Factors Affecting the Social Participation of Disabled People:
A New Perspective on Social Connectedness

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Abstract

Evidence shows that the quantity, diversity, and quality of one's social relationships are significant predictors of overall well-being and longevity. Social relationships are built through participation in activities with others, in community and shared spaces. Historically, disabled people have experienced persistent barriers to participation, resulting in their social exclusion from several areas of daily life. The thesis objective was to contribute to the understanding of the nature and patterning of barriers obstructing disabled people's social participation and to evaluate what this means for their social connectedness. A conceptual framework of social relations was developed to define the thesis concept of social connectedness and to inform the mixed methods research design. A secondary analysis of the UK Life Opportunities Survey (LOS) compared restricted participation and barriers to participation between disabled and non-disabled populations and explored patterns of barriers characterising restricted participation in the disabled sample using Latent Class Analysis. A longitudinal study, using LOS Wave 1-3, examined transitions in social participation and changes in barriers to participation reported by disabled and non-disabled people. A qualitative study used semi-structured interviews to explore experiences of establishing and maintaining social relationships in a sample of autistic adults. Disabled people had significantly higher rates of restricted participation in the LOS across all life areas. LCA identified three broad types of barrier profiles, characterised by time-driven, health-driven, and multiple environmental barriers. Reporting multiple social and physical environmental barriers to participation were significantly associated with being aged 16-24, reporting a high severity mental health impairment, or a neurodevelopmental condition. The qualitative study findings suggest that beyond environmental factors, the functional and qualitative features of social interactions play a vital role in autistic adults' social connectedness. The thesis findings build on a new model of social relations to extend the understanding of social connectedness and constructions of disability.

Author’s declaration

I declare that this thesis is a presentation of original work, and I am the sole author. This work has not previously been presented for a degree or other qualification at this University or elsewhere. All sources are acknowledged as references.

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Glossary

access	Being able to join in, take part in a service, social interaction or activity.
auditory processing	Differences in auditory processing is an autistic sensory trait characterised by enhanced pitch perception, sensitivity to loud noises, lack of auditory orientation, impaired perception of prosody and diminished auditory stream segregation.
autistic trait	A personal characteristic that is associated with being diagnosed with an Autism Spectrum Condition.
barrier profile	Latent classes comprising of sets of barriers that restrict the social participation of disabled populations.
barrier typology	The result of Latent Class Analysis on LOS barriers. It comprises of distinct 'barrier profiles' which characterise common combinations of barriers reported by disabled people experiencing restricted participation.
belonging	The subjective dimension of connectedness derived from the extent to which an individual's social network is perceived to fulfil their emotional and psychological needs.
camouflaging	Hiding or suppressing autistic traits by not revealing true feelings or preferences and by conforming to and imitating neurotypical communication styles. E.g.: camouflaging might involve forcing eye contact and smiles, standing uncomfortably close to others or

	engaging in small talk. Masking is another term for camouflaging.
communication mode	The method by which communication takes place. Examples are written, electronic, face to face, over the phone communication methods.
communication style	A person's way of communicating that is based on their thinking style, cognitive orientation and perceptions. Autistic people have been described to have a literal thinking style that interferes with the interpretation of multiple meanings. Autistic people need more contextual information when communicating with others to enable them to decode implied meaning.
community tie	Social relations with people in the wider community, including public spaces (e.g.: parenting groups, regularly attended playgrounds, sports facilities, volunteer organisations). People from these domains are familiar but not well known to the person and are often considered acquaintances.
conceptual framework of social connectedness	Framework illustrating how social relations are established within social and environmental conditions through participating in social interaction in different life areas. The framework incorporates the structural, functional and qualitative elements of network formation.
connectedness, also social connectedness	Social connectedness is the aggregation of the qualitative and quantitative features of one's social network. The qualitative dimension of social connectedness is a sense of belonging derived from one's perceived sense of closeness to their network members. The quantitative dimension of social connectedness is characterised by the

	number of social relations on each zone of the social network from most intimate to the most distant. (Townsend and McWirter, 2005)
connections	People we know (have at least met several times) and interact with regularly and consider part of our social network.
ego-centric network	Social network that centres around one individual, also called personal network.
executive functioning	Ability to plan and carry out an activity.
formal network layer	A layer of the social network consisting of the relationships the individual maintains in a formal institutional/organisational setting.
formal tie	Relationships with network members known from institutional settings with whom there is no (informal) contact outside of the setting.
friend	A network member in the informal network layer.
friendship	A usually reciprocal relationship characterised by positive affect and regular social interaction in informal settings.
informal network layer	Consists of relationships the individual maintains primarily in informal settings.
internalised stigma	Negative social attitudes that are internalised by disabled people, leading to negative constructions of the self.
intimate network layer	The inner most circle of relationships belonging to the close personal sphere. Consists of friends and family members who the individual perceives as close.

intimate tie	Intimate ties can be both symmetrical (e.g. friends, partners) or asymmetrical (e.g. parent-child relationships) and their main function is the provision of care giving, intimacy and affection.
life areas	The Life Opportunities Survey collected information on barriers and facilitators to participation across eight life areas: education and training, work, economic life, transport, leisure activities, accessibility in the home, accessibility outside the home, social contact. LOS terminology.
life domain	Same as life area. ICF terminology.
loneliness	Associated with the qualitative dimension of social connectedness. Loneliness is associated with feelings of lack of belonging, control and perceived support, resulting from one's perception of the quality of their relationships.
masking	See camouflaging
multiplexity (of a tie/relationship)	The number of different functions the tie fulfils. The number of different types of support flowing through the tie.
network failure	Not being able to participate in a life area because of the unavailability of a network member.
network structure	The patterns between network nodes and ties characterised by the number of nodes and the distance and level of interconnectedness between them.
neurodivergent	Neurological functioning that is different from the mainstream norm, in terms of social preferences, ways of

	learning, communicating and ways of perceiving the environment
neurodiversity movement	A prevailing perspective of neurodivergent conditions that arose from the disability rights movement. It builds on the social model of disability and aims to normalise autism and other neurodivergent conditions, seeing them as part of the naturally occurring neurological diversity across humans.
neurotypical	‘Typical’ or standard neurological functioning resulting in social behaviours that follow the norm, set by majority values
node	A person who is a member of a social network. They can be characterised by their location in the network, e.g.: intimate domain, informal, formal or community domains.
node quality	The attributes of a network member in terms of the resources they can provide and the influence they have in relation to the central individual.
objective connectedness	Refers to the extent to which a person possesses an adequate number of nodes with relevant structural and qualitative attributes on every layer on their social network.
participation domain	In the thesis four participation domains were defined as the intimate, informal, formal, and community domains based on participation in different life areas.
participation restriction	Expressing an interest in engaging in an activity but not being able to do so because of a social/environmental

	barrier, health condition due to an impairment, or network failure.
personal network	The personal network is an equivalent term to the ego-centric network, which is a social network that is centred around one individual. It only contains people (nodes) that the individual is personally acquainted with. It excludes people who are known to the other members of the network but not to the individual (e.g.: friends of friends).
relatedness	Shared characteristics between the participants of the social interaction that could stem from a variety of sources, e.g. demographic characteristics, genetic attributes, health characteristics and life experience.
social battery	The amount of physical and cognitive energy a person has for social interaction. The capacity to interact with others varies across individuals and it can be drained or recharged by different activities at different rates.
social capital	The accumulation of social resources that reside in one's networks of relationships. Social connectedness is a prerequisite to social capital, to the extent that it determines the quality and quantity of resources available to one through their social network.
social connectedness	A sense of closeness to others that is critical to one’s sense of belonging and is based on the aggregate experiences of proximal and distal relationships (Townsend and McWhirter, 2005)
social connection	relationship with a network member

social interaction	Social interaction is an instance of social participation involving an exchange of social resources between two or more people (network nodes).
social isolation	Associated with the structural dimension of social connectedness. Social isolation is the outcome of reduced social participation resulting in few or no ties on one or more layers of the social network.
social network	A social network consists of people (nodes) and the relationships between them (ties). Social networks can be described by their structure (e.g.: number and configuration of nodes) and content (e.g.: the resources they transmit.)
social network layers	Social networks operate across at least three broad hierarchical zones: the personal sphere (friends and family), the formal sphere (organisations) and the broader community. In this thesis, the personal sphere was split into two: the intimate network layer of close friends and family and the informal network layer of wider friendships, creating 4 network layers. LOS life areas were mapped onto network layers to assess access to participation across them.
social participation	An individual's involvement in activities meaningful to them, which provide interactions with others in community life and shared spaces. The ICF defines participation as social involvement across four life domains: (1) domestic life, (2) interpersonal life (formal and informal), (3) major life activities (employment and education) and (4) community, civic and social life.

social relations	The dynamic set of conditions, structures, and mechanisms within which social networks are established and maintained through social participation.
social resource	The functional feature of network ties. According to the pipe or flow model of Network Theory, social resources are conducted through ties in the form of social support (e.g. instrumental, emotional), information, power, material support, etc…
stimming	Self-stimulatory behaviour aimed at the regulation of emotions, often manifested in bodily movements or vocalisations.
subjective connectedness	Depends on individual perceptions and it is defined as the extent to which a person perceives that they participate in a sufficient number of reciprocal interactions which provide attachment, belonging or solidarity support on enough layers of their social network. Feelings of belongingness, alienation and loneliness are dimensions of subjective connectedness.
tie	A relationship between two people formed by regular interaction.
tie function	Function refers to the exchange of different kinds of social support. The two main types are emotional and instrumental support, which have several subcategories each.
tie quality	Subjective evaluation of a relationship, based on its power dynamics, reciprocity, types of support it conveys and perceived closeness.

List of Abbreviations

ASC	Autism Spectrum Conditions
ASD	Autism Spectrum Disorder
DPI	Disabled People's International
DSM-5	Diagnostic and Statistical Manual
DWP	Department for Work and Pensions
EHCP	Education and Health Care Plan
ICD	International Classification of Diseases
ICF	International Classification of Functioning, Disability and Health
ID	Intellectual Disability
LCA	Latent Class Analysis
LI	Functional Language Impairment
LOS	Life Opportunities Survey
OCD	Obsessive Compulsive Disorder
ODI	Office for Disability Issues
ONS	Office for National Statistics
RRB	Restricted Repetitive Behaviours
UN CRPD	United Nations Convention on the Rights of Persons with Disabilities
UPIAS	Union of Physically Impaired Against Segregation
WHO	World Health Organisation

PART I

A CONCEPTUAL FRAMEWORK OF SOCIAL RELATIONS

Chapter 1. Conceptualising social connectedness

1.1. Introduction

The focus of this thesis is to explore how disabled people's social connectedness is mediated through their access to social participation. In this chapter, a theoretical framework for social connectedness is developed incorporating multiple bodies of literature pertaining to previous conceptualisations of the structure and functions of social relationships. The chapter consists of five sections. The first sets out the thesis objectives and the research paradigms that will guide the quantitative and qualitative studies. The next three sections provide an overview of seminal theoretical approaches and conceptualisations of social relationships. The first of these summarises the principles of Network Theory and introduces the terminology that will be used in the rest of the thesis to describe social networks. The second critically reviews key models of social support which will inform the development of the thesis conceptual framework of social relations. The third section reviews common uses and definitions related to the concept of social connectedness in the social sciences literature. The final section in this chapter synthesises previous research on social relationships to present a model of social relations that accommodates a multi-dimensional definition of social connectedness, incorporating both its qualitative and structural elements.

1.1.1. Thesis rationale

The research undertaken in this thesis rests on the assumption that connectedness within a wider social network is vital for individual well-being. A person's social network consists of their relationships with others that they have established and maintained through social participation. Social participation is defined as an individual's involvement in activities meaningful to them, which provide interactions with others in community life and shared spaces (Levasseur & Lussier-Therrien, 2022).

Historically, disabled people have experienced persistent barriers to participation across numerous areas of daily life, perpetuating their social exclusion (Barnes & Sheldon, 2010; Dimakos & Kamenetsky, 2016; Galer, 2014; Isaac & Dharma Raja, 2010). Disabled people often encounter numerous obstacles preventing them from accessing social activities, such as environmental, transport, communication, attitudinal, social, and policy barriers. Policy and service failures early on in life mean that disabled people achieve lower educational attainment and experience a higher unemployment rate than the general population (see Chapter 2). The cumulative effect of these barriers to participation in most areas of life expose disabled people to a heightened risk of social isolation. The social networks of disabled people – especially of those with neurodevelopmental and mental health conditions – have been shown to be smaller and to contain fewer reciprocal relationships than those of non-disabled people (Mithen & Aitken, 2015; Orsmond & Shattuck, 2013; van Asselt-Goverts & Embregts, 2018).

This thesis aims to explore and classify barriers and facilitators to the social participation of disabled people and to situate these in a theoretical model of social relations which offers a new perspective on the understanding of social connectedness.

1.2. The importance of social connectedness

In Maslow's hierarchy of needs, 'belongingness and love needs' constitute the foundation block of human psychological needs (Maslow, 1943). The need to integrate into the social matrix through ties of affiliation has important implications for people's emotional, psychological, and physical health (Baumeister & Leary, 1995). Emile Durkheim's work, at the end of the 19th century, on the sociology of suicide is regarded as one of the most influential pieces of social science that highlighted the relationship between social integration, cohesion, and mortality (Durkheim, 2006 [1897]). Durkheim shifted emphasis from individual attributes (such as psychological states) to social structures to explain different levels of suicide rates across communities, cultures and nations. He recognised that the sense of social belonging and inclusion that flows from social relationships create well-integrated, stable, and cohesive social groups. These secure, durable, and supportive structures function as safety nets for the individuals inside them, reducing their vulnerability to suicide (Wray & Colen, 2011).

Durkheim's seminal work influenced the rise and application of Social Network Theory to explore the social determinants of illness. Since the 1970s, anthropologists and sociologists have consistently demonstrated that there is a link between social networks and well-being. The extent to which an individual is ‘embedded’ or connected within their social network has been shown to be related to them experiencing negative life events and the onset and progression of disease (Cassel, 1976; Cobb, 1976).

More recent research confirmed that having a social network that lacks a range of social relationships across both formal and informal social spheres predicts mortality from almost every cause of death (Berkman, 2000; Berkman & Glass, 2000; Cohen, 2004; House & Landis, 1988) It appears that both the quantity and quality of relationships an individual is engaged in have significant effect on their mental and physical health as well as their longevity (Ertel & Glymour, 2009; Kawachi & Berkman, 2001; Yang & Boen, 2016). Having a social network that is rich in a diverse range of relationships and provides opportunities to fulfil multiple different social roles are shown to be positively associated with individual health outcomes (Barefoot & Grønbæk, 2005).

In this thesis, social connectedness is defined as a multidimensional construct with a structural and qualitative component. The structural component can be characterised by the extent and variety of one’s personal relationships and the qualitative component by the sense of satisfaction and identification one feels with their social roles and network (Holt-Lunstad & Lefler, 2019; Holt-Lunstad & Smith, 2015). Social participation is the primary mechanism for social connectedness, and barriers to participation experienced by disabled people constitute the central research focus of the thesis.

1.2.1. Research paradigms

Research is conducted in the context of a philosophical belief system or paradigm. Paradigms, also called epistemologies, are the principal beliefs, worldviews with their associated theoretical frameworks that guide the scientific investigation (Creswell & Creswell, 2018). This thesis contributes to the understanding of social connectedness from three perspectives. First, a conceptual model of social relations is developed, refining current theoretical models of connectedness. Second, the factors affecting social connectedness in disabled populations is investigated using secondary data analysis. Third, qualitative techniques are employed to explore the subjective experiences of a small group of autistic adults in relation to how they build and maintain social relationships. These three distinct research elements require drawing on different research paradigms to achieve their objectives.

Structuralism

The structuralist paradigm was first applied in the field of sociology during the late 1970s by Blau and Mayhew (Blau, 1977; Mayhew, 1980). It employs a retroductive research strategy, which aims at explaining social phenomena by modelling their underlying structures and mechanisms (Blaikie, 2007). Network theory belongs to the structuralist paradigm and the methodology it employs is called structural analysis or network analysis. In structuralism, structural analysis is the central tool to study the implications of social structures for the individual, groups, and communities. Structuralism posits that human behaviour, attitudes and experiences can be explained and even predicted by examining the structure of the social networks within which people are situated. In this thesis, structuralist principles are employed to define the conceptual framework of social relations and social connectedness.

Post-positivism

Postpositivist or empirical approaches to social enquiry seek to understand phenomena through observation. Their goal is to find evidence to support theories which describe observed regularities in the external world. These approaches are grounded in a realist ontology, that attributes social reality and human behaviour to factors external to the individual. Empirical research is guided by a deductive research logic and relies on collecting observations of the external world to be analysed using quantitative methods. The quantitative study in this thesis relies on empirical principles for the definition of barriers and facilitators to participation.

Constructivism

The constructivist paradigm is directly opposed to post-positivism. It is based on an idealist ontology, maintaining that reality is constructed in people’s minds (Blaikie, 2007). This entails that reality is experienced as a subjective representation of the external world. In social constructivism, reality is constructed through social interactions in the context of historical and cultural settings. Research strategies founded on a constructivist paradigm, use inductive research strategies to arrive at patterns of socially constructed meanings from a set of data collected through interactions. Since the primary source of information is human interaction within specific contexts, constructivist approaches often employ qualitative research methodologies (Blaikie, 2007; Creswell & Creswell, 2018). The qualitative study will rely on constructivist principles to explore how current models of disability accommodate the lived experiences of social participation and social network formation in a small sample of autistic adults.

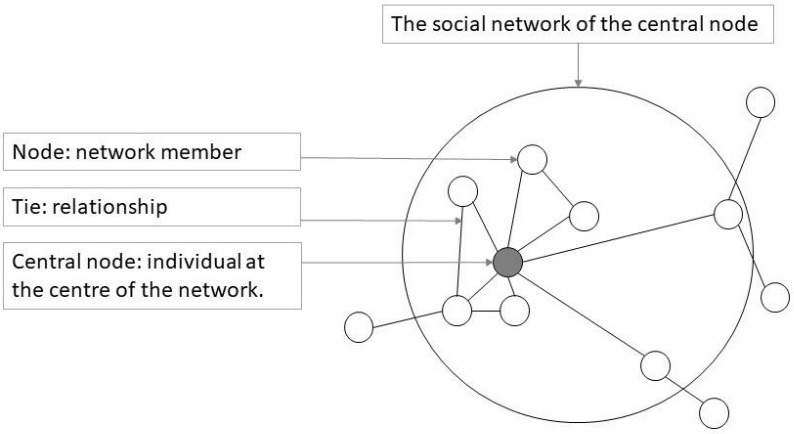
The following three main sections provide a short introduction to (1) network theory, (2) models of social support and (3) concepts related to social connectedness. Each of these sections will play a role in the development of the thesis' conceptual framework of social relations. Network theory provides the terminology to describe the structure and functions of social networks. Models of social support provide a visual blueprint for the thesis' conceptual framework. The literature review on concepts related to social connectedness aids the delineation of the thesis' definition of social connectedness in contrast to other definitions found in the literature.

1.3. Network theory

This section provides and introduction to network theory, initially developed by sociologists to describe the fundamental role that social structures play in predicting human behaviour and health outcomes. The development of network theory was strongly influenced by the work of Simmel who suggested that the structure of social interaction generated its own content (Adler & Seok-Woo, 2002; Wellman & Berkowitz, 1988). The main hypothesis of this paradigm is that a person's physical, genetic, and acquired attributes have lower predictive power of their behaviour and health outcomes than the relationships they engage in. This implies that well-being is not solely the result of one's personal attributes, but it is a consequence of their level of access to the scarce resources embedded in their social network. An individual's access to resources is determined by the size and quality of their social network and the position they occupy within it.

Social networks consist of the web of social connections surrounding individuals (Figure 1.1). In network theory terms, the members of social networks are referred to as nodes, and the relationships between members are referred to as ties. Ties can link network members directly and also indirectly through other members. Network nodes can be characterised by their position (e.g.: centrality) within the network and by the number and positioning of the other nodes in the network that they are connected to. Social networks are often described in terms of their structure and content. Network structure refers to the patterns between nodes and ties characterised by the distance and level of interconnectedness between nodes (Section 3.1.2). Network content refers to the resources a network conveys (see Section 3.1.3).

Figure 1.1 An example of an 'egocentric' social network, illustrating nodes and ties



Social networks can be studied in their entirety, the 'whole network' approach; or from the point of view of focal individuals (termed 'the ego'), the 'egocentric' or 'personal network' approach. The whole network approach is used to study connectivity and cleavage in social systems, whilst the egocentric network approach examines how the node position and tie structure of an individual within a network facilitates the flow of resources to and from them (Wellman & Berkowitz, 1988). This thesis utilises the egocentric approach to social networks to define social connectedness. References to the social network should be interpreted throughout the thesis as the 'personal network' around a focal individual.

1.3.1. Network structure

The structural features of networks include their size (or range), density, closure, and node centrality. Network density is the extent to which the nodes within the network are interconnected with each other by means of direct ties. Node centrality refers to the position of the node in relation to other nodes in the network, in terms of the numbers of direct ties leading to it. Network closure refers to the extent to which the network can be characterised as a cluster of direct ties (Hall & Wellman, 1985). The size and configuration of an egocentric social network has important implications for the access and types of resources available to the focal individual.

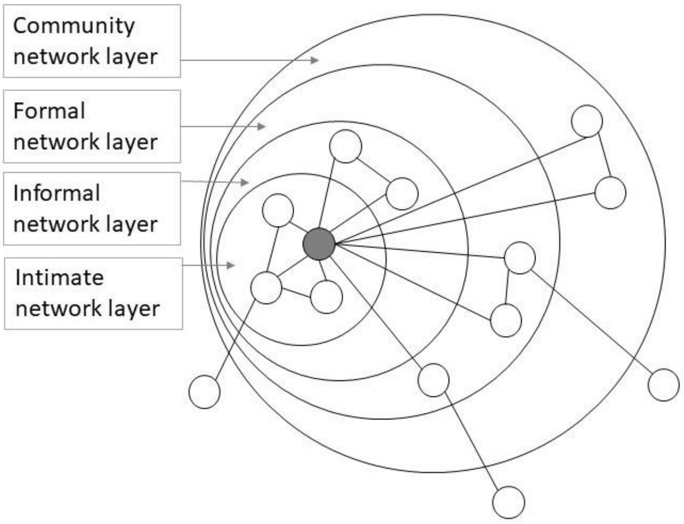
Social networks can also be understood as consisting of a number of hierarchical zones or layers. These network layers correspond to the social life domains on which network ties are formed. Commonly, at least three levels of social network layers are distinguished: informal, generalised, and institutional (Stone & Hughes, 2002). Boissevain described at least seven different relationship zones which broadly corresponded to the personal sphere (friends and family), the formal sphere (organisations) and the sphere of the broader community (Boissevain, 1974).

Each network layer contributes to a different aspect of a person's social and psychological integration. The intimate network layer comprises of relationships characterised by care giving, intimacy and affection. These connections contribute to the formation of individual identity and psychological and emotional well-being. The formal network layer, associated for example with participation in education and employment, comprises of both formal and informal relationships which primarily provide information, advice, and appraisal support. Interactions with others in formal spheres shape individuals' self-perception in relation to their social status and social roles. Having ties in the wider community, for example through participating in religious activities, sport, or hobbies, contribute to one's feelings of group belonging, social integration and solidarity (Hall & Wellman, 1985).

This thesis explores social participation and relationships across four network layers: the intimate, informal, formal and community layers (Figure 1.2). The intimate network layer consists of the individual's relationships with close friends, family, and significant others. The informal network layer consists of the friends and family with whom the individual regularly interacts with in informal settings. The formal layer consists of ties formed by participation in formal activities at the workplace and educational/institutional settings. The broader community network layer consists of relationships formed through the individual's affiliation or membership to institutions, interest groups and the relationships they established with neighbours and acquaintances in their local community.

Social networks are subject to change, and a tie that was formed on one life domain may become stronger or weaker over time and as a result traverse network layers. For example, ties established on the formal or community network layers may later become consolidated on the informal or intimate network layers. Because of this reason, social participation and social network characteristics need to be evaluated within the timeframe of the individual's current social and demographic circumstances.

Figure 1.2 Layers of the social network



1.3.2. Network content

The content of a social network is characterised by the quality and diversity of its nodes, and the function, quality, and strength of its ties.

Node quality

Node quality and diversity refer to the attributes of the people included in one's social network (Stone & Hughes, 2002). These attributes relate to any expertise, information, power or influence the network member has in relation to the central individual. Tie function, tie quality and tie strength relate to the perceived needs that a relationship fulfils between two individuals and the significance they attach to it (Stone & Hughes, 2002).

Tie function

A network tie is a relationship between two people (also known as a 'dyad') and it is characterised by the resource it provides. The function of ties is to conduit information and different types of social resources between dyads (this is referred to as the flow or pipes model in network theory (Burt, 2000)). Besides the traditional categories of instrumental, emotional and information support, social support can serve a wide variety of other functions such as: bonding, appraisal, cognitive, belonging and self-esteem support (House & Kahn, 1985; House et al., 1988; Wellman & Berkowitz, 1988).

Tie quality

The value and meaning attributed to a tie in one's network is dependent on the number and types of resources it conveys (its multiplexity), the intensity of the interaction between the dyad, the frequency of interaction, the tie duration, and its degree of reciprocity and intimacy (perceived social closeness) (Stone & Hughes, 2002). As people's resource needs change so does the importance that they attribute to particular ties in their network. Hence social networks are not static, they change dynamically with the disappearance of some nodes and the reappearance of others as demand arises for new types of resources (Wellman, 1988).

Network ties are by nature reciprocal, but often asymmetrical. This means that one member of the dyad will give or receive more resources than the other. Asymmetrical ties result in hierarchical social networks, which distribute scarce resources unevenly, resulting in cumulative differences in access to resources (J. A. Davis, 1970). This is especially relevant to disabled populations, who are more likely to experience asymmetrical relationships and social exclusion due to lack of access to resources than non-disabled populations (see Chapter 2).

