bearing on the co-researchers' engagement with the research than I had initially identified. Further discussions about the impact of the UR in participatory projects are included in section 10.7

#### 3.5.4 Reflexivity

Reflexivity refers to the continuous process of critical self-reflection, whereby the researcher examines the ways in which their background, experiences, assumptions, and opinions may affect their approach to research (Finlay & Gough, 2003). While reflexivity is an important practice in all social research, it may be particularly important for participatory/action researchers who are often "intimately involved with the subject and context of the research, as well as the practitioners that participate in it" (Lyngsnes, 2016, p.197). Indeed, Robertson (2000) states that "reflexivity is integral to the process of action research" (p.320).

Participatory research is, by its nature, a reflexive research process, which requires constant reflection of one's role in the research, the direction of research, remaining questions and recommendations for change (Robertson, 2000). In PAR projects, reflexivity is an important process for both URs and co-researchers, since the project is co-produced. Reflexivity may therefore be considered as a shared and collaborative endeavour (Olmos-Vega, 2023), which acts as an important tool to situate the research within its broader context (Finlay, 2002). Since there was more than one researcher in this project, this reflexivity statement will include reflection on the potential biases, assumptions and backgrounds of both myself, as the UR and the PRG, as co-researchers.

As a research team we came to this project from very different backgrounds, and therefore different expectations, assumptions and experiences. My position within the research is impacted by my six years of experience as a support worker supporting disabled young people, including autistic young people and children with learning disabilities. It was

my experiences and observations as a support worker that led to me to undertake research exploring the musical experiences of autistic young people for my Masters dissertation (Kirby & Burland, 2022), and later to this doctoral research topic. I therefore began this research with direct experience of working with and supporting disabled people in a range of contexts and of using varied communication styles (including Makaton) and adapted research methods to support disabled people's engagement with research. I also began the research with a good understanding of learning disabilities and of the support needs of people with learning disabilities, alongside pre-established beliefs that adults with learning disabilities should be directly involved in research. These views and experiences undoubtedly shaped and influenced the research process. Nevertheless, as a researcher who does not identify as disabled, I believe that non-disabled people cannot be experts on topics relating to the lived experiences of disabled people and the choice of a participatory approach to the research is commensurate with this.

In contrast, my co-researchers began this project as experts by experience, both in relation to their experiences of learning disabilities and as PPA participants. One of the key strengths of collaborating with adults with learning disabilities in research is that disabled co-researchers bring their varied expertise, experiences and ideas to the research process, including the design of research, interpretation of data and approaches to dissemination. While none of the co-researchers had ever done research before, some had experience of interacting with researchers. The PRG therefore approached the project with varied expectations surrounding research and their role in the research. I was aware that my position as a non-disabled researcher based within a research institution may impact how I was viewed by co-researchers, and therefore how the group chose to interact and collaborate with me. Balancing power, control and hierarchy in PAR is challenging, particularly when working with individuals who are ordinarily excluded from research/from doing research (Baum et al., 2006). Research is often considered to be hierarchical, and given my position as a 'university researcher', it was important to consider that the group may view me as both an outsider, and as someone in a greater position of power than them. Reflecting on the roles and responsibilities of all members of the research team is therefore crucial to balance the varied expertise and experiences in a PAR project and to build an inclusive research environment.

Ruokonen-Engler and Siouti (2016) highlight the need for continuous reflexive practice throughout the research. It was therefore important to continually reflect on my role(s) in the research, to support co-researchers to take ownership over the research process and at times re-position myself within the project. In order to actively analyse my

approach to the research process, I kept a research journal and noted my reflections at key stages in the project. This was a useful tool to document my observations, experiences and feelings. Through my own critical reflection about my role in the research, I therefore also became a subject of research (a full exploration of the various roles I occupied in this project are discussed in chapter 10). Additionally, Atkinson (2005) states that it is crucial for participatory researchers to have people to talk to. Throughout the research I had regular supervisions with both my supervisors and with the CEO of PPA, where I was able to share my experiences in the project and raise any issues which I felt would benefit from further discussion (for example, discussing potential power imbalances in the research, sharing concerns regarding my responsibility for the welfare of co-researchers and challenges relating to conducting research in the Covid-19 pandemic).

The collaborative nature of PAR means that both the UR and co-researchers should be encouraged to reflect on their thoughts, action, and experiences throughout the project (Bergold & Thomas, 2012). Reflexivity in the present study was therefore a shared experience and involved reflective discussions with co-researchers throughout the project. Reflexivity was particularly important at the end of each cycle of research, as reflections on the research process so far guided the PRG's decisions concerning the approach to future cycles of research and facilitated the identification of recommendations for change. Co-researchers' reflections relating to the research process are included in the final section of each cycle of research. Additionally, their reflections on their experiences as researchers in this project are included in chapter 9. While PPA participants were best placed to evaluate their own experiences of arts-based learning at PPA, their experiences as current PPA participants had the potential to impact their approach to the research. Their position in the research may therefore be viewed as both a strength and a limitation. Co-researchers were encouraged to be open, honest and self-reflective and to utilise their research journals to make a note of their experiences and feelings throughout the project. Additionally, a collaborative approach to analysis ensured that all researchers in the present study were challenged to reflect on their assumptions and biases when analysing the data. The process of data validation described in the previous section also provided an additional perspective on the interpretation of these data.

### 3.5.5 Reporting results

Each cycle of research will be presented as its own chapter, split into planning, action and review sections. Planning sections include an overview of how the research in each cycle was planned, including decisions regarding how particular research questions and methods were selected. Action sections include an overview of how the research was implemented,

including specific details concerning the activities undertaken in each cycle, how these were adapted, what support was provided by the UR, and the materials used by the group for each activity. Finally, in review sections the approach to analysis chosen by the PRG will be presented, alongside the results of the cycle. Quotes from co-researchers, alongside examples of data collected in each cycle (see a full list of the varied data collected across the project in section 3.5.1) are included throughout each cycle of research. Quotes include the name of the individual who is quoted, alongside the cycle of research this quote is taken from. Details about which cycle the quote is taken from are either included in the description of the quote, or as a code which corresponds to that cycle (e.g. 'C1' included in brackets after a quote indicates that the quote was said in cycle 1). Unsurprisingly, many quotes are included in the chapter corresponding to the cycle in which they were said. However, on some occasions, quotations from one cycle are used to support statements in a different cycle. While cycles in the research were themed, the interconnected nature of the chosen topics meant that co-researchers' discussions occasionally ventured into other topics. For example, during cycle two (Arts and Variety), co-researchers discussed topics relating to cycle three (Accessibility and Support) while considering the accessibility of arts-based activities. In order to represent the co-researchers' views and experiences as accurately as possible, quotes included in the following chapters are considered to be the most representative examples of the co-researchers' perspectives on the topic, regardless of the cycle the quote was spoken in.

## 4 Cycle One – People

### 4.1 Planning

#### 4.1.1 Research Questions

In cycle one co-researchers chose to explore the impact of people at PPA. The planning stage of cycle one consisted of two one-hour meetings for each group. In these initial meetings the researchers engaged with previous literature that was related to the theme ‘people’ (Hall, 2012; Rickson et al, 2014). The UR prepared easy read versions of these papers, which included simplified text and images, outlining the key approaches and findings of this research, in line with the approach described in section 3.4.4.2. These were read together in the first research meeting. This was followed by a guided discussion on each paper, including their perceived strengths and weaknesses and observations on the chosen methods and key findings. The purpose of this activity was to provide the co-researchers with some context and to help them to focus on the theme, as well as to give examples of potential methods which may be used in their own work. These research examples included some projects utilising a PAR approach. This was important in order to model this approach to the group, and to demonstrate the role that people with learning disabilities can have in the research processes. Engaging with easy read literature was also used to introduce the researchers to some key terms which would be used throughout the project, such as ‘research questions’, ‘methods’ and ‘analysis’.

In subsequent meetings, the PRG worked together to decide on the research questions (RQ) for cycle 1. Initially the group brainstormed several questions about ‘people’ at PPA that they were interested in addressing. These questions were inspired by the previous research that the group had engaged with, as well as aspects of social relationships at PPA that interested them. Due to the time constraints of the cycle, three key questions were selected by the PRG as the focus of cycle one, these are:

RQ1: What motivates attendance at PPA?

RQ2: Are people important to our PPA experience? If so, why?

RQ3: What ‘roles’ do people at Purple Patch fill in our lives?

#### 4.1.2 Choosing methods

Co-researchers in the present study filled a dual role of co-researcher and PPA participant and were considered experts in their experiences at PPA and their lived experience of disability. Therefore, in this cycle (and subsequent cycles) methods were chosen to support co-researchers to draw on their expertise and reflect on their own and/or each other’s

experiences at PPA.

As with many PAR projects (c.f Liddiard et al., 2018; Rickson et al., 2014; White & Morgan, 2012), the present study makes use of multiple methods of data collection. The methods for cycle one were chosen collaboratively by the PRG, through a series of group discussions. The UR first introduced the group to methods that have been used in previous PAR projects, such as arts-based methods (Aldridge, 2007; Liddiard et al., 2018), interviews (White & Morgan, 2012) focus groups and research journals (Rickson et al., 2014) through easy read summaries of research. The group then discussed these methods and considered their application to the present study and their suitability to answer the research questions for cycle one. The UR supported these discussions, by asking the group to consider each question in turn and to think about ways they might be able to answer it. Prompt questions to aid these discussions included: who do you think could answer this question? (e.g. can we answer this question ourselves? Do we need help from anyone else?); What do we need to know to answer this question? (e.g. is the answer already in our heads? Is there anything we need to know before we answer this question?); How could we show others our answers to this question? (e.g. thinking about the methods we have looked at already, can we write, draw, speak, sign, sing, show or act out the answer to this question?). Alongside choosing methods which were appropriate for the research questions, the group aimed to select creative and accessible methods, which could be adapted to meet the diverse needs and interests of the PRG.

An additional consideration when choosing methods was Covid-19, which restricted the PRG's contact with others. Some of the PRG's initial ideas for data collection in this cycle involved recruiting other PPA participants. For example, the group discussed asking other PPA participants about their motivations for attendance at PPA. This approach would have allowed the PRG to explore a wider range of perspectives and experiences at PPA. However, the closure of PPA programmes due to the pandemic meant that it was impossible to access other PPA participants in-person. While PPA continued to offer an online provision for participants, it was decided after discussions with PPA staff and the PRG that these sessions would not be a suitable platform for undertaking research with other participants. The following factors were considered in this decision:

- Time - Online PPA sessions during the pandemic were significantly shorter than in-person sessions. Therefore, undertaking research within these sessions would have further reduced the time available for participants to access their usual PPA activities. This was a particularly important ethical consideration during Covid-19, where

opportunities for socializing and participation in activities for adults with learning disabilities were limited (Bartlett et al., 2022; Kim et al., 2021). Additionally, due to the range of communication needs and preferences within each PPA programme, multiple approaches to understanding participants' experiences would have had to be developed to ensure online data collection was accessible to all PPA participants. The development of such approaches on a large scale was not within the scope of this project.

- Ethical considerations – Obtaining informed consent from adults with learning disabilities online (particularly in a group context) was considered to be a challenge to ethical recruitment. Many participants at PPA do not communicate verbally and/or through written communication. While there are accessible alternatives to providing consent that do not rely on these communication methods (e.g. signing or choosing from options), particular attention must still be paid to providing accessible explanations of the aims of the research, the participants' role in the project, how the data they provide will be used and how they may withdraw from the study. Indeed, the process of recruiting the PRG online in a way that was both ethically sound and inclusive involved several months of planning and the design of specially developed resources. Therefore, while the process of providing consent was possible online, providing additional participants with diverse needs with adequate information to make an informed choice was deemed to be beyond the scope of this project.

The main methods chosen for cycle one were arts-based methods and group discussion. To address research question one, co-researchers chose to create a 'Then and Now' poster. This activity was created in collaboration with co-researchers and is comparable to draw, write, tell methods (Angell et al., 2015). The aim of this activity was to explore the PRG's perceptions and experiences at PPA, by reflecting on their expectations prior to attending (and in doing so understand their motivations to attend), versus their experience after attending PPA. Initially, the UR was unsure about the inclusion of this activity in this cycle, since it does not specifically concern 'people'. However, Johnson and Walmsley (2003) state that PAR should further the interests of disabled people and that disabled co-researchers should be able to exert some control over the research process. Therefore, despite the UR's initial reservations, the activity was included in cycle one. This experience highlights a challenging but arguably necessary facet of PAR, whereby co-researchers' ideas for the direction of the project may not necessarily align with the UR's. These variations in opinion on the direction and focus of the study are to be expected, given the varying expertise and

motivations of the members of the PRG. This scenario provides an example of how participatory approaches can facilitate the reallocation of control in research, from those who are traditionally in control (non-disabled researchers) to those who traditionally have limited control (disabled people; Johnson & Walmsley, 2003).

While not specifically 'people' focused, the 'Then and Now' activity became a useful reflective task, which enabled co-researchers to transition from participant to researcher, by considering their experiences at PPA as a whole, before focusing on specific aspects of their experience. The usefulness of this task at this stage of the project illustrates the value of PAR approaches, as this activity would not have taken place if the UR was solely responsible for the research. Undertaking this activity in cycle one set a precedent for the remainder of the project. In particular, it was important to reinforce the collaborative nature of the project, develop trust with the group and actively break down any perceived hierarchy within the group by demonstrating that co-researchers' ideas and goals for the research were equally important to those of the UR.

To address research questions two and three, the PRG chose to have discussions about the role of people in their PPA experience. Additionally, three co-researchers chose to produce an artistic response to these questions, which involved drawing people at PPA and labelling them as to the roles they filled in the lives. While the majority of the group chose to answer the research questions in cycle one using visual methods (e.g. drawing and creating posters), Tracey chose to write a story in her own time about her experiences with people at PPA, using a process of self-interview (Keightley et al., 2012). Additionally, John chose to be interviewed by the UR about his experiences at PPA and the role of people at PPA, as opposed to completing the poster activity. This was predominantly because John finds drawing and writing challenging without in-person support and/or specialist equipment and is more comfortable communicating verbally. At PPA, John uses a table that attaches to his wheelchair, which supports him to draw, paint and write. However, during the pandemic this equipment was not accessible to him. This highlights the need for a flexible approach to activities and the importance of working to the co-researchers' individual strengths and needs.

## 4.2 Action

### 4.2.1 Procedure

Research sessions took place fortnightly and were divided into planning, action and review-focused meetings. Co-researchers attended sessions in two small groups, according to their availability. Each session lasted approximately one hour, apart from the sessions where co-



researchers created their ‘Then and Now’ posters, which lasted for two hours to allow co-researchers enough time to create their work. Table 5 provides an overview of the content of each session undertaken in cycle one of the project and the co-researchers involved in each session. There were several instances during cycle one in particular where co-researchers opted to attend more than one session on a particular topic (e.g. Tracey attended both planning sessions for planning one and two). This was due to the timing of this cycle, which took place during the first national lockdown of the Covid-19 pandemic. Co-researchers who attended multiple sessions reported doing so to avoid boredom and to keep busy during this time (“as many weeks as possible to keep us busy [...] I think everybody else is in the same boat aren’t they, keep themselves busy” – Tracey, C1).

*Table 5: Outline of research sessions undertaken in cycle one*

Session Type	Co-researchers involved	Session content
Planning 1, group 1	Ella, Leanne, Tracey, Charlie, Jo, UR	Looking at previous literature (Hall, 2012; Rickson et al., 2014) and Brainstorming research questions
Planning 1, group 2	Tracey, John, Janine, Sam, Liam, UR	
Planning 2, group 2	Tracey, John, Ella, Leanne, UR	Finalising research questions and choosing methods.
Planning 2, group 2	Tracey, John, Liam, Sam, Janine, UR	
Action 1, group1	John, Liam, Sam, Janine, Charlie, Jo, UR	Creating Then and Now posters
Action 1, group 2	Ella, Leanne, UR	
Action 1 (individual)	John and UR	Then and Now interview
Action 1 (individual)	Tracey and UR	Discussing Then and Now/people story
Action 2 + Review 1, group 1	Janine, Sam, John, Tracey, UR	Roles at Purple Patch and analysis
Action 2 + Review 1, group 2	Ella, Leanne, UR	
Review 2, group 1	Tracey, John, Charlie, Jo, Sam, Janine, Liam, UR	Highlighting important aspects of each other’s work
Review 2, group 2	Tracey, Ella, Leanne, UR	
Review 3, group 1	Ella and UR	Cutting and checking themes
Review 3, group 2	John, Tracey, Liam, Sam, Janine, Leanne, UR	

#### 4.2.1.1 Planning session one

In planning session one, the PRG were shown easy read versions of relevant previous literature selected by the UR (Hall, 2012; Rickson et al., 2014). Chosen literature was linked to the theme of 'people' (e.g. investigated the impact of social connections at arts-based programmes), involved adults with learning disabilities and utilised arts-based methods. Co-researchers were asked what they thought of the research, what was good about it and what, if anything, could be better. These discussions supported the PRG to consider their own research in relation to previous literature. For example, during cycle one Ella compared the findings of Hall (2012) to her own experiences at PPA:

UR: people who went to the programmes felt like they belonged to a team, and they said it was like a community and talked a lot about their friends

[...]

Ella: I agree with that, it's like, just like Purple Patch is um, a community for me

After engaging with previous literature, each group brainstormed some questions they were interested in answering during cycle one. The process of selecting research questions in all cycles involved the following process:

1. In line with previous research (Richardson, 2002), open conversation about the theme for the cycle was encouraged to allow the PRG to identify aspects of this theme that were important to them. The UR supported these conversations by asking questions about the PRG's experiences and encouraging co-researchers to reflect on the literature they had been shown for the cycle.
2. The UR supported the PRG to consider what questions remained regarding this theme (e.g. what do we know? what don't we know? What questions would help us to find out more about this theme?). Co-researchers were encouraged to think of questions which were not simple 'yes' or 'no' questions.
3. The UR collated all question suggestions after both meetings had taken place and shared these in the PRG Facebook group. Often there were too many questions identified at this stage to fit into the cycle.
4. The UR supported the PRG to narrow questions down by asking; which questions are most important/interesting? At this stage, some similar questions were combined. The process of selecting questions took place via different activities in each cycle. In cycles one and two, co-researchers voted on the questions they would like to address via the PRG Facebook group. In cycle three, co-researchers voted for the questions

they would like to address through group discussion and/or by pushing an imaginary golden buzzer to indicate their choice.

#### 4.2.1.2 Planning session two

During planning session two, methods for cycle one were selected through group discussion. Since this was the PRG's first experience of choosing appropriate research methods, the UR supported these decisions by asking the group to consider what information they needed to answer the question. The UR also provided the group with options about how they could answer these questions, by using examples from the easy read literature provided to the group. Co-researchers decided that they were able to answer all three research questions themselves, by reflecting on and visually representing their own experiences (e.g. via the Then and Now task).

#### 4.2.1.3 Action session one

During the first 'action' session, co-researchers created their 'Then and Now' posters, using their research journals as a canvas. Co-researchers worked independently to create their posters, supported by the UR and a parent/carer if required. Posters were split into two pages, with one A4 page dedicated to capturing the co-researchers' perceptions and expectations of Purple Patch before they attended ('Then') and another capturing their experiences at Purple Patch ('Now'). Co-researchers discussed and responded to a series of prompts designed to help them to reflect on their experiences at PPA. These were as follows:

Think back to before you started at PPA...

- How did you feel?
- What did you think PPA would be like?
- What did you think you would do at PPA?
- What were you hoping to get out of going to PPA? /What did you think you would get out of going to PPA?

Thinking about your experience at PPA now...

- How do you feel about PPA now?
- What do you think PPA is like now?
- What do you do at PPA?
- What do you think you get out of going to PPA?

This arts-based method was selected as it was a flexible and adaptable way to capture a researcher's ideas and experiences on a particular topic. Co-researchers completed the task in multiple ways, using different materials and approaches depending on their needs, preferences, and the resources they had available at home (see figures 12 and 13). Most of the group chose drawing as their main medium, however some researchers also opted to label their illustrations and one researcher chose to write down their ideas and organise them into a diagram. In line with draw, write, tell approaches, completed posters were used as the basis for discussion within the group (Angell et al., 2015). Co-researchers were asked whether the 'Then' and 'Now' pages of their posters were the same or different and why this might be. Additionally, co-researchers were asked to consider how important people are to their PPA experience by considering what content in their posters related to the theme 'people'. While John chose to attend a poster session, a separate meeting was arranged to explore his experiences at PPA through his preferred method ('Then and Now' interview). An additional meeting was also scheduled with Tracey to discuss the story she had written outside of research sessions, titled 'People (Purple Patch Arts)'.

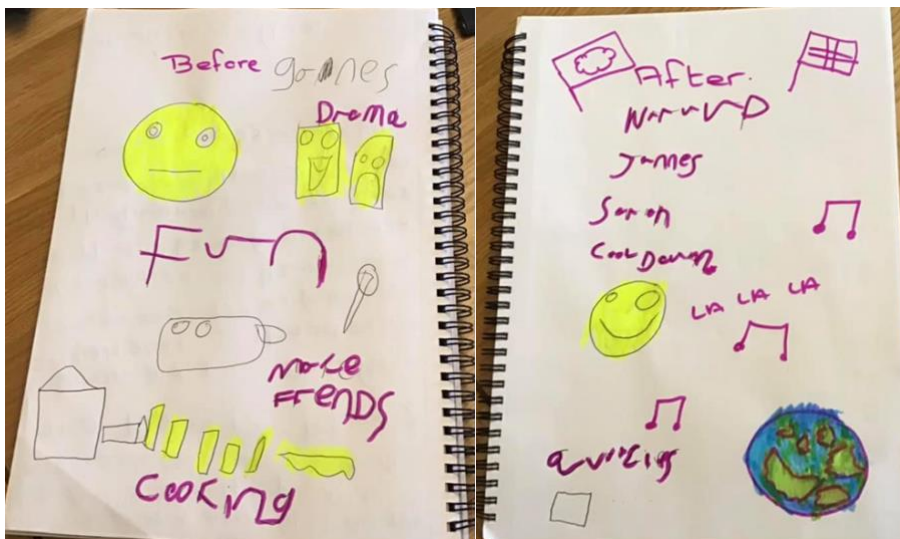


Figure 12: : Leanne's 'Then and Now' poster

Leanne's poster from C1 includes a combination of illustrations, symbols and written text to summarize her experiences. Her poster is an example of a 'free-from' response, where the content on each page is not organised (e.g. thematically or by question) but rather captures a snapshot of her experiences in a collage-like display.

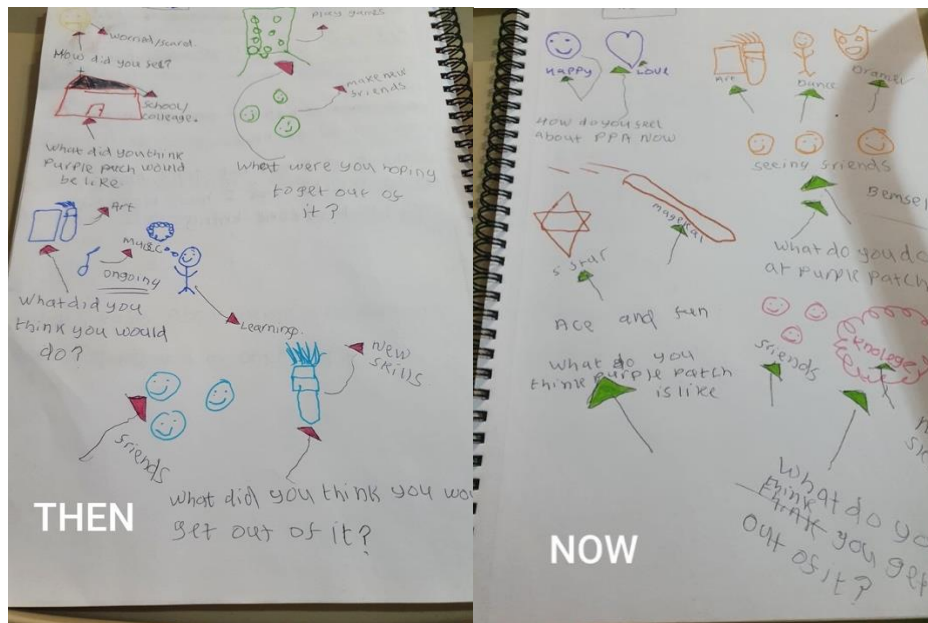


Figure 13: Liam's 'Then and Now' poster

Liam's poster from C1 demonstrates a more structured approach to this activity. Liam's poster is organised into sections relating to each prompt question, with illustrations and written labels that demonstrate connections between different aspects of his experiences.

#### 4.2.1.4 Action session two

In the second 'action' session, co-researchers discussed the different 'roles' that people at PPA fill in their lives. Ella, Leanne and Sam created drawings which captured the different roles present at PPA. These were used to aid discussion on this topic. After discussing their artistic responses, co-researchers were asked to consider which roles were most important and why. At the end of the 'action' phase, co-researchers were asked to take photographs of their work and either share it in the PRG Facebook group or send it directly to the UR via email.

### 4.3 Review

#### 4.3.1 Analysis

'Review' sessions focused on analysis of the data and reflections on cycle one of the project. All research meetings were recorded, transcribed and analysed by the UR following the steps outlined in section 3.5.2.2. All work produced by the co-researchers was collated and sent to co-researchers individually at the end of cycle one for them to check. Co-researchers had the opportunity to edit and/or remove any work that they did not wish to be included in the thesis. Therefore, all examples of work included in this thesis are done so with the permission of the co-researcher who created them.

The review phase of cycle one took place over three one-hour meetings per group, focusing on data analysis and drawing conclusions from the first cycle of research. An adaptive form of thematic analysis was employed in cycle one. Co-researchers were sent

physical copies of all of the data generated in cycle one, including: 'Then and Now' posters, roles at PPA work, Tracey's story and a transcript of John's interview. Co-researchers were first asked to look at and familiarise themselves with each other's work, both prior to the first review session and during the first online review session. Review sessions therefore began with the UR sharing co-researchers' work on Zoom, using the screen share function. After this process of familiarisation, co-researchers were asked to identify aspects of their own and others work that they felt were most important, or interesting in a research meeting. Co-researchers looked at each piece of work in turn and instructed the UR on which aspects of the work they wanted to look at in more detail (for example, by requesting that the UR zoom in on a specific drawing). This process is comparable to the approach taken in previous PAR projects, where researchers have been asked to highlight or underline parts of an interview transcript which they deemed to be important (Stevenson, 2014). Due to research meetings taking place via Zoom, this process was adapted so that the UR wrote down recurring important features identified by co-researchers on post-it notes. This was followed by a group discussion about which post-it notes might be similar and therefore could be grouped together, and which may be different and therefore belong in different groups. Alongside verbal discussion, the UR demonstrated the different ways in which the content of post-it notes may be linked together by using movement and proximity between post-it notes on camera. For example, the UR showed co-researchers that post-it notes with related content may be placed directly next to each other, whereas post-it notes with unrelated content may have a larger amount of space between them. After this session exploring the connections between initial codes, the UR independently collated the post-it notes (codes) into potential themes. This revealed four overarching themes: Learning, Environment, Community and Wellbeing.

In the final research meeting of the review phase, co-researchers checked these four themes against the original data set to ensure that they accurately represented the data. This was achieved by cutting up the groups' 'Then and Now' posters, stories and interview transcripts and organising their clippings into the four themes. Co-researchers were encouraged to be creative about how they organised their clippings. Co-researchers chose a range of sorting techniques, including making piles for each theme, using different containers from around their homes to organise their clippings, and inspired by Rickson et al. (2014), creating post boxes out of cereal boxes to 'post' their quotes and drawings into each theme (see figure 14). Co-researchers discussed the decision-making process while sorting their data. In some cases, there was a high level of agreement between co-researchers. However,

when analysing some data from cycle one, co-researchers occasionally disagreed on which theme the data were most closely related to.

UR: Tracey's talked about art, drama, writing, do we think that, what category do we think that could be in, out of learning, community, environment or wellbeing?

Tracey: first one

UR: learning, mhm. So maybe some...

John: maybe wellbeing, to keep you happy, keep you going.

Tracey: yeah, it could be John

Discussions around these variations in opinion revealed that co-researchers conceived these categories as being highly related and interlinked.



Figure 14: Themed post boxes created by Leanne in cycle one

After checking the data, the PRG discussed each theme and wrote a description for each one. As will be clear from subsequent 'Analysis' sections, in later cycles co-researchers gained confidence in their ability to analyse data and took more ownership over the process, with the UR ultimately providing less guidance and fewer prompts. The process of adaptive thematic analysis in cycle one revealed four overarching and interlinking themes (Environment, Wellbeing, Learning and People at PPA), which summarise the co-researchers' experiences at PPA as well as their motivations to attend (thus addressing research question one: what motivates attendance at PPA?). These themes are discussed in turn below. Findings relating to 'People at PPA' will be reported in greater detail, since the focus of cycle one was 'people'. Findings reported in this theme therefore address research question two (are people important to our PPA experience? If so, why?). The theme 'People at PPA' contains several sub-themes, including 'Roles at Purple Patch' and 'Purple Patch Family', which address research question three (what 'roles' do people at Purple Patch fill in our lives?) and 'Negative Experiences with Disabled People', which considers the co-

researchers' negative experiences with people and how this impacted their experiences at PPA.

#### 4.3.2 Results and Discussion

##### 4.3.2.1 Learning

Learning was a core component of the co-researchers' experiences at PPA. Learning (in particular, learning new skills) was a key motivator for attendance, featuring in all of the PRG's 'Then' pages, and was also considered to be an important outcome of attendance, as Tracey suggested in cycle one: "I have moved on in my mind with more learning and gaining more information that I got through Purple Patch Arts that I didn't know before"

The PRG discussed what was learned at PPA and how it was learned. 'Types' of learning included gaining knowledge about different topics, including learning about the real world ("They do proper real-world things" – John, C1). Examples of 'real world' topics included world cultures and celebrations, history, music and the arts. Co-researchers also discussed learning practical skills that could be applied to their everyday lives, such as cooking, using a elevator and money management, as Ella explained in cycle one: "\*programme leader\* is trying to teach us about using money and stuff like that now [...] about real life skills". Additional life skills learned at PPA included adapting to change and challenge (for example, by learning to use Zoom in the pandemic) and interacting with people, including managing difficult/complex relationships. Ella stated that through interacting with different people at PPA, she was better able to manage her relationships with others ("Purple Patch taught me to get along with \*name\*" - Ella, C1).



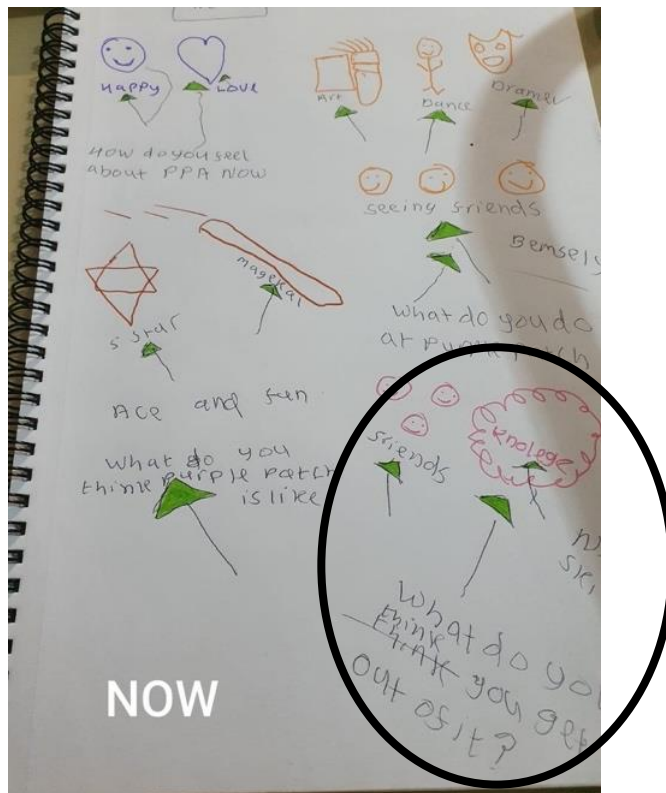


Figure 15: Liam's 'Now' poster demonstrates that learning is considered a key outcome of attendance at PPA

Text says: "what do you get out of it? Knolege [sic], new skills".

Co-researchers enjoyed the variety of topics covered in PPA sessions ("I like to learn different things each week" – Tracey, C1), but noted the importance of learning content being aimed at adults. The importance of 'adult' content was emphasised by John, who reflected on his earliest experiences at PPA in his 'Then and Now' interview, reporting that content was initially considered to be 'too childish' by participants:

When we first started, it was like different...the focus was a bit more babyish, so we were just laughing about. Now they've got proper schedules. They've made it much more adult and dealing with things in the real world. Although there's a bit of fantasy there, that's a great thing to be fantasy, but you've got to get in the real world sometimes

Additionally, age-appropriate communication with participants was also discussed. Tracey shared her experience of the evolution of PPA's approach to learning, noting their responsiveness to participant feedback regarding the nature of communication: "they listened to us saying 'do not talk down to us like kids' and now they talk to us as adults and listen to us" (C1). Adults with learning disabilities face many forms of stigma throughout their life, including being labelled as 'childlike' in adulthood (Jahoda et al., 2010). Misconceptions around learning disabilities can have a negative impact on adults with learning disabilities' wellbeing (Ali et al., 2012) and may also influence the types of learning opportunities available to adults with learning disabilities. Indeed, whether learning should be age-

appropriate or developmentally appropriate is a contentious issue (Smith, 1996). On the one hand, Nind and Hewett (1996) note that utilising developmentally appropriate activities as opposed to age-appropriate activities were viewed as disrespectful towards adults with learning disabilities by support staff. Similarly, Fairbairn and Fairbairn (2014) shared the story of Jan, a facilitator who received negative feedback from colleagues for using children's songs in a warmup activity for adults with learning disabilities, due to their lack of age-appropriateness. However, Nind and Hewett (1996) suggest that enforcing age-appropriate activities may be related to 'normalisation', whereby activities are used to control/alter the behaviours of adults with learning disabilities to be more socially acceptable or "socially valued" (Chappell, 1992, p.40). Nind and Hewett (1996) therefore advocate for the use of developmentally appropriate activities, which they suggest are less likely to alienate learners with learning disabilities through activities that are not in-line with their current developmental stage. Regardless of whether activities are age or developmentally appropriate, this suggests that the 'type' and nature of learning opportunities available to adults with learning disabilities may be impacted by societal views of appropriate behaviour and interests.

However, what appears to be missing from these debates are the views of adults with learning disabilities. The present study suggests that a combination of 'age and stage' appropriate activities are important for a positive learning environment. While co-researchers were clear that content should be 'adult' and not childish, they were also aware of the need for accessible approaches to learning. The distinction then, is between what is learned and the way in which it is learned. For example, traditional learning may include reading and writing (Harrison, 2003). While this approach may not be accessible to adults with learning disabilities, for whom reading and writing may pose challenges (Abedin, 2010), adaptation of the way in which content is taught may allow for age-appropriate content to be delivered via a range of accessible activities, which are also developmentally appropriate. In other words, age-appropriate content does not necessarily equate to inaccessible content and developmentally appropriate content need not be 'childish'.

It is also important to note that when describing their learning experiences at PPA co-researchers frequently used the term 'adult' synonymously with 'real world'. For example, John explained that by using 'real' songs in the warmup as opposed to made-up songs, that this was deemed to be more age-appropriate for adults with learning disabilities, highlighting the need for accessible activities and varied approaches to learning, which focus on real-world content:

Some of the things we were doing, like the cool down is real songs you know, but they made up these songs... You had to laugh really, you know, when I first started [...] but yeah, now they're real songs you can do

While learning was still considered to be challenging at times (“sometimes it's [learning] hard” – Ella, C1), the varied approaches to learning utilised at PPA supported co-researchers to learn through accessible, and often arts-based approaches. During this cycle, further questions were raised by the group about the importance of the programme content, in particular, about the role of the arts in LLL. This topic was incorporated into cycle two.

Learning at PPA was often compared to learning that the PRG had experienced in other contexts (such as school and college). Co-researchers' expectations of what PPA would be like prior to attending was also based on their experiences of school/college (see figure 16). Co-researchers provided mixed feedback on these previous learning contexts, however the group agreed that they preferred learning in adulthood (at PPA and other programmes that they attended) than school or college (“I think Purple Patch was [more] fun than school was [...] I didn't like school that much” - Ella, C3). Reasons for preferring learning at PPA included that it was more fun and less serious (“we could never have a laugh at school it was always serious, like no laughing” – Leanne, C1), more creative and did not include subjects that co-researchers do not enjoy (such as mathematics; “more fun than doing your time tables” – Leanne, C2).



Figure 16: Liam's 'Then' poster demonstrates that he expected PPA to be similar to school

Co-researchers' previous experiences at school influenced their perceptions of future learning experiences. When considering how they felt about attending PPA, many co-researchers stated that they felt nervous or anxious about attending PPA due to their previous experiences of learning, such as those discussed above ("how I felt was worried and scared, I think Purple Patch would be like school and college" – Liam, C1).

Additionally, co-researchers considered the social environment of the learning context at PPA to be very important. For example, Ella stated that she did not enjoy learning at school due to "the bullies", highlighting that a negative social environment can have a negative impact on learners. People were therefore reported to play an important role in learning at PPA. While staff are responsible for leading sessions and teaching content, co-researchers also reported learning from other PPA participants. Liam discussed the opportunities for peer learning at PPA: "we know how best to support each other and um at times who might need us to go over something again, so that they understand it better" (C1). Indeed, previous research suggests that peer-mediated learning facilitates greater opportunities for feedback and engagement with learning for young people with learning disabilities (Harper & Maheady, 2007). The present study therefore supports previous research which suggests that those with lived experience of learning disabilities can play an

active role in supporting the learning of other adults with learning disabilities (Inglis & Cook, 2011).

#### 4.3.2.2 Environment

The PRG identified several aspects of the environment at PPA which were important to their experience. Environmental factors considered by the group included the longevity, structure and atmosphere of PPA.

##### 4.3.2.2.1 Longevity

The longevity of the PPA programme was an important aspect of the environment at PPA, as John explained in cycle one: “If there’s been a course it would be 8 weeks and then you’re done, but it’s [PPA] like an ongoing thing”. Due to the lack of imposed limit on the length of engagement, co-researchers trusted that PPA would be there for a “lifetime” (John, C1). The possibility of lifelong engagement with PPA was a key motivator for co-researchers when joining PPA, particularly when compared to their previous experiences of short-term programmes/courses and programmes that had closed, often unexpectedly:

I’ve found out over the years with Sam, it \*previous programme\* fizzled out after about 6 months [...] the more I found out about Purple Patch prior to sort of signing on, the happier I was for Sam. I was quite happy to pay the money for...because of the longevity (Janine, C1).

Some co-researchers reported attending short courses to support their LLL. While these courses were valued by members of the group, John noted in cycle one that they did not support continued social engagement, since these learning environments do not facilitate continued contact with the same people: “A course would be like 8 weeks and then you’re done, and then you might see the people again, you might not [...] with this [PPA] is like having a way to contact”. In contrast, the longevity of the PPA programme supported co-researchers to develop long-term important relationships and foster a sense of belonging (“the belonging [...] it’s the biggest thing where you just feel part of something that, other courses and things don’t do” – John, C1).

For most of the PRG, PPA was their first experience of education which was not time-restricted. Indeed, previous research regarding inclusive learning for adults with learning disabilities is often time-limited (Björnsdótti, 2016; Brown et al., 2011; Rodríguez Herrero et al., 2020). Previous research suggests that transitions out of education can be a particularly challenging experiences for adults with learning disabilities, often resulting in feelings of uncertainty (Pallisera et al., 2016). Indeed, co-researchers stated that during key transition periods in their life, they often did not know what they would do next (I didn’t know what I

would do when I left college [...] then I found Purple Patch” – Ella, C1). The present study suggests that programmes for adults with learning disabilities may support periods of transitions, particularly between college and adult life, and provide long-term access to opportunities for LLL.

#### 4.3.2.2.2 Structure

Another aspect of the environment at PPA which was important to co-researchers was structure. Since PPA programmes take place at a regular time and place each week, attending PPA became an important part of co-researchers’ routines. John suggested that routine formation was an important motivator for participants to attend PPA programmes:

UR: why do people come to Purple Patch? Does anyone have any ideas?  
[...]  
John: I’d say for routine I think

Attending PPA provided co-researchers with a sense of structure to their week. Ella discussed how routines are often tied to educational institutions, with these routines being lost once individuals are required to leave these spaces. PPA therefore provided Ella with a structure which was both familiar and desired, as it emulated her experience of structure at college:

Ella: I’m so lucky I get to go to Purple Patch in the daytime, I think I’m lucky  
UR: yeah? Why do you think you’re lucky?  
Ella: when I left college, I didn’t know how my day would be structured, will I UR, couldn’t just stay at home watching TV all day [...] I wanted the same routine as college

Alongside the regularity of PPA providing a structure to co-researchers’ lives, the content of the programme was also considered to aid structure. PPA was considered to be a well-structured programme, as Janine discussed in cycle one: “We’re more than happy to keep it up, because it’s such a well-structured erm, programme”. Regular activities such as a warm-up and cool-down were considered to be important parts of the PPA day, as co-researchers knew to expect these activities at particular times in the day (“We do a warmup every, every Thursday morning” - Ella, C1). Additionally, the themed content at PPA provided a structure to co-researchers’ learning. Themes for programmes are shared in advance each term, and co-researchers were therefore familiar with the structure of the term and the kind of content they would be learning (“they have like themes, and you’re learning something from that theme every week” – John, C1). Co-researchers were initially surprised by the structure of the PPA programme, particularly in comparison to other groups organised by disabled people’s organisations that they had previously attended:

John: I thought it [PPA] was just for sitting round having a coffee like some, some groups do but  
 UR: mhm  
 John: I was glad to see they were doing something else as well  
 UR: yeah  
 John: there's a schedule to structure the day

Overall, routine and structure were considered to be important for co-researchers' wellbeing, as Tracey discussed in cycle one: "I need to be in a routine. If I don't get in a routine I am lost in my mind and my confidence would go down". Through the regularity of PPA programmes and the structure of activities within the PPA day, attendance at PPA supported the formation of a routine for co-researchers, thus positively impacting their wellbeing.

#### 4.3.2.2.3 Atmosphere

The atmosphere within PPA programmes was a highly valued aspect of the environment at PPA. PPA programmes were described as "happy and welcoming" (Liam, C1), accepting ("it could be acceptance alright" – John, C3) and supportive ("maybe helping sort of thing" – Sam, C1). The atmosphere of PPA was reported to support learning, as Liam suggested in cycle one:

UR: what are some ways that we might learn or that we might try to learn?  
 [...]
   
Liam: good atmosphere

While structure was an important aspect of the PPA programme, a supportive and inclusive atmosphere, which promoted freedom and choice was also considered to play a key role in creating a positive learning experience at PPA: "I don't feel you're pressured to it, that's what I like about it. I wasn't pressured or told, you know, you do this or that" (John, C1). The relaxed atmosphere at PPA therefore meant that co-researchers felt the goal of programmes was having fun, with learning as a by-product of enjoyment and engagement with activities: "I know we will have a laugh time over; I know we will drink and chat [...] between the fun and things we learn" (Liam, C1).

The positive atmosphere reported by co-researchers also supported their sense of belonging and inclusion. PPA was reported to be a welcoming space ("make you feel welcome, unlike some" – Tracey, C1). In particular, people at PPA played an important role in making co-researchers feel welcome ("\*Programme Leader\* was there to welcome me" – Ella, C1; "they [staff] made me feel welcome, sort of adopted us really" – John, C1). Co-researchers therefore trusted that people at PPA would be kind and supportive. Co-researchers reported emulating this welcoming and inclusive atmosphere by actively

supporting new members to feel welcome (“whenever there’s a newcomer I make sure they’re welcome, I make sure I stick with them for a few weeks, introduce them to everyone” – Ella, C1). Additionally, the inclusive and supportive atmosphere at PPA meant that co-researchers felt that the focus of the programme was on what they *could* achieve, rather than barriers and challenges to learning that they may experience. This supported co-researchers to be themselves and to focus on enjoyment of the programme, as opposed to their disability, as Tracey discussed in cycle one:

I can’t change who I am, that I am dyslexic or me being Deaf, but I can help others in other ways [...] at Purple Patch Arts I can relax about this because it isn’t all about my dyslexia, it’s about learning and having fun

The importance of the atmosphere at PPA was related to the co-researchers’ previous negative experiences in places, groups and of people (see section 4.3.4). John described the atmosphere of previous programmes he had attended as “dull” and “awkward”, noting that he decided not to return as he felt the atmosphere and activities were not the right ‘fit’ for him. This highlights the importance of a positive atmosphere on motivation to attend programmes such as PPA in the long-term.

#### 4.3.2.3 Wellbeing

Attending PPA supported co-researchers’ wellbeing (“It lifts your spirits up a bit” – John, C1). Co-researchers reported having fun at PPA, alongside feeling less stressed and more relaxed, particularly in comparison to other programmes and learning environments such as school and college (“I feel more relaxed at Purple Patch” – Ella, C1).

Co-researchers also agreed that the arts specifically played an important role in supporting wellbeing at PPA. Arts-based activities at PPA facilitated positive emotions, aided escapism from the stressors of daily life, and supported co-researchers to feel calm and less stressed (“I find when you go there, you can leave your troubles behind for a day” – John, C1). Due to the time constraints of each cycle, co-researchers were not able to fully explore the reasons why the arts supported their wellbeing in cycle one. Co-researchers therefore agreed to explore the relationship between the arts and wellbeing further in cycle two.

People at PPA were also considered to play an important role in supporting the wellbeing of co-researchers, through the development of meaningful relationships, support networks and friendships (“I have made some great friends at PPA over the years” – Tracey, C1). This is in contrast to the co-researchers’ previous experiences of others (particularly non-disabled people), which were often negative:



Ella: I used to get bullied a lot  
 UR: oh, did you, Ella? I'm sorry. That's not very nice  
 Ella: that's why Purple Patch is more relaxed for me

People at PPA therefore supported co-researchers' wellbeing by providing a safe and supportive environment which was "free from bullies" (Leanne, C1). The role(s) of people at PPA and potential negative impact of non-disabled people in the lives of co-researchers will be explored further in the sections below.

#### 4.3.3 People at Purple Patch Arts

Co-researchers discussed the impact of people at PPA on their experiences in programmes and in their daily lives. Social engagement at PPA was considered as equally important to the activities at PPA by the PRG. ("We like doing the activities, but we also really like chatting in social breaks" – Leanne, C1). It is important to note that the PRG reflected on their social experiences at PPA during a period of social isolation. The importance of PPA as a site for social contact was particularly evident during the pandemic, where social opportunities at PPA were reduced due to a lack of in-person delivery ("We miss having social time now Purple Patch is on Zoom" – Leanne, C1). The following sections explore the roles of people at PPA in the lives of the PRG.

##### 4.3.3.1 Roles at Purple Patch Arts

Co-researchers explored the impact of PPA staff, including programme leader (PL), programme artist (PA), programme support (PS) and office staff (OS), parents and carers, and other PPA participants on their experiences. People were considered to be an important part of co-researchers' experiences, fulfilling a range of different roles in their lives. Table 6 outlines the roles identified by the PRG, a definition of these role and who was reported as filling it.

*Table 6: Roles at PPA identified by the PRG*

Role	Role description	Individuals who fill this role
Leader	People who organise, set-up and/or lead sessions at PPA	PL, PA, PPA participants
Teacher	People who help participants to learn new things (often used synonymously with 'leader')	PL, PA
Supporter	People who provide support to participants and/or parents at PPA	PA, PS, OS, PPA participants

Helper	People who help participants and/or parents at PPA (e.g. by explaining things or providing information)	PL, PA, PS, OS
Mentor	People who provide advice, support and guidance to participants at PPA	PL, PA, PS
Communicator	People who keep participants, parents and carers informed about PPA	OS
Recruiter	Somebody who recruits new people to join PPA by telling others about it (“it was primarily because of *participant’s* mum that Sam got into Purple Patch, or we got to know about Purple Patch” – Janine, C1).	OS, PPA participants, parents
Friend	People who we like and have a close connection with at PPA	PL, PA, PS, OS, PPA participants, parents/carers
Family	The phrase ‘Purple Patch Family’ was used collectively to describe anyone who is connected to PPA (“we are a family who care about each other” – Leanne, C1). Discussed further in section 4.3.3.2.	PL, PA, PS, OS, PPA participants, parents/carers

Some of these roles, such as teachers and leaders, relate to the PPA delivery team’s official roles in programmes. Unsurprisingly, co-researchers associated these roles with individuals based on their job title and responsibilities, as Ella demonstrated:

Ella: I know \*programme leader\* is the group leader of my group, that’s his title  
 UR: yeah so, he’s a leader is he?  
 Ella: yeah, a leader

Staff were also reported to fill a range of ‘supporting’ roles, such as helper, mentor and supporter. These roles provided support to participants’ learning (“If I didn’t understand things, she tells me a bit more about it” – Ella describing a ‘helper’ in C1) alongside emotional support in programmes (“if I’m upset about something just with the, something not going right at Purple Patch in the day, if I’m confused [...] I talk to her – Ella describing a ‘mentor’ in C1). ‘Friends’ and ‘family’ were the only two roles identified by co-researchers which were assigned to everyone (office staff, delivery staff, parents, carers and PPA participants). Interestingly, the individual’s official role within the organisation did not appear to influence these ‘companion roles’ being assigned to them. For example, we might expect PPA participants to be labelled as friends since they are the PRG’s peers. However, office staff, including those in charge of the running of the organisation, were also considered as friends and family. This indicates a lack of perceived hierarchy within the social structure of PPA

(discussed further in section 2.3.3.6). The Purple Patch Family will be discussed further in the next section.

#### 4.3.3.2 Purple Patch Family

The phrases 'Purple Patch family', 'extended family' or 'second family' were used by the PRG throughout the project to collectively refer to those connected to PPA, regardless of their official position. Individuals were considered as 'part of the family' if they currently or previously attended or worked at PPA. Co-researchers reported a sense of belonging associated with being a part of the Purple Patch family, as Tracey described in cycle one: "we are belonging to something, we are Purple Patch family". Co-researchers discussed the values and characteristics of the 'Purple Patch family'. These are: familiarity and consistency, having things in common, acceptance, support and belonging and no perceived hierarchy. These characteristics were identified as the reasons why people at PPA were so valued (e.g. why they are a 'family'). Association with this group and its core characteristics also formed an important part of the co-researchers' social identities. In line with Tajfel's (1979) Social Identity Theory, which suggests that an individual's sense of self is related to their association with a particular group, co-researchers discussed with pride how these 'values' were also adopted and emulated by the group's individual members, impacting their view of the world and their behaviour. For example, Tracey discussed how members of the 'Purple Patch family' behave towards new group members: "we make everybody feel welcome when they're new and everything don't we" (C1). The following sections will introduce the four key characteristics of the Purple Patch family outlined by the PRG.

##### 4.3.3.2.1 Familiarity and Consistency

Level of familiarity and the consistency of contact with others were considered to be important aspects of the PRG's social experiences at PPA. While co-researchers reported enjoying meeting new people at their programmes, the group also discussed the benefits of seeing the same people every week ("it's good meet new people but it's also good to have someone you know as well" – John, C1). Familiarity was either developed through consistent contact with others, or in some cases it was pre-existing. Indeed, all but one co-researcher reported that they already knew someone who attended PPA prior to their attendance. This individual served the role of 'recruiter' and played a key role in the PRG's motivations for attending PPA. Co-researchers reported that pre-existing familiarity with other PPA participants helped them to feel less nervous, and more confident to attend programmes in the first instance. These individuals also supported co-researchers' transitions to becoming PPA participants, by making them feel welcome on their first day, as Ella explained: "we [Ella

and ‘recruiter’] both go to the same, \*organisation\* and Purple Patch [...] he made me feel really welcome when I first joined”. This suggests that peers can play an important role in making adults with learning disabilities feel comfortable, particularly in new environments.

Alongside familiarity, consistency of contact was also considered to be an important aspect of the ‘Purple Patch family’. John discussed the importance of consistent social contact, identifying the ‘ongoing’ nature of social relationships at PPA as a key reason why PPA is considered a ‘family’, particularly when compared to short-term programmes: “I’d say, like a group family really, as I’ve said before, with a course you’ve got 10 weeks to do it and you don’t see the people, but it’s an ongoing family type”. Both familiarity and consistency were important for the development and maintenance of social relationships within each group. Indeed, during the pandemic where contact with others was reduced, co-researchers described the desire to maintain regular and ongoing contact with their friends online through PPA Zoom sessions:

UR: what made you want to carry on going to Purple Patch even if it was on zoom in the pandemic?

Ella: just to do a bit of connection with my friends

UR: mhm

Ella: I wanted to see my friends

This indicates that consistent contact with people at PPA was considered to be a valuable part of the co-researchers’ social learning experiences.

#### 4.3.3.2.2 Things in Common

Having things in common with others at PPA was reported to be an important characteristic of the ‘Purple Patch family’ and of the learning community within PPA. For example, having an interest in the arts was considered to be an important unifying characteristic of the Purple Patch family, as Liam discussed: “unless you’ve got passion for the arts, you’re not going to do, you’re not going to engage properly” – Liam, C1. This is consistent with Wenger’s (1999) writings on community of practice, which suggest that a shared interest (such as interest in the arts) is a key component of a learning community.

Lived experience of disability was also considered to be an important shared experience for co-researchers. Tracey reported the desire to socialise with “people like me”, indicating a preference for contact with other disabled people, as opposed to non-disabled people (“I don’t mix with ‘normal’ people”<sup>6</sup> – Tracey, C1). This preference for socialising with

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<sup>6</sup> Throughout the project, Tracey used the word ‘normal’ synonymously with ‘non-disabled’ (“what I mean by ‘normal’ is people who haven’t got disabilities” – Tracey, C1). The word ‘normal’ when used to describe non-disabled people may be considered to be harmful to disabled people as it implies

those who understand disability was often as a result of the PRG's previous negative experiences with non-disabled people (discussed further in section 4.3.4). Additionally, co-researchers suggested that having shared experiences of disability (regardless of diagnosis) supported a greater level of understanding from other disabled people, as Ella discussed: "I understand \*participant\* [...] don't know what his disability is, but I understand him. I understand what same thing he's going through as me" (C1). The present study therefore suggests that social spaces where participants have a shared identity as disabled adults were perceived as being more accepting, and therefore adults with learning disabilities felt more confident to enter and be an active participant in these spaces. This will be discussed further in the following section.

#### 4.3.3.2.3 Support, Acceptance and Belonging

PPA was viewed as a source of support for co-researchers and parents. PPA staff and peers provided support to PPA participants with programme-related matters (e.g. support with learning) and personal matters, including bullying, financial, transport and housing challenges, bereavement and family illness ("they supported me through the hard times" – Ella, C1). Support at PPA can be described according to the four 'types' of support identified by House (1981): Emotional support (providing empathy, love and care), instrumental support (providing practical services that directly support the individual), informational support (providing advice and information) and appraisal support (providing feedback and encouragement). For example, Tracey discussed receiving emotional support at PPA when she confided in staff about a family member who was seriously ill: "I spoke to \*staff member\* about it today [...] If I kept my mouth shut and not told \*staff member\*, I would have been lost without 'em" (C1). In this case, having someone to discuss this challenging situation with enabled Tracey to feel more emotionally supported. In contrast, PPA staff provided instrumental support to Ella when she had difficulties with her transport:

Ella: we had a little incident with the taxi last week  
 UR: oh, did you?  
 Ella: yeah, at Purple Patch  
 UR: right  
 Ella: it didn't turn up, but \*staff member\* was on it, she rang them up

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that disabled people are therefore 'abnormal'. The author notes that this term may be considered to be offensive when used in relation to disabled people. However, as this word was used by a co-researcher it has been retained. It is worth noting that Tracey uses the word 'normal' to describe non-disabled individuals, usually when relaying the negative experiences she has had with this population. Therefore, in this context, 'normal' may be considered to be a negative label/association.

Informational support was most commonly reported by parents, as Janine discussed: “I can call up if I need anything. [...] so the response from them is reassuring as well”. Finally, appraisal support was most likely to be incorporated into programmes by PPA staff and other PPA participants, as Ella suggests: “My friends at Purple Patch is good, because they encourage me to try new things”. People with learning disabilities often have smaller social circles than their peers without a learning disability and may therefore have limited access to appropriate support networks (Taheri et al., 2016). Indeed, Forrester-Jones et al’s (2006) study of the types of support received by 213 adults with learning disabilities revealed that only 20% of participants received ‘confiding’ support. The present study suggests that through engagement with PPA, adults with learning disabilities formed meaningful connections and access to reliable support networks in times of challenge.