Tie strength

The strength of ties in a social network also contribute to its quality and diversity. Tie strength refers to the perceived closeness or affinity between dyad members. Research indicates that close and weak ties have different roles to play for social connectedness, and it is beneficial to have both types in one's social network.

Bonding ties

People tend to socialise more with others who are similar to themselves (McPherson & Smith-Lovin, 2001). People with similar attributes to ourselves are more likely to hold similar beliefs and attitudes, hence we are more likely to agree with each other (B. H. Erickson, 1988). Salient similarities between dyad members lead to the formation of strong ties. This phenomenon is called homophily (McPherson et al., 2001). People with strong ties are likely to share some of their social network, i.e. know each other's friends (Freeman, 1978; Granovetter, 1973). Strong ties within social networks are also described as bonding ties and are characterised by frequent interaction and close, supportive relationships, enabling the individual to 'get by' (Stone & Hughes, 2002). Bonding ties, however, are also described as having high redundancy of information, because in a social network where the nodes have similar attributes and relatively high levels of interaction, there will be very little new information flowing through the ties (Granovetter, 1973).

Bridging ties

Bridging ties are weak ties situated on the periphery on the personal network that can connect an individual to nodes in another social network (i.e.: they act as a bridge between two disconnected networks). Weak ties are characterised by low intensity, infrequent interactions, they are not necessarily reciprocal or intimate. This makes weak ties transitory and subject to decay (Wellman, 1988). At the same time, weak ties have the potential to become invaluable to an individual, if they connect them to a social network that has highly prized resources (e.g.: prospective employers). In this way, weak ties can act as gateways to new information and opportunities in other networks. These ideas form the foundations for Granovetter's Strength of Weak Ties Theory (Granovetter, 1973).

Research indicates that some disabled populations are more likely to have social networks that are especially rich in bonding ties and lack bridging ties (see Chapter 2, Section 2.4, p.75). This is concerning because restricted formal and community network layers lead to reduced opportunities and social isolation.

The following sections review how theories of social support employed network theoretical principles to conceptualise social relationships. These models are drawn on for the development of the thesis conceptual framework of social relations.

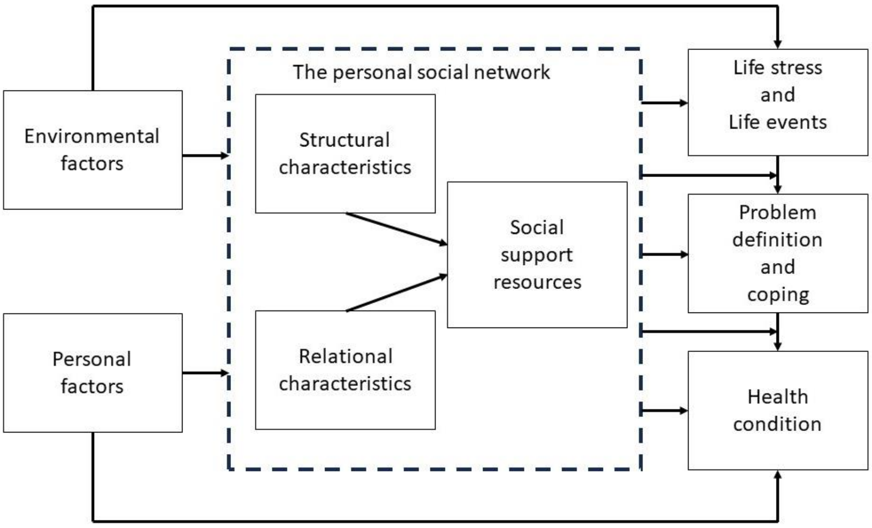
1.4. Models of social support

One of the main routes through which social relationships protect our emotional and physical health is social support. Hence the first conceptualisations of the workings of social networks originated from studying the mechanisms of social support. The following sections briefly review how theories of social support at the end of the 20th century employed network theoretical concepts of tie structure and function to explain the distribution of social resources across the social network.

1.4.1. Social networks as mediators of social support

In the conceptual framework of Hall and Wellman, social networks function as mediators of social resource flow to the focal individual (Hall & Wellman, 1985). Moreover, social networks are placed within the context of the environmental and personal factors within which they operate (Figure 1.3). The mediating model characterises the personal social network by its tie structure and node relations. Tie structure extends beyond the dyad and social support is seen as a resource embedded in the larger structure of hierarchical relations. Node relations are evaluated in terms of their multiplexity and affect (both positive and negative). In this model, the social network is seen as a mediator or moderator of the effects of the environmental and personal factors on individual outcomes with regards to life events, mental and physical health.

Figure 1.3 The mediating model of social networks



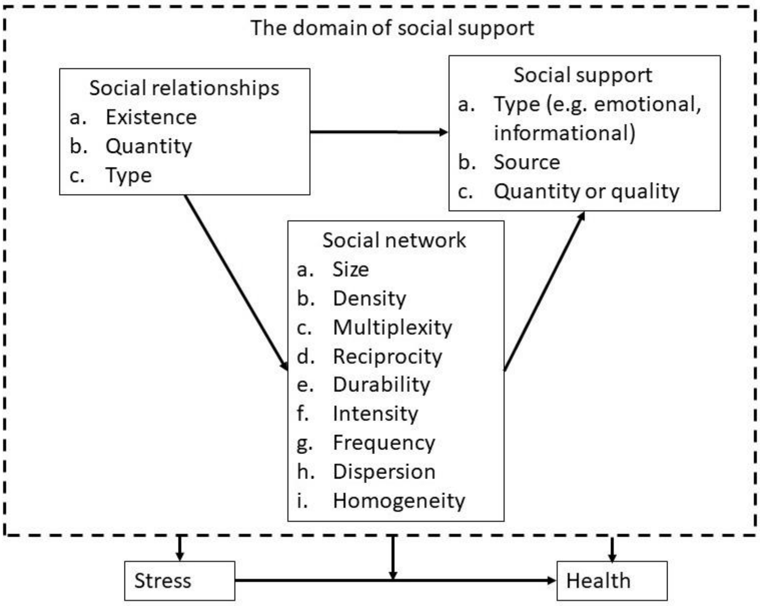
Source: Hall and Wellman (1985), Figure 2.1, p.34

The strength of Hall and Wellman's mediating model of social support is that it establishes causal links between contextual factors, social network characteristics and health and well-being outcomes. It does not define social support as a one-dimensional function of ties, instead it regards it as a multifaceted resource that may flow through the network when conditions allow. The model facilitates the illustration of complex social phenomena (e.g.: relationship strain) as the consequence of the social network's structural and relational characteristics. As a result, this model has both high generalisability and explanatory value.

1.4.2. Social networks as the source of social support

House and Kahn's work (House & Kahn, 1985) on conceptualising social support has a narrower focus that attempts to describe and map the quantity, structure, and function of social relations, regardless of their wider context. Their conceptual model (Figure 1.4) defines the quantity dimension as 'social relationships', the structural dimension as the 'social network', and the functional dimension as 'social support'. Each of these elements are further specified by quantitative and qualitative features. Mental and physical health outcomes are seen as being directly impacted by the level and types of social support received by the individual.

Figure 1.4 Theoretical framework for assessing measures of social support



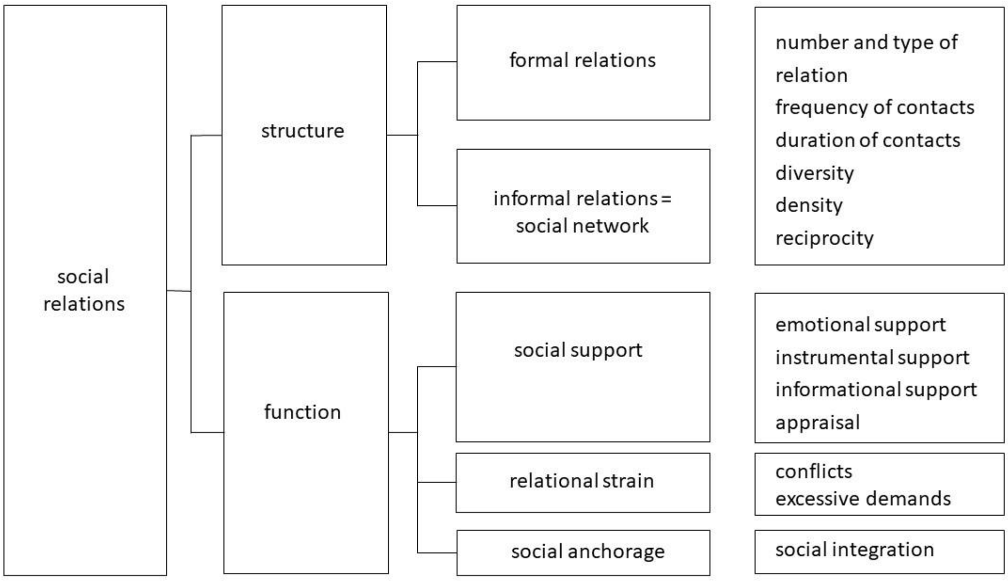
Source: House and Kahn (1985), Figure 5.1, p.86

House and Kahn’s framework for measuring social support has several conceptual flaws which relate to overlapping definitions of ‘*social relationships*’, ‘*social network*’ and ‘*social support*’ (Figure 1.4). The conceptual distinction between social relationships and social network is not clear and they both seem to contain elements that refer to network size and structure. Social support, which is confusingly defined as the functional dimension of the domain of social support is derived both from ‘*social relationships*’ and the ‘*social network*’. The model would gain greater conceptual clarity if ‘*social relationships*’ were renamed as the ‘social network’, the ‘*social network*’ was renamed as ‘tie characteristics’ and ‘*social support*’ was renamed as ‘tie function’.

1.4.3. The social network as an analytical concept

O’Reilly’s conceptualisation of social support aims to dispel the confusion surrounding its structural and functional elements (O'Reilly, 1988). He suggests that social networks are the main analytical concept which have structural and functional features. Social support is but one of the functions the social network fulfils. Due et al (Due & Holstein, 1999) build on O’Reilly’s work by separating the structural and functional features of networks. But instead of the term social network, they use ‘social relations’ as their main concept (Figure 1.5). Under structural features, Due et al incorporate two types of ties: formal and informal relations. Under the functional features, they include three types of function: social support, relational strain, and social anchorage. Similar to House and Kahn, Due et al employ network theory tools to measure the structural and functional dimensions social networks.

Figure 1.5 Conceptual framework of social relations



Source: Due et al (1999), Figure 1, p. 662

Separating the structural and functional features of social relationships does bring more transparency to the conceptualisation of how social networks transmit support. At the same time, Due et al's framework contains some flaws. First of all, conceptually, there is no clear distinction between social relations and the structural subcomponents of informal and formal relations (Figure 1.5). The term 'social relations' is chosen by way of elimination of other terms because 'it covers none of the other key concepts' p. 662 (Due et al., 1999). Secondly, the term 'social network' is used to refer only to one's informal relationships (see Figure 1.5) which narrows down its scope and contradicts the multi-layered conceptualisation of the social network described earlier, where ties are formed across several life areas. In the wider literature, the social network encompasses a wide range of diverse ties (see Section 1.3.1). Finally, the choice of functional dimensions does not differentiate social support from its outcomes. Providing (or receiving) too much social support can result in relational strain, hence it is one of its negative outcomes. Receiving social support may contribute to psychological integration and anchorage, hence it is one of its positive outcomes.

The above-described models of social support incorporate the structural/quantitative and functional/qualitative elements of the social network to varying degrees. The main difference between the models relate to their definition of the social domain, their distinction between structural and functional network features, and whether they also account for the contextual elements of social networks.

The next section provides a brief review about the different concepts used in relation to social connectedness across the social sciences. The review will help to situate the thesis definition of social connectedness within the wider interdisciplinary context.

1.5. Social connectedness and related concepts

The notion of social connectedness is central to the explanation for a range of human behaviours and experience. Hence a diverse set of disciplines made it their subject of study (e.g.: social psychology, sociology, political science, economics, marketing, communication science etc.). Social connectedness is the dimension of social relationships that fulfils the psychological need for attachment and belonging. From the moment we are born, our long-term psychological (and physical) well-being depends on the quality of the attachments we form with our main care giver and the wider world (Bowlby, 1976). Emotional self-regulation and the ability to form positive, nurturing, reciprocal ties with partners and friends depends on the intensity and reliability of the affective support we received in our early lives. The need to belong continues throughout the life-course and extends beyond our intimate circle of close friends and relatives to the community and larger social groups we live in (Berkman, 2000). Baumeister and Leary express this idea in their belongingness hypothesis: “human beings have a pervasive drive to form and maintain at least a minimum quantity of lasting, positive, and significant interpersonal relationships” (Baumeister & Leary, 1995).

The following sections describe the different dimensions of social connectedness used in the literature, what we know about how social connectedness changes over the life course, and how social connectedness relates to the notion of ‘social capital’.

1.5.1. Dimensions of social connectedness

Most of the social research community agrees that social connectedness has a quantitative/ objective and a qualitative/subjective element (C. S. Ang, 2016; S. Ang, 2019; Barlott & Aplin, 2019; Hare-Duke & Dening, 2019; Townsend & McWhirter, 2005). One of the most complete definitions of connectedness, which encompasses both its quantitative and qualitative dimensions comes from the field of psychology. Townsend and McWhirter's interpretation of Lee and Robbins' definition expresses the dual nature connectedness with great clarity (R. M. Lee & Robbins, 2000; Townsend & McWhirter, 2005):

> "…social connectedness includes a sense of closeness to others that is critical to one's sense of belonging and is based on the aggregate experiences of proximal and distal relationships (e.g., parents, friends, peers, strangers, communities, and society)." (Townsend and McWhirter, 2005, p. 193)

This definition highlights the qualitative dimension of connectedness that enhances sense of belonging through closeness. The quantitative dimension is expressed through the reference to the proximal and distal relationships which encompass a range of close and weak network ties. Embeddedness and belonging are recurring themes in the discussions of social connectedness. Townsend and McWhirter tie the two notions together when referring to connectedness as an enduring sense of the self in relation with the social world in which the person embeds (Townsend & McWhirter, 2005).

The dual nature of social connectedness gives rise to a substantial amount of confusion and blurred conceptual categories in the literature. Some authors conceptualise connectedness focusing predominantly on its structural features e.g.: social participation, network size, volume of social interaction (S. Ang, 2019; E. Y. Cornwell & Waite, 2009). Others prefer to define connectedness in terms of subjective experiences e.g.: loneliness, belonging, subjective psychological bond (Biordi & Nichilson, 2013; Hare-Duke et al., 2019; Haslam & Cruwys, 2015).

There are conflicted views in the literature regarding the social network zones on which connectedness arises. Some authors define connectedness as a functional property of close social ties (found on the intimate network layer) and differentiate it from 'community integration' (B. Cornwell & Laumann, 2008). Whilst others believe that connectedness operates across all the layers of the social network (O'Rourke & Collins, 2018).

1.5.2. Social connectedness across the life-course

Social connectedness is a time-bound phenomenon. In the short-term, it is experienced in the immediate wake of our social interactions (Van Bel & Smolders, 2009); whilst in the long-term it fluctuates as we progress through the life-course and our role-relations change. The sources of long-term change in connectedness are thought to be caused in part by age effects (progression through life stages) and cohort effects (generational differences) (S. Ang, 2019). The life course perspective emphasises the social norms and expectations that are age-bound and change as we progress through life. The social roles and statuses that individuals fulfil follow a regular pattern through their life-course, structured by culturally determined social attitudes, stereotypes and beliefs about appropriate behaviour (S. Ang, 2019; Riley, 1987). Cohort effects refer to the similar historical circumstances and events experienced by generations growing up together as a group. These shared experiences often influence subsequent life trajectories, leading to generational differences across outcomes (S. Ang, 2019). Research indicates, that although there are fluctuations in connectedness surrounding life-transitions (e.g.: marriage, parenthood, retirement, widowhood), individuals generally compensate for losses and maintain quite stable social networks throughout their lives. Some types of chronic illness and very old age, however, may compromise the individual’s ability to sustain their social engagement and retain their access to social support (Ertel et al., 2009).

There is some evidence that embeddedness in social networks is most important during the formative years of adolescence, and during the later adult years (Yang et al., 2016). Social integration during adolescence impacts on metabolic and cardiovascular functioning, setting the individual on a health pathway that influences their long-term risk of developing disease. For older adults, having social connections delays the onset of chronic conditions associated with ageing (Yang et al., 2016).

1.5.3. Social connectedness versus social capital

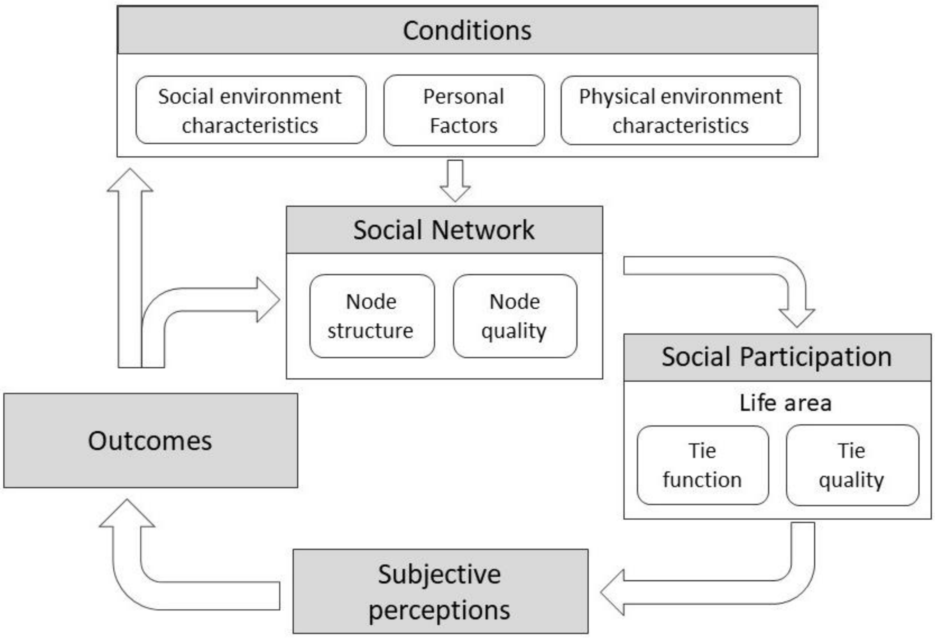
Social connectedness and social capital are closely related concepts, but they are not interchangeable. Theories of social capital were initially developed by Coleman (Coleman, 1988), Bourdieu (Bourdieu, 1986) and Putnam (Putnam, 1995) as an analogous concept to economic and human capital. The idea behind the notion of social capital is that human relations, besides providing people with intrinsic enjoyment, benefit the individual and society in more tangible ways (OECD, 2011). At the community level, high levels of social capital result in group cohesion, high levels of trust between members and group identity formation. At the individual level, access to social capital advances personal health and well-being in a myriad of ways, on both the formal (advancement, promotion, influence, attaining information) and informal spheres (feeling supported, valued, respected). Hence social capital is often defined as the instrumental value derived from one's relationships (Adler & Seok-Woo, 2002; Dimakos et al., 2016). Like other forms of capital, social capital needs investment and maintenance to yield returns. Social capital can be defined as the accumulation of social resources that reside in one's networks of relationships. This entails that social connectedness is a prerequisite to social capital, to the extent that it determines the quality and quantity of resources available to one through their social network.

1.6. Thesis conceptual framework

In this section the two distinct bodies of literature on social network theory and models of social support are brought together to develop a conceptual framework of social relations that accommodates the concepts of social participation and social connectedness as defined in this thesis.

The term 'social relations' refers to the dynamic set of conditions, structures, and mechanisms within which social networks are established and maintained through social participation (Figure 1.6). Within this model, social relations are composed of five main elements: (1) conditions, (2) the social network, (3) social interaction, (3) subjective perceptions, and (4) outcomes shaping conditions and the existing social network. The framework described below aims to capture social relations as comprising of a dynamic flow between structures and processes which continuously feed into each other.

Figure 1.6. Thesis conceptual framework of social relations



This model of social relations builds on the mediating model of Hall and Wellman (Hall & Wellman, 1985), because it views social networks and social participation as mediators between conditions and outcomes. At the same time, this model adds an extra dimension of conditions (compared to the model of Hall and Wellman) by separating the physical and the social environments. Emphasising the impact that the social environment has on the participation of disabled people extends traditional approaches to disability which focus primarily on the removal of physical environmental barriers to participation (e.g.: the Social Model of Disability).

Another way in which the model refines existing conceptualisations of social relationships, is by distinguishing between the relatively static structural/qualitative elements of the social network and the in person interactive processes which have a psychological impact that shapes people's self-perception and social relationships. Conceptually, it is important to make a distinction between the structure and quality of the social network and the function and quality of the social interaction. This model is generalisable to a diverse range of social phenomena and accommodates a wide variety of concepts present in the literature.

In Table 1.1 the thesis theoretical framework of social relations is described using network theoretical concepts.

Table 1.1 Describing the elements of the thesis conceptual framework of social relations

Element	Characterised by	Measured by
Social network	Structure: quantity and configuration of ties	• existence of ties • number of ties • network size • density • frequency of interaction • dispersion
	Quality: node characteristics	• node attributes • homogeneity/diversity • node location in network
Social participation	Function: type of resource flowing through tie	• any type of social support • influence/power
	Quality: tie characteristics	• multiplexity • durability • intensity • reciprocity
Subjective perceptions	The social interaction is subjectively evaluated by the individual eliciting positive or negative mental states.	• perceived support • feelings of belonging • feelings of power/influence • relationship strain
Outcomes	On basis of the subjective evaluation, a range of outcomes arise, affecting the individual's health and well-being.	• health behaviour • mental/physical health outcomes • mortality/longevity • constructed identity

The sections below describe in more detail how each element of the conceptual framework explains the dynamic nature of social network creation.

1.6.1. Conditions

Within this model, social networks are formed in the context of conditions, comprised of social and physical environmental, and individual factors. Social environment characteristics include the political and education systems, labour market, cultural belief systems, norms, and expectations. Physical environment characteristics include rural/urban location, accessible spaces, transport, adaptive technologies, and virtual spaces. Individual attributes include, for example, physical and mental health, cognitive ability, social skills, and socio-economic circumstances.

Accounting for the interaction between the environment and personal factors when thinking about social relationships and participation is the core element of the definition of disability in the International Classification of Functioning (ICF) (see Chapter 2, Section 2.2, p.59). In a similar way, the Social Model of disability emphasises the need for adjusting the social and physical environment in order to accommodate functional limitations due to an impairment to a bodily structure (see Chapter 2, Section 2.2, p.57).

1.6.2. The social network

In the thesis model of social relations, the social network is seen as a person's primary facilitator to social participation. The social network is comprised of existing network members with whom ties have been formed. The structure of the social network is characterised by the number and configuration of its nodes, whilst its quality is characterised by the attributes of its nodes (which is a slight departure from the literature reviewed in Section 1.5). A person's existing social network is central to their capacity to initiate and take part in social interactions with others. The quality of their existing relationships, including the function they fulfil contribute to the person's evaluation of themselves in relation to others in their social network and wider society.

1.6.3. Social participation

As defined earlier, social participation involves interaction with others, in activities that are meaningful to the person, in the context of community life and shared spaces (Levasseur et al., 2022). The ICF defines social participation across four life domains: (1) domestic life; (2) interpersonal life (formal and informal relationships); (3) major life activities (education and employment); and (4) community, civic and social life (Donelly & Hillman, 2019; WHO, 2001a). These domains broadly correspond to the social network layers of intimate, informal, formal and community zones as described in Section 1.3. In the thesis model of social relations, social participation involves tapping into existing relationships on the social network or creating new ones through the exchange of social resources. Interaction with others is seen as the trigger that activates the latent resources in a social network and determines which network function is called upon.

Social network characteristics play an important role in social interactions because the network's structural (i.e.: hierarchical) and qualitative attributes determine the role and power relations between the dyad (e.g.: partners, friends, relatives, employer/employee, etc…) and the extent to which social resources can reach the central individual (i.e.: the focal individual in the egocentric network). The types and quality of role-relations between the individual and their network members affect the function and quality of their social interactions (Agneessens & Waege, 2006). Because of the vital role played by the relationship between the dyad, social interactions are characterised by tie function and tie quality (see Section 1.3).

1.6.4. Subjective perceptions

Subjective perceptions refer to the process of personal evaluation of social interactions and relationships. Interactions that conform to social norms and stay within the parameters of the expectations within the given role relation are beneficial to the individual (Giesbers & Tournier, 2019). They tend to enhance feelings of belonging, control, perceived support, and social identity. Social interactions that violate social norms or cross personal boundaries are harmful. These types of interactions tend to elicit feelings of powerlessness, exclusion, discrimination, loneliness, and relationship strain (Gottlieb & Bergen, 2010; Umberson & Montez, 2010).