*Choosing* to support others was considered to be a key characteristic of the Purple Patch family. Regardless of the type of support offered, staff were perceived as making the active decision to support PPA participants and parents. In cycle one, John discussed his experiences of receiving support with housing challenges, emphasising that while staff were not required to support him with this challenge, they chose to do so anyway:

They’ve always offered \*staff member\* or \*staff member\* over the years, when I’ve had issues with, when I had issues at the house [...] they’ve always offered, they will help if they can [...] they don’t have to, they don’t have to, that’s the difference, but they’re willing to help

It is worth considering that the importance of staff *choosing* to support, particularly with matters that are not considered to be part of their role, may be amplified by the fact that many individuals who ordinarily support participants are either paid or required to do so. Previous research investigating the social networks of adults with learning disabilities found that the majority of participants’ contacts were paid carers and family members (Forrester-Jones et al., 2006; Pockney, 2006). Evans and Murcott (1990) suggest an important distinction between feeling ‘cared about’ and ‘cared for’. Being ‘cared for’ suggests a relationship whereby the individual doing the caring is filling a formal caring role (e.g. a paid carer or family carer). In contrast, being ‘cared about’ indicates a more personal relationship categorised by choice, which may facilitate feelings of social inclusion (Evans & Murcott, 1990). By fostering an environment whereby PPA participants feel that they are ‘cared about’ as opposed to ‘cared for’, co-researchers felt a sense of belonging and acceptance within their programmes and PPA as a whole. This is in line with previous research investigating inclusive learning environments, which suggests that belonging is “at the heart of inclusion” (Slee, 2019, p.917). Co-researchers’ experiences of belonging at PPA contrasted with their previous experiences of a lack of acceptance from others in other learning contexts:

Ella: I had a hard time for people trying to accept me  
 UR: yeah  
 Tracey: but at Purple Patch  
 Ella: it was really hard  
 Tracey: they all accept you, we are a family, a Purple Patch family  
 Ella: yeah

Feeling accepted by the community was crucial for co-researchers to feel comfortable and therefore fully engage with the learning programme. A lack of judgement from others in particular enabled co-researchers to be themselves, as John discussed: “you’re not judged there, you can play stuff on the drums, or whatever you want to be there”.

#### 4.3.3.2.4 No Perceived Hierarchy

Co-researchers considered themselves as equal to other PPA participants and staff, indicating a perceived lack of hierarchy within the organisation. Factors influencing this lack of hierarchy included the frequency and type of contact between PPA participants and staff. Co-researchers reported that office staff frequently visited them in their programmes (“\*office staff\* just comes into our sessions [...] just to say hello and ask us if we need anything” - Ella, C1). Programme visits enabled office staff to get to know participants as individuals, reinforcing a non-hierarchical organisational structure, as Janine discussed in cycle one: “For \*office staff\* who come into, came into the groups [...] they come round all of them. But they know the people [...] know about them and they can relate to each one.”

Additionally, co-researchers commented on non-hierarchical behaviours exhibited by programme staff, such as sitting with participants during social time (“at lunchtime, they all come and sit with us at the tables” – Ella, C1). Behaviours that challenged the traditional hierarchical structures within an organisation were considered to be more ‘accessible’ by co-researchers, and therefore influenced whether or not an individual was considered to be an ‘accessible person’ (discussed further in section 6.3.2.2.5.1). The perceived lack of hierarchy between participants, parents and staff also impacted the approachability of office and programme staff (“It’s not like you’re going to the headmaster or the bank manager” – Janine, C1) and enabled staff to fulfil a range of roles in the lives of participants, which were not directly related to their professional roles at PPA, such as supporters, friends and family.

Pockney (2006) notes that the relationships between adults with learning disabilities and paid support staff are often “denied friendship status” (p.5) since this relationship is not viewed as equal or reciprocal. In other words, while PPA participants may consider staff to be ‘friends’, staff may not label this relationship in the same way. However, it is interesting to note that PPA staff have adopted the label of ‘Purple Patch family’ and identify themselves as

members of this group alongside participants and parents. This reciprocated label of being a 'family' reinforces participants' integration within the PPA community, while acknowledging that, as with a biological family, different members have different roles and responsibilities.

#### 4.3.3.3 Negative experiences with non-disabled people

Co-researchers identified acceptance of others as an important aspect of their group identity. This is in contrast to the PRG's previous negative experiences with others outside of PPA, which were discussed throughout the research. Co-researchers described instances of physical and emotional abuse, bullying, discrimination, lack of understanding and negative attitudes, often involving their non-disabled peers (e.g. peers in school and/or college) and members of the public. For example, John and Tracey discussed experiencing judgement from others while out in their local community:

Tracey: you get a lot of stares don't you mate

John: well, that's what Tracey says, but I don't really notice that because I'm used to them and I'm not bothered really, once I start to speak, I think people get a bit shocked

Ella and Leanne discussed the perceived conflict between disabled and non-disabled people, indicating an awareness of the negative attitudes of others, particularly in relation to inclusion in group settings:

Leanne: don't ...understand an argument between the disabilities and other people.

UR: you don't understand an argument between them?

Leanne: yeah

UR: mhmm

Ella: why do they have this argument about disabilities for everybody, why then UR?

UR: yeah, I think that's a good question Ella, what argument do you think there is between disabled people and people without disabilities?

Ella: well, they say they can be...

Leanne: we should be able to go to all groups even if we have a disability or not

Non-disabled people were generally considered to have a lack of understanding and awareness about learning disabilities ("the people who don't have a disability, they don't know how, how hard it is" – Leanne, C3). Ella shared her desire for greater understanding from others in order to tackle misconceptions about the differences between those with learning disabilities and those without learning disabilities:

Ella: I want other people to know what it's like with me having a learning difficulty

UR: yeah, you want other people to know

Ella: I do the same as other people



People with learning disabilities are often aware that others may view the label ‘learning disabilities’ negatively (Ali et al., 2015). Scior and Werner (2015) suggest that misconceptions around people with learning disabilities are widespread and negative interactions with others, particularly strangers, are common. Indeed, in a survey of 1000 people with learning disabilities, a third of participants reported that they worried about being bullied when leaving their home and approximately 9 out of 10 participants stated that they had been bullied or harassed in the previous year (Mencap, 2019b). Increasing understanding of learning disabilities was therefore considered by co-researchers to be an important aspect of tackling negative attitudes, stereotyping and behaviours from others.

It is worth noting that while the majority of staff at PPA do not identify as disabled and therefore may not have a direct understanding of disability, they were accepted by co-researchers as a trusted part of the PPA community. This may be due to the shared values between staff and co-researchers, as discussed previously. However, Leanne also notes that “Purple Patch understands how hard it is so they know where we’re coming from”. This suggests that despite a lack of lived experiences of disability, PPA staff were considered as knowledgeable and understanding about learning disability. Previous research suggests that understanding and awareness of learning disability facilitates trust between people with learning disabilities and non-disabled people (Howard et al., 2015). This may be due to the fact that negative interactions with others (including bullying and stigma) are often related to a lack of understanding and negative attitudes (Scior & Werner, 2015).

Stories of negative interactions with other people were often shared to highlight the contrast between the PRG’s social experiences at PPA versus the outside world, as Ella and Tracey discussed:

Ella: I got picked on a lot at college, at college and this boy \*name\* headbutted me on the shoulder

UR: oh no! That’s not very nice

Ella: he came up and just head butted me right on the shoulder

UR: oh dear, that’s not kind is it

Ella: no

UR: no, definitely not

Tracey: we don’t have any of that at Purple Patch do we?

Ella: no, that’s what I like about Purple Patch, everybody is so welcome

Similarly, Ella discussed the importance of staff support when responding to bullying, by comparing hypothetical negative experiences at PPA to her real-life experiences of bullying at school:

Ella: if I did get bullied, the staff are there, the purple staff are there

UR: yeah, that's right

Ella: if I did get bullied

UR: yeah, and did you feel like, at school, did you feel like you could talk to somebody at school when you got bullied Ella?

Ella: no, well I could talk to the behaviour team, I was frightened to go to the behaviour team about \*name\* but in the end I did, I'm glad I did in the end

This comparison between the behaviours of 'PPA participants' and those outside of Purple Patch reinforces the 'Purple Patch Family's' core values of support, acceptance and belonging ("There's no bullying at Purple Patch" – Ella, C1). The present study therefore highlights the importance of fostering a welcoming environment for adults with learning disabilities, particularly in spaces where adults with learning disabilities may have previously had negative experiences (e.g. learning environments).

Negative experiences with non-disabled people resulted in co-researchers experiencing social isolation ("I used to keep to myself, that's what I did in school, just kept to my, just to myself" – Ella, C1), low mood ("I've had a few ups and downs" – John, C1) and reduced self-esteem ("I'm always doing something wrong" – Ella, C2). Experiences of stigma and bullying also impacted co-researchers' perceptions of themselves, their capabilities and of having a learning disability. This is in keeping with previous research which suggests that negative attitudes, discrimination and misconceptions around the capabilities of adults with learning disabilities can have long-term negative consequences for disabled people, such as lower psychological wellbeing (Ali et al., 2012), reduced opportunities for choice (Pelleboer-Gunnink et al., 2021) and social isolation (Mencap, 2019b). However, it is interesting to note that in the present study having a learning disability was viewed more or less negatively depending on the context in which it was discussed. For example, Ella reported feeling bad about having a learning disability while discussing her experiences of bullying in cycle one:

Ella: I feel bad about me having a learning difficulty sometimes

UR: do you?

Ella: yeah

UR: ah, why do you feel bad about it Ella?

Ella: because people look, stare at me when I go out

However, in the following research session in cycle one, Ella's perspective on LDs shifted towards that of acceptance while discussing people at PPA.

Ella: I've got a learning difficulty. I've got a learning difficulty

UR: mhm Yeah

Ella: and I can't change that [...] I feel ok about what I have

Ella's negative views of learning disabilities may be considered as an example of self-stigma, whereby people with learning disabilities internalise the negative attitudes and judgements

of others (Ali et al., 2012). Self-stigma may be considered as an example of psycho-emotional disablism and can lead to negative perceptions of oneself, alongside low self-esteem, reduced aspirations and reduced quality of life (Ali et al., 2015; Paterson et al., 2012). Ella's experiences with self-stigma appear to be related to her encounters with bullies at school. When reflecting on her experiences at PPA Ella's perception of herself was more positive and she did not report any instances of self-stigma. Previous research suggests that the negative impact of self-stigma can be reduced by stigmatised communities filling meaningful roles in society, such as being a member of a group (Dagnan & Sandhu, 1999). Additionally, involvement in services that promote empowerment may help to reduce self-stigma (Corrigan & Calabrese, 2005). The present study suggests that active involvement in inclusive learning programmes such as PPA, which seek to empower adults with learning disabilities, may support participants to internalise positive views of themselves and therefore begin to counteract the impact of stigma and negative experiences with others. Co-researchers also used their attendance at groups and programmes to challenge the negative perceptions of others. For example, Ella shared her belief that her attendance at PPA proved that those who bullied her were wrong about her capabilities:

Ella: this girl \*name\* said I won't, I weren't able to be good at anything  
 UR: well, we know that's not true!  
 Ella: no, I proved her wrong by coming to Purple Patch

The present study therefore suggests that attendance at PPA supported positive self-image and empowered co-researchers to self-advocate and actively challenge the negative perceptions of others.

#### 4.4 Reflections and recommendations from cycle one

One of the most important aspects of PAR is reflection (Johnson & Walmsley, 2003). Indeed, Robertson (2006) cites 'reflection-on-reality' as one of the 'three R's' of action research. Reflection took many forms throughout the project. Co-researchers were encouraged to reflect on their experiences at PPA (and at times, outside of PPA) throughout the project. Additionally, both the co-researchers and the UR reflected on the research process alongside their own engagement and experiences with the project as researchers. Robertson (2000) notes that reflection is a constant process throughout PAR, and this was certainly true of the present study. However, the end of each cycle also provided an opportunity for focused reflection on the research from that cycle, alongside the identification of recommendations from the research. Recommendations from cycle one mostly concerned the ways in which

recruitment and initial attendance at PPA could be supported more effectively through inclusive advertising and a buddy system.

#### 4.4.1 Inclusive advertising

Through reflection on their experiences of joining PPA, alongside their perceptions of what they thought PPA would be like prior to joining, co-researchers highlighted the need for more inclusive and transparent advertising of PPA's service. Co-researchers believed that advertising materials (e.g. a flyer advertising PPA) were not necessarily aimed at potential participants, but rather at the parents/carers of participants. This resulted in co-researchers feeling unsure as to what to expect at PPA. Additionally, since the PRG's perceptions of learning environments were often based on negative previous experiences, co-researchers initially reported feeling scared and anxious regarding attending PPA ("I was very scared at first, I didn't know what to think about Purple Patch Arts" – Tracey, C1). While it is important for parents and carers to be aware of the service PPA provides so that they may support potential participants to make decisions concerning their involvement, co-researchers expressed a desire for the creation of additional materials that were specifically designed for prospective participants. This was also important to address any misconceptions or concerns participants may have around the learning environment.

Suggestions for alternative materials included a video introduction to PPA, featuring current participants discussing their experiences. Videos were considered to be a more accessible way of sharing information than an easy read leaflet. The group revisited the idea of a video in cycle two, when providing feedback on an easy read leaflet designed by PPA:

UR: so, imagine you're a new person who wants to go to Purple Patch and you've never been before, do you think it would be better to get a leaflet like this one, or a video?

Leanne: Video

Ella: video

UR: a video, mhm, and why do we think that?

Ella: because it explains what it is and what we do

UR: mhm, and what makes a video better than a leaflet?

Ella: more clear and easy to understand [...] if someone has a learning difficulty like me, and other people with disabilities

UR: they might find the video easier?

Ella: yeah

#### 4.4.2 Buddy system

All co-researchers reported feeling nervous prior to starting Purple Patch:

Ella: I remember what I feel like, I know what I felt like before Purple Patch.

UR: how did you feel, Ella?

Ella: a little bit nervous

Nerves were often related to trying something new, meeting new people (particularly after prior negative experiences with people), and not knowing what PPA would be like. During cycle one, co-researchers suggested that knowing somebody who already attends a programme enabled them to feel more confident to attend themselves. Indeed, all members of the PRG knew at least one person at PPA prior to attending. These ‘recruiters’ provided co-researchers with information concerning the nature of the PPA programme, including information about the content, accessibility and staff, as Ella discussed in cycle three:

Ella: I’d heard \*participant\* talking about it [PPA] in the \*inclusive arts group\*, in \*inclusive arts group\*, I heard \*participant\* talking about it [PPA]

UR: ok, you heard him taking about it, and what kind of things was he saying about Purple Patch?

Ella: how he really enjoys it!

UR: mhm, yep, and did the

Ella: and he said he, they’re friendly staff

UR: right ok, so he told you that he really enjoyed it and that the staff were really friendly

Ella: and caring

UR: and caring as well ok, yeah, and did he tell you anything about kinds of activities they do at Purple Patch?

Ella: yeah

These individuals also provided practical, emotional and social support to new participants upon their arrival at their PPA programme, becoming ‘supporters’. Co-researchers reflected on the value of these individuals during their first few weeks of attendance at PPA, noting that supporters helped them to settle in and to feel welcome (“he made me feel really welcome when I first joined” – Ella, C1).

Based on these experiences, co-researchers recommended formalising this process of peer support through a buddy scheme, whereby new participants are matched to pre-existing group members. Co-researchers shared their idea for a buddy scheme during the feedback session for cycle one. PPA began developing buddy training, with support and feedback from the PRG, in January 2022. The first cohort of PPA buddies completed their buddy training in in September 2022. The scheme is still ongoing and PPA buddy training is now publicly available for free use by other organisations.

## 5 Cycle Two - Arts and Variety

### 5.1 Planning

#### 5.1.1 Research Questions

In cycle two, co-researchers chose to explore arts and variety at PPA. Arts and variety were described by the PRG as “the different things we do” (C1) and concerned the use of varied arts-based and themed activities to support engagement with learning. The planning stage of cycle two consisted of two one-hour meetings for each group. In these initial meetings the groups engaged with previous literature relating to the theme ‘arts and variety’ (Richards et al., 2019; Hall, 2012). Easy read versions of this literature were created by the UR and shared with the group via Zoom. The UR supported the PRG to discuss the aims, methods and findings of each paper, with the goal of increasing the co-researchers’ understanding of previous PAR that explores the impact of the arts/arts-based activities and programmes for people with learning disabilities.

Co-researchers were supported to select research questions via the process outlined in section 4.2.1.1. When selecting research questions, the group also considered the findings and remaining questions identified in the review phase of cycle one. For example, during cycle one, the group discussed the impact of the arts on their experiences at PPA, attributing the accessibility and enjoyment of learning activities to ‘the arts’. The arts were considered to be innately ‘special’ in comparison to other activities, such as sport or subjects perceived to be ‘traditionally academic’ (e.g. maths or English). While the PRG agreed that the arts were an important part of their experiences and learning at PPA, the specific aspects of what made the arts a successful avenue for LLL had not yet been identified by the group. Co-researchers therefore chose to explore this concept further in cycle two. Four research questions were selected by the PRG as the focus of cycle two:

RQ1: What, if anything, is special about the arts?

RQ2: Do the arts at PPA help us to learn? If so, how?

RQ3: How does engaging with the arts make us feel?

RQ4: What are our favourite and least favourite things to do at PPA?

#### 5.1.2 Choosing methods

As in cycle one, the methods for cycle two were chosen collaboratively by the PRG, through a series of group discussions. The PRG first discussed methods that had been used in previous literature exploring the arts-based experiences of adults with learning disabilities, including observation and interviews (Hall, 2012) and creative approaches which capture participants’

experiences visually, such as through photography, drawing and collage (Aldridge, 2007; Richards et al., 2019).

To address research question one (what, if anything, is special about the arts?), co-researchers chose to create an artistic response (e.g. creating a poster, collage or drawing, in line with draw, write tell approaches; Angel et al., 2015). Arts-based methods were deemed to be appropriate, as creative methods provided co-researchers with the freedom to express their views and feelings via accessible mediums. While this activity was designed to address research question one, the integration of the arts throughout PPA programmes meant that co-researchers' responses also provided some useful insights for research questions two (do the arts at Purple Patch help us to learn?) and three (how does engaging with the arts make us feel?). Alongside her artistic response, Tracey chose to write a story/self-interview outside of research sessions about her experiences with the arts and variety at PPA. Additionally, John chose not to create an artistic response, instead discussing his perspectives on the arts at PPA during research sessions.

To address research questions two, three and four, the PRG chose to create a questionnaire to document their learning experiences with the arts, including how engagement with the arts made them feel and their favourite and least favourite aspects of the PPA programme (see figure 17). An accessible questionnaire was created in order to track the co-researchers' experiences with the arts over a five-week period (the remaining number of weeks before the end of the term). This allowed co-researchers to reflect on their experiences in five different virtual PPA sessions, each with their own topic and activities. The questionnaire was created collaboratively in planning session two and was organised into three main sections. Section one directly addressed research question four, by collecting information about the session theme and encouraging co-researchers to reflect on their favourite and least favourite parts of the day. Section two of the survey captured information about the activities in each PPA session, alongside how they felt during each activity using emojis:

UR: how do you think we can measure how we feel?  
 Tracey: yeah, pictures! Pictures and we could circle it  
 UR: that's a great idea Tracey, I think that's brilliant  
 John: yeah you could have the  
 Janine: emoticons  
 UR: yeah  
 John: those bubbles, you know those yellow ones  
 UR: emojis?  
 John: emojis yeah, we've used them before

Section three captured approaches to learning at PPA, including what was learned and how it was learned. The survey was designed to facilitate varied types of responses. For example, large answer boxes enabled co-researchers to write or draw their responses, depending on their needs and preferences.

























<p>Name <input type="text"/></p> <p>Date <input type="text"/></p> <p>Today's topic:</p> <div style="border: 1px solid #ccc; height: 60px; width: 100%;"></div> <p>My favourite part of today's session was:</p> <div style="border: 1px solid #ccc; height: 60px; width: 100%;"></div> <p>My least favourite part of today's session was:</p> <div style="border: 1px solid #ccc; height: 60px; width: 100%;"></div>	<table border="1"> <thead> <tr> <th>Activity</th> <th>What we did (circle)</th> <th>How I felt (circle or draw your own)</th> </tr> </thead> <tbody> <tr> <td></td> <td>  </td> <td>  </td> </tr> <tr> <td></td> <td>  </td> <td>  </td> </tr> <tr> <td></td> <td>  </td> <td>  </td> </tr> <tr> <td></td> <td>  </td> <td>  </td> </tr> </tbody> </table> <p>Did you learn something new today?  Yes <input type="checkbox"/> No <input type="checkbox"/> Not sure <input type="checkbox"/></p> <p>If Yes, what did you learn?</p> <div style="border: 1px solid #ccc; height: 40px; width: 100%;"></div> <p>How did you learn?  <small>(If you get stuck you can use the activity emojis to help you!)</small></p> <div style="border: 1px solid #ccc; height: 40px; width: 100%;"></div>	Activity	What we did (circle)	How I felt (circle or draw your own)												
Activity	What we did (circle)	How I felt (circle or draw your own)														
																
																
																
																

Figure 17: Arts and variety questionnaire designed by the PRG

## 5.2 Action

### 5.2.1 Procedure

Research sessions in cycle two took place fortnightly and lasted approximately one hour. Table 7 provides an overview of the content addressed in each session of cycle two, including which co-researchers were present. Co-researchers completed their arts and variety questionnaires in their own time. Therefore a large proportion of the action phase in cycle two took place outside of research sessions. This five-week period of data collection is included in table 7 as 'Independent action period'.



Table 7: Outline of research sessions undertaken in cycle two

Session Type	Co-researchers involved	Session content
Planning 1, group 1	Ella, Leanne, John, Charlie, Jo, UR	Looking at previous literature (Richards et al., 2019; Hall, 2012) and brainstorming research questions.
Planning 1, group 2	Sam, Janine, John, Liam, Tracey, UR	
Planning 2, group 1	Leanne, Ella, UR	Arts and identity discussion. Planning activities 1 feedback session with PPA staff. Choosing method, creating questionnaire
Planning 2, group 2	Sam, Janine, Tracey, John, Jo, Charlie, UR	
Feedback session	Ella, Leanne, Tracey, John, Liam, UR, PPA office staff	Research feedback session with PPA staff
Action 1, group 1	Tracey, John, Charlie, Jo, Ella, Leanne, UR	What's special about the arts?
Action 1, group 2	Sam, Janine, Liam, UR	
Independent action period (five weeks)	All co-researchers	Completing questionnaires independently
Review 1, group 1	Ella, Tracey, Leanne, UR	Analysis of artistic responses.
Review 1, group 2	Tracey, Liam, John, Sam, Janine,	
Review 2, group 1	Leanne, Ella, Tracey, UR	Analysis of artistic responses (creating theme map)
Review 2, group 2	John, Tracey, Sam, Janine, Charlie, Jo, UR	
Review 3, group 1	Ella, UR	Checking and naming themes
Review 3, group 2	Tracey, John, UR	

#### 5.2.1.1 Planning session one

In the first planning session, the PRG were shown easy read versions of relevant previous literature selected by the UR (Richards et al., 2019; Hall, 2012). Chosen literature involved adults with learning disabilities, utilised arts-based methods and were linked to the theme of 'arts and variety' (e.g. papers investigating the impact of engagement with the arts). Co-researchers discussed the strengths and limitations of this literature, alongside the suitability of the chosen methods. Co-researchers incorporated the knowledge and experience developed in cycle one into these discussions, demonstrating increased understanding of research terminology, methodologies and the application of research in the real world. For example, Ella demonstrated her understanding of the term 'observation' (which was first

introduced to the group in cycle one) by drawing on an example of observation from her life outside of the project while discussing potential methods in cycle two:

UR: the researcher watched each programme, so they went to go and visit, and they wrote down all the things they noticed in their research diary, and we talked about how this was called observation  
 Ella: observation  
 UR: observation yeah, so when we go, and we watch  
 Ella: that's a big word  
 UR: it is a big word Ella, yeah, it is almost a smaller word though  
 Ella: oh yeah, I remember, I remember, Ofsted coming to watch my tutors teach  
 UR: yeah! That's a really good example of observation Ella! So, you can see observation, it has the word observe in it  
 Ella: oh, thank you!

After discussing previous literature relating to the theme, co-researchers brainstormed questions concerning the arts and variety at PPA that they were interested in addressing in cycle two. Research questions were finalised by discussing which questions the PRG considered to be most important/interesting, using the approach outlined in section 4.2.1.1. Methods to answer these questions were selected through group discussion (e.g. by discussing which methods would be best suited to answer the questions and which methods were most accessible to the members of the PRG). The group discussed each research question in turn, and with support from the UR, considered which methods would be most appropriate for the present study. The UR supported this process by asking co-researchers prompt questions to aid their decision making, providing suggestions or options for the PRG to choose from (e.g. do you think we should interview someone or do a drawing to share what we think?) and encouraging the group to share their ideas.

#### 5.2.1.2 Planning session two

The first half of planning session two was used to design a feedback session for PPA staff. PPA staff did not attend research meetings. Therefore, the feedback sessions provided an opportunity for the PRG to share their research progress and findings with staff ("I really wanted to show the office staff, because they don't get to see what we do [research]" – Ella, C2). An important aspect of PAR is action and social change (Selenger, 1997). Therefore, sharing the research findings alongside recommendations for future development at PPA was an important stage of the project. Co-researchers chose to share the outcomes of cycle one via a video, as this was deemed to be a clear and accessible way to share the findings of research with others. The video was created by the UR using PowToon and shared with the PRG to check/edit via the Facebook group. The finished video was played for PPA staff over Zoom.

In the final part of planning session two, the PRG co-created a questionnaire, which was designed to support co-researchers to reflect on their experiences at PPA in relation to research questions two, three and four. The questionnaire was designed using Canva. The UR used the 'share screen' function on Zoom so that co-researchers could contribute to the creation of the survey in real time (e.g. by suggesting questions, layout, or general design ideas that the UR then implemented; see extract from planning session two below).

UR: do we have any ideas of what questions we can have on our form?

Ella: why did you enjoy doing volcanos [the theme]

UR: yeah, that's a good thing, so shall we say, we could maybe say, what did we like the best and what did we like the least?

Ella: yeah

Leanne: yeah

The group chose to include emojis to record the activities undertaken in each PPA session and their emotional response to these activities. Co-researchers were asked to post emojis that they felt represented the most common activities at PPA, alongside emojis to represent a scale of emotions on the PRG Facebook group. Emojis included in the questionnaire were then selected by the group from those that were posted on the Facebook group. Figure 18 demonstrates the collaborative process of choosing emojis via the Facebook group. Here, Tracey identifies a missing activity (using sign language), which was later added to the questionnaire.



Figure 18: Tracey suggests including an emoji for sign language in the questionnaire via the PRG Facebook group

Chosen activity emojis represented games, dancing/movement, social breaks, writing, signing, art/drawing, acting, music and reading. Emotion was measured on a 5-point scale, from very happy (represented by the purple heart) to very sad (crying emoji). Co-researchers were also provided with a blank emoji which they could draw on to represent their emotional response if they felt that the options provided did not capture how they were feeling. A key was created and circulated to each co-researcher in the post, alongside five paper copies of the questionnaire for them to complete as soon as possible after their PPA programme.

#### 5.2.1.3 Action session one

At the start of the action phase, co-researchers completed a brainstorm activity about what constitutes ‘the arts’ (e.g. examples of different activities which may be referred to collectively as ‘the arts’). Conversations with the PRG during cycle one indicated that some co-researchers may have misinterpreted the meaning of ‘the arts’ as referring to just the creation of visual artwork. The purpose of this discussion was therefore to ensure that the group were considering the range of creative activities that may be included under the umbrella of ‘the arts’, before exploring what, if anything, may be considered as special about these activities. This example highlights the different perspectives with which co-researchers approached the theme of arts and variety and emphasises the need for clear and thorough discussions and explanations about key terms and topics. The PRG shared a variety of activities that they perceived to be examples of the arts, including music, drama, drawing, painting and using your imagination.

During the first action sessions, six co-researchers created artistic responses to the question ‘what (if anything) is special about the arts?’, using their research journals and any creative resources they had available to them at home (e.g. coloured pens and pencils). Co-researchers created their artistic responses while discussing their views on a set of prompts. Prompts were designed to facilitate conversations around the specific qualities of the arts that made it ‘special’ (or not) in comparison to other activities, alongside the suitability of the arts as a vessel for LLL experiences. These were as follows:

- Are the arts special? And if so, why do we think they are special?
- Are the arts different to other activities?
- Why do you think that PPA uses the arts in their LLL programmes?
- Imagine PPA without the arts – what it would be like if we took the arts away? What would be left?

The creative format of this task allowed co-researchers to express their experiences and responses to these questions in varied ways that suited their preferences and needs. These included written words, drawings, colouring and symbols. John suggested that this approach to data collection was more accessible to co-researchers with varied communication needs: “I think the visual pictures show it easier, more accessible than say writing it down isn’t it, for a lot of people, if that makes sense” (C2). Some co-researchers chose to depict an overview of their perspectives on the qualities of the arts which they felt made it ‘special’, such as Tracey, whose vibrant artwork includes multiple ideas and perspectives on her arts-based experiences at PPA (see figure 19).



Figure 19: Tracey’s artistic response to the question, what (if anything) is special about the arts?

Tracey took inspiration from book covers when creating this piece of artwork and also wrote an accompanying story. Her drawing includes statements about the arts and her experiences with arts-based activities which highlight the aspects of the arts that she considers to be most important at PPA.

Sam (supported by Janine) took a diagrammatic approach to map out the key qualities of the arts that were special to her, focusing on the central idea that the arts promote freedom (see figure 20).

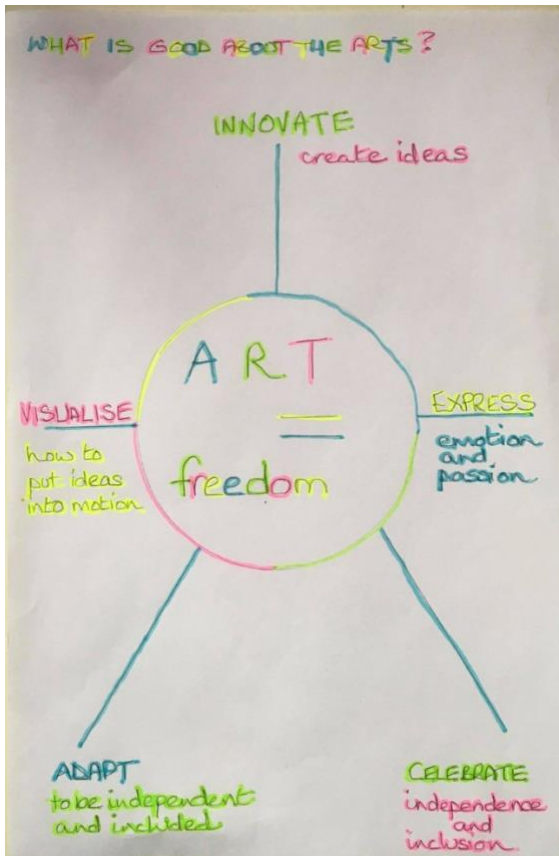


Figure 20: Sam and Janine's artistic response to the question, what (if anything) is special about the arts?

Sam and Janine's diagram highlights 5 key features of the arts that make it 'special'; Innovation, visualising, expression, adaptation and celebration.

In contrast, Ella chose to focus on a single aspect of her experience with the arts, which she described as being particularly special and important to her (see figure 21). Ella's artwork depicts two characters who represent her experiences of imagination and arts-based sensory storytelling, both within PPA programmes and in her daily life.



Figure 21: Ella's artistic response to the question, what (if anything) is special about the arts?

*Ella's drawing of two of her favourite characters (Pip and Freddy from the animated series T.O.T.S) represents her use of imagination, sensory storytelling and fictional play to support her wellbeing.*

Alongside her artistic response, Tracey chose to write a story about her experiences with the arts and variety at PPA in her own time. Additionally, John opted to share his views verbally by contributing to group discussions, as opposed to creating a physical artistic piece. Completed posters and Tracey's story were shared in the PRG Facebook page for co-researchers to see and respond to.

#### 5.2.1.4 Independent action phase

Co-researchers completed their arts and variety questionnaires during an independent action phase, which lasted five weeks. A total of 16 questionnaires were completed by five co-researchers during this independent action period. Completed questionnaires were photographed by co-researchers and sent to the UR via email. Once all the completed questionnaires had been received, the UR compiled the data into a presentation, which the group discussed during review session two.

### 5.3 Review

#### 5.3.1 Analysis

The review phase of cycle two took place over three one-hour meetings per group. As in cycle one, an adaptive form of thematic analysis was used to analyse the data. Co-researchers were sent physical copies of each other's artistic responses, alongside Tracey's arts and variety story, in the post. In review session one, co-researchers familiarised themselves with

each other's work and identified the features of their own and others artistic responses that they felt were most important or interesting. The UR wrote down recurring ideas on post-it notes, which served as initial codes. Co-researchers played a more active role in the formation of themes in cycle two than in the previous cycle, demonstrating the development of their research skills and increased understanding of the process of adaptive thematic analysis. In cycle one, the UR grouped initial codes into themes and the PRG checked these through a cutting and sorting exercise. However, in cycle two, themes were formed collaboratively over the course of review sessions two and three. The UR combined the post-it notes from both groups and read out each one in turn. Co-researchers discussed which codes should be grouped together based on whether the content was considered to be related or unrelated. Similar codes were grouped together to form themes. Due to the online setting of the research, a visual map of these themes was created by organising post-it notes (codes) into groups on the UR's wall on Zoom (figure 22). The UR supported co-researchers to generate this theme map by providing options for the placement of post-it notes on the wall, for example by indicating two or three location/grouping options and asking the group to choose which one they felt was most appropriate. Additionally, physical space between post-it notes was used to indicate connections between codes (e.g. post-it notes arranged in close proximity to each other represented a close connection between ideas/concepts).

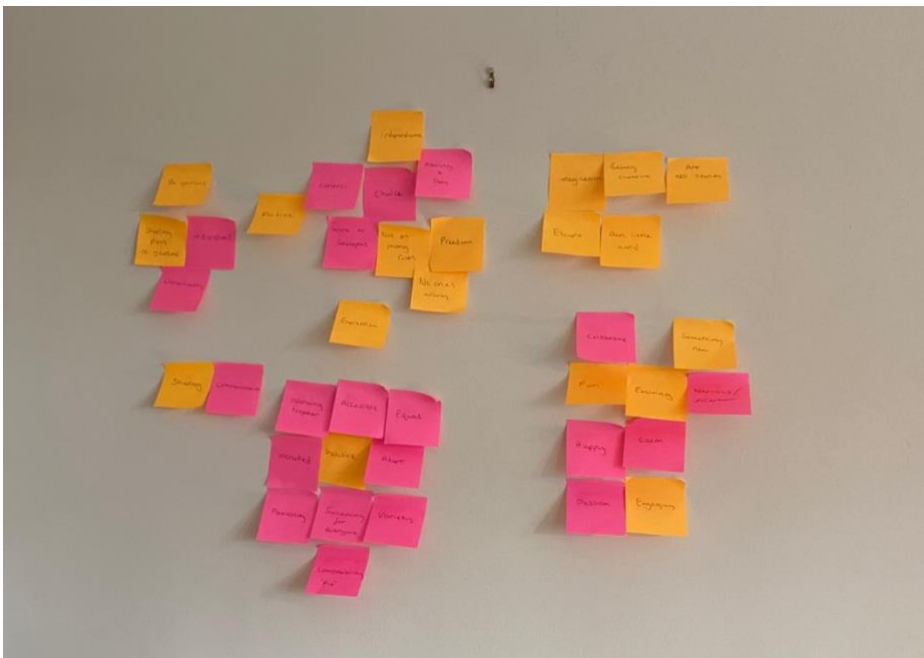


Figure 22: The PRG's theme map for 'arts and variety'

*Pink post-it notes are codes identified by group one and orange post-it notes are codes identified by group two.*

Finally, in review session three, co-researchers reflected on and refined the content of each theme. While there was a high level of agreement between the two groups with regards to



how codes were organised, any codes that the groups had categorised differently or were unsure about were discussed further in this session. For example, during review session two, both groups were unsure which theme the word 'accessible' belonged to. Since accessibility was considered to be a core underlying feature of PPA, co-researchers initially put this code in the middle of the theme map to indicate its connection to all arts and variety themes. However, further discussions in review session three revealed that co-researchers had identified different types of accessibility that related to each theme in different ways. Therefore, rather than considering accessibility as one individual code, co-researchers discussed the different facets of accessibility and how these were connected to each of the identified themes. Tracey and John discussed how accessibility can relate to places, activities, feelings and even people:

UR: so, if we say something is accessible, what do we mean?  
 John: it's positive and it's there to be used, um like a train, accessible or a bus is available for us to use  
 UR: yeah, so it might mean that everybody can use it?  
 John: yeah  
 Tracey: it can go underneath independent  
 UR: what have we got, independent  
 Tracey: three  
 UR: group three, yeah, so, do we think, can a person be accessible?  
 John: oh, it depends on the person  
 UR: or is it, can a place that be accessible or not accessible  
 Tracey: the place and the person  
 UR: mhm, so it might be that, what does an accessible place look like, or what might it be like  
 John: it's easy to access, you can access it and come and go as you please  
 UR: right yeah, that makes sense  
 John: which is really not accessible at the moment  
 UR: right yeah, so it's not accessible for you at the moment because you can't, you can't come and go as you please?  
 John: no, no  
 UR: so, what about an accessible person, what does that look like, or what are they like?  
 John: usually easy going  
 UR: mhm, yeah  
 John: and can adapt  
 UR: ok, so what do you think Tracey, what do you think an accessible person is like?  
 Tracey: it's John  
 UR: \*laughs\*

This resulted in the initial code 'accessibility' being split and therefore considered as three sub-codes: arts and accessibility, accessible people and accessibility and positive meaning. Additionally, this discussion was the UR's first introduction to the idea that people could be accessible. Indeed, in the extract above, the UR questions whether or not people can be described as accessible. As a non-disabled adult, the UR had never considered the concept of 'accessible people' and how these individuals may impact the accessibility of spaces and activities. Therefore, this discussion highlights the importance of the involvement of adults

with learning disabilities in research, so that the experiences of disabled people are captured fully. Based on these discussions, the PRG chose to investigate ‘accessible people’ further in cycle three.

After refining each theme, co-researchers named and wrote descriptions for each. For example, the extract below demonstrates the collaborative process of naming the ‘personal escapes’ theme.

Tracey: the thing is imagination and on your own little world  
 UR: mhm  
 Tracey: being creative, all similar  
 UR: yeah  
 Tracey: so, what can we say about this John?  
 John: well, they’re all things to do with personal things really  
 UR: mm  
 John: that’s personal isn’t it  
 UR: mhm  
 John: personal escapes  
 UR: personal escapes, that’s a good idea  
 Tracey: brilliant, see I’m trying to help John and then John is helping me

Alongside the PRG’s collaborative analysis of their artistic responses, the UR completed their own analysis of the transcripts from cycle two. This identified one additional theme (‘Learning with, from and through the arts’) and one additional sub-theme (‘Ownership and achievement’, discussed as part of the theme ‘Being and sharing you’).

Questionnaire responses were collated by the UR and data were presented back to the PRG via a PowerPoint presentation. Data were presented via pie charts, which provided a visual representation of the results of the questionnaire. The UR also used this as an opportunity to discuss the different ways in which data can be shared after it has been collected (using pie charts as an example; see figure 23). The prompt “what do you think we have learned by doing these questionnaires?” was used in review session two to initiate discussion about the findings from this reflective exercise. During these discussions, co-researchers acknowledged that this method of collecting data about the emotional responses of Purple Patch participants, and therefore the results presented, were limited to the members of the PRG (“I don’t know everybody else’s moods at Purple Patch, my friends” – Ella, C2). During cycle two Covid-19 restrictions meant that PPA operated online and therefore co-researchers were not able to ask their peers to complete the questionnaire (as was suggested during the planning stage of cycle two; “you could ask, what’s your favourite thing that you learn at Purple Patch? What do you really enjoy doing?” – Jo, C2). However, as co-researchers filled a dual role in this project as researchers and PPA participants, co-

researchers determined that this questionnaire could be used by the group as a tool for self-reflection to understand their own emotional engagement with the arts at PPA.

The following section will discuss the themes that were identified through the co-researchers' and UR's analyses in cycle two. Firstly, 'the arts at PPA' provides an overview of the types of arts-based activities discussed by co-researchers in cycle two. Five additional themes were identified by the PRG through adapted thematic analysis and one theme was identified by the UR's analysis. Descriptions of each of these themes written by the PRG are included below in quotation marks:

1. 'Positive Meaning' discusses "all the good feelings that we feel inside of us at PPA", including our emotional responses to the arts, as identified in the co-researchers' questionnaire responses.
2. 'Personal Escapes' explores how "the arts helps us to escape into our own personal spaces and to use our creativity", both within PPA programmes and outside of PPA.
3. 'Learning with, through and from the arts' was identified through analysis of the PRG's questionnaire responses, alongside the UR's independent thematic analysis (see section 3.5.2.2 for details about this process). This theme concerns the relationship between the arts and learning at PPA.
4. 'Freedom and Choice' concerns the co-researchers' experiences of "trying to be independent, to grow and to work on your own".
5. 'Equality and Inclusion' specifically concerns the relationship between the arts and accessibility at PPA. Sub-themes explain the qualities and features of the arts which support equality and inclusion at PPA.
6. The final theme, 'Being (and sharing) you', considers the relationship between the arts and identity, including how "the arts helps us to be ourselves and to share our individuality with others". The sub-theme, 'ownership and achievement', concerns co-researchers' pride and ownership of their creations at PPA.

### 5.3.2 Results and Discussion

#### 5.3.2.1 The Arts at PPA

The results of the PRG's arts and variety questionnaire indicate that a broad range of art forms were used within PPA, including drama, visual arts (including drawing, painting, sculpture, photography), music, movement, sensory activities and arts-based games. Figure 23 indicates how often co-researchers reported the inclusion of each activity type in their PPA day during the independent action phase of cycle two. The most commonly reported activity undertaken at PPA was drama, which included acting out scenarios/role play, creating

characters and pretending/imagining. For example, in cycle two Sam shared an example of the use of acting/pretending in a PPA session about the Rowntree factory: “pretended that sweets were people and acted as we thought the sweets were”. Social time was the least commonly reported activity in PPA sessions, despite the fact that opportunities for socializing were highly valued by co-researchers. The PRG concluded that this may be due to the fact that data were collected during the Covid-19 lockdown, while PPA was operating online. As such, social opportunities, particularly informal/chance social interactions such as having a chat with other participants during break times, were limited due to the virtual nature of PPA. Despite this, the PRG reported that their participation in group arts-based activities provided opportunities for social interaction and support from others, such as sharing and helping others (“maybe I say help with someone like me, help with something, talk about it” – Sam, C2). This is in keeping with previous research undertaken with non-disabled adults, which demonstrates that participation in arts-based adult education enhanced social networks (Pearce, 2017).

Despite the virtual context of PPA programmes during the action phase of cycle two, figure 23 demonstrates that arts-based activities were used consistently and proportionately within PPA programmes. Co-researchers’ questionnaire responses also indicated that arts-based activities were rarely used in isolation. Instead, activities often combined multiple art forms and/or sensory activities to support engagement with learning content and the theme for the week. For example, Sam described using music, movement and drama during a ‘Spring’ themed session to embody spring flowers: “Thinking of spring flowers and using yoga poses to express to music” (C2).

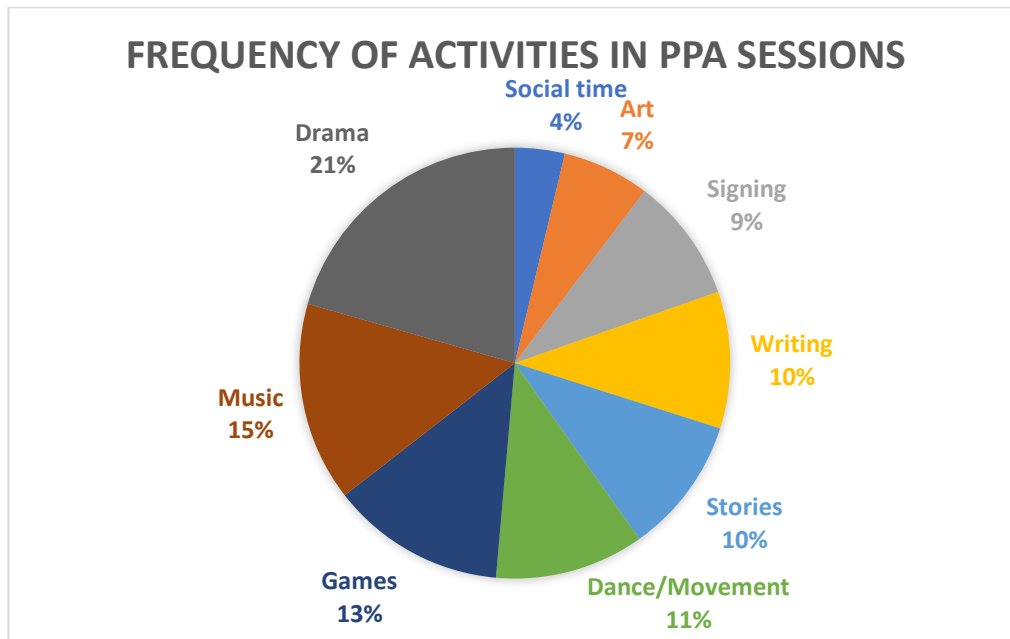


Figure 23: Frequency of activities used in PPA session across a five-week period during the independent action phase

### 5.3.2.2 Positive Meaning

Co-researchers described their emotional responses to engagement with the arts at PPA during group discussions and via their questionnaire responses. The PRG's responses indicated that positive emotional responses were prevalent, including happiness, excitement, passion, interest and enjoyment. Co-researchers' questionnaire responses indicated that they felt happy while engaging with arts-based activities at PPA 69% of the time and very happy 31% of the time ("We all had good feelings [at PPA], we were so happy" – Ella, C2). No co-researchers who completed the questionnaire reported feeling 'ok', 'sad' or 'very sad' in response to activities at PPA. This is not to say that co-researchers were consistently happy at PPA, but rather that engagement with arts-based activities often elicited positive emotional responses from the group. Indeed, the arts were considered to combat negative feelings of stress and anxiety ("If I'm stressed, I go to Purple Patch and I just do anything I want on a piece of paper" – Ella, C2), alongside inducing positive emotions at PPA, as Tracey explained:

UR: so, with these moods, what do we think is making us feel calm, happy and excited?

Tracey: activities, the art

UR: the arts, mhm,

Tracey: and imagination as well, which I put on my poster

Co-researchers also included 'accessibility' amongst words indicating positive emotional responses to the arts, as John discussed in cycle two:

UR: so, if we say something is accessible, what do we mean?

John: It's positive

Initially, the UR was unsure as to whether the word 'accessibility' should be included in the theme 'positive meaning'. While accessibility may support wellbeing through increased inclusion (Beresford et al., 2010), it is not considered as an emotion in itself. For non-disabled people, including the UR, the term 'accessible' may simply be viewed as a way of describing the characteristics of a place or activity. In contrast, the PRG considered this word to have strong connotations with positive emotions and experiences, such as happiness, belonging and feeling welcome. This suggests that non-disabled people may have different and/or fewer emotional associations with words relating to accessibility and inclusion, due to a lack of lived experience of disability. The present study emphasises the link between accessible spaces and the wellbeing and quality of life of disabled people, and therefore the importance of creating and maintaining accessible experiences, places and programmes. The variation in the ways that the PRG and UR related to words describing accessibility in the present study also highlights the importance of research that is led by and/or directly informed by disabled people, to ensure that research accurately captures their experiences.

Enjoyment of activities and having fun were considered to be a crucial aspect of positive engagement with the arts ("you've got to have fun doing them [the arts]" – John, C2). The survey responses demonstrated that arts-based activities were among the PRG's favourite aspects of PPA and that enjoyment of these activities was linked to positive mood and wellbeing. The PRG's favourite parts of PPA relating to the arts included sensory storytelling, using their imagination/pretending, visual arts (e.g. drawing and artwork) and music (including singing and playing instruments with others; "I used to love holding a drum for John and he does this part and I do mine. Anyway, maybe music is another part of my favourite part of Purple Patch as well" – Tracey, C2). Additionally, working with others, social activities (e.g. seeing and talking to friends), quizzes/competitions and learning new things were also cited as some of the PRG's favourite activities at PPA. In contrast, the PRG's least favourite aspects of PPA included people talking over each other during sessions ("when people are talking while I am trying to listen to staff. Not good manners" – Sam, C2), staff absence and drawing. The latter highlights the subjective nature of engagement with the arts, demonstrating that not all arts-based activities were enjoyed equally by all co-researchers and that engagement with the arts does not automatically result in a positive emotional response.

### 5.3.2.3 Personal Escapes

Co-researchers reported that engagement with the arts facilitated experiences of escapism, both within PPA programmes and in their lives outside of PPA (“This is another way to lose yourself in art and each picture you do” – Tracey, C2). Escapism was used as a tool by co-researchers to support their wellbeing, reduce stress and aid relaxation (“when I am doing art, I always feel relaxed” – Tracey, C2). Strategies for escapism described by co-researchers can be categorised into imagined personal escapes and physical escapism.

Imagined personal escapes were often described by co-researchers as using their imagination to create and/or enter their “own little world” (Tracey, C2). This form of escapism was often realised through imaginative storytelling, which allowed co-researchers to engage with new experiences, ‘go to’ imagined places or ‘become’ imagined people, and in doing so leave their daily lives behind. For example, Ella described using her imagination to act out scenarios and stories with her favourite characters at home to support her wellbeing:

Ella: I like going on adventures with my characters [...] with my characters in my room [...] I can make this one fly  
 [...]
 UR: why do you think you like doing that?  
 Ella: I get really stressed out sometimes  
 UR: mhm, so you get really stressed out and?  
 Ella: and that helps me to feel calm

Additionally, Tracey described how engagement with the arts supported her to go to imaginary ‘special places’: “it [the arts] makes me be somewhere else for that short time too. I don’t know where I go, it’s my special place and each time it’s different” – Tracey, C2).



Figure 24: Tracey's artistic response included reference to using your imagination and being in your own little world

Physical escapism refers to experiences where co-researchers entered physical spaces (such as their PPA programme) that enabled them to retreat from the outside world and get “out of your situation” (John, C2). Ella and Tracey discussed leaving their troubles from the outside world behind when attending PPA, suggesting that perceived safety of physical environments plays an important role in supporting escapism and wellbeing:

UR: what do you think you're escaping from?

Ella: well

Tracey: everything in the world

UR: everything in the world?

Tracey: Activities

Ella: I'm escaping, I try, when I've got appointments, like appointments for my Diabetes, going to Purple Patch takes my mind off it

Tracey noted that it was challenging to investigate the reasons why the arts specifically facilitated escapism, perhaps due to the subjective nature of these experiences (“when I do art(s), I am in my own little world, I can't explain why this is” – Tracey, C2). Co-researchers discussed three characteristics of the arts which were considered to facilitate escapism. These were: the subjective nature of arts-based experiences, engagement with the arts as ‘something different’ and accessing ‘impossible’ experiences.



### 5.3.2.3.1 Subjective engagement with the arts

Engagement with the arts, including using the arts as a means of escapism, was subjective and personal (“it’s [arts] personable, it’s to the person, how they see it – John, C2). Co-researchers also made purposeful and personalised decisions regarding the type of arts-based activities that most suited their personal escapes. For example, while Ella’s arts-based escapism included drama and sensory-storytelling, Tracey discussed choosing to write and draw as a way of entering her own personal world in cycle two: “I love to draw; it helps me to relax and be lost for hours in my little world”.

### 5.3.2.3.2 Something different

John described how engagement with the arts aided escapism by providing ‘something different’ and out of the ordinary from his daily life: “I think the arts helps because it’s something completely different, that you wouldn’t do normally [...] it takes you out of your normal way and your normal life” (John, C2). This suggests that the arts at PPA may support escapism by interrupting an individual’s daily life and providing a distraction.

### 5.3.2.3.3 Accessing impossible experiences

The creative nature of the arts supported co-researchers to create and tell stories, which often included experiences that were not possible in real world and/or at PPA. For example, Ella described making her characters ‘fly’ while acting out self-imagined scenarios and stories. This approach to imaginative storytelling is described by Heath (2008) as ‘radical’ imagination, whereby the individual has no prior experience of what they are imagining, usually because the experience is impossible or novel. Creating and acting out stories in this way was reported to be an enjoyable experience for co-researchers. This is in keeping with previous research which suggests that imaginative storytelling, particularly when accompanied by arts-based activities, may be used as a tool to enhance the quality of life of people with learning disabilities, for example, by providing opportunities to relate to others (real and imagined; Grove, 2015). In the extract below, Ella shared her views about the contexts in which imagined personal escapes are appropriate, noting that making characters fly (e.g. the use of personal ‘radical’ imagination) is not allowed at PPA:

Ella: I know I can’t do this in person [...] I know I can’t do this sort of stuff in Purple Patch  
 UR: mhm  
 Ella: I know I can’t fly really [...] I’m not allowed to do it in purple patch

Ella’s perspective that making her characters fly is not allowed at PPA was due to the perception that imagined personal escapes could be considered as a barrier to engagement

with the PPA programme, since this use of imagination/escapism is not necessarily related to the learning content/theme (“when I’m at Purple Patch, I have to focus on \*programme leader\* [...] that’s when I couldn’t go in my own little world” – Ella, C2).

While imagined personal escapism may be discouraged at PPA, group imaginative activities were often used as a learning tool in PPA programmes, to support theme-based learning and role playing. For example, participants may be asked to imagine what it would be like to trek through a jungle when learning about the rainforest, before acting this out. While few individuals will have the opportunity to experience visiting the rainforest in person, through imagination and arts-based sensory activities participants can visit their own personal imagined jungle, thus facilitating engagement with the theme in ways that may not be possible in real life. While still a personal experience, this experience of ‘visiting’ imaginary places is also a group endeavour, with applications to the learning objectives and topics within programmes.

#### 5.3.2.4 Learning with, from and through the arts

During cycle two, co-researchers sought to understand how they learned at PPA, with a specific focus on the role of the arts and learning. Analysis of the questionnaires completed by the group revealed that learning at PPA was common, with co-researchers learning something new 73% of the time during the independent action phase. Co-researchers’ questionnaire responses detailed a range of approaches to learning at PPA, including through gamification, learning with and from others, and arts-based approaches (see figure 25). Visual methods (e.g. videos and pictures) were the most commonly reported method of learning at PPA, occurring in 19% of sessions included in the independent action phase.

Enjoyment of arts-based activities played an important role in creating an inclusive learning environment:

UR what do you think it would be like to learn about all of those things without doing any of the arts?

[...]

Ella: miserable

Leanne: miserable

UR: yeah?

Leanne: it would be boring wouldn’t it

Ella: yeah

John: boring yeah that’s it

[...]

Tracey: it wouldn’t be the same at Purple Patch

The arts were considered to be more fun than other subjects as Leanne noted (“[the arts are] more fun than doing your times tables” - Leanne, C2). The creative learning

environment at PPA was compared to other learning environments (such as school) which were considered to be less creative and therefore less enjoyable (“it’s [PPA] more fun than school was” – Leanne, C2). Despite this, questionnaire results revealed that while learning was considered to be an important part of the PPA programme (“I look forward to learn something new, that I’ve never done before – Ella, C1”), no relationship was observed between learning something new and how co-researchers reported feeling at PPA programmes during cycle two. This suggests that while learning had positive emotional implications for co-researchers and may contribute to enjoyment, it was not the only factor influencing enjoyment of PPA programmes.

### HOW CO-RESEARCHERS REPORTED LEARNING AT PPA

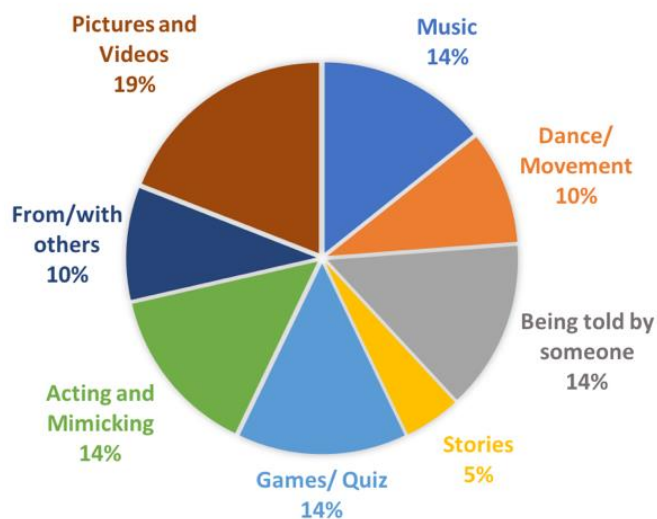


Figure 25: Methods of learning at PPA reported by co-researchers

The arts were used to support engagement with a variety of topics, including topics concerning the arts themselves (e.g. through themes such as ‘LGBTQ+ artists’ or developing arts-based skills) and topics not related directly to the arts (e.g. volcanos). Arts-based activities supported learning by providing opportunities for participants to engage with the topic through the lens of different creative activities. Inglis and Cook (2011) suggest that in order to engage diverse groups of learners, information should be presented in a range of ways, to appeal to the needs and preferences of different types of learners. Indeed, co-researchers reported that arts-based activities were rarely used in isolation during PPA programmes. Ella described learning about dinosaurs through music (singing a song about dinosaurs) and visual media (watching a video about the history of dinosaurs):

UR: So maybe you sang a song about something, or you listened to a piece of music?

Ella: Oh yeah, about dinosaurs with \*programme leader\*

UR: Yeah?

Ella: I've forgotten how it goes now

MK: Yeah. But you learned about dinosaurs through a song did you?

Ella: Yeah and \*programme leader\* showed us a video and told us about how they used to live a long time ago

Arts-based learning was combined with active learning techniques to aid learning at PPA. In line with previous research (Abdoola et al., 2017), role playing supported co-researchers to embody ideas, experiences, people and objects, and to reflect on these experiences to aid learning of a topic. Liam and John described how imaginative role playing allowed co-researchers to explore impossible experiences, such as what it is like to be a cactus:

Liam: you might pretend you're a cactus

UR: yeah, pretend you're a cactus, and what that might feel like

[...]

John: I mean it's tactile as well, because you don't want to put your finger on a cactus, but you know it's going to be sharp, so looking at the pictures, the pictures would show you that

PPA utilise a theme-based approach to learning. Each year at PPA a different theme is chosen (e.g. adventure) and each week within the year is assigned a different topic within this theme (e.g. adventurous places: the ocean). Activities in each session, which were often arts-based, were linked to and supported understanding of this theme ("each theme helps me to learn" - Ella, C2). Themes were reported to aid learning by providing a sense of structure to programmes, while also enabling a variety of perspectives on the topic to be explored, as John notes: "the theme is a good thing to bring everyone together because we've all got different views on it" (C2). Co-researchers suggested that theme-based learning at PPA aided accessibility, as co-researchers knew the learning content in advance ("so we know what we're doing each week" – Ella, C2). This allowed them to think about the theme prior to attending the session, which supported their engagement with the topic ("I'm just thinking about the theme tomorrow [...] I'm always having a think before I go to the group" – Ella, C3).

This is not to say that arts-based and thematic learning was always successful. Tracey described how learning was initially challenging at PPA when the organisation first opened. However, through listening to participants' feedback, the approach to learning became more accessible:

They've changed it now, they do one subject, before it was three different subjects in one day. I didn't like the three subjects in one day, I like the one subject and then different things around the subject

This highlights the subjective nature of learning and the importance of gathering and addressing feedback from service users regarding their learning experiences. Additionally, participants' preferences around learning topics and themes also influenced their level of engagement. For example, Janine noted that participants who were not interested in learning about a particular topic were less likely to engage with the PPA programme: "yesterday the theme was volcanoes, and one of the lads, he didn't want to do volcanoes, so as fast as he signed in, he signed out again" (Janine, C2).

Alongside the approaches to creative learning outlined above, co-researchers identified three overarching themes which contributed to inclusive learning opportunities at PPA. The first theme, 'Equality and Inclusion', explores four characteristics of the arts at PPA which promoted an inclusive learning environment: these are, 'Adaptability', 'Fewer Rules', 'Lack of Competitiveness' and 'Individuality'. The second theme, 'Freedom and Choice', explores the role of the arts in promoting autonomy within PPA programmes. Finally, 'Being (and Sharing) You' considers the ways in which the arts at PPA supported co-researchers to be themselves, share aspect of themselves with others and experience a sense of 'ownership and achievement' over their creative endeavours.

#### 5.3.2.4.1 Equality and Inclusion

Arts-based activities at PPA were perceived by the PRG to be intrinsically accessible and inclusive, thus contributing to the perceived accessibility of PPA and of learning more generally ("I think arts is more accessible out of all of them, or anything" – John, C2). The 'accessible nature' of the arts was included in all of the co-researchers' artistic responses to the question 'what, if anything, is special about the arts?'. Despite this, previous research suggests that people with learning disabilities face multiple barriers to accessing the arts in their local communities and homes, including insufficient staff and/or support to facilitate activities and/or a lack of resources (Reynolds, 2002). By examining the barriers to arts-based activities from the perspective of residential home managers, Reynolds (2002) provides a useful insight into factors influencing the accessibility of engagement with the arts for adults with learning disabilities in this context. However, at the time of writing, there is limited research which considers the components of accessible and/or inaccessible activities from the perspective of adults with learning disabilities. Therefore, before discussing the characteristics of the arts, which co-researchers identified as contributing to the accessibility of arts-based learning at PPA, it is important to understand what co-researchers considered

to be an 'accessible activity'. The PRG described two basic requirements of accessible activities<sup>7</sup>. These requirements relate to the accessibility of any activity, including but not limited to activities involving the arts.

The first requirement of an accessible activity identified by the PRG is that the activity should be easily understood by all. Co-researchers were aware that the range of needs and preferences of PPA participants meant that not everybody would access an activity in the same. Therefore, as Tracey and John acknowledge, 'understanding' is open to interpretation and does not necessarily equate to all individuals comprehending an activity in exactly the same way. Rather, activities should be designed to allow for multiple understandings and responses:

UR: what do we mean by accessible?  
 John: that everyone can understand it [...] easy to understand too  
 UR: mhm  
 John: or someone, because different levels might see things different  
 UR: yeah  
 John: people's levels are different aren't they

Relating to this, the second requirement identified by the PRG is that the activity should be compatible with the individual. In keeping with the Social Model of Disability (Oliver & Sapey, 1983), the emphasis here is that the activity should be able to be adapted to 'fit' each person, rather than the person being required to change to fit the activity. In practice, this could include providing multiple ways to access an activity, supplying specialist equipment to promote participation or directly supporting participants to engage with the activity. In cycle two, John compared a lack of compatibility with activities to being "a square peg in a round hole" (C2), emphasising the importance of adapting activities to fit the needs and preferences of the individual, to avoid participants feeling excluded:

UR: are there any other ingredients of inclusive activities that we can think of, or what makes something inclusive?  
 Janine: compatibility, compatible  
 UR: yeah, yeah, compatibility yeah, so we could say, could we describe that like a 'fit'? how do you fit with the activity?  
 Liam: yes, how do you fit with things  
 [...]  
 John: a lot of us are square pegs in round holes, but we don't fit, a lot of us don't fit you know  
 \*laughs\*

---

<sup>7</sup> There are, of course, a range of additional logistical, contextual and social factors influencing accessibility more broadly. These factors outline above were considered to be key characteristics around which accessible activities may be designed. The absence of these factors may result in barriers to participation. A full discussion of the co-researchers' perspectives and experiences of accessibility and inclusion, both within and outside of PPA, is included in cycle three.

Co-researchers identified four features of the arts which contributed to the accessibility of arts-based activities at PPA. These are: adaptability, individuality, fewer rules and lack of competitiveness. These characteristics are inter-related and therefore challenging to consider in isolation. Additionally, while these characteristics were identified in relation to arts-based activities at PPA, these features may be present in other inclusive activities and could therefore be considered more broadly when designing accessible activities/learning opportunities for adults with learning disabilities.

#### 5.3.2.4.1.1 Adaptability

The arts were considered to be adaptable when used as the basis of accessible activities at PPA. Participants were offered different ways to access these activities, depending on their needs and preferences. This adaptable approach to engagement with the arts led to the PRG's assessment that "everyone can do the arts" regardless of ability and/or experience, as Liam and Janine discussed:

Liam: you can do it no matter what your level

UR: mhm

Liam: arts can always get adapted to suit your ability

UR: mm, sure, so you can adapt it to meet your ability, that's a good point, why do you think it's easier, why do we think the arts is easy to adapt?

Janine: because there's so many ways to use it

Liam's artistic response (figure 26) includes direct reference to the arts as "accessible and adaptable", suggesting that the adaptability of the arts was considered to be an important feature of activities at PPA.

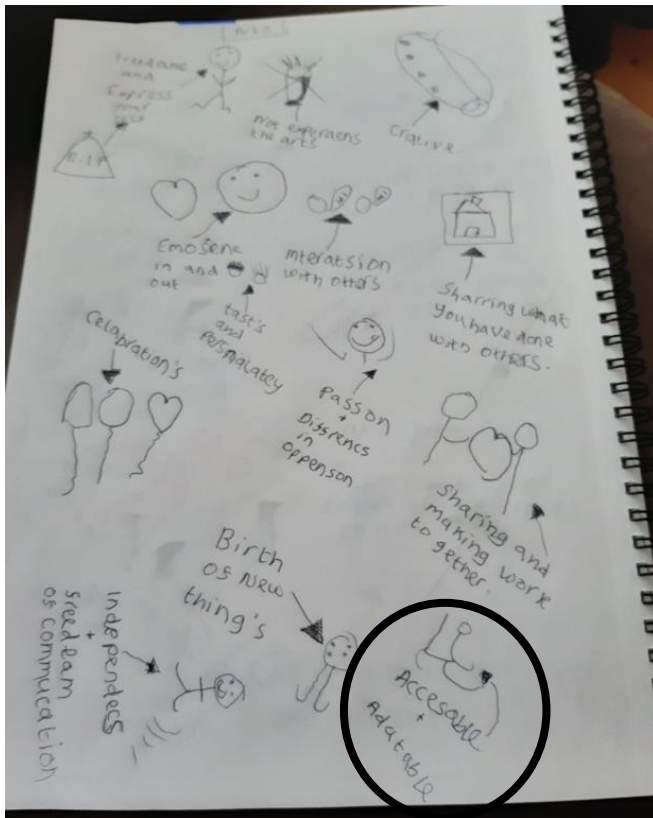


Figure 26: Liam's artistic response demonstrates that the adaptability of the arts was deemed to be an important and 'special' characteristic of arts-based activities at PPA

However, it is important to note that while the arts have the potential for adaptation, inclusive participation with arts-based activities may still be context-dependent. Adaptation of arts activities at PPA often required specific resources, such as spatial requirements, adapted equipment and individualised support to facilitate varied approaches to the activity. The nature of these adaptations suggests that the arts may not be accessible to all adults with learning disabilities in all contexts. John reflected on his own access needs in cycle two when engaging with the arts, highlighting that arts-based activities were inaccessible to him at home due to a lack of space and equipment:

I'd like to do art in the house, there's nobody who would set up the table, in Purple Patch in our art classes someone would set up a table and give you a chance to just go berserk on it [...] whereas you couldn't do it in your own house, there's just not the space

John's experiences suggest that beliefs around how accessible an activity is may be impacted by the context in which the activity is usually experienced. In other words, co-researchers' perceptions of the arts as accessible and adaptable may be specifically due to their experiences at PPA. Therefore, while the arts may lend itself to accessible experiences, the present study suggests that the place and people who facilitate these experiences are equally important for inclusive practice.



The variety of approaches to arts-based activities at PPA facilitated feelings of equality and independence in programmes and reinforced the belief that there is “no one right way” to access arts-based activities, as John discussed:

But there's not one set way to do it, that's the thing. You know reading a book is, you read it from left to right, you don't go back to front... you could do but \*laughs\*, that's the bit what it's like, but you could do a backwards picture if you wanted because no one would know

Co-researchers discussed feeling more similar and/or equal, because of the potential differences in the way in which arts-based activities at PPA could be approached. The arts were therefore considered to be an ‘equaliser’, whereby all participants were similarly encouraged to engage with activities in different ways, depending on their needs, preferences and interests:

Tracey: everybody's the same when they do the arts, nobody is different, meaning is everybody is equal

UR: so why do we think that when we do the arts we're more equal?

Tracey: because everybody's at their own pace

UR: mhm, everybody's at their own pace, yeah

Leanne: everybody does art differently

Indeed, Tracey's artistic response reflects this conversation, through the inclusion of the statements “something for everyone” and “everyone is equal [sic]”.



Figure 27: Tracey's artistic response to the question 'what (if anything) is special about the arts' includes written statements relating to 'equality' in arts-based activities

### 5.3.2.4.1.2 Fewer rules

Relating to the adaptability of the arts was the co-researchers' perception that arts-based activities were less strict, less structured and therefore had "less rules" (Leanne, C2).

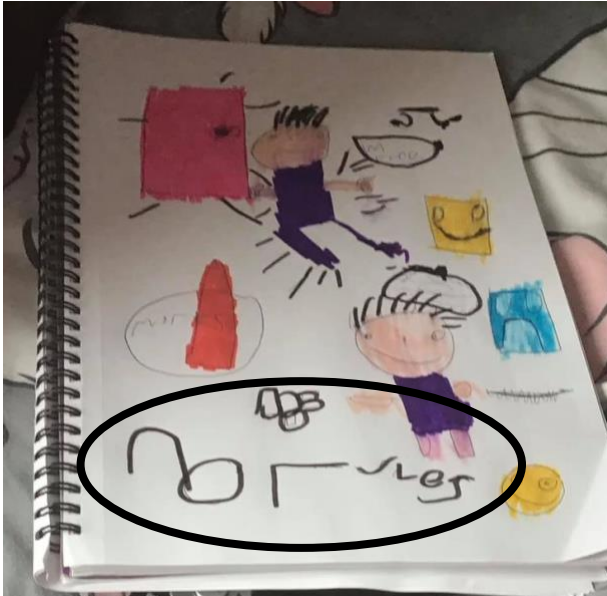


Figure 28: Leanne's artistic response to the question 'what (if anything) is special about the arts' includes the written statement 'no rules', in large text

While the structure of the day was described in cycle one as a positive aspect of PPA, activities/subjects that were deemed to be overly structured or strict were viewed negatively and considered to be less accessible than those that were viewed as more flexible. For example, John compared engagement with the arts to maths, suggesting that enjoyment of a topic may be related to the level of structure/flexibility (i.e., maths was viewed to be more structured and therefore less enjoyable):

It's [the arts] not as structured as say, you know have maths, a maths lesson [...] you wouldn't go to that class, would you? But everybody seems to like the arts more (C2)

Activities categorised by the PRG as having strict rules, such as maths and sport, were considered to have limited options for engagement. For example, John discussed the 'right' and 'wrong' ways to engage with sporting activities, based on the pre-established rules associated with a particular sport:

What it is sports are structured isn't it, it has to be you know, you can't put a racing car on the road, it has to stay on the track, and then in tennis it has to stay between the lines, you whereas you can't go beyond the lines, if that makes sense (C2)

The adaptability of the arts at PPA, combined with the perception of fewer rules associated with arts-based activities resulted in the PRG's belief that, in contrast to other topics and

activities, “you can’t get arts wrong” (Liam, C1). Liam and John discussed this idea further in cycle two, noting that a flexible approach to the arts resulted in less pressure around engagement with the arts at PPA:

Liam: I see it as, with art there’s no wrong or right, so  
 UR: yeah, there’s no wrong, or right?  
 Liam: have a go  
 UR: yeah  
 John: whereas sport you have to get it right more

Similarly, Janine and Sam discussed how the flexible approach to activities at PPA supported the idea that “no-one is wrong”, demonstrating how the adaptability of arts-based activities and fewer rules associated with participation supported inclusion in PPA:

Janine: no-one is wrong, you’re still coming out with the same things, just in a different way  
 UR: yeah, that’s a good point  
 Sam: I do, do it with a left hand, but Janine does it with her right hand, and you write it down, but both ways is right

This is in keeping with previous research which suggests that involvement in creative activities are less likely to result in pressure to be ‘right’ than work-related or everyday tasks (Samdahl, 1992). Participation in activities which are considered to be more flexible and less strict may also be particularly important for adults with learning disabilities, who are often told in educational spaces that they are either not good at things or doing activities incorrectly (Corr McEvoy & Keenan, 2013). Indeed, Ella stated that she often felt she was doing activities outside of PPA incorrectly: “I always do everything wrong me. Sometimes I’m always doing something wrong” (C2). Engagement with activities that were identified as flexible, with fewer rules and therefore fewer opportunities to be ‘wrong’, supported co-researchers’ creativity and sense of freedom, alongside feelings of acceptance within PPA programmes.

#### 5.3.2.4.1.3 Lack of competitiveness

Another factor that the PRG cited as contributing to the accessibility of the arts was the perceived lack of competitiveness within PPA programmes (“It’s not a competition” – Liam, C2). Skill-level in relation to the arts was not considered to be important at PPA. Instead, greater emphasis was placed on the process of engagement with the arts as opposed to the perceived ‘quality’ of the creative output:

John: have a good singing session, probably kill the cat with the singing, but you know what I mean

UR: \*laughs\*

John: but that's, that's part of it isn't it

Similarly, co-researchers agreed that skill-level was not related to enjoyment of arts-based activities at PPA:

UR: do we think, do we have to be good at the arts to enjoy it?

Janine: No, not at all, with my singing not at all

Liam: no

Clover (2000) describes community arts in adult education as “process oriented” noting that “the act of creating, discussing and reflecting as the critical learning dimension, often takes precedent over the object(s) produced” (p.20). Similarly, while co-researchers expressed pride in their creations and artistic outputs at PPA (see section 5.3.2.7.1), the PRG were more likely to discuss the process of engagement with activities, enjoyment of activities and the social aspect of PPA, than the output produced in programmes. Of course, the arts may be considered as competitive in some contexts. Therefore, as previously discussed, the PRG's understanding of the arts as non-competitive may be specifically related to the context(s) in which the arts were experienced, and the approach to the arts adopted in these contexts. In particular, a focus on the process over the output, teamwork and valuing the unique contributions of participants at PPA resulted in co-researchers' associations with the arts as cooperative rather than competitive, facilitating feelings of acceptance in programmes (“you're accepted for what you can do” – Janine, C2).

#### 5.3.2.4.1.4 Individuality

Individualised engagement was considered to be a key aspect of the accessibility of the arts at PPA. John described the importance of individuality when approaching creative activities at PPA, noting that a key component of a creative output is the individual who created it:

It's got to have a bit of you as a person, so you do art, it is a little bit individual [...] there is a difference, even if you're supposed to copy what's there [...] you make it different somehow

This suggests that the arts at PPA were used to facilitate self-expression, including sharing aspects of the co-researchers' personality and identity with others (discussed further in section 5.3.2.7). The focus on the individual as a key part of the creative process supported co-researchers to engage with activities in their own individual way. This, in combination with previously discussed characteristics of the arts at PPA, such the adaptable and flexible use of the arts within programmes, contributed to the accessibility of arts-based activities at PPA. For example, the range of approaches and options offered within the PPA programme

supported co-researchers to form their own interpretations of creative activities and their engagement with arts (“In a way it is individual [...] because it’s to you, you interpret it” – John, C2). An individualised approach also supports the notion that “no-one is wrong”, since all participants approach the arts in a way that is unique to them.

#### 5.3.2.4.2 Freedom and Choice

Engagement with the arts at PPA was reported to facilitate feelings of freedom and choice for co-researchers (“you feel free at Purple Patch” – Tracey, C3). The language used by co-researchers to describe freedom at PPA included phrases such as “it [the arts] lets you” (Liam, C3) and “it [arts] is giving you” (John, C3). This indicates that the arts specifically were considered as a medium that provided opportunities for choice that may not be considered to be as readily available in other contexts. Indeed, engagement with the arts was considered to facilitate a greater sense of freedom for co-researchers in comparison to non-arts-based activities (“I think that the arts gives you your freedom more than most” – John, C2). John and Tracey compared the ‘level’ of choice associated with the arts versus other subjects, such as maths and english:

John: English there’s a couple of choices, whereas maths there isn’t, no choice  
 UR: so, if there’s no choice, and English there’s a few choices, how many choices do you have when you do the arts?  
 Tracey: loads

This is in keeping with previous research which suggests that involvement in creative activities can provide opportunities for participants to make choices (Reynolds, 2002), resulting in a greater sense of freedom when compared to engagement with other activities/tasks (Samdahl, 1992). Activities and environments which promote choice may be particularly important for adults with learning disabilities, as they often experience a lack of autonomy in their lives (Brown & Brown, 2009). Tracey discussed how having choices at PPA was particularly important in her life:

Tracey: you’ve got different options [...] and choice of doing what art you like as well  
 UR: a choice, yeah, is choice important?  
 Tracey: yes  
 UR: why do we think choice is important?  
 Tracey: it’s a big one in our life isn’t it

The ‘ongoing’ nature of the arts also supported co-researchers to engage with arts-based learning and activities flexibly: “most things have a beginning and an end, but art can go on. You can use it for one day and then go back to it” (John, C2). Here, John describes how the flexible boundaries of the arts meant that co-researchers were able to engage with arts-

based activities in whichever way they preferred, whenever they preferred. John's consideration that you can choose to "go back to" (C2) the arts also indicates his belief that he would be able to access the arts for the long-term. The perception of the arts as 'ongoing' is also reflected in the structure of PPA, which was understood to be long-term, particularly when compared to short-term courses available to adults with learning disabilities. It is therefore important to consider that the nature of the PPA programme may have impacted the co-researchers' view of the arts as an ongoing activity.

Opportunities for choice were also integrated within the PPA programme. In cycle two, John shared an example of how arts activities within PPA provided participants with opportunities for choice, while still related to the learning theme:

It is giving you an hour or two to decide what you can draw on the theme isn't it, it's based on the theme, if it's water they'll tell us to do some fish or anything else under water that you think about, but it's your choice to put whatever you want on there

Similarly, Leanne discussed how PPA staff provided options to participants, enabling them to choose their creative approach to an activity: "when we're doing an activity at Purple Patch they ask us do you want to paint or do you want to draw?" (C2).

The approach to learning at PPA also enabled co-researchers to be creative for the sole purpose of being creative. Co-researchers' previous experiences of engagement with the arts were often linked to learning environments, such as school and college, where creative outputs were examined for the purpose of obtaining a grade or qualification. Ella discussed how the removal of the goal of a qualification allowed her to have greater creative freedom at PPA:

At college when we did art at college, I was doing same old things [...] I didn't get to do much, do platform 9 and ¾, I didn't get to do that at college [...] I had to work towards my qualifications (C2)

Co-researchers therefore identified creative freedom and expression as a key goal of PPA.

#### 5.3.2.4.3 Being (and sharing) you

Co-researchers reported that the arts supported them to be themselves and to share aspects of themselves and their identity through creative engagement and the creation of artistic output ("you're doing a picture, that's your personality" - John, C2). The arts were viewed as an activity that co-researchers did "for themselves", suggesting that engagement with the arts was valued and enjoyed by the group ("it lets you do, be yourself and be able to do something for yourself" – John, C2).

Co-researchers also discussed the potential for the arts to represent different aspects of themselves within creative outputs. For example, John noted in cycle two that the arts may allow you to showcase and explore different sides of your personality and identity through artistic engagement: “A person, how you act as you are, in the art it can be something different completely, so it’s almost like another person has done it” (C2). Reynolds (2002) suggests that adults with learning disabilities may have fewer opportunities for self-expression, as their experiences are often shaped by a compliance with the goals of others. In contrast, engagement in creative activities may “provide a vehicle for expressing a personal voice” (Reynolds, 2002, p.64). This demonstrates the importance of facilitating individuality and fostering the personal interests of adults with learning disabilities. However, these experiences are only accessible to adults with learning disabilities if they have access to appropriate resources (e.g. staff and appropriate materials). This may be particularly pertinent for individuals who are residents in assisted living homes, who rely on staff availability to support their artistic engagement (Reynolds, 2002). For example, John shared that he was unable to participate in arts activities such as drawing or painting during the pandemic, as “there was nobody to set up the table” (C2). Therefore, inclusive arts-based learning programmes such as PPA, which are designed to facilitate creative self-expression, may be particularly valuable for adults with learning disabilities by allowing participants to pursue their personal interests and share their individual views.

#### 5.3.2.4.3.1 Ownership and achievement

An important experience relating to sharing aspects of oneself through the arts was creating physical ‘products’ which could be taken away from programmes (“at Purple Patch, you find you’re coming back with a drawing” – John, C1). Co-researchers emphasised the importance of ownership of these creative outputs, which facilitated a sense of belonging (“It’s your creation, it’s you [who] made it, it’s not anyone else’s” – John C2). Tracey, who identified as dyslexic, enjoys writing stories in PPA programmes and wrote several stories about her experiences at PPA throughout the project. While dyslexia presented some challenges for Tracey’s writing, she described how a sense of ownership over her stories meant this was less impactful: “I am dyslexic. I don’t let it bother me when it comes to writing stories and writing poems, they make me feel that I belong because they are mine” (C2).

Co-researchers were often proud of their creations and achievements at PPA and frequently shared their work with others (e.g. friends and family: “we’ve shown Sam’s to um, our neighbours” – Janine, C1). In cycle two, Liam recalled feelings of pride associated with completing artwork at PPA, which resulted in him surprising himself by his capabilities:

I must admit, it's that feeling of pride to know that you've made that piece of art. You might not at the beginning thought, 'how on earth am I gonna do this, I'm not gonna be able to do this', this and that, but then by then end you've actually surprised yourself

This is in keeping with previous research which suggests that engagement with creative activities may encourage a sense of achievement for adults with learning disabilities (Pearce, 2017). By creating a 'visual record of achievement', producing physical artistic outputs may support the self-efficacy and self-esteem of adults with learning disabilities (Hall, 2012).

Alongside surprising themselves, co-researchers were also able to challenge the perceptions of others regarding their capabilities, as John explained in cycle two: "people say, oh I didn't know you could do that, or some people like, you know the house, they don't know exactly what we do at the Purple Patch". Similarly, Janine discussed how sharing Sam's end of year profile, which showcases a participant's work and progress throughout the year altered others' perceptions of her capabilities and of the approach at PPA

I thought it would be good to show them [neighbours] the book at the end of the year and they've taken it with them for a couple of days and brought it back and said I didn't realise that's what she got up to [...] it's amazing, they just thought she went ad sat in a room and had a few hours away from us and that was it (C2)

Previous research suggests that creative outputs produced by adults with learning disabilities may help to share their stories and experiences, and therefore act as a medium for self-advocacy (Richards et al., 2019). Hall (2012) worked with a group of 40 men with learning disabilities to produce and display creative outputs relating to their sexuality in a gallery. Hall (2012) found that by sharing their experiences through creative methods, participants' creations challenged expectations and misconceptions around adults with learning disabilities, resulting in greater understanding and acceptance. Similarly, in the present study, co-researchers used their creations (and their attendance) at PPA to demonstrate their skills and achievements to others.

#### 5.4 Reflections and Recommendations from Cycle Two

Reflections on cycle two of the research did not result in any recommendations regarding PPA. However, co-researchers identified 'accessible people' as a topic that required further exploration in cycle three, since the group felt that there was more to understand about this concept than the present cycle had allowed for. Additionally, at this stage of the project co-researchers began to reflect more regularly on their own experiences as researchers, having been involved in the project for over six months. In the extract below, Tracey reflects on her involvement in the project so far, identifying aspects of the research that she had enjoyed,



her hopes for the future and areas of personal development impacted by the research (discussed further in section 9.1.2)

This is what I've found out while researching art and variety. I really enjoyed doing research about what I love, and what I find hard. It shows that I've improved myself through topics. It's been very interesting; I can't wait to find more information out. We might find new things out. I can't wait to learn more about the other subjects in the future, and to find out the outcome at the end about why Purple Patch Arts is Purple Patch Arts! (extract from Tracey's 'Arts and Variety' research story, written in C2)

Additionally, co-researchers used their experience of research methods to reflect on the accessibility of the methods chosen for cycle two. In the extract below from cycle two, Janine and Sam discussed how arts-based methods allowed for multiple approaches to engagement with research:

Janine: my picture's different to Liam's picture, which is different to yours, we're all doing the same thing but in different ways  
UR: different ways yeah  
Janine: so, no-one is wrong, you're still coming out with the same things just in a different way  
UR: yeah, that's a good point  
Sam: I do, do it with a left hand, but Janine does it with her right hand, and you right it down but both ways is right

Reflections on the suitability of chosen research methods supported the PRG's decisions concerning appropriate methodologies in cycle three.

## 6 Cycle three – Accessibility and Support

### 6.1 Planning

#### 6.1.1 Research Questions

In cycle three, co-researchers chose to explore accessibility and support at PPA, and in the outside world. The planning stage of cycle three consisted of four one-hour meetings for each group. In these initial meetings the groups looked at previous research investigating accessibility and support with and for disabled people (Liddiard et al., 2018; White & Morgan, 2012). Easy read versions of this literature were created by the UR and shared with the group over Zoom (see appendix F). The UR supported the PRG to discuss the aims, methods and findings of each paper, with the goal of increasing the PRG's understanding of different approaches to researching accessibility and support in different contexts. Both papers that were examined by the PRG in cycle three included disabled people as co-researchers, to demonstrate the role of accessibility and support in a research context.

When selecting research questions for this cycle, the PRG considered the recommendations identified in the review phase of cycle two, namely, the idea of 'accessible people'. The PRG's first research question for cycle three was therefore designed to further investigate the notion of 'accessible people'. Further consideration of the aspects of accessibility and support that were most important to the group resulted in the identification of seven research questions. Due to the time constraints of each cycle, the PRG discussed these questions with the goal of reducing the number of questions included in the cycle. Through these discussions, two questions (Is there enough support for everyone at PPA? and what is 'good quality' support?) were removed from the PRG's initial list. These questions were removed as the group felt they were not able to answer these questions on behalf of all PPA participants due to their subjective and personal nature. While all participants receive some level of support from PPA staff, some participants attend PPA with additional support (e.g. a support worker, carer or parent), while others attend independently. Co-researchers suggested that for some participants, additional support may be beneficial, however this was not always possible due to a range of factors (such as financial barriers and/or logistical challenges). Co-researchers therefore recognised that while additional support in programmes may be beneficial, this was not necessarily the responsibility of PPA, since participants who require specific support are required to bring a support worker with them to their programme.

That thing [support at PPA] though we will have to look at carefully, Purple Patch would be like, if you require X amount of support, should bring a support worker cos we don't have the staffing [...] even so it's like, a bit like, there's a support yes, it's always there if you need it, but

then maybe sometimes there could be more (Liam, C3)

Therefore, since not all support at PPA is provided directly by PPA staff and may be arranged through social care or privately, the group felt on reflection that these questions were beyond the scope of the present study. Despite this, co-researchers reflected generally on the impact of support from others on accessibility, both at PPA and in the inside world throughout cycle three.

After this process of narrowing down the PRG's initial questions, five were selected as the focus of cycle three:

RQ1: What makes a person 'accessible'?

RQ2: What makes PPA accessible or not accessible?

RQ3: What does an accessible space look and feel like?

RQ4: What makes learning more or less accessible?

RQ5: How accessible is the information that PPA share?

#### 6.1.2 Change in Covid-19 restrictions

It is important to note that during cycle three co-researchers were able to return to PPA programmes in person. While restrictions such as social distancing and mask wearing were still in place, this was the first time co-researchers had returned to their PPA programme physically for over 12 months. This change in how participants attended PPA shaped the ways in which co-researchers approached their research in cycle three. Firstly, having not attended PPA programmes physically for over a year, co-researchers were able to approach their investigation of accessibility at PPA with a fresh perspective. Additionally, in some cases, co-researchers' experience of both online and physical attendance provided the group with a point of comparison regarding the accessibility of people, activities and places. However, it is worth noting that the Covid-19 restrictions in place within programmes may have impacted the PRG's experiences and perceptions of accessibility. For example, John and Liam discussed the impact of social distancing on the layout of PPA programmes during a discussion about accessibility and space:

Liam: yeah, so like it's all level, open plan, you've got enough room to sort of swing a cat or something

UR: yeah

John: exactly, certainly for warm-up circle or chairs [wheelchairs] or

UR: yeah

John: and walking round and, you know, enough space

UR: mhm

John: and I think space now will be big time premium now [...] everybody'll have to have the distances and the measuring tapes and all that business

It is therefore important to recognise that the PRG examined the accessibility of PPA during a time when programmes were subject to strict Covid-19 regulations. Therefore, the PRG's approach to understanding accessibility and support at PPA may have been impacted by factors specifically relating to the pandemic.

### 6.1.3 Choosing methods

Before choosing methods in cycle three, it was important to understand what 'accessibility' meant to different members of the group, since interpretation of this term would inform the PRG's approach to this cycle. The importance of discussing key terms was evident from cycle two, where there was some disagreement in the group regarding the definition of the word 'inclusive':

UR: what does inclusive mean?

John: it means um, it's only important to you, it's inclusive to you

[...]

MK: so, if I said that we were going to do an activity together and it was going to be inclusive what do you think I might mean?

Tracey: UR, that means only us would know

Jo: is it that everyone would be able to do the activity?

UR: yeah that's right

[...]

Tracey: I think the word that I meant like, only us would know, what is going to happen

UR: yeah, you know what Tracey, that might be exclusive

It is worth noting that the way key terms are defined may vary depending on an individual's relationship with words such as 'inclusive', and their personal experiences (e.g. disabled and non-disabled people may consider these words differently, as discussed in relation to the word 'accessible' in section 5.3.2.2). The extract above demonstrates the importance of discussing these terms at the beginning of the research, so that a) all members were aware of the basic meanings of keywords relating to the research and consequently felt confident to contribute to conversations and b) so that differing perspectives relating to key words could be explored and taken into consideration in the research. Therefore, during planning session one, the group discussed what accessibility meant to them, aspects of accessibility that they felt were most important and the factors that might influence whether something is categorized as accessible or inaccessible (both at PPA programmes and in the outside world). This facilitated discussions about how the factors impacting accessibility related to the PRG's research questions concerning accessibility and support at PPA. A mind map, which included the key themes from these conversations, was produced by the UR and shared in the PRG

Facebook group so that co-researchers could remind themselves of their discussions about accessibility at any time (see figure 29). Factors identified as impacting access through these conversations will be discussed further in section 6.3.2.1.

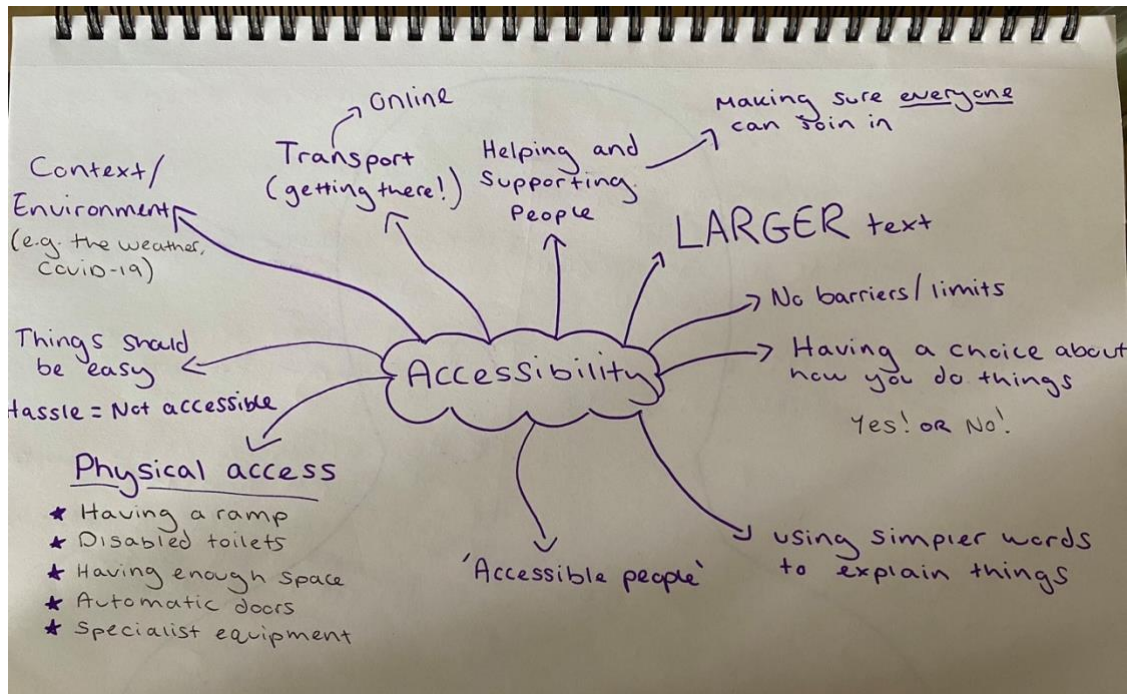


Figure 29: Accessibility mind map

As in the previous two cycles, the methods for cycle three were chosen collaboratively by the PRG, through a series of group discussions. Each research question was considered in turn, and co-researchers shared their ideas about how to address the question based on their knowledge of suitable research methods and their experiences from previous cycles of research. Having previously completed the process of selecting methods in cycles one and two, co-researchers were more aware of the methods available to them and therefore took a more active lead in these discussions than in previous cycles. For example, Leanne's suggestion to use a poster to understand the co-researchers' personal experiences of accessibility (as discussed below).

To address research question one (what makes a person 'accessible?') co-researchers chose to discuss the features of accessible people in a research session. During this session, some co-researchers also chose to draw their ideas around accessible people. While this activity was specifically designed to understand the PRG's perceptions of and experiences with accessible people, the PRG also shared their views on accessible (and inaccessible) people in relation to research questions two, three and four. This demonstrated that accessible people were a key aspect of the PRG's experiences with accessibility, both within

PPA programmes and in the outside world.

As a central and important question for this cycle, research question two (what makes PPA accessible or not accessible?) was discussed throughout cycle three. To capture an initial snapshot of the PRG's experiences of accessibility/inaccessibility at PPA programmes, co-researchers chose to create an accessible questionnaire. The questionnaire was designed collaboratively in planning session four and provided a space for co-researchers to log their experiences across four key areas, which were identified by the group as impacting the accessibility of PPA programmes. These were: transport, venue, staff/support and activities. Each of these categories were split into six contributing factors. These factors were chosen by the PRG through a group discussion about the specific factors influencing accessibility in each of the four areas outlined above. The perceived accessibility of these factors were rated using a traffic light system. Co-researchers coloured in the emoji that corresponded with how accessible they considered each aspect of their experience to be, using the traffic light colours (red/sad face for inaccessible, orange/'ok' face for neither accessible not inaccessible and green/smiley face for accessible). A traffic light system was chosen as the method was familiar to the group. PPA have previously used a similar system when asking participants about their experiences at PPA during their internal evaluation sessions. Co-researchers were therefore familiar with using traffic light colours to indicate their feelings about various topics:

Ella: oh yeah, I remember doing it [traffic light system] with \*programme leader\*

UR: yeah, you did the traffic lights with \*programme leader\*?

Leanne: yeah

[...]

ES: used to ask about how we feel about coming to Purple Patch on a morning

Descriptions were added under each of the factors to support co-researchers to evaluate their experiences when completing the questionnaire. Additionally, co-researchers chose to include the portion of the arts and variety questionnaire (see figure 30) which logged emotional responses to arts-based activities at PPA using emojis. As cycle two occurred while PPA was operating solely online, this activity was repeated to capture any similarities or differences in the types of activities included in the PPA programme in person, versus online.

**Name**

**Transport**  
How do you get to Purple Patch Arts?

Car  Bus  Taxi  Walk  Other

**Time**  
How long does it take to get to Purple Patch Arts?

**Distance**  
How far away is your Purple Patch Arts programme?

**Enjoyment**  
Do you enjoy the journey to Purple Patch Arts?

**Cost**  
How much does it cost to get to Purple Patch Arts?

**Flexibility**  
How flexible is your transport? Can you leave when you want to?

**Reliability**  
How trustworthy is your transport? Does it arrive when it's meant to?

**Activities**

**Variety**  
How varied are the activities? Is there something for everyone?

**Structure**  
Are the activities well-structured? Is there a good structure to the day?

**Enjoyment**  
Do you enjoy the activities?

**Can everyone do them?**  
Are the activities accessible to everyone?

**Options**  
Were you given different options of how to do the activity?

**Is it the right 'level' for you?**  
Are the activities too hard, too easy, or just right?

**Notes**

**Venue**  
Where does your Purple Patch Arts session take place?

**Entrance**  
Is the entrance/doors accessible? How easy is it to get in the building?

**Toilets**  
Are the toilets accessible for everyone?

**The room**  
Is the room accessible? Is it easy for everyone to be in the room?

**Moving around**  
How easy is it for people to move around the space?

**Furniture**  
Is the furniture accessible to everyone? Can everyone use it?

**Signage**  
How easy is it to read the signs in the building?

**Staff/ Support**

**Helpful**  
How helpful are the staff at Purple Patch Arts?

**Approachable**  
How approachable are the staff at Purple Patch Arts?

**Easy to understand**  
How easy is it to understand the staff?

**Friendly**  
How friendly are the staff at Purple Patch Arts?

**Knowledge of participants**  
How well do the staff know you?

**Adaptable**  
How adaptable are the staff at Purple Patch Arts?

Activity	What we did (circle)	How I felt (circle or draw your own)

Figure 30: Questionnaire exploring accessibility at PPA

For research question three (what does an accessible space look and feel like?) co-researchers opted to utilise creative approaches to demonstrate their varied experiences of accessible and inaccessible spaces<sup>8</sup>. While planning their research about accessible spaces, co-researchers naturally shared their experiences at PPA (consequently contributing to the PRG’s understanding of research question two: what makes Purple Patch Arts accessible or not accessible?). However, co-researchers also reflected on their experiences of accessibility in the outside world (in settings outside PPA) and made natural comparisons between the two. It became clear from discussions in the planning phase of cycle three that a) the PRG’s

<sup>8</sup> The PRG considered accessible/inaccessible ‘spaces’ as physical areas (e.g. places and venues), alongside broader environments, communities and systems. For example, the research community/academia was considered as a ‘space’ which was often not occupied by adults with learning disabilities due to concerns around accessibility. Therefore, descriptions of spaces in relation to this question do not simply focus on the physicality of a space (although physical attributes were often considered) but included a range of factors which will be discussed in the results and discussion section.

experiences of accessibility at PPA and in the outside world were not always consistent and b) that the PRG's ideals regarding what an accessible space should look and feel like, were not always comparable to spaces that they had encountered in real life. Co-researchers therefore chose to approach this question by considering their 'accessible dream worlds'. This activity, which involved co-creating acrostic poems (see appendix H), aimed to capture co-researchers' views on what their dream accessible world would be like, look like and feel like. Co-researchers then compared this to their real-world experiences (at PPA and in the outside world). Acrostic poems are used regularly in PPA to support participants to share their views on a particular topic, and co-researchers were therefore familiar with this approach. In an acrostic poem, the first letter of each line spells out a word. Prompt words, which were chosen by the PRG, provided a structure to discussions and the process of co-creating the poems while providing co-researchers with the freedom to use their imagination when considering their ideal accessible world. Further details about how co-researchers co-created their poems are included in section 6.2.1.7.

Additionally, to visually capture the co-researchers' experiences of accessibility in the outside world, two researchers chose to take photographs of accessible and inaccessible spaces they encountered during a week. This occurred during the action phase of cycle three and photographs were used as the basis of a group discussion in action session four. Co-researchers initially wanted to take photographs of accessible and inaccessible aspects of the PPA programme, however this was not possible due to the Covid-19 restrictions in place at the time. For example, co-researchers were not able to use a shared device to take photographs (e.g. the PPA iPad) and were not able to move around the room freely due to social distancing measures. Additionally, taking photographs within programmes raised concerns around the ethical implications of photo consent, particularly from PPA participants who were not involved in this research. Therefore, the group decided to focus their photographs on their experiences outside of PPA, and then use these images as a point of comparison to discuss the accessibility of PPA programmes.

To address research question four (what makes learning more or less accessible?) co-researchers chose to discuss the characteristics of accessible and inaccessible learning during a research session. Some co-researchers also opted to create an artistic response to this question (e.g. creating a poster, collage or drawing). Having previously used arts-based methods successfully in both cycle one and two, the group were familiar with this approach and therefore used visual methods to support their discussions.

Research question five (how accessible is the information that PPA share?) was chosen as cycle one revealed that the information shared by PPA was not always accessible



to them. To address this question, co-researchers decided to evaluate PPA's current communication methods by looking at the PPA website and letters sent to participants' homes. The UR shared these forms of communication with the group via Zoom and the group discussed what was accessible or inaccessible about the information and how it was shared in action session one.

Finally, while not explicitly a research question in itself, discussions during the planning phase of this cycle highlighted the importance of understanding the subjective and personal nature of co-researchers' experiences of accessible/inaccessible spaces. Since co-researchers frequently drew on their personal experiences, both within PPA programmes and in the outside world, the group decided to dedicate a research session to actively reflect on these experiences. Co-researchers also shared a desire for greater understanding of adults with learning disabilities and in particular, understanding from others about what it is like "in my shoes":

Leanne: it's like that saying, why not put yourself in my shoes?

[...]

Ella: I've got a learning difficulty

UR: yeah, that's right

Ella: and some shops don't understand

UR: [...] I think it's interesting what you said there Leanne about putting yourself in, 'in my shoes'. What would it, what would it be like in your shoes, Leanne?

Leanne: hard

UR: hard, yeah

Ella: yeah, just to see

UR: yeah

Ella: and to know what it's like for me, for people for people like me

This discussion led to the co-creation of the activity 'in my shoes', which was designed to support co-researchers to reflect on and share their personal experiences of accessibility/lack of accessibility in everyday life (including at PPA, where appropriate). As suggested by Leanne in the extract below, the group chose to create a poster, which shared the challenges and barriers to accessibility they faced, alongside important aspects of their lives as adults with learning disabilities that they wished others knew:

UR: do you think we could do something about, what it's like to be in your shoes?

Leanne: yeah [...] we could do a poster

The process of selecting this activity provides an example of where co-researchers took an active lead in the decision-making regarding choosing (and designing) research methods.

## 6.2 Action

### 6.2.1 Procedure

Research sessions in cycle three took place fortnightly and lasted approximately one hour. Table 8 provides an overview of the content addressed in each session of cycle three, including which co-researchers were involved. Co-researchers completed final interviews in their own time over a period of one month (see section 6.3.3.5). Final interviews and the review phase of cycle three occurred simultaneously.

*Table 8: Outline of research sessions in cycle three*

Session Type	Co-researchers involved	Session content
Planning 1, group 1	Ella, Leanne, UR	Looking at previous literature (White & Morgan, 2012, Liddiard et al., 2018). Discussing what we mean by 'accessibility'. Brainstorming research questions.
Planning 1, group 2	Sam, Janine, John, UR	
Planning 2, group 1	Ella, Leanne, UR	Planning feedback session with PPA staff, selecting research questions, discussing potential methods
Planning 2, group 2	Sam, Janine, Tracey, John, Liam, UR	
Planning 3, group 1	Ella, Leanne, UR	Choosing research methods
Planning 3, group 2	John, Tracey, Sam, Janine, Charlie, Jo, UR	
Feedback session	Ella, Leanne, Tracey, John, Liam, UR, PPA office staff	Research feedback session with PPA staff
Planning 4, group 1	Ella, Leanne, UR	Creating accessibility questionnaire, discussion about accessibility at PPA
Planning 4, group 2	John, Tracey, Janine, Sam, UR	
Action 1, group 1	Ella, Leanne, Jo, Charlie, UR	Accessible Learning, discussion about accessibility of information shared by PPA
Action 1	Sam, Janine, UR	
Action 2, group 1	Ella, Leanne, UR	Accessible people discussion
Action 2, group 2	John, Tracey, Charlie, Jo, Sam, Janine, UR	
Action 3, group 1	Ella, Leanne, John, Tracey, UR	'Accessible dream world' acrostic poems
Action 3, group 2	Sam, Janine, Liam, UR	
Accessibility photographs	Leanne, Tracey	Taking photographs of accessible and inaccessible spaces independently
Accessibility questionnaire	Sam, Janine, Tracey, Liam	Completing accessibility questionnaire independently

Action 4	Ella, Leanne, Tracey, John, UR	Finishing acrostic poems, looking at accessibility photographs
Action 5	Ella, Leanne, Tracey, John, UR	'In my shoes' activity
Review 1, group 1	John, Tracey, Charlie, Jo, UR	Analysis of poems
Review 1, group 2	Sam, Janine, UR	
Review 2 + 3	Ella, Tracey, John, Liam, Sam, Janine, UR	Analysis of cycle three data
Review 4 (in person session)	Ella, Tracey, John, Liam, Sam, Janine, UR	Reflection on being a researcher

#### 6.2.1.1 Planning session one

As previously discussed, during planning session one co-researchers engaged with easy read adaptations of previous literature (Liddiard et al., 2018; White & Morgan, 2012). In line with the theme of this cycle, co-researchers were asked to consider what was accessible or not accessible about the specific research presented in the easy read adaptations, alongside what they thought could be improved and what they thought was successful about the research. For example, Ella identified the participatory design of Liddiard et al's. (2018) work as a positive aspect of this project:

UR: what did you like about it? [Liddiard et al., 2018]

Ella: I like that the people with learning disabilities is teaching the people with non-learning disabilities

However, co-researchers also identified presentational features of the easy read documents when discussing the accessibility/success of the research. For example, when asked why they thought White and Morgan's (2012) research was accessible, Leanne noted "I like the pictures" and Ella stated, "they just blew it up bigger so the people who couldn't read, could see it better". These comments suggest that the easy read adaptations of the research produced for this project were successful in improving access to wider literature for co-researchers. Additionally, the PRG raised interesting points regarding how the accessibility of research outputs may impact the perceived accessibility of research as a whole. However, these discussions revealed that co-researchers believed that all published research was presented in the style of an easy read document. This resulted in some confronting conversations regarding the lack of accessibility of published literature ("They [publications] are not easily accessible" – Leanne). A key ethical consideration of this project was to ensure that co-researchers were included at all stages of the project's design, delivery and dissemination. Therefore, adaptation of aspects of the research process was crucial to facilitate co-researchers' full participation in this project. However, by re-formatting relevant

literature to increase their accessibility, the UR neglected to present an accurate picture of the research landscape and in particular, the accessibility of publications. Therefore, a key learning from this (as discussed further in section 11.3.2) is the need for open and transparent conversations with disabled co-researchers regarding the accessibility of research processes and materials.

Additionally, while reflecting on previous literature, the PRG became increasingly aware of the lack of representation of disabled people as researchers. Ella discussed this with the UR while reflecting on Emma's role as a disabled researcher in White and Morgan's (2012) research exploring the everyday literacy of adults with learning disabilities. The extract below demonstrates the importance of sharing previous literature which includes researchers with learning disabilities in PAR projects:

UR: So, what do we think about this piece of research?

Ella: Really good, I wish there was more researchers \*inaudible\* with learning difficulties [...]

Maybe with more people who have disabilities out there in Leeds

During planning session one, co-researchers also discussed aspects of accessibility that they felt were most important (both at PPA programmes and in the outside world). Factors impacting access identified through these conversations will be discussed further in section 6.2.1.1. Some of these aspects were discussed further in planning session four and used to inform the creation of the accessibility questionnaire.

Using their understanding of previous literature and the PRG's discussions about accessibility, co-researchers brainstormed seven questions relating to accessibility and support at PPA following the process outlined in section 4.2.1.1.

#### 6.2.1.2 Planning session two

Planning session two was split into two activities. The first was to design a feedback session for PPA staff. Similarly to the feedback session in cycle two, an animated Powtoon video was produced to share the findings and recommendations from the previous cycle with PPA staff. The finished video was played for PPA staff over Zoom. Secondly, having brainstormed seven research questions in planning session one, co-researchers voted on which questions they would like to focus on during planning session two. The process of narrowing down these questions differed in each group. Group one opted to have a discussion about which questions were most important and relevant. Meanwhile group two chose to vote for their favourite questions by pressing an imaginary golden buzzer to indicate their favourite questions. Using this process, five questions were selected for inclusion in cycle three. The final stage of planning session two involved some brief discussions about potential methods

to address the PRG's chosen questions. The group discussed their chosen research questions and considered which methods would allow them to capture their experiences. For example, Ella suggests an arts-based approach to understanding the PRG's experiences of accessible learning:

UR: How do we think we could try and answer our question about what makes learning accessible or not accessible, what kind of things could we do to try and answer that question?  
Ella: a piece of art

These initial ideas were revisited and refined by the group in planning session three.

#### 6.2.1.3 Planning session three

Planning session three aimed to finalise the research methods the group intended to use to explore their research questions in the action phase. The group discussed each research question in turn, considering any ideas for research methods from planning session two, alongside methods that the group had used successfully in previous cycles of research. Research methods were selected based on how appropriately they captured the experiences of co-researchers, their accessibility and flexibility and the timescale of the action phase. All research methods included multiple options for co-researchers to choose from, based on their personal needs and preferences. For example, to address research question four (what makes learning more or less accessible?) co-researchers participated in a group discussion, with the option of concurrently creating an artistic response to this question.

#### 6.2.1.4 Planning session four

Planning session four was used to co-create an accessibility questionnaire, which was the chosen method to address research question two (what makes PPA accessible or not accessible?) The questionnaire was designed collaboratively using Canva. The UR shared their screen, and the co-researchers' design and content ideas were added in real time. The questionnaire was designed to collect information/experiences concerning four key aspects of accessibility at PPA. These were: transport, venue, staff/support and activities. These topics and their six contributing factors were chosen by the group, via a group discussion about the most important aspects of accessibility at PPA and in the outside world. While there will, of course, be additional aspects that impact accessibility for adults with learning disabilities, the topics chosen for inclusion in the questionnaire were deemed to be the most important to the PRG within the context of PPA. Additionally, the questionnaire aimed to provide an overview of accessibility at PPA. Additional aspects of accessibility (such as accessibility and learning) were explored in response to other research questions.

A physical copy of the questionnaire was sent to co-researchers in the post. Three co-researchers completed the accessibility questionnaire (Liam, Tracey and Sam) during the action phase of cycle three. Since completion of the questionnaire occurred during the PRG's own time, co-researchers were given the option of when/if to complete the survey. Many of the factors measured through the survey were reported to be constant across PPA sessions (e.g. co-researchers reported using the same method of transport to travel to PPA each week). Therefore, the group decided that completing the questionnaire once would provide an effective overview of the accessibility of the four PPA programmes represented by co-researchers. Co-researchers rated the accessibility of PPA using a traffic light system (As discussed in section 6.1.3). A notes section was included for co-researchers to expand on their answers, if required. Co-researchers used this section for different purposes, including to reflect on the access needs of others in their PPA group. For example, Sam (with support from Janine) shared her ideas concerning the accessibility of her PPA programme for those who use a wheelchair, despite not using a wheelchair herself (see figure 31). While the questionnaire was intended as a self-reflection tool, this suggests that co-researchers were also aware of and evaluating the accessibility of the PPA programme based on the access needs of others.

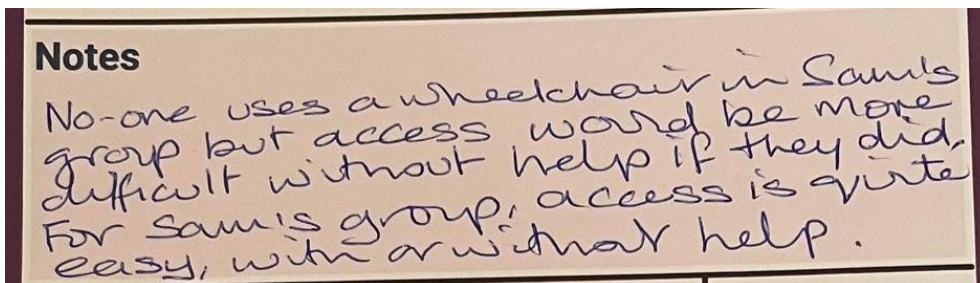


Figure 31: Sam's 'note' section from her accessibility questionnaire

Sam and Janine used the 'notes' section of the accessibility questionnaire to reflect on the accessibility of the PPA programme based on the access needs of others, alongside Sam's personal experiences.

Tracey used the notes section of her questionnaire to reflect on her experiences returning to PPA in a post-pandemic world, including the positive and negative changes associated with this (e.g. positive changes to routine and negative changes to staffing: see figure 32). While the questionnaire was specifically designed to support co-researchers' reflections on accessibility, Tracey also shared detailed reflections on her experiences as a researcher, including hopes for her future engagement with research ("I hope one day we can do more things like we as researchers have done" – C3).