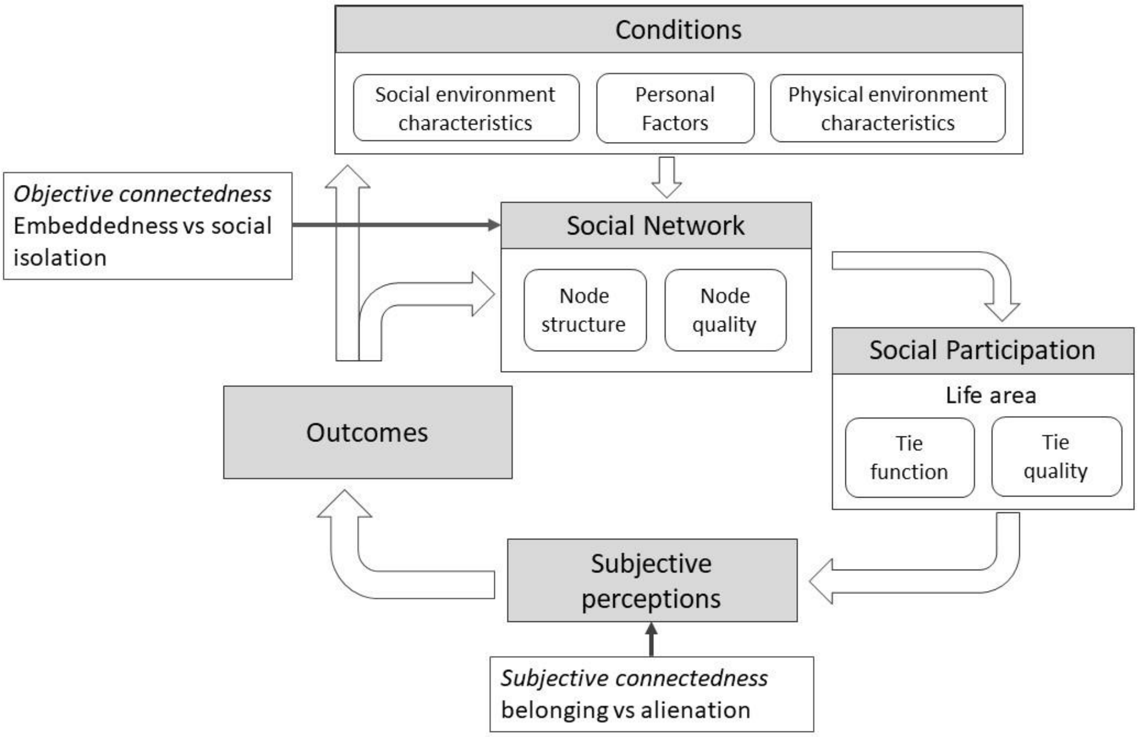
1.6.5. Outcomes

The subjective evaluation of interactions and relationships leads to short and long-term psychological and physical health outcomes thereby shaping future conditions of participation. Subjective perceptions also have an impact on the structural features of the social network by creating, consolidating, or dissolving network ties.

1.7. Social connectedness within the framework of social relations

The definition of social connectedness in this thesis draws on the definition of Townsend and McWhirter (Townsend & McWhirter, 2005), and it encompasses the structural, functional, and qualitative aspects of social relations. Social connectedness is defined in an objective, measurable sense as aspects of the social network that pertain to its structure and quality; and in a subjective sense, as aspects of social interactions that pertain to tie function and quality, leading to subjective evaluations of belonging or alienation (Figure 1.7).

Figure 1.7 Locating 'social connectedness' within the thesis framework of social relations



Objective connectedness refers to the extent to which a person possesses an adequate number of nodes with relevant structural and qualitative attributes on every layer on their social network. The structural attributes contribute to the extent of embeddedness in the social network. Within this model of social relations, social isolation is defined as having poor objective connectedness, characterised by an absence or sparsity of network nodes on one or more network layer (especially those of relevant quality).

Subjective connectedness depends on individual perceptions and it is defined as the extent to which a person perceives that they participate in a sufficient number of reciprocal interactions which provide attachment, belonging or solidarity support on enough layers of their social network. Feelings of belongingness, alienation and loneliness are dimensions of subjective connectedness.

1.8. Conclusion

In this chapter a theoretical framework of social relations was developed which synthesised different bodies of literature to illustrate how social networks are built and maintained through social participation in activities within the context of environmental and personal conditions. The chapter introduced the terminology of network theory to describe the structure, quality, and functions of social relationships. Moreover, the understanding of ‘social connectedness’ that was set out in this chapter will be used to guide the data analyses and interpretation of the quantitative and qualitative studies.

Chapter 2. Perceptions and social participation of disabled people in the UK

2.1. Introduction

This chapter provides an overview of society's perception and historical treatment of disability and reviews the participation restrictions that disabled populations experience across a range of life areas. The chapter comprises of three sections. The first one introduces some of the prevalent models of disability and provides a critical analysis of their shortcomings. The second section presents the current UK context regarding disability prevalence, participation rates and the barriers encountered by disabled people across the domains of education, employment, leisure, and community activities. The third section provides a brief overview of what is known about the social networks of disabled people and their subjective perceptions of these. The chapter concludes with a summary of the main barriers to disabled people's participation and identifies gaps in knowledge.

2.2. Models of disability

The way disability is conceptualised and talked about shapes the national disability legislation and the treatment and perceptions of disabled people in societies (Haegele 2016).

2.2.1. The Medical Model

In developed nations, historically, it has been scientists and clinical professionals who had the authority to define the disability discourse and societal values surrounding it (Humpage, 2007). This professional-led approach to disability resulted in the development of the medical model which saw disability as a deficit in individual functioning due to physical or cognitive 'abnormalities'. The medical model saw disability as something to be cured with the aim of restoring the individual to functioning in a mainstream environment (Bingham & Clarke, 2013; Burchardt, 2004). Where cure and rehabilitation were not seen as viable, specialist services and environments were developed where disabled people were segregated from the majority of the population, leading to their social exclusion. The medical model of disability still influences social policy in the United Kingdom, which is apparent in the requirement of diagnostic labels to access education, social and health care services, and financial support designed to help disabled people integrate into mainstream society (UN Committee on the Rights of Persons with Disabilities, 2017). In this system, the gatekeepers to services and other publicly funded support (e.g.: welfare benefits) are medical and educational professionals, who determine the diagnostic criteria and treatment of disability. The responsibility to integrate with the mainstream rests with the disabled individual.

Criticism of the Medical Model

The medical model of disability attracted criticism from the academic community and disabled activists alike. One of the main drawbacks of the medical model is that it entrenches the segregation of disabled people from the rest of society by linking social support and benefit entitlements to having a diagnostic label. Thereby it sanctions the perception of disabled people as functionally deficient, consolidating the high levels of social stigma attached to being disabled that still prevails today.

Another legacy of the medical model of disability is that by pathologising disability (Bingham et al., 2013), it blurs the distinction between ill health and disability. Although some chronic conditions may lead to impaired functioning, this does not always lead to restricted participation. Equally, some impairments are not caused by illness or chronic conditions (e.g.: genetic sensory and neurodevelopmental conditions), yet they may restrict participation in daily activities. The presence of a bodily impairment does not necessarily entail poor health status. People living with impairments can still enjoy good health and high levels of well-being (previously termed the ‘disability paradox’) (Krahn & Fujiura, 2009). The conceptual distinction between impairment, functioning and health status is important to be able to assess their separate impact and track changes in outcomes over time in the population (including disabled populations) (Krahn et al., 2009). This conceptual distinction was achieved by the Social and ICF models of disability.

2.2.2. The Social Model

From the 1960s and 1970s, new, social models of disability emerged across the UK, Scandinavia, and the US, which were influenced by the disability rights movement. The 'Social Model of disability' was a term coined by Oliver (Oliver, 1983, 2013) who drew on the disabled people's movement to differentiate between impairment and disability (Lawson & Beckett, 2021). In the UK, the movement was initiated in the 1980s by the Union of Physically Impaired Against Segregation (UPIAS) and the Disabled People's International (DPI) who saw disability as a form of oppression by capitalist societies which prevented disabled people's full participation because of their impairments (Driedger, 1989; Lawson & Beckett, 2021). Hence the social model is primarily concerned with achieving equal political and economic participation for disabled people. In the UK social model, impairment is seen as a personal attribute, whilst disability is defined as limited equality of opportunity to participate in society and especially in the labour market (Bingham et al., 2013). The social model of disability asserts that disability cannot be understood without the social context within which it arises. Disability is not caused by a physical, sensory, or cognitive impairment of functioning, but it results from the societal structures, policies and practices which do not accommodate differences in functioning (Bingham et al., 2013). Hence the social model of disability places the onus of the social integration and accommodation of disabled people with society instead of the individual, through political action and social and environmental change (Haegele & Hodge, 2016).

Criticism of the Social Model

The UK social model of disability also received criticism on several counts. Some of these relate to its disregard of the 'embodiment' of disability; its overemphasis on social oppression and its prioritisation of physical and sensory impairments at the cost of others (Owens, 2015; Woods, 2017). The 'embodiment' critique refers to the way the model separates impairment from disability, thereby denying the role of the impairment as an essential individual attribute in shaping the lived experience of the individual (Haegele & Hodge, 2016). Some researchers observed that assigning the responsibility for disability to primarily social structures achieved political gains, but ignoring the direct impact of the impairment on the individual, diminished disabled people's identities (Owens, 2015; Shakespeare & Watson, 2010; Thomas, 2010).

The UK social model's overemphasis on social inequality overlooks the variety of lived experiences of impairment (Owens, 2015). The social model aims to build solidarity across disabled people by highlighting their shared experiences of oppression and challenging established norms, but it fails to differentiate between disabled people based on their impairments which would imply drawing on the medical model. Failing to differentiate between disabled individuals disregards the heterogeneity in lived experience across the disabled population and impedes the recognition of the ways in which disability intersects with other forms of disadvantage (e.g.: ethnicity and gender) (Haegele & Hodge, 2016). Alternatives to the social model of disability have evolved since the 1990s, the most influential of these was the human rights model, which focuses on the inherent dignity of the human being, placing them centre stage in all decisions affecting them (Lawson & Beckett, 2021; Quinn & Degener, 2002).

The social model's lack of differentiation between disabled people, moreover, leads to a one-dimensional view of disability that focuses primarily on adjusting the physical environment to accommodate physical and sensory impairments. Making changes to the social environment (for example by changing social attitudes towards disabled people or introducing inclusive recruitment and workplace practices) is more problematic, hence impairments involving personal and social differences tend to be left unacknowledged by the social model, thereby limiting understandings of disability (Owens, 2015). For example, autistic people are still bearing most of the burden of adaptation to societal structures, practices and attitudes set by the predominant neurotype (Woods, 2017). Autism advocates highlight how the prevailing discourse around autism is still based on seeing the condition as a deficit or disorder. The resulting culture of 'ableism' (including internalised ableism) is considered to be a profound barrier to autistic people's participation (Graby, 2015; Woods, 2017).

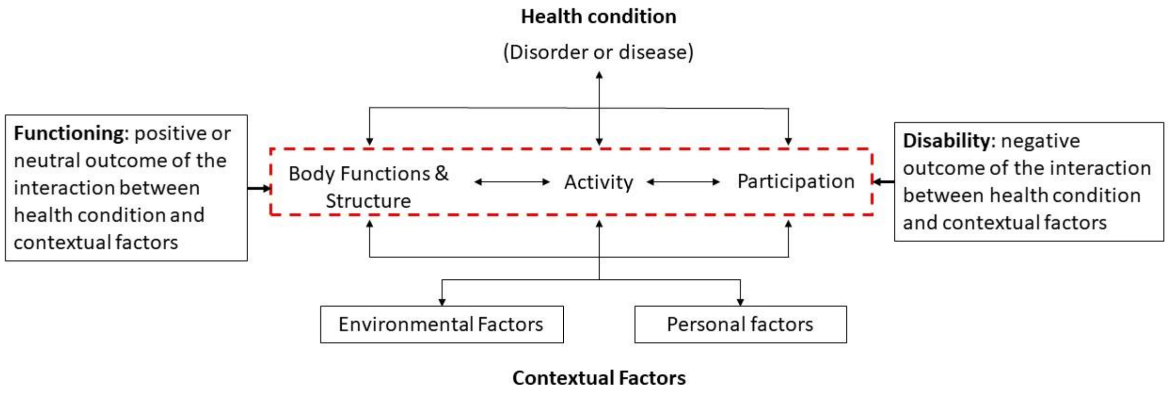
2.2.3. The International Classification of Functioning

In 2001, the World Health Organization developed the International Classification of Functioning, Disability and Health (ICF) model of disability, which is a hybrid model, also called the biopsychosocial model, amalgamating some aspects of the medical and some of the social models. The aim of the ICF model was to provide a scientific basis for understanding and studying health, to establish a common language for the understanding, study and description of health and disability, and to permit comparison of data across countries and health care disciplines (WHO, 2001a).

Based on the ICF model, the interaction between a person's 'health conditions' and their 'contextual factors' (including personal and environmental factors) may result in neutral, positive, or negative consequences to body functions and structures, activities, and participation (Figure 2.1). The ICF model defines impairment as a "problem in bodily function or structure as significant deviation or loss" (WHO, 2001a). Activity refers to the execution of a task or action, and participation is defined as involvement in a life situation (WHO, 2001a).

The ICF defines 'disability' as a negative aspect of the interaction between a 'disorder or disease' (i.e.: health condition) and contextual factors, resulting in an impairment in functioning, a limitation in activities, or a restriction in participation. 'Functioning', on the other hand, results from the positive or neutral interaction between an individual's health condition and their contextual factors (Figure 2.1).

Figure 2.1 The ICF model of disability



Source: Adapted from (WHO, 2001b), Figure 1, p.18

Within the ICF framework, the concept of health encompasses states of physical, mental, and social well-being, not merely the presence or absence of disease (WHO, 2001b). Within the ICF model of disability, being disabled and reporting high levels of health and well-being are not mutually exclusive.

The conceptual and methodological strength of the ICF model is that it distinguishes between disability, functioning and health. Moreover, it introduces a neutral terminology to describe health conditions, which allows the observation of both negative and positive aspects of functioning and disability (WHO, 2001b). Its definition of disability is broader than that of the Social Model, encompassing impaired functioning and activity limitations, beyond restrictions in participation only.

Criticism of the ICF model

The ICF model of disability attracted criticism both in relation to its content and the way it operationalises disability. Some authors found that the ICF model does not present a significant enough departure from the Medical Model because of the central role it attributes to the 'disorder, injury or disease' in its definition of disability. The ICF requires health conditions to be categorised using the International Classification of Diseases (ICD), resulting in over a thousand different categories which are difficult to identify in daily practice (Heerkens & de Weerd, 2018; Lundälv & Törnbom, 2015). Moreover, the model does not seem to account enough for the impact of contextual factors (e.g.: demographic, social, and genetic factors) on health conditions (Heerkens et al., 2018; Mitra & Shakespeare, 2019).

The ICF model's ontological structure has also been brought into question. Presently there are several definitions within the ICF model that are ambiguous or overlap with others. For example, there is no clear differentiation between 'activity' and 'participation' (Heerkens et al., 2018; Heinemann & Tulsky, 2010). Personal factors are not clearly defined and may overlap with health conditions, for example 'mental functions' may be classified as personal factors or as comorbidities (Bornbaum & Doyle, 2013; Heerkens et al., 2018). The term 'health condition' has also been debated in the literature, as it refers to a range of health states and circumstances such as pregnancy, ageing, congenital anomaly or genetic predisposition which suggest a lot broader definition than what is currently included in the ICF, where functional impairments are caused by 'disorder or disease' (Heerkens et al., 2018).

Some representatives of disability organisations argue that the ICF model lacks a holistic, person-centred view of disability, stemming from its overt focus on body functions, activities, and participation (Duchan, 2004; Heerkens et al., 2018; Lundälv et al., 2015; Mitra & Shakespeare, 2019). There are calls to rectify this by incorporating ‘quality of life’ and ‘well-being’ into the model and extend it to include measures of ‘agency’. Mitra et al (Mitra & Shakespeare, 2019) suggest that future revisions to the ICF need to consider whether an individual is able to act, participate or live in accordance with what matters to them.

2.2.4. Language used to describe disability

Language use around disability shapes the way disabled people are perceived by society. Historically, disabled people were often referred to by their condition, e.g.: the blind, the deaf. This language was associated with victimhood, and it contributed to disabled people’s marginalised position in society (Mackelprang & Salsgiver, 2016). Social models of disability, building on the human rights perspective, introduced the ‘person-first’ language use to differentiate the individual from their health condition (e.g.: people with sight impairment). As mentioned previously, although this improved disabled people’s standing in society, it came at the cost of acknowledging their lived experience and the aspects of their identity that were constructed around their impairment.

As the disability rights movement gained strength, activists started to embrace disability as an indicator of minority group belonging and are now working to create a ‘disability culture’. The language associated with disability culture is putting disability once more at the forefront, but not in a pejorative way or to refer to whole groups of people. Instead, the new disability discourse views people with disability as a minority group, whose access to human rights is framed in terms of their status of being disabled. This new perspective on disability sees disabled people as part of human diversity, with equal rights to any other minority group (e.g.: ethnic, religious groups). Hence, depending on the discourse, and whether the emphasis is on the social model of disability or disability rights, the language describing disabled people can be either person- or impairment- centred (Mackelprang & Salsgiver, 2016).

2.3. Disability in the UK context

In the UK, the Equality Act 2010 is the primary legislative framework to govern disabled people's rights (Haves, 2018) . The Act replaces several pieces of previous legislation, including the Disability Discrimination Act 1995. It makes provision for the protection from discrimination of people with nine protected characteristics, including disability. In the Equality Act 2010, disability is defined as "having a physical or mental impairment that has a substantial and long-term adverse effect on a person's ability to carry out normal and day-to-day activities" (Haves, 2018, p.1). The act requires services, public organisations, employment, and educational institutions to make reasonable adjustments for disabled people to avoid being placed at a substantial disadvantage in comparison with non-disabled people. Reasonable adjustments include changes in practice, adaptation of the built environment and the provision of auxiliary aids and services.

The UK ratified the UN Convention on the Rights of Persons with Disabilities in 2007 (UN CRPD). The convention outlines several rights found within the Universal Declaration of Human Rights and qualifies them to include people with impairments. Some of these rights include: a right to education and employment, a right to an adequate standard of living and social protection, a right to justice and recognition before the law, a right to access to healthcare and services (Jones & Wilson, 2017). The UN CRDP builds on the values expressed in the social model of disability to support disabled people in resisting exclusionary socio-political systems and practices. It is sometimes referred to as the human rights model because it focuses on the inherent dignity of the human being, and only refers to their medical characteristics when necessary (Lawson & Beckett, 2021; Quinn & Degener, 2002). The UN CRDP is a legislative tool that aids the involvement of disabled people's organisations to influence disability-related policies, practices, and procedures. It provides the framework for creating human-rights-consistent law and policy as well as systems for monitoring progress (Lawson & Beckett, 2021).

The UN Committee on the Rights of People with Disabilities has been monitoring the implementation of the UN CRPD in the UK since its adoption. The Committee published a report in 2016 in which it expressed concern about the level of protection and support for disabled people provided by the government (Jones et al., 2017). During their investigation, the Committee found that post-financial crisis UK restricted disabled people's participation through lack of access to appropriate disability aids and shrinking and problematic access to a range of benefits (Jones et al., 2017). Moreover, reforms to the social security system (grounded in the medical model) introduced from 2012 onwards by consecutive governments, had a disproportionate impact on disabled people and curtailed their rights to independent living and adequate living standards. Research evidence shows that cuts to welfare also disproportionally affected different disabled groups and increased the segregation between impairment types (Graby, 2015).

2.3.1. Disability prevalence in the UK

The UK national statistics data follows the definition of disability as set out in the Equality Act 2010, as a long-term impairment that causes activity limitation. It also incorporates three levels of severity measuring the extent to which carrying out day-to-day activities are affected 'a lot', 'a little' or 'not at all'. In 2021, the proportion of disabled people across England and Wales was 17.8% (10.4 million), which is a 1.7% decrease since 2011, when it was 19.5% (10 million) (Office for National Statistics, 2023). According to 2021 Office for National Statistics (ONS) Census data, in England disability prevalence was slightly higher among women (18.7%) compared to men (16.5%), with disability rates rising considerably after age 74 for both genders. Disability severity also increases rapidly with age, especially over 80.

In the 2021 Census, severe disability was reported by just over 5% of working age (16-64) men and women. Over the age of 64, a quarter of women and a fifth of men reported a lot of activity limitations due to their impairment (own analysis of ONS Census data). Since 2001, there has been an increase in disability reported by younger age groups, which may be attributed to a better capturing of 'mental health' in the 2021 census questionnaire (ONS, 2023). Fifteen percent of women aged 20 to 24 reported a disability in 2021, which was a threefold increase from 5.2% in 2011.

The primary mechanism for social connectedness is social participation. The UK national statistics on disabled people's participation and outcomes indicate that they are still at significant disadvantage compared to non-disabled populations across several life areas (Office for National Statistics, 2015, 2023). The following sections summarise existing evidence regarding barriers to participation on the domains of education, employment, community, and leisure activities.

2.3.2. Education

Research shows that the life course follows a culturally and institutionally determined progression through a set of transitions (G. A. Erickson & Macmillan, 2018). Progression from educational institutions to workplaces facilitates financial independence, marriage, cohabitation, and parenthood (Furstenberg, 2006). Variations in the order and timing of these transitions result in different pathways through the life course (Furstenberg, 2010). Research evidence indicates that disability may disrupt, delay, or hinder making some of these life transitions (Tisdall, 2001) which has long-term implications for the individual's subsequent life-course, including their social connectedness, health, and well-being. This section reviews disabled people's participation in further and higher education in the UK, as well as international evidence about what we know about the barriers and facilitators to disabled people's education and the associated outcomes.

Participation in education

Although similar rates of disabled students continue into further education as non-disabled students (85% and 88% respectively), significantly fewer disabled students progress to higher education by age 19 (8.4% compared to 48%) (Department for Education, 2022). In 2015/16 in Britain, disabled young people aged 16-18 were at least twice as likely as their non-disabled peers to not be in education, employment, or training (Equality and Human Rights Commission, 2017).

Across the working age population (aged 21-64) in 2021, 13% of disabled adults had no qualifications at all compared to 5% of non-disabled people; and a quarter of disabled adults had a degree compared to 43% of the rest of the population (Office for National Statistics, 2023). The largest disparity in education between disabled and non-disabled populations was in the youngest age groups (21 to 24 years) (HM Government, 2021).

Differences in educational attainment are prevalent across impairment types. There is consistent evidence that cognitive rather than physical disabilities are strongly connected to disadvantaged transition pathways, largely because they are associated with disrupted educational attainments which act as a barrier to the more advantageous pathways into adulthood (G. A. Erickson & Macmillan, 2018). At the same time, recent UK government statistics revealed that “a disabled person with a degree is still no more likely to be in work than a non-disabled person whose highest qualification is at GCSE” (HM Government 2021, National Disability Strategy, p. 67).

Barriers to education

The inclusive education model introduced in the 1990s meant a move away from segregated learning and the inclusion of disabled children into mainstream schools (Allan & Slee, 2008; Lourens & McKinney, 2016; WHO & World Bank, 2011). The inclusive education system aims to meet the full range of learning needs of all young people, instead of excluding disabled learners from the mainstream system (Peel & Posas, 2009; Schuelka, 2018). Although, since the introduction of the inclusive model, the numbers of disabled young people have grown across primary, secondary, and higher education, there are indications that this increase does not translate into the attainment of equality and inclusion (Lourens et al., 2016).

In further education, disabled learners are often segregated from their peers when there is no adequate support to accommodate their perceived needs to participate in mainstream learning or physical activity (Lourens et al., 2016). As a result, disabled pupils are not always considered to be part of the classroom in terms of social and learning membership (Ferguson, 2008). Disabled children and young people are also significantly more likely to experience bullying than non-disabled pupils (Chatzitheochari & Parsons, 2016; Long & Roberts, 2020) leading to their increased levels of non-attendance, home-schooling and adverse long-term economic and psychological outcomes. In 2020-21, Nearly 11% of 16–17-year-olds with an EHCP were absent from education, compared to 6% of those without special needs (Department for Education, 2022).

The education gap between disabled and non-disabled young people is widest in higher education. Barriers to accessing higher education include a range of physical/social environmental and personal factors. Physical environmental factors relate to access to the university ground and transport links to the local environment. The university’s proximity to the home and existing support networks are also vital in case the student needs additional support to what the university is providing (Beauchamp-Pryor, 2012). Disabled young people often receive overly high amounts of support in primary and further education which can leave them unprepared and lacking in the independence skills necessary for the transition to a higher education setting (Hopkins, 2011; Lourens et al., 2016).

2.3.3. Employment

Participation in employment is an important way of expanding one's social network. Relationships formed with colleagues, act as gateways to the social networks of others, thereby creating new opportunities for participation (Granovetter, 1973). The World Health Organisation and the World Bank recognised disabled people's employment as vital for maximising human resources, promoting human dignity and cohesion and accommodating the increasing prevalence of disability expected form ageing populations (Honey & Kariuki, 2014; WHO & World Bank, 2011). It is a defining feature of identity and an absolute marker of success, where human value is closely associated with labour value (Goodley, 2018). However, and central to the focus of this thesis, engaging in work also leads to increased community participation because it funds participation in social and leisure activities.

Employment participation

Disabled people have historically experienced low levels of employment in the UK. A 2011 longitudinal report by Berthoud found a 'disability penalty' of 28% in the British labour market that remained stable between 2000 and 2010 (Berthoud, 2011). The disability penalty is the measure of the extent to which disabled people are less likely to be employed than non-disabled people, even after accounting for their socio-demographic characteristics. The inequality in employment between disabled and non-disabled people in the UK persists today. The 2022 UK governmental figures estimate the employment gap between disabled and non-disabled working age (16-64) populations at 28.1%. Just over 53% of working age (16-64) disabled people were in employment compared to nearly 82% of non-disabled people (Office for National Statistics, 2022b). Employment rates for disabled men and women were similar at 53% and the largest employment gap was between disabled and non-disabled men (whose employment rate was 84.9%).

Disabled people are twice as likely as the rest of the population to undertake insecure, temporary, or casual jobs (Honey et al., 2014). In 2022, higher proportions of disabled people were self-employed and worked in elementary, service (sales and hospitality), and administrative occupations than non-disabled people in the UK (Office for National Statistics, 2022b). Poor job security, low pay and inflexible working arrangements lead to reduced job satisfaction among disabled people with high rates of in-work poverty and low rates of job retention (Holland & Clayton, 2020; Schur & Han, 2017).

There are also disparities among impairment types with regards to levels of employment. In 2022, less than 30% of people with severe learning difficulties, autism or mental illness were in employment in the UK. A 2013 study found that less than 10% of people with learning disabilities were in paid work, a figure that remained stable for 20 years (Bates & Goodley, 2017; Humber, 2014). In 2022, employment rates ranged between 40 to 71 percent across the rest of the impairment types, with highest levels of employment among those with diabetes, hearing difficulties, digestive problems, skin conditions and allergies (Office for National Statistics, 2022b).