Notes  
 Had to be back with Harrogate Purple Patch arts group and to take things off my mind so back in a rule teen to.  
 New stages are great but miss the old ones but have to help them along the way like we did I hope one day I can do more things like we

Activity	What we did (circle)	How I felt (circle or draw your own)
Getting to know each other our goals		
Painting Bubbles and other art		
Cool down Song		

as researchers have done with you melissa and maybe with purple patch arts will miss you all so much when we get to end this journey together Purple Researchers Journey we have had together we had been a great team thanks Team Purple and melissa have to be said sorry one of us had too.

Which I usually find very hard New people and doing new things  
 I have a good confidence doing this to and learn something new to and meet some great people too Thank you!

Figure 32: Tracey's 'note' section from her accessibility questionnaire

Tracey used the 'notes' section of the accessibility questionnaire as a space to reflect on the changes associated with returning to PPA in person. Tracey also shared detailed reflections on her role as a researcher, her "purple researchers' journey" and her hopes for the future.

Tracey's reflections on the role of the research in her life, alongside her hopes for futures engagement with research indicate her awareness of the approaching end to the project. This demonstrates that co-researchers may have considered their changing role in the project from as early as the beginning of cycle three. Co-researchers shared photographs of their completed questionnaire with the UR. Questionnaire responses were collated, and analysed during the in-person research session discussed in section 6.3.1.1.

#### 6.2.1.5 Action session one

During the first action session, co-researchers aimed to address research question four (what makes learning more or less accessible?) through a group discussion about learning at PPA, alongside any other learning environments the group had experienced. The UR supported these discussions via a series of prompt questions designed to facilitate reflection on the aspects of learning that were accessible or not accessible to co-researchers. Prompt questions included:

**Accessible learning**

- What makes learning accessible? /What helps us to learn?
- What things do we need for learning to be accessible? What would happen if we took those things away?
- How does it feel when learning is accessible? Can you think of anywhere where learning is accessible?

**Inaccessible learning**

- What makes learning not accessible/less accessible? /What makes learning difficult?
- How does it feel when learning is not accessible?
- Can you think of anywhere where learning is not accessible?

**Learning at PPA**

- What do you think is accessible or inaccessible about learning at PPA?
- Can you remember a time where you learned something new at PPA? How did you learn it? Was this an easy or hard way to learn something new?
- What is it like to learn at PPA in person vs online?

Co-researchers reflected on the most important aspects of accessible learning during the review sessions. Transcripts of action session one were also analysed by the UR (see section 3.5.2.2 for full details of this process).

**6.2.1.6 Action session two**

During action session two, the PRG addressed research question one (what makes a person 'accessible?') by discussing their experiences of accessible people. The aim of this session was to consider how the group defined accessible and inaccessible people, and to investigate the impact of accessible people on the accessibility of spaces and experiences more broadly. The UR supported these conversations through a series of prompt questions.

- What does it mean if someone is 'accessible' or 'inaccessible'?
- What does an accessible person do? Say? Think? and feel?
- How does an accessible person act? Make you feel? Communicate?
- Do we know any accessible people? How do we know they are accessible?



Prompt questions encouraged co-researchers to reflect on their own experiences with accessible people and create a profile of features/characteristics associated with accessible people (see section 6.3.2.2.5.1). Co-researchers were also encouraged to produce their own diagrams/drawings of accessibility people during the session (see for example, figure 33)



Figure 33: Charlie's 'accessible person' drawing

Charlie's artwork features descriptive words and thoughts that accessible people may have, such as "I can help you with that".

#### 6.2.1.7 Action session three

During action session three, co-researchers considered their accessible dream worlds by co-creating acrostic poems (see appendix H). This activity was designed to encourage the PRG to imagine the components of their ideal accessible world, and then compare this to a) their lived experience of accessibility and b) their experiences at PPA. Previous research suggests that 'wishing tasks', where participants are asked to share their magic wishes and/or ideal scenarios in relation to a particular theme, can be a useful method to understand the innermost thoughts, feelings and dreams of adults with learning disabilities (Dykens et al., 2007). In particular, a wishing task was chosen to understand the co-researchers' perspectives on accessibility as it encouraged the PRG to share their ideal accessible worlds, free from the imposed limitations and realities of accessibility in the real world.

Co-researchers wrote their poems in two separate groups via Zoom. Word prompts

for the acrostic poems were chosen by the co-researchers in each group. Words selected for the acrostic poems were: 'Accessible dream world', 'Accessible dream' and 'Freedom'. Both groups also opted to create a poem using the prompt 'Purple Patch Arts' to reflect on accessibility at PPA. The UR shared a word document, which included the chosen prompt word, with co-researchers via screen share on Zoom. Co-researchers took turns to share their ideas for the acrostic poems by indicating which letter of the prompt word their idea related to. Co-researchers were also asked to explain how their suggestion related to the theme of the poem. For example, John explained his suggestion of 'compromise' for inclusion in the 'accessible dream world' poem ("I've got a good one, you can have accessibility means, that C at the top, could be accessibility means compromise [...] because you have to compromise" – John, C3). While co-creating the poems, co-researchers often shared their personal experiences with inaccessible spaces, activities and people. For example, Ella shared her negative experiences relating to acceptance after John suggested including 'acceptance' as part of the PRG's 'accessible dream world' poem:

John: it could be acceptance alright

Ella: I had a time for people trying to accept me [...] it was really hard

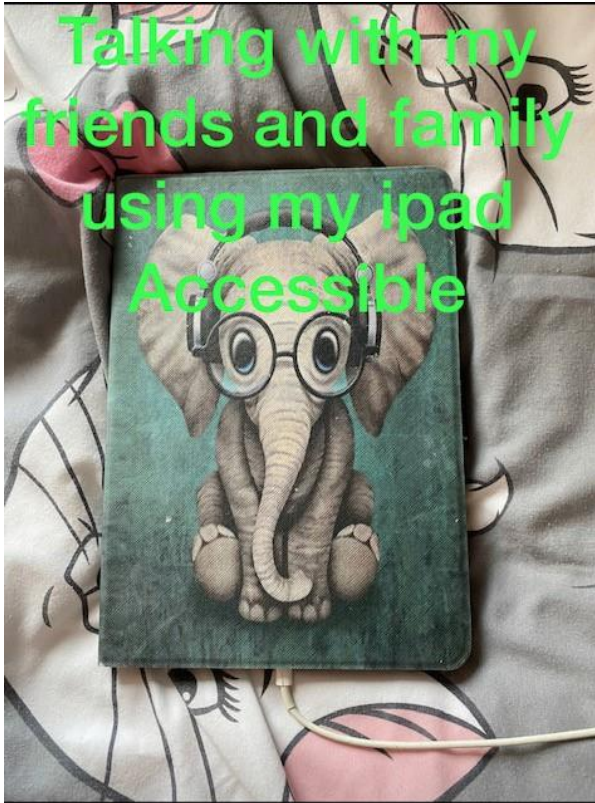
Poems were therefore used to support the PRG's reflection on their personal experiences with accessible and inaccessible spaces, including the impact of engagement with these spaces on co-researchers' wellbeing and quality of life.

#### 6.2.1.8 Action session four

During action session four, co-researchers completed their acrostic poems from the previous session (when required). Completed poems were shared in the PRG Facebook group so that co-researchers could see and respond to each other's poems. Poems were included for analysis in the in-person analysis session (reported in section 6.3.1.1).

Alongside co-creating acrostic poems, two co-researchers (Tracey and Leanne) chose to take photographs of things that they encountered in their lives, which they felt were or were not accessible, during the period of one week. Photographs were shared with the group by the UR via the screen share function on Zoom. This allowed co-researchers to engage with the photographs by asking the UR to zoom in/out on features of the photographs they found interesting, or to compare photographs. These photographs were used as the basis of a discussion during action session four about the realities of accessibility and the different ways in which co-researchers approached and experienced accessibility in the real world. Both Tracey and Leanne were present during this session and were therefore able to provide additional context about the photographs they had taken and why they represented

accessible or inaccessible experiences for them. Leanne's photographs captured accessible and inaccessible experiences relating to communication, physical access, distance/location and engagement with inclusive programmes. Leanne chose to label her photographs to explain why they were accessible or inaccessible (see figure 34). In contrast, Tracey chose to focus on physical accessibility in her photographs, which featured buildings she encountered (see figure 35). In particular, Tracey chose to take photographs representing contrasting experiences of physical accessibility and inaccessibility.



*Figure 34: Leanne's 'accessibility photograph' of her iPad*

*Leanne described her iPad as aiding accessibility as it enabled her to communicate with friends and family*



*Figure 35: Tracey's photographs focused on the physical accessibility/inaccessibility of buildings in her local area.*

*This photograph was taken to show an inaccessible building entrance.*

#### 6.2.1.9 Action session five

In this final action session, co-researchers completed an activity titled 'in my shoes'. This activity was inspired by a conversation between Leanne, Ella and the UR in the planning stage of cycle three about the lack of accessibility in some venues and the lack of understanding from others ("it's like that saying, why not put yourself in my shoes" – Leanne, C3). This arts-based activity was therefore designed to support co-researchers to reflect on and share their personal experiences of accessibility by considering what it's like to be "in your shoes".

Co-researchers created physical drawings of a shoe of their choice and then filled their shoes with drawings, words and symbols to represent their personal experiences of accessibility. Ella chose to trace an outline of one her shoes, while Tracey, Leanne and John chose to draw shoes that they felt represented them (see figures 36 and 37). John drew his shoe using the whiteboard feature on Zoom. All other co-researchers completed the activity

using their research journals. The UR supported this activity via prompt questions, including:

- What is it like to be in your shoes?
- What do you wish other people knew about you? (e.g. likes, dislikes, personality, what things are important to you that you wish others knew?)
- What is it like to be you?
- What would it be like if people knew what it was like to be in your shoes?

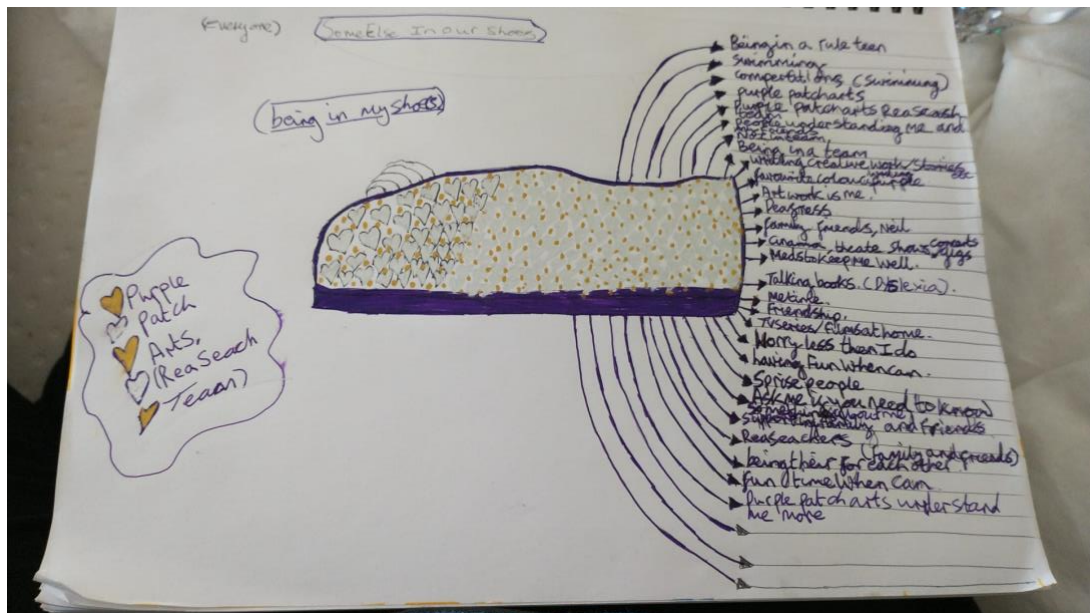


Figure 36: Tracey's 'in my shoes' response.

Tracey's work depicts detailed annotations pertaining to her personal experiences. Tracey's responses focus on things that are important to her in her life, such as family, hobbies, PPA and having fun. However, she also discussed the importance of others understanding her, stating that people should "ask me if you need to know something about me".



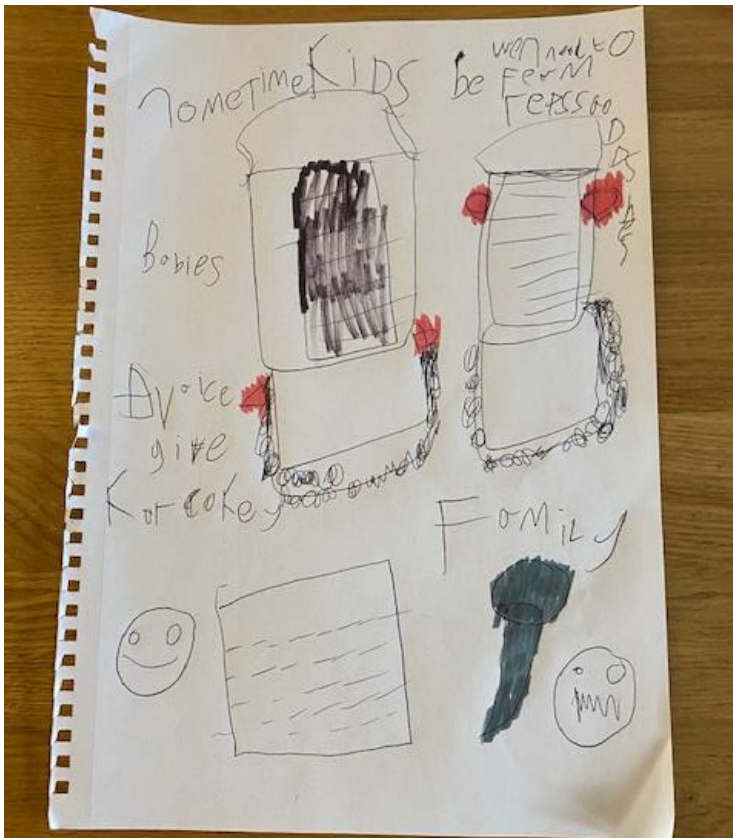


Figure 37: Leanne's 'in my shoes' response

Leanne's drawing includes drawings and written descriptions of what it is like to be in her shoes, alongside a drawing of a pair of football boots. Leanne discussed her responsibilities for looking after younger family members ("You've got two little ones running round... running rings around you [...] that I'm responsible for" – Leanne, C3), her dislike of doing karaoke due to challenges with her speech and her strengths of knowing "when to be ferm [sic]" with her cousins.

Initially, co-researchers approached this activity by sharing experiences that they found challenging in everyday life, particularly relating to accessibility of places and activities. Co-researchers were not specifically asked to share everyday experiences that they found challenging. Despite this, Ella focused on sharing tasks that she found difficult, such as navigating the supermarket:

Ella: I like shopping at Sainsbury's [...] It's something I find hard  
 UR: Mhm. So, going to Sainsbury's is something you find hard?  
 Ella: Finding an item [...] I struggle in the supermarket

This highlights that co-researchers felt an important part of understanding what it is like in their shoes was to make others aware of the challenges they may face in everyday life. Indeed, in cycle three, Leanne suggested that "the people who don't have a disability, they don't know how, how hard it is", reiterating the importance of sharing the more challenging aspects of what it is like in your shoes with others, to increase understanding. However,

Tracey noted that sharing what it is like to be in your shoes does not simply refer to aspects of your life that are challenging, but also your strengths:

Ella: What else do I find hard?

[...]

Tracey: It can be good as well...

UR: Yeah, it can be good things as well, that's right! It doesn't have to be all things you find difficult

After encouragement from Tracey to consider her strengths and interests alongside the challenges, Ella discussed the importance of her independence ("I need to keep on top of my appointments [...] gives me independence skills"), and hobbies she enjoys ("I put activities on like Purple Patch, \*Yorkshire-based programme\*"). This conversation between Ella and Tracey demonstrates the importance of peer interaction and team work to support co-researchers to share their varied experiences, perspectives and ideas.

Overall, co-researchers discussed positive, negative and neutral emotions, responsibilities and experiences (relating to everyday life, accessibility and disability) when considering what it was like to be in their shoes. This activity provided an insight into how the co-researchers viewed themselves, alongside their personal experiences of accessibility in their everyday lives. Co-researchers' 'in my shoes' responses were analysed by the group during the in-person research session described in section 6.3.1.1.

## 6.3 Review

### 6.3.1 Analysis

The review phase of cycle three took place over one one-hour Zoom meeting per group, alongside one full in-person research day (discussed further below). As in cycle one and two, a collaborative and adaptive form of thematic analysis was used to analyse the PRG's acrostic poems. Co-researchers were sent physical copies of the poems and questionnaire responses. In review session one, co-researchers familiarised themselves with the acrostic poems and then identified the features of their own and others' poems that they felt were most important or interesting by highlighting extracts of text. The group revisited their highlighted poems during the in-person session, where the remaining data were analysed by the group, as detailed in the section below.

#### 6.3.1.1 In person research day

Due to the Covid-19 Pandemic, the in-person research day was the first time the PRG had met in person. Five co-researchers attended this session, which took place at the PPA office in Leeds. The day was split into three one-hour sessions (review sessions two, three and four, as described in table 8). Review sessions two and three focused on analysing the data from

cycle three of the project, including accessibility photographs, highlighted acrostic poems, accessibility questionnaires and ‘in my shoes’ responses. Conducting the analyses for cycle three in person, as opposed to solely on Zoom, provided an opportunity for the group to use creative methods to analyse the data. Additionally, in-person analysis enabled the group to have greater control over how the data were analysed. During review session two, the group discussed the best approach to analysing data from cycle three. Due to the broad range of data types included in the analyses for cycle three (including photographs, drawings, poems and extracts from transcripts) the group used a creative visual mapping exercise to explore the data.

After a process of familiarisation with all of the data collected in cycle three, the group worked together to cut, stick, arrange and annotate data from cycle three on a large piece of paper, which sought to demonstrate connections between the varied data types (figure 38). Co-researchers identified important and recurring ideas from the data, using a similar process to that described in both cycles one and two. Physical space and groupings on the page were used to represent the relationships between identified themes and ideas. Similarly, annotations provided context on these themes and their relationships, including the PRG’s experiences and feelings associated with each theme. Co-researchers also named and described identified groups/themes. This mapping exercise is comparable to thematic network analysis (Attride-Stirling, 2001). This qualitative analytical approach, similar to thematic analysis (Braun & Clarke, 2006), is based on a process of generating codes and themes at different levels of abstraction, usually from textual data. In Thematic Network Analysis, these themes are used to create “web-like illustrations that summarize the main themes constituting a piece of text” (Attride-Stirling, 2001, p.386), thus producing a visual map of the themes identified and the relationships between them. Co-researchers chose to construct their visual map based on the central theme of ‘dreams vs reality’ in relation to accessibility, both at PPA and in the outside world. This is discussed further in section 6.3.2.4.

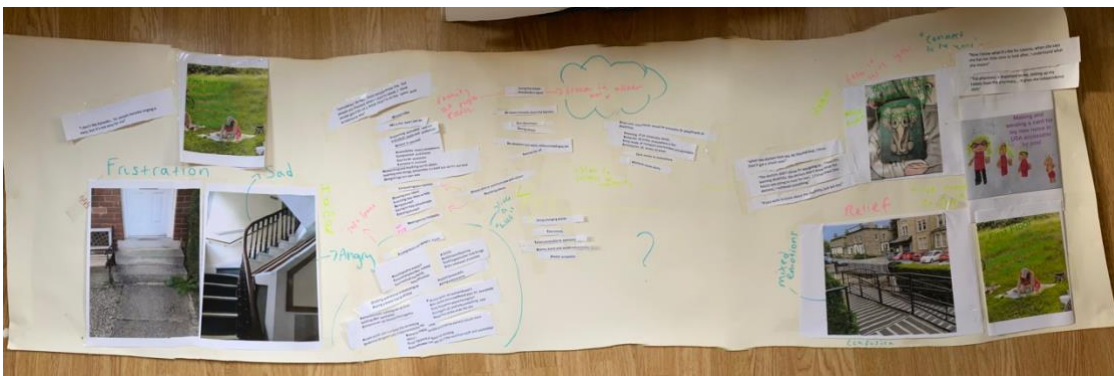


Figure 38: Visual map of themes identified during the in-person session



Review session four supported co-researchers to reflect on their experiences as researchers and on the project as a whole. The session also aimed to celebrate the PRG's achievements through their involvement in the project. This final session may therefore be considered as both data collection and analysis, since the session generated new data concerning the PRG's experiences with research, but also encouraged the group to reflect on and evaluate their own experiences in the project. Data collected in review session four was analysed by the UR. Results from these analyses concerning the co-researchers' experiences as a researcher, and the outcomes of their engagement in PAR are reported in chapter 9.

The following sections will discuss the themes that were identified through the co-researchers' and UR's analyses in cycle three. Firstly, 'Aspects of Access' provides an overview of the four aspects of access which impacted the PRG's experiences of accessibility within PPA and in the wider world. These are 'Physical', 'Transport', 'Cost' and 'Resources, information and activities'<sup>9</sup>. A further six higher level 'factors influencing access' were also identified by the group. These factors positively or negatively influenced the co-researchers' experiences of accessibility. These are: 'Location', 'Ease of access', 'Subjectivity', 'Context' and 'People'. An additional theme, 'Accessible Learning' outlines the co-researchers' perceptions of accessibility specifically relating to the learning approach at PPA. Finally, 'Dreams Vs Reality' concerns the ways in which the PRG conceptualised experiences of accessibility and identifies the PRG's expectations, ideals and lived experience of accessibility within learning environments and in their everyday life.

### 6.3.2 Results and Discussion

#### 6.3.2.1 Aspects of access

Four key aspects of access were identified by the PRG. In line with the Social Model of Disability (Oliver & Sapey, 1983), aspects of access identified by the PRG had the potential to disable and exclude co-researchers from a range of everyday activities, spaces and experiences. Identification of these aspects of access, which overlap and influence each other, provided an important framework for co-researchers' discussions about accessibility throughout cycle three. Through discussion and activities (as outlined above) designed to explore the co-researchers' experiences and perceptions of accessibility, the PRG identified

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<sup>9</sup> It is important to note that while the PRG identified the four aspects of accessibility listed here, the subjective nature of accessibility and wide-ranging experiences of disabled people mean that these aspects are specific to the PRG's experiences. There may therefore be additional aspects of access which have not been identified in the present study but are nonetheless important for disabled people's engagement with activities, spaces and facilities. The subjective nature of accessibility is discussed further in section 6.3.2.2.3.

key features of accessible spaces (thus addressing research question three), and considered which of these features were present within the PPA programme (thus addressing research question two).

Discussions during sessions about aspect of access often deviated from the co-researchers' experiences of arts-based learning at PPA/of PPA generally. While these discussions may not have always been directly related to PPA, co-researchers shared the broad range of considerations, thoughts and experiences relating to accessibility, which influenced their participation at PPA. Past seemingly unrelated experiences of inaccessible places, activities and facilities were reported to influence the PRG's expectations, perceptions and decisions concerning attendance at PPA and other organizations and activities for adults with learning disabilities. It was therefore important to understand co-researchers' broader experiences of accessibility, to provide context to their experiences within PPA. The following sections will introduce each identified aspect of accessibility in turn and in doing so, provide a snapshot into the aspects of accessibility that co-researchers considered when making decisions around attendance at programmes and activities, including PPA.

#### 6.3.2.1.1 Physical

Physical accessibility was one of the most commonly identified aspects of accessibility and was also often one of the first aspects of access that co-researchers raised in group discussions ("that would be one of our first questions, is, is it wheelchair friendly?" – Leanne, C3). As described in previous research, co-researchers were often required to negotiate barriers in the physical environment in order to access activities and spaces (Anaby et al., 2013). Potential physical barriers identified by the PRG included entrances and exits to buildings, navigating the space (e.g. routes, room layouts, signage) and the absence of and/or challenges associated with accessing facilities such as toilets, changing places, equipment and parking. It is therefore unsurprising that the accessibility of the physical environment is an important factor impacting disabled people's participation in community activities (World Health Organisation, 2001).

Entrances to buildings provided co-researchers with a first impression of the accessibility of a space (although, as discussed in section 6.3.2.4, first impressions were not always accurate). Co-researchers identified that sloped entrances and automatic doors were important features of accessible buildings ("the downstairs from the car park is not an accessible door, it doesn't open uh, automatically" – Janine, C3). Additionally, spacious buildings and routes were considered to be more accessible than those with limited space ("ability to move easily" – acrostic poem 1, C3). When asked to describe what an accessible

space looks like, Leanne stated that accessible places were “big and colourful” (C3). Additionally, John discussed the importance of space within buildings for accessibility, particularly for wheelchair users:

John: basically, it has to be wide enough, wide enough... accessibility... to get through somewhere  
 UR: right yeah  
 John: with the chair. Even the house we live in can be tight sometimes

Indeed, negotiating space, particularly narrow spaces or tight corners was a concern for co-researchers who used wheelchairs (“there’s always a corner to get round” – John, C3). Navigating physical barriers such as narrow spaces were considered to be an important skill that co-researchers had developed over time. John shared his skills relating to navigating narrow spaces in his wheelchair in cycle three, noting that others may have to practice this skill in order to access particular spaces: “I could manage it, but I don’t think everyone could drive as good [...] they’d have to practice”

Accessible spaces made co-researchers feel that they were welcome and safe within the space they were visiting (“Do you feel safe there? Yeah, I do” – John, C3). This was particularly important in order to encourage participation with learning programmes such as PPA. Accessible spaces were also reported to support feelings of escapism as Ella and Leanne discussed in cycle three:

Ella: I like being there, UR  
 UR: Why do you think you like being there Ella?  
 Ella: Because I have lots of fun at...  
 Leanne: You can forget about everything [...] you can go into your own world  
 [...]  
 Ella: That’s why it’s my favourite room

This suggests that alongside the content of PPA sessions, accessible spaces themselves may be associated with feelings of enjoyment and safety, thus aiding escapism for adults with learning disabilities. The accessibility of the venue where activities and services for adults with learning disabilities are based may therefore be as important as the accessibility of the activities themselves.

In contrast, inaccessible spaces had the potential to have a negative impact on the psychological and physical wellbeing of co-researchers, both in the short and long-term. Co-researchers reported feeling disappointed and sad when inaccessible environments excluded them. A lack of physical access prevented co-researchers from participating in activities that they enjoyed, or that were accessible to non-disabled people, such as leisure activities, learning opportunities and visiting their friends and family. John shared that due a lack of

physical access he was unable to visit Tracey in her home, noting that he could only “meet them in the garden” (John, C3). Indeed, previous research indicates that inaccessible environments have been found to reduce participation with a range of community activities, particularly for those with limited mobility (Anaby et al., 2013; Williams & Willmott, 2012). However, concerns around accessibility extended beyond participation to safety in inaccessible spaces, particularly in an emergency situation (“access out in emergency like, you know, um, like a fire, is it easy to get out?” – John, C3).

Inaccessible spaces also reduced co-researchers’ independence and autonomy, as Janine described in cycle three:

There’s a second door between that and the lift, so again, you need, if you can’t manage it yourself you need somebody to help you open the door [...] you have to press the buzzer to ask somebody, it’s if somebody’s on the desk at the time

A lack of independence often resulted in an increased reliance on other people to access spaces and facilities. This posed additional challenges for adults with learning disabilities as not only did this reduce opportunities for independence, ‘inaccessible people’ (discussed further in section 6.3.2.2.5), had the potential to be a barrier in themselves to accessibility.

Negative experiences with physical accessibility resulted in some co-researchers experiencing ongoing anxiety around going to new places or trying new activities, particularly when they were not familiar with the space. In cycle one, John recalled his experiences of attending a conference about accessibility and encountering inaccessible spaces within the conference venue: “the actual place where we were doing the conference, the lift was really tiny, I mean, I can drive through small spaces, but it was only the size of maybe a closet [...] it was really ironic. It was weird”. John’s experiences of being invited to an ‘accessible’ space, only to discover the space was not accessible to him resulted in anxiety around visiting new and unfamiliar venues in the future. This was observed during the present study, when Tracey shared John’s concerns around visiting the venue for the in-person research day in cycle three: “he’s [John] worried about the house, the place where we’re going because he’s seen a picture [...] how will he get in, is there a ramp?”. Despite the fact the venue for the in-person day was accessible and wheelchair friendly, John’s concerns around the venue, based on his past experiences, almost resulted in him not attending the session. Only after speaking to both the UR and PPA staff concerning the accessibility of the space did John agree to attend the session.

This highlights the important relationship between trust and physical attendance at programmes or activities for disabled people who have experienced inaccessible environments. Many of the co-researchers were untrusting of the accessibility of spaces and

facilities, often expecting the worst even when environments were advertised as accessible. This was likely due to the co-researchers' experiences of feeling mis-led by spaces which were advertised as accessible, but in reality, were inaccessible to them and/or others (as with John's example above). It is therefore important to note that disabled people's perceptions of the accessibility of spaces and activities (even when inaccurate) may be as much of a barrier to participation as spaces that are inaccessible.

In the present study, an influencing factor relating to co-researchers' perceptions of the accessibility of spaces was people. Specifically, people who provide information about and/or support the accessibility of services, and whether these individuals or organisations were considered to be a trusted source. In the example above, John's perception of the accessibility of the venue was based on information he gathered from Google. This information alone did not reassure John that the building was accessible. However, after speaking directly with the UR and staff from PPA, who were both familiar and trusted, John was reassured that the building was accessible to him. The present study therefore suggests that adults with learning disabilities' attendance at learning programmes and activities may be supported by providing detailed information about the accessibility of the space, ideally from a trusted individual or organisation. Additionally, adults with learning disabilities may need reassurance about accessibility in the time leading up to their attendance, to reduce anxiety around their participation and support them to feel comfortable and confident.

Reflections on accessibility at PPA suggested that accessibility within programmes was viewed positively. Co-researchers who completed the accessibility questionnaire rated all aspects of accessibility included in this survey (transport, venue, staff/support and activities) as accessible, by circling the smiley face option. However, due to the small number of co-researchers who completed the survey, only three PPA programmes were represented. During discussions about the accessibility of PPA programmes in cycle three, the PRG identified some variety in their experiences of physical access between different venues. For example, in cycle one Liam shared his views that his PPA programme was held in an accessible venue: "It's actually fully disabled friendly because its, we hire two rooms in \*programme location\* they're actually a disability run charity so they're fully disabled friendly". However, John, who attended a different programme, discussed varied experiences of physical accessibility within the venue he attends: "it has a ramp to go inside, but the access is not that good inside. It's a hall - the toilets can be small" (C3). There are, of course, a number of factors to consider when assessing the physical accessibility of PPA programmes. Firstly, it is important to note that co-researchers had varying perspectives of and experiences with accessibility. Indeed, as a wheelchair user, John's experiences of physical

access differed to other co-researchers who did not use a wheelchair (discussed further in section 6.3.2.2.3). Additionally, since PPA operate from pre-existing venues across Yorkshire, co-researchers recognised that additional factors such as the availability and commonality of accessible venues in their local area impacted the accessibility of their PPA programmes.

While venues and facilities were expected to vary in their accessibility, the PRG agreed on the importance of sharing information about the accessibility of a venue ahead of time to reduce stress and anxiety related to accessing the space and ensure that disabled people feel comfortable and welcome in the space. Relating to this, co-researchers made recommendations around the transparency of accessibility at PPA venues, which will be discussed further in section 6.3.3.3. Additionally, holding programmes and/or activities in spaces that are familiar to adults with learning disabilities may increase the likelihood of participation, and reduce anxiety around attending an unfamiliar venue. Similarly, researchers hoping to actively involve adults with learning disabilities in research may wish to consider holding research meetings in venues that are familiar to the group, where possible.

#### 6.3.2.1.2 Transport

Relating to physical access was transport, particularly transport to and from PPA programmes, as John explained:

UR: So, if we say something is accessible, what do we mean?

John: it's positive and it's there to be, used, um like a train, accessible or a bus is available for us to use

In a survey completed by 1,674 disabled adults, 26% stated that transport was the biggest challenge in their life (Copestake et al., 2014). Transport was a particularly important aspect of accessibility as it often determined whether or not co-researchers could attend learning programmes, appointments and social activities. For example, in cycle three Ella shared that issues with taxis impacted her ability to attend PPA: “we had a little incident with the taxi last week [...] it didn't turn up”. Co-researchers discussed the accessibility of various modes of transport, including public transport (e.g. trains and busses), private transport (e.g. taxis and minibuses) and the use of personal vehicles (e.g. family car). Regardless of the mode of transport used by co-researchers to access PPA programmes, all members of the PRG reported experiencing barriers relating to transport.

As noted in previous research, barriers to accessing public transport were often due to deficits in the transport system which resulted in a lack of accessibility, particularly for individuals with physical disabilities (Casas, 2008). For example, co-researchers with mobility challenges described difficulties accessing public transport, as John explained in cycle three:

“I’m in a chair so I have issues sometimes with the bus”. However, the accessibility of these modes of transport were also impacted by the attitudes and behaviours of drivers and staff members (see section 6.3.2.2.5 for further discussion about the impact of people on accessibility). Additionally, factors such as the cost of transport, distance between transport and the activity (“how near it is to a bus stop?” – John, C3) and a lack of information and/or lack of skills or experience impacted the accessibility of transport. Ella discussed not being able to access public transport without support due to not being ‘travel trained’ (“I still can’t go into town on my own, I’m not travel trained” – Ella, C2). Therefore, while public transport was physically accessible to Ella, she was not able to travel independently.

Negative experiences with transport resulted in anxiety around using transport in the future. For example, after having several negative experiences while taking a taxi to PPA, Ella shared her concerns about using this mode of transport to access PPA in the future: “what if it [taxi] doesn’t turn up for the first day tomorrow?” (C3). The range of transport-related challenges described by the PRG are in keeping with previous research which suggests that access to “adapted and affordable transport” was a key challenge for disabled people, particularly for those with physical disabilities (Copestake et al., 2014, p.54). Delbosc and Currie (2011) describe individuals facing barriers to transportation as ‘transportation disadvantaged’. Those who experience transportation disadvantage are reported to have reduced access to employment opportunities, health services and education, alongside opportunities for social interaction with others (Currie & Stanley, 2008). This highlights the importance of ensuring that learning programmes and activities for disabled people are within easy reach of accessible modes of transport to facilitate attendance. Accessible transport may also have a positive impact on the quality of life of disabled people, by supporting independence, autonomy and social interaction (Bascom & Christensen, 2017; Christensen & Byrne, 2014).

#### 6.3.2.1.3 Cost

Cost of attendance at learning programmes such as PPA was considered to be an important aspect of accessibility. The cost of attendance at PPA is subsidised by the organisation to ensure that attendance at programmes is as affordable as possible. Additionally, one co-researcher was also in receipt of a bursary which supported them to attend PPA programmes by covering the cost of attendance. Leanne noted that without subsidised attendance “we wouldn’t be able to go” (C3). However, many co-researchers were responsible for covering (either partially or fully) the cost of their attendance. The cost of attendance was therefore considered as a barrier to attendance at PPA for some individuals, as Leanne noted in cycle

three: “some people might not have enough money”.

This is in keeping with previous research, which found that 41% of disabled adults reported finance as the biggest challenges in their life (Copestake et al., 2014). This may be, in part, because adults with learning disabilities are less likely to be employed. Indeed, only 6% of adults with a learning disability in England are in paid employment, compared to 52% of adults with any type of disability and 76% of non-disabled adults in the general population (NHS Digital, 2022). However, the concept of ‘crip tax’, described by disability rights activists suggests that disabled people may also face a multitude of additional hidden costs directly related to their disability, such as travel costs, accommodation and support (Blanchard, 2020). Therefore, costs associated with attendance and/or travel to programmes or activities may be a significant barrier for adults with learning disabilities.

Outside of PPA, co-researchers considered the cost of accessing equipment and resources which aided accessibility. While the PRG acknowledged a range of devices and equipment which would aid access to activities and opportunities, many of these accessible accessories/resources were inaccessible to the PRG due to the cost of purchasing them:

There’s a new reader for books. Like a pen. So, you can just run the pen over and it reads the words [...] of course, it’s rather expensive, but something like that would be... if they could make it more user friendly, or cheaper – Janine (C3)

This raises the important point that the existence of accessible resources, technologies and activities does not mean they are accessible. Accessibility could instead be considered based on the ease with which a particular activity or item is accessed, as discussed further in section 6.3.2.2.2.

#### 6.3.2.1.4 Resources, information and activities

The ways in which information was communicated to co-researchers was considered to be an important aspect of accessibility. Presentational factors such as colour, layout, and text size impacted the accessibility of visual information and resources size (“I need bigger font, I need comic sans or new roman [...] in size 16 or up” – Tracey, C3). Similarly, information, resources and activities provided in multiple formats were considered to aid accessibility. In particular, reliance on written communication alone was viewed as less accessible. The group agreed that “making words readable” (acrostic poem 3, C3) was a key consideration of accessible resources. This included the use of simpler language and avoiding sharing “too much information” at once (Tracey, C3). The PRG also discussed how the use of images alongside written words supported the accessibility of information and resources, particularly for



people who cannot read:

John: I can read but there aren't many who can read  
 [...]
   
Tracey: you know, you know the \*project external to PPA\*
   
UR: mm
   
Tracey: that information, on one side there was pictures on the other side there was words
   
UR: mm
   
Tracey: I thought that was very helpful

Inaccurate or insufficient information/resources were considered to negatively impact accessibility, since co-researchers relied on this information to make informed decisions concerning their engagement with activities and learning opportunities (“If you’ve got people who are telling you the wrong messages, when you know you’ve got the right, what do you do?” – Janine, C1).

Co-researchers agreed that in order for activities to be truly accessible “everybody joins in, so you’re all on the same page doing things” (Janine, C3). However, as previously discussed, this does not necessarily mean that everyone does the same activity in the same way. “Compromise and choice” (acrostic poem 1, C3) were considered to be important to facilitate accessible activities. The PRG discussed the relationship between accessible learning activities, freedom and choice during cycle three:

Jo: \*to Charlie\* is it important to be free and do what you want to do? Do what you want to do and not be told what to do. Yeah? Yeah, it is important for Charlie to have his freedom and choose what he wants to do [...] and his choices, and you know, choice
   
John: the choice is there, yeah
   
[...]
   
John: to have the choice is important I think
   
UR: Yeah
   
John: and a lot don't have the choice, you know they won't give a choice, some people. Most people of us do, we all do, we know what it's about. The world needs uh, it needs a wakeup call sometimes, even today you know, even these times

In the extract above John alludes to the relationship between accessible learning activities, and whether those facilitating activities offer participants freedom and choice. The attitudes of people may therefore be considered as a mediating factor, influencing the level of choice provided and therefore the accessibility of the activity. Due to the arts-based nature of activities experienced at PPA, additional arts-related features of accessible activities were discussed by the group in cycle two and have therefore been reported in chapter 5.

### 6.3.2.2 Factors influencing access

Alongside the aspects of access discussed above, the PRG identified six factors which may independently or collectively influence an individual's experience of accessibility. For example, location may influence an individual's access to various services (e.g. by impacting physical access, available transport, the cost of services, and the activities available to an individual). Factors may influence each other (e.g. location may impact people) and may also be experienced in isolation or in combination.

#### 6.3.2.2.1 Location

Co-researchers suggested that geographical location influenced the availability and accessibility of learning opportunities and activities. Cities such as Leeds were considered to positively impact accessibility due to the range of organisations providing activities and support for adults with learning disabilities ("Leeds is a really good place to live if you've got a family with a child, or a young person with a leaning difficulty [...] because there's organisations to help" – Ella, C3)

Meanwhile other locations were considered to be less accessible, due to a lack of opportunities for adults with learning disabilities. This resulted in some locations having a negative reputation for inaccessible, or unreliable services, as Janine discussed in cycle three: "\*location in Yorkshire\* is notorious unfortunately for not having long-lasting programmes, but Purple Patch comes from Leeds". Similarly, the location of PPA programmes were considered as an important contributing factor when considering the accessibility of these programmes. For example, co-researchers attributed the variation in the accessibility of buildings used by PPA to location, including the priorities and resources of local authorities. Indeed, while some locations benefited from specially built and fully accessible venues, other buildings were less accessible, particularly for those with physical access needs. Of course, the location in which co-researchers resided, alongside the location of their nearest PPA programme also impacted the accessibility of other aspects considered by the group, such as public transport and cost. The overall accessibility of a location therefore also influenced ease of access, which will be discussed further in the following section.

#### 6.3.2.2.2 Ease of Access

The existence of accessible services, learning opportunities, activities or spaces alone did not guarantee accessible experiences for adults with learning disabilities. Rather, the ease of access to these experiences was considered to be a more important factor when considering how accessible they were. Rather than being considered as either accessible or inaccessible,

co-researchers experiences were considered on an individual sliding scale of accessibility, from inaccessible to *easily* accessible.

Barriers impacting ease of access included time, such as waiting for services of support (“ongoing support, without long waits” – Liam, C3) and logistics, such as complicated processes for accessing support, benefits, or facilities. Sometimes barriers faced by co-researchers included literal ones. Sam and Janine discussed their experiences of accessing disabled toilets, which were often locked. This meant that there were several obstacles to accessing the toilet, including: difficulties obtaining a key (“you have the key, on its own. If someone maybe borrowed, the key, you can’t buy a key, you get it on its own” – Sam, C3), challenges associated with reliance on others and the time and discomfort associated with having to wait for access:

When you look at the door it says to get the key go to the WHSmith’s counter. But if it’s after hours you have to ring a number. So, when you’re desperate to go, you’ve got to ring someone then get them to go and get the key themselves, you know [...] they don’t make it, erm, that accessible to get into the bathroom (Janine, C3)

Therefore, while the bathroom itself may considered to be accessible, the process of accessing the bathroom was not. A lack of ease of access resulted in some co-researchers taking accessibility into their own hands, for example, by sourcing their own radar keys<sup>10</sup> to avoid the challenges associated with locked bathrooms discussed above (“I have a stash of radar keys” – Janine, C3).

Co-researchers’ experiences of responding to and/or planning for limited ‘ease of access’ highlights the additional mental load experienced by adults with learning disabilities and their families in daily life. Discussed most recently in feminist literature, particularly in relation to the experiences of mothers, mental load refers to the often invisible and unpaid cognitive and emotional labour associated everyday life (Dean et al., 2021; Robertson et al., 2019). This may include cognitive load, such as thinking, predicting, planning and organising (Daming, 2019) and the emotional labour associated with this, such as worrying, stress and managing one’s emotions and the emotions of others (Dean et al., 2021). Previous research has considered the emotional impact of inaccessible experiences for disabled people, which may be as a result of direct or indirect psycho-emotional disablism (Reeve, 2006). Reeve (2006) notes that inaccessible spaces and people may exclude disabled people, resulting in additional emotional labour. While previous research has investigated the mental load of

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<sup>10</sup> A radar key allows an individual to independently access locked public bathrooms in the UK using the National Key Scheme (Disability Rights UK, n.d). Radar keys are designed to improve access to accessible toilets for disabled people and can be purchased from UK-based disabled people’s organisations.

those supporting adults with learning disabilities, such as learning disability nurses (Mitchell & Smith, 2003), the mental load of adults with learning disabilities is relatively unexplored. Despite this, co-researchers described the forward planning/research, anticipation, financial investment and emotional labour that was required in order to meet their basic needs and/or participate in everyday activities (“I had researched it ahead of time” – Janine, C1).

The Social Model of Disability proposes that it is society’s responsibility as a whole to ensure that facilities, spaces, services and activities are accessible to disabled people, rather than the individual’s responsibility (Oliver & Sapey, 1983). However, even when accessible facilities are provided, the responsibility for accessibility (and therefore the associated cognitive and emotional labour) often falls on the individual. This is illustrated by the PRG’s acknowledgement of their personal responsibility when attempting to access daily activities, as John noted in cycle three: “that’s just life, you deal with it”. This highlights that a lack of ease of access were often the norm for co-researchers. When applied to the experiences of the PRG, the concept of mental load demonstrates that a lack of ease of access can place additional responsibility and stress on adults with learning disabilities, as they attempt to negotiate the challenges of accessibility in everyday life. Individuals and organisations who hope to improve accessibility may therefore wish to consider reducing the mental load experienced by adults with learning disabilities, by focusing not only on providing accessible services, but considering the ease of access to these services.

#### 6.3.2.2.3 Subjectivity

Perceptions of accessibility varied within the PRG depending on each individual’s lived experience and personal access needs. Co-researchers’ experiences of accessibility at PPA and in everyday life, were impacted by their mobility, level of independence and the characteristics of the space, activity or experience that was being discussed. During cycle three, co-researchers shared photographs that they had taken of accessible and inaccessible spaces (see figures 39 and 40).



Figure 39: A photograph of the entrance to a family member's home, taken by Tracey



Figure 40: A photograph of a building entrance, taken by Tracey

Discussions about these photographs revealed that co-researchers made varying judgements about the of the accessibility of these spaces. Ella reported that the building entrance captured in figure 39 was more accessible than figure 40, since the former depicted fewer steps in order to access the desired location. However, as a wheelchair user, John noted that the entrances in both pictures were equally inaccessible to him:

UR: so, what do we think about this photograph? [figure 39]

Ella: it's more access

John: well, that wasn't access-, that isn't accessible really

[...]

UR: yeah, so you were saying Ella that you thought it looked more accessible, yeah? Do you

think more accessible than the picture of the stairs [figure 40]

Ella: yes

UR: and why do you think that?

Ella: there's only 2 steps

[...]

UR: yeah, so, do we think, so does that look more or less accessible than the, the big flight of stairs

Leanne: um

John: well, to me it's still looks unaccessible, not flat or a ramp [...] it's still bad

This example illustrates the impact of subjectivity and personal experience on the PRG's views about accessibility. Similarly, the impact of subjectivity was also considered in relation to non-disabled people, whose lack of lived experience may impact their views on accessibility. Co-researchers emphasized the importance of actively involving disabled people in decisions concerning accessibility. As Tracey noted in cycle three, "I think they should ask all disabilities and wheelchairs and disabilities if it is able for everybody to do before they use it". A person-centred approach, which prioritises active collaboration with disabled people with a range of experiences may therefore support the effective design and evaluation of accessible learning environments and facilities.

#### 6.3.2.2.4 Context

Some factors impacting accessibility were reported to be context-specific and therefore difficult to predict and/or control. One example of a contextual factor was the Covid-19 pandemic, which co-researchers described as negatively impacting physical accessibility, transport and the support they received from others. For example, John in particular noted that the pandemic had a negative impact on the accessibility of facilities, such as toilets: "because of Covid there's gonna be a lot of issues about accessibility [...] actually, the toilets in town are closed because of Covid, so... It's awkward".

Additionally, John discussed the potential impact of the pandemic on the attitudes of others and expressed concerns that anxiety due to the pandemic may reduce the support available to disabled people: "I get the feeling with this Covid there's even more paranoia [...] I wonder if people also will be less inclined to help". While the pandemic impacted the population a whole, it is important to note that Covid-19 disproportionately affected disabled people, further reducing access to everyday activities and experiences (Brennan et al., 2020). The pandemic may therefore have a long-term impact on the support needs of adults with learning disabilities.

Another example of a context-specific factor discussed by the PRG is the weather. John noted in cycle three that wet weather conditions in particular resulted in

challenges using an electric wheelchair, thus reducing access to everyday tasks and activities, alongside PPA attendance:

On bad rainy days when you couldn't get there, it's true as well you know with the weather I guess, when you've been out and it's been pouring [...] got to make sure you're waterproof, your chair, you know

In these instances, Zoom was viewed as mitigating the effects of poor weather conditions by providing an alternative method of accessing PPA, as Janine discussed: "I have to admit, doing the zoom sessions mean that I don't have to go out when it's really bad weather and it starts snowing" (C3). This demonstrated how digital skills and access to technology may increase the accessibility of activities and programmes for adults with learning disabilities, when external and/or contextual factors reduce access to these services ("on Zoom it breaks down the barriers" – Acrostic poem 1, C3).

#### 6.3.2.2.5 People

The potential for people to have a positive or negative impact on accessibility in a range of contexts was discussed throughout cycle three ("it's people really sometimes isn't it" – John, C3). Negative attitudes, behaviours and assumptions, alongside lack of support from others may be a significant barrier to accessibility for disabled people (Anaby, 2013). John suggested that the negative attitudes of bus drivers had previously prevented him from accessing public transport, thus reducing his access to other activities and learning experiences:

It was the actual bus driver. The busses were the worst one [...] sometimes the bus driver will say the ramp wasn't working. I don't know if it was working or whether the decided to just not bother putting you on the bus

Similarly, Ella's negative experience with a taxi driver resulted in her being removed from the taxi on her way to college:

Ella: You know when I had \*cab company\* they were awful to me when I was having them for college

UR: Oh really, they weren't very nice?

Ella: No. One morning this one taxi driver told me to get out of his taxi

Co-researchers also shared varying experiences with others in the public. In particular, Tracey and John, who often socialised together noted differences in the way in which John was treated as a wheelchair user ("when I go out with John to places, they talk to me rather than John" – Tracey, C3). John shared his experiences of receiving negative reactions from

members of the public, who often made assumptions about him prior to speaking to him: "I have had a few people that's gone by and cringed and I didn't know what they were on about [...] but once I started to talk, people were like, my brain's like him". Tracey and John's experiences are in keeping with Reeve's (2006) discussions of direct psycho-emotional disablism, which includes negative remarks, prejudice and attention (or indeed, lack of attention/avoidance of disabled people), that adults with learning disabilities may experience from others. Reeve (2006) notes that these negative experiences with others may negatively impact disabled people's wellbeing, sense of self and social participation as much as a lack of physical access.

Co-researchers' perceived negative interactions with people (particularly non-disabled people) related to a lack of understanding about learning disability. During the 'in my shoes' activity, the PRG discussed how a lack of understanding from others often resulted in people underestimating them and their capabilities:

John: there's always bits, that people don't recognise, don't realise

UR: Yeah

John: 'Can you do that? oh really?' And you're really surprised sometimes

UR: yeah, so surprising people? Yeah

Ella: the doctors did not know if I was going to... you know I have this learning difficulty

UR: mhm

Ella: the doctors did not know what the future was gonna hold for me

[...]

UR: what would you say to those doctors now, about what your life's like?

Ella: I'd tell them I achieved something

[...]

John: a bit like all of us is that [...] you know when the doctors first say, you know do this and that, would we have done so much. They, they would get a shock now, I think

Additionally, a lack of understanding from others meant that co-researchers were not always provided with the support that they needed in order to engage with daily activities: "I go in a shop sometimes, the customers doesn't, the staff doesn't understand I need time to, I need time to ask them questions [...] sometimes they rush me UR" (Ella, C3). During cycle three, Ella and Tracey shared their desire for others to learn more about them and their experiences as disabled people and therefore increase understanding and awareness of learning disabilities:

Ella: my disability, they just have to ask

UR: you just have to ask? Yeah

Tracey: this is what I put, UR [...] ask me if you need to know something

While people were often considered as a barrier to accessibility in themselves, co-researchers often relied on others to access various activities and services, as Janine noted in cycle three:



“there’s barriers and you have to wait for someone to open the barriers”. Indeed, Liam discussed reliance on others when travelling noting that: “if you book for a train, for someone to meet you, to do the ramp and that, and they don’t turn up, then what do you do?”. This highlights the importance of people in the lives of adults with learning disabilities, and the potential for others to reduce or increase accessibility.

Previous research suggests that the most common facilitators of accessibility include inclusive attitudes (World Health Organisation, 2011) and social support of family and friends. Co-researchers discussed the positive impact of people, or ‘accessible people’ as facilitators of accessible environments and experiences. The concept of accessible people was first discussed by the group in cycle two, when analysing data relating to accessibility and the arts. During this session, co-researchers identified that people could be described as both accessible or not accessible, depending on their characteristics, behaviours and attitudes. The following section provides an overview of the characteristics of accessible people identified by the PRG and investigates the impact of these individuals on accessibility, both within PPA programmes and in everyday life.

#### 6.3.2.2.5.1 Accessible People

Research question one sought to understand ‘what makes a person accessible?’. Co-researchers explored the characteristics of accessible people through discussions about the common values and behaviours of these individuals. Additionally, some co-researchers chose to draw an accessible person (see figures 33 and 41). Co-researchers identified 10 characteristics of accessible people. Table 9 summarises each of these characteristics and provides examples of how these facilitated accessible experiences.

*Table 9: Characteristics of accessible people outline by the PRG*

Characteristic	Description and examples
Helpful and supportive	Accessible people were considered to be willing to help. For example by providing information and/or practical support, such as opening doors (e.g. “If I see someone struggling to get up the ramp, like a Purple Patch member, maybe I will help them” – Ella, C3). Co-researchers suggested that an accessible person might say things like “I can help you any time” (John, C3) and “I can find that out” (Charlie, C3). Accessible people were supportive of co-researchers and often filled official (e.g. carers and parent) and unofficial (e.g. mentor and friend) support roles in the PRG’s lives
Accommodating	Accessible people were described as accommodating (“Somebody who can accommodate you” – John, C3). John described how an accommodating approach to support meant having a good attitude and being flexible to the needs of the individual you are working with: “If they’re accommodating, they’ve got to have a good personal, well, like a good attitude, otherwise if you’re not gonna say ‘I’ll do it later mate’, ah, that means you’re not really bothered” – John, C3.

Person Centred	A person-centred approach to interacting with others was considered to be a key characteristic of accessible people. Co-researchers stated that accessible people focused on them as individuals and were interested in finding out more about the people they met. For example, Leanne suggested that accessible people might ask “about your personality” and “find out what you like, have in common” (Leanne, C3). Accessible people also directed their questions and communication directly to co-researchers as opposed to non-disabled people (e.g. a parent or carer). Accessible people took a person-centred approach to support. For example, by treating co-researchers as individuals as opposed to focusing solely on their disability: “Who doesn’t mind, they’re not bothered, they don’t... Basically, UR, for me, it’s somebody who doesn’t see the chair and just sees me, and just let me do thing things I normally did” – John, C3. This approach to support is in line with previous research concerning Active Support (Mansell & Beadle-Brown, 2012), which promotes a shift in mentality from ‘caring for’ to ‘working with’.
Open-minded	Accessible people were considered to be open-minded in their opinions and approach to support (“They’re up for anything, that would be an accessible person” – John, C3). Co-researchers compared the open-mindedness of accessible people and inaccessible people, noting that the latter were less flexible in their thinking: “Non-accessible people are people who are stuck in their own way” – John, C3.
Authentic	Accessible people were considered by the PRG to be authentic and genuine: “They don’t pretend to be anyone but themselves. Just like us” – Leanne, C3. By being open, honest and matching words and actions, accessible people built trust with co-researchers, which facilitated meaningful relationships between staff and participants: “Trust is important and rewarding” – Accessibility poem 5, C3.
Friendly and welcoming	Co-researchers valued individuals who fostered a welcoming environment, particularly at PPA:  UR: what kind of things do you think an accessible person would do? Ella: Welcome other people into the group  Accessible people created a welcoming atmosphere by being friendly and kind to everyone, talking to participants (“she welcomes us, says good morning” – Ella, C3) and being approachable (“approachable as well” – John, C3).
Respectful	Accessible people were respectful of the PRG’s boundaries (“I didn’t feel I was forced” – John, C3) and balanced providing support and facilitating autonomy and respect (“privacy when we want and need it” – Accessibility poem 5, C3.)
Understanding	In contrast to the lack of understanding from others discussed in section 4.3.3.3, accessible people were considered to be understanding and have a good knowledge of learning disabilities and the access needs of others (“[accessible people] know what it’s like for me, for people, for people like me” – Ella, C3). PPA Staff were considered to have a good understanding of co-researchers’ needs and lived experiences, particularly when compared to staff from services outside of PPA:  Leanne: Purple Patch understands how hard it is, so they know where we’re coming from

	<p>UR: yeah, they understand, they know where you're coming from? Yeah, that's a good point Ella: I have told *programme leader* loads of times about when I go to shops, I say to *programme leader*, I've said it to *programme leader* loads of times UR: mm, yeah definitely, okay Ella: and he understands and *programme leader* understands</p> <p>Understanding of others was also considered to be related to people's ability to be empathetic, which was identified as an important trait of accessible people:</p> <p>UR: What kinds of features or characteristics might an accessible person have? Janine: Empathy</p>
Easy to communicate with	<p>Accessible people were considered to be easy to communicate with, because they were approachable and reassuring and adapted their communication to meet the needs and preferences of co-researchers: "communicating with others [...] communicate it means, um, signing, um, Makaton, body language, all sorts" (Tracey, C3). By using varied approaches to communication, accessible people supported co-researchers to share their views and preferences (e.g. by asking "what do you like?" – Charlie, C3)</p>
Reassuring	<p>Accessible people provided co-researchers with reassurance, particularly in times of stress. For example, Ella shared how the programme leader at PPA reassured her that others in the programme would like her:</p> <p>Ella: I said to *Programme Leader*, I'm not sure if they would like me or not That's what I thought, really, UR UR: Mhmm, and what did *Programme Leader* say? Ella: He said, I bet they will like you UR: Yeah, oh that's good Ella: That was good of *Programme Leader* to... reassuring me.</p> <p>By reassuring others, accessible people supported co-researchers to feel happier and more confident, particularly when trying new things for the first time. Co-researchers also took it upon themselves to reassure others who were new to PPA ("if we get new people when we're back, I might have to reassure them" – Ella, C3).</p>

Co-researchers shared examples of people that they knew in real life who embodied the characteristics of accessible people outlined in table 9. Examples of accessible people included peers (e.g. other PPA participants or friends), members of the emergency services, organisations (such as Citizens Advice and PPA) and PPA staff. Leanne's visualisation of an accessible person (see figure 41) included a drawing of her programme leader at PPA, surrounded by characteristics of this individual which made them accessible. The present study therefore supports previous research which suggests that the characteristics and behaviours of others may improve accessibility for adults with learning disabilities (World Health Organisation, 2011). This highlights the importance of ensuring that those working

within inclusive learning organisations align with the characteristics of accessible people, to ensure that these services are as accessible and inclusive as possible.