Barriers to employment

Across all life areas, disabled people's participation in employment is the most researched area (Hastbacka & Nygard, 2016). This might be due to the vital role that the labour market plays in the redistribution of social and financial resources which makes employment an important facilitator of equality and social justice when viewing disability from a human rights perspective (Fraser, 2008). Research focus on the labour market also mirrors national priorities set by governments' determination to maximise overall national employment rates (Hastbacka et al., 2016). The literature suggests that disabled people's primary barriers to employment (in order of magnitude) are lack of opportunities, social attitudes, and poor health. To a lesser extent, access to the built physical environment is also cited in the literature as a barrier to employment (Hastbacka et al., 2016).

Limited opportunities

There is a growing body of literature suggesting that neo-liberal market economies that place increased emphasis on independence and self-sufficiency are inhibitive to disabled people's employment (Bates et al., 2017; Bingham et al., 2013; Jakobsen & Svendsen, 2013; Patrick, 2012). The austerity policies and welfare-to-work programmes introduced by post-financial crisis UK governments facilitated the creation of low-paid, short-term, insecure, and casual employment. The rise in zero-hour contracts, increased job insecurity and trapped employees in low wage jobs with scaled back employment support from the government. In this economic and political climate, disabled people find themselves competing with non-disabled people for a scarcity of limited and often unsuitable employment opportunities (Bates et al., 2017). In a scoping review of barriers to disabled people's participation, Hastbacka et al found that 10 out of the 11 studies that focused specifically on labour market participation, cited unemployment and unfavourable or insufficient employment policies as major barriers to disabled people's participation (Hastbacka et al., 2016).

Negative social attitudes

Social attitudes, shaped by the wider political and economic context, form another key set of barriers to disabled people's employment. Negative social attitudes manifest themselves in several different forms. They may be openly expressed through direct discrimination or unfriendly behaviour by managers and colleagues (Bingham et al., 2013; Schur et al., 2017). They may also be communicated indirectly through exhibiting ignorance, fears, and prejudices with regards to disability (Hastbacka et al., 2016; Honey et al., 2014; International Institute for Labour Studies, 2010). Discriminating procedures, institutional structures and practices are also commonly cited employment barriers in workplaces (Bingham et al., 2013).

Personal and health characteristics

Socio-demographic characteristics and the type and severity of impairment play important roles in work attainment and retention. Research evidence suggests that the employment outcomes of disabled people with chronic conditions and pain impairment are better predicted by their socio-demographic characteristics and work-related factors than by health-related factors (Holland & Clayton, 2020). The employment status of disabled people with rheumatoid arthritis, for example, are strongly associated with their age, educational attainment and the level of physical demand and flexibility their job involves (Holland & Clayton, 2020). Impairment types that involve a learning disability on the other hand, are associated with high rates of unemployment regardless of socio-economic characteristics (Bates et al., 2017). This is primarily due to the persisting cultural beliefs around the innate incapacity of learning-disabled people for work and a decrease in governmental funding for supported employment (Malli & Sams, 2018; O'Hara, 2015).

Young disabled people (aged 16-29) are at a disadvantage in the labour market compared to middle aged workers but not compared to the oldest age groups. Young people with impairments are the most likely to be part-time employed or unemployed and have low rates of job retention (Honey et al., 2014). They also report multiple barriers to employment including fear of losing benefit income, inaccessible transport, discrimination, and concern about being isolated by other workers (Lindsay, 2011). Gender differences persist regardless of impairment status with regards to employment and work-life balance (Arber & Ginn, 1995; Chandola & Rouxel, 2021). Disabled women are more likely to be unemployed or to be in low-status occupations compared to disabled men (Honey et al., 2014). They are also more likely to encounter caregiving as a barrier to employment and bear the greater share of family and work conflicts compared to men (Chandola & Rouxel, 2021; Pagan, 2013; Shockley & Shen, 2017).

Facilitators to employment

Unsurprisingly, legislation and policies associated with the implementation of the UN CRPD are reported as playing a fundamental role in counteracting the detrimental effects of neo-liberalist economies on disabled people's employment (Hastbacka 2016). International research evidence suggests that making the workplace environment more disability friendly is associated with higher rates of employment than using individual interventions to increase disabled people's employability (Hastbacka et al., 2016; Nazarov & Manuwald, 2019). In the UK, half of disabled workers and 60 percent of unemployed disabled people reported that reasonable adjustments helped them to stay in work or would help them to gain employment. The most common workplace adjustments reported were modified or reduced working hours or days (Office for National Statistics, 2022b). Ongoing support is seen as the most effective type of accommodation for people with intellectual and mental health disabilities (Honey et al., 2014).

Other workplace policies that facilitate disabled people's labour market participation are those that are directed at shaping people's attitudes through improving awareness and knowledge about different types of disabilities, removing social stigma and prejudice. Disability awareness training, the visibility of disabled people in the workplace and the availability of information and knowledge about disability are important facilitators to disabled people's employment (Bingham et al., 2013).

There is research evidence that psychosocial approaches that support disabled people in acquiring and improving self-management techniques can play a significant role in facilitating their job retention. Coaching and cognitive behavioural therapies have been proven to be especially effective for the self-management of chronic conditions (like rheumatoid arthritis) and seem to significantly improve self-perception of working capacity and fatigue (Nazarov et al., 2019). The ability to manage the symptoms of chronic conditions were also dependent on workplace conditions and adaptations, the individual's own perceptions of their worker identity, interpersonal communication and the level of support received from their social network (de Vries & Reneman, 2012; Holland & Clayton, 2020).

Workplace accommodations are not equally accessible for all disability types. Employees with pain impairments are most likely to receive a work accommodation, at the same time, workers with mental health impairments have been shown to benefit most from workplace accommodations (Chandola & Rouxel, 2021) yet they have the lowest employment rates.

2.3.4. Community and leisure activities

Participation outside the formal realms of work and education constitute an important building block for social connectedness. Interacting with close and informal network members and being active in one's local community contribute to social inclusion and subjective wellbeing (see Chapter 1). Most of the research into disabled people's participation in community and leisure activities focuses on formal and informal volunteering and access to sports and physical activity. To those who encounter difficulties in accessing paid employment, volunteering provides an opportunity to participate in social interactions in the domestic and community spheres (e.g.: care giving, volunteering) (Shandra, 2017). Physical activity has been shown to increase disabled people's self-efficacy and self-determination, perception of social and bodily competence, and community integration (Kissow, 2015). The following sections review what we know about disabled people's access to and participation in community activities, volunteering, and leisure.

Participation in community and leisure activities

UK national statistic figures suggest that in 2022, the civic engagement and social action rates among disabled people were similar to the non-disabled population (45 and 43 percent respectively) regardless of impairment severity (Office for National Statistics, 2023).

Civic participation relates to engagement in local democratic processes and political activism. Government figures show that in England, disabled young people's (aged 16 to 24 year) civic participation was significantly higher (17.5% difference) than that of non-disabled young people in 2017-18 (Office for National Statistics, 2019).

In 2022, disabled people participated in informal (56%) and formal volunteering (30%) at similar rates to the rest of the population. Disability severity affected the rates of volunteering, with those reporting high levels of activity limitations being less likely to volunteer (22.9% compared to 33.8% of those with mild limitations) (Office for National Statistics, 2023).

There is limited information on disabled people's regular participation in groups, clubs, and organisations in the UK. The Office for National Statistics collects data on the attendance of these type of activities at least once a year (Community Life Survey, England) but there is no further data published on the frequency of participation. ONS figures suggest that the overall participation rates in groups, clubs and other organisations were similar between working age (16 to 64) disabled and non-disabled populations and were estimated at around 60% in 2021. (During the Covid-19 pandemic there was a larger gap in group/club activity participation, with disabled people having a participation rate of 64% whilst non-disabled people 69%. By 2021, participation rates dropped in both populations by 10% from pre-pandemic levels). Across age groups, disabled people have on average 5 percent lower participation rates than non-disabled people, except for those aged 16 to 24. In 2021, disabled young people had a 9% higher participation rate in groups, clubs, and organisations than non-disabled young people. (Own analysis of ONS participation tables (Office for National Statistics, 2022a)). The largest disparity in participation rates was in sport clubs, with at least 15% fewer working age disabled people participating in sport and exercise than non-disabled people (Community Life Survey, England 2017-18).

Barriers to participation in community and leisure activities

With regards to disabled people's participation in community and leisure activities, the most researched impairment types are intellectual disabilities followed by physical impairment and severe psychiatric conditions. The literature about the participation rates of people with developmental disabilities (including autism) primarily focus on children and often target populations with co-occurring cognitive impairment, and often make no distinction between autism and intellectual impairment.

Barriers to participation in community and leisure activities seem more heavily influenced by personal factors than participation in major life activities (i.e.: education and employment). Personal factors affecting the ability to participate in leisure include impairment-related time use, socio-economic circumstances, self-perceptions and availability of social support (Hastbacka et al., 2016). Social attitudes and policies play an important role both in shaping perceptions of self-competence, and in creating social environments where disabled people could be at risk of or be protected from discrimination and harassment (Badia & Orgaz, 2011). Support with accessing transportation and buildings are also cited in the literature as factors affecting participation in leisure activities for people with physical and intellectual impairments (Hastbacka et al., 2016).

Stigma and negative social attitudes affect disabled people's participation in community and leisure activities (Badia et al., 2011; Shandra, 2017). Lack of awareness is a 'barrier of omission', which implies organisations not knowing enough about how to recruit and retain disabled people in volunteering roles (Shandra, 2017). Another set of barriers consist of lack of commitment or resources to provide assistive devices, transportation, or individual support. For some volunteer organisations the cost of supporting disabled volunteers may be considered to outweigh the benefits of their contributions (Shandra, 2017).

Negative social attitudes have been shown to be internalised by disabled people, leading to negative constructions of the self (i.e.: internalised stigma) and lower self-esteem (van Asselt-Goverts et al., 2018) which reduce participation in a range of activities (Kissow, 2015; Taub & Blinde, 1999). Fear of being teased has been reported as barrier to participating in leisure activities by people with learning disability (Buttimer & Tierney, 2005).

2.3.5. Barriers to participation affecting most areas of life

Most barriers to participation affect several different life domains, but some are more prevalent than others. Barriers that have been reported to affect most types of social activities relate to disabled people's use of time, socio-economic factors, and the physical environment.

Time use

Research on disabled people's time use suggests that they allocate different proportions of their time to paid and unpaid work, leisure, and self-care activities than non-disabled people (Shandra, 2017, 2018). Oi (Oi, 1991) was the first author to point out that disability "steals time" because disabled people need to spend more time on managing their health conditions, resting, obtaining health care and to accomplish everyday tasks. Disability may also involve taking longer time to travel to and from activities (Pagan, 2013). Research on disabled people's time use indicates that they spend less time in paid work and more time on self-care including rest and sleep than the rest of the population (Eklund & Leufstadius, 2009; Gaskin & Andersen, 2012; Kissow, 2015; Lutz & Bowers, 2005; Shandra, 2017). Disabled people also spend more time on leisure than non-disabled people, but this is more likely to be passive leisure (e.g.: reading or watching TV) than active leisure (e.g.: engaging in sports or cultural activities) (Shandra, 2018).

In the literature examining factors affecting participation, self-care and recovery-time needs are sometimes identified as a 'time barrier' by disabled people. People with a learning disability reported 'not having enough time' and 'feeling tired' as barriers to physical exercise (Badia et al., 2011; Buttimer & Tierney, 2005). Studies of people with schizophrenia found that they participate in less active leisure and social activities and spend more time on sleeping, eating, self-care and performing quiet activities (Bejerholm & Eklund, 2004; Eklund et al., 2009).

Socio-economic barriers

Due to lower educational attainment rates and difficulties with accessing the labour market, disabled populations are more likely to have a low household income and experience in-work poverty (see Sections 2.3.2 and 2.3.3, pp. 64-67). This leads to inequalities in financial capacity to consume and participate in leisure activities compared to the rest of the population (Hastbacka et al., 2016; Martin Ginis & Ma, 2016; Merrells & Buchanan, 2018). Financial support and the provision of assistive technology, on the other hand, have been reported as important facilitators of participation across all life areas (Andrich & Mathiassen, 2013; Hastbacka et al., 2016).

The physical environment

In spite of the progress made in recent years to create more accessible buildings and public spaces, the physical environment and access to transport still pose major barriers to disabled people's participation. In the UK, significantly fewer disabled people have a driving license than non-disabled people (61% compared to 80% of adults over 17) and they are more likely to be passengers in cars or to rely on public transport (Department for Transport, 2023). The availability of someone to support the disabled person in accessing transportation and activities are important facilitators for the participation of people with intellectual disability (Kissow, 2015).

2.4. The social networks of disabled people

There is scant research on the social networks of disabled populations, especially studies comparing networks across different impairment types. The most researched disabled population in this area is those with mild intellectual disability (ID), and most studies make no clear distinction between ID and neurodevelopmental conditions (Donelly et al., 2019; Giesbers et al., 2019; Merrells et al., 2018; Simplican & Leader, 2015; van Asselt-Goverts & Embregts, 2015; van Asselt-Goverts et al., 2018). There is some but limited research evidence on the social participation and networks of people with mental health impairments (Webber & Reidy, 2015) and physical disabilities (Lippold & Burns, 2009).

A systematic review comparing access to social resources across different types disabled and non-disabled populations, indicates that disabled people have comparatively fewer ties on their informal and formal network layers to non-disabled people (Mithen et al., 2015). They are also less likely to belong to a community group and report lower levels of financial and emotional support (Mithen et al., 2015). Across disability groups, people with ID and autism spectrum conditions (ASC) have the most restricted social networks and those with physical impairments the largest and most diverse networks (Lippold & Burns, 2009). Populations with psychiatric disabilities have been shown to experience a significant loss in their network size at the onset of their mental health difficulties (Hawkins & Maurer, 2012; Merrells et al., 2018; Webber et al., 2015).

The social network of disabled populations with mild ID and neurodevelopmental conditions have been found to be dominated by relationships with family members and professionals (Giesbers et al., 2019; van Asselt-Goverts et al., 2018). They report having fewer friends and the ones they have are likely to have ID or ASC themselves. Friendship ties appear to be less close and supportive in this population than in non-disabled populations (Baron-Cohen & Wheelwright, 2003; Orsmond et al., 2013). The social relationships of disabled people with ID are more likely to be characterised by asymmetrical power dynamics, low levels of reciprocity and an emphasis on instrumental and emotional support delivered by professionals (Lippold & Burns, 2009).

Restricted social networks and lack of reciprocal relationships contribute to lower network satisfaction among people with ID compared to other populations and high reported rates of loneliness (Gilmore & Cuskelly, 2014; van Asselt-Goverts et al., 2015, 2018). Mental health difficulties have also been shown to significantly increase exposure to loneliness (Emerson & Stancliffe, 2021). Outcomes related to social connectedness seem to be the worst in autistic populations. A comparative study of young disabled people's participation on the informal network layer found that young people with ASC experienced higher rates of social isolation than those with an intellectual or learning disability. Nearly two-thirds of young autistic adults reported having no close friendships and were significantly more likely to report never meeting their friends, never being called up by their friends, and never being invited to social activities than those with ID (Billstedt & Carina Gillberg, 2007; Orsmond et al., 2013).

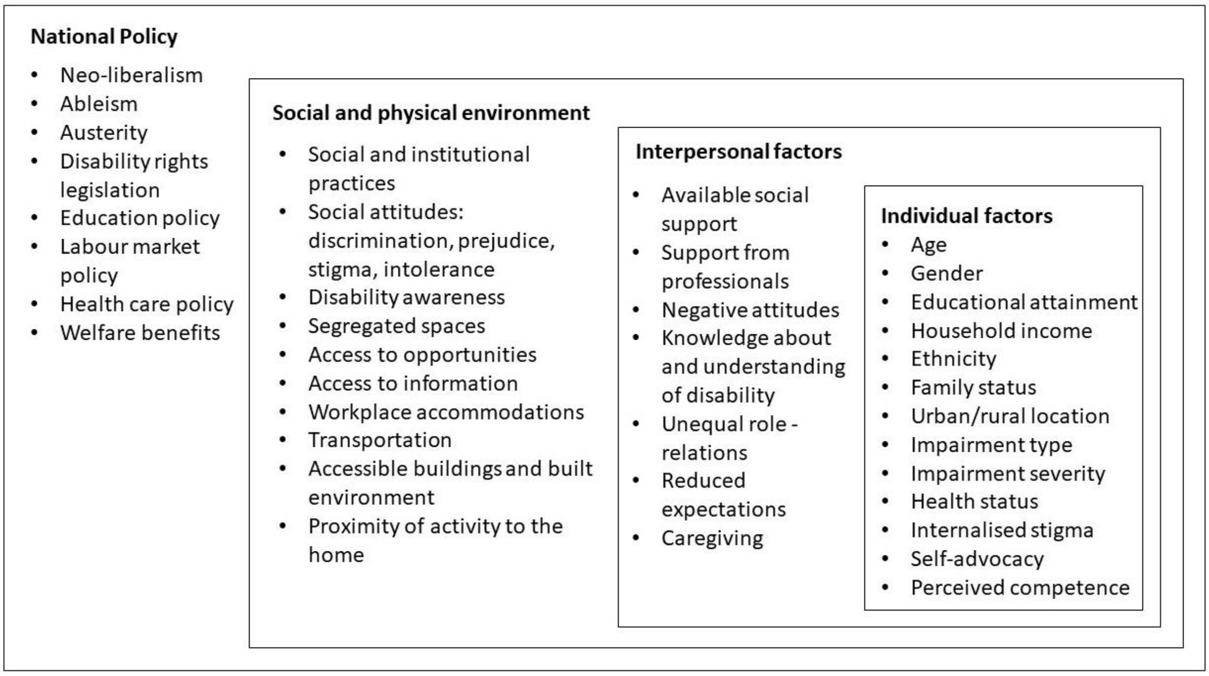
2.5. Conclusion

This chapter presented a complex picture regarding disabled people's participation and barriers to social activities across a range of life areas. The review reveals big disparities in participation between disabled and non-disabled populations especially in the major life domains of education and employment. The relatively lower educational attainment across disabled populations exerts a long-term effect on their employment prospects, which adds to the 'disability penalty' that is the direct consequence of having an impairment. Participation in civic life and rates volunteering are comparatively equal between disabled and non-disabled populations, suggesting the importance attached to social activism in disabled people's lives.

Barriers to participation across different life areas are broadly similar yet vary in impact. Whilst the opportunities provided by the labour market coupled with workplace policies are the most important factor for accessing paid employment, participation in community and leisure activities is more influenced by a combination of personal and environmental factors. The primary personal factors are functional limitations due to impairment, poor health, time constraints, as well as costs, gender roles and age (with younger age groups experiencing worse outcomes). Some barriers to participation affect some types of impairment more than others. Physical environmental factors are more prevalent barriers across motor and sensory impairment, whilst negative social attitudes and lack of opportunities are more likely to affect those with cognitive and developmental impairments.

Figure 2.2 uses the social ecological model (McLeroy & Bibeau, 1988) to summarise the factors affecting disabled people's participation in a hierarchical manner. The social ecological model was first developed to depict multiple levels of influence on health behaviour (Martin Ginis et al., 2016). In this review, the social ecological model is adapted to portray the hierarchical nature of disabled people's barriers and facilitators to participation, pertaining to individual, interpersonal, social and physical environmental, and national contexts.

Figure 2.2 Summary of factors affecting disabled people's social participation



National Policy

- Neo-liberalism
- Ableism
- Austerity
- Disability rights legislation
- Education policy
- Labour market policy
- Health care policy
- Welfare benefits

Social and physical environment

- Social and institutional practices
- Social attitudes: discrimination, prejudice, stigma, intolerance
- Disability awareness
- Segregated spaces
- Access to opportunities
- Access to information
- Workplace accommodations
- Transportation
- Accessible buildings and built environment
- Proximity of activity to the home

Interpersonal factors

- Available social support
- Support from professionals
- Negative attitudes
- Knowledge about and understanding of disability
- Unequal role - relations
- Reduced expectations
- Caregiving

Individual factors

- Age
- Gender
- Educational attainment
- Household income
- Ethnicity
- Family status
- Urban/rural location
- Impairment type
- Impairment severity
- Health status
- Internalised stigma
- Self-advocacy
- Perceived competence

Historically there has been a lot of focus on adapting the built and natural environments to accommodate the access needs of those with mobility impairment. The research evidence presented here suggests that physical environmental barriers have been overtaken by negative social attitudes as a major limiting factor to disabled people's participation (Drum & Krahn, 2009; McDonald & Williamson, 2015). Negative perceptions and stigma attached to especially cognitive and developmental impairments impedes participation across all major life areas. Discrimination, prejudice, and low disability awareness also contribute to the development of internalised stigma, mental health difficulties and withdrawal from participation due to not feeling safe in public spaces. One autistic researcher called for the application of the social model of disability not just to the physical environment but also to the social environment, including communication practices (Woods, 2017). Disability awareness training, workplace accommodations that empower disabled people to create better work-life balance and provision of education and support in mental and physical health care are for example very effective ways of adjusting the social environment to create equal opportunities for participation for all. There is no current data about the degree of coverage of this type of social interventions and services across different life areas, although there is evidence of their presence at some but not all workplaces (Hastbacka et al., 2016).

2.5.1. Gaps in knowledge

Significant gaps in knowledge remain regarding differences across impairment types in relation to barriers to participation and social network outcomes. Not understanding how specific personal, social and physical environmental barriers are experienced by different disabled groups impedes the creation of truly inclusive environments and entrenches the hierarchy across disabilities. Most studies on disabled people's participation relate to adults with mild cognitive or severe mental health disabilities and the elderly with physical impairments. There is relatively little known about the participation and social networks of young disabled adults, especially those with developmental disabilities without intellectual impairment (Orsmond et al., 2013). Across life areas, research focuses mainly on the employment domain and there is limited evidence about the composition and functions of the intimate, informal and community network layers in disabled populations. There is also a lack of understanding about how the experience of disability is moderated or mediated by environmental and individual characteristics. The aim of this thesis to generate evidence that will help to fill some of these gaps.

2.5.2. Research questions and study design

The thesis follows a convergent mixed methods design, where secondary data analysis of the Life Opportunities Survey is complemented by a qualitative exploration of the factors affecting the social participation of autistic adults. The overall thesis aim is to provide a comprehensive picture of the sources of barriers to social participation and resulting feelings of connectedness in disabled populations.

The thesis research objective is to identify the factors obstructing or facilitating social participation for disabled populations and to explore the experiences of neurodivergent adults in relation to social connectedness and participation. The thesis is organised around three main research questions:

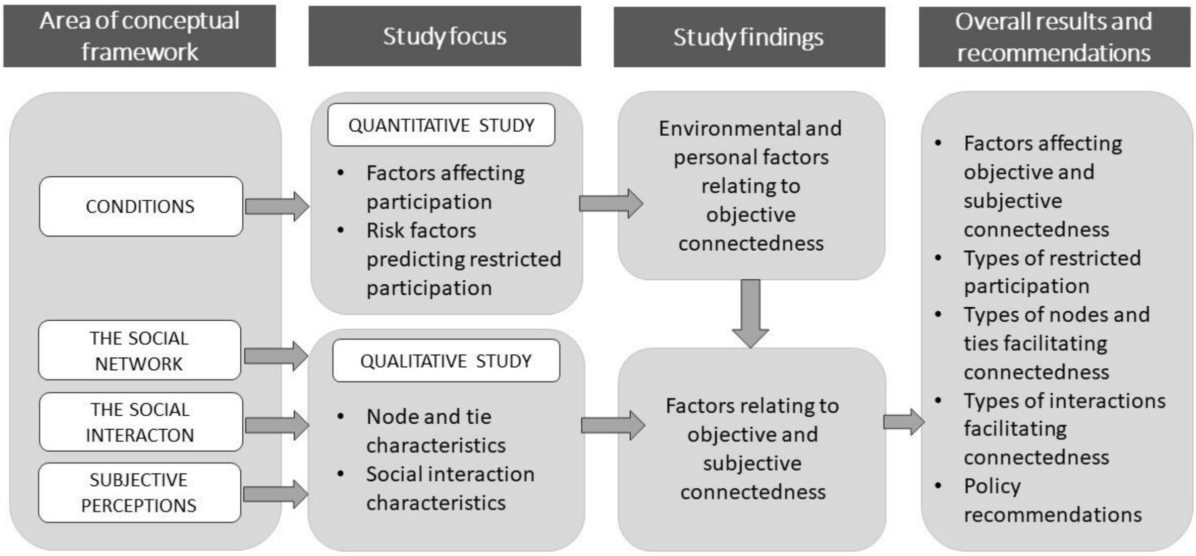
1. Are there differences in the factors affecting social participation between disabled and non-disabled populations, and within disabled populations?
2. Do personal characteristics (including demographic, health, and disability) predict the types of barriers encountered to social participation?

3. To what extent do existing understandings of social connectedness and disability accommodate and respond to the social participation needs of people with neurodivergent conditions?

The second part of the thesis uses the UK Life Opportunities Survey to explore the mediating role of the social and physical environment for social participation and the role of personal characteristics in experiencing different barriers to participation (questions 1 and 2). The third part of the thesis employs qualitative methods to explore autistic adults' experiences of social participation and social network formation (question 3). The fourth and final part comprises of a discussion that evaluates the implications of the qualitative and quantitative study findings for policy and practice, and for current understandings of disability.

Figure 2.3 describes the broad aims, methodology and desired outcomes of this thesis. The design and methodology of the quantitative and qualitative studies are described in detail in Chapters 3 and 8.

Figure 2.3 Factors affecting the social participation of disabled people: study design



PART II

FACTORS AFFECTING THE SOCIAL PARTICIPATION OF DISABLED PEOPLE:

A SECONDARY ANALYSIS OF THE LIFE OPPORTUNITIES SURVEY

Chapter 3. Preparing the Life Opportunities Survey for quantitative analysis

3.1. Introduction

This chapter describes the national survey dataset and the methods used to examine barriers to disabled people's social participation in the UK. The chapter comprises of four main sections. Section one establishes the quantitative study objectives. Section two introduces the Life Opportunities Survey (LOS). Section three describes how the LOS survey data was prepared and modified for the purposes of the thesis. Finally, section four describes the quantitative techniques chosen to answer each research objective and the data analysis protocol.

3.1.1. Quantitative study objectives

The overarching aim of this thesis is to map reported barriers to participation in disabled populations and to deepen understanding of how these barriers affect the development and maintenance of social ties. Building on the review of the literature regarding disabled people's participation in different life areas (Chapter 2) and guided by the theoretical framework developed in Chapter 1, the quantitative study aimed to answer four research questions:

1. Understand differences in restricted participation and barriers to participation across disabled and non-disabled people.
2. Develop a typology of barriers that characterises restricted participation in different social activities (disabled sample only).
3. Understand the risk factors (in terms of situational and personal characteristics) that make it more likely for someone to experience a certain type of barrier profile.
4. Understand the factors affecting changes in social participation over time for disabled and non-disabled people.

The sections below document the steps undertaken to answer these objectives.

3.2. The Life Opportunities Survey

The quantitative study is based on the secondary data analysis of the Life Opportunities Survey (Office for National Statistics, 2013). The LOS is a longitudinal survey of disability – spanning from 2009 to 2014 – covering England, Scotland, and Wales. It was carried out by the Office for National Statistics (ONS) for the Office for Disability Issues (ODI), part of the Department for Work and Pensions (DWP). The LOS was designed to meet the ODI's commitment to improve the evidence base on disability issues and to help meet the government's commitment to measure progress to equality by 2025 (Office for National Statistics, 2013). The LOS was the first major national survey to explore disability within the framework of the social model of disability (Office for National Statistics, 2013). It aimed to update and extend data coverage on the prevalence of different impairment types in Britain and to document 'socially disabling' barriers to participation. It compared disabled and non-disabled people's participation in society in the areas of work, education, social participation, transport, and use of public services. It also investigated the reasons why people did not participate in these areas as much as they would have liked to. The LOS tracked the experiences of disabled people and a non-disabled comparison group over time to assess transitions through key life stages.

3.2.1. Rationale for using the LOS

The LOS is grounded in the social model of disability and therefore collected information on how social and environmental factors created or removed barriers to people's participation across a wide range of life areas. The LOS collected an extensive list of environmental and personal barriers to individuals' participation (e.g.: difficulty with transport, access to buildings, financial considerations, health condition, public attitudes) for a range of social activities (see Section 3.2.4, Box 3.1). The way in which LOS data could be mapped to the theoretical framework introduced in Chapter 1, made it especially suitable for the purposes of this thesis. The LOS barriers to participation mapped directly to the conditions within which social networks are created (see Chapter 1, Section 1.6, Figure 1.6, p. 50), whilst the social activities contained in the LOS could be linked to different social network layers (see Chapter 1, Section 1.3.1, Figure 1.2, p. 39). The way in which the LOS data was applied to examine barriers to social participation within the theoretical framework of this thesis is described in Section 3.4.

3.2.2. Life Opportunities Survey modules

The LOS contains two Modules, the Integrated Household Survey (IHS) Core Module, and the Life Opportunities Module.

3.2.3. Integrated Household Survey Core Module

This module collected sociodemographic information at both household and individual levels. Main topics covered were: household composition, accommodation, nationality, ethnicity, gender and sexual identity, religion, health status, employment and education.

3.2.4. Life Opportunities Module

This module collected information across four broad topic areas: (1) participation in different life areas; (2) barriers to participation in these life areas; (3) impairments/health conditions and (4) personal experiences whilst participating in the public and private sphere. In Wave 3 a set of questions were added regarding changes in participation, and some assessing life satisfaction. Box 3.1 summarises the four main elements of the Life Opportunities Module. The quantitative study used information collected in the first three topic areas, namely data on participation, barriers to participation and impairment type and severity.

Box 3.1 The structure of the LOS Life Opportunities

1. **Participation**: data on restricted social participation was collected separately across (1) the ICF life domains and (2) the LOS domains. LOS participation restrictions were collected across eight life areas: education and training, work, economic life, transport, leisure activities, accessibility in and outside the home, and social contact.
2. **Barriers**: self-reported barriers to participation were collected for each life area and their subdomains. Barriers included for example: negative social attitudes, difficulty with transport, family responsibilities, lack of help, financial considerations.
3. **Impairment**: three types of information were collected on impairment:
    a. Impairment type
    b. Difficulty level of impairment
    c. Frequency with which impairment restricts activities of daily living
4. **Personal experiences**: accessing public services and policies, domestic life, caring for others, experiences of discrimination and crime.

3.3. Preparation of the dataset

Using the LOS variable dictionary, a subset of the variables relevant to the research aims was selected and exported to create a new, study-specific longitudinal dataset, containing Wave 1 and Wave 3 data. A variable dictionary was created in Excel containing the selected variable names, values, and definitions in the reduced dataset. The LOS derived data documentation was consulted to examine if the LOS derived variables were suitable for the purposes of the study or if they needed to undergo modification (UK Data Archive, 2015).

Before starting statistical analysis, the sample eligibility criteria were determined based on the literature review in Chapter 2. Variables operationalising the primary research concepts were constructed based on the thesis conceptual framework in Chapter 1. This included identifying variables within the LOS dataset to create derived variables for health conditions/impairment types, disability status, participation rates and barriers to participation across selected life areas.

3.3.1. Sample eligibility criteria

The target population was working age (16-64) adults who completed their Wave 1 interviews and had been assigned a LOS calibration weight. Respondents reporting at least one impairment at Wave 1 constituted the disabled sample (n=5,563), respondents reporting no impairments constituted the non-disabled comparison sample (n=17,832). The final Wave 1 study sample size was 23,395.

The longitudinal sample also comprised of a disabled group and a non-disabled group. The disabled group included those respondents who were of working age at W1 and reported at least one impairment causing activity limitations both at Wave 1 and at Wave 3 (n=1,435). The non-disabled group comprised of those individuals who were of working age at Wave 1 and reported no impairments at either wave (n=2,861).

3.3.2. Defining disability

The LOS was grounded in the social model of disability where disability is understood as the disadvantage people with impairments experience due to the social/contextual barriers that may cause restrictions to their participation in different areas of life. Based on this model, participants who reported an impairment were not considered ‘disabled’ in the LOS. The LOS used a dual criteria for determining disability, defined as experiencing both restricted participation *and* reporting an impairment (Office for National Statistics, 2010).

Compared to the LOS, the thesis used a wider definition of disability where participants who reported an impairment in functioning leading to any activity limitations of daily living were considered as disabled. This definition aligns with the Equality Act 2010 which defines disability as any physical or mental impairment that causes long-term mild to severe activity limitations (see Chapter 2, Section 2.3, p. 63). The following sections describe how the LOS data on impairments were adapted for the purposes of this thesis.

3.3.3. Defining impairment types

The LOS dataset collected data on self-reported impairments where impairment was defined as experiencing at least moderate difficulty within at least one area of physical or mental functioning (e.g.: walking, climbing stairs or reading a newspaper) leading to (at least occasional) limitations in carrying out activities of daily living (Office for National Statistics, 2013). The following impairment types were included in the LOS dataset: seeing, hearing, speaking, mobility, dexterity, pain, breathing, learning, intellectual, behavioural, memory, mental health, chronic, and other.

LOS data on impairment type and severity were used for two purposes: (1) to identify the disabled sample, (2) to be used in regression analyses as predictors of experiencing different types of restricted participation. Some impairment types were aggregated based on their definition in the LOS questionnaire (see Appendix 1) and conceptual sense. The following sections set out the steps involved in the preparation of the LOS data on impairment for statistical analyses.

Neurodevelopmental impairments

The wording of the LOS questionnaire on impairment types contained a considerable overlap between ‘Learning’, ‘Intellectual’ and ‘Behavioural’ impairments (Appendix 1). The International Classification of Diseases 11 (ICD-11) defines neurodevelopmental disorders as comprising of difficulties with behavioural and cognitive functions “involving significant difficulties in the acquisition and execution of intellectual, motor, language or social functions” (ICD-11). This definition encompasses the LOS definitions for learning, intellectual and behavioural impairments. Because of this reason, these three impairments were combined into a single category called ‘Neurodevelopmental’ impairment.

Sensory, motor, and breathing impairments

Impairment categories that cause similar functional limitations were grouped together. ‘Seeing’ and ‘Hearing’ impairments were combined to create a ‘Sensory’ category; ‘Mobility’ and ‘Dexterity’ impairments were combined to create a ‘Motor’ category and ‘Breathing’ impairment constituted its own category.

Pain and mental health impairments and comorbidities

Pain and mental health conditions are impairments that may cause an activity limitation on their own or they may occur as comorbidities associated with another condition (Kinn, 2016). In the literature, mental health impairment and pain impairment are both reported as significant barriers to participation in disabled populations (Holland & Clayton, 2020; Honey & Emerson, 2011). Derived variables were created which indicated whether the pain or mental health impairment was reported as a single condition in the absence of other impairments, or as a comorbid condition that co-existed with other impairments. In the statistical analyses, pain and mental health comorbidities were regarded as indicators of additional barriers to participation by adding an extra layer of severity to another impairment.

Impairments excluded from regressions

Impairments which were rarely reported in the dataset (i.e.: ‘speaking’ and ‘memory’), or which offered little explanatory value (i.e.: ‘chronic’ and ‘other’) were not included in regression analyses as predictors but still contributed to the definition of disability and impairment severity. Table 3.1 summarises how the LOS impairment variables were adapted for use in this thesis.

Table 3.1 Use of LOS impairments in quantitative analyses

LOS Impairment	**Derived impairment variables used as predictors in regression analyses**	
	Impairment	**Comorbidity**
Seeing Hearing	Sensory	
Mobility Dexterity	Motor	
Breathing	Breathing	
Learning Intellectual Behavioural	Neurodevelopmental	
Mental health	Mental health	✓
Pain	Pain	✓
Memory	-	
Speaking	-	
Chronic	-	
Other	-	

3.3.4. Impairment severity

In the LOS, respondents could report several impairments, and each impairment was given a severity score on a scale from 1 to 4, that took into account the difficulty level (with respect to functioning) and the frequency with which this difficulty was encountered (Table 3.2).

Table 3.2 Impairment severity: level of functioning and level of activity limitations

	Frequency difficulty encountered			
Difficulty level	**Rarely**	**Sometimes**	**Often**	**Always**
Mild	1	1	1	2
Moderate	1	2	2	3
Severe	2	3	3	4
Cannot do	3	4	4	4

Source: (Office for National Statistics, 2010)

To measure an individual's overall impairment severity, the LOS-derived severity score was used in statistical analyses. The score was computed by assigning the individual the highest severity score across all their impairments as their overall impairment score (UK Data Archive, 2015). The LOS derived severity score does not incorporate the total number and severity of an individual's impairments. Several different global measures of impairment severity were tested, taking into account the number and severity of each impairment reported. When comparing the score distribution and predictive performance of these variables to the LOS severity score variable, they did not perform as well, hence the decision was taken to carry the original LOS severity score further to the final analyses. Table 3.3 presents the full list of LOS impairments and the sample size of each severity score by impairment type.

Table 3.3 Sample sizes and severity levels of LOS impairments causing activity limitations*

Impairment type/severity	Level 1	Level 2	Level 3	Level 4	Total
Seeing	96 (18.6)	213 (42.2)	96 (18.9)	102 (20.2)	507 (100)
Hearing	81 (21.7)	232 (65.4)	50 (12.8)	19 (4.9)	382 (100)
Speaking	5 (2.4)	120 (67.5)	44 (26.0)	11 (6.2)	180 (100)
Mobility	12 (0.8)	632 (47.2)	421 (30.8)	284 (21.2)	1,349 (100)
Dexterity	21 (1.9)	542 (53.7)	242 (23.7)	220 (20.7)	1,025 (100)
Pain	460 (11.8)	1,976 (50.8)	1,007 (25.9)	451 (11.6)	3,894 (100)
Breathing	36 (7.7)	250 (51.8)	131 (26.6)	68 (14.0)	485 (100)
Learning	62 (12.9)	228 (46.7)	123 (26.8)	68 (13.6)	481 (100)
Intellectual	6 (9.2)	41 (51.4)	23 (26.6)	11 (12.8)	81 (100)
Behavioural	12 (5.7)	102 (46.6)	65 (31.9)	37 (15.8)	216 (100)
Memory	61 (9.7)	370 (62.7)	110 (17.6)	64 (10.3)	605 (100)
Mental health	83 (7.9)	563 (49.8)	259 (24.7)	198 (17.6)	1,103 (100)
Chronic	65 (3.1)	1,054 (51.1)	552 (26.6)	407 (19.2)	2,078 (100)
Other	4 (2.4)	82 (46.6)	47 (26.5)	45 (24.5)	178 (100)

*Population aged 16-64, LOS Wave 1. Unweighted observations, (weighted percentages).

3.4. Implementing the concept of social network layers

Chapter 1 set out the conceptual framework for this thesis, which combines elements of network theory and theories of social support to define social connectedness in terms of the structural and functional characteristics of ego-centric social networks. Based on this framework, social participation in different life areas builds ties on the hierarchical network layers that ego-centric networks are comprised of (Chapter 1, Section 1.3.1, Figure 1.2, p. 39). LOS data on participation across a range of life areas were mapped onto these social network layers (Table 3.4). This resulted in four participation domains on which to explore participation restrictions. These four domains were defined as the intimate, informal, formal and community domains. The intimate domain was linked to social activities relating to meeting close personal contacts. Participation on the informal domain was associated with meeting friends and family. The formal domain was associated with participation in education and employment. Finally, the community domain comprised of participation in sport and volunteering activities.

Table 3.4 Mapping LOS participation data to social network layers

LOS data on participation restrictions *Whether respondent has a restriction in …*	Selected for study	Social network layer -> participation domain
Learning	✓	formal
Employment	✓	formal
Economic (household level)	No	-
Transport	Barrier	-
Going on holiday	No	-
Meeting friends	✓	informal
Meeting family	✓	informal
Playing sport	✓	community
Doing voluntary work	✓	community
Going to the museum or place of historic interest	No	-
Going to the theatre or cinema	No	-
Going to the library or National Archive	No	-
Accessibility in the home	Barrier	-
Accessibility outside the home	Barrier	-
Social (close) contact	✓	close/intimate

Organising participation data around domains linked to social network layers benefited data analyses and interpretation in two ways. Firstly, it helped to break down the data analysis into meaningful stages. Secondly, interpreting restricted participation and barriers to participation within the context of the 'social network', aided the comparison between disabled and non-disabled people and helped linking the findings to the wider literature.

3.4.1. Social activities excluded from the study

The activities of ‘going on holiday’, ‘to the theatre/ cinema’, ‘visiting museums’ or ‘the library’ were not included in the study selection of participation domains. Driven by the theoretical model, the scope of the analysis was narrowed down to include only those types of activities which had the potential to extend one’s social network.

3.5. Defining participation restriction

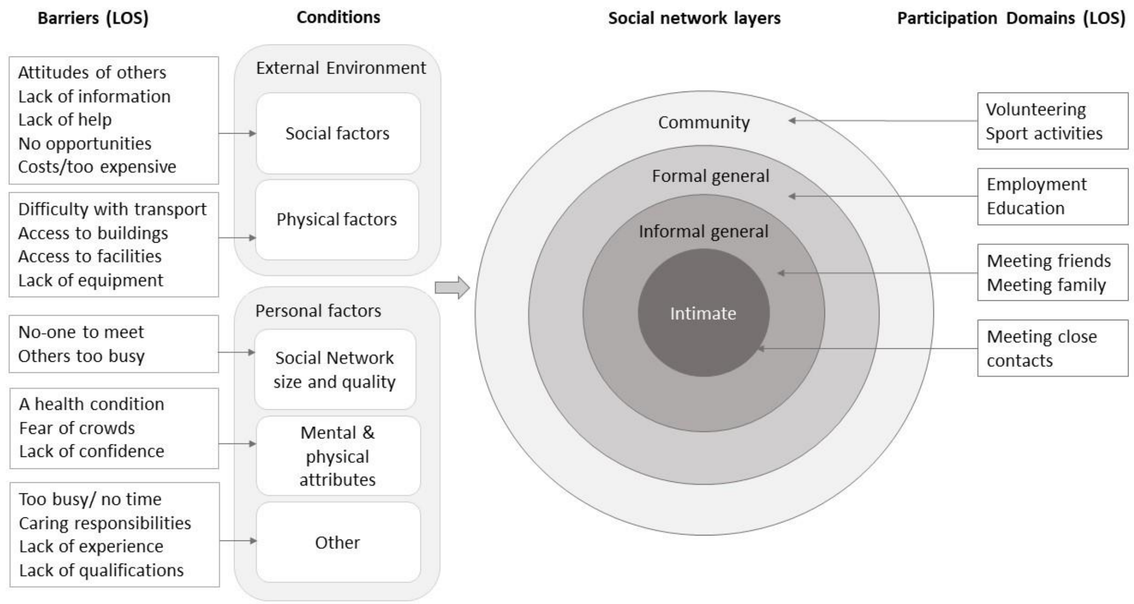
Participation restriction was defined as expressing an interest in engaging in an activity but not being able to do so because of a social/environmental barrier, health condition due to an impairment, or network failure. Network failure was defined as not being able to participate in a life area because of the unavailability of a network member.

Across the participation domains of ‘meeting close contacts’, ‘employment’ and ‘education’, the LOS definition of restricted participation included people who were not interested in engaging in these activities. The thesis definition of participation only included those participants who expressed an interest to participate but could not.

3.6. Defining barriers to participation

The LOS collected barriers to participation for every social activity included in the dataset. The conceptual model of social relations developed in Chapter 1 was used to categorise the LOS barriers as social or physical environment factors or personal characteristics. Barriers to participation were regarded as the conditions which shape access to the personal social network and the wider social environment. Figure 3.1 illustrates how the LOS variables were organised with reference to the conceptual model.

Figure 3.1 Locating the LOS in the thesis' conceptual framework



3.6.1. Data on barriers excluded from the analyses

Statistical analyses included the comprehensive list of LOS barriers to participation except for two: 'disability' and 'do not need or want to' were excluded from analyses. Reporting 'disability' as a barrier to participation does not fit in with the social model of disability and overlaps with 'health condition'.

3.7. Statistical analyses

The quantitative analysis was conducted in four stages, each corresponding to one of the four research objectives (Table 3.5).

Table 3.5 Quantitative analyses addressing the research objectives

Research objective	Quantitative method	Results presented in
Understand differences in restricted social participation and barriers to participation across disabled and non-disabled populations.	• Cross-tabulations • Chi-square tests • T-tests	Chapter 4
Develop a typology of barriers that characterise disabled people's restricted social participation in different activities.	• Latent Class Analysis	Chapter 5
Understand the risk factors associated with different participation barrier profiles.	• Logistic regression	Chapter 5
Understand the factors affecting changes in social participation over time for disabled and non-disabled people.	• Frequencies • Cross-tabulations	Chapter 6

The statistical software used to perform the majority of the quantitative analysis was STATA/SE version 17.0. The SEM software package MPLUS version 8.5 (Muthen & Muthen) was used to perform the Latent Class Analyses (LCA). Both of these statistical software packages are widely used by the research community as robust and efficient tools for data analysis. I undertook training in MPLUS specifically for this study and had previous experience of using STATA.

3.7.1. LOS sampling and weights

The LOS dataset was accessed and downloaded in Stata format free of charge from the UK Data Archive (dataset name: w1w2w3losmar2016eul.dta). The majority of the analysis in this study (Chapter 4 and 5) was carried out on the Wave 1 LOS dataset (collected between 2009-2011). The longitudinal element of the study (Chapter 6) used the Wave 1 to Wave 3 (2012-2014) longitudinal dataset. The time elapsed between the Wave 1 and Wave 3 interview was on average 3 and a half years (Office for National Statistics, 2015).

Wave 1 of the LOS used a single-stage (unclustered) household sample drawn from the small users Postcode Address File. Unclustered samples consist of addresses that are spread out across postcode sectors, avoiding clustering effects introduced by the similarity of households within geographical clusters. The household's sample selection probabilities were set to reflect the total population of England (86%), Scotland (9%) and Wales (5%) (Office for National Statistics, 2011b). The final total of participating households was 19,951 in Wave 1, with 36,161 adult interviews conducted. Wave 2 and 3 contain households which have either (1) an individual who reported an impairment at W1, (2) households in the non-disabled group or (3) households containing an individual identified as having acquired an impairment since W1. Wave 2 has a final sample size of 14,100 participating households and that of W3 is 6,474 participating households (LOS Wave 3 Final Report, Annex 3 Response rates).

The LOS data contains three types of weights. The selection weight accounts for the chance of a household being selected. The non-response weight compensates the data for non-response. Finally, the calibration weight adjusts the selection and non-response weights and re-weights the data so that it matches population totals in terms of region, age, and gender (Office for National Statistics, 2011b). The LOS weighted data is likely to underestimate the number of people in certain populations because of the presence of missing answers across several LOS variables. Hence it is not recommended to use weighted LOS data for population estimates (Office for National Statistics, 2011).

The LOS calibration weights were applied to all statistical analyses except when reporting initial sample sizes and missing observations. The descriptive analyses, latent class analysis and regression models performed on the Wave 1 dataset used the Wave 1 calibration weight. The descriptive analyses examining change in participation, used the Wave 1 to Wave 3 longitudinal calibration weight.

The following sections describe and justify the methods used at every stage of the quantitative analysis.

3.7.2. Participation rates and barriers to participation

The first stage of the quantitative analysis had three broad aims: (1) to describe and compare the main demographic and socio-economic characteristics of the disabled sample and the non-disabled group; (2) to describe and compare the engagement rates and participation restrictions reported across the two groups; (3) to explore the barriers to participation reported, comparing the disabled population to the non-disabled group.

The descriptive analyses of the disabled and non-disabled groups included the following characteristics:

- age
- gender
- ethnicity
- marital status
- being able to make ends meet
- informal care responsibilities
- weekly hours spent on informal care
- employment status
- location (rural/urban)

Crosstabulations, Chi-square and T-tests were used to explore if there were any significant differences between the disabled sample and the non-disabled group on the above measures.

Levels of engagement rates across the selected social activities, were compared between disabled and non-disabled people. Engagement was defined in terms of ‘interest shown’ in participating in an activity. The age and gender characteristics of respondents who expressed no interest in participation were compared to those who did express engagement to look for systematic differences between the two groups. Missing values and the source of missingness were also explored for each life area.

Participation restriction rates were measured for each social activity and compared between the disabled and non-disabled samples. Cross-tabulations were run to determine the numbers and percentages of disabled and non-disabled participants reporting specific barriers to participation for each social activity.

3.7.3. Creating a barrier typology of restricted participation

In the second stage of the quantitative analysis, Latent Class Analysis (LCA) was used to discover if the barriers to participation reported by disabled people followed any meaningful patterns. The outcome of the LCA was a barrier typology, comprising of distinct 'barrier profiles' which characterised common combinations of barriers reported by disabled people experiencing restricted participation. The following sections introduce the main principles of LCA as a statistical technique and describe how it was applied to the LOS data to identify different barrier profiles associated with restricted participation.

Latent Class Analysis

Latent Class Analysis is a 'person-centred' statistical modelling technique that is used to identify qualitatively different subgroups of people (or latent/unobserved classes) within populations (Hagenaars & McCutcheon, 2002; Weller & Bowen, 2020). A person's membership of a latent class is identified based on their patterns of responses to observed categorical (indicator) variables (McCutcheon, 1987; Muthen & Muthen, 2000). The assumption underlying LCA is that membership of a latent class explains the observed patterns of behaviour across a population. In other words, the pattern of responses on a set of indicator variables is driven by class membership.

For the creation of latent classes, indicator variables are chosen to identify symmetrical relationships in categorical data (McCutcheon, 1987). Symmetrical relationships are those where there is significant association between two or more observed indicator variables that is likely to be attributable to a third factor (i.e.: membership of a latent class). Although the indicator variables are themselves uncorrelated (independent), the patterns of responses across them are predictable by an unobserved latent variable. The aim of LCA is to identify these latent variables or classes.

Justification of the use of LCA and limitations

LCA is a useful technique for identifying subgroups of vulnerable populations who could benefit from social and health interventions based on their shared characteristics (Weller et al., 2020). It builds on a long history of statistical theory and is seen as a reliable method of creating subgroups within populations sharing behavioural traits (Weller 2020). LCA is more suitable to be used with categorical data, than for example cluster analysis, which is more apt for continuous variables. The difference between LCA and cluster analysis is that LCA is based on the assumption that latent classes exist and drive patterns of behaviour within the data, whilst in cluster analysis the assumption is that people with similar (mean) scores belong to the same cluster (Weller 2020). Both methods generate categorical classifications (i.e.: classes and clusters) that can be used in further statistical analyses. For the purposes of this thesis, LCA was the appropriate technique because the LOS data on barriers was of categorical nature and because the focus of interest was identifying population groups that experienced similar restrictions due to a set of unobserved common characteristics. The assumption was that different types of health impairments may give rise to similar and until now unobserved patterns of barriers to participation.

LCA also has its limitations. LCA assigns individuals the probability of belonging to a latent class based on the pattern of their responses. Depending on the distribution of answers across the selection of the indicator variables used, appropriate class assignment might not be achieved. Because the classes are based on probabilities, the numbers, and percentages of sample members within each class are not exact. The correct identification and interpretation of latent classes relies largely on the researcher’s subject knowledge.

Conducting LCA

The minimum recommended sample size for LCA is 300-500 observations (Nylund-Gibson & Choi, 2018). In order to build an LCA model, first a set of indicator variables need to be identified. The selection of indicator variables is ideally theory driven. Being led by a strong theoretical rationale in the preparation of variables to be entered into the LCA model aids the interpretation and real-world applicability of the results (Weller 2020).

LCA is conducted in several iterations starting with a one-class model (assuming the absence of latent classes in the dataset). Next, a series of LCA models are run sequentially increasing the number of latent classes specified in the models by adding one class at a time (i.e.: 2-classes, 3 classes, etc…). Statistical criteria and conceptual sense are used to identify the model that best fits the data.