Figure 41: Leanne's visual interpretation of an 'accessible person' features a drawing of a staff member at PPA and the words 'happy', 'kind' and 'nice'.

### 6.3.2.3 Accessible and inclusive Learning

Research question four sought to understand what makes learning more or less accessible. Co-researchers described accessible learning as something that everybody can engage with and understand: "I think accessible learning means everybody should be able to understand it" - John, C3. Inaccessible learning was reported to have a negative emotional impact on co-researchers, highlighting the importance of feelings of inclusion within learning environments:

UR: what is learning like when it's not accessible? what is that like?

Leanne: uh, sad

[...]

Ella: ups, feel upset

Leanne: be like, black and white

There were many factors which influenced the co-researchers' experiences of accessible learning. These included learning approaches that have been discussed in previous sections, including theme-based and arts-based learning in section 5.3.2.4. Additionally, the aspects of

accessibility identified above influenced the physical and social accessibility of the learning environment at PPA.

Inclusive learning was considered to social, collaborative and fun. The following sections will discuss two key approaches to learning at PPA which facilitated inclusive learning experiences, and in particular, enhanced belonging and collaboration. These are Communities of Practice (CoP) and active learning techniques.

#### 6.3.2.3.1 PPA as a Community of Practice (CoP)

Inclusive learning at PPA was considered to be a social experience, whereby participants and staff co-created and shared knowledge, through regular interactions. PPA may therefore be considered as a CoP. According to Wenger (1999), CoP consist of three key elements: domain, community and practice. These elements facilitate context-specific, collaborative social learning experiences in a group setting:

**Domain** - PPA participants and staff shared an interest in the arts and a desire to access arts-based LLL. Similarly, co-researchers suggested that the shared identities of participants as adults with learning disabilities (as discussed in section 4.3.3.2.2) contributed to the shared domain and sense of community within PPA programmes.

**Community** - People played an important role in facilitating inclusive learning experiences within the CoP. The community at PPA included participants, staff, support workers and families. Collaborative approaches to learning that took place in person were preferred by co-researchers, highlighting the positive impact of social approaches to learning within PPA programmes:

UR: what does accessible learning mean?

Ella: in person

[...]

MK: why do you think that accessible learning is in person?

ES: we can all learn together

While PPA staff and support workers did not always share identities relating to disability with PPA participants, they were nonetheless considered to be part of the PPA family. Previous research has suggested that power imbalances in CoP may be considered as a limitation of this approach to learning (Roberts, 2006). However, the present study suggests that through reduced sense of hierarchy, familiarity and consistency, acceptance and belonging and having things in common with staff, power became more evenly distributed within the CoP, thus

aiding a more equitable learning environment. Support also played an important role within the PPA CoP. For example, staff provided practical assistance to co-researchers, by providing one-to-one support (“The staff always comes round and help you whenever you’re stuck” – Ella, C3) and checking understanding of key concepts ([staff] asks us if we understand before moving on to the next” – Ella, C3). Similarly, co-researchers supported each other through their direct understanding of the support needs of adults with learning disabilities (“we know how best to support each other” – Liam, C1).

**Practice** - The practice element of PPA related to the PRG’s co-created approaches to learning, including sharing stories (“we share our stories and learn about each other, and other people in the world” – Sam, C1), support, and peer learning (“learning from me, they were learning” – Ella, C3). PPA participants became arts practitioners, who developed and co-produced creative outputs, which were shared with others.

The present study suggests that CoP may support inclusive learning experiences for adults with learning disabilities, by facilitating co-created and collaborative learning opportunities, which are tailored to the diverse needs of the community. Treating learners as equals, while offering tailored support when required fostered a supportive learning community for co-researchers to develop their creative and personal skills. While CoP cannot be specifically ‘created’, Wenger et al. (2002) note that the conditions required for CoP to develop may be influenced by learning organisations. For example, by encouraging collaboration, peer support and feedback. CoP may also enhance inclusive learning opportunities through collaborative approaches to learning, including active learning techniques (Tomkin et al., 2019). Active learning at PPA is discussed further below.

#### 6.3.2.3.2 Active learning at PPA

The approach to learning at PPA utilised active learning techniques, including game-based learning (or gamification), role playing and elements of experiential learning. Active learning suggests that individuals learn better when knowledge is co-created through active involvement in the learning process (Petress, 2008). Group activities at PPA were designed to be collaborative, through activities such as group discussion, problem-solving activities and hands-on activities (such as creative tasks, experiments and sensory activities) in order to aid inclusion.

Game-based learning, whereby games are incorporated into learning activities to aid understanding of a topic, were used to support learning at PPA (“we play games to help us learn what we’re doing” – Leanne, C1). Game-based learning included quizzes and sensory

games, as described by Ella: “I remember playing a game at Purple Patch with objects [...] we did a taste test of different fruit and vegetables” (C3). Games were used to support learning across a range of topics:

Ella: we do play loads of games at Purple Patch

UR: mhm, what kinds of games do you play?

Ella: learning games, like learning about the world, learning where our food comes from and what country it comes from

Additionally, co-researchers reported that games support learning by testing their knowledge of specific subjects (“\*programme leader\* is always testing our knowledge – Ella, C1) and promoting healthy competition (“we all become competitive” – Leanne, C1). This is in keeping with previous research, which suggests that game-based learning can provide learners with opportunities for feedback, thus supporting learning outcomes (Pivec, 2007).

Learning was considered to be a collaborative and social endeavour within the PPA community, with co-researchers’ shaping learning approaches and content by sharing feedback and suggestions. Participant feedback directly influenced learning topics and themes. For example, Ella shared her desire to learn more about penguins: “I want to look at penguins, I want to learn about penguins. I might need to tell \*programme leader\* that”. Additionally, participant feedback regarding inaccessible learning experiences was used to improve the PPA programme, as Tracey discussed:

When I first started it was very hard to learn from every week, but PPA seemed to change it. It took a while, but they got there. I had to leave early because I had a headache because of too much information for me to cope with, so I’m happy with the way it is now

This highlights the importance of collaboration with adults with learning disabilities to ensure that learning environments and content are accessible to diverse learners. Through meaningful feedback from service users, learning programmes may co-create inclusive learning experiences.

#### 6.3.2.4 Dreams vs Reality

As previously discussed in the sections above, often the reality of accessibility for adults with learning disabilities was highly contrasting to a) their ideals concerning accessibility and b) their expectations of accessibility based on the information provided to them. Analysis of research meetings, accessibility photographs and acrostic poems demonstrated that co-researchers’ experiences and perceptions of accessibility could be organised into ‘accessibility dreams’ and the ‘realities of accessibility’.

#### 6.3.2.4.1 Accessibility Dreams

Accessibility dreams captured the co-researchers' ideals relating to accessibility. These ideals could be organised into 'accessibility fantasies' and 'achievable accessibility goals.'

Accessibility fantasies were examples of accessible dreams that were currently not possible in the real world. These accessibility fantasies were often related to spaces and landscapes. For example, John shared "my dream world would be flat" (C3). Additionally, co-researchers discussed the idea of a magic key card, which opens every door to mitigate the challenges associated with locked doors and physically inaccessible spaces. This was included in accessibility poem three as "card access to everywhere" (C3). PPA also featured in the PRG's dream accessible worlds. Tracey described her dream accessible place, which included having everything she needed (including PPA) under one roof, and services specifically for disabled people:

It [dream accessible place] would be a nice building with Purple Patch with your day centre, and then above it, with a ramp, maybe three floors where everybody has disability problems, and you don't have to go anywhere but everything there in once place

While these accessible fantasies may not be achievable exactly as they were described by the group, the PRG's wishes concerning accessibility provide an interesting insight into the ways in which organisations and services may be able to support accessibility. For example, the PRG's wish for a magic key card which provides access to all spaces highlights the importance of easy access within spaces and buildings, and the physical and psychological barriers of locked doors (as discussed previously in section 6.3.2.2.2).

In contrast, achievable accessibility goals were examples of accessible dreams that were theoretically possible in the real world. These goals often related to basic access to services and facilities in everyday life, for example "Ability to move easily" (Accessibility poem 3, C3). and "shops and restaurants would be accessible for people with all disabilities" (Accessibility poem 1, C3). Additionally, co-researchers shared their accessibility goals relating to independence, such as "do whatever you want, without needing to ask" (Accessibility poem 3, C3) and "free to do what you want" (Accessibility poem 2, C3).

Achievable accessibility goals described by the group often represented the bare minimum access required in order for disabled people to be included in society. Under the Social Model of Disability (Oliver & Sapey, 1983), it is society's responsibility to make these accessibility goals a reality, by adapting spaces, activities and learning opportunities to create accessible environments. In other words, these accessibility goals *should* be a reality (and may well be for some disabled people) but were often not for members of the PRG due to a wide range of factors (such as those discussed in section 6.3.2.2). For example, relating to the



goal of accessible shops, Ella noted: “I’ve got a learning difficulty [...] and some shops don’t understand”. In this instance, the goal of accessible shops may be influenced by external factors, such as the location, people and context related to Ella’s experience while shopping. However, individual factors relating to co-researchers’ needs and preferences may also impact the achievability of accessibility goals. Indeed, the achievability of independence as an accessibility goal may differ depending on the co-researchers’ support needs, the level of independence required/desired by the individual, and the activity that they wished to do independently.

#### 6.3.2.4.2 Realities of accessibility

The realities of accessibility in the real world often differed to the expectations and ideals of the PRG. As such, the realities of accessibility often included negative experiences and stories shared by the group concerning a lack of accessible environments and people.

Co-researchers made judgements about accessibility based on their past experiences and the information provided to them. Information included: information from others shared via word of mouth (e.g. hearing about the accessibility of facilities from friends/family), advertised information about the accessibility of a venue, activity or service (e.g. on a website) and information based on co-researchers’ observations about a space or activity (e.g. making assumptions about the accessibility of a spaces or activities based on the outside view of the venue in which these were hosted). In some cases, co-researchers reported discrepancies between the information they received about accessibility (and therefore their expectations) and the realities of accessibility (“these places say that they’re accessible. When it actually comes down to it, they’re not” – Janine, C3). For example, during the accessibility photography task in cycle three, Tracey took a picture of a building with a large ramp at the entrance (see figure 42) indicating that this was an accessible venue (“you’d think it had a bit of access to it” – John, C3). However, a second photo revealed that visitors to the building are immediately greeted by a large staircase leading to the upper floors of the building



Figure 42: Tracey's accessibility photographs depict the contrast between the entrance to a building, versus the inside.

The juxtaposition of these two images communicated contrasting information to co-researchers about the accessibility of the building, as John discussed in cycle three: “you can understand where the ramp goes and then where you get inside it’s like, okay, there’s a ramp and then suddenly, oh dear”. These photographs provide an example of when looks can be deceiving in relation to the accessibility of spaces (“it makes you think its accessible, but inside it’s not” – John, C3). A lack of trust in the accessibility of services and facilities (as discussed in section 6.3.2.1.1) may therefore be due to experiences such as these, where co-researchers were led to believe they were able to access a space or activity based on the information available to them, before realising that it was actually not accessible to them (“It’s gotta be true to what it says” – John, C3). Indeed, co-researchers reported feeling “disappointed” (Ella, C3) when their expectations of accessibility did not align with the reality of their experiences. This demonstrates the importance of co-researchers’ experiences of the accessibility of environments aligning with the way in which they have been advertised.

Unreliable services and facilities were also a common reality for co-researchers. For example, in cycle three John shared his experiences of unreliable/faulty lifts in his accommodation, which resulted in him having to sleep in his chair: “where you ended up is where you stayed you know, you’d end up on the bottom floor, sometimes I had to stay in the lounge all night sleeping in my chair”. This highlights the importance and value of trust in services, facilities and people. Co-researchers trusted that PPA programmes would be accessible to them, and that they would be supported when needed. Trust between co-researchers and PPA therefore meant that co-researchers felt safe to attend programmes, even if the reality of accessibility in the outside world as a contrasting experience.

Similarly, the group recognised that often attempts had been made by organisations or buildings to ensure accessibility, but in reality, the execution of accessibility adaptations were not always successful. For example, John described how a local organisation had built a sloped entry into the building to improve physical access, but had lined the path with gravel, which made it difficult for wheelchair users to access (“gravel paths for chairs aren’t so good” – John, C3). John described these misguided attempts at accessibility as “half-accessible”, whereby the concept itself was accessible, but the execution (in this case, due to the choice of terrain) meant that the environment was not as accessible as intended. This reinforces the importance of consulting disabled people on the accessibility of a space or service, taking into account that since accessibility is a subjective experience, multiple perspectives should be considered to ensure maximum accessibility.

#### 6.3.2.4.3 Purple Patch Arts: Dream or Reality?

Co-researchers naturally compared their experiences of accessibility at PPA to the outside world. This was depicted visually during the in-person analysis session (see section 6.3.1.1), where co-researchers mapped their accessibility dreams and experiences of accessibility realities (see figure 38). Figure 43 below shows that co-researchers organised their experiences of accessibility into four categories:

1. Realities of accessibility in the outside world (i.e., the co-researchers lived experiences of accessibility and/or inaccessibility)
2. Realities of accessibility at PPA (i.e., the co-researchers lived experiences of accessibility and/or inaccessibility of PPA)
3. Accessibility dreams in the outside world (i.e., co-researchers’ accessibility ideals in the outside world)
4. Accessibility dreams at PPA (i.e., co-researchers ideas surrounding their accessibility ideals within PPA programmes)



organisation for adults with learning disabilities, particularly when compared to other environments:

UR: Is it [PPA] more or less accessible than other places?

Leanne: more

Ella: I think more

[...]

UR: what would that be like if everywhere was as accessible as Purple Patch, what would the world be like?

Leanne: It'll make a big difference

Further opportunities for sharing best practice of creating accessible environments would be beneficial in order for organisations to learn from their service users and from each other.

## 6.4 Reflections and Recommendations

Co-researchers' reflections on cycle three resulted in recommendations relating to responsibility and accessibility, online formats and information and accessible research outputs. Unlike cycles one and two, the PRG's reflections from cycle three resulted in an additional data collection stage of the project, in the form of final interviews (discussed below).

### 6.4.1 Whose responsibility is accessibility?

This recommendation was identified by the UR through their independent analysis. Co-researchers identified a range of individuals, organisations and services who were responsible for accessibility, as Tracey, John and Jo discussed in cycle three:

UR: Whose responsibility is it to make things accessible?

Tracey: Purple Patch Arts

UR: Yeah

Tracey: and the place

[...]

Jo: I think everybody's got a responsibility to make it accessible for everybody

[...]

John: or like, um, the councils [...] it's like a big chain isn't it

Factors influencing the accessibility of PPA, and of activities and spaces more broadly, were considered to be external to PPA. For example, inaccessible transport was cited as influencing the accessibility of PPA programmes, and therefore had a negative impact on co-researchers' access to learning opportunities. Indeed, almost all members of the PRG reported negative experiences with the accessibility of transport, regardless of the mode of transport they used. Despite the impact of transport on the perceived accessibility of PPA, issues with transport may be considered as outside of PPA's responsibilities for accessibility, since: a) transport is

not organised by the organisation; b) limited staffing, particularly within smaller organisations, may prevent some organisations from taking responsibility for external factors influencing accessibility; and c) it may be challenging, or in some instances impossible, for organisations like PPA to alter pre-established systems (e.g. the transport system), even when the inaccessibility of these systems influences the overall accessibility of a programme/activity. This therefore raises important questions concerning who is, or should be, responsible for accessibility. For organisations supporting adults with learning disabilities, responsibility for accessibility may extend beyond their programme and/or organisation, into the outside world.

Despite the constraints described above, PPA were often described as supporting with a range of external issues impacting accessibility. For example, during her final interview Ella shared that PPA staff arranged alternative transport for her when her taxi did not arrive: “it [taxi] didn’t turn up, but \*staff member\* was on it, she rang them up”. This highlights the range of responsibilities undertaken by PPA staff, which extend beyond providing inclusive creative learning opportunities to supporting the welfare and overall quality of life of participants.

Alongside providing practical support (when possible), organisations providing learning opportunities or activities for adults with learning disabilities may wish to consider what adaptations they could make as an organisation, to increase the accessibility of the programmes and/or activities they provide. In keeping with the Social Model of Disability (Oliver & Sapey, 1983), co-researchers believed that groups and services should adapt in order to meet the needs of service users, as opposed the individual being at fault or needing to change (“you shouldn’t have to fit in with the group” – John, C3). Although the access needs of participants will vary depending on the type of activities provided and the individual needs of participants, table 10 provides an overview of adaptations that organisations may consider when evaluating the accessibility of their services. Recommended adaptations listed in table 10 below were collated by the UR, based on discussions by the PRG throughout the project, but predominantly from cycle three.

Table 10: Examples of accessibility adaptations that may be considered by organisations supporting adults with learning disabilities

Aspect of access	Potential adaptations
Physical access	<ul style="list-style-type: none"> <li>• Consider the accessibility of any venues based on the individual needs of participants</li> <li>• Clearly advertise the accessibility of any buildings, including: information about entrances and exits (e.g. does the building have automatic doors? Where is the accessible entrance?); information concerning the use of lifts and stairs (including lift dimensions where possible, or clearly stating whether these are wheelchair accessible); locations of changing places and accessible toilets; details about the space within the venue (e.g. how large is the room and/or any corridors required to access the space)</li> <li>• Where possible, share the route that participants will need to take through the venue in advance (this may be particularly important for new participants). Highlight where the main activities will take place in relation to all of the features of the building mentioned above. This could be via a video 'walk through' or accessible floorplan</li> <li>• Make sure the venue has clear signage to key spaces participants may need to access</li> <li>• Share clear safety information concerning accessible emergency exits</li> <li>• Where possible, consult with participants about the accessibility of venues, as they may identify additional aspects of accessibility that need to be addressed</li> </ul>
Transport	<ul style="list-style-type: none"> <li>• Where possible, choose programme locations/venues which are accessible via multiple modes of transport</li> <li>• Consider bus and train timetables in the local area and how these align with the start time of programmes/activities</li> <li>• Creative learning organisations may wish to consider incorporating learning around travel and transport to increase participants' confidence around travel</li> <li>• Share information with participants in advance concerning accessible travel routes, directions to venues, availability of disabled parking</li> <li>• Consider offering a virtual programme/activities or hybrid attendance options for those who are unable to travel to a venue (discussed further in section 6.3.3.2)</li> </ul>
Cost	<ul style="list-style-type: none"> <li>• Consider whether support may be made available to subsidise and/or cover the cost of attendance (where applicable)</li> </ul>
Information, Resources and Activities	<ul style="list-style-type: none"> <li>• Consider sharing information and resources via a range of methods (e.g. written text, videos, easy read documents)</li> <li>• Consider co-creating resources with adults with learning disabilities to ensure they are accessible</li> <li>• Design activities/ learning approaches which facilitate choice for adults with learning disabilities and utilise a range of learning approaches and resources</li> </ul>

#### 6.4.2 Continuation of Zoom sessions

Co-researchers shared a desire for Zoom session to continue alongside in-person delivery of the PPA programme ("I think they should use Zoom, if the Covid comes back or say if it's a bad day with travelling, people could use the zoom on another basis as well" – John, C3).

While co-researchers preferred physical attendance at PPA, virtual attendance was viewed as useful alternative method of accessing PPA sessions when co-researchers were not able to attend in person (e.g. due to adverse weather or illness), or to mitigate physical barriers to

attendance (e.g. issues with transport; “You might have people that might struggle to get there cos they’ve not having the transport and stuff [...] at least now if they do a blended offer, they’ve got an option to still zoom – Liam, C3). The continuation of Zoom sessions, particularly when external factors prevented participation, was therefore recommended to support attendance at PPA programmes.

#### 6.4.3 Website accessibility and information

Research question five aimed to investigate ‘how accessible is the information that PPA share?’. During action session one, the PRG evaluated the accessibility of information shared by PPA, including the PPA website. Discussion about the PPA website in particular revealed that co-researchers did not feel that the information shared on this page was for them, and many co-researchers had never visited the webpage (“I’ve never seen the website I never got to know there was a website for Purple Patch” – Ella, C3). The group identified additional information which could be included on this website in order to make it more accessible and useful for them. For example, co-researchers recommended that additional information about the accessibility of venues should be included on the website:

John: on the actual website, you know, they don’t actually tell you about the accessible buildings, do they?

Tracey: no, they don’t

John: and what is accessible and what is not

Additionally, co-researchers felt that further information was needed to clarify that participants could choose to bring their support worker/carer with them to programmes or attend independently:

Tracey: and there’s no mention that you can go on your own or with a carer

UR: mhm, okay

Tracey: is that important or not?

John: um, well yeah, I suppose that information would be good to know that you know you can bring your own support if needed

As previously discussed, the PRG reported that a lack of information about accessibility caused anxiety around attendance at new programmes/venues, and occasionally resulted in non-attendance. The PRG’s recommendation to provide further information about accessibility and support at PPA was designed to reassure prospective participants so that they felt safe and comfortable to attend a PPA session. The importance of providing up to date, clear information concerning accessibility to adults with learning disabilities, so that



they have a clear understanding of what to expect with regards to accessibility should not be underestimated.

#### 6.4.4 Research comic book

According to Johnson and Walmsley (2003), an important goal of inclusive research is that “reports must be accessible to people with learning disabilities” (p.64). During cycle three of the project, co-researchers recognised that very few research outputs were accessible to them (“They are not easily accessible [publications]” – Leanne, C3). Academic publications are traditionally text-based, may include specialist language/jargon, and may be challenging to access for those outside of academia. These features of traditional publications often exclude adults with learning disabilities from engaging with research outputs, even when they have been directly involved as co-researchers and/or the research is designed for the benefit of disabled people. After discussions with the PRG about the inaccessibility of research outputs, including the thesis, the group discussed their ideas regarding the accessible dissemination of the research. These discussions led to the suggestion of a research comic:

Tracey: what about a comic?

UR: a comic? That’s a good idea Tracey [...] I think that’s a really cool idea

Liam: yeah

Sam: a reading board, when you’re reading

UR: yeah, with pictures and writing yeah

[...]

Tracey: and then we could publish it as a separate book

UR: yeah, we could share it with other people couldn’t we, yeah

Liam: I reckon that would just be really fun to share

UR: yeah

John: unusual as well

The goal of the comic was therefore to co-create and disseminate an accessible research output, which was suitable for both adults with learning disabilities and non-disabled people. Co-researchers shared a desire to see more adults with learning disabilities as researchers (“I wish there were other researchers with learning disabilities” – Ella, C3). One of the key aims of the comic book was therefore to increase the representation of disabled people in research roles and challenge common assumptions about learning disability and who can be a researcher: “It would prove to people we could do it [...] that if you have a disability you could do a comic and you can do research” (John, C3).

A comic book was chosen as the format for this research output as it was considered to be an accessible method of sharing information, as John described: “It is [the comic] more accessible and fun so that they can understand it more easier [sic], because not everyone has

accessible books and magazines”. Indeed, comic books are recognised as an accessible and engaging way to tell stories (Whalen et al., 2016). Comic books have previously been used as an engaging, arts-based and accessible format for the dissemination of research across a range of disciplines (Pleace, 2015; Priego, 2016; Vigurs et al., 2016). Due to their emphasis on visual communication, comics can be an accessible resource for more “visually orientated readers” (Polgreen, 2014, p.12) and may therefore support understanding of complex information (Lewis & Coles-Kemp, 2014).

During the final stages of cycle three, co-researchers supported the UR to write a funding application to support the co-creation, illustration and dissemination of a research comic. This process provided further opportunities for the PRG’s active involvement in a new aspect of research and facilitated conversations about research funding and dissemination. The group received news that their funding application to the Society for Education, Music and Psychology Research was successful in July 2022. The group began co-creating the comic book during the concluding phase of the project (see section 7.2.2.1) and it is expected to be published in 2024. Two pilot pages from the comic are included in appendix I.



*Figure 44: The PRG as their comic book characters, illustrated by Molly Pukes*

#### 6.4.5 Final interviews

During cycle three of the research, co-researchers planned a series of final interviews. The idea for these interviews had been discussed throughout the project, as a way of capturing

the elements of the co-researchers' experiences at PPA that were not directly addressed in cycles one, two or three. In line with the PAR approach of this project, co-researchers were asked to indicate whether they would like to interview someone, be interviewed by someone or both, by responding to a poll on the PRG Facebook group. Four co-researchers chose to be involved in the final interviews. The UR paired co-researchers based on their preferences and availability. Additionally, Tracey requested to interview the UR and due to a lack of availability from other co-researchers, Ella was interviewed by the UR. Table 11 shows the interview pairings. All interviews took place online via Zoom and lasted between 23 minutes to 1 hour. The UR researcher attended all interviews to support co-researchers when required.

*Table 11: Interview pairings for final interviews*

<b>Interviewer</b>	<b>Interviewee</b>
Ella (with support from her mum)	John
John	Tracey
Tracey	UR
John	Sam (with support from Janine)
UR	Ella

Interview questions were written collaboratively by the group during an interview planning session in the concluding phase of the project (see chapter 7). These interview questions were used to create a semi-structured interview plan, which was split into two sections. Questions in section one pertained to the co-researchers' experiences as a participant at PPA, including:

- What made you start going to PPA?
- What does PPA mean to you?
- What is your PPA day like?
- What motivated you to come to PPA during the pandemic and now?
- How would you describe PPA in three words?

Questions in section two were used to support co-researchers to reflect on their experience in the project as researchers, including:

- What has your personal journey been in the research?
- How did you feel at the start, middle and end of the research?
- What, if anything, have you learned about yourself by being a researcher?
- What have you enjoyed the most and least about being a researcher?
- What are your plans after the research? /what would you like to do next?

Interview questions were shared with all interviewers via the Facebook group. Co-researchers used this interview plan as a rough structure for their interviews but were also encouraged to add their own additional questions, depending on their interests. For example, Ella chose to add additional questions concerning John's experiences in the pandemic. After writing the interview questions, the UR provided informal training on how to conduct an interview. Since this was the co-researchers' first experience of interviewing others, it was important to ensure they felt comfortable and prepared. Training included: advice on starting an interview (including ethical considerations such as checking for consent and informing participants that they can stop the interview at any time), *do's* and *don'ts* of conducting an interview (e.g. *do* give the person time to answer your question and *don't* interrupt the person while they are speaking), and tips for ending the interview (e.g. asking the person if they have anything else they would like to share and thanking them for their time). Key points were shared with the co-researchers via a PowerPoint presentation. Opportunities to practice elements of the interview process were built into this research session, to support co-researchers' interview preparation.

All interviews were recorded and transcribed verbatim. Interviews were analysed by the UR in line with the methods described in section 3.5.2.2. Themes relating to the co-researchers experiences at PPA were combined with the results from cycles 1-3 according to their content. Additionally, analyses of interview transcripts informed understanding of the overall outcomes of attendance at PPA, alongside the underpinning mechanisms supporting these outcomes (reported in chapter 8). Themes relating to the co-researchers' experiences of being a researcher and the outcomes of engagement with PAR for co-researchers are reported in section chapter 9.

Final interviews were the last formal activity the PRG led in this project and theoretically signalled the ending of the research. However, ending the research became an important stage of the project in itself, involving additional activities, new considerations and questions that the PRG were actively involved with. The following section details the process of ending the present study, and the role of co-researchers in this stage of the project.

## 7 Ending the project

While previous literature has specifically discussed the process of setting up a PAR project (Herr & Anderson, 2005; Kelly, 2005; Pain et al., 2019) fewer papers have reviewed the process of ending a PAR project. Indeed, Northway (2000b) notes that the ends of participatory projects are a “stage in the research process which needs to be given much more emphasis than has previously been the case” (p.27). Tuckman and Jensen’s (1977) model of small group development includes ‘adjourning’ as a key stage in a group’s life cycle. The nature in which a PAR project ends can therefore be considered as equally important to the way it begins, particularly when considering the level of involvement of co-researchers, who are often considered to be vulnerable, in the research process. The following sections will outline the UR’s plans concerning the end of the present study versus the reality of ending the project, alongside the practical, social and ethical factors, which influenced the approach to ending the present study.

### 7.1 Planning the end of a PAR project: what is possible?

When planning the present study, the UR was aware that ending a PAR project required a different approach and process to ending a non-participatory project. PAR often involves long-term contact with co-researchers and may provide a valued social and learning experience for adults with learning disabilities (Nind, 2014b). PAR therefore has the potential to become a valued part of co-researchers’ lives. Indeed, when reflecting on the role of PAR projects in the lives of adults with learning disabilities, Tilly et al. (2015) note that the research group became “something more than simply ‘research’; it was an important part of their life” (p.124). Therefore, the most important consideration when ending the project was to support co-researchers’ transition from regular contact with the research group, to less frequent contact and ultimately, the end of the research.

This transition to the concluding phase of the project required a shift in role and focus, both for the UR and the PRG, from active data collection and analysis, to reflection on the project as a whole and planning research outputs. These activities required less regular contact with the group. An in-person research session and celebration (see section 6.3.1.1) was planned as a final research session, which signalled the end of data collection and a transition into the concluding stages of the research. To avoid a sudden end to the project, the UR planned that after the in-person meeting, sessions would gradually become less frequent and eventually stop altogether. As such, co-researchers were initially informed that their involvement in the project would last approximately 12 months. The UR anticipated that research sessions during the concluding phase would focus on data validation (e.g. sharing

any analyses undertaken solely by the UR and/or by other members of the group) and consulting on the write-up of the research to ensure that co-researchers felt their experiences were being accurately represented.

However, in reality, ending the project was a difficult and messy process, which at the time of writing is still ongoing. Co-researchers have therefore been involved in the project for over double the initial expected time period. While previous literature highlights the importance of planning for the end of a PAR project (Northway, 2000b), it was not possible to fully plan for this stage of the project before having undertaken research with the PRG. The UR was aware that the co-researchers' experiences with the research (such as, their level of enjoyment of the project), the nature of PRG's relationships with each other, and the co-researchers' opinions and preferences concerning the way in which the project should end, would impact the concluding phase. The concluding phase therefore required the UR to adapt the planned approach in real-time to balance the needs and preferences of the PRG alongside factors such as time and logistics, shifting roles and responsibilities, and ethical considerations. These factors, which influenced the nature of the co-researchers' involvement in this concluding phase and therefore the approach taken to ending the research, will now be discussed.

#### 7.1.1 Time and logistics

PAR requires a considerable time commitment from both the UR and co-researchers (Baum et al., 2006). Since the PRG had already dedicated a year of their time to the research, it was initially unknown whether co-researchers would want to continue to dedicate their time to the project after cycle three. Additionally, the project began during the pandemic when social contact was limited and many activities that co-researchers usually attended were cancelled. Despite this, a key challenge of this project was finding time for the group to meet. The UR was therefore unsure whether the PRG would want to and/or be able to continue their involvement in the project beyond cycle three, since this stage in the research coincided with the end of national lockdowns and the re-opening of the PRG's usual programmes. It was therefore important that the concluding phase of the research provided a balance between a) respecting the PRG's time and ensuring that they felt that any further participation in the project was entirely voluntary and b) providing enough contact with the group to support co-researchers to navigate the end of the project (particularly taking in to account the ethical considerations discussed in section 7.1.3).

### 7.1.2 Shifting roles and responsibilities

Due to the structural constraints of doctoral research, the concluding phase of the project inevitably provided fewer opportunities for the involvement of co-researchers as equal partners in the project. For example, writing up the thesis was not only an inaccessible activity for co-researchers, but also one that they were not able to be actively involved with, since the thesis must be written by the UR. Therefore, during the concluding phase the PRG's role shifted from that of a research collaborator, to a research consultant on aspects of the thesis write-up.

It was initially unclear how the co-researchers would respond to this shift in their pre-established role, particularly since a key goal of the project was to support co-researchers to take ownership and control over the project from start to finish. Explaining that some aspects of the research could not be fully collaborative due to the nature of doctoral research felt uncomfortable and at odds with the goals of the project and of PAR. However, this was mitigated by the decision to co-create an accessible research output in the form of a comic book (discussed further in section 6.3.3.4). Co-writing the comic book influenced the frequency and type of research sessions included in the concluding phase of the project. Since the comic book was an accessible output, co-researchers were encouraged to take a leadership role in its creation. The comic book therefore provided an additional but related project for co-researchers to engage with, meaning that the PRG's change in responsibilities were related to a new and positive experience, as opposed to the ending of the research.

### 7.1.3 Ethical considerations

Previous literature has noted a number of ethical implications of ending PAR, including: the impact on co-researchers' relationships and social networks, loss of 'researcher' identity and the removal of a learning/personal development opportunity. These ethical considerations will now be discussed in turn in the context of the present study, supported by quotations from co-researchers and the UR's written reflections from cycle three of the project.

#### 7.1.3.1 Impact of co-researchers' relationships and support networks

One major consideration of ending a PAR project is the nature of the relationship between the UR and co-researchers, and the impact of the ending of this relationship for all parties. PAR projects require researchers to collaborate and build trusting relationships with communities that may be considered to be 'vulnerable', often over an extended period of time (Johnson & Walmsley, 2003). During the course of the research, co-researchers may therefore form close interpersonal relationships with others in group (Atkinson, 1993; Tilly et al., 2015). In the present study, co-researchers dedicated a considerable amount of time to

the project and in doing so, developed friendships and strong working relationships with other co-researchers, as Ella discussed in cycle three:

UR: and what do you think about research has helped your independence skills?  
Ella: making new friends

As co-researchers attended different PPA programmes across Yorkshire, research sessions were often the only place where this particular community could meet. Additionally, unlike other approaches to research, co-researchers in PAR projects often build close relationships with the UR and may even consider them as a friend (Chalachanová, 2020; discussed further in section 10.5). This was certainly the case in the present study, as co-researchers shared their hopes around retaining contact with the UR, alongside meeting and working together in the future (“I hope we can meet in person every so often, if not, we’ll have to do Zoom” – Tracey, C3). Indeed, previous research suggests that the end of a PAR project may be viewed negatively by co-researchers as it symbolises the potential loss of relationships associated with research (Atkinson, 1993). This presents additional ethical challenges and responsibilities for participatory researchers, who must support co-researchers to manage the reduced contact associated with ending a project. This may require extending contact with co-researchers beyond the original project end date, as the UR noted in their reflections at the end of cycle three:

While it may be standard procedure for researchers to end relationships with participants as soon as their involvement in the project is over, the same cannot be said for PAR, where a lot of time is invested in building relationships and trust with co-researchers and between co-researchers over a significant period of time

Indeed, Northway states that due to the nature of the relationships developed within PAR projects, “it is essential that researchers are prepared to maintain long-term contact with their co-researchers if this is desired” (Northway, 2000b, p.33)

A gradual reduction in contact with the group was therefore required, as the PRG became an important support network for co-researchers. Co-researchers shared personal and often challenging aspects of their lives with the group and research sessions therefore provided a space for the PRG to give and receive support from their peers. It is therefore essential to consider that ending a PAR project may also remove co-researchers’ access to valued relationships and an important support network (we’ll miss each other all so much when we have to end this research journey – Tracey, C3). An important ethical consideration when ending a PAR project is therefore to consider the support needs of co-researchers during this transition period and ensure that they have access to alternative support



networks.

As a non-disabled researcher who was unknown to the members of the PRG, a key aspect of the UR's role, particularly in cycle one, was to earn their place within the community by developing strong working relationships with co-researchers and PPA. Due to the co-researchers' perceptions of non-disabled people, which were often based on negative past experiences (see section 4.3.4), it was particularly important to develop trusting relationships with the group in order to work together effectively ("I never like new things, especially new people who are 'normal', which is you" – Tracey). Indeed, Bigby et al. (2014) cite 'trusting relationships' as a core component of collaboration in inclusive research. A key goal of this project was to support adults with learning disabilities to have ownership over research that concerns them and in doing so, challenge ideas around who can be a researcher. Since the present study was the co-researchers' first experience of active participation in research, the UR recognised that their experiences in this project may shape their future involvement in research. A key ethical consideration was therefore to ensure that the project ended positively, so that co-researchers felt valued for their contributions and remained open to engaging with research (either with the UR or with other researchers/organisations) in the future.

#### 7.1.3.2 Loss of the role of researcher

For all but one of the co-researchers<sup>11</sup>, the end of this project symbolised the end of the PRG's current role as researchers and subsequently the removal of the "valued status" of a 'researcher' (Northway, 2000b, p.30). As previously discussed, being a researcher was a valued and desired role, to which co-researchers were very committed. Indeed, Tracey compared participating in the research to her previous experiences of employment, highlighting the seriousness with which co-researchers considered their role in the project. During cycle three with the end of the project imminent, members of the PRG began to enquire about the potential to extend their role as researchers by participating in future research projects ("I'd like to do something else" – John, C3). An important ethical consideration was therefore how to support co-researchers with the potential loss of the role of researcher. This was particularly challenging since it may not be possible to signpost researchers with learning disabilities to additional opportunities to actively engage with research, due to limited widespread opportunities for this (discussed further in section 10.6).

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<sup>11</sup> As previously discussed in, during the in-person research session Liam shared that he was going to continue his role as a researcher in an unrelated research project.

### 7.1.3.3 Removal of a learning/personal development opportunity

Nind (2014a) notes that PAR projects can provide a platform for learning and personal development for co-researchers. Indeed, the PRG became a community of practice in itself, with co-researchers self-reporting the development of research-specific skills alongside areas of personal growth (see chapter 9). Adults with learning disabilities often have fewer opportunities to access learning experiences than their non-disabled peers, since common sites of learning (such as adult courses or learning associated with employment) are often inaccessible to them. In particular, the opportunity to develop research skills is most commonly associated with higher education institutions, which are widely considered to be inaccessible to adults with learning disabilities. It is therefore important to consider that ending PAR may also remove access to a valued learning opportunity for co-researchers. To mitigate this, previous research has suggested signposting co-researchers to other opportunities.

## 7.2 Ending a PAR project with sensitivity

Due to a combination of the factors discussed above, co-researchers are often reluctant for PAR projects to end (Northway, 2000b; Tilly et al., 2015). Indeed, during cycle three members of the PRG shared their desire for the research to continue (“I’m afraid I don’t want it to end” – Tracey, C3). Previous research has noted the ethical implications (Northway, 2000b) and ‘messiness’ associated with ending PAR (Cook, 2009). However, there is a lack of transparency around how PAR projects have practically addressed these challenges when ending the research (Smith et al., 2022). As a key stage of the research process, the following sections will outline the four key ways that the present study sought to mitigate the challenges associated with ending a PAR project during the ‘concluding’ phase. These are: information and managing expectations; ending the project gradually; reflection and celebration and continued support. The following sections intend to provide a snapshot of the ongoing process of ending this PAR project and the ways this process sought to mitigate challenges outlined above. Reflections on the successes and challenges of each of these steps to concluding the project are included in each section.

### 7.2.1 Information and managing expectations

The process of ending PAR should ideally begin when the project does, with the UR providing as much information as possible regarding when and how the project will end to co-researchers. Providing time scales for each stage of the project (where possible) may be helpful to support co-researchers’ involvement in research. Timelines produced for the present study supported co-researchers to manage their time and schedules effectively and

ensured that the group knew what to expect from each stage of the project. However, as previously discussed, the collaborative nature of participatory research means that it is not always possible to provide information about all aspects of the project in advance, since decisions are made collaboratively by the group. It is therefore important to take a flexible and adaptable approach, particularly when ending PAR. The present study sought to provide co-researchers with as much information as possible to support their engagement and manage expectations around the project, while allowing space for collaborative decision making. The PRG were informed that meetings could continue, albeit less frequently and the group discussed what they envisaged their engagement with the project during this stage would involve.

However, it is worth considering that co-researchers and/or the UR may not agree on how and when the project should end. Northway (2000b) notes the importance of understanding the level of commitment both expected and desired, by everyone involved in PAR. In the present study, the end of the research highlighted a difference in the level of contact both expected and desired by different members of the PRG (including the UR). While some co-researchers were happy to end their involvement in the project, others expressed a desire to continue to meet regularly (“might meet each other once a month on zoom after this, but it won’t be the same” – Tracey, C3). A range of factors may therefore impact co-researchers’ desire to end or continue their engagement in a project, including personal interests, enjoyment of research and availability.

In the present study, transparency around the practical considerations of the research process (such as funding and project deadlines) was required in order to facilitate honest conversations about ending the project. For example, co-researchers were aware that the time restrictions of doctoral research meant there was a time restriction imposed on the PRG’s research meetings. Addressing challenging and particularly uncomfortable aspects of research may also lead to additional opportunities. For example, the idea for the research comic was conceived by a co-researcher after a discussion about the inaccessibility of most research outputs (“they [publications] are not accessible” - Leanne). Open conversations with the group about research dissemination therefore increased the PRG’s understanding of important aspects of research and supported them to engage with new areas of the research process.

Alongside information concerning the process of ending the project, previous research highlights the importance of signposting co-researchers to additional opportunities they may be interested in. Indeed, research by VIPER (2013) notes that “When a project ends, make sure you prepare the young people for the end and do exit interviews which look at

possible other opportunities for the young people.” (p.5) While the UR was able to signpost co-researchers to additional learning and development opportunities, such as the buddy training scheme and steering group at PPA, signposting to additional research opportunities was more challenging due to a) a lack of opportunities for adults with learning disabilities to be actively involved with research (see section 10.6) and b) limited pre-existing networks to connect researchers with LDs to projects/organisations conducting inclusive research. The development of such networks would be beneficial to support adults with learning disabilities’ long-term involvement in research.

### 7.2.2 Ending the project gradually and collaboratively

The concluding phase of the present study was designed to facilitate a gradual end to the project. Co-researchers reported positive outcomes of engagement with the research on their social networks, personal development and research identity (see chapter 9). Therefore, ending the project gradually was intended to avoid the sudden removal of research sessions, especially given the positive impact on the co-researchers’ wellbeing observed throughout the research.

An important factor underpinning the UR’s approach to the concluding phase of the research was understanding and responding to the needs and preferences of the group. As Johnson and Walmsley (2003) state, a key characteristic of inclusive research is that “disabled people should be involved in the process of doing the research and should be able to exert some control over process and outcomes” (p.64). The subjective nature of PAR projects means that the process of ending of participatory research will inevitably differ between projects, depending on the preferences of the individuals involved. It was therefore important to continue to involve the PRG as much as possible in decisions relating to the nature and frequency of contact within the concluding phase.

As previously discussed, perspectives on how the project should (or in some cases, should not) end differed between members of the PRG. In the present study, like other PAR projects (Atkinson, 1993; Northway, 2000b), some co-researchers expressed a desire to continue their involvement in the project, and to continue conducting research more broadly. This resulted in some tensions between the time constraints of the PhD and the UR’s ability to continue to allocate time for regular research sessions during the concluding phase, and the desire of some co-researchers to continue research sessions as normal. It was therefore helpful to work with the group to discuss the nature of the meetings during the concluding phase, while thinking realistically about factors such as the co-researchers’/UR’s time, schedules, funding and the overall timescale of the project. The content and regularity of these sessions are discussed further in the following section.

### 7.2.2.1 Content of concluding sessions

Concluding research sessions took place on an ad-hoc basis between October 2022 to July 2023. While these sessions are currently ongoing, meetings with the PRG became less regular as the PhD came to end. Co-researchers were informed that they could stop attending sessions during the concluding phase at any time. Despite this, only one co-researcher did not attend any meetings during the concluding phase.

Topics discussed in these sessions included validating data/conceptualisations of data analysed by the UR. For example, by providing feedback on the Purple Patch Potion discussed in chapter 8. Feedback provided by the PRG during these sessions ensured that the PRG's views continued to inform the concluding phase of the project, during a stage where the UR was solely responsible for representing the PRG's research and their experiences. Concluding research sessions were also used to discuss the dissemination of the research. This included planning and co-writing the research comic book (appendix I) through a series of meetings specifically designed to co-create this accessible research output. Additionally, the PRG planned and participated in other research dissemination activities during the concluding phase, such as meeting with the University of Leeds' Music Psychology Group to share their research in February 2023.

### 7.2.3 Reflection and Celebration

A key stage of ending the project was reflecting on and formally recognising the PRG's efforts and achievements. Formally recognising the time and commitment the group had shown to the project reaffirmed how valuable the PRG's contributions were. This is in keeping with previous research, which suggests that celebrating the achievements of co-researchers is an essential stage of successful co-production (VIPER, 2013).

Reflection and celebration were integrated within the concluding stages of the project but were particularly important during the in-person research day in cycle three. During this session, co-researchers were encouraged to reflect on their roles in the project and to identify members of the group that they were proud of and why. This supported the group to recognise and celebrate their own achievements, the achievements of others and to receive positive feedback from other members of the group and PPA staff. All co-researchers were awarded with a certificate for their dedicated and hard work throughout the project. The in-person session symbolised the beginning of the concluding phase. While some co-researchers were apprehensive about the approaching end of the project, the concluding phase of the cycle was presented as an exciting stage in the project, with new opportunities and activities for the group to be involved in. Additionally, since some members of the group

had already indicated that they would prefer to continue with the research, there was a risk that ending the project may be viewed negatively by the group. By celebrating the co-researchers' role in the project, the UR aimed to retain a positive experience of research and in doing so reduce the potential for negative emotions associated with ending the project.

#### 7.2.4 Continued Support

As previously discussed, the PRG became a valued support network for the PRG (see section 7.1.3.1). Although Zoom sessions were focused on the research itself, co-researchers often shared their good and bad news with the group, from bereavement, illness and stress to friendships, expanding families and holidays. The UR provided practical and emotional support to co-researchers throughout the project, during and outside of research sessions (see section 10.5). Having built trusting relationships with co-researchers, the UR became somebody that the PRG felt they could confide in. This was particularly evident during the pandemic, when co-researchers did not have access to spaces and communities who may ordinarily provide support (e.g. inclusive programmes, family and friends).

To maintain the support network developed throughout the project, the UR continued to have contact with the PRG throughout the concluding phase, both within research sessions and via the Facebook group. The PRG continued to share their news on the Facebook group, both relating to the project and their personal lives. The PRG Facebook group will remain open for as long as needed to provide a place for co-researchers to continue to communicate and maintain their relationships, with or without the involvement of the UR. At the time of writing the UR has also maintained contact with the group about ongoing projects the PRG are involved with, such as the co-creation of the comic book.

Additionally, throughout the concluding phase the UR continued to work closely with PPA, who provided welfare and practical support to ensure that co-researchers were supported through and beyond the end of the project. The present study highlights the importance of a strong partnership and communication with community partners to ensure that co-researchers are provided with the support they need. This is particularly important when URs must inevitably dedicate less time to a project due to project deadlines, and therefore have less capacity to provide support to co-researchers. PPA arranged check-in calls with co-researchers (when required), and also encouraged the PRG to access new opportunities to use their research skills, such as through involvement in the PPA steering group.

This chapter highlights the long-term ethical responsibilities of participatory researchers to ensure that ending the project does not result in negative outcomes or risk to co-researchers. While this stage of the research is often not reported fully, the present study

argues that the importance of the concluding phase of PAR should not be underestimated or understated. Future research should clearly outline the process of ending PAR projects, to support understanding of best practice with regards to managing this crucial stage in the project. Further reflections on the implications of involvement in PAR for co-researchers and URs will be discussed in chapters 9 and 10 respectively.

## 8 Outcomes of Engagement with PPA: A Purple Patch Potion

The first aim of the present study was to identify the outcomes of participation in PPA from the perspective of participants. Combined analyses conducted by the UR and PRG (see section 3.5 for further details) revealed five overarching outcomes of engagement with inclusive learning at PPA: 'Increased Social Network', 'Enhanced Wellbeing', 'Inclusive Learning Experiences', 'Personal Growth' and 'Opportunities for Advocacy'. These outcomes were presented to (and validated by) the PRG in the form of a 'Purple Patch Potion' (see figure 45). As discussed in section 3.5.2.2, the content of the Purple Patch Potion derived from the combined analyses undertaken by the PRG and UR of all data from across all three cycles of research. A creative easy read output was designed by the UR to provide an accessible overview of the co-researchers' experiences at PPA, and the outcomes they reported throughout the project. Within the context of the potion, the outcomes of engagement with PPA may be considered as the effects of taking the potion. Taking the potion (attending PPA) did not guarantee that participants would experience all outcomes. Since all participants brought their own unique experiences, preferences and needs to PPA programmes, co-researchers' experiences of these outcomes were individualised and subjective. Some outcomes were reported more frequently than others, and the impact of these outcomes on co-researchers varied depending on the individual. Additionally, while reported individually within this thesis, outcomes of PPA were rarely experienced in isolation, and were often related to and influenced each other. For example, co-researchers who reported an increased social network may also report increased wellbeing as a result.

While the outcomes of attendance at PPA provided an insight into the effects of the PPA Potion, they do not tell us the ingredients of the potion or how it is created. Previous research suggests that the evaluation of participants' experiences within a programme frequently focus on the outcomes or effects of engagement with programmes, with less attention paid to how and why these outcomes are achieved (Pawson and Tilley, 1997). This is often referred to as the 'black box problem' (Astbury & Leeuw, 2010). To address this, the opposite approach, known as 'white box' or 'clear box' evaluation, aims to investigate the inner mechanisms, features and contexts of a programme, which contribute to the identified outcomes (Scriven, 1994). Investigation of the relationship between the outcomes of engagement with PPA (the effects of the potion) and the underlying mechanisms (ingredients and instructions) can therefore support understanding of how inclusive learning experiences were facilitated at PPA. Overall, the PPA Potion seeks to explain what occurs within PPA (ingredients/instructions), what this has achieved (outcomes) and why (the relationship between the two). The following section will briefly introduce each identified outcome of



engagement with PPA in turn, drawing on examples from all three cycles of research to demonstrate the impact of these outcomes in the lives of co-researchers. Section 8.2 will then introduce the underlying mechanisms which facilitated these outcomes.

### The Purple Patch Potion

#### Ingredients



A pinch of *people (accessible ones are best)*





A sprinkle of the *arts and variety*



A splash of *accessibility and support*



A dollop of *different ways to learn*



A teaspoon of *trust*



*Freedom* carefully combined with *routine*



The feeling that you are *listened to and valued*

### The Purple Patch Potion

#### Instructions

Brew your potion in a *safe space*



Creating this potion should be a *challenge, but not impossible! You can ask for help if you need it.*



Don't forget to *celebrate* when you are done!



**CAUTION!**

Taking this potion may mean you...

-  Learn about the real world
-  Make new friends and connections
-  Feel good
-  Change in yourself and learn new skills
-  Want to show/tell others what you can do!

Figure 45: The Purple Patch Potion

## 8.1 Increased Social Connections

One of the most commonly reported outcomes of engagement with the PPA programme was increased opportunities for social connections. Attendance at PPA was motivated by and provided additional opportunities for co-researchers to meet new people, form friendships and build their personal support network, thus reducing loneliness and social isolation (“it’s helped us to interact with people a bit more. I was just a bit of a loner sometimes, but it’s good to see people and to meet them on a regular basis” – John, C1). As previously discussed, people with learning disabilities often have significantly smaller social networks, and may therefore have reduced access to support systems (Taheri et al., 2016). This was particularly evident during the Covid-19 pandemic, when many adults with learning disabilities experienced extended periods of social isolation. Attendance at PPA provided additional opportunities for co-researchers to receive and provide support to others, developing larger social networks, which became important sources of support in their lives.

While an increase in the size of co-researchers' social networks was reported as a valued outcome of attendance at PPA; it was the nature of these relationships that was considered to be particularly important to the PRG. Cycle one highlighted the positive impact of *meaningful* social connections in the lives of PPA participants, and the range of personal, instructional and support roles that staff and participants filled in their lives. Additionally, a key experience shared by all co-researchers was the sense of belonging to the Purple Patch family (defined in section 4.3.3.2). This term was used independently by all co-researchers across all three cycles of research and provides an important insight into the characteristics of the relationships developed within PPA programmes. The Purple Patch Family represented acceptance in a social group and the opportunity for consistent, long-term support and friendship ("Purple Patch Arts is a family that we belong to" – Accessibility poem, C3). This was particularly valued given the negative experiences of bullying and a lack of acceptance from others reported by the PRG.

Cycle three reported that some characteristics of people were particularly valued by the PRG. Individuals who demonstrated these characteristics were described as 'accessible people' and facilitated inclusive and accessible environments, learning opportunities and experiences. Many of the accessible people named by the group were staff members and peers at PPA. This suggests that the characteristics of the individuals present at PPA programmes support the formation of strong, long-term relationships. PPA therefore facilitated opportunities for adults with learning disabilities to create new and meaningful social connections in a safe and supportive environment, which had a positive impact in their everyday lives, but particularly on their wellbeing.

## 8.2 Enhanced Wellbeing

Attendance at PPA contributed to co-researchers' overall wellbeing and quality of life. Co-researchers reported that attending PPA resulted in them feeling happier, more relaxed and more positive ("I'm happy there" – Ella, C1). Of course, co-researchers did not always experience positive emotions at PPA. Co-researchers described feeling overwhelmed and nervous, particularly when attending PPA for the first time. This was often due to a lack of information around what to expect from PPA. However, negative experiences /emotions at PPA were often mitigated by staff support (as described above) and the way in which PPA responded to feedback (discussed further in section 8.2.4).

In cycle one, co-researchers considered the impact of people on their experiences at PPA. Positive relationships are considered to be a key component of wellbeing models (Ryff, 1989; Seligman, 2012). Indeed, previous research suggests that a social lifestyle can support

adults with learning disabilities to feel happier and foster a greater sense of belonging and inclusion (Mason et al., 2013; Wilson et al., 2017). Attendance at PPA increased co-researchers' access to support networks and long-term social relationships (see section 8.1.1). Co-researchers often continued the development of these relationships outside of PPA, by meeting up with their peers for social activities and staying in contact via social media. The impact of social experiences on wellbeing at PPA were particularly contrasting to the PRG's social experiences in other settings, which included instances of bullying, exclusion and ableism. These experiences negatively impacted co-researchers' wellbeing and sense of self-worth, resulting in self-stigma ("I always do everything wrong" – Ella, C2). Attendance at PPA enhanced co-researchers' wellbeing by fostering a supportive and accepting community, which provided opportunities for the development of meaningful and trusting relationships with others. Additionally, the structure and atmosphere within PPA programmes supported the development of co-researchers' routines, which was important to their wellbeing. Routine supported co-researchers' sense of purpose and provided regular opportunities for social interaction ("I would be quiet, not confident [...] I wouldn't leave the house" – Tracey, C2). This is discussed further in section 8.6.2.

In cycle two, co-researchers specifically related qualities of the arts to their wellbeing. Engagement with arts-based activities were reported to aid escapism and relaxation. Additionally, creative approaches to learning at PPA facilitated inclusive learning opportunities (discussed further in the following section). Engagement with inclusive learning experiences resulted in co-researchers' sense of achievement and pride in their learning, meeting their personal goals and the development of creative outputs. This is in line with the PERMA model of wellbeing (Seligman, 2012) which proposes that achieving one's goals (achievement/accomplishment) is a key component of wellbeing. Moreover, some PPA sessions were specifically designed to support participants' wellbeing (e.g. themed sessions on 'adventures in feeling good' and 'adventurous people: you!', which focused on self-care and wellbeing tips and activities). However, co-researchers also reported using arts-based activities and techniques they had learned at PPA to support their wellbeing in everyday life. For example, in cycle two Tracey discussed using art and drawing to support her wellbeing at home: "It [art] relaxes me when I can do it at Purple Patch Arts and at home". This suggests that engagement with the PPA programme supported self-discovery in relation to wellbeing techniques and the application of these approaches in everyday life.

In cycle three, the PRG noted that accessible environments and experiences, including people, supported their wellbeing. The realities of inaccessible spaces (or in some cases the idea/perception that spaces and activities would be inaccessible) resulted in

anxiety, discomfort, non-attendance and high cognitive load for co-researchers and their families. PPA was generally considered to be an accessible and inclusive space and was described by co-researchers as the closest real-world example of their dream accessible world. Attendance at PPA therefore aided wellbeing, as co-researchers trusted that PPA programmes would be accessible to them, thus reducing the stress and anxiety associated with attending activities.