LCA model diagnostics

Although there is no consensus about the best model diagnostic criteria to be used with LCA, multiple fit statistics are often used to assess model fit. The Bayesian Information Criterion (BIC) is considered one of the most reliable model fit statistic, with lower values signifying better model fit (Nylund & Asparouhov, 2007). The Akaike Information Criterion (AIC) is a similar test statistic with lower values indicating better fit. The Vuong-Lo-Mendell-Rubin adjusted likelihood ratio test (Lo & Mendell, 2001) is a statistic used to select the final class. A significant p value ($p<0.05$) on this test suggests that the given model is significantly better at differentiating between the latent classes than if one class was removed. Entropy is another diagnostic statistic (Wang & Deng, 2017) that indicates how accurately a model defines classes. Entropy values range from 0 to 1, with 1 indicating perfect differentiation between classes, hence higher entropy values (preferably over 0.8) are preferred. Reliance on statistical diagnostic criteria alone is not recommended when identifying latent classes. In order for the LCA results to have meaningful practical applications, the theoretical interpretability of latent classes must be taken into consideration (Weller 2020).

Interpretation of LCA output

LCA class solutions represent typologies that can help researchers understand commonalities and differences among groups of respondents under study. LCA produces two main parameters: latent class probabilities and conditional probabilities.

Latent class probabilities provide two important pieces of information about the latent class model: the number of categories within the latent variable and their sizes. The number of categories stand for the latent types (classes) identified by the LCA for the observed data. The size of the latent classes indicates how these latent types are distributed across the population. There could be a relatively even distribution of classes, or some classes could represent larger segments of the population with other classes being in relative minority. The sum of the latent class probabilities always adds up to 1 (McCutcheon, 1987).

For each latent class, the LCA calculates the conditional probabilities for every individual (in that class) of affirming a certain response within the variables included in the model. The classes are mutually exhaustive and exclusive, which means that all participants are assigned a class, and nobody is assigned to more than one classes. Every latent class is associated with a relatively unique pattern of affirmative answers across the categories of the variables included. The conditional probabilities are analogous to factor loadings in factor analysis, in that for each variable they represent the degree of association between the (categories of the) variable with the latent class (or factor in factor analysis). Hence, conditional probabilities indicate the probability that a respondent within a latent type, will affirm a particular variable category of a given variable (McCutcheon, 1987).

3.7.4. Applying LCA to the LOS data on barriers

Creating the barrier typology characterising restricted participation across different LOS life areas involved three stages. The first stage of the LCA comprised of model building, using the information gained from the first stage of descriptive analyses (presented in Chapter 4). A set of indicator variables were chosen, representing barriers to engagement in social activities across the 4 participation domains established earlier. Barriers to participation that were reported by at least 3% (or c.a. 50 observations) of people with restricted participation were included in the LCA models (see Chapter 4, Table 4.7, p. 128). Each barrier was given a binary coding, assigning 0 to 'barrier absent' and 1 to 'barrier present'. Besides barriers to participation, the LCA models also included the participant ID number and the W1 calibration weight.

At the second stage of analysis, LCA was performed in MPLUS through several iterations using maximum likelihood estimation. Starting with a one class model specification, and rerunning the models specifying 2, 3 and 4 class solutions. At the third stage, the best class solution was selected based on model diagnostics and theoretical considerations.

Transforming the LCA results to visualise barrier profiles

Latent class conditional probabilities were transformed to create a visual representation of the barrier typology. The transformation involved expressing each conditional probability (of a barrier being reported) within a latent class, as a proportion of the total class conditional probabilities. This resulted in each barrier within a latent class being assigned a percentage that expresses their share of the total barriers likely to be reported within that subgroup of respondents. Barrier profiles were visualised in the form of pie charts, where each latent class (or barrier profile) constitutes one pie chart which represents the share or weight of the individual barriers relative to the total barriers (100%) likely to be reported in the class (for results see Chapter 5).

3.7.5. Personal characteristics associated with barrier profiles

The third part of the quantitative analysis explored whether individual demographic and health characteristics were associated with being member of a latent class, using logistic regression analyses. Logistic regressions are commonly used to obtain the odds ratios of a binary outcome in the presence of more than one explanatory variables. There were three steps involved in conducting this analysis: (1) the creation of the binary dependent variables based on the LCA results; (2) the selection of a set of independent variables; (3) running and evaluating the logistic regressions.

To create the dependent variables for the logistic regression models, the LCA latent class probabilities, (i.e.: the barrier profile that a person was assigned to for a specific social activity) were imported into STATA. Binary dummy variables were created for each barrier profile within every social activity (e.g.: 'meeting friends type 1', 'meeting friends type 2', 'meeting friends type 3') where belonging to a class was coded 1 and belonging to the other classes in the same domain was coded 0.

A set of independent variables were selected to test the odds of a person being assigned to a latent class based on their individual characteristics (Table 3.6). Multicollinearity was minimised when choosing the independent variables for example by not including both 'marital status' and 'presence of children' as predictors. Each latent class (or barrier profile) was cross tabulated with the independent variables to examine whether there were at least 10 cases per category for each variable in the model. The sample sizes of people with Asian and Black ethnic backgrounds were relatively low across different participation domains, hence the odds ratios relating to 'Ethnicity' must be treated with caution.

Table 3.6 Independent variables used in logistic regression models

Independent variable	Categories
Age	16-24 (reference) 25-44 45-64
Gender	Male (reference) Female
Ethnicity	White (reference) Asian Black
Presence of dependent child	No (reference) Yes
Sensory impairment	No (reference) Yes
Motor impairment	No (reference) Yes
Neurodevelopmental impairment	No (reference) Yes
Breathing impairment	No (reference) Yes
Pain impairment	No (reference) Pain only Pain comorbidity
Mental health impairment	No (reference) Mental health only Mental health comorbidity
Impairment severity	Level 1 (reference) Level 2 Level 3 Level 4

When running the logistic regressions, the calibration weight was applied to adjust the results to population estimates. Odds ratios were evaluated for significance at the 99% confidence interval.

3.7.6. Changes in participation rates over time

The final objective of the quantitative analyses was to examine changes in social participation for the subset of participants who provided data at both Wave 1 and 3. The time elapsed between the 1st and 3rd interview was on average 3 and a half years, with Wave 1 conducted during 2009-11 and Wave 3 conducted during 2012-14 (Office for National Statistics, 2015).

The longitudinal analysis used descriptive statistics to examine movement into and out of restricted participation across the two waves comparing the disabled and non-disabled samples. It also explored changes in the barriers to participation reported by those disabled people who still reported restricted participation at Wave 3. At Wave 3, the LOS collected additional data on facilitators to participation which were not collected in the previous waves. Reported facilitators to participation were examined for those subgroups of people who moved out of restricted participation at Wave 3. All the longitudinal analyses report within sample change, in other words, examine change in participation reported by individual participants.

Chapter 4. Restricted participation and barriers to participation in the Life Opportunities Survey

4.1. Introduction

The objective of this chapter is to address the thesis' first research objective which is to understand differences in restricted participation and barriers to participation across people living with and without a disability. The chapter consists of three sections. The first one describes and compares the main demographic and socio-economic characteristics of the disabled and non-disabled respondents in the Life Opportunities Survey (LOS). In the second section, levels of engagement and reported activity restrictions are compared between the two groups. The third section explores and contrasts the main barriers to participation reported across disabled and non-disabled populations. All the analyses in this chapter use the Wave 1 dataset of the Life Opportunities Survey. The chapter concludes with a discussion of the findings.

4.2. Sample characteristics

The Life Opportunities Survey was sampled to reflect population characteristics; hence it contains significantly more respondents who do not report a mental or physical impairment than those who report at least one impairment. Just over 76% of the sample reported having no impairment as opposed to 23.8% of those who did, with a total sample size of 23,395 at Wave 1 (Table 4.1). People of working age who reported at least one impairment were significantly older than those who did not, by five and a half years on average (Mean diff=5.56, $p<0.001$, CI= 5.96 - 5.16). This reflects the higher prevalence of disability in older age groups even in those under 65 (see Chapter 2).

Table 4.1 The age distribution of the Wave 1 sample (unweighted observations)

	Mean	Sd	Median	Min	Max	Count
Sample reporting no impairment	40.89	13.58	41	16.0	64.0	17,832
Sample reporting at least one impairment	46.45	12.58	48	16.0	64.0	5,563
Total	*42.21*	*13.55*	*43*	*16.0*	64.0	*23,395*

Table 4.2 presents the composition and sample sizes of the impairment types derived from the LOS data (see Chapter 3, Section 3.3.3, p. 86). It also illustrates the representation of each impairment type within the disabled sample, in terms of the percentage of the disabled sample reporting the impairment. Pain was the most frequently reported impairment, followed by motor and mental health impairments.

Table 4.2 Sample sizes of thesis defined impairment types* (unweighted observations)

Impairment type	**Impairment present**	**Single impairment**	**Comorbidity**	**Representation in disabled sample**
Sensory	841			15.1%
Motor	1,772			31.9%
Breathing	486			8.7%
Neurodevelopmental	633			11.4%
Pain	3,897	1,573	2,324	70.1%
Mental health	1,104	240	864	19.8%
Total disabled sample	5,563			100%

*Wave 1 disabled sample aged 16-64.

Table 4.3 presents the socio-demographic composition of the study samples and the weighted chi-square tests for significant differences between them. With regards to gender, there were slightly more women than men in both samples, moreover disabled people were slightly more likely to be female than male (56% to 44%), a finding that reflects ONS population estimates (Chapter 2, Section 2.3.1, p. 64). The age distributions of disabled and non-disabled samples were significantly different (F=294.3, p<0.001), just under half (45%) of the non-disabled sample being aged 25 to 44, whilst over half of the disabled sample (57%) being in the 45 to 64 age category. Comparing the two samples based on family status, disabled people were significantly more likely to be divorced (14.7% versus 7.4%) or widowed (2.9% compared to 1.3%) than the non-disabled group and slightly less likely to have a partner (F=103.56, p<0.001).

There were also significant differences between disabled and non-disabled respondents in terms of employment status (F=1009.82, p<0.001). Just over half (50.9%) of the disabled sample were in paid employment, compared to three quarters (74.9%) of people in the non-disabled group. People in the disabled sample were also slightly more likely to be retired or unemployed, and nearly a quarter of the population (24%) was not working due to their disability. With regards to informal care, disabled people were twice as likely to care for another household member than non-disabled people (10.6% versus 5.4%) and they were also more likely to engage in high intensity informal care, involving more than one people that took up most of their time. Almost 4% of disabled participants were informal carers both at home and outside their home, and nearly a fifth (18.7%) were involved in full-time informal care taking up 35 to 100+ hours per week. In comparison, over 81% of respondents in the non-disabled group were not carers and most of those who were, provided care that took fewer than 20 hours per week (75.7%).

The relatively low rates of economic activity and high levels of informal care were reflected in significant differences between disabled and non-disabled respondents' subjective assessment whether 'they could make ends meet' (F=278.29, p<0.001). Over half of the disabled sample (51.5%) reported to have some or great difficulty in making ends meet, which compares to 31.8% of people in the non-disabled sample. A fifth of the non-disabled sample reported to make ends meet very easily, compared to just over 11% of the disabled population. There were no significant differences between the two samples regarding their housing location, with about a fifth of respondents in both samples living in rural areas and 80% in towns.

Table 4.3 Demographic and social characteristics of Wave 1 sample: non-weighted observations and weighted percentages and test statistic

	Non-disabled sample		**Disabled sample**		**Total**		**Adjusted Pearson's Chi-square (F)***
	Nr	%	Nr	%	Nr	%	
Gender							
Male	8,171	47.3	2,377	44.3	10,548	46.6	p<0.001
Female	9,661	52.7	3,186	55.7	12,847	53.4	F=13.64
Total	*17,832*	*100*	*5,563*	*100*	*23,395*	*100*	
Age							
16 to 24	2,649	16.8	394	7.8	3,043	14.7	p<0.001
25 to 44	7,659	45.1	1,840	35.3	9,499	42.9	F=294.3
45 to 64	7,524	38.1	3,329	56.9	10,853	42.4	
Total	*17,832*	*100*	*5,563*	*100*	*23,395*	*100*	
Ethnicity							
White	15,977	87.9	5,120	90.7	21,097	88.5	p<0.001
Mixed	144	0.9	52	1.1	196	0.9	F=8.35
Asian or Asian British	960	6.1	223	4.5	1,183	5.8	
Black or Black British	398	2.7	95	2.1	493	2.6	
Chinese or Other Ethnic Group	347	2.4	71	1.6	418	2.2	
Total	*17,826*	*100*	*5,561*	*100*	*23,387*	*100*	

	Non-disabled sample		**Disabled sample**		**Total**		**Adjusted Pearson's Chi-square (F)***
	Nr	%	Nr	%	Nr	%	
Marital Status							
Single	4,277	*26.9*	1,109	*21.8*	5,386	*25.7*	p<0.001
Partnered	11,928	*64.4*	3,494	*60.7*	15,422	*63.5*	F=103.56
Divorced	1,378	*7.4*	798	*14.7*	2,176	*9.1*	
Widowed	249	*1.3*	162	*2.9*	411	*1.7*	
Total	17,832	*100*	5,563	*100*	23,395	*100*	
Making ends meet							
With great difficulty	965	*5.5*	823	*15.6*	1,788	*7.9*	p<0.001
With some difficulty	4,579	*26.3*	1,978	*35.9*	6,557	*28.6*	F=278.29
Fairly easily	8,596	*48.0*	2,101	*37.1*	10,697	*45.5*	
Very easily	3,673	*20.1*	655	*11.4*	4,328	*18.1*	
Total	17,813	*100*	5,557	*100*	23,370	*100*	
Informal care responsibilities							
Not a carer	12,828	*81.4*	3,179	*70.7*	16,007	*79.1*	p<0.001
Caring at home	885	*5.4*	488	*10.6*	1,373	*6.5*	F=96.82
Caring outside home	1,944	*11.5*	693	*14.9*	2,637	*12.2*	
Caring in and outside home	293	*1.7*	172	*3.8*	465	*2.2*	
Total	15,950	*100*	4,532	*100*	20,482	*100*	

	Non-disabled sample		Disabled sample		Total		Adjusted Pearson's Chi-square (F)**
	Nr	%	Nr	%	Nr	%	Nr
Hours spent caring per week							
0-19 hrs	2,601	*75.7*	1,016	*66.3*	3,617	*72.8*	p<0.001
20-34 hrs	350	*10.2*	239	*15.1*	589	*11.7*	F=18.29
35-99 hrs	263	*7.5*	131	*8.1*	394	*7.6*	
100 or more hrs	230	*6.6*	172	*10.6*	402	*7.8*	
Total	3,444	*100*	1,558	*100*	5,002	*100*	
Employment status							
Employed	13,352	*74.9*	2,834	*50.9*	16,186	*69.3*	p<0.001
Retired	1,002	*4.8*	485	*7.8*	1,487	*5.5*	F=1009.82
Unemployed	951	*5.5*	357	*7.0*	1,308	*5.9*	
Disabled	102	*0.6*	1,313	*24.0*	1,415	*6.0*	
Inactive	2,413	*14.2*	568	*10.3*	2,981	*13.3*	
Total	17,820	*100*	5,557	*100*	23,377	*100*	
Location							
Urban	13,896	*80.3*	4,432	*81.6*	18,328	*80.6*	P=0.04
Rural	3,926	*19.7*	1,124	*18.5*	5,050	*19.4*	F=4.18
Total	17,822	*100*	5,556	*100*	23,378	*100*	

*The adjusted Pearson Chi-square was used which is an F statistic that was adjusted to the survey design using the LOS calibration weight.

4.2.1. Participation rates across different life areas

The next stage of the analysis investigated how many participants reported restricted versus non-restricted participation, or no interest in participation across different life areas. The number of missing values were also examined. Tables 4.4 and 4.5 present the results for the disabled and non-disabled sample respectively.

Disabled people reported the highest levels of unrestricted participation in the areas of meeting close contacts and education (71% for each). The lowest unrestricted participation rates were reported in volunteering and sport (around 10%), which were also the life areas that had the highest rates of 'no interest' (c.a. 59% on both). Over a fifth of disabled people reported experiencing participation restrictions in employment, whilst 15% reported having no interest in paid work and 27% replied that this question was not applicable to them.

Table 4.4 Disabled sample: engagement in different life areas*

LOS life areas	Not restricted	Restricted	No interest	Missing/NA	Total (100%)
Close contacts	3,980 (71.5)	1,580 (28.4)	-	3 (0.1)	5,563
Meeting friends	1,886 (33.9)	2,104 (37.8)	1,568 (28.2)	5 (0.1)	5,563
Meeting family	2,568 (46.2)	1,883 (33.8)	1,103 (19.8)	9 (0.2)	5,563
Education	3,949 (71.0)	1,130 (20.3)	462 (8.3)	22 (0.4)	5,563
Employment	2,049 (36.8)	1,179 (21.2)	835 (15.0)	1,500 (27.0)	5,563
Volunteering	561 (10.1)	1,724 (31.0)	3,272 (58.8)	6 (0.1)	5,563
Sport	510 (9.2)	1,732 (31.1)	3,316 (59.6)	5 (0.1)	5,563

*Unweighted observations (weighted percentages). - LOS collected no data.

In the non-disabled group, unrestricted participation rates were the highest in education (86%) followed by meeting close connections (77%), and the highest rate of activity restriction was reported on the domain of meeting friends. Nearly 65% of the non-disabled group reported no participation restrictions in employment, whilst 16% reported restrictions and 4% had no interest in paid work.

Table 4.5 Non-disabled sample: engagement in different life areas*

LOS life areas	Not restricted	Restricted	No interest	Missing/NA	Total (100%)
Close contacts	13,742 (77.1)	4,081 (22.9)	-	9 (0.1)	17,832
Meeting friends	8,063 (45.2)	5,899 (33.1)	3,849 (21.6)	22 (0.1)	17,832
Meeting family	9,671 (54.2)	5,332 (29.9)	2,799 (15.7)	30 (0.2)	17,832
Education	15,275 (85.7)	1,776 (10.0)	751 (4.2)	30 (0.2)	17,832
Employment	11,536 (64.7)	2,844 (15.9)	724 (4.1)	2,724 (15.3)	17,832
Volunteering	2,199 (12.3)	5,318 (29.8)	10,292 (57.7)	23 (0.1)	17,832
Sport	3,914 (21.9)	5,027 (28.9)	8,870 (49.7)	21 (0.1)	17,832

*Unweighted observations (weighted percentages). - LOS collected no data.

Disabled people were more likely than non-disabled people to report experiencing restrictions to employment (21.2% vs 15.9) and education (20.3% vs 10.0%). Across all other life areas, greater proportions of disabled people reported restrictions compared to non-disabled people, though the difference in proportions between to the two groups was much smaller (~5%). Higher proportions of disabled people expressed 'no interest' in participating across each life area compared to non-disabled people.

No interest in participation

Sensitivity analyses were conducted to test whether respondents who were not interested in participation had significantly different demographic characteristics to those who did. Logistic regression models were created where 'being interested in participation' was the binary outcome variable and age, gender and disability status were predictors. The results, presented in Table 4.6, suggest that with every year increase in age, the odds of being interested in participation significantly decreased (by 1 to 4%) in the life areas of meeting friends, engaging in education, employment, and sport activities. Respondents' age did not seem to be significantly associated with being interested in volunteering. At the same time, expressing an interest in seeing family members was significantly more likely in the older age groups.

Being female, was associated with a 21 to 54 percent higher likelihood of being interested in participating across all life areas compared to men, except for the life areas of employment and sport (where women were less than half as likely to want to participate as men).

The logistic regression results moreover indicate, that having controlled for age and gender, the presence of at least one impairment that significantly affected the carrying out of daily activities, significantly reduced the odds of being interested in participation across all life areas except for volunteering. The life areas that disabled participants were least likely to be interested in participating, were employment (79% less likely compared to non-disabled respondents) and education (42% less likely than non-disabled people).

Table 4.6 Logistic regressions, testing whether demographic characteristics and disability status predict being interested in participation across different life areas. Odds ratios.

	Friends	Family	Education	Employment	Volunteering	Sport
Age	0.99***	1.01***	0.96***	0.99***	1.00	0.98***
Gender						
Male (ref)						
Female	1.28***	1.54***	1.21**	0.41***	1.53**	0.42***
Disabled						
No (ref)						
Yes	0.72***	0.72***	0.58***	0.19***	0.95	0.76***
Nr of observations	23,387	23,387	23,343	19,171	23,387	23,387
Constant	5.14***	3.45***	146.11***	57.71***	0.53***	4.29***
F	(3, 23384) = 80.73	(3, 23384) = 57.79	(3, 23340) = 135.8	(3, 19,168) = 417.4	(3, 23384) = 72.53	(3, 23384) = 374.84

LOS collected no data on being interested in meeting close contacts. p<0.001***, p<0.01**

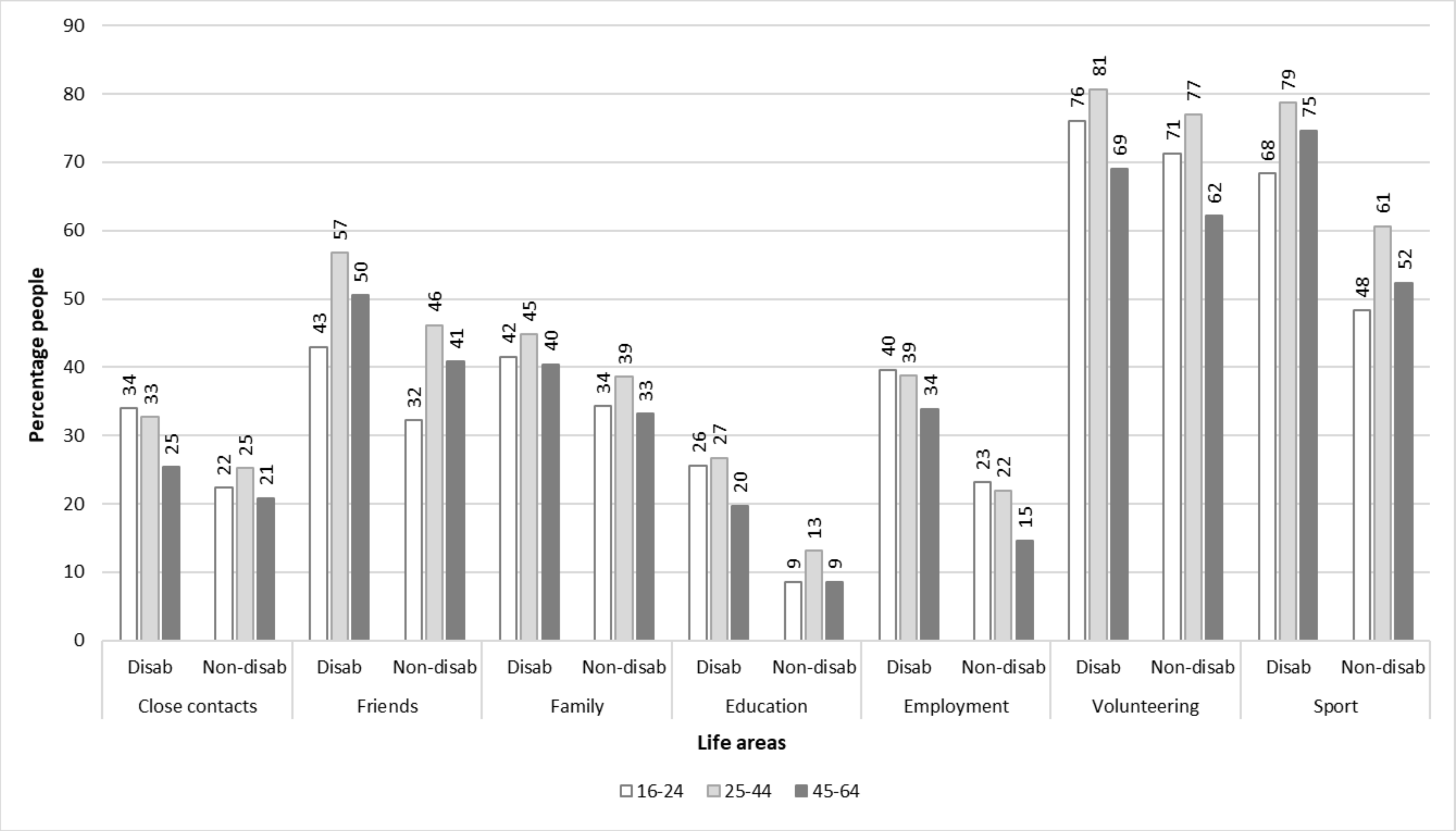
Non-response

The data collected on most life areas contained negligible numbers of missing values which made up less than 0.1% of the sample (Tables 4.4 and 4.5). The life domain of employment was the only exception, where 15% of non-disabled respondents and 27% of the disabled sample declared ‘Not Applicable’ to the question whether they participated in employment. Table A2.1 in Appendix 2 presents the descriptive analyses that explored the reasons why respondents might have felt that participation in employment did not apply to them. Disabled people were more likely to tick ‘N/A’ for participating in employment because of ‘disability’ reasons, whilst non-disabled people were more likely to answer with ‘N/A’ if they were ‘students’ or ‘economically inactive’ (Appendix 2, Table A 2.1, p. 290). Further statistical analyses excluded respondents with missing data and those who expressed ‘no interest’ in participating in a given life area.

4.3. Restricted participation in the LOS

This section takes a closer look at differences in restricted participation in each life area, comparing restrictions reported by different age groups within the disabled and non-disabled samples (Figure 4.1). Chi-square analyses were performed to test whether the differences in restricted participation between the disabled sample and the non-disabled group were statistically significant. The results indicate that non-disabled populations reported significantly lower rates of participation restrictions than disabled people across every life area, except for volunteering. There is no significant difference in the participation rates of disabled and non-disabled populations in the 16-24 and 25-44 age groups on this domain.

Figure 4.1 Reporting participation restrictions by age groups: comparing disabled and non-disabled respondents



4.3.1. Restricted participation by type of activity

Disabled and non-disabled people reported different rates of restricted participation across different life areas (Figure 4.1). The largest difference in participation restrictions between disabled and non-disabled people were in employment and education, followed by meeting friends and close connections. The highest rates of participation restrictions were reported in volunteering and sport activities by both samples (Figure 4.1). Discounting volunteering and sport, disabled people were more likely to encounter participation restrictions in meeting friends, family, and employment, whilst the non-disabled group was more likely to report being restricted in meeting friends and family, and least likely to report restrictions in education and employment.

4.3.2. Restricted participation by age group

The highest rates of restricted participation were reported by 25- to 44-year-olds across almost all life areas, and the lowest rates by the oldest age group (45 to 64) (Figure 4.1, p. 114). Disabled young people (aged 16 to 25) reported the highest rates of participation restriction across all respondents in meeting close contacts and employment. Some of the greatest differences in restricted participation (between disabled and non-disabled respondents) were also found in the youngest age groups. Seventeen percent more disabled young people experienced restrictions in paid work, 12% more reported restricted participation in meeting close connections, and 20% more reported barriers to participating in sport, compared to non-disabled 16 to 25-year-olds (Figure 4.1). There was a large difference in reporting restricted participation in education between disabled and non-disabled young people; over a quarter of disabled young people reported barriers to education compared to less than 10% of 16 to 25-year-olds in the non-disabled group.

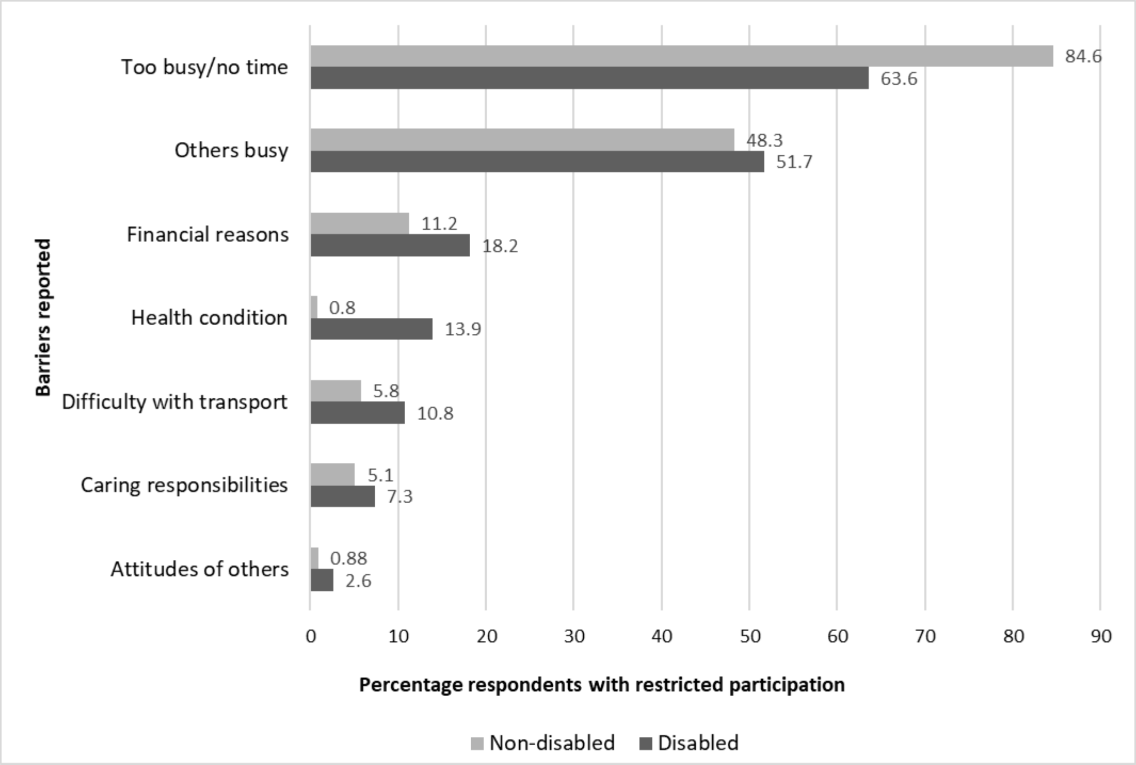
4.4. Barriers to participation

This section explores barriers to participation for each life area across disabled and non-disabled populations. The barriers presented in the following sections are those that were reported by at least 3% of people (or at least 50 observations) within the group experiencing restricted participation in a given life area. Barriers to participation were used as indicator variables for the Latent Class Analyses and setting a minimum number of observations for each barrier was necessary for the successful convergence of the latent class models. For the complete set of barriers that the LOS collected data on together with Chi-square test results, please refer to Appendix 2.

4.4.1. The intimate domain: barriers to meeting close contacts

Figure 4.2 presents the top seven barriers to meeting one's close contacts by disabled and non-disabled respondents. The complete set of barriers collected by the LOS for this life area are presented in Appendix 2, Table A2.2. Adjusted Chi-square tests indicate that the differences between the disabled and non-disabled groups were significant on each barrier reported except for 'difficulties with transport' and 'caring responsibilities' (Figure 4.2 and Appendix 2, Table A.2.2, p. 290). 'Too busy/no time' was the most common barrier reported by both samples to meeting close contacts, followed by 'others busy'. Over 18% of disabled people with restricted participation in the intimate domain reported 'financial reasons' as a barrier, compared to 11% of non-disabled people. An 'existing health condition' was reported by nearly 14% of the disabled sample as a barrier to meeting close contacts.

Figure 4.2 Barriers to meeting close contacts



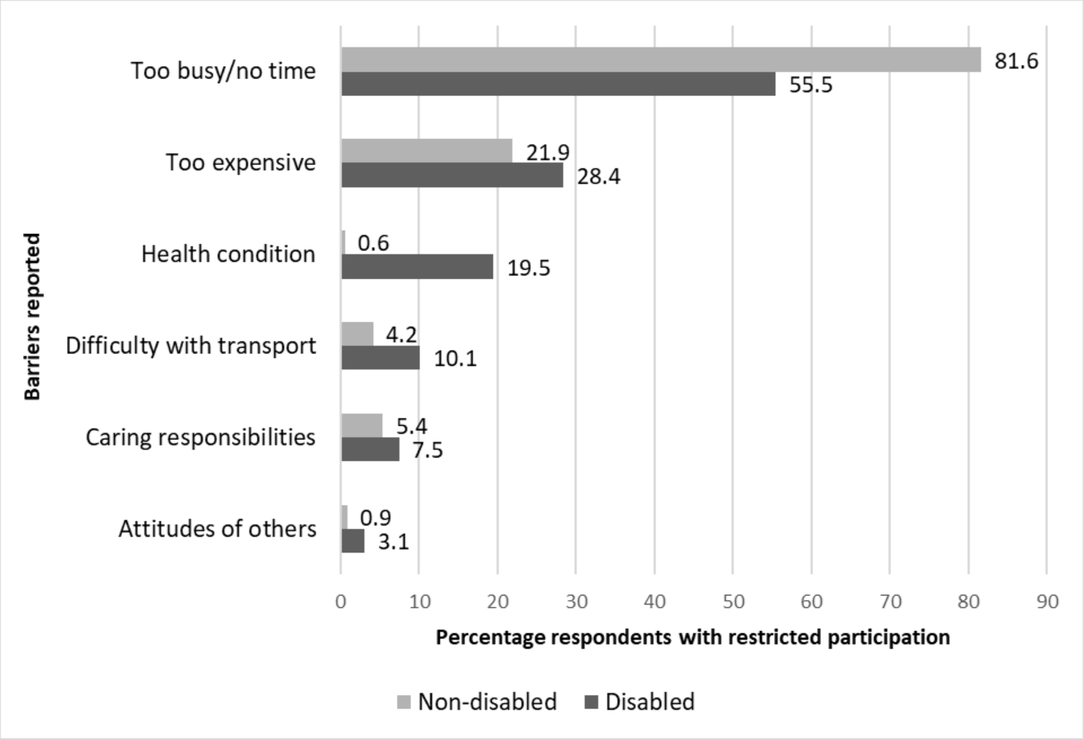
Sample sizes: disabled n=1,580, non-disabled n=4,081

4.4.2. The informal domain: barriers to meeting friends and family

Figures 4.3 and 4.4 present barriers reported to meeting friends and family. Appendix 2 presents the full set of barriers collected on this participation domain together with adjusted Chi-square results testing whether disabled and non-disabled respondents reported significantly different barriers to participation (Tables A.2.3 and A.2.4, pp. 291-92). The results suggest that there were significant differences in the percentages of disabled versus non-disabled respondents reporting barriers to participation across the top six most frequently reported barriers.

Similar patterns of barriers were reported to meeting friends and family, as those to meeting close contacts. 'No time' was the most frequently reported barrier to meeting friends, followed by 'expenses' for both disabled and non-disabled people. The presence of a 'health condition' were reported as a barrier to meeting friends by nearly 20% of disabled people (Figure 4.3), whilst 'difficulty with transport' were reported by 10%. A minority of non-disabled participants (around 3%) reported 'difficulties with transport' and 'caring responsibilities' as barriers to meeting their friends.

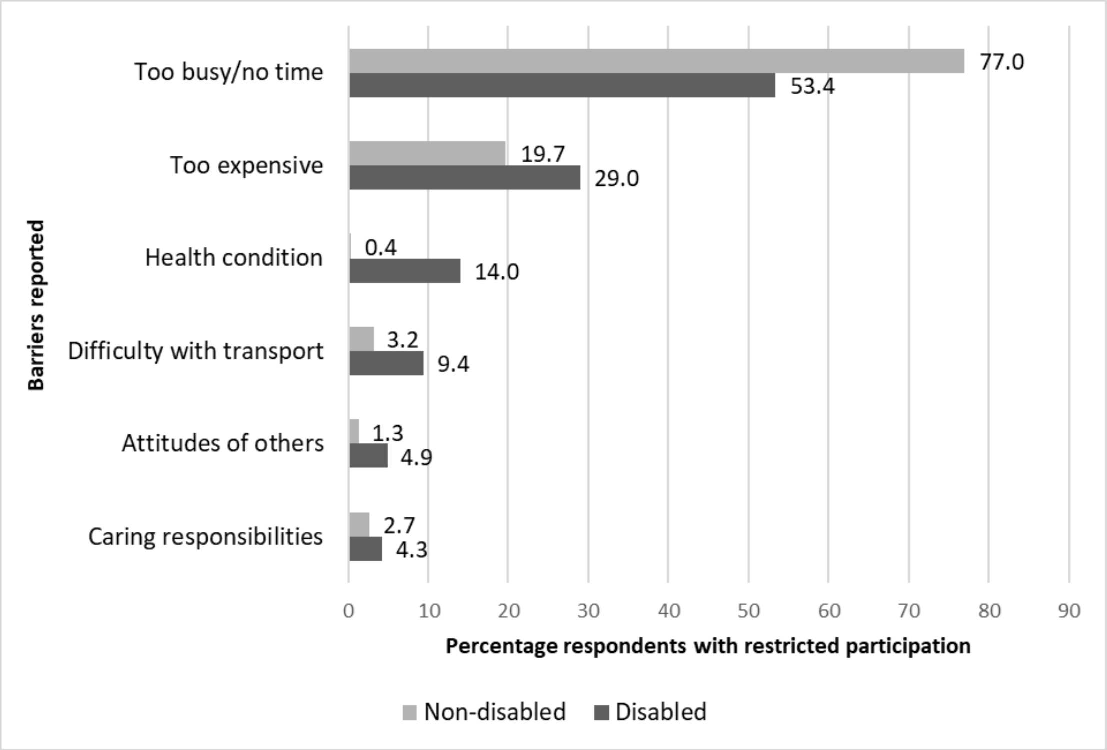
Figure 4.3 Barriers to meeting friends



Sample sizes: disabled n=2,104, non-disabled n=4,081

The presence of a ‘health condition’ was reported by relatively fewer disabled people (14%) as a barrier to meeting family, compared to meeting friends (19.5%) (Figure 4.4). ‘Caring responsibilities’ were reported by slightly more disabled respondents as a barrier to meeting friends (7.5%) compared to meeting family (4.3%), a trend mirrored by the non-disabled group.

Figure 4.4 Barriers to meeting family



Sample sizes: disabled n=1,883, non-disabled n=5,332

4.4.3. The formal domain: barriers to education and employment

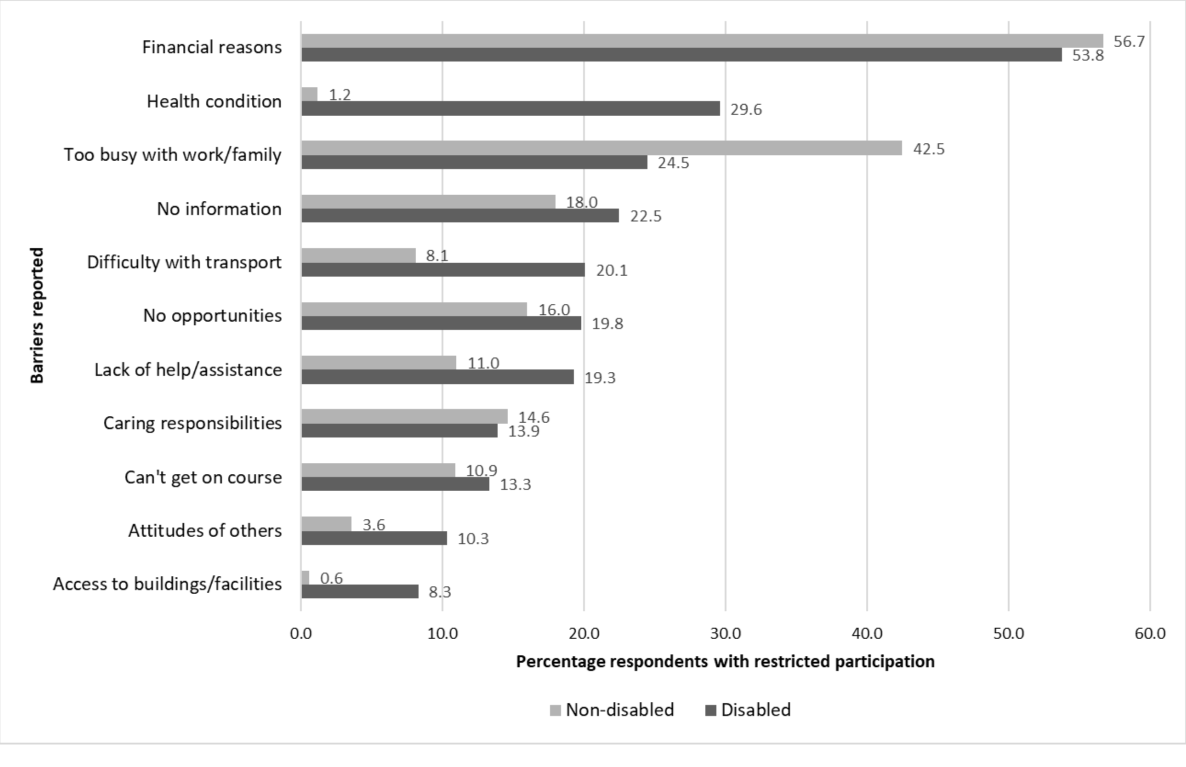
Figures 4.5 and 4.6 present commonly reported barriers to participation in education and employment. For the full list of barriers collected by the LOS on this participation domain, please refer to Tables A.2.5 and A.2.6 in Appendix 2 (pp. 293-94). Compared to the intimate and informal participation domains, the barriers reported on the formal domain were more numerous and diverse.

Education

Financial reasons were the most often reported barrier to participation in education (Figure 4.5). Over half of both disabled and non-disabled samples reported a financial barrier to education, with no statistically significant difference between the two groups (for Chi-square results, refer to Table A.2.5 in Appendix 2, p. 293). Other barriers to education reported by disabled and non-disabled people with no statistically significant difference, were ‘lack of opportunities’, ‘not being able to get on a course’, and ‘caring responsibilities’.

The second most often reported barrier to participation in education was a ‘health condition’ for disabled participants (29%) and ‘too busy with work or family’ for non-disabled people (42.5%). Compared to non-disabled people, disabled respondents were significantly more likely to report barriers to education stemming from social environmental factors, for example ‘no information’ (23%), ‘lack of help’ (19%) and the ‘attitudes of others’ (10%) (Figure 4.5). They were also significantly more likely to report barriers posed by the physical environment and infrastructure, for example ‘difficulties with transport’ (20%) and ‘difficulty with accessing buildings and facilities’ (8%).

Figure 4.5 Barriers to participating in education



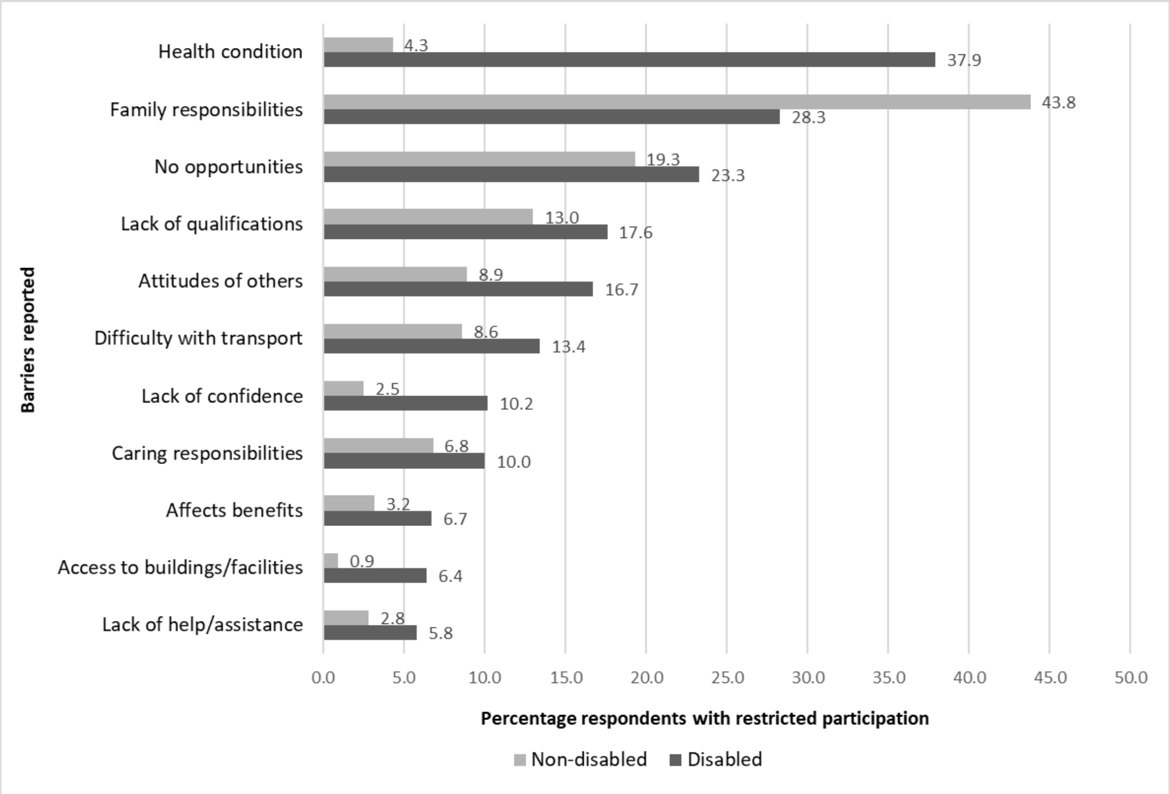
Sample sizes: disabled n= 1,130, non-disabled n=1,776

Employment

The most frequently reported barrier to participation in employment among disabled people was an existing ‘health condition’ (38%), whilst for non-disabled participants it was ‘family responsibilities’ (44%) (Figure 4.6). Nearly a quarter of disabled people with restricted participation in employment reported ‘no opportunities’ as a barrier, compared to one fifth of non-disabled people. The Chi-square results, presented in table A.2.6 in Appendix 2, indicate that ‘Lack of qualifications’ and ‘attitudes of others’ were reported as barriers to employment at significantly higher rates across the disabled group than in the non-disabled group (Table A.2.6, p. 294).

Over 10% percent of disabled people reported ‘lack of confidence’ as a barrier to participating in employment, compared to 2.5% of non-disabled people. Whilst not commonly identified as a barrier to employment, disabled adults were significantly more likely than non-disabled adults to report employment ‘affecting benefits’ as a barrier to participating in paid work (6.7% versus 3.2%) (Appendix 2, Table A.2.6, p. 294).

Figure 4.6 Barriers to employment

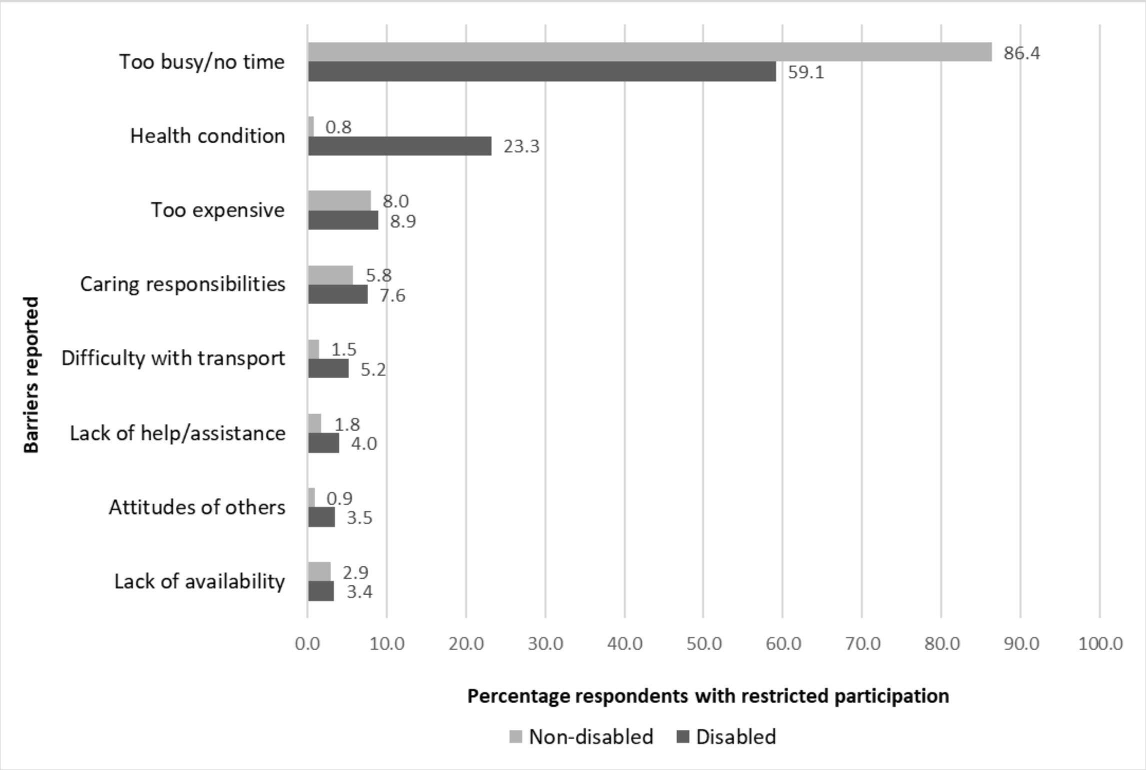


Sample sizes: disabled n=1,179, non-disabled n=2,844

4.4.4. The community domain: barriers to volunteering and sport activities

Figures 4.7 and 4.8 present barriers to participation in volunteering and sport. For the full list of barriers collected by the LOS on the community participation domain, please refer to Tables A.2.7 and A.2.8 in Appendix 2. The most frequently reported barrier to volunteering was ‘too busy/no time’ by both disabled (59%) and non-disabled people (86%). Nearly a quarter of disabled respondents (23%) also reported a ‘health condition’ as a barrier to volunteering. Social and physical environmental barriers to volunteering, such as ‘difficulty with transport’, ‘lack of help/assistance’ and the ‘attitudes of others’ were significantly more likely to be reported by disabled participants (Appendix 2, Table A.2.7, p. 295). There were no significant differences in the percentage of disabled and non-disabled respondents reporting ‘expenses’, ‘caring responsibilities’ and ‘lack of availability’ as barriers to volunteering (Appendix 2, Table A.2.7, p. 295).

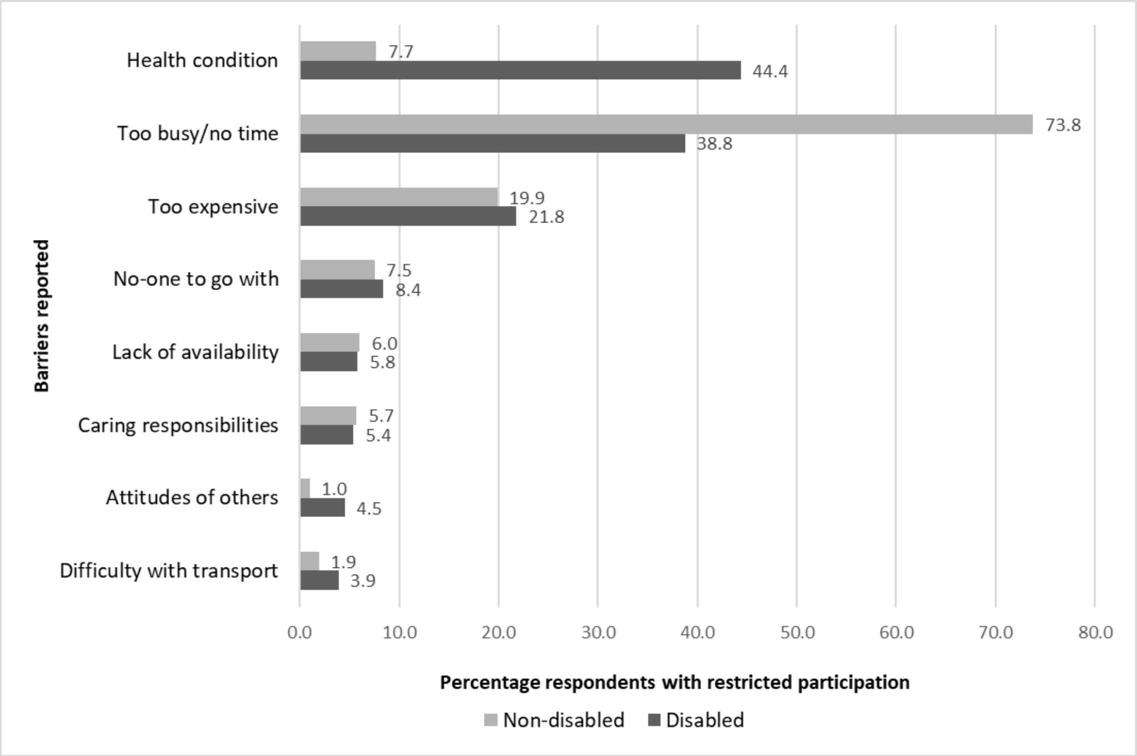
Figure 4.7 Barriers to volunteering



Volunteering: disabled n=1,724, non-disabled n=5,318

A ‘health condition’ was the most frequently reported barrier to sport by disabled people (44%), followed by ‘too busy/no time’ (38%). In contrast, the top two barriers to sport activities among non-disabled people were ‘no time’ (74%) and ‘too expensive’ (22%). There were no significant differences between disabled and non-disabled people in reporting ‘expenses’, ‘no-one to go with’, ‘lack of availability’ and ‘caring responsibilities’ as barriers to engaging in sport activities. A minority of disabled people reported ‘attitudes of others’ and ‘difficulty with transport’ as barriers to sport activities.