### 8.3 Inclusive Learning Experiences

Engagement with PPA provided co-researchers with opportunities for inclusive learning experiences, which they may not have otherwise had access to. Learning at PPA was described as long-term, based in/on the real world, age-appropriate (aimed at adults) and inclusive. Engagement with PPA supported the development of co-researchers' skills and knowledge relating to a variety of topics. These included:

- Increased knowledge of the world and a broad range of topics, including world cultures and celebrations, history, literature, art, geography and science
- Arts-based skills and techniques
- Practical 'life skills' such as road safety, travel, self-care and money management (“\*programme leader\* is trying to teach us about using money [...] real life skills” – Ella, C1)
- Learning about oneself through self-reflective activities designed to support co-researchers' understanding of their likes and dislikes, personal skills and goals.
- Personal growth (i.e., the development of interpersonal skills, confidence and independence; discussed further in the following section)

Learning content and experiences were often new to co-researchers (“I look forward to learn something new, that I've never done before” – Ella, C1). However, the PRG also reported regaining skills through PPA, which were perceived as 'lost'. For example, Ella discussed re-learning skills at PPA that she had previously learned from other learning contexts: “I have lost some of my skills since I left college [...] now I'm in Purple Patch I can start picking up my skills again” (Ella, C3).

Co-researchers recognised the connection between the learning content at PPA and its application to their lives outside of PPA. For example, Ella shared how her learning experiences at PPA related to road safety in her everyday life:

Ella: We go and learn about road safety [...] and \*staff member\* is telling us how to catch a bus, as well

UR: How to catch a bus, that's good

Ella: \*Staff member\* is teaching us all these skills isn't he

UR: That's good

Ella: Maybe one day he wants us to go out on a bus on our own and go out to town

Similarly, Charlie and Jo shared that learning about healthy eating at PPA informed Charlie's routine and eating habits: "we learnt how to make smoothies, vegetable and fruit ones, and then Charlie then decided he'd like a smoothie every day at breakfast time" (Jo, C2). The development and application of these practical skills therefore supported and enhanced co-researchers' everyday lives.

LLL is considered to be a right for all adults, with varied positive implications for learners (United Nations, 2016). PPA provided co-researchers with access to inclusive LLL experiences, which are often limited for adults with learning disabilities, due to a range of environmental, social and institutional barriers. The present study suggests that engagement with inclusive learning activities provides opportunities for adults with learning disabilities to expand their skillset, develop their knowledge of a range of topics and enhance quality of life.

#### 8.4 Personal Growth

Alongside the development of specific knowledge and skills identified above, co-researchers experienced personal growth in a number of areas as a result of attending PPA programmes. These areas of personal growth impacted co-researchers' experiences within PPA and in their everyday lives.

Attendance at PPA supported co-researchers to be "more independent" (Liam, C1) within PPA. For example, by learning to make drinks for themselves or by engaging with PPA activities independently. Varied approaches to learning (described further in section 8.2.5) supported co-researchers' independence at PPA by providing multiple methods of accessing activities. PPA therefore provided opportunities for co-researchers to apply their independence skills, which in turn aided the development of other personal skills, such as organisation: "I need to think what I need at Purple Patch every Thursday when I go to the venue [...] I do it the night before". Co-researchers also discussed an increase in independence in their everyday lives. This included: collecting medication; using public transport (including to attend PPA programmes); and using an elevator independently, a skill that Sam developed specifically through her attendance at PPA programmes, where she is required to use a lift when accessing the toilet ("for Sam it was independence [...] she can get in the lift now and go down one floor, along to the bathroom and back up" – Janine, C1). Ella

also attributed an increase in independent thought to attending PPA:

Ella: I think Purple Patch has changed my life UR, and helped me to get more independent [...]

UR: what do you think you're more independent with? Or what kind of things do you think you're more independent at doing?

Ella: thinking for myself

By providing additional opportunities for co-researchers to meet and interact with others, attendance at PPA supported the development of co-researchers' social skills, including: sharing ("I'm sharing pens with the other people at Purple Patch" – Ella, C2); working and communicating with others ("I learned about working as a group" – John, C1) and managing difficult relationships:

Ella: Purple Patch taught me to get along with \*person\*

[...]

UR: how do you think Purple Patch taught you to do that?

Ella: by getting on with the other people in Purple Patch

UR: mhm

Ella: I took that away from Purple Patch and I can try it on \*person\*

Co-researchers also reported an increase in confidence in a range of areas in their life, including: confidence with specific skills ("since leaving college I lost the confidence of cooking and now \*programme leader\* is trying to get it back" – Ella, C1), confidence to undertake tasks independently and increased self-confidence ("I am more confident in myself" – Tracey, C1). Recognition of participants' achievements and skills at PPA supported their self-confidence and impacted co-researchers' self-concept, resulting in increased pride in themselves and their abilities ("Me is the best I can be" – Accessibility Poem 1, C3).

Experiences at PPA challenged assumptions of co-researchers concerning their own capabilities as learners. Through self-examination and reflection within PPA programmes, co-researchers were supported to recognise their strengths, resulting in a shift in perspective, behaviours and confidence ("Believe in yourself"- Accessibility Poem 1, C3). The present study therefore suggests that inclusive learning experiences may support adults with learning disabilities to consider their learning capabilities based on their own self-reflections and experiences, rather than the misconceptions and judgement of others. Increased self-confidence and self-efficacy supported co-researchers to advocate for their need and interests, as discussed in the following section.

## 8.5 Opportunities for Advocacy

Attendance at PPA provided co-researchers with opportunities for self-advocacy and the development of skills and beliefs which support self-advocacy (such as independence, self-confidence and communication skills). The development of self-advocacy skills may be particularly important for adults with learning disabilities, who have historically had their voices excluded from society (Oliver & Sapey, 1983).

Co-researchers were encouraged to advocate for themselves within PPA programmes. For example, by sharing their views and opinions and being empowered to share their preferences concerning participation in the PPA programme and the support they received (“if you didn’t like it you can tell them, look I don’t really want to do that today” – John, C1). Attendance at PPA was also used by co-researchers to challenge misconceptions about themselves and to prove others wrong: “this girl \*name\* said I won’t, I weren’t able to be good at anything [...] I proved her wrong by coming to Purple Patch”. This demonstrates co-researchers’ desire to share their personal strengths and experiences with others, and to advocate for themselves.

Alongside self-advocacy, co-researchers advocated for other adults with learning disabilities, by sharing their views and opinions around the strengths of adults with learning disabilities, and their inclusion in society: “Having a learning disability can offer something great” (John, C2). Previous research has suggested a relationship between learning opportunities and self-advocacy. Petri et al. (2020) note that learning enables people to do advocacy, for example by learning about oneself and developing new skills, which aid advocacy. Therefore, while PPA is not specifically a self-advocacy organisation, the present study demonstrates that access to LLL opportunities services may support the skills needed for advocacy.

## 8.6 Underlying Mechanisms within Purple Patch Arts (Ingredients)

Analyses conducted by the UR (see section 3.5.2.2) revealed five underlying mechanisms at PPA: These are: ‘Safe space’, ‘Freedom within structure’, ‘Reaching maximum effort’, ‘Valuing participant voice’ and ‘Varied approaches to learning’. These features were observed across all three cycles of research and may therefore influence and be influenced by ‘People’, ‘Arts and Variety’ ‘Accessibility and Support’. Some underlying mechanisms may appear to be more directly related to specific outcomes (e.g. varied learning approaches as directly influencing inclusive learning opportunities). However, the interaction between and combination of these mechanisms supported an inclusive learning environment at PPA, reducing barriers to participation and generating the outcomes described above.

These ‘ingredients’ shine a light on the inner mechanisms, features and interactions at PPA, but also provide an insight into the broader characteristics of inclusive learning environments for adults with learning disabilities. The mechanisms described below may therefore be applicable to other inclusive learning environments, including other LLL programmes/organisations for adults with learning disabilities, or perhaps even learning specifically within inclusive research environments. While not all mechanisms may be activated in all inclusive learning contexts, the present study suggests that these mechanisms may provide a useful framework for the design and evaluation of inclusive learning environments across a range of disciplines.

### 8.6.1 Safe Space

Safe space refers to the facilitation of a physically, socially and emotionally safe environment for learners. Trust was important to creating a safe space (“trust is important and rewarding” – Accessibility poem 5, C3). People at PPA formed the basis of a safe learning environment. As noted in cycle one, trust in people was facilitated through consistent support, promoting a culture of acceptance, knowledge of participants, mutual respect and reducing perceptions of hierarchy:

John: do you feel safe there? Yeah, I do. Do you feel safe with them all? They know you...  
Tracey: Yes, I do

Additionally, cycle three demonstrated the importance of embodying the characteristics of ‘accessible people’, which contributed to the development of authentic and trusting relationships with participants. Trust in people was multi-directional, including between staff and participants, and between PPA peers. Sam noted in cycle one that the safe environment fostered by staff and peers helped her to feel confident to explore and learn:

I feel safe in my Purple Patch world because even when I visit other people and countries, by eating some foods they might eat, and playing some games they might play, I am still right in our group with my friends and our supporters

The unpredictability of the reactions of others (as manifest in psycho-emotional disablism) may prevent disabled people from attending social or learning activities, due to anxiety around how people will respond (Reeve, 2006). ‘Social safety’ was therefore promoted at PPA, as co-researchers trusted that they would be accepted and supported, which enabled them to feel safe and to be themselves without fear of social exclusion or bullying (“You shouldn’t have to change to fit in with the group, you should just be yourself regardless” – John). Trust in others therefore facilitated a positive atmosphere and sense of belonging for co-researchers, which contributed to the categorisation of people at PPA as ‘accessible’ and



part of a 'family'.

Another core feature of a safe space was trust in the wider organisation. PPA was considered to be reliable, and co-researchers trusted that PPA would be available to them for a lifetime. This provided participants with the confidence to include attendance at PPA as part of their long-term routine. Trust concerning the longevity of PPA was particularly important to support co-researchers' wellbeing, as many participants had previously experienced the removal of services and therefore the removal of activities which had become important aspects of their daily life.

Trust in PPA also supported learning opportunities for co-researchers. PPA participants and parents/carers trusted that PPA's approach to learning was informed by knowledge and expertise ("there really is the advice behind it, you know the psychological as well as the educational" – Janine, C1). Co-researchers trusted that learning at PPA would be accessible to them, and that their views and concerns around accessibility would be listened to and acted upon (discussed further in section 8.2.4). Maintaining a safe space at PPA also contributed to the development of a Community of Practice (CoP). As Roberts (2006) notes, trust is key to ensure that individuals belonging to a CoP feel comfortable to share their knowledge and experiences.

Safety and accessibility in the physical space was crucial to co-researchers. As discussed in cycle three, inaccessible spaces communicated information to co-researchers concerning whether they felt welcome in the space. The accessibility of a space influenced co-researchers' likelihood of re-attendance as well as their views concerning attendance at similar activities in the future. Therefore, as discussed in cycle three, one of the most obvious yet important features of a safe learning space is the *ease* of access for learners.

Overall, safe space referred to the creation of an environment where co-researchers were supported to learn and grow, express their views openly and to connect with others. The importance of a safe space for adult learners with learning disabilities may be especially important, since this community may have been excluded from previous learning environments (e.g. through inaccessible learning experiences, ableism or social exclusion). Inclusive learning programmes for adults with learning disabilities may therefore need to actively counteract these experiences, to support adults with learning disabilities' active engagement with learning.

#### 8.6.2 Freedom within Structure

Both freedom and structure were considered to be important characteristics of inclusive learning environments. This mechanism refers to the need for a balance of these characteristics in order to facilitate an environment that was both structured and flexible ("it

is structured but, I don't feel you're pressured to it" – John, C1).

Structure was embedded within the PPA programme. For example, each session followed a familiar routine, with timings allocated to each session in the day. Programmes also included repeated elements, such as the warm-up/cool-down, which was included in every session through the year. Additionally, the learning theme (e.g. 'Adventure'), which was consistent across the year, provided PPA participants with an indication of the types of content they would be learning. Structural elements may therefore be important features of inclusive learning experiences as they by provide a routine and sense of familiarity.

Freedom was also an important characteristic of PPA programmes. Freedom was facilitated by: providing co-researchers with options within programmes (e.g. by providing a variety of adaptable arts-based activities/approaches to learning; discussed further in section 8.6.5); encouraging autonomy, by supporting co-researchers to make choices and promoting an atmosphere which was flexible, fun, not strict ("It's not like strict, it's just fun" – Leanne, C1) and relaxed ("it's a bit of light relief but you learn at the same time [...] it's not intense you know" – C1). Flexibility may therefore support co-researchers' autonomy, learning and wellbeing, by providing a sense of freedom and facilitating adaptable and varied learning experiences.

A balance and interactions between characteristics, or 'freedom within structure', is therefore required to facilitate inclusive learning experiences ("it's a good structure, it's not totally regimented, you know it's like, gives you a bit of flexibly" – John, C1). When structure outweighed freedom, the accessibility of PPA was negatively impacted:

John: sometimes you know I think they just need to uh, I know they've got a schedule, but they need to ease up on the schedule for some people \*unclear\* different  
 UR: yeah  
 John: I think they do try their best  
 UR: yeah  
 John: you know there are some, some people who just can't do what, what's asked

Equally, when sessions were not structured enough, this impacted co-researchers' wellbeing and enjoyment of PPA programmes ("I need to be in a routine. If I don't get in a routine I am lost in my mind and my confidence would go down" – Tracey, C1).

Cultivating the right balance between freedom and structure was therefore crucial to facilitate inclusive learning environments, by supporting feelings of safety and familiarity, while enhancing the autonomy of learners.

### 8.6.3 Reaching Maximum Effort

Reaching maximum effort concerned the approach to support within inclusive learning environments, which enabled co-researchers to reach their potential, experience challenge and meet their goals. This required the balance of several factors influencing the treatment of disabled learners.

The views of others (e.g. conscious or unconscious bias and/or negative perceptions of people with learning disabilities) may intentionally or unintentionally impose limitations on learners with learning disabilities. A common example of this is the impact of benevolent ableism. Benevolent ableism, a form of discrimination or bias that occurs when peoples' attitudes towards disability (e.g. viewing disabled people as weak; Graff & Russell, 2023), result in assumptions about when and how disabled people may require support without considering their choices or preference. Benevolent ableism may be well-meaning, but ultimately discriminates against disabled people (Robb, 2015). This form of ableism may result in disabled people being infantilised (Robb, 2015), receiving unwanted help (Nario-Redmond, 2019) or having their independence disregarded. A practical example of benevolent ableism within a learning context may include observing an adult with a learning disability experiencing challenge and automatically assuming that this challenge is undesired. This may result in staff within learning environments doing activities on behalf of learners with learning disabilities, rather than asking them about their support needs. Within a learning context, benevolent ableism may therefore result in reduced expectations around the capabilities of disabled learners (Lynch, 2013).

Inclusive learning environments were considered to be those where these barriers imposed by others were removed (“no-one telling you what you can and can’t do – Liam, C2”). Reaching maximum effort therefore refers to the social interactions within inclusive learning environments, which enable adults with learning disabilities to be in control of their support, experience an appropriate level of challenge, and to reach their full potential.

The approach to support within inclusive learning environments therefore plays an important role in the experiences of learners with learning disabilities. Co-researchers described how ‘active’ approaches to support empowered them to actively engage in their own lives, by promoting independence and self-reliance. For example, Ella described how PPA staff consulted her regarding her support needs before offering assistance (“he asked me, what do you need help with? I say to him, cutting out” – Ella, C3). This approach to support balanced providing encouragement and guidance (when needed), without pressuring learners (“there’s no pressure to do it, you know, no pressure [...] I’ve in the past been pushed to the limit with pressure” – John, C1). The autonomy of learners was therefore an

important feature of inclusive learning environments (“nobody should be pushed into it, they can be guided [...] but you have a choice don’t you?” – John, C2). Providing levels of involvement and challenge within inclusive learning programmes (e.g. by setting individualised goals, or providing a range of adapted activities for different learners), may therefore support engagement by providing learners with options regarding the nature of their learning experiences.

People, and particularly the attitudes of staff and peers, played an important role in facilitating inclusive learning opportunities that supported adults with learning disabilities to reach their maximum effort and potential. Janine reported observing change in her daughter Sam, noting that this change was not forced by PPA, but rather, occurred naturally due to the community within PPA (“no one tries to change you, but you change over the time, just because of the people around you” – Janine, C1). Supporting co-researchers to reach their maximum effort therefore required staff and support workers to embody many of the qualities of ‘accessible people’ (reported in section 6.3.2.2.5.1). The attitudes of others and their approach to learning therefore impacted co-researchers’ perceptions and experiences of learning.

#### 8.6.4 Valuing participant voice

Valuing participant voice relates to the ways in which participants’ views and opinions regarding their learning experiences were used to influence the learning environment. In the present study, making change based on participants’ recommendations and feedback resulted in co-researchers’ belief that a) their views were respected and valued and b) that their feedback would result in positive action within the PPA programme “[PPA are] very supportive and open to our ideas” (Liam, C3).

Honouring co-researchers’ feedback on their learning experiences facilitated feelings of belonging and autonomy, and encouraged them to share their views in other settings, including through self-advocacy. Co-researchers’ feedback informed the approach to learning, the learning environment and the learning content (as described in the previous section). Responding to participants’ feedback therefore fostered more impactful, accessible and tailored learning experiences, which reflected the needs and interests of participants, thus resulting in positive outcomes for learners (“When I first started it was very hard to learn from every week, but PPA seemed to change it [...] I’m happy with the way it is now” – Tracey, C2).

### 8.6.5 Varied Approaches to Learning

Discussion of the underlying components of inclusive learning environments described a wide range of approaches and activities. Varied approaches to learning were particularly important, as these appealed to different learning styles, supported the inclusion of learners with diverse needs and interests and provided varying levels of challenge depending on individual's ability level and preferences. Inclusive learning environments should therefore seek to provide a variety of learning approaches, activities, resources and techniques, to support learners' autonomy. This may include:

- Arts-based learning approaches, including activities utilising movement, visual arts, music and drama. Arts-based activities supported learning, as there was no wrong or right way to approach them. Arts-based activities were also viewed as adaptable and promoting choice and individuality, and were not considered to be competitive (although this was linked to the learning atmosphere promoted by PPA, which encouraged fun over learning). Additionally, sensory activities provided multiple ways for participants to access an activity, including those with complex needs, or whose disability impacts one or more of their senses.
- Thematic approaches to learning, which provided learners with opportunities to engage with a range of subjects (and therefore a variety of activities) to explore a single topic.
- Resources and activities utilising multiple methods of communication, including: verbal, written, Makaton, signs and symbols (e.g. easy read).
- Active learning techniques, including role playing, game-based learning and experiential learning, which actively involved learners in the co-creation of learning content.

While a variety of learning approaches was considered to support inclusive learning at PPA, some consistency in the characteristics of learning was also required:

- Learning was rooted in the real world and was therefore considered to be practical and applied. Co-researchers acknowledged a relationship between learning content and the application of this learning in their lives.
- Learning was age-appropriate and stage-appropriate (i.e. learning was aimed at adults, but was adapted to be inclusive for diverse learners, using multiple approaches to learning described above).

- Learning was social and facilitated opportunities for collaboration (e.g. via CoP) and the development of social relationships.
- The learning environment was supportive and safe. Programmes focused on what co-researchers could achieve, rather than the challenges associated with their disability. This promoted self-acceptance, increased self-efficacy and self-advocacy.
- Learning goals were individualised. Since PPA was not related to a qualification, co-researchers set their own goals to work towards, thus allowing co-researchers to set their own level of challenge.
- Learning was enjoyed and celebrated. Enjoyment of learning and learning activities increased motivation to attend PPA, supported engagement with PPA and therefore a desire to continue learning.

The present study therefore suggests that while varied approaches to learning should be offered to adults with learning disabilities, inclusive learning organisations' attitudes towards learning should be consistently learner-centred and collaborative. The active involvement of adults with learning disabilities in co-creating and evaluating learning experiences in particular may support the development of more equitable LLL opportunities for this community.

## 9 Outcomes of Engagement with PAR for Co-researchers

The third aim of the present study was to explore the outcomes of engagement in PAR from the perspective of co-researchers. In particular, the present study sought to investigate the potential for learning opportunities and personal and professional development through involvement in the research processes. Co-researchers reflected on their involvement in research throughout the project, but particularly in cycle three during the in-person research session (section 6.3.1.1) and final interviews (see section 6.3.3.5).

Thematic analysis of transcripts from research meetings across all three cycles revealed five overarching themes in relation to the outcomes of engagement with PAR for co-researchers. These outcomes are: 'Learning and Development', 'Community', 'Combatting the Negative Impact of Covid-19', 'Research Identity', and 'Fun'. Each theme contains several sub-themes, which are discussed below.

### 9.1 Learning and Development

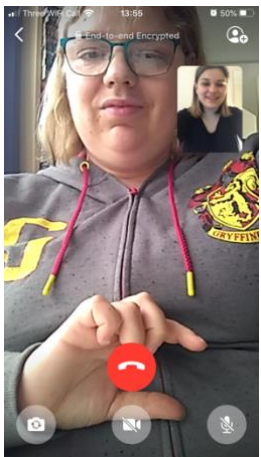


Co-researchers in the present study reported that they enjoyed learning new things and developing new and pre-existing skills through their involvement in the project ("I've enjoyed being... just learning. I've learned" – John, C3). Previous research has suggested that PAR may provide opportunities for LLL for adults with learning disabilities (Nind, 2014b). This may in part be due to the development of a range of skills, which were required as part of the PRG's new role as co-researchers (Billet, 2010). Analysis of the research transcripts and final interviews in the present study revealed four specific areas of development self-identified by co-researchers. These are: research skills and experience, working and communicating with others, personal development and overcoming challenge, and an increased knowledge of PPA. This theme explores the potential for PAR to serve as a learning opportunity in itself and identifies the ways in which co-researchers learned through the project.

#### 9.1.1 Research skills and experience







By undertaking the role of co-researchers, the PRG learned about the process of planning and delivering research, including the key stages of a research project (e.g. looking at previous literature, choosing research questions and collecting and analysing data). The cyclical nature of PAR enabled co-researchers to repeat the research process several times, resulting in an increase in understanding of how research may be undertaken. Ella demonstrated her knowledge of the early stages of research in her final interview: "we looked at other researchers [...] before we came up with our questions." Alongside an increase in knowledge of the research process, co-researchers developed practical research-specific skills through



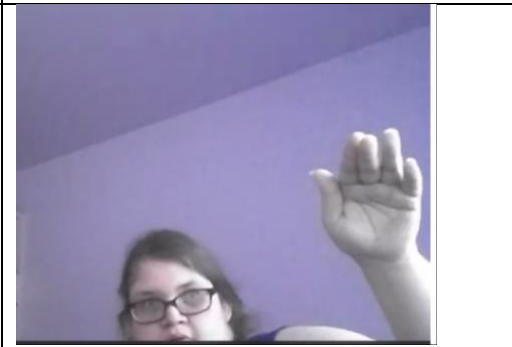

direct experience in the PRG. These included: narrowing down the topic area and choosing research questions (“Help to narrow it down, the question down [...] that’s a new thing I learned” – Ella, C3), processing information, data collection and analysis and collating and interpreting data (“How to bring everything together [...] like all this information we’ve done today” – Janine, C3). Two additional research-related skills (learning to use Zoom and analytical thinking), were reported by researchers as skills that they had developed within the research context, but had since incorporated into their everyday lives (“Before doing research, I didn’t know how to do Zoom” – Tracey, C3). By the end of the project, co-researchers recognised that their research skills had improved (“I’ve learned how to do research and that a lot better” – Liam, C3). Co-researchers identified research as something that they were good at, as Tracey expressed to the group during the in-person research session in cycle three: “There is new things you are good at, and one of them, for all of us today, is research”. Table 12 shows the difference in research confidence of co-researchers at the beginning of the project compared to the end of the project.

Table 12: Co-researchers' research confidence at the beginning of the project compared to the end of the project

Co-researcher	Research confidence at the beginning of the project	Photograph indicating confidence level
Tracey	 <p>Low</p>	 <p>High</p>
John	<p>One-to-one meeting was undertaken on the phone therefore it was not possible to capture a photograph of John’s research confidence.</p> <p>Medium</p>	



<p>Ella</p>	 <p>Medium</p>	<p>High</p>  <p>High</p>
<p>Leanne</p>	 <p>Medium</p>	 <p>High</p>
<p>Liam</p>	 <p>Medium</p>	 <p>High</p>

Charlie		
	Medium	High
Sam		
	Just above medium	High

Billet (2010) suggests that a change in ‘role’ (e.g. from participant to co-researcher) can prompt informal LLL, due to the specific knowledge and/or skills required to negotiate this new role. Indeed, previous participatory projects suggest that the development of research skills and experience are a key outcome for adults with learning disabilities undertaking the role of co-researchers (Nind, 2014b; Rickson et al., 2014; White & Morgan, 2012). The present study facilitated research-specific learning and opportunities for personal development as the PRG negotiated their new role as co-researchers. This suggests that PAR can serve as a site for LLL for disabled co-researchers and for the URs/organisations who benefit from understanding their experiences. Personal development and research skills appeared to develop simultaneously and influence each other. The following section will discuss examples of personal development outlined by the PRG, and how overcoming challenges in the research led to opportunities for personal growth.

### 9.1.2 Personal Development and Overcoming Challenge

Co-researchers discussed their personal development during the project with members of the PRG, sharing areas of personal growth at different points in the research. Co-researchers reported an increased ability to focus (“I’ve learned a bit more that I can focus a bit on something” – John, C3), increased independence (“I can edit my own work now” – Tracey, C3) and improved organisation skills (“It [research] has taught me a bit about organising stuff, so

now I've got a system" – Ella, C2) as a direct result of involvement in the research. Co-researchers expressed pride in themselves and others for their research-based and personal achievements (including those discussed in sections in the section above) as Tracey and Janine discussed during the in person session:

Janine: I'm proud of her [Sam], for everything she's done  
Tracey: you should be proud of yourself as well as someone else

In keeping with previous research, a commonly reported area of personal development for disabled co-researchers was confidence (Rickson et al., 2014; White & Morgan, 2012). Co-researchers in the present study discussed an increased confidence in relation to research, themselves (i.e. self-belief), and in application to other activities and experiences. All of the co-researchers reported feeling more confident in doing research at the end of the project, compared to the beginning (see table 12). During cycle three, Liam explained how his growth in confidence as a researcher had led to a desire to pursue this role outside of the project, leading to other research opportunities: "It's given me confidence to go on and do a two and a half year more research programme, which I don't think I might have had the confidence to have done". Additionally, during cycle three Ella explained how her role in the research helped her to approach a new experience with confidence:

I starred in the Mencap video [...] they wanted me to be first on camera [...] after me coming to be a Purple Patch researcher, at first I was not afraid to go first, because I am a Purple Patch researcher, that helped me get my confidence

The present study therefore demonstrates the potential for personal development through involvement in PAR to impact the everyday lives of adults with learning disabilities, including activities and experiences outside of the research.

Additionally, the online nature of the project supported co-researchers to develop digital skills and therefore digital inclusion. In line with previous research (Mikulak, et al., 2023) co-researchers in the present study grew in confidence using Zoom, the internet and social media to collaborate in the research:

John: Zoom was new  
Tracey: yeah, it was new, so we didn't know how to use it. So if it wasn't for UR and Purple Patch doing it, we wouldn't have known how to use it

However, it is important to note the development of these skills was reliant on the co-researchers having access to a device and often to individuals who were willing to support their digital inclusion:

Overcoming challenges in the research also provided the PRG with opportunities for personal development. For example, co-researchers reported overcoming personal challenges, such as using scissors (e.g. to cut out data during analysis), trying new things, and making friends, as Tracey explained in cycle three: “I didn’t like new people or new things, but by the middle of being a researcher I changed, I liked new things, not all new things, you know, anyway, so I’ve changed a bit.” Research was considered as a ‘good challenge’, which required co-researchers to think differently and challenge themselves in different ways (“It [analysis] does make me proper think” – Liam, C2). Becoming a researcher also required some co-researchers to challenge their perceptions of themselves. For example, in cycle 1 in particular, Ella appeared to be surprised by her contributions to the project, particularly when the UR or other members of the group praised her good ideas (“Where are my good ideas coming from today?”). During the project, Ella shared her previous experiences of bullying. Ella’s negative social experiences resulted in her experiencing low self-confidence and negative perceptions of her abilities. Indeed, previous research suggests that people with learning disabilities are more likely to experience low self-esteem than their non-disabled peers, particularly when there is a lack of social support from peers (LaBarbera, 2008). The present study suggests that direct involvement in research, combined with peer support, can encourage disabled co-researchers to challenge their perceptions of themselves and their capabilities (“I learned skills I didn’t know I had” – Ella, C3) and in doing so provide opportunities for personal growth and increase in self-esteem (“I prove myself wrong and others that I can do it, that is all it takes really” – Tracey, C3).

Some challenges were related to the perceived accessibility of research. For example, as previous discussed in section 6.3.2.1.1, John’s concerns about the accessibility of the in person research venue almost resulted in him not attending the session. While the building was indeed accessible, the perceived inaccessibility of the building, which was based on previous negative experiences and a lack of clear information available online, had a significant impact on John’s decisions concerning attendance. Therefore, while a lack of accessibility is clearly a barrier to inclusive research, John’s experience demonstrates that concerns around accessibility may also prevent participation and can therefore be considered as a barrier to research in itself.

### 9.1.3 Working and Communicating with others

Co-researchers reported developing their communication and teamwork skills through their involvement in the project. This included listening to and communicating with others, which are important aspects of PAR, since decisions regarding the research are made collaboratively (Johnson and Walmsley, 2003). Sam highlighted the importance of listening to the ideas of

others while reflecting on the project in cycle three: “We talked about it [research] and take your time [...] someone might say something important about it”. At times, the nature of online research made it difficult to listen to and communicate with each other, as Tracey explained: “[on Zoom] someone speaks and you don’t know who’s the first person, you don’t know who was going to talk.” However, the group discussed tactics such as taking turns and making sure everyone had a chance to share their thoughts as ways to combat the challenges of online delivery (“What else I’ve learned is make sure everybody has the information or idea across before we’ve finished the zoom” – Tracey, C3). Additionally, getting to know each other and developing trust in the group was an important aspect of working together, particularly when disagreeing with others or discussing more sensitive topics, such as bullying and accessibility challenges (“Now we’ve all met you guys, we can sort of interact with you well, so that’s a good thing” – John, C3).

The inclusive approach to the project meant that co-researchers were required to adapt their communication during research sessions to meet the varied needs of the group (“We have learnt different ways of communicating with different people” – Tracey, C3). For example, some co-researchers communicated verbally, while others preferred to type responses in the chat or respond through physical movement or gesture. Sam and Charlie were also supported to share their views in research sessions by their support worker/parent. Co-researchers recognised the benefits of working within a diverse team, with varied strengths and preferences. Through peer support and adaptive activities, the group were able to work to their strengths and participate in research sessions according to their needs and preferences (“We all contribute to this sort of thing in different ways [...] whatever is easiest for each person” – Liam, C1).

Alongside communicating with each other, co-researchers also reported enjoying communicating their ideas to others, including those within and external to the PRG. John acknowledged the potential impact of sharing his experiences and expertise in accessibility, recognising that others may benefit from hearing his perspectives: “In slightly helping you guys on this I feel, what with the access I think it can really help you, give you my view across and it’s a good thing to help people” (C3). Some co-researchers also described applying their communication skills to their day to day lives. During cycle two, Ella discussed how her role as a researcher had supported her to share her preferences with her mum: “Since I’ve been doing the Purple Patch researchers, I know how to give my mum instructions”. This suggests that involvement as co-researchers can support adults with learning disabilities to develop their skills in communicating their views and preferences with others, thus promoting greater autonomy in their lives.

#### 9.1.4 Knowledge of PPA

Co-researchers reported an increase in knowledge of PPA and the way the programme is managed and delivered, as explained by Tracey in cycle three: “If it wasn’t for Purple Patch for thinking about you for your degree, we wouldn’t have known the ins and outs of Purple Patch.” As an important part of their lives, the PRG enjoyed learning more about PPA through the research, including the roles and responsibilities of office-based staff, approaches to session planning, and how new ideas are raised and implemented. Additionally, co-researchers were curious to learn about and consider how PPA operated, particularly their status as a charity and approach to fundraising, as Ella and Leanne discussed in cycle three:

Ella: I wonder if Purple Patch is a charity?

[...]

UR: yeah, it is a charity

Ella: why?

UR: so they, so people pay to come to Purple Patch don’t they?

Leanne: yeah

Ella: and that pays the um, staffing, the staff wages

UR: it does yeah, that’s right

Ella: like \*staff members\*’s

UR: that’s right

Ella: \*unclear\* paying for me to come to Purple Patch, but I have to put money towards to it

UR: yeah

Ella: use that service

UR: that’s right [...] so they [PPA] ask for money from people to help, to help them [...] if they didn’t, if they weren’t a charity and they didn’t have other people giving them money, then it would be a lot more

Feedback sessions with PPA staff also provided co-researchers with the opportunity to share their preliminary findings and influence practice within PPA. For example, after sharing their ideas for a buddy system in cycle one of the project, PPA developed a buddy training programme. Getting to see ‘behind the scenes’ and contributing to the running of PPA was considered to be an exciting and important aspect of being a co-researcher. Ella acknowledged the importance of sharing feedback with PPA staff during a discussion prior to the PRG’s first feedback meeting: “it’s a big day for us on Friday, isn’t it?” (C1). Providing opportunities for co-researchers to see the applications of their research reinforced the importance of their role in making real change within their organisation.

## 9.2 Community

The formation of the PRG resulted in the formation of a new research community, which served multiple social functions for co-researchers. This theme explores these social functions and the impact of participation in the research on the co-researchers’ social networks.

### 9.2.1 Development of Social Relationships

Co-researchers reported developing new social connections through involvement in the research, by meeting and forming relationships with new people, as well as developing pre-existing relationships. Making new friends was one of the most commonly reported outcomes of engagement with the research (“We’ve gained new friendships along the way” – Tracey, C3). Participation in the research therefore widened the social circle of co-researchers, by exposing them to new people (e.g. other co-researchers, the UR and PPA staff), as Ella stated in her reflections on the social nature of her involvement in the research: “You’ll get to meet people you don’t normally get to meet” – Ella, C3. The development of new relationships was supported by the online context of the research, which enabled co-researchers to meet and work with individuals who were not usually accessible to them (e.g. due to physical distance or being based in different PPA programmes). This is in keeping with previous research which suggests that a key benefit of PAR is the development of new connections and networks (Nind, 2017).

The virtual setting of the research was reported to have a positive impact on the co-researchers’ ability to make new friends. Co-researchers described how they typically find meeting and engaging with new people challenging. This was discussed in relation to general anxiety around meeting new people, as well as nervousness to interact with specific individuals due to previous negative experiences (e.g. bullying and negative interactions with non-disabled people). Initial nervousness around participating in the project was largely centred on *who* the co-researchers would be conducting the research with, rather than the research itself (although this was discussed). When explaining in her final interview why she felt nervous at the beginning of the project, Ella explained: “I didn’t know who was on my research team”. While co-researchers felt that making new friends and meeting new people was difficult, the virtual setting of this project mitigated some of these challenges and made it easier to connect with new people (“I don’t like new people, but it felt easier on Zoom, because you can see the new people” - Tracey, C3).

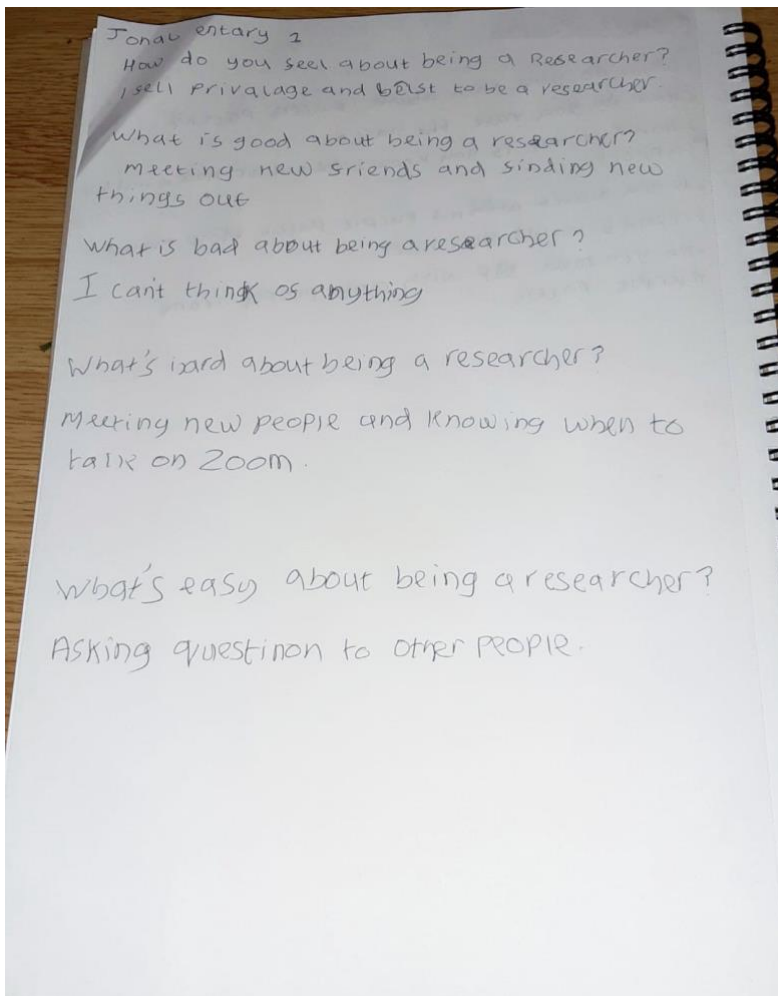


Figure 46: Liam's reflections on being a researcher, taken from his research journal

The virtual nature of the PRG's relationship meant that when they met in person for the first time for an in-person research day in September 2021, they knew and had built relationships with each other, but hadn't officially 'met'. Some co-researchers were unsure how to view and respond to these relationships, now that they were in person rather than online. The group considered the ways in which they would usually behave in the presence of people they 'knew' and weighed up whether the online relationships they had developed met their individual criteria of familiarity. An example of this is Tracey's consideration of whether she should eat in front of the group ("I don't usually eat in front of people I don't know, but I do know you from Zoom" – Tracey, C3). Despite this, co-researchers expressed a desire to move their friendships from an online context to 'real life' and to continue to build these relationships after the end of the project ("How often we gonna meet hopefully in real life after this?" – Tracey, C3)

While this theme has mainly considered the development of social relationships for adults with learning disabilities, the PRG was also used as the basis to form new connections



between parents, as demonstrated by Janine:

I met Liam's mum at the parent evening, after we'd had a [research] session [...] I said, 'oh are you Liam's mum?' [...] she said yes! (C3)

This demonstrates the potential for the shared experience of PAR to support the social networks of all members, including parents/ supporting staff.

#### 9.2.1.1 Celebration and Support

The PRG served as a support network for co-researchers (consisting of other co-researchers, support staff/parents, the UR and PPA staff), which they could 'tap in' to throughout the pandemic. Co-researchers used this network to celebrate and support one another.

Co-researchers shared their research-based and personal achievements with others in the PRG. This included posting to the Facebook group, sharing news during research sessions and messaging members of the group directly. Co-researchers shared things they were proud of, and the group responded by celebrating their achievements through positive comments (verbal and posted) and 'reactions' on Facebook. Examples of positive news that were shared with the group included: research achievements (e.g. completing a piece of work); personal growth/achievements (e.g. doing an interview for Sky News, being more independent or achieving a good swimming time); receiving an award/certificate (such as Ella sharing her PPA certificate; see figure 47); and personal news (e.g. the birth of new family members). This demonstrates the co-researchers' desire to share their achievements with the group, as Ella discusses: "I put my certificate up, I got from Purple Patch, on the Facebook page [...] I wanted to share that with the group." Co-researchers also celebrated their return to physical attendance at PPA post-pandemic by discussing their excitement in research sessions. Leanne and Ella compared the feelings they anticipated they would experience in their first session back at PPA to 'Christmas morning'.

I got a certificate from purple patch



Figure 47: Ella shares her Purple Patch Superstar certificate with the PRG via the Facebook page

Co-researchers also supported each other through challenging moments, including past negative experiences and current challenges. These included: bereavement, illness, conflict with others, reliving experiences of bullying and negative views of self/of disability. The PRG supported each other through reassuring comments, both via Facebook and verbally during research sessions, and through supportive Facebook 'reactions' (e.g. the 'care' or 'love' reactions). An example of this is when one co-researcher (anonymised for privacy) shared a family bereavement that occurred during the research in the PRG Facebook group. As can be seen in figure 48, co-researchers responded to this news through comments and supportive 'reactions'. This demonstrates that the PRG provided a valued support network for co-researchers. This was particularly important during the pandemic, where access to usual support networks was limited, particularly for disabled people (Kim et al., 2021).

Just to let you all know that my nanna died yesterday at 10.30pm in her sleep with my auntie and cousin by her side. Also nanna didn't die because of covid than god, now she isn't suffering anymore and now with grandad again in heaven

Bless her

Miss her so much and nanna's going to be missed by all. I thought I would let you know [REDACTED]

thank you xx



4 comments Seen by 9

Figure 48: A screenshot of a co-researchers' post on the PRG Facebook group sharing a recent bereavement

### 9.3 Combatting the Negative Impact of Covid-19

It is well-acknowledged that disabled people have been disproportionately impacted by Covid-19 (Brennan et al., 2020; Office for National Statistics, 2022). Previous literature has documented the first-hand experiences of adults with learning disabilities during the pandemic, including its negative impact on social contact (Bartlett et al., 2022; Embregts et al., 2020; Kim et al., 2021), changes to daily routine and activities (Bartlett et al., 2022; Kim et al., 2021) and the challenges of understanding Covid-19 restrictions (Embregts et al., 2020). Co-researchers in the present study reported that engagement with the project mitigated some of the negative impacts of Covid-19, by providing “something to do”, combatting isolation, and providing a Covid-19 support network. These sub-themes will now be discussed individually.

#### 9.3.1 “Something to do”

Co-researchers in the present study reported significant disruption to their usual routines as a consequence of Covid-19, such as the closure of programmes they attended regularly before the pandemic (including PPA and other groups). Ella reflected on the negative impact of the pandemic on her routine during her final interview in cycle 3 of the project. Here she shares her experiences of the repetitive nature of life during lockdown, resulting in extended periods of boredom:

I was so bored in the house. For weeks and weeks and weeks I was bored [...] I ate and I slept and ate and I did, I eat and then I went for a nap, and then... that's what I did

Ella's mum also highlighted the contrast between Ella's life pre- and post-pandemic in a discussion with another co-researcher about life in lockdown during cycle three:

Ella has activities on most days and a couple of evenings and she's very busy [...] but it went from being like that and it all just stopped

Covid-19 lockdowns resulted in severe disruption to our daily routines, with activities outside the home cancelled, and working/learning from home prevalent. Adults with learning disabilities therefore had to adjust to life at home, and a routine without the inclusion and support of their usual activities (Bartlett et al., 2022; Kim et al., 2021). For some, this adjustment and lack of structure was particularly challenging, resulting in anxiety and boredom ("I'm not the same in lockdown" – Tracey, C1).

After the initial closure of groups supporting adults with learning disabilities many activities adapted to online forms of delivery (Mikulak et al., 2023). This required a considerable adjustment, both for organisations, and their participants. Co-researchers discussed the benefits of these virtual groups in their lives during the pandemic. However, with the knowledge of what their groups were like prior to Covid-19, co-researchers reported a desire to return to 'normal' delivery, acknowledging that in person is "better" (Leanne, C3). In contrast, research sessions began during Covid-19 and were therefore consistent in their format and virtual nature. The co-researchers' only experience of research was during the pandemic, and therefore their knowledge of the research process was based entirely on the virtual nature of this project. The PRG was therefore one of the few activities during the pandemic that was not cancelled or adapted from its usual format.

Co-researchers reported that involvement in the research replaced their regular activities in their schedules, giving co-researchers "something to do" (Leanne, C1) and combatting boredom during extended periods of lockdown ("this has also given me something else to do while Covid 2019 was happening and we couldn't go out to meet in person" – Tracey, C2). While having something to occupy their time was considered as an outcome of engagement with the project, co-researchers also reported this as a factor influencing their motivation to become a researcher ("Give me something to do until we're back to normal" – Leanne, C1). The research was also reported to support aspects of the co-researchers' lives, which were ordinarily reinforced by attendance at their usual programmes. For example, Tracey shared that her decision to become a researcher was linked to her desire to continue to learn during the pandemic, when access to learning organisations was limited ("I signed up so we would learn more during lockdown [...] so we could do something in lockdown, because we weren't doing anything and we were at home" – Tracey, C3).

The regularity of the research, including bi-weekly online meetings and regular contact with other co-researchers via Facebook was reported to provide a sense of structure

to the co-researchers' lives ("It's really good that we've done this [research] because its kept, that's a schedule for us as well you know" – John, C1). This was particularly important for Tracey, who spoke frequently about the significance of routine in her life ("My routine is up the spout at the moment [...] you've helped me with doing research" – Tracey, C1). Finally, the research served as a distraction from Covid-19, by providing co-researchers with something to focus on aside from the pandemic ("It's given me some focus... this has helped me focus on something other than sitting in the house, so it's given me something to do that is different" – John, C3).

### 9.3.2 Combatting isolation

Co-researchers discussed missing seeing their friends, family, and members of their programmes in person during the pandemic ("I feel a bit isolated from my friends" – Ella, C3). This is in keeping with previous research, which suggests that a lack of social contact was a common experience for adults with learning disabilities (Embregts et al., 2020), with more than double the number of disabled people reporting that they felt lonely during the pandemic (40%) than non-disabled people (18%; Office for National Statistics, 2022). Similarly, Bartlett (2022) found that the most common theme in stories created by adults with learning disabilities during the pandemic was "missing people".

Despite the virtual format of this project, co-researchers reported that being a researcher helped them to feel less socially isolated during extended periods of lockdown. Ella stated that Zoom calls helped her to feel less alone, even when she was physically home alone during the pandemic, demonstrating the potential for PAR to combat loneliness and facilitate feelings of connectedness to others:

When my mum went out, and I was on my own, when she went out it panicked me because I was in the house on my own, but [when] I had a Zoom meeting with you and the rest of the Purple Patch researchers, I wasn't on my own (C3)

Zoom research sessions also supported co-researchers to feel connected to others, including facilitating valued social time with pre-existing friends within the group. While many of the co-researchers reported communicating with friends and family via messaging services or phone calls throughout the pandemic, group Zoom calls enabled them to regularly see others outside of their household, which was deemed to be an important part of the social experience, as Tracey explained in cycle three: "If you wouldn't have been for the Zooms then me and John wouldn't have been able to see each other because most of that time he was in the house because of Covid-19."

Finally, attending research sessions provided access to people outside of the co-researchers' lockdown 'bubbles', enabling them to connect with new people they would not have ordinarily met while in-person social activities were not possible ("with lockdown, it's good to talk to someone outside of your environment" – John, C1). This resulted in the widening of co-researchers' social circles and provided access to a support network throughout the pandemic. Caton et al. (2022) interviewed adults with learning disabilities about their internet use during the Covid-19 pandemic. Findings identified social connections as a positive outcomes of internet use during this time, including the use of social media and doing activities online with others. The present study supports these findings and suggests that the online nature of this PAR project supported co-researchers' to combat loneliness and foster a sense of connection with others during extended periods of isolation.

### 9.3.3 Covid-19 support

The PRG formed the basis of a new virtual community and support network for co-researchers. While section 9.2.1 discussed the impact of engagement with the project on co-researchers' social networks more generally, this sub-theme pertains to the support provided by the group specifically relating to the pandemic. Co-researchers used research sessions and the research Facebook group as platforms to share and discuss their concerns and experiences around Covid-19. Discussions around the pandemic often took place at the beginning of research sessions as the group took some time to catch up and check in with each other. Common topics of discussion included: catching Covid-19, taking Coronavirus tests, self-isolation, missing friends/family/activities, vaccinations, Covid-19 restrictions, Covid-19-related fears/anxiety and the negative impact of Covid-19 on mental health and wellbeing. Previous research suggests that the pandemic had a negative impact on disabled people's wellbeing, with 79% feeling stressed or anxious, and 50% reporting that their mental health was worse due to Covid-19 (Office for National Statistics, 2022). 37% of disabled people also experienced depression during the pandemic (compared with 9% of non-disabled people; Office for National Statistics, 2022). In the present study, Tracey and John shared their feelings and experiences relating to extended periods of isolation, the loss of their regular activities and the impact of the pandemic on their wellbeing with the group:

Now we're in lockdown I'm really down in myself, because there's no swimming. I only go out once a week to shopping or post office, that's all I do at the moment – Tracey, C1

It was hard. It was really difficult, yeah. There's only so many sides to a room – John, C3

Members of the group also provided advice to each other on Covid-19 restrictions and the latest news around the pandemic. Researchers reported difficulties understanding changing

regulations and the news around the pandemic (“sometimes it’s hard [...] when I don’t know what the news means” – Ella, C1). This is in keeping with previous research, which suggests that adults with learning disabilities may have found accessing and/or understanding covid-19 restrictions challenging, resulting in anxiety for some individuals (Embregts et al., 2020). Peer-to-peer knowledge exchange in the present study therefore enabled co-researchers to share important information about the pandemic, in an accessible way.

In keeping with other PAR projects that took place during the pandemic, the present study found that members of the PRG provided active support and advice to one-another throughout the pandemic (De Castro et al., 2023). For example, by raising common issues, validating each other's feelings, discussing similar experiences and sharing Covid-19 updates. These experiences highlight the importance of access to support networks during the pandemic as well as the potential for engagement with PAR to provide access to new support networks and a space for co-researchers to openly discuss challenging topics.

#### 9.4 Research Identity

Becoming a researcher was described by the PRG as a “journey”. Throughout this journey, co-researchers were exposed to a variety of possible identities that were new to them (e.g. researcher, teacher, author). This theme introduces the new and possible identities adopted by co-researchers throughout the project.

##### 9.4.1 “I am a researcher”

During the project, members of the PRG experienced a shift in identity, from PPA participants to researchers. The adoption of this identity was a gradual process for most of the PRG and occurred at different stages of the project for different individuals.

The language used by co-researchers to describe themselves provides an indication of when members of the PRG began to self-identity as co-researchers. For example, in cycle one Ella states: “Maybe after I’ve become a researcher, I’ll use this [highlighter] for everyday life.” The quote demonstrates that at this stage in the research, Ella had not yet adopted the identity of a researcher. Instead, Ella referred to her future possible self as a researcher, indicating that while she believed that this role was a possibility, she had not yet “become” this version of herself. By cycle two Ella’s perception of her role in the project had changed: “I am a Purple Patch researcher, that helped me get my confidence.” This quote indicates that at this stage in the project, Ella had adopted the identity of a researcher and was using this new identity and the skills associated with it to support other activities in her life (in this case, an interview with Sky News).

Co-researchers described changes in mind-set, responsibilities and behaviour as a result of adopting the identity of a researcher. Co-researchers described “changing in themselves” and “becoming a new person” (Tracey, C3) through their involvement in PAR, such as Tracey, whose identity as a researcher led her to take on activities she had previously avoided: “English is my worst subject, but I will always give it a go now and I didn’t before, so that’s why I call it ‘a new me’”. Similarly, in cycle two Ella reported communicating a change in preference around present wrapping to her mum, which she attributed to her new research identity:

Ella: since I’ve been doing Purple Patch researchers, UR [...] I know how to give my mum instructions

UR: ah, you can give her instructions now?

ES: yeah, like say ‘don’t take it out the Amazon box, wrap it up in the Amazon box’ [...] before I became a researcher, she would take it out the box, look at it and just wrap it up [...] but now I am a researcher, I like her to do it a different way

By comparing her preferences from before she became a researcher to after, Ella suggests that her shift in mind-set is related to her shift in identity. Alongside this change of preference, Ella indicated a change in her communication style as a consequence of her new role as a researcher. This suggests that as part of Ella’s shift in identity, she adopted new strategies for expressing her opinions and preferences to those around her.

The role of a ‘researcher’ was considered to come with new responsibilities and opportunities for the PRG. Tracey took her new role as a researcher very seriously, comparing the new responsibilities she associated with research to a job (“I tried to work at \*shop\* [...] now I can’t work anyway... I’m helping you instead. Helping you is my job instead” – Tracey, C3). As one of the first members of the group to openly consider themselves as a researcher, Tracey demonstrated the impact of adopting this new identity on her priorities and decision-making outside of the project. For example, Tracey assigned herself a number of additional self-directed responsibilities, including writing two stories about her experiences in her spare time. Similarly, John considered his ‘responsibilities’ as a researcher in relation to others, recognising the potential benefits of sharing his experience and expertise with students: “I’m gonna help the people in the college or the schools to understand disability a bit more” (C1).

Being a researcher was described as a desired and valued role by the PRG. The PRG’s shift in identity was linked to a sense of pride, both in their association with their role as researchers (“I’m really proud of that [being a researcher] and I mean that” – Tracey, C3) and with the research itself (“I think we’ve done well with it [the research]” – Tracey, C3). Pride in their role in the research also contributed to the groups’ desire to share their new identity with others. For example, Ella shared her desire to share her identity as a researcher with her



old teachers from college: “I wish people at \*college\* would know I’m part of Purple Patch researchers [...] wait til \*teacher\*, my \*teacher\* sees what I’m doing now!” (C3).

Additionally, Sam discussed sharing her research work with family members in cycle one:

Sam: I spoke to my brother all the time, he’s asking, what you doing? [...] I showed him the picture what you asked for, and talked about the paper with the drawing  
[...]  
Janine: they live down in \*location\* so when we get to see them next, we’ll take everything with us and show them

Co-researchers also shared their ideas about the new behaviours and ‘accessories’ they may adopt as part of their researcher identity. This is demonstrated by Ella’s quote above, where she considers highlighters to be a research ‘accessory’ that she may incorporate into her everyday life, once this shift in identity has occurred. This association with particular objects as research tools may be because they were included in the research pack sent out to co-researchers at the beginning of the project (see section 3.4.4.1). The purpose of this pack was to ensure co-researchers had the resources they needed to participate in the project, but also to formalise their role as researchers and encourage them to consider themselves as researchers. The present study therefore suggests that providing co-researchers with the ‘tools’ to become researchers (e.g. through resources and training) can facilitate the shift in identity from participant to researcher.

As co-researchers gained confidence in their research skills and adopted the identity of a ‘researcher’, ownership and control of the research began to shift from the UR to the PRG collectively (“we’ve all led on it [the research] as equals” – Liam, C3). The present study followed the principles of inclusive research, as outlined by Johnson and Walmsley (2003), who suggest that adults with learning disabilities “should be able to exert some control over process and outcomes” (p.64). However, at the beginning of the project, control over the decision making and therefore a larger proportion of ownership, remained largely with the UR. For example, co-researchers were *invited* to work on the project by the UR. This implies a hierarchy in the research (i.e. that the UR was the leader of the group) regardless of the fact that co-researchers were told that all members of the PRG would play an equally important role in the project. Additionally, as the PRG had never conducted research before, the UR supported them through the process, and provided activities designed to facilitate the development of research skills. The idea of ‘teaching’ others therefore reinforces the hierarchical relationship of a ‘teacher’ and a ‘student’. The project was designed so that through the cycles of research, co-researchers would become more confident in their research skills and gradually adopt more responsibility and control of the project. Tracey

demonstrated this shift in ownership when discussing the research project during her interview in cycle three (“UR, it’s *ours*” – Tracey, C3). Navigating issues of power and control are discussed further in chapter 10.

As the project progressed, the PRG began to consider themselves as experts in research and recognised the value in sharing their experiences with others. For example, when reflecting on their strengths during the ‘in my shoes activity’ Tracey stated: “I have one for everybody: researchers.” The PRG connected over their shared identities as researchers and as PPA participants. While the PRG was innately connected to, and considered a part of the wider PPA community, the co-researchers considered the PRG as its own separate community, with its own team identity. Co-researchers shared their commitment to and sense of belonging to the PRG, often discussing their experiences with the research within the context of the group (“we did it as a group” – John, C3). Research learning experiences in particular were frequently discussed in relation to others (e.g. learning “as a group” and “from the group”). This demonstrated the development of co-researchers’ individual identities as a researchers alongside a group identity as the PRG. This finding resonates with Social Identity Theory (Turner & Tajfel, 1986), which highlights that group affiliation plays an important role in identity development. A key part of the PRG’s group identity became advocating for the inclusion of adults with learning disabilities in research, which will now be discussed.



Figure 49: Tracey holds up her 'I am a researcher' colouring sheet at the in-person research day

#### 9.4.2 Advocates

Through their role as researchers, the PRG became advocates for the inclusion of themselves and other adults with learning disabilities in research:

If there's a student who's planning to ever do some research, ask and do it with disabled people because you'll learn so much more – Liam, C2

If anything comes up with Purple Patch, or anyone else at the university, I think they should give disabilities a chance, people with disabilities – Tracey, C3

Co-researchers expressed a desire to challenge misconceptions surrounding the capabilities of adults with learning disabilities, by championing their strengths and those of other adults with learning disabilities (“Having a learning disability can offer something great” – John, C2). Similarly, co-researchers challenged ideas around who can be a researcher by advocating for the inclusion of adults with learning disabilities in research: “whatever you want to research, we, people with learning disabilities, we could help you” (John, C3).

Being a researcher and sharing their experiences of research with others was considered as a way to actively challenge the negative perceptions of others as Ella stated: “I want to prove people wrong [...] everybody thinks I can't do it. I learned how to do the research. I want to show them how I can do research”. Previous research suggests that adults with learning disabilities may experience negative attitudes, discrimination and

misconceptions around concerning their capabilities (Seewooruttun & Scior, 2014). PAR may therefore provide a platform for adults with learning disabilities to advocate for themselves, by sharing their skills and experiences with others and actively challenging the perceptions of others (Ham, et al., 2004). Alongside the role of an advocate, co-researchers discussed additional possible future identities relating to the research, which will now be discussed.

#### 9.4.3 Future selves

Co-researchers shared their ideas for their future, including research-related activities and identities they hoped they would adopt. Possible Selves Theory proposes that possible versions of oneself may be considered based on an individual's sense of self (Markus & Nurius, 1986). Projected future selves are based on an individual's understanding of themselves and their capabilities and may be 'expected' (who we think we can become) or 'desired' (who we would like to become).

Engagement with the present study resulted in the co-researchers' exploration of future possible selves relating to research. This included a desire to continue their role as a researcher ("I am really enjoying doing research so much, I can't wait do more in the future" – Tracey, C1; "I would literally do something like this year on year on" – Liam, C1). As part of their future roles as researchers, the PRG hoped to experience traditional academic spaces, such as visiting a university ("hopefully we can go to the university" – Tracey, C3). Additionally, Tracey shared her ideas for future research during her final interview in cycle three: "It [research] could be about what we do as a disability person, outside of our house of something". Tracey's consideration of future research projects demonstrates her proactive approach to her continued involvement in research.

Co-researchers also shared their desire to educate others about research, in the role of a teacher. This included teaching other adults with learning disabilities how to do research ("I think we could say we'll help other people to learn as well" – John, C3) alongside educating others about their research, including university students and staff, as John and Tracey discussed in cycle three:

Tracey: I think we should have a course about it  
 John: Yes, well we're having a course about research  
 Tracey: No, another course to teach people about what we've done  
 John: The research?  
 Tracey: Yeah

Finally, Co-researchers explored the future possible identity of an author as they considered the dissemination of the research via the research comic ("I'm gonna be like, a proper author!" - Ella, C3). Co-researchers' consideration of their future possible selves demonstrate

that co-researchers believed that research and the identities associated with it were an important part of their future. This suggests that engagement with PAR can impact both the current and future identities of adults with learning disabilities.

### 9.5 Fun

Participating in the research was described as fun and enjoyable experience by co-researchers (“This was a great big step for me, but I did it and guess what, I really enjoyed every minute of it!” – Tracey, C2). Different aspects and stages of the research were enjoyed by different members of the group. For example, during her final interview in cycle three Ella described enjoying the social side of the research (“it’s [research] good fun, you’ll get to meet people you don’t normally get to meet”), alongside engaging with previous literature:

UR: what have you enjoyed the most about being a researcher?  
 Ella: just looking at, do you remember when we looked at other researchers?  
 UR: yeah, I do  
 Ella: in the first, before we came up with our questions  
 UR: that’s right yeah  
 Ella: that’s what I enjoyed

It is interesting to note that activities co-researchers reported enjoying the most were often those designed by, or led by, members of the group. For example, the ‘In my shoes’ activity, which was designed collaboratively by the group in cycle three, was considered to be a fun and enjoyable activity by several members of the PRG:

John: it was a good thing  
 Liam: it was really good  
 UR: it was really good?  
 John: it was a getting to know you more session, that  
 UR: mhm. Yeah, what’s that Tracey?  
 Tracey: can we do another one like that?

In their ten top tips for engaging people with learning disabilities in research, Inglis and Cook (2011), note that having fun facilitated learning about research and supported engagement with learning activities. The present study suggests that fun alongside co-produced approaches to research may support engagement in research for adults with learning disabilities.

However, not all aspects of the research were described as enjoyable. In particular, technical issues with Zoom were cited as a negative experience in the research:

UR: what have you enjoyed the least about being a researcher?  
 Ella: I liked all of it

UR: you liked all of it?

Ella: you know, you know when we cut out on zoom first of all

UR: oh, yeah when we cut out on zoom, yep, yeah that wasn't very fun was it?

Ella: no

Additionally, Charlie suggested that “thinking of the right questions” (C2) was a challenging and less enjoyable aspect of research. Furthermore, as previously discussed, ending the research was considered be a less enjoyable stage of the project, as co-researchers expressed a desire to continue the research (“coming to the end, I’m afraid I don’t want it to end” – Tracey, C3).

## 9.6 Co-researcher case study

Themes pertaining to the outcomes of engagement with PAR for co-researchers have been reported as separate themes for convenience. However, co-researchers’ experiences transcended these themes, with the project impacting various aspects of co-researchers’ personal development, identity and social relationships at different stages of the project. The outcomes reported by co-researchers were often connected, developed in combination, influenced by each other and/or not present for every individual in the project. Additionally, the outcomes of engagement in the research were mediated by a range of external factors including: the co-researchers’ personality, perceptions and knowledge of research, goals for their involvement in the project, past experiences and perceptions of themselves. To demonstrate the overlap between the outcomes of engagement in the project reported above and to show a truer reflection of what engagement in PAR meant in reality for co-researchers, the following section will focus on Ella’s research journey. This case study is based on a compilation of Ella’s own words (shown in purple text). Black text indicates where the UR has added information to contextualise Ella’s experiences. For example, when quotes included below were provided in response to a specific question, the UR has included text relating to this question to contextualise Ella’s responses (e.g. “I joined the PRG because I’m interested about Purple Patch” – the UR asked Ella why she joined the PRG. Her response is included in purple and the black text “I joined the PRG because” is included to provide context to this response).

Quotes included in Ella’s research journey were captured across all three cycles of research and have been grouped thematically based on the outcomes of engagement with PAR identified by the UR. Quotes were therefore not always spoken in the order presented, but provide an overall picture of Ella’s experiences as a researcher.

### 9.6.1 Ella's Research Journey

I am Ella, I go to the [REDACTED] Purple Patch group. I also enjoy being part of other groups. I joined the PRG because I'm interested about Purple Patch. I wanted to get more confidence and improve my speech. Before being a researcher, I felt nervous, [...] I didn't know, who was on my research team. I had never done research before, and I felt medium confidence about being a researcher.



Figure 50: Ella's research confidence rating at the beginning of the research: 'medium'

#### Research Skills and experience

I helped with setting questions, help to narrow it down, the questions down (that's a new thing I learned) and doing analysis. When we looked at other researchers, in the first, before we came up with our questions, that's what I enjoyed, so I know what I was getting in to. I didn't like when we cut out on zoom first of all. Thinking wasn't hard, it was the time, knowing what time I needed to log on to Zoom.

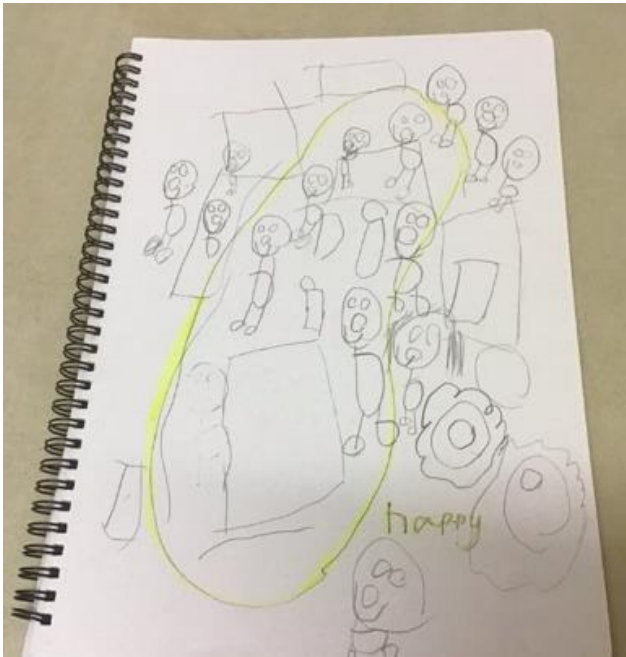


Figure 51: Ella's research work for the 'in my shoes' activity

### Personal development and overcoming challenge

I learned skills I didn't know I did, I had like confidence skills and independence skills. Doing the research gave me confidence to do the interview with Sky News. I got more confident by just chatting to my team every week, and then I put my certificate up, I got from Purple Patch [...] I wanted to share that with the group. What helped my independence was making new friends. It has taught me [research] a bit about organising stuff, so now I've got a system. I go and check things on Facebook every morning when I wake up, so that's how I know I've got a Purple Patch research meeting. Every time I finish at Purple Patch researching session, I put it [research journal] back on my desk. During the research I asked UR am I doing well? She said yes. We did some analysis and I thought, I don't get it, why am I thinking so much today! Where are my good ideas coming from today? When we do the research, nobody is wrong, we're doing it all together.

### Combatting isolation in Covid-19

When I heard about the pandemic it panicked me, and when my mum went out, and I was on my own. When she went out it panicked me because I was in the house on my own, but I had a Zoom meeting with you and the rest of the Purple Patch researchers, I wasn't on my own.

### Working and communicating with others



Since I've been doing Purple Patch researchers, I know how to give my mum instructions [...] like I say 'don't take it [presents] out the Amazon box, wrap it up in the Amazon box [...] before I became a researcher, she would take it out the box, look at it and just wrap it up, but now I am a researcher, I like her to do it a different way.

### I am a researcher

This girl \*name\* said I won't, I weren't able to be good at anything. Everybody thinks I can't do it. I learned how to do the research. I want to show them how I can do research. This book is going to get published. I'm gonna be like a proper author, like the author who wrote Peter Pan. I wish there were other researchers with learning disabilities. Will they ever write about my story about being a researcher?



Figure 52: Ella's research confidence rating at the end of the research: 'high'

## 10 Reflections on PAR from the perspective of a non-disabled researcher

Alongside reflections on engagement with research from the perspective of adults with learning disabilities, the third aim of this study sought to explore the outcomes of engagement in PAR from the perspective of the non-disabled UR. Recent accounts of the experiences of non-disabled participatory researchers provide useful insights into the process of conducting PAR and therefore valuable learning for future PAR with adults with learning disabilities (Liddiard et al., 2018; Smith et al., 2022). This chapter aims to contribute to this literature, by sharing my experiences as a non-disabled researcher undertaking research with adults with learning disabilities through the lenses of the various roles I occupied throughout the project. Discussions about the decisions and considerations relating to these roles provide an insight into the key responsibilities, opportunities, barriers and challenges of PAR with adults with learning disabilities.

The role(s) of the participatory researcher is often considered as ambiguous and there are numerous understandings and opinions as to what these roles should be (Conder et al. 2011; Walmsley, 2004). Johnson and Walmsley (2003) note that it is important for everyone involved in participatory research to understand their role; when roles become muddled, the result is often confusion and/or a lack of focus on the voices of disabled co-researchers. While understanding one's role and positionality is crucial, I found the role of a participatory researcher to be multi-faceted, complicated and something that I questioned throughout the project. The responsibilities, positions, and questions that I found myself encountering during this project differed considerably to those I had experienced in non-participatory research projects. Participatory researchers may therefore find themselves filling roles that they were not initially expecting or that may not be explicitly related to that of a traditional researcher.

Negotiating my role in the project involved reflecting on and balancing a number of factors, including: power and control, perceptions of hierarchy, academic rigour versus accessibility, varied expertise, experiences and identities, responding to the interests, and needs of the PRG and the demands of doctoral research. It was also necessary to reflect on and adapt my role throughout the project to support the various roles undertaken by the PRG. This process of constant self-reflection on my position within the project often resulted in uncomfortable and challenging questions and conversations:

I realised quickly that constant self-reflection was required throughout the project. This was more often useful than not, but has also forced me to confront some challenging and

potentially uncomfortable questions: what is my place in this research? Is my voice needed at this point in the project, or ever? How much say should I have? Finding my place as a non-disabled researcher in a project highlighting the experiences of disabled people was not simple, and there were times where I wondered if I should be involved at all – UR reflections (C3)

In reality, the role(s) of a participatory researcher vary depending on the context, discipline and needs of the co-researchers involved. Some roles may be more prominent at different stages of the research, experienced in isolation or in combination with each other and may also be subject to change throughout the project. It is crucial for participatory researchers to carefully and continuously reflect on the role(s) that they are occupying in the research, since this will impact the approach to the research, the level of possible collaboration, the experiences of co-researchers and the project outcomes. The present study suggests that an awareness of the range of roles and responsibilities undertaken by participatory researchers and how these interact will support others to have a greater understanding of what it means to undertake PAR with co-researchers with learning disabilities.

In addition to this, exploration of the roles of a participatory researcher provide a chance to reflect on the opportunities, facilitators, barriers and challenges of this approach to research. Many of the opportunities and challenges of PAR identified in previous research concerns the collaborative relationship between the UR and co-researchers, including the balance of power and development of trust (Conder et al., 2011; Gilbert, 2004). Part of the responsibility of a participatory researcher is therefore to negotiate and mitigate these challenges, while attempting to enhance the opportunities of this approach. However, Phillips and Kristiansen (2013, p. 257) suggest that previous literature may “romanticise” collaborative research by overlooking the challenges and tensions in the research process. Indeed, Johnson and Walmsley (2003, P.14) state:

To suggest that inclusive research is easy, always positive and fulfilling for all parties would be a fairytale [...] we believe that there are real difficulties in undertaking inclusive research for the researcher as well as for people with learning disabilities

While there were many positives to undertaking PAR, the process was also challenging, and the UR and co-researchers experienced a range of barriers throughout the project. It is crucial for URs to not only acknowledge the challenges and opportunities of inclusive research, but also to consider the impact of their role on the ways in which these challenges and opportunities are realised and experienced within the project.

With this in mind, sections 10.1-10.7 will explore the eight roles identified through my reflections from this project, these are: ‘Researcher’ (and ‘Doctoral Researcher’), ‘Equal’, ‘Facilitator’, ‘Supporter (and friend)’ and ‘Advocate’. The final role ‘Being you’ concerns the

impact of the participatory researchers' personal characteristics and experiences on the project. Additionally, the opportunities and challenge of PAR will be considered through the lenses of these roles. Extracts from my research journal entries from key stages of the project are included in order to provide context to the discussions regarding my role as non-disabled researcher in research that focuses on the experiences of disabled people.

### 10.1 Being a researcher

The first and most obvious role fulfilled by a participatory researcher is that of a researcher. While this may be a role that many researchers are familiar with and expecting, the approach to being a researcher is fundamentally different in PAR projects, since this role is a shared one. A key goal of PAR is that members of the community, who are ordinarily excluded from research (in this case, adults with learning disabilities), are recruited as co-researchers and equally valued members of a research team (Johnson & Walmsley, 2003). This means that URs in PAR projects must consider the boundaries and responsibilities of their role carefully at each stage of the research by considering what is needed and by whom. Sharing the role of the researcher also required me to carefully consider the distribution of power and control in the project (discussed further in section 10.2).

Participatory researchers who are not members of the community who they are collaborating with may be considered as outsiders within the project (Herr & Anderson, 2005). In the present study, my identity as a non-disabled, neurotypical researcher from outside of the PPA community influenced the co-researchers' perceptions of me and my role in the project. It was important to recognise that I shared identities with individuals with whom the PRG had had negative previous experiences with and that this influenced the co-researchers' interactions with me ("I don't mix with normal people, ha, not like you" – Tracey, C1). Indeed, previous research has acknowledged that past negative experiences with others impacted adults with learning disabilities' expectations surrounding how they would be treated in the future (Kenyon et al., 2013). While my experiences as a support worker meant that I had a good understanding of and experience working with people with learning disabilities, it was still important for me to prove myself as an ally to co-researchers. Acknowledging my position in the research and what the role of a researcher may represent for those who have often been excluded from research and from society, was therefore crucial in order to work collaboratively.

Additionally, research institutions and those associated with them may be viewed as unfamiliar, untrustworthy and/or alienating (Oliver, 1992). While none of the co-researchers had been a researcher before, co-researchers reported negative experiences relating to university-run events and academic researchers (e.g. the accessibility conference described

by John in section 6.3.2.1.1). This presented both an opportunity and a challenge. Negotiating potentially negative views of research and researchers was initially challenging and I recognised the importance of my role in ensuring that co-researchers' experiences of the research were positive. However, I also had the opportunity to influence co-researchers' perceptions of research, to encourage their future engagement with research and therefore to support a more inclusive and diverse research community.

Naples (1996) notes that insider-outsider roles in research are not fixed, but rather "ever-shifting" (p.84). Throughout the project, I worked to develop trust with co-researchers and PPA staff and move towards the role of an 'alongsider' (Carroll, 2009), whereby researchers with and without learning disabilities work and learn alongside each other (Chalachanová et al., 2020). This was a gradual process, which was supported by taking time to get to know co-researchers/staff members, building understanding of their interests and needs and facilitating an environment where co-researchers felt able to have open and honest conversations. My initial position as an outsider in the project was also mitigated by the fact that I was introduced to co-researchers by PPA and was therefore 'Purple Patch approved'. This highlights the benefits of working with a trusted partner organisation, particularly when working to develop relationships with co-researchers as an outsider.

Overall, as a researcher entering the PPA community, it was important to acknowledge and respect co-researchers' perceptions of researchers, non-disabled people and research. Over time and through open conversations, support, and listening and responding to the PRG's interests and concerns, I feel I was able to become a trusted member of the PPA community. Trust and the development of strong relationships within the PRG were the first and most important step towards co-developing research as equals.

#### 10.1.1.1 Being a doctoral researcher

It is important to consider the wider context of this research, as part of a doctoral research project. My role and responsibilities in the project were therefore influenced by my identity as a Postgraduate Researcher. In particular, many of the challenges within the present study related to tensions between PAR and doctoral research.

Firstly, the time constraints of doctoral research limited what was possible in the present study. Previous literature has acknowledged that PAR, and particularly the development of relationships with excluded communities, takes time (Baum et al., 2006; Byrne & Miller, 2009). However, time within doctoral research is limited and therefore the research must meet the timeline of the PhD. As noted in previous research (Huisman, 2008; Mason, 2023), I experienced an internal conflict between the need to adhere to the pre-

established timescale of the PhD, and the desire to take the time required to conduct meaningful research with my co-researchers. While I modelled the timeline of the project on the term dates of PPA, to provide a familiar structure to co-researchers, each stage of the project took longer than I initially expected. In particular, the processes of 'ending' the project required a much larger time commitment than I had first anticipated<sup>12</sup>. Doctoral researchers may mitigate some of these time-related challenges by building flexibility into the research process and planning for additional time for research sessions where possible.

The time constraints discussed above resulted in some aspects of the project being undertaken in a manner which was less collaborative. An example of this is the independent analyses undertaken by the UR. This was necessary due to limited time in the project and the amount of time required for effective collaborative analyses. However, I felt uncomfortable that this aspect of the project was not led by co-researchers as this felt at odds with the goals of PAR. Despite attempting to involve co-researchers as equal partners in all stages of the project (discussed further in the following section), conducting PAR within the context of a PhD meant that co-researchers were excluded from some stages. For example, University of Leeds' ethical procedures required me to complete an ethical review detailing the overarching aims and approach of the project prior to the involvement of the PRG. Therefore, co-researchers were not involved in these early decisions concerning the development of the project. Of course, ethical procedures are imperative to ensure that populations who are considered to be vulnerable are protected throughout the research process. However, this process of protection also excludes adults with learning disabilities from being involved in the initial stages of PAR. This results in a 'chicken and the egg' situation for URs who wish to actively involve people with learning disabilities in the design and implementation of a project, but must first complete an ethical review in order to access this population in line with the university's ethical procedure. In the present study, my initial ethical review detailed the planned participatory approach to the project and included information concerning recruitment and the overall protection and safeguarding of co-researchers throughout the study. However, I was clear that the specific questions and methods utilised in the project

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<sup>12</sup> A range of factors influenced how long different stages of research took, including how familiar research processes were to co-researchers (e.g. in cycle one I spent more time explaining key concepts than in cycle three) and how complex the research stage/activity was (e.g. deciding on research questions took less time than analysis). Additionally, the lack of other activities/social opportunities during the pandemic meant that a large amount of time in each research session was used to provide support and opportunities for socialising. While this was exacerbated by the pandemic, previous research has stated that PAR may become a site for the development of close relationships (Nind, 2017). Therefore, URs may need to incorporate social time into research sessions to avoid delays to the research as a consequence of not anticipating the social element of PAR.

would remain unknown until my co-researchers were recruited. Multiple ethical amendments were therefore required, resulting in a time-consuming and continuous ethics process. Future research should investigate how institutional ethical procedures may be adapted to support effective PAR (e.g. by designing an ethics process which includes and is accessible to co-researchers).

Writing the thesis was undoubtedly the least participatory aspect of the research that I undertook as part of my role as a doctoral researcher. This aspect of the PhD directly conflicted with the goals of inclusive research, namely, that research outputs should be accessible to co-researchers (Johnson & Walmsley, 2003). Since the thesis is a traditionally inaccessible document (“we won’t understand it [thesis]” - Tracey, C3) I attempted to mitigate this by supporting the PRG to co-produce a research comic as an accessible research output for the project. An opportunity of PAR is therefore the potential for doctoral researchers to develop creative research outputs, which are accessible to a wider audience. However, the development of such research outputs requires a substantial time commitment (and potentially additional funding), which I had not initially anticipated. Doctoral researchers hoping to utilise PAR should therefore be aware that they may need to produce multiple outputs for the project, to retain the participatory approach within the dissemination stage.

Seymour and Garbutt (1998, p.1) note that “the individualised construction of research degrees such as PhDs [...] requires a thesis to be the exclusive product of one individual”. Co-researchers expressed a desire to contribute to the thesis (“[Do] you need something to do with the writing bit?” – Tracey, C3). However, it was not possible to co-write the thesis, since this document is submitted as part of the requirements of a qualification and only one person in the research team can receive a PhD (Seymour & Garbutt, 1998). This highlights the additional challenge of PAR within the context of doctoral research, whereby me and my co-researchers did not have access to equal opportunities within the research sector (e.g. payment, reputational development or qualifications, which acknowledge their role in doctoral research; Nind & Vinha, 2014). For this reason, there is a risk of PAR becoming exploitative, as co-researchers share their expertise for limited or no official recognition (Edwards & Alexander, 2011).

There were of course benefits to conducting PAR within a PhD, for both myself and my co-researchers. In particular, the learning opportunities for all members of the team (discussed further in section 10.4) and ongoing relationships (with co-researchers, PPA and me), which were developed through the project. Utilising PAR centralised the expertise of those with lived experience, which supported this project to gain meaningful and applicable insights into the PRG’s experiences and to make real change in co-researchers’ lives.

However, in order to fully support participatory approaches within PhD projects, issues such as fair compensation and appropriate recognition of the contributions made by co-researchers must therefore be addressed. The present study suggests that while these challenges of conducting PAR within the context of a PhD can be mitigated by the doctoral researcher, change to the research sector is required to ensure that PAR projects can meet their full potential in academic settings. It is therefore important for academic institutions to understand that processes and practices may need to be adapted when undertaking PAR in an academic context.

## 10.2 Becoming an equal

Herr and Anderson (2005) describe action research as “designing the plane while flying it” (p.69). However, since a key goal of PAR is to actively collaborate with those who are ordinarily excluded from research, I argue that a more accurate description of PAR is ‘co-designing the plane, while co-piloting it’. In order to ‘co-pilot’ research effectively, URs must address the power imbalance and hierarchy that traditionally occurs in research with disabled people. Garcia-Iriarte et al. (2009) suggest that the active involvement of co-researchers does not equate to control in the research. The level of ownership co-researchers have within the research may instead be impacted by the level of support which is provided to co-researchers. PAR therefore requires URs to actively facilitate the equal distribution of power among all parties involved (Chappell, 2000).

Becoming an equal is a gradual and ongoing process, which challenges URs to relinquish control of the research design and process (Chapman & McNulty, 2004). Sharing responsibility for the direction of research can be challenging and time-consuming, since decisions are made jointly (Cook, 2012). However, the equal involvement of adults with learning disabilities in the project provided additional opportunities to learn from experts by lived experience, and to design research that was more meaningful and equitable for co-researchers. In order to facilitate a shift in control from myself to co-researchers with lived experience, I faced a series of decisions concerning how to support co-researchers to feel confident to take ownership of the project. These included when to offer suggestions and guidance and when to take a step back from the decision-making process (without co-researchers feeling abandoned in the process). Through open conversations with the PRG, we sought to create a dynamic which valued everyone in the project as equal contributors, built understanding and affinity, and supported co-researchers to take control over the design and implementation of the research:



Some of the best things that have come out of the project have been suggestions that other people have made and when they [co-researchers] first said them, I thought, 'oh I'm not sure if that's gonna work', but actually they have, so it's been, um, um, a good lesson in letting go of some control (UR, C3. Extract taken from final interview with Tracey)

As a first-time participatory researcher, I had a limited understanding of what collaboration and ownership would look like at each stage of the project and initially felt disheartened when the research process was not as participatory as I had hoped. For example, in cycle one, analyses of the data were less of a participatory process, with co-researchers fulfilling the role of consultants who checked the analyses conducted by the UR (see section 4.3.1). This initially felt at odds with the goals of the project. However, I quickly realised that shifting control over the research process was not something that could be rushed. In the early stages of a PAR project, it is natural that co-researchers may feel that they do not have the experience or expertise to fulfil the role of a researcher and may therefore not identify as a researcher. In the present study, the process of building research confidence and identity was gradual (as discussed in section 9.4). It is important to acknowledge that co-researchers may consider themselves as outsiders of the research community, due to the lack of inclusivity in the research sector, the lack of representation of adults with learning disabilities in research roles and their initial lack of research experience. The present study suggests that ownership and control in PAR are not static, but rather can shift throughout the research process as disabled co-researchers gain more experience, confidence and begin to feel part of the research community. This was evident in the present study through the increase in control over specific research tasks in the project. For example, table 4 in section 3.5.2.1 outlines the level of involvement of co-researchers in the analyses stage of each cycle in the project, demonstrating the increase in the co-researchers' level of control as the project progressed.

An important aspect of becoming an equal in participatory research is acknowledging the barriers that may prevent co-researchers from exerting control over the direction of the research. Firstly, despite efforts to remove traditional hierarchies that exist in research, it is impossible to remove these hierarchies completely. In the present study, I, alongside PPA, initiated the project and co-researchers were recruited into their role. The fact that co-researchers entered the research after the project was conceived may have contributed to a sense of hierarchy within the project. Additionally, since co-researchers had never undertaken research before, the PRG considered me as the expert in research. It was therefore important to highlight the varying expertise in the group, and to be honest about the boundaries of my own expertise and experience. An important part of the UR's role is

therefore to acknowledge and discuss the varied expertise, experiences, ideas and expectations that various stakeholders in the research may bring to the process:

As the project went on, I began to view my role as a researcher differently. The PRG became a place for the exchange of expertise and teamwork. My co-researchers gave up their time to share their experiences and expertise in learning disabilities and accessibility in research and I shared my expertise around research design and implementation. By the end of the project, we were most definitely a team, and each individual was valued equally for their contribution to the project - UR reflections (C2)

Collaborating as equals in research also involved being receptive to being questioned or challenged by co-researchers. For example, while being interviewed by Tracey in cycle three, Tracey challenged my description of traditional power dynamics in research when compared to this project:

UR: as a researcher, you normally, you have all the control, normally, like if I wasn't working with a group of people it would be my project, I would make all of the decisions, I would be, you know...

Tracey: UR, its *ours*

UR: exactly, and this is the, this is the thing. And that's why I think that it's been an important, an important experience. But it's quite different to any other research project I've ever done

This was a positive challenge, as it meant that Tracey felt that the group collectively owned the research, which is of course the aim of PAR. Additional experiences of being challenged in the project included challenging my own understanding and assumptions. For example, due to my own misconceptions around what adults with learning disabilities may find challenging, I wrongly assumed that co-researchers would prefer the visual arts-based task when creating their Purple Patch Worlds, as opposed to the writing task. However, all but one of the co-researchers chose to write a story. This highlights the importance of self-reflection when creating an environment where all co-researchers are equally valued, to ensure that UR's do not unknowingly and/or unintentionally limit co-researchers based on preconceived ideas of what they may prefer.

While PAR attempts to facilitate equal relationships in the research, as discussed previously, URs still have access to additional opportunities, including recognition, pay and qualifications that co-researchers do not currently have access to due to systemic issues that exclude adults with learning disabilities from equal opportunities in the research sector. For example, since this research was funded by the Leeds Doctoral Award, I received a stipend for my role in the research, whereas my co-researchers were not financially compensated for

their time<sup>13</sup>. URs may also have additional research responsibilities (e.g. funding and ethics applications, progress reviews/supervisions). These research tasks often involve processes which are inaccessible, and therefore it is difficult to include co-researchers. This demonstrates that becoming an equal within PAR may be influenced by the inaccessibility of research processes and practices and the limited available incentives for co-researchers.

While attempting to remove hierarchies in the research, it may feel counterintuitive to distinguish between the roles of co-researchers and the UR. However, through the present study, I learned that transparency around the inaccessibility of these tasks and the differences in opportunities available to URs and co-researchers was important in order to support group cohesion. An important part of my roles was therefore balancing transparency (e.g. via open and honest conversations about all aspects of research, including the potential barriers, challenges and complexities) and safeguarding co-researchers from inaccessible and exclusionary experiences. Through my attempts to protect co-researchers from the negative aspects of research, I initially opted to 'keep things simple' by avoiding discussions about more complex aspects of the research process. There are, of course, challenges to explaining complex research topics in an accessible and engaging way for adults with learning disabilities. I was also aware that discussing less accessible research processes may highlight the lack of inclusivity in the research sector, and in doing so, may negatively impact the PRG's perceptions about who can do research and who research is for. However, instances in the present study where research concepts or processes were not fully explained often resulted in confusion and consequently required additional time to clarify. For example, throughout the project, the PRG understandably expressed interest in 'the book' (thesis) that the UR was writing about the research. Members of the PRG shared their desire to own and share copies of the thesis, as well as for others to buy a copy of 'the book' ("Need more information of when people can buy books of all of our hard work" – Tracey, C2). Since the UR had described the thesis as a 'book' from the beginning of the project, it was understandable that the PRG would assume that the thesis was similar to other books they had encountered. This is one example of where not fully explaining more complex aspects of research resulted in a misunderstanding, in this case about the purpose and content of a thesis. It was therefore ultimately beneficial to take the time to break down complex topics to ensure that co-

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<sup>13</sup> It is considered best practice to pay disabled co-researchers for their time and expertise, and the lack of financial recognition for the PRG was not something I felt comfortable with. However, there are a number of barriers to payment, including a lack of funding available to doctoral researchers to pay co-researchers adequately and systemic barriers, such as the potential negative impact of paying those in receipt of benefits. Since many research opportunities are fixed term, it is crucial that URs carefully consider and discuss the long-term impact of financial reimbursement for adults with learning disabilities involved in research. Additional research is needed to explore the best ways to recognise the contributions of researchers with learning disabilities.

researchers were fully informed and had a greater understanding of what they could expect from different stages of the project.

Becoming an equal is not only crucial for the PAR process, but also for enabling opportunities for reciprocal learning (Smith et al. 2022). A strength of PAR projects are the varied learning opportunities that are facilitated by collaborating with communities with varied experiences and expertise. Becoming an equal therefore promoted the exchange of expertise, allowing research to be rooted in community knowledge and lived experience, while promoting a more equitable research environment. The manner in which research sessions were facilitated had a direct impact on the effectiveness of collaboration in the project. My role as a facilitator in the project will now be discussed.

### 10.3 Being a facilitator

Since participatory projects often involve individuals who have never been involved in research before, URs, at least in the first instance, often fill the role of a facilitator. Previous research notes that the role of a participatory researcher involves “providing methodological tools and skills to others involved in the research project” (Seymour & Garbutt, 1998, p.3). In cycle one in particular, it was important to take the time to break down key concepts and research terminology (e.g. research questions, methods and analysis) so that co-researchers were familiar with the research process and understood the kinds of activities we might do at each stage and cycle of the project. To support this, and the recruitment of co-researchers, I developed a series of animated interactive videos, which sought to introduce the research process and key research concepts to co-researchers. However, co-researchers developed research skills mainly via hands-on experience and active involvement in the process of conducting research. Nind et al. (2016) describe this approach to learning research skills as the apprenticeship model, whereby co-researchers work in collaboration with a more experienced researcher. This approach to learning research skills echoes Kolb’s (1984) writing on Experiential Learning Theory, which suggests that knowledge is constructed based on real-world experiences. Co-researchers’ research skills, knowledge and experience grew throughout the project based on their practical experiences. Gradually, my role as a facilitator therefore adapted to that of a co-facilitator, as co-researchers took greater ownership over the research process. Co-researchers began to facilitate aspects of the research process, by supporting the understanding of their peers, initiating and designing research activities (e.g. undertaking final interviews) and considering the future of their involvement in research, as discussed in section 9.4.3.

In the present study I facilitated/co-facilitated 57 research sessions designed to

support the PRG to develop their research skills and confidence, and make decisions concerning the design and implementation of the research. In my role as a facilitator, I negotiated various practical considerations, such as scheduling research sessions around the varying availability of group members, supporting the PRG to access Zoom and online resources via the Facebook group and responding to questions from co-researchers. Online research sessions presented technical challenges (“It [Zoom] kept freezing like you just then. Or logging ourselves off” – Tracey, C3). However, in line with other online PAR projects, the online format of the present study reduced barriers to participation for the PRG, such as transport and finding a suitable time for the group to meet (Allam et al., 2023). A full discussion of the strengths and limitations of online PAR is beyond the scope of this study. However, future research should consider the opportunities of online PAR to support the involvement of co-researchers with learning disabilities.

Facilitating an equitable research environment also involved developing inclusive research activities and adapting/re-constructing resources and methods to be more accessible to adults with learning disabilities (including individuals who communicate non-verbally). For example, by: adapting easy read literature; utilising arts-based and creative methods to co-design new approaches to capturing co-researchers’ experiences; adapting traditional research methods and materials (such as questionnaires in C2 and C3); and reconsidering what academic outputs should look like, through the co-creation of the research comic. Additionally, I utilised aspects of the PPA approach and activities which co-researchers were familiar with (such as the creation of acrostic poems in cycle three). The online nature of the project imposed limits on the ways creative methodologies were used throughout the project, since the group were not able to physically meet until the end of cycle three. However, many activities were adapted for the online context (e.g. by using the features of Zoom described in section 3.4.5 to aid interactivity) and by providing co-researchers with creative supplies so that they could engage with arts-based methods from home. URs therefore have the opportunity to contribute to the development/co-development of inclusive and innovative approaches to research, which support the involvement of adults with learning disabilities in research. Resources and activities were developed in real-time throughout the project, in response to co-researchers’ suggestions, preferences and needs. The role of a facilitator in PAR was therefore a time-consuming but crucial role, which centred around ensuring co-researchers could access and fully engage with the research process:

Each session needed to be planned so that it was accessible to co-researchers, and this often included designing accessible resources to support sessions, or for co-researchers to use in-

between sessions. PAR can therefore be extremely time-consuming, and one of the biggest challenges I experienced was the relentlessness of planning, delivering and reviewing research sessions across the year, while keeping up with messages and posts from co-researchers on social media - UR reflections (C3)

Light and Akama (2012) state that the UR's style of facilitation can help to create a safe space where co-researchers feel able to share their views and experiences. Creating a safe space within a research context involved building rapport with co-researchers and allowing for additional time and flexibility to ensure co-researchers had the space to share their experiences. While there was generally a high level of agreement within the PRG, occasionally co-researchers disagreed. For example, in cycle one, Tracey and Liam disagreed about to how to answer a question concerning whether co-researchers had made friends at PPA:

Liam: it's simple, like a yes/no question

Tracey: it isn't really Liam because at Purple Patch you're with people like yourself, with disabilities

A key part of my role as a facilitator was therefore to encourage co-researchers to share their diverse views and opinions while managing differences of opinion within the group, to support group cohesion.

Despite the challenges associated with the role of a facilitator, I found this role to be enjoyable and rewarding:

Tracey: are you enjoying teaching us how to be a researcher?

UR: definitely yeah! I think it's been really fun to, um, to, talk about research [...] and work out the best way to do it because we've got different people in our group with different needs and different personalities. And um, and I think it was quite fun to think about how you know, how do we break down something that could be quite difficult and complicated and make it a bit more simple so that everyone can get involved, and it makes me really proud when I see you all doing it

Being a facilitator supported new learning opportunities for me as a researcher, including skills relating to making research more accessible and collaborating with disabled co-researchers. The role of the UR as a learner will be discussed.

#### 10.4 Being a learner

One of the opportunities of inclusive research is to facilitate new learning experiences for and with individuals who may a) have limited access to opportunities for LLL and b) may have limited opportunities to develop research skills. However, PAR also provides opportunities for the UR to learn from co-researchers' varied experiences and expertise and to develop skills in participatory research facilitation. In the present study, I simultaneously fulfilled the role of

both a facilitator and learner. While the PRG learned research skills and developed a greater understanding of the research world, I learned from their lived experience, their perspectives on research, accessibility and inclusion and their goals for the future. An opportunity of PAR is therefore that URs have the chance to learn from those with direct expertise, while developing skills which aid an inclusive learning and research environment. My experiences are comparable to other URs collaborating with adults with learning disabilities. For example, Conder et al. (2011) state that “researchers were themselves enriched by the learning that they received from the co-researchers” (p.47). This highlights the importance and value of fulfilling the role of a learner.

Reinforcing the idea of a shared learning experience, whereby everyone in the project is both ‘teaching’ and ‘learning’, tackled some of the hierarchical connotations of the roles of a ‘facilitator’ or ‘researcher’:

Liam: I’m excited by this journey  
 John: a journey, that’s right  
 UR: it is a journey yeah, it’s definitely a journey and I’m learning as I go just like you guys so thanks for coming with me!  
 John: you’re welcome!  
 Liam: yeah, you’re welcome UR

In order to facilitate an equitable research environment, it was important to highlight that everyone in this project was an expert in something. To reinforce the idea of the UR as a learner, we discussed our expertise openly as a group:

UR: what do we want to say about access first of all?  
 Tracey: well, John is the expert

Additionally, we looked at previous literature which focused on the exchange of expertise between non-disabled people and adults with learning disabilities. In particular, White and Morgan (2012) provided a useful example of how URs and researchers with a learning disability learned from each other in their project about everyday literacy of adults with learning disabilities:

John: having a learning disability can offer something great  
 UR: yeah, definitely  
 John: that’s what I think  
 Sam: can help... someone, maybe...  
 Janine: helping them, yes  
 Sam: maybe, she might be helping Emma with...  
 Janine: Michelle was helping Emma, but then Emma was helping everyone else to understand how she was  
 [...]

UR: they said in the paper that Michelle was an expert in research [...] so she was teaching Emma about that, but Emma was an expert in having a learning disability, so she was an expert in that, so she was teaching Michelle about that

Nind (2014a) positions learning within PAR as a social endeavour, noting that for her, becoming an inclusive researcher was a shared commitment among the group, where everyone learned with and from each other. PAR teams may therefore become a research Community of Practice. United by our shared interest in understanding the arts-based learning experiences of PPA participants, the PRG co-created knowledge and research skills through collaboration and regular social interactions. Together we developed methodologies, tools, stories, recommendations and outputs, within real-world research scenarios. The development of research Communities of Practice is not a new concept. However, future research should further investigate the development of CoP within PAR projects, to fully understand the learning potential of PAR.

#### 10.5 Being a supporter (and a friend)

A key aspect of the role of a participatory researcher is that of a supporter. In the present study, support took many forms, including practical support, research support and emotional/personal support. In the first instance, I supported co-researchers to access research sessions by providing practical support. This included providing guidance on accessing and utilising Zoom and the Facebook group, alongside sharing research session timings/information about sessions in advance and providing recaps of research sessions to support co-researchers' engagement with the project.

Research support included any support provided by the UR that facilitated the PRG's engagement with the research itself. This included creating a supportive research environment. As previously discussed, the environment in which learning takes places was a key part of creating accessible environments for adults with learning disabilities. Building shared understanding and affinity was crucial to the development of a supportive research environment. I supported co-researchers to create community guidelines for the PRG Facebook group and research sessions. I also supported co-researchers to share their views and opinions (e.g. by asking and responding to questions, offering choice/options and encouraging co-researchers to share their views), to work together, and to develop their research skills and experience (e.g. by adapting activities and information to meet co-researchers' needs and preferences, explaining key research concepts and providing time and space for co-researchers to gain hands-on experiences).

Some adults with learning disabilities may require additional support to access



research, beyond that provided by the UR. For example, in the present study, Charlie and Sam were supported to share their views by their carers/parent Jo and Janine. Jo and Janine were heavily involved in the research and dedicated a significant amount of time to supporting Charlie and Sam, both within research sessions and outside of sessions with independent research activities. Willingness and encouragement from carers may therefore be crucial for adults with learning disabilities who require one-to-one support to actively participate in research. However, it is important to consider that support staff may feel they lack relevant experience and knowledge required to support adults with learning disabilities to participate in research. Consequently, concerns from support staff may prevent participation in research for adults with learning disabilities. It is therefore important to ensure that carers involved in PAR understand their role and what may be expected of them during the research (including the fact that knowledge of research is not a requirement for good quality support). The role of the UR as a supporter, may therefore extend to those supporting co-researchers within the project. Engagement with PAR may also provide opportunities for carers to experience new roles, as co-facilitators of the research process. Janine noted during cycle three that involvement in the research became a positive learning experience for herself as much as for her daughter, Sam (“It’s all just so exciting!” – Janine, C3). At the time of writing, there is very little guidance specifically for carers on how to support an adult with a learning disability to access research and what this may mean for them. Future research should consider the range of stakeholders involved with supporting adults with learning disabilities to access research, and how best to support these individuals within the context of PAR.

It is common for URs to also provide emotional and personal support to co-researchers. In the present study, co-researchers shared personal details of their life with me, including their achievements, personal and family news, emotional past experiences and challenging circumstances, such as bullying, bereavement and illness. The context of this research, which took place during the Covid-19 pandemic, also impacted the type of support provided to co-researchers. For example, co-researchers often shared their concerns about the pandemic, experiences of social isolation and questions concerning the latest news and guidelines. Research sessions were one of the few activities that remained ongoing throughout the pandemic where co-researchers had a chance to speak openly with others. I therefore felt I had a greater responsibility for the welfare of co-researchers through this challenging period, and my role as a supporter extended to checking in with co-researchers at the beginning of research sessions to see how they were doing in light of the pandemic and providing reassurance, validation and information about the pandemic when needed:

Ella: when COVID was here, my mum was going out of the house, I was freaked out all the time. When I heard about the pandemic it panicked me [...]

UR: yeah, it was scary wasn't it? There were things that were really scary, that's definitely a very normal thing to feel about the pandemic

The collaborative and immersive nature of PAR means that participatory researchers will build strong relationships within the communities they are working with, often becoming an important part of the lives of their co-researchers (Atkinson, 2005). This can “blur the boundaries” between research relationships and other kinds of relationships with members of the community (Mayan & Daum, 2015, p.72). Previous research has shared varied perspectives on the impact of close relationships with co-researchers. Some participatory researchers have noted that relationships between researchers and communities can facilitate open conversations, trusting relationships and therefore effective collaboration (Mayan & Daum, 2015). Close relationships with members of the community can also be observed in ethnographic research, where researchers are often intimately involved in the lives of vulnerable people (Huisman, 2008; Hemer, 2023). Huisman (2008) notes that many of their participants, who were Bosnian Muslim refugees, referred to them as a friend and some even considered them as a family member.

While I did not specifically plan for the development of friendships with co-researchers, members of the PRG nonetheless began to consider me, and other members of the group, as a friend (“If we can meet up once a month, that would be great and then we can keep our friendship going” – Tracey, C3). Not unlike the formation of friendships in other settings, the PRG and I spent a large amount of time together, exchanged ideas and experiences, worked as a team and confided in each other during times of challenge (particularly regarding experiences through the Covid-19 pandemic). Additionally, as described in section 10.2, I worked to become an equal alongside the co-researchers, by actively attempting to remove traditional hierarchies, focusing on the voices of the PRG and shifting power and ownership of the project to co-researchers.



Figure 53: Tracey's re-creation of a group photo of the PRG, which includes the label 'Friends'

However, it is, of course, important to recognise the negative implications of closeness with co-researchers, including the ethical dilemmas associated with relationships within PAR. Previous research suggests that close relationships with co-researchers may become exploitative (Stacey, 1991) or result in feelings of loss when the research comes to an end (Northway, 2000b). Indeed, much of the research concerned with the potential dangers of forming close relationships with co-researchers relates to the temporary nature of research, and therefore, the temporality of relationships developed within the context of research (Cox et al., 2014; Mason, 2023; Northway, 2000b). This means that, unlike friendships outside of a research context, the UR will eventually leave “the field” (Mason, 2023, p.706), which may result in co-researchers feeling rejected and URs feeling guilty (Cox et al., 2014). A growing body of literature discusses what happens when researchers choose to stay involved with the community they have been collaborating with (Mason, 2023). Booth (1998) recounts how contact with her co-researchers continued for over 10 years. Similarly, Mason (2023) discusses their experiences of continuing to volunteer in the Youth programme they conducted research with, noting that staying “disrupts the temporality of research” (p.716). While not all researchers will have capacity to dedicate a significant amount time to maintaining relationships with co-researchers, Northway (2000b) suggests that it can be problematic when URs do not foresee their long-term involvement in the lives of co-researchers. PAR researchers must be aware of the ethical responsibilities of entering the lives of vulnerable people, working to gain trust with individuals and then exiting their lives at the end of a project. The UR should therefore consider what long-term support is available to co-researchers and who will provide this support, particularly after their role in the project has officially ended (Plummer, 2001). Challenges associated with removing oneself from the project may also relate to the lack of opportunities for co-researchers to continue their role

as researchers, resulting in co-researchers' reliance on the UR for continued engagement in research. In the present study, this was mitigated by the PRG's involvement in additional projects that I facilitated, including the co-creation of the comic, and involvement in additional funded research projects with PPA.

An additional ethical consideration relating to close relationships in research is that by deconstructing the traditional research hierarchy and promoting equal involvement from all co-researchers, there are also less traditional boundaries in place between co-researchers. For example, two co-researchers, who did not have access to an email address, had my personal phone number so that I could support them to access Zoom sessions when required. While this was necessary to support these individuals, I began to receive sporadic phone calls from co-researchers for reasons not relating to the research (e.g. wanting to have a chat or share some news):

Due to the impact of Covid-19, many of the co-researchers experienced social isolation and loneliness, which resulted in them contacting me for personal reasons outside of the research. This resulted in some careful consideration about where my responsibility for pastoral care and safeguarding should start and end -UR reflections (C3)

Previous research notes that URs might experience a sense of duty to engage in activities typically associated with close friendships, such as receiving phone calls from co-researchers outside of research sessions (Mayan & Daum 2015). Indeed, Atkinson (2005) suggests that research may even go so far as to take on social work. Co-researchers may begin to view the UR as a "potential helper" (Atkinson, 2005, p.427), who can provide support and assistance with everyday tasks and challenges. In the present study, co-researchers asked for my support in relation to arranging transport, attending PPA sessions and participating in other research projects and activities ("I'll feel a lot better if you do come because I don't really know \*staff member\*" – Tracey, C2). Navigating what support falls under the remit of the researcher may be particularly challenging when the UR has a background in support, which often seems to be the case in research involving adults with learning disabilities. My experience as a support worker meant I felt confident supporting co-researchers throughout the project. However, in some cases this became a hinderance, as I felt guilty and uncomfortable when I had to deny or defer co-researchers' requests for support, even when they were not directly linked to my role in the project. For this reason, I found it difficult to identify when the role of the supporter (and friend) began and ended.

Simultaneously fulfilling the roles of a researcher and supporter involved negotiating complex feelings, situations and questions. These roles often felt at odds with each other, with conflicting advice published regarding how to manage relationships within participatory projects. While some literature proposes that long-term relationships are inevitable

(Northway, 2000b; Chalachanová et al., 2020), others warn URs about the risks of being perceived as a friend (Plummer, 2001). While the negative implications of such relationships should be carefully considered and managed, previous research neglects to consider the ethical implications of denying friendship status and/or long-term relationships with adult co-researchers (if this is mutually agreeable), particularly when a) URs have emphasised the 'equalness' of the relationship and b) when the population involved is often denied friendship status by other individuals in their life (Pockney, 2006). It is also interesting to note the difference in language describing close relationships with co-researchers through the lifecycle of a participatory project. During the formation of a PAR the development of positive, trusting relationships is encouraged and often considered to be 'crucial' for effective collaboration and participatory research (Chalachanová et al., 2020; Nind & Vinha, 2014; Seale et al., 2015). In contrast, these relationships are often problematised towards the conclusion of the project, with researchers describing close relationships at this stage as "risky" (Mayan & Daum 2015, p.72). The variation in how relationships are perceived at each stage of the project may represent the different ethical challenges experienced at the beginning of the research versus the end. However, a more uncomfortable consideration is that these relationships may be conceived differently depending on the implications of the relationship for the UR. While close relationships at the beginning of the project may serve the development of the project and establish the foundations of effective collaboration, close relationships at the end of the project no longer serve the needs of URs, who are often moving on to other projects and may not always have the capacity or desire for continued relationships with co-researchers. URs must therefore take serious care to consider the exploitative potential of developing personal relationships with vulnerable people purely for the purpose of research.

In the present study, I often felt conflicted when co-researchers referred to me as a friend. On the one hand, I felt it was important to consider the ethics and potential hypocrisy of denying friendship to my research collaborators. However, on the other hand I also struggled with the challenges of the responsibility to support the continuation of these relationships. Through reflections on the project as a whole, I began to recognise that my discomfort was not only due to the nature of these relationships, but also due to how these relationships may be perceived. I was aware that others in the research community may view these relationships negatively or as having negative implications for co-researchers. I was particularly concerned with co-researchers feeling that the relationships developed in the study were not genuine or, as is often the case between 'staff' and people with learning

disabilities, that I was avoiding the label of friendship due to the co-researchers' identities as adults with learning disabilities.

My experience in the present study suggests that PAR fast-tracks close relationships in research, due to the focus on collaboration, the amount of time spent with co-researchers and the categorisation of co-researchers as equals. While not all URs may be labelled as a friend in collaborative/inclusive research, this seems almost inevitable when a key goal of PAR is to develop trusting relationships in order to authentically collaborate with others. The development of 'non-standard' relationships with communities involved in research should therefore be expected and planned for. As I noted in my research diary in cycle three: "if you work to ensure co-researchers feel they are your equals, you cannot be too surprised when they begin to treat you as one". Therefore, when co-researchers began to label me as a friend, I did not deny or reject this label. I have continued to maintain contact with co-researchers, in both a professional and social capacity (e.g. by attending a co-researcher's art exhibition alongside PPA staff and attending social events run by PPA for staff and participants). However, as with any long-term relationship, I put boundaries in place to manage the expectations of co-researchers. During the research, I attempted to manage my role as a supporter/friend by working closely with PPA to ensure that responsibility for the welfare of co-researchers was shared. Before the project began, we also developed a plan for managing disclosures and concerns about welfare, which I referred to and utilised throughout the project. I also created working hours, where co-researchers were free to contact me to discuss the project or to ask any questions they may have. This ensured that any contact outside of research sessions was at appropriate times of the day, without removing opportunities for contact altogether. I also advocated for the place of research activities within PPA, to support continued contact within the group (discussed further in the next section). This ensured that the PRG (myself included) continued to have regular contact in a professional capacity, with opportunities for socialising built into the design of the project.

Through reflections on the way I managed relationships with co-researchers, I believe there is no single correct way to approach close relationships in research. The nature of how these relationships develop is influenced by the individuals involved, the context and discipline of the research, the contact time between co-researchers and the UR, and the UR's approach and perspective of long-term relationships with co-researchers. How these relationships are managed is crucial. To ensure that participatory research remains a positive experience for all, URs should a) consider the nature of the relationships that they are comfortable with prior to meeting with co-researchers, b) establish and communicate

boundaries relating to these relationships at the beginning of the project and c) support co-researchers to consider and establish their own boundaries with regards to research relationships.

Overall, the role of a supporter and friend was perhaps the most complex and conflicting role I occupied in the project. It is also possibly the most long-term role in PAR, as URs must be aware and willing to provide long-term support to co-researchers (either directly or indirectly via partner organisations/signposting to support networks). Additionally, URs should also be aware that contact with co-researchers is likely to extend beyond the scope of the project. This provides opportunities for long-term collaboration with researchers with lived experience. However, it is important for URs to consider whether they have capacity to commit their time and support to a community, before entering their lives. The topic of close relationships within PAR therefore warrants further investigation, to ensure that co-researchers are protected and respected.

Additionally, regardless of the research topic, URs should expect that co-researchers may confide in them or disclose challenging and/or important concerns and prepare for how they will handle these disclosures. Ideally, support should be a shared endeavour, with co-researchers, URs and organisations offering and receiving support when required and appropriate. As co-researchers grew in confidence and developed friendships with each other, support became a shared responsibility between the group. Peer support was particularly important for effective teamwork and was one of the key aspects of the project that co-researchers reflected on during cycle three (“As a group, we learned more as a group than we would, if say I’d done this myself” – John, C3). By sharing the responsibility for support, this may reduce the sense of responsibility and pressure felt by URs to support the wellbeing of co-researchers alongside their additional research responsibilities. Indeed, previous research has noted that providing a high level of support to co-researchers may be emotionally taxing (Alexandra, 2017) and therefore has the potential to negatively impact URs’ wellbeing (Lennette et al., 2019). Currently there is limited training and support available to participatory researchers to assist them in navigating the complex relationships and roles within PAR. Future research should therefore consider the support needs of all members of a participatory research team, including co-researchers and URs.

## 10.6 Being an advocate

A core aspect of PAR is action (Johnson & Walmsley, 2003) and Nind (2017) states that good inclusive research should contribute to advocacy. An important part of the role of a participatory researcher is therefore to facilitate change, based on the recommendations of co-researchers. As with the role of a supporter, the role of an advocate may also be

considered as long-term, whereby participatory researchers are (to some extent) responsible for advocating for the short and long-term changes that co-researchers identify. Co-researchers' active engagement with research resulted in the realisation that there are inequalities in research that they were not previously aware of, such as issues with the payment of co-researchers, limited accessible literature, lack of long-term research opportunities for disabled co-researchers, and the exclusivity of academic spaces. For example, in cycle two, Ella shared her excitement being asked to co-write a blog for the University of Leeds website, demonstrating her disbelief at being invited to be a part of the academic community: "I've never got the opportunity to talk to Leeds University and now I've got a chance [...] talking to the... I can't believe it I'm, keep calm, keep calm!". The UR's role as an advocate may therefore extend beyond the scope of the project, to advocating for change to the research sector and broader systems which prevent inclusive research practice. An opportunity of PAR is therefore that this approach can disrupt research practices, traditions and processes, which exclude underrepresented communities, with the UR playing a key role in this (Pettican, 2022). In the present study, PAR supported the PRG to challenge ideas around who can be a researcher and what constitutes as an expert. These ideas formed the basis of the research comic book, which was co-written by the group and designed to challenge misconceptions around adults with learning disabilities, while advocating for the inclusion of diverse communities in research.

In the present study, I felt a sense of responsibility to solve problems raised by co-researchers, even when these issues did not initially seem related to the research topic itself. However, a key learning from this project was that disabled peoples' inclusive engagement with research and learning is impacted by a range of everyday factors, which influence accessibility overall (such as those discussed in section 6.3.2.2). Disabled people, particularly disabled researchers, are best placed to identify the wide-ranging barriers to their engagement in research. However, URs have the opportunity to use their experience and position to challenge research processes, systems and communities to be a more inclusive spaces for researchers with learning disabilities.

My role as an advocate included working with PPA to develop the research culture of the organisation and ensure that there would be long-term opportunities for co-researchers to share their views, with or without my involvement. These ongoing conversations with PPA regarding their relationship with research contributed to the formation of a Steering Group<sup>14</sup> and PPA's long-term commitment to seeking out additional research opportunities for the

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<sup>14</sup> PPA had intended to create a Steering Group prior to this project. However conversations with the PRG highlighted co-researchers' long-term interest in sharing their views and shaping the future of the organisation, which served as a catalyst for the development of this group.



PRG to be involved with. These included the development of Buddy Training and a project funded by The Young Foundation titled 'Making Research Accessible', which sought to explore ways of making research more accessible and inclusive for adults with learning disabilities.

### 10.7 Being you

As a participatory researcher it can be challenging and uncomfortable to identify and reflect on your personal role in research (i.e., the characteristics that you specifically bring to the project, which may influence the research experience and atmosphere). Indeed, Walmsley (2004) argues that the roles of the non-disabled researchers in inclusive research "have been hidden and obscure" (p.65). This was also the case in the present study, as I initially undervalued my personal role in the project. An example of this is my analyses of the co-researchers' final interviews and reflections on the project. I noted that members of the group expressed a desire to continue conducting research and that URs may play an important role in supporting this. However, as discussed in section 3.5.3, the external researcher who validated these data identified not only the importance of the UR, but the importance of *who* the UR is. Indeed, the external researcher noted that co-researchers' relationships with research was mitigated by their relationship with me. For example, when describing their interest in continuing their engagement with research, this was often conditional on my continued involvement in future projects with the PRG ("we don't want to leave you" – Tracey, C3). It is therefore important for URs to actively reflect on their personal role in the project, since this may have a direct impact on co-researchers' experiences within the project.

Additionally, since PAR often involves vulnerable people it is crucial for URs to evaluate the positive and negative impact of their personal characteristics and skills in order to avoid problematic and/or tokenistic research collaborations. Despite this, there are several reasons why it may be challenging for URs to acknowledge their personal role in participatory research. My reflections from the present study revealed three key challenges to acknowledging my role in the project, these were: awkwardness surrounding the individualisation of the UR's role, closeness to the project and 'making space' for excluded voices.

Firstly, since a key goal of PAR is to work alongside co-researchers as equals, distinguishing myself and my role in the project from my co-researchers initially felt counterintuitive and at odds with the aims and approach of the project. For example, I initially reflected on the relationships developed broadly within the PRG, without specifically

acknowledging the co-researchers' relationships with me. However, as identified through the data validation process, the PRG's relationship with me specifically influenced their experiences within the project and of research more generally. Therefore, while URs may feel awkwardness relating to the individualised consideration of their role in the project, it is important to specifically examine the role(s) and impact of the UR, since co-researchers and URs bring different skills, experiences and attributes to research, which facilitate effective collaboration.

The closeness of the UR to the project may also impact how they view themselves and reflect on their personal role. Participatory researchers are often closely connected with the research topic and with co-researchers (Lyngsnes, 2016). As a member of the research team, I became closely connected with the research and my co-researchers, and therefore found it challenging to identify the impact of my role while the project was ongoing. In contrast, the external researcher, who observed the project/data as an outsider, was able to clearly identify my personal role in the project. This highlights the importance of reflexive practice throughout PAR. Time and space from the project, alongside concluding reflection sessions with co-researchers (such as the in-person session described in section 6.3.1.1), supported me to reflect on my role in the project more objectively.

Finally, non-disabled researchers in particular may feel that they need to reduce the focus on themselves and their personal role in PAR, in order to 'make space' for disabled co-researchers. In the present study, my attempts to minimize hierarchy in the project resulted in me removing myself from the narrative to make space for the voices of the PRG. However, in doing so, I initially neglected to identify the importance of the relationships that I developed with PRG and the impact of this on their experiences of this project and on their views of research more generally. Minimising the role of the UR therefore risks minimising the human element of PAR, which is reliant on trusting relationships between those who are ordinarily excluded from research and those within the research world. Through reflections on the project as a whole, it became clear that it was not possible nor helpful to completely remove myself from the project. Indeed, as a member of the research team, I too became a subject of research. Therefore, rather than viewing my personal impact in the research as removing focus from co-researchers, I began to understand my personal role in the project as necessary in order to support and amplify the experiences of the PRG.

The characteristics of a participatory researcher may be particularly important when developing a collaborative research team with individuals who are ordinarily excluded from research. Mayan & Daum (2015) note that the personal qualities of URs can support the crucial development of relationships in participatory research. The personal characteristics of

URs may also impact co-researchers' and community partners' willingness to collaborate and/or share their experiences. Indeed, in Pinto's (2009) investigation of collaboration in public health research, community-based organisations identified characteristics of researchers which made them preferable to work with, including "expertise, availability and social skills" (p.942). Reflections on my personal characteristics, approach and skills throughout the project, alongside feedback from the PRG regarding what they valued in research collaborators, revealed which of these attributes supported effective PAR with adults with learning disabilities in the context of the present study<sup>15</sup>.

Personal characteristics which were identified as supporting the present study included being friendly, open-minded, transparent and patient. Shared understanding also supported co-researchers' engagement in the project by developing trust within the group and reducing barriers relating to the co-researchers' negative perceptions of non-disabled people. As Tracey discussed in cycle three:

I've never seen a normal person with no disability, like yourself, more interested in working with disability people. I think I've got more understanding, understanding of you, than I have of another normal person, does that make sense?

Many of these personal characteristics were also discussed in relation to accessible people in cycle three (see table 9). The PRG's description of accessible people may therefore provide additional guidance concerning the attributes of URs, which may support an inclusive research environment. It may also be important to consider how these characteristics relate to attributes and values of the partner organisation in the project. Mirroring the values of PPA and the characteristics of PPA staff, who were identified as trusted individuals, supported the development of trusting relationships and effective teamwork. This confirms the significance of early conversations with potential partner organisations, to ensure that the values of URs and community partners are aligned.

What constitutes as desirable characteristics of URs may depend on the context of the research, and therefore the approach to research and co-researchers. My approach in this project centred around being flexible, receptive to the ideas of co-researchers, being

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<sup>15</sup> This is not to say that I was always successful in my personal approach to the project. My involvement in the present study was, as previously discussed, as much of a learning experience for myself as it was for co-researchers. In some cases, the identification of these characteristics, skills and experiences as important for effective research were identified through the absence of these qualities. For example, transparency was identified as an important characteristic of URs in response to my own lack of transparency relating to academic literature (discussed in section 10.2). Therefore, this section does not intend to suggest that my personal role in the project *always* supported effective collaboration. Rather, I aim to share my learnings from the present study regarding what personal qualities, approaches and experiences supported PAR in the context of this project.

prepared to learn (and apply this learning within the project), and to be reflective (including acknowledging and challenging where my own assumptions and biases may impact the research). While these approaches to research may be considered as core features of PAR, actively modelling inclusive approaches to research was challenging in practice, particularly when negotiating barriers to inclusive research, such as the limited time period of a PhD, the Covid-19 pandemic, and inaccessible resources and research processes.

The approach to the research may also be impacted by the UR's experience and skills. In the present study, my prior experience of working with adults with learning disabilities, of varied methods of communication and of adapting research methods and processes to be more inclusive supported the development of relationships and the inclusivity of the research. As noted by the PRG in chapter 6, accessible people were crucial when facilitating inclusive environments. A core feature of accessible people was an understanding of learning disabilities. It is therefore crucial for URs to build time into the research design to get to know the communities they are working with and to develop reciprocal understanding with co-researchers.

Overall, it is crucial to acknowledge the potential for the UR's personal role in the project to have a positive (and therefore potentially negative) effect on the relationships developed with co-researchers, and therefore the success of PAR. Consideration of the personal role of a researcher is a reflexive tool, which URs may use to examine the personal nature of the relationships within PAR, and their own qualities, skills and experiences that support these relationships. Identification of the characteristics of participatory researchers may aid the development of guidance and training to support URs to develop skills as a participatory researchers, thus facilitating more equitable research.

## 11 Conclusions

This thesis sought to address three overarching aims. The first aim was to identify the outcomes of engagement with arts-based learning for adults with learning disabilities, by exploring co-researchers' experiences at PPA. Section 11.1 will overview the conclusions and key insights regarding the facilitation of inclusive creative learning environments for adults with learning disabilities. The second and third aims of this project relate to the process of conducting PAR research with adults with learning disabilities. Aim two was to utilise a PAR approach to explore and capture adults with learning disabilities' experiences of inclusive arts-based learning. Aim three explored the outcomes of engagement in PAR from the perspective of co-researchers and the non-disabled researcher. Section 11.2 will overview the conclusions relating to these aims, by considering the impact of the PAR approach on the project, co-researchers and the UR. Each conclusion section below will also consider the limitations of the study and suggest avenues for future research. Finally, given the focus on action and social change within this project, recommendations based on the findings of the research are presented in section 11.3.

### 11.1 Conclusions for inclusive arts-based learning experiences

The arts-based learning experiences of adults with learning disabilities have rarely been explored. Therefore, the present study makes a valuable contribution to the literature by centralising the views and experiences of adult learners with learning disabilities. Through three themed cycles of research, the PRG explored their experiences of learning at PPA and identified the outcomes of engagement with inclusive arts-based learning.

Cycle one (people), highlighted the importance of people and the various roles they play in supporting adults with learning disabilities to access inclusive learning opportunities. Through identification of the characteristics of the 'Purple Patch family', cycle one demonstrates the importance of familiarity and consistency, shared interests and identities, support, acceptance and belonging and a lack of perceived hierarchy in fostering an effective social learning environment. These findings, alongside the co-researchers' accounts of negative experiences with non-disabled people, demonstrate the responsibilities and impact (both positive and negative) of people on the learning experiences of adults with learning disabilities. The results of cycle one therefore have implications for organisations working with adults with learning disabilities, which aim to foster the development of meaningful, trusting relationships between staff and participants. The present study suggests that social learning opportunities, which centralise collaboration and the co-creating of knowledge, may be particularly beneficial for adults with learning disabilities who may have reduced access to

social opportunities and networks.

Additionally, through exploration of the environmental and structural features of PPA, the present study demonstrates the importance of a long-term, semi-structured approach to learning opportunities for adults with learning disabilities. This is in contrast to many of the pre-existing learning programmes currently available to adults with learning disabilities, which are mainly short-term, structured and focused on the acquirement of specific skills (Björnsdótti, 2016; Brown et al., 2011; Rodríguez Herrero et al., 2020). The present study suggests that additional long-term learning opportunities would enhance the learning provision for adults with learning disabilities.

Cycle two (arts and variety), demonstrated the effectiveness of arts-based, active and theme-based learning approaches in facilitating inclusive learning experiences for adults with learning disabilities. Features of arts-based activities, (in particular, their adaptability, fewer rules, lack of competitiveness and opportunities for individuality), were considered to aid the inclusivity of learning for the adults with learning disabilities. The results of cycle two have implications for facilitators and educators, who may wish to consider utilising arts-based approaches to support inclusive learning experiences. However, this cycle also indicated that the attitude and approach of the learning organisation shaped the learning experiences of co-researchers and therefore arts-based/creative approaches alone did not ensure inclusive learning experiences.

Finally, cycle three (accessibility and support), recognised the ways in which accessibility and support influence adults with learning disabilities' experiences of learning. Four key aspects of accessibility influenced the learning environment: 'physical', 'transport', 'cost' and 'resources, information, and activities'. Additionally, a range of factors influenced accessibility, such as location, ease of access, subjectivity, context, and particularly people. The results of cycle three have implications for any organisations working with adults with learning disabilities who wish to evaluate or improve the accessibility of their services. An important finding from this cycle is that perceptions of inaccessibility had the potential to be just as much of a barrier to learning as the factors influencing accessibility listed above, even when these perceptions were wrong. Perceptions of accessibility were developed through direct experience (including past negative and positive experiences of learning) and information provided by others. However, the trustworthiness of the source that provided this information impacted how co-researchers interpreted it. This was due to co-researchers' past experiences of inaccurate information and/or their expectations of accessibility contrasting to the realities of accessibility. Developing trust within the community, by providing clear and accurate information, which corresponds to adults with learning

disabilities' experiences may support engagement with learning experiences. Accessible people, in particular, were a significant mediating factor when establishing inclusive learning environments. These individuals influenced the learning atmosphere, accessibility of the learning experience and overall enjoyment of learning. Greater understanding of the qualities of accessible people may influence hiring practices of support staff and facilitators within learning organisations and indeed any organisation that supports adults with learning disabilities.

The present study suggests that engagement with inclusive creative learning opportunities facilitated a range of positive outcomes for adults with learning disabilities, including: increased social network, enhanced wellbeing, inclusive learning experiences, personal growth, and opportunities for advocacy. These outcomes may directly address the barriers faced by adults with learning disabilities in everyday life, such as social isolation (Mencap, 2019b), poor psychological wellbeing (Ali et al., 2012) and reduced access to leisure and learning activities (Copestake et al., 2014). The present study therefore advocates for the development of additional inclusive learning programmes/opportunities, to support adults with learning disabilities in their ongoing personal and professional development and overall quality of life.

Exploration of the underlying mechanisms, which supported the outcomes of engagement PPA, suggest that inclusive learning opportunities were underpinned by: the creation of a safe space for learning to take place (through the development of trust in people and the organisation); balancing freedom and choice with structure and routine; supporting learners to reach their maximum potential and effort; providing varied approaches to learning and valuing the participant voice by listening to and responding to learner feedback. Understanding these mechanisms provides an insight into how inclusive learning experiences may be developed and maintained. The present study makes a valuable contribution to our understanding of the components of inclusive learning environments from the perspective of adults with learning disabilities. The findings of this research therefore have implications for learning organisations, which may wish to develop their practice and support inclusive learning experiences.

#### 11.1.1 Limitations and recommendations for future research concerning inclusive learning experiences

The involvement of PPA participants as co-researchers in the present study provided a direct first-person account of their experiences at PPA. However, the limited number of co-researchers, and therefore the limited viewpoints involved in the study may be considered as

a limitation of this research. The small cohort of co-researchers is a direct reflection of the challenges of PAR (discussed further in section 11.2.1). Co-researchers required individual support, and due to the online nature of the project it was not possible to involve a larger group of co-researchers since this would have negatively impacted the PRG's ability to share their views during Zoom sessions. Future research investigating the inclusive learning experiences of adults with learning disabilities could consider collaborating with a core team of co-researchers to design and implement the study, while also recruiting additional service users as participants (for example, by using an adapted peer researcher model; Hopkins et al., 2022). While it was important to understand the experiences of those who attend arts-based learning programmes, it may also be important to understand the perceptions of those who do not attend. Future research investigating why adults with learning disabilities may *not* attend inclusive learning opportunities would be useful for understanding the barriers and motivators for attendance at organisations such as PPA. Greater understanding of the experiences of individuals who do not engage with lifelong learning may support the reduction of barriers to inclusive learning opportunities. Additionally, the present study only investigated the experiences of adults with learning disabilities attending one inclusive learning programme (PPA). The time required to develop and sustain the present study meant that it was not possible to involve multiple learning programmes within this doctoral project. However, comparison with other inclusive learning programmes would strengthen the study and allow for further exploration of best practice within these organisations.

### 11.2 Conclusions for the PAR approach

The present study utilised a PAR approach to explore the inclusive arts-based learning experiences of adults with learning disabilities. By recruiting adults with learning disabilities as co-researchers, who were actively involved in the design, implementation and dissemination of the study, the project demonstrates the potential for collaboration with communities who are ordinarily excluded from research. This project echoes the findings of previous research, which suggest that the active involvement of adults with learning disabilities results in meaningful and relevant research, which benefits the community (Wright, 2021). In a society where adults with learning disabilities are excluded and underestimated (Oliver & Sapey, 1983), the findings of this research demonstrate that adults with learning disabilities can enrich research projects through their varied expertise, experiences and perspectives. The present study therefore seeks to challenge ideas and misconceptions surrounding who can be a researcher, and who research is for.



Throughout the research, a range of adapted and arts-based methods/analytical techniques were used to capture co-researchers' experiences. The present study suggests that, despite the online setting of the research, creative and arts-based methods were effective in supporting co-researchers' engagement in all stages of the project. Additionally, the PRG were involved with the design of new reflective methods (the 'In my Shoes' activity described in section 6.2.1.9) and the co-creation of a research comic as a creative and accessible research output. This demonstrates the potential for PAR approaches to contribute to the development of inclusive research methods and outputs. The present study therefore has implications for researchers who may wish to utilise creative, arts-based approaches to involve diverse communities in research.

This thesis began by noting the lack of learning opportunities for adults with learning disabilities. In keeping with previous PAR (Nind, 2014b), the present study suggests that engagement with PAR can be a valuable learning experience for both disabled and non-disabled researchers. Engagement with the present study provided learning opportunities for the UR, to further understand the lived experiences of adults with learning disabilities. Additionally, co-researchers reported varied outcomes from their engagement with the project, including the development of research specific skills, personal development (including increased confidence, independence and communication skills), increased social relationships and support networks and the development of research identities. Finally, co-researchers reported that engagement with the project reduced the negative impact of Covid-19, such as social isolation and boredom. The findings of this project suggest that PAR may provide a valuable and valued learning experience for adults with learning disabilities, while improving access to and participation in research for individuals with lived experience of disability. However, current opportunities for adults with learning disabilities to develop research skills and experiences are often contained within one-off participatory projects, which are predominantly initiated by non-disabled people (such as the present study). There are therefore few sustainable opportunities for adults with learning disabilities to *choose* to develop the skills they need to directly influence, engage with and lead research. Future research should therefore consider the development of sustainable and accessible opportunities for adults with learning disabilities to develop research skills, so that more individuals from this community can share their expertise and experiences.

Previous research has drawn parallels between inclusive education and inclusive research (Nind, 2014b). If we consider PAR as an example of an inclusive learning environment, then the mechanisms identified in the present study as fostering inclusive learning (discussed in section 8.6) may also apply to inclusive PAR with adults with learning

disabilities. These mechanisms may therefore provide researchers and organisations with guidance concerning how to support learning within the context of PAR. Another similarity between inclusive approaches to research and inclusive learning is the role of people. Just as people were reported to influence the learning environment, the UR's role in PAR was identified as multi-faceted and crucial for effective PAR. Personal characteristics of the UR, which support effective collaborative research, were brought to the fore through the present study. It is interesting to note that many of these characteristics, including being friendly, open-minded, transparent and understanding, were also discussed in relation to accessible people within learning environments. The PRG's description of accessible people may therefore provide guidance concerning the required attributes and skills of URs/organisations who wish to facilitate PAR. Future research could consider how the identified characteristics of participatory researchers may influence training designed to develop the participatory skills of URs.

#### 11.2.1 Limitations and recommendations for future research relating to PAR

The PAR approach employed in the present study supported co-researchers to share their views and experiences. However, it is important to consider the limitations of this project, which specifically relate to this approach. Firstly, while efforts were made to ensure that co-researchers were equally involved in all aspects of the study, some stages of the project were less participatory than others. In particular, the analysis stage may be considered as the least participatory, as co-researchers were not able to analyse all data. This was mainly due to the time-constraints of doctoral research and highlights the need for additional time when conducting PAR to support the involvement of co-researchers in all stages of the project. Additionally, the impact of Covid-19 and the online nature of the project limited what creative methods and activities were possible, alongside who could be recruited to participate in the study. Moreover, the online context of the research presented challenges when attempting to communicate with groups on Zoom. The reliance on proficiency with a computer or tablet (and/or support from parents/carers) restricted who could be a researcher, and highlights the importance of digital skills for adults with learning disabilities.

The 'end' of the research was a particularly complex and challenging stage, exacerbated by the lack of guidance concerning how to end PAR. The present study directly addresses the lack of transparency concerning this important stage of the research, by providing a detailed overview of the approach to ending the project (see chapter 7). However, greater focus is needed on the practicalities and ethics of ending PAR projects, to ensure that the removal of these research and learning opportunities does not result in

negative implications for co-researchers. In addressing the issues of ‘ending’ the research, the UR worked with PPA to support the development of further research opportunities and projects with co-researchers, thus establishing a sustainable research culture, which now forms an important part of the organisation’s aims. The present study therefore demonstrates the potential for PAR to have long-lasting impact in the local community.

Finally, despite the inclusive aims of PAR, a range of barriers to research still remain. Issues that impacted the accessibility and inclusivity of the project included the lack of: accessible literature/research outputs; financial or official recognition; readily available research training and access to research spaces. Attempting to combat some of these issues (e.g. by creating easy read literature and supporting the creation of an accessible research comic) also placed a strain on the UR’s time, during an already time-restricted project. Future research should aim to address the barriers faced by co-researchers with learning disabilities, in order to diversify the research sector and promote truly inclusive research.

### 11.3 Recommendations

The present study’s chosen approach (PAR) focuses on the opportunity for research to generate action and social change, which benefits the community involved. The following sections overview recommendations for key stakeholders relating to the present study: inclusive learning programmes/organisations; researchers and organisations undertaking PAR and the research sector as a whole. These recommendations were collated by the UR, based on their reflections and the research of the PRG. It is hoped that these recommendations may support the development of additional inclusive learning and inclusive research opportunities for adults with learning disabilities.

#### 11.3.1 Recommendations for inclusive learning programmes

The present study makes the following recommendations for inclusive learning programmes for adults with learning disabilities:

- **Provide clear and accessible information.** Current and accurate information is key to encouraging attendance and facilitating trust in learning organisations. In particular, information concerning the accessibility of programmes is required to ensure adults with learning disabilities feel comfortable to attend learning experiences. Information should be designed for and with adults with learning disabilities, and therefore provided in a variety of formats.
- **Prioritise creating a safe space for learners.** Inclusive learning programmes should ensure that the learning environment is physically, emotionally and socially

accessible/safe for participants. Initiatives such as buddy schemes may support the development of social relationships and promote a welcoming and supportive atmosphere.

- **Support learners to reach their maximum effort.** Support within inclusive learning environments should be tailored, person-centred and focus on ‘working with’ learners to ensure they receive the support they need and want.
- **Embody accessible people.** Accessible people are a key component of inclusive learning programmes. It is therefore important for staff within these programmes to embody the characteristics of accessible people (see section 6.3.2.2.5.1). Training (ideally developed by/in collaboration with adults with learning disabilities) on how to be an accessible person may support the development of these skills.
- **Balance freedom and structure.** Providing choice within inclusive learning environments (e.g. through choice of activity, medium, approach) supports learners’ autonomy and facilitates feelings of freedom. However, structure (e.g. fixed session times, pre-determined themes or regularly occurring activities) supports learners’ wellbeing and sense of routine. Balancing these elements fosters flexible yet supportive inclusive learning environments.
- **Utilise varied approaches to learning.** Regardless of the learning content and/or topics, inclusive learning programmes should aim to incorporate varied approaches to learning, which account for the varied needs and interests of learners. Collaborative, practical and social approaches learning, which are aimed at adults, may support engagement.
- **Gather feedback from service users.** Evaluation of inclusive learning programmes should focus on capturing the participant voice. Meaningful evaluation, which is co-designed with service users, will ensure that evaluations are asking the right questions of the right people.

### 11.3.2 Recommendations for PAR researchers

The present study makes the following recommendations regarding undertaking effective PAR with adults with learning disabilities. These recommendations may therefore have implications for researchers and/or organisations hoping to utilise PAR to work collaboratively with adults with learning disabilities:

- **Transparency is key.** Open and honest conversations are needed throughout PAR. It may be tempting to avoid talking to co-researchers with learning disabilities about

complex and/or potentially uncomfortable topics concerning the (often) inaccessible nature of research. However, these conversations are crucial in order to build an accurate picture of research. Being honest with co-researchers about the challenges of PAR may facilitate creative solutions to these challenges.

- **Plan for flexibility.** PAR approaches can be time-consuming. A flexible approach is therefore necessary to ensure that co-researchers are able to influence the course of the research. Additionally, since PAR projects may provide opportunities for the development of social networks for adults with learning disabilities, additional time may be required to allow for the social element of PAR.
- **Plan for the end.** The end of PAR can be an uncomfortable and challenging time for co-researchers and URs. Consider how you will manage the end of the project from the beginning (including factors such as: providing ongoing support for co-researchers and signposting, where possible, to additional research opportunities). The process of ending the project may also be supported by directly involving adults with learning disabilities in these decisions and once again, being transparent about the reasons why research ends.
- **Prioritise relationships.** The development of trusting relationships/partnerships (between co-researchers, URs and organisations) is crucial in order to facilitate effective PAR. URs should therefore allow plenty of time to establish and build these relationships. Embodying the characteristics of 'accessible people' may support the development of trust with co-researchers.
- **Consider your current and future role in the project.** The nature of PAR means that co-researchers and URs will fill many roles in the research. Some of these roles will be familiar and others may be unfamiliar or uncomfortable. URs should expect that they may eventually fill important roles in the lives of co-researchers and be prepared for this eventuality prior to undertaking PAR.
- **Ensure support is available.** PAR can be an emotionally challenging experience for all stakeholders. Ensure that co-researchers have access to support (aside from the UR) throughout the project, by agreeing a welfare plan with partner organisations or signposting co-researchers to relevant support. Additionally, URs/organisations conducting research should consider their own support needs and not underestimate the emotional impact of undertaking PAR.
- **Foster an inclusive learning environment.** Recommendations above concerning inclusive learning environments may also apply to inclusive research settings. URs could therefore consider these mechanisms when establishing PAR projects. For

example, by: establishing a safe research space; providing freedom within structure; offering varied approaches to learning about/engaging with research; supporting co-researchers in ways that allow them to reach their maximum effort and valuing and celebrating the voices/contributions of co-researchers.

### 11.3.3 Recommendations for the research sector

Alongside recommendations for the involvement of adults with learning disabilities in PAR, the present study makes the following recommendations for the research sector more generally, to support inclusive research practices, processes and policies:

- **Accessible publications are required.** It is important for academic publishers/URs to recognise that the format in which they publish research sends a direct message concerning who research is for and who is welcome in the research community. More accessible publication formats (e.g. videos, easy read documents and creative outputs such as illustrations and comics) should be encouraged and supported. Additionally, all journals should consider the implementation of accessible/easy read summaries as standard.
- **Ethics committees should collaborate with PAR researchers.** Institutional ethics committees should work in partnership with participatory researchers to develop ethics processes and procedures which a) recognise the specific ethical challenges of PAR and b) support URs and disabled co-researchers to collaborate as soon as possible, while still ensuring that vulnerable people are protected. Ideally, ethical procedures should also be accessible to disabled co-researchers to ensure that they are not excluded from this important stage of the research.
- **Fair compensation is needed.** Researchers and research institutions should consider methods of providing fair compensation and recognition of the work of co-researchers in PAR projects. For example, through the development of initiatives that officially recognise the contributions and skills of co-researchers and the impact of their involvement in research on the research sector. Further research, which addresses the challenges associated with the payment of researchers with a learning disability, is needed.
- **Long-term research opportunities for adults with learning disabilities should be investigated.**  
Long-term and sustainable opportunities for adults with learning disabilities to undertake research and learn research skills are needed in order to foster a more diverse and inclusive research community. Projects which actively seek to address

these issues in collaboration with adults with learning disabilities are therefore required.

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## Appendices

### Appendix A: Ethical approval and application

Hi Melissa,

**FAHC19-078 Amendment May 2020 / Exploring the outcomes of participation in inclusive creative arts programmes for people with learning disabilities and/or autism**

Thank you for submitting your amendment documents related to the above application.

I am pleased to inform you that your documents have been reviewed by the AHC Committee and I can confirm a favourable ethical opinion based on the documentation received at date of this email. Reviewers commented:

'The risks and challenges of this project are considerable (as was noted in the response to the first iteration of the project); however, they have, once again, been anticipated and where possible mitigated with tremendous care and lucidity. The community benefit are clear and provide significant counterweight to burdens and risks of PAR work in the field. On this basis it would be possible to approve this project; but it is hard not to be struck when reading these meticulous and thoughtful forms of the amount of work that the researcher has devoted to the project, and to worry, if only a little, about the amount of work and commitment they expect from others at a time of national crisis.

Regarding the use of technology – this seems appropriate and clearly articulated, though I was struck by the reappearance (so it seemed to me) of the Dictaphone as a means of capturing participant responses. Is this a better solution that the record functions of some social media and communication platforms, which might produce data in ways easier to store?'

***Please retain this email as evidence of approval in your study file.***

If you need this confirmation in a letter form (for an external funder for example) then please let me know.

Please notify the committee if you intend to make any further amendments to the original research as submitted and approved to date. This includes recruitment methodology; all changes must receive ethical approval prior to implementation. Please see [http://ris.leeds.ac.uk/downloads/download/179/amendment\\_form](http://ris.leeds.ac.uk/downloads/download/179/amendment_form) or contact the Research Ethics & Governance Administrator for further information ([ahcresearchethics@leeds.ac.uk](mailto:ahcresearchethics@leeds.ac.uk)) if required.

Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

*Please note:* You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, risk assessments and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

If any of the above raises any questions then please do let me know. I would be very happy to help if you do have any questions.

Best wishes,

**Ethics application can be accessed here: [Appendix A](#)**



**Appendix B: 'Using real names' information sheet and consent form**

This information sheet is all about using your name in our research



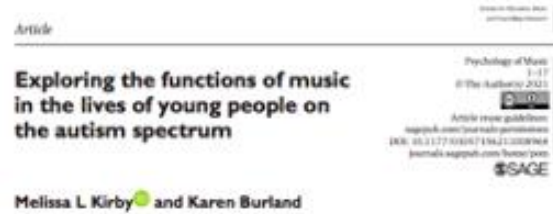
It's important that you know what it means if you use your real name in research, so you can make the right choice for you!

**What kinds of things might have my name on?**

Publications are things that other people can read – like books, journals, comic books and blogs. These can be online or printed



Here is an example of my name on an article which is online

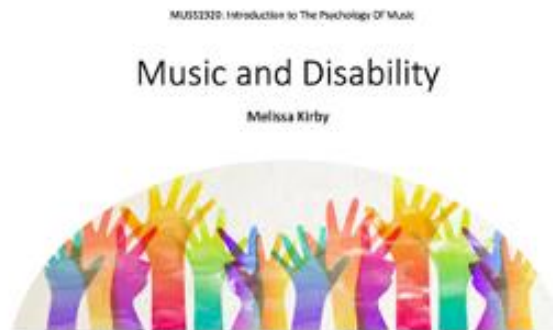


Researchers also talk about their research to other people at conferences.

Conferences are big meetings for lots of people interested in a topic to learn about each other's research



Researchers put their names on conference presentations and in booklets about the conference so that people know they did the research!



**Why do researchers want to put their name on publications and conferences?**

People put their names on publications and at conferences so that other people know they worked on the research



It also means they get credit for doing the research



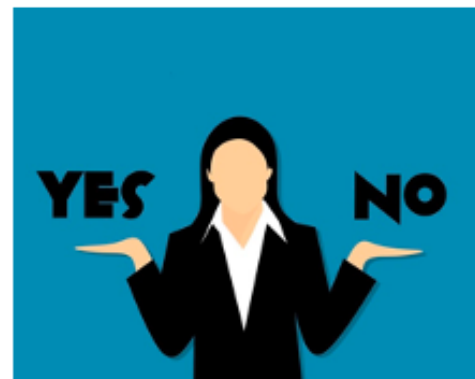
But it also means that people know who they are, and find out about them and their research



### **Do I have to put my name on the research?**

No! you do not have to have your name put on the research if you don't want to.

It's up to you to choose if you would like to have your name put on any publications or conferences.



**What will happen if I choose to put my name on the research?**

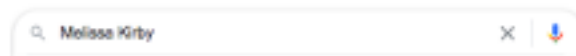
If you choose to put your name on the research, people will know you have been a part of the purple research group



People who read about our research will know that you go to Purple Patch Arts



People will be able to google your name and see that you were part of the research team



People will know what you said and did in the research, so they might learn about some of your thoughts and opinions



Once a publication is on the internet, it stays there forever, and anyone can read it



If you choose to put your name in the research, there are some things we will keep private



We won't tell people which Purple Patch Arts programme you go to



We won't include personal information, like your date of birth or contact details





We will remove any information that might tell people things about you that are private.

For example, if you have talked about where you live, or other groups you go to, this won't be included in any of our research.



### **What will happen if I choose not to put my name on the research**

If you choose not to put your name on the research, people will not know you have been a part of the purple research group or that you go to purple patch arts



You can either choose not to have your name included at all, or you can choose to go by a code name – like a spy!



**What do I need to do next?**



You need to decide if you would like your name included in publications and conferences.

There are three different options....



**Option 1**

You can choose to have your real name included in the research.

**1** Melissa Kirby

If you choose this option people will know you have been a researcher for this project.

**Option 2**

You can choose to have a code name included in the research.  
For example, my code name could be Mary Smith

**2** Mary Smith

If you choose this option people will only know you have been a researcher for this project if you tell them your code name.

**Option 3**

You can choose not to have your name included in the research at all.

**3** ~~Name~~

If you choose this option people will not know you were a researcher for this project.

You can choose a different option for publications and conferences if you want to!

You can talk to your friends and family about using your name in the research to help you make your decision



Once you have made a decision, you need to fill in the form to let me know what option you have chosen

Full name

I have read the information sheet about including my name in the research (colour your answer)

**YES**      **NO**

---

**Publications**  
 - Online (blogs, articles, websites)  
 - Physical copies (Melissa's university book, comic book, journal articles)

**Would you like me to include your name in publications?**  
 (please only pick one)

Yes! Please use my real name       No, please don't include my name

Yes! Please use my code name (write it here)

---

**Conferences**  
 - Presentations and talks about the research

**Would you like me to include your name in conferences?**  
 (please only pick one)

Yes! Please use my real name       No, please don't include my name

Yes! Please use my code name (write it here)

Remember, there is no right or wrong choice – you can choose whatever is best for you



Once you have filled in the form, take a picture of it and send it to me at [mc13mlk@leeds.ac.uk](mailto:mc13mlk@leeds.ac.uk)

Please send me your form by Friday 22<sup>nd</sup> October.



If you have any questions, just ask!

You can message me on Facebook or email me at [mc13mlk@leeds.ac.uk](mailto:mc13mlk@leeds.ac.uk)



Full name

I have read the information sheet about  
including my name in the research  
(colour your answer!)

YES

NO

### Publications

- Online (blogs, articles, websites)
- Physical copies (Melissa's university book, comic book, journal articles)

**Would you like me to include your name in publications?**

(please only pick one!)

Yes! Please use my  
real name

No, please don't include  
my name

Yes! Please use my code name (write it here)

### Conferences

- Presentations and talks about the research

**Would you like me to include your name in conferences?**

(please only pick one!)

Yes! Please use my  
real name

No, please don't include  
my name

Yes! Please use my code name (write it here)

**Appendix C: Information and Consent Videos**

Information Video	<a href="https://youtu.be/DQlu6mvIFzw">https://youtu.be/DQlu6mvIFzw</a>	
Consent Video	<a href="https://youtu.be/cgElfLIRmlk">https://youtu.be/cgElfLIRmlk</a>	

## Appendix D: Information booklet for parents

16/04/2020

Dear Sir/Madam,

My name is Melissa and I am a Postgraduate Researcher at the University of Leeds. My research explores the outcomes of engagement with creative arts education programmes for people with learning disabilities and/or autism. I am collaborating with Purple Patch Arts on this project and I am particularly interested in gaining an insight into the experiences of participants at Purple Patch Arts. For this reason, I hope to recruit several participants from Purple Patch Arts to help me with this project. Participants who are recruited to take part in the project will be trained to fulfil a 'Co-researcher' role. Co-researchers will have an active role in the project, including making decisions about the research and collecting and analysing data.

I am writing to you as the parent of an individual I have invited to take part in this project. Your son/daughter does not have to take part in this research; it is up to them to decide if they would like to take part or not. This booklet will give you some more information about the project so that you can support them to make an informed decision about their participation. If there is something you do not understand or if you have any questions, please contact me at [mc13mlk@leeds.ac.uk](mailto:mc13mlk@leeds.ac.uk) and I will be happy to help!

### **What is the purpose of the project?**

The project is all about capturing the experiences of Purple Patch participants, by involving them directly in research, as researchers in their own right!

- To work collaboratively with adults with learning disabilities/autism to explore and capture their experiences at Purple Patch Arts
- To identify the outcomes of participation in the Purple Patch Arts Lifelong Learning programme
- To explore and assess methods of evaluating the impact of participation in inclusive creative arts programmes

### **Why has my son/daughter been asked to participate?**

Approximately 10 participants who usually attend a Purple Patch Arts Lifelong Learning will be recruited for this project. Your son/ daughter is being asked to participate as they attend a Lifelong learning programme and have been identified by Purple Patch Arts staff as someone who may be interested in participating in this project.

### **What will my son/daughter have to do?**

If your son/daughter thinks they might be interested in being a researcher, they will be asked to complete the research taster activities which will be posted in the 'Purple People' section of the Purple Patch website. These activities will include instructional videos, followed by creative arts-based activities, similar to those they may do at Purple Patch. Don't worry, we're not expecting you to have endless craft supplies! All activities can be completed by using things around your home. These activities are designed to give your son/daughter an idea of what it's like to be a researcher in this project so that they can make an informed decision about their participation.

Once your son/daughter has completed the taster activities, they will need to decide if they would like to be a researcher. They will be asked to watch an information video about the project and then complete an online consent form if they would like to participate. After completing the consent form, they will be sent instructions on how to join a private Facebook group. This group will form the basis of our virtual research community and co-researchers will be encouraged to interact, share ideas, make decisions together and share their work in this group.

If your son/ daughter decides to take part in the project, they will play a very important role. Together we will decide what kind of research we want to do and how we want to do it. All co-researchers will be invited to complete some training to get them thinking about what being a researcher involves. This training will be uploaded to the Facebook group and will include instructional videos and activities for your son/daughter to complete, including:

- Research journal training (practicing creating research journal entries, learning about what should and shouldn't go in a research journal)
- Research activities (introduction to the jobs we might do as researchers – see page 5)

- Facebook group training (creating group rules, introducing yourself to others)

There will also be lots of training and learning as we go along. Co-researchers will be supported to make decisions about the research, but there is no right or wrong answer! The main aim of this research is to explore the experiences of the participants at PPA and the different ways we may be able to capture this.

After completing the training activities, your son/daughter will be sent bi-weekly research activities to complete at home. These will start in August 2020. Research activities will be fun, adaptable, and arts based. Research activities will be organised into three phases. Each phase will have its own theme, which will influence the kind of research we do (the themes for each cycle will be decided by the co-researchers, but examples of potential themes are: 'emotions', 'skills' or 'people').

In each phase of the project co-researchers will work together to plan the research for that theme (e.g. we will decide on some questions we would like to ask and how we will answer them). Co-researchers will then be supported collect data to answer these questions. Examples of data collection might include creating art/ collages, taking photographs, writing stories, interviewing others etc. All co-researchers will also be sent a research journal which they will be asked to write/draw/colour/stick and create in as often as they wish to. Some activities will require co-researchers to send information back to the lead researcher, via email or Facebook messenger or to share their work on the Facebook group. After we have collected our data, we will analyse it to see if we answered the question. This process will happen three times, once for each 'theme'.

#### **What happens when PPA programmes resume?**

This project was designed prior to the COVID19 outbreak and has since been adapted to operate remotely. When restrictions relating to COVID-19 are lifted, it is possible that some co-researchers will be invited to attend in-person meetings and research activities will be an option. If attending these sessions in person is not possible for your son/daughter, they will be able to continue their involvement in the project remotely. At this time everything your son/daughter will be asked to do can be done in the home. Once Purple Patch sessions resume, you will be provided with an update as to how this may impact the project.

#### **What will I have to do?**

As a parent of a participant your role in the research would be to support your son/ daughter's involvement. This may include helping them to decide whether or not to participate and supporting them to complete the research activities and engage with the Facebook group. The lead researcher will always be on hand to help and can arrange to support your son/daughter to complete an activity via email, phone call or video call.

#### **What if my son/daughter decides they do not want to take part?**

Participation in this study is entirely voluntary, so if your son/ daughter does not want to take part that is fine! If your son/ daughter consents to take part in the project and then decides at a later date (either before or during the project) that they no longer wish to participate then they will be able to leave the project immediately. It is recommended that your son/daughter completes as many research activities as possible in order to get the most out of the project. However, as participation in the project is entirely optional, if they do not want to complete a particular activity, then this is fine. Skipping an activity will not hinder your son/daughter's ability to participate in the project long-term.

Co-researchers also have the right to withdraw any data collected from them (including any data they have collected themselves, as well as personal data), up until the end of each phase. Co-researchers will have the opportunity to review all of the data they have collected in each phase in a 'data checking' activity, before it is prepared to be included in the PhD thesis. In this activity they will be send all of the data they have collected so far in a document and will be able to make amendments and/or delete any data they no longer wish to be included. After this session no further amendments can be made as I will need to begin collating the final thesis.

#### **What are the possible risks of taking part in this project?**

There are no known risks to taking part in research of this kind, however the lead researcher understands that interacting with new people or being involved in a new experience, such as research, may be stressful for some participants. The researcher will work closely with each co-researcher, PPA staff and yourself/support workers to ensure that co-researchers are supported appropriately and that their needs and preferences are met.

#### **What are the possible benefits of taking part?**

Whilst there is no formal incentive provided to co-researchers in this project, the collaborative design of the study poses opportunities for your son/daughter to be involved in meaningful research and have their views heard. Co-researchers will also receive training which will enable them to gain an understanding of the research process and develop research skills in critical thinking, research design, data collection and analysis, as well as interpersonal skills such as confidence, leadership and communication skills. Co-researchers may also have the opportunity to be named as an author on publications that are produced as a result of this project.

**What will happen to the results of the research project?**

Data collected during this project will be used to form the basis of my PhD thesis and may be used in subsequent publications. Examples of data that may be included are as follows:

- Transcriptions of video calls/phone calls (in full or in part as quotations)
- Quotations from the Facebook group
- Entries from research journals
- Photographs of anything produced from research activities (e.g. brainstorming, arts-based output)
- Any other data collected by co-researchers in relation to the project (the exact type of data will be decided in collaboration with co-researchers)

Co-researchers will have the opportunity to edit, amend or delete any data that relates to them before it is included in the thesis. Any personal information that is collected from your son/ daughter during the project will be kept strictly confidential and will be stored on a secure server. Data will be used in an anonymised form (your son/daughter will be provided with a pseudonym for the purpose of the thesis), unless otherwise decided by your son/daughter. Participants will have a year to decide if they would like their real name to be included in the thesis or whether they would prefer to use a pseudonym.

**Will my son/daughter be recorded, and how will the recorded media be used?**

Any video calls/ phone calls will be audio recorded so that I can keep a log of how decisions regarding the research were made. Full or part transcriptions may be made of these meetings, and direct quotations from these transcriptions may be included in the thesis. The original audio recordings of these sessions will be used for reflection and analysis only and will be stored on a secure server. No other use will be made of them without further written permission, and no one outside the project will be allowed access to the original recordings. Co-researchers will be able to view, edit and/or amend any transcriptions that are made of recordings before they are included in the thesis.

**Do you have ethical approval for this project?**

This study has been reviewed and given a favourable opinion by Arts, Humanities and Cultures Research Ethics Committee on 01/06/2020, ethics reference: **PVAR FHAC19-078**

Thank you for reading this information booklet! If you have any questions, please do not hesitate to contact me at [mc13mlk@leeds.ac.uk](mailto:mc13mlk@leeds.ac.uk)

Best wishes,  
Melissa Kirby

**Co-researcher 'Activities'**

- Complete researcher training
- Complete researcher activities and share the output of these with the lead researcher and/or other co-researchers through the Facebook group
- Keep a research journal (co-researchers will also be asked to photograph their research journal entries and send these to the lead researcher every other week).
- Collect data via the methods we decide upon (this could include, diary entries, taking photographs, creating arts-based work, conducting/participating in interviews etc)
- Participate in data analysis/sorting activities





# Purple Patch Researchers - Consent Form

## Page 1: About you



What is your name?: \* Required

How old are you? \* Required

What is your gender? \* Required



The best way to contact me is

(This could be your email address or phone number, or the contact details of an individual who you live with) \* Required

## Page 2: You're going to be a researcher!

Click 'yes' to show you understand each statement. If there's something you're not sure about you can email Melissa at [mc13mlk@leeds.ac.uk](mailto:mc13mlk@leeds.ac.uk)



I want to be a researcher \* Required

Yes



I have read the information sheet and I understand it \*

*Required*

Yes



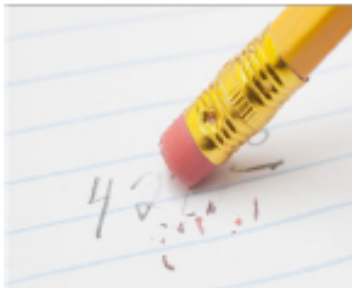
I know that it is ok to change my mind about being a researcher. If I don't want to be a researcher anymore I just need to tell Melissa or someone from Purple Patch \* *Required*

Yes



I know that the things I say, do and make might be put into the book about Purple Patch \* *Required*

Yes



I know that if there is something I have said, written or made that I don't want to go in the book about Purple Patch I need to tell Melissa. I will be able to check my work before it is put in the book, but after I have checked it I will not be able to change anything. \* *Required*

Yes



I know that any phone calls or video calls I have with Melissa about the research will be recorded with a microphone \* *Required*

Yes



I know that I can ask Melissa or a member of Purple Patch staff if I have a question about the research \* *Required*

Yes

Page 3: All done!



Thank you for filling in this form!

If you said you want to be a researcher you need to join the Purple Patch Researchers Facebook group: <https://www.facebook.com/groups/PurplePatchResearchers>

If you have any questions you can email Melissa at [mc13mlk@leeds.ac.uk](mailto:mc13mlk@leeds.ac.uk)

## Appendix F: Easy read research example

### Research that other people have done

Liddiard et al. (2018)

#### What is this research all about?



This research wanted to find out about the lives, hopes, desires, and contributions of disabled children and young people



The project is called 'Living Life to the Fullest'



A group of disabled and non-disabled researchers worked together to do the research – they are called 'The Co-researcher Collective'



A lot of the research was done online – this was easier for the young people

### What questions did the researcher ask?



The researchers wanted to find out:

- What are the dreams, hopes and lives of disabled young people like?

They asked questions like:

- What are your ambitions?
- What would you like to do with your life?
- What contributions do you make?

It was all about their experience

### How did the researchers try to answer the questions? (Methods)

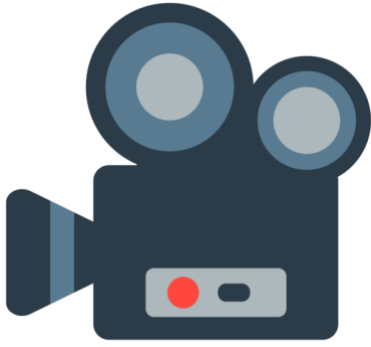


The researchers had meetings, wrote blogs, did interviews, asked other people if they would like to be interviewed and went to an Arts retreat (this was run by Purple Patch Arts!)

### What did the researchers find out?



The project is still going on now!



They share blogs, journal articles, make films and videos, and talk at conferences all about what it's like to be a young person with a disability



They want to help people to understand what their lives are like, what they want from the future and what they can contribute to the world!



The team are helping each other to do the research, and to make it accessible, by doing it in lots of different ways



The disabled young people are the experts (they know the most). They are helping the non-disabled researchers to understand more about their lives



**Appendix G: Purple Patch Arts Worlds (stories)****Sam**

I am Sammi and this is my Purple Patch world. I was born in a country in the usual world called Qatar and I lived in another country called Saudi Arabia. Now I live back in England with my Mum and Dad.

My Mum and Dad are in my Purple Patch world because they love me and look after me. My Nana and Grandpa are in my Purple Patch world too because they share in all my adventures. They like to see the work I do in the Purple Patch group and they have shared the group presentations we have done at the end of each year.

My Purple Patch friends have helped me in my world, and we share our stories and learn about each other, and other people in the world. I feel safe in my Purple Patch world because even when I visit other people and countries by eating some foods they might eat, and playing some games they might play, I am still right in our group with my friends and our supporters, Lorna, Sarah and Grace.

I would like to fly to other places in my Purple Patch world to visit other people in my family who don't live where I do. They speak a different language, and I would learn to say words so we could say 'hello' and 'how are you'.

I like to hear all kinds of sounds from people and animals, from machines likes cars and from things like television and radios. People would sound different in my world because we speak different words in our own languages, but cars sound the same, and animals do. But the sounds from television and radios could be the same language for me and sound different to my cousins in another country.

My Purple Patch world is shared with others from Purple Patch and we all enjoy sharing our stories.

**Leanne**

**PURPLE PATCH STORY**

BY LH

Let me tell you about a place called Purple Patch, home to the purple patch people where we have lots of adventures and lots of fun, we are a family who care about each other.

We do fun things including singing, art and games and we learn about the things like we did in school but then in March a big purple virus called Covid-19 arrived, which makes you sad and miserable and stay at home and lockdown, then a rainbow came in the sky and lockdown was easing we could see our friends and family. We were lost without purple patch then a super hero called zoom came in to our life's we could see our friends whenever we wanted and over time we got used to it. We will continue to get through this with our friends and family by our side and maybe next year will be better and we can go back to the Purple patch group.

And there you have it all the words that sum up Purple patch. The end

**Liam**

Once upon a time there was a mysterious world called purple patch, home to the purple people. The purple people had many adventures one day the purple people discussed to go for a walk to learn more fun and silly songs, pomes and storeys. So off they went they, climed mounts, swam rivers, rum thought grass, treded thought quick sand and then reached the sea of music where they needed to leap over it or they would sink in the sea. One of the purple people discided to go first and managed to leap over the sea, the first person incoraced the other purple people and they all mad it over the sea, and had a rest.

The purple people were feeling happy and excited so after they had rested they carid on, they all started to sing we will be singing when we have finished, after they had finished singing they all felt earched to carry on, they rud houses, climed trees, pushed through wind. While doing all that they heard the calling of fun, silly pomes, songs, and storeys they had made it they ran to it all and souched it all in, they were tiyered and relived and spent many hours there.

The end.

## Appendix H: Acrostic poems

### Accessibility Poem 1 – Accessible Dream World

**A**ccessibility means acceptance  
**C**ompromise and choice  
**C**ool to be accessible  
**E**veryone is involved  
**S**hops and restaurants would be accessible for people with all disabilities  
**S**upporting each other and our  
**I**ndividual needs and preferences  
**B**elieve in yourself  
**L**iving the dream  
**E**verybody is equal

**D**reaming of an accessible world...  
**R**amps for all areas, everywhere is flat  
**E**very mode of transport and holidays are accessible  
**A**ctivities for all, access all areas  
**M**e is the best I can be

**W**icked rules  
**O**n Zoom it breaks down the barriers  
**R**esearching and reaching out to others  
**L**earning new things, sometimes it's hard but we try our best  
**D**oing things our own way

### Accessibility Poem 2 – Freedom

**F**ree to do what you want  
**R**ead any book by yourself  
**E**njoying independence  
**E**xciting opportunities  
**D**oing things that make you feel good  
**O**ngoing support without long waits  
**M**aking use of different technology for independence

Accessibility Poem 3 – Accessible Dream

**A**bility to move easily  
**C**onquering your barriers  
**C**ard access to everywhere  
**E**asy movement  
**S**eeing ahead  
**S**howing your talent  
**I**nventing new ideas to help  
**B**eing yourself  
**L**oving to help other people  
**E**njoying yourself

**D**o whatever you want, without needing to ask  
**R**eaching others  
**E**xercise for all  
**A**lways able to communicate with others  
**M**aking words readable

Accessibility Poem 4 – Purple Patch Arts (group 1)

**P**ushing doors isn't always easy  
**U**sing changing places  
**R**eaching out to everyone  
**P**arent and carers feel involved  
**L**unch with all our friends  
**E**asy access, easy instructions

**P**racticing new skills  
**A**cting out scenarios  
**T**oilets accessible to everyone  
**C**hating with friends and catching up  
**H**aving a break, having a KitKat

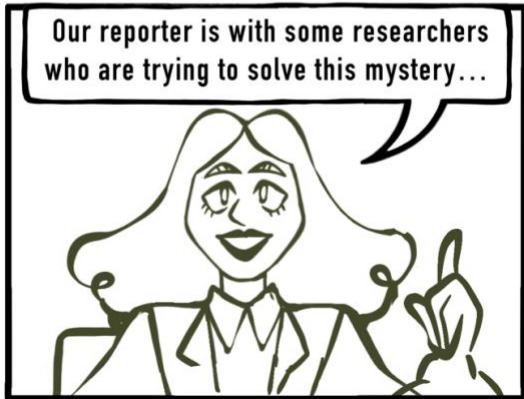
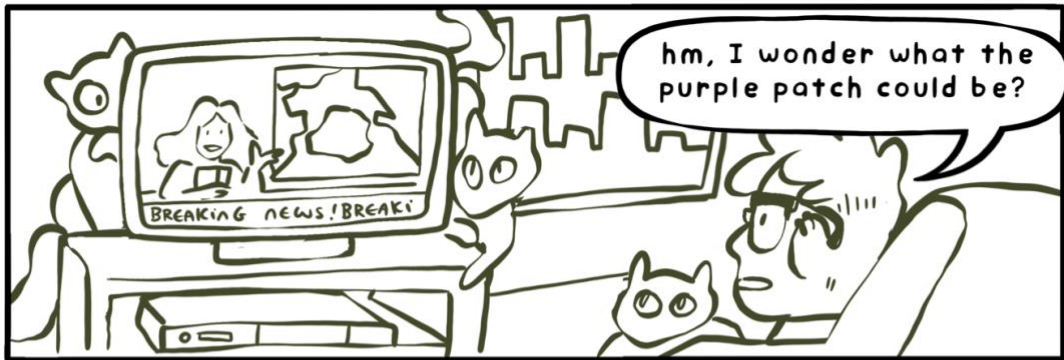
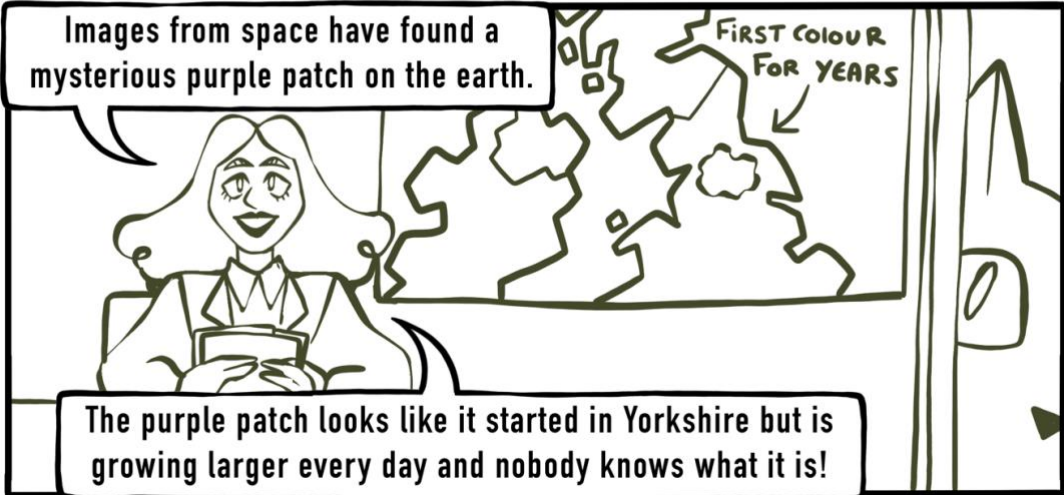
**A** family  
**R**eality based learning  
**T**eaching each other new things  
**S**teps not always accessible

Accessibility Poem 5 – Purple Patch Arts (group 2)

Purple Patch Arts is a family that we belong to  
Understanding everyone's needs and point of view  
Rooms, doors and toilets are accessible  
Politeness costs nothing, we are kind  
Looking after each other  
Everyone can do the activities together

Privacy when we want and need it  
Arts can be done in different ways by everybody  
Time flies when you're having fun!  
Courage to go, and to try something new  
Happiness at the end of the day

Always accessible  
Researching purple patch, we've learned so much more about it  
Trust is important and rewarding  
Support when we need it the most, from staff and each other





Well Maya, research is when somebody tries to answer a question that they don't know the answer to, like a detective trying to solve a mystery!



Researchers from around the world are trying to figure out what the purple patch is and what has caused it, but for now, it is still unsolved!



hm, I bet there are people at the purple patch who could tell us all about what is going on there. Why doesn't somebody just ask them?



I might not be a researcher, but I am up for adventure! I'm going to go to the purple patch and find out what is going on for myself!