Figure 4.8 Barriers to sport activities



Sport: disabled n=1,732, non-disabled n=5,027

4.5. Discussion

The aim of the analyses reported in this chapter was to explore differences in participation rates and barriers to participation between disabled and non-disabled people, using data collected by Wave 1 of the Life Opportunities Survey. This section evaluates the findings.

4.5.1. The LOS Wave 1 sample

The sample characteristics of the LOS Wave 1 disabled population reflect ONS population estimates. Disabled respondents were on average slightly older than non-disabled people, comprised of slightly more women and were also more likely to be divorced, unemployed, or not working due to a disability. A significantly larger proportion of people in the disabled sample reported financial difficulties than those in the non-disabled group (for Chi-square results refer to the tables in Appendix 2, p. 290). These differences in socio-demographic characteristics might underlie some of the differences in participation rates and barriers to participation reported between the two groups.

The difference in average age between the disabled and non-disabled sample might account for some of the differences between the two samples in expressing an interest in participation. The results of the sensitivity analyses suggest that with each year increase in age, respondents were less likely to express an interest in participating in most life areas except for meeting family members (Table 4.6, p.112). This entails that if the disabled sample is on average older than the non-disabled sample, a relatively higher proportion of them will show no interest in social participation. This should be borne in mind when comparing rates of 'disinterest' between the two samples, but it does not affect the validity of the findings in relation to participation restrictions and barriers to participation.

The disabled sample contained slightly more women compared to the non-disabled sample (56% vs 53%). The sensitivity analysis indicates that women were more likely to be interested in participation across most life areas than men (except for employment and sport) (Table 4.6, p. 112). This entails that restricted participation might disproportionally affect disabled women, especially in the intimate (i.e.: meeting close connections) and informal domains (i.e.: meeting friends and family). This finding will have implications for those trying to formulate and target social interventions to facilitate the social participation of disabled people in these life areas.

Irrespective of age or gender, disabled participants were significantly less likely to express an interest in participation across all life areas except for volunteering (Table 4.6, p. 112). This finding needs further exploration because disinterest may result from a perceived lack of choice due to the presence of persistent barriers to participation. For example, a disabled person on a low income might not think it viable to take part in a social activity that they would have to pay for. In addition, evidence suggests, that encountering stigma and negative social attitudes relating to disability affect disabled people's self-esteem and confidence leading to reduced participation in a range of activities (Kissow, 2015; Shandra, 2017). Further research is necessary to investigate the underlying reasons for disabled people's relative lack of interest in social participation.

4.5.2. Participation rates and restrictions

There were consistent differences between disabled and non-disabled respondents in terms of their participation rates and reported restrictions to participation. Across every life area, disabled people reported higher rates of restricted participation compared to non-disabled people.

Close contacts, friends, and family

In the Wave 1 LOS, disabled young people (aged 16-24) reported the highest levels of participation restriction to meeting close contacts and employment across all age groups (Figure 4.1). These results are concerning, because the social relationships formed in the intimate and formal network layers contribute to both the structural and qualitative aspects of social connectedness. The intimate network layer is the main source of emotional support, and it plays an important role in the development of personal identity and the preservation of psychological and emotional well-being (Hall & Wellman, 1985). Engagement in employment is associated with the formal participation domain which is linked to social roles that shape one's perceptions of their social status. Ties in the formal network layer are vital sources of appraisal and information support and may contain bridging ties which provide access to opportunities embedded in others' social networks (Hall & Wellman, 1985). Recent government statistics indicate that since the LOS survey was undertaken, young disabled adults continue to face social exclusion in the UK, evidenced by the high rates of self-reported loneliness and mental health difficulties prevalent among this population group (Office for National Statistics, 2023).

Employment and education

The largest difference in participation restrictions between disabled and non-disabled people were found on the formal participation domain of education and employment. These findings reflect disabled people's historically poorer education and employment outcomes compared to the rest of the population (Berthoud, 2011; Dimakos et al., 2016).

The LOS wave 1 data was collected in 2009-10 and it estimated a 51% employment rate for the working age disabled population compared to 75% for non-disabled people (Table 4.3). The latest equivalent Labour Force Survey estimates are 53% and 82% respectively (Office for National Statistics, 2022b), suggesting that disabled people's access to the labour market has only improved slightly in the intervening years and their participation in employment is still far behind that of non-disabled people.

Additionally, over a quarter of disabled participants (27%) did not feel that they were in the position to seek employment (responded with 'N/A' to whether they participated in work), and 15% of them expressed no interest in employment (Table 4.4). These findings are concerning because employment plays both a direct and indirect role in social connectedness. Interacting with others in the workplace is an important source of social connections and stable earnings enable participation in social activities outside formal settings.

Another concern with regards to employment participation is the large disparity between disabled and non-disabled people among the younger age groups. In the Wave 1 LOS dataset, 17% more disabled people experienced restricted participation in employment compared to non-disabled people both in the 16 to 24 and the 26 to 44 age groups (Figure 4.1). These findings constitute a major concern and are in line with current government statistics which recorded the lowest rates of educational attainment and the highest rates of unemployment among young disabled populations in 2021 (Office for National Statistics, 2022b).

4.5.3. Commonly reported barriers in the LOS

The LOS collected barriers to participation relating to a range of environmental factors and personal characteristics. The results suggest that only 6 to 10 of the full list of LOS barriers

(16 in total) were regularly reported by more than 3% (or 50 observations) of the samples with restricted participation. (For the full list of barriers that the LOS collected data on for each life area, please refer to tables A.2.2 to A.2.8 in Appendix 2.) The top two most often reported barriers to participation were ‘too busy/no time’ and ‘expenses’ for both disabled and non-disabled participants. Disabled participants also frequently reported an existing ‘health condition’ as a barrier to participation. Table 4.7 (p. 128), focusing on the disabled sample only, presents the barriers reported by at least 50 disabled people with restricted participation for each life area. Barriers that were not reported by significantly more disabled people compared to non-disabled people are shaded in grey.

Formal and community domains

There were no significant differences in the numbers of disabled and non-disabled people reporting ‘expenses’, ‘caring responsibilities’ and ‘lack of opportunities’ as barriers to participation in the formal (i.e.: education and employment) and community domains (i.e.: volunteering and sport activities) (For Chi-square results refer to tables A.2.5 to A.2.8 in Appendix 2, pp. 293-296). The reason for this could be that certain segments of the population may encounter very similar barriers to participation based primarily on their demographic characteristics (i.e.: age and gender), irrespective of their disability status.

Significantly higher proportions of disabled respondents reported a ‘health condition’, ‘lack of qualifications’, ‘lack of confidence’ and ‘attitudes of others’ as barriers to employment compared to the non-disabled group (Table A.2.6 in Appendix 2). Reporting ‘lack of qualifications’ as a barrier to employment reflects disabled people’s relatively poorer educational outcomes (Department for Education, 2022), whilst ‘attitudes of others’ and ‘lack of confidence’ point to unfavourable labour market conditions. Disabled people are more likely to work in insecure, temporary, or casual jobs (Honey et al., 2014) and elementary and service occupations (Office for National Statistics, 2022b). These types of employment often do not offer flexible working arrangements and disability friendly working environments (Holland & Clayton, 2020; Honey et al., 2014; Schur et al., 2017). Inflexible working hours may hinder disabled people’s ability to take care of their health care needs and attend medical appointments which is why an existing ‘health condition’ may become a barrier to employment. Moreover, there is evidence suggesting that disabled people internalise ableist attitudes and institutional discrimination, which are manifested in lowered self-esteem and confidence, leading to reduced rates of participation in a range of life areas, including employment (van Asselt-Goverts et al., 2018).

Financial considerations, such as ‘effect on benefits’, was as a barrier to employment participation reported by 6.7% of disabled people, compared to 3.2% of non-disabled people out of those experiencing participation restrictions in this life area. This finding supports previous evidence that suggests that the post-financial crisis social security system in the UK provides limited government support and reduced access to benefits for disabled people (Jones et al., 2017). Young disabled people were shown to be especially at risk of restricted participation in employment because of fear of losing benefit income (Lindsay, 2011).

Intimate and informal domains

In the intimate and informal domains of meeting close contacts, friends, and family, ‘no time’ and ‘expenses’ were reported as the top two barriers by disabled people and non-disabled people alike. At the same time, significantly more disabled people cited ‘expenses’ as a barrier and significantly more non-disabled people reported ‘lack of time’ as a barrier to participation in these domains (Figures 4.2 to 4.4 and Tables A.2.2 to A.2.4, pp. 290-92). This finding aligns with the literature review, which suggests that disabled people are more likely to experience low household income and in-work poverty resulting in financial limitations to participation in leisure activities (Badia et al., 2011; Merrells et al., 2018). There is also evidence in the literature that disabled people use time differently to non-disabled people, which suggests that ‘lack of time’ covers a different set of meanings when reported by disabled people compared to non-disabled populations (Eklund et al., 2009; Oi, 1991; Pagan, 2013). Restricted participation in the informal domain due to limited finances and lack of time, place disabled people at risk of not being able to build or maintain their intimate and informal social networks which are important sources of emotional and instrumental support (Chapter 1).

Table 4.7 Barriers reported by at least 3% of disabled populations across each life area

	Close contact	Friends	Family	Education	Employment	Volunteering	Sport
ENVIRONMENTAL FACTORS							
Social environment							
Costs/ affects benefits	✓	✓*	✓*	✓*	✓	✓	✓*
Attitudes of others		✓	✓	✓	✓	✓	✓
Lack of opportunities				✓	✓*	✓	✓
Lack of information				✓			
Lack of help/ assistance				✓	✓	✓	✓
Physical environment							
Difficulty with transport	✓	✓	✓	✓	✓	✓	✓
Difficulty accessing buildings/facilities				✓	✓		
PERSONAL FACTORS							
Socio-economic							
Others have no time	✓*						
No-one to meet/ go with						✓	✓
Lack of time/ family responsibilities	✓*	✓*	✓*	✓*	✓*	✓*	✓*
Caring responsibilities	✓	✓	✓	✓	✓	✓	✓
Lack of qualifications					✓		
Can't get on a course				✓			
Mental health							
Lack of confidence					✓		
Physical health							
Health condition	✓	✓	✓	✓*	✓*	✓*	✓*

Cells shaded in grey indicate that the percentage of disabled people reporting the barrier is not significantly different to non-disabled populations (for Chi-square test results refer to Appendix 2).

*Reported by over 25% of disabled people experiencing participation restriction in the given life area.

4.5.4. The meaning of time and health in disabled populations

The finding that ‘too busy/no time’ and ‘health condition’ are the most frequently reported barriers to participation by disabled populations is worth further exploration. ‘Lack of time’ is the barrier that is reported most frequently by non-disabled populations, between 74% and 86% of non-disabled people report it as a barrier to participation in the intimate, informal and community domains (compared to ca. 40%-60% of disabled people). ‘Health condition’ is nearly exclusively only reported by (14%-44% of) disabled people as a barrier to participation across all life areas. Although reported across all life areas, these two barriers are under-specified in the LOS. It is not clear what they mean or whether they are interpreted differently by disabled and non-disabled people. This is a very important point to raise because in order to successfully remove barriers to the social participation of disabled people, one must seek to understand the nature and underlying sources of these.

The literature reviewed in Chapter 2 suggests that time use and disability are closely interlinked (Oi, 1991). There is evidence that disabled populations use time differently to non-disabled populations in at least three main ways. The first of these is self-care, which includes the time taken up by the daily management of a health condition and the attendance of healthcare related appointments (Pagan-Rodriguez, 2014; Pagan, 2013). The second difference in time consumption between disabled and non-disabled populations concerns rest and recovery time (Eklund et al., 2009; Shandra, 2017). Most people with a chronic health or developmental condition experience significant amounts of fatigue following engagement in a social activity, hence they require extra time both to prepare and to recover from participation. Finally, some disabilities cause functional limitations which may lead to an extended length of time to complete activities of daily living (Oi, 1991).

In future surveys of disability, framing questions about time use within the context of a wider understanding of how the presence of an impairment affects daily functioning would aid the generation of data that was fit for the purpose of tackling time-related barriers to participation. Survey questions could cover areas around time spent on self-care, rest and recovery, and the length of time spent on completing tasks of daily living. Data collection in relation to ‘health condition’ could also be refined with a focus on the ways in which an impairment may impact respondents’ energy levels and daily functioning.

4.5.5. Limitations to the LOS survey

Limited data on barriers to participation

There are several barriers present in the literature review that were absent from the LOS (see Chapter 2, Figure 2.2, p. 78). Apart from the above discussed time and health barriers, there are factors across the social, physical environments and personal characteristics that could have been included or better specified in the LOS.

The LOS barrier ‘attitudes of others’, in the literature referred to as ‘negative social attitudes’ is a concept that covers a myriad of different behaviours that might not have been recognised by respondents under this heading. The literature review identifies the following types of negative attitudes: bullying, discrimination, lack of awareness, ignorance, assumptions, unfavourable policies and practices, and barriers of omission (i.e.: not making provisions necessary for disabled people’s inclusion) (Bingham et al., 2013; Hastbacka et al., 2016; Schur et al., 2017; Shandra, 2017).

‘Lack of opportunities’ is a barrier that plays different roles across different life domains. On the domain of employment for example, lack of opportunities may mean access to ‘unsuitable employment’ or ‘insecure/temporary/low-paid employment’ (Bates et al., 2017). On the domain of volunteering, lack of opportunities may be present in the form of organisational structures characterised by low disability awareness that do not provide supported opportunities to disabled populations (Shandra, 2017).

‘Difficulties using transport’ and ‘difficulty accessing buildings’ were also LOS barriers that were reported by fewer respondents than what would be expected based on the literature review and government statistics (Beauchamp-Pryor, 2012; Department for Transport, 2023; Hastbacka et al., 2016). A possible reason for the underreporting of these environmental barriers could be that they are only encountered once a person leaves their home environment. Some disabled people may never encounter these barriers because they may not feel able to leave their homes due to other barriers, for example financial considerations or lack of appropriate activities in their local area. In addition, recent research suggests that barriers to using transport may relate to a complex set of conditions, comprising of elements that make up the entire journey chain (Park & Chowdhury, 2022).

These elements include navigating the built environment to a stop or station, boarding the vehicle, journey time, getting off at the appropriate stop, and navigating to the destination. A social or environmental barrier encountered at any stage of the journey chain will make it less likely that the journey will be repeated again (Park & Chowdhury, 2022). Further research is necessary to identify the barriers within journey chains that are likely to be encountered by people with different types of disabilities.

Sample limitations due to the LOS sampling strategy

Another possible reason for the low numbers of people reporting certain barriers to participation which are otherwise well-evidenced in the literature is the lack of LOS data on some impairment types. The LOS was sampled to reflect the demographic structure of the UK population, which led to the underrepresentation of people with minority characteristics, both in relation to race/ethnicity and in relation to impairment types. In the LOS, the majority of disabled sample reported a pain impairment (3,887) or a motor disability (1,772) (Table 4.2, p. 105). Other impairment types were relatively underrepresented in the sample. This entails that barriers to participation encountered by ethnic minorities and disabled people with less prevalent impairment types were underrepresented in the LOS data.

Likewise, the age distribution of the LOS reflected population estimates. This entails an underrepresentation of young people who are known to be vulnerable to unemployment and mental health disability (Honey et al., 2011; Honey et al., 2014; Lindsay, 2011). Recent ONS statistics indicate that mental health impairment and neurological conditions are on the rise in the UK population, and people with these impairment types face the most complex and multiple disadvantages across all areas of life (Office for National Statistics, 2022b). By not oversampling these populations, the LOS failed to collect vital data on barriers to the participation of the most vulnerable groups in society. The LOS was promoted as a ‘longitudinal survey of disability’ but unfortunately with its adherence to reflect ‘population estimates’ it failed in its goal to highlight barriers to participation across all disability groups.

Limitations relating to the identification of neurodevelopmental conditions

The LOS was based on the social model of disability, which meant that it collected data related to functional impairments instead of diagnostic labels. This made it difficult to identify people with neurodevelopmental conditions in the dataset. Neurodevelopmental conditions may involve functional limitations across a range of bodily and mental functions (see Chapter 7). This makes the symptomology of neurodevelopmental conditions fundamentally different from impairments that are limited to bodily functions only. Autism and other related neurodevelopmental conditions affect daily functioning in a range of contexts that encompass both the physical and social environment. Because of this complexity of neurodevelopmental conditions, it is not beneficial to collect data on each functional impairment related to these conditions separately. Moreover, it could be argued that it would be a more respectful and less medicalised approach to ask a survey respondent if they had a neurodevelopmental condition, than to ask them to report separately any ‘behavioural’, ‘social’, ‘learning’, or ‘intellectual’ impairments. Labelling a certain type of neurological functioning as a ‘social’ or ‘behavioural’ impairment is language use that inherently represents majority values and perpetuates negative perceptions of autism spectrum conditions.

Next, the findings from this chapter are used to build a barrier typology describing different barrier profiles present in the disabled sample. In addition, Chapter 5 will also explore if distinct barrier profiles are associated with risk factors deriving from personal demographic and health characteristics.

Chapter 5. Barrier profiles characterising restricted participation in the LOS

5.1. Introduction

This chapter reports findings from an analysis of the LOS which sought to answer two of the research questions set out at the start of the quantitative study. Firstly, it describes the patterns of barriers that were commonly experienced by disabled populations in the LOS across the intimate, informal, formal, and community participation domains. Secondly, it explores the demographic and health characteristics that made it more likely for someone to experience a certain type of barrier profile.

5.1.1. Visualisation of the results

As described in Chapter 3 (Section 3.7.4, p. 100), Latent Class Analyses (LCA) were performed in each life area to identify systematic patterns of barriers reported by those with restricted participation. The LCA was run several times, applying 1 to 4 class solutions and choosing the model of best fit based on a combination of statistical diagnostic criteria (see Chapter 3, Section 3.7.3, p. 97) and theoretical considerations. The latent classes resulting from these analyses are from here on referred to as ‘barrier profiles’. Each barrier profile was comprised of conditional probabilities representing the proportion of people likely to report a type of barrier within the given profile. To aid the visualisation of the results, the conditional probabilities were transformed to express *the share of an individual barrier relative to all other barriers* likely to be reported within the profile. The conditional probabilities and the LCA model diagnostics are presented in Appendix 3 (p. 297). Logistic regressions were used to test whether personal demographic and health characteristics were significantly associated with different barrier profiles (Chapter 3, Table 3.6, p. 102).

5.2. The intimate participation domain

This section presents the barrier profiles characterising restricted participation in meeting close contacts and explores the demographic and health-related personal characteristics that were associated with each barrier profile in the LOS. The LOS calibration weight was used to estimate the numbers of people in the UK population with different barrier profiles for each participation domain.

5.2.1. Barrier profiles: meeting close contacts

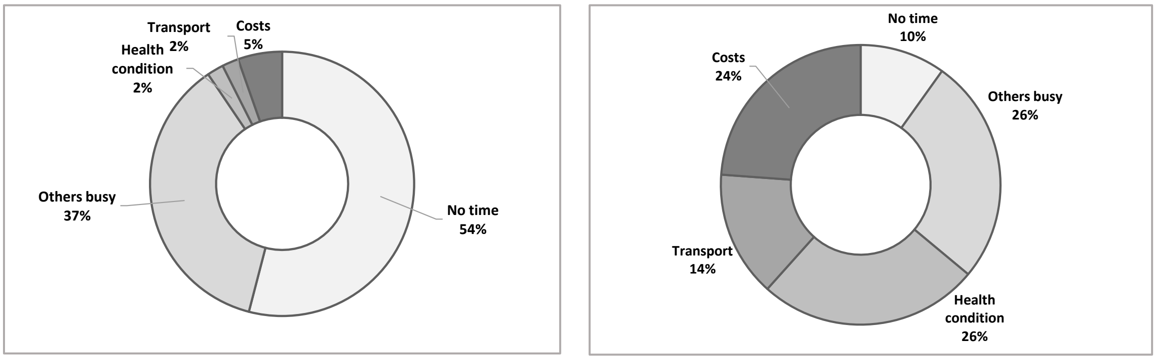
The latent class model with the three class solution was identified as having the best classification quality in the life area of meeting close contacts, with substantial overlap in the barriers likely to be reported in two out of the three classes (Figure 5.1 and Appendix 3, Section A3.1 p. 297).

The most dominant barrier profile reported by nearly 80% (n=1,232) of people with restricted participation in this life area comprised of primarily time related barriers (Figure 5.1a). Besides reporting ‘no time’ and ‘others busy’, only a minority of respondents within this profile were likely to report ‘costs’, ‘difficulty with transport’, and a ‘health condition’ as barriers to participation in the intimate domain. Population estimates (using the LOS calibration weight) suggest that over 1.5 million disabled people had a time driven barrier profile to meeting close contacts at the time of data collection.

About a fifth of respondents (n=317) had a barrier profile that comprised of barriers from multiple environmental and personal sources (Figure 5.1b). Social and physical environmental barriers like ‘costs’ and ‘difficulty with transport’ made up around one third of the barriers likely to be reported within this profile, whilst personal factors, such as ‘no time’, ‘others busy’ and ‘a health condition’ made up the rest of the two thirds of the barriers to meeting close friends and family. Population estimates suggest that approximately 411,900 disabled people experienced this combination of barriers to meeting intimate contacts at the time that the LOS data was collected.

A small minority of respondents with restricted participation in this life area were assigned to a barrier profile that was driven by a similar combination of multiple barriers as described previously, but without a ‘health condition’ being one of these (Figure 5.1c). These participants were nearly equally likely to report four main barriers to meeting their close contacts, which consisted of ‘no time’, ‘other people busy’, ‘financial reasons’ and ‘difficulty with using transport’. Although in the LOS this group had a very low sample size (n=31), the LCA model diagnostics (Appendix 3, Tables A3.1, A3.2, p.297) and the average latent class probabilities indicating likely latent class membership (in MPLUS output) suggested that the three-class solution had the best classification quality compared to the 2 and 4 class solutions. However, beyond solely statistical considerations, the identified profiles were deemed valid also on theoretical grounds (Weller 2020). It was conceivable that there was a minority of disabled participants reporting multiple social and environmental barriers (Figure 5.1.c) to their participation without reporting a health condition as a barrier, who were sufficiently different (in terms of their demographic and health characteristics) to a relatively larger number of disabled people who reported multiple restrictions together with a health condition as barriers to participation (Figure 5.1b). Applying the LOS calibration weight suggests that the estimated UK population size of this group was 40,640 people.

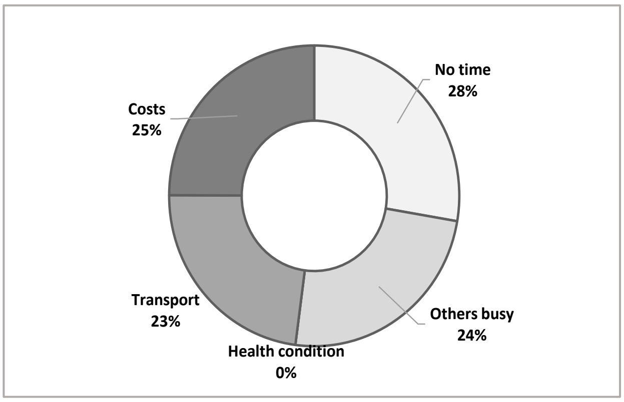
Figure 5.1 Barrier profiles characterising restricted participation to meeting close contacts*



a. Time driven **b. Multiple barriers with health**

n=1,232 Estimated population size=1,600,000 n=317 Estimated population size= 411,900

c. Multiple barriers without health



n=31 Estimated population size= 40,640

*Percentages indicate the relative contribution of a barrier in relation to other barriers reported within a profile.

Personal characteristics

Table 5.1 presents the results of logistic regression analyses testing the likelihood of membership of a barrier profile based on one’s demographic and health characteristics.

Respondents who had a time driven barrier profile to meeting close contacts (Figure 5.1a) were significantly more likely to be aged over 45 compared to under 25. People with this profile were also significantly less likely to report pain as a comorbid impairment and were more likely to report impairments that were mild in severity.

Respondents with a barrier profile driven by multiple barriers with a health condition (Figure 5.1b) were significantly more likely to have reported a pain or mental health comorbidity, and a medium to high severity impairment compared to respondents with the other two barrier profiles. They were also over 3 times as likely to report the presence of a primary mental health impairment than not.

The minority of participants with the barrier profile driven by multiple barriers without a health condition (Figure 5.1c), were significantly more likely to be young adults (aged 16-24) than middle aged or older adults. Respondents with this profile were also significantly more likely to be of Black or Black British ethnic background (compared to White), and over 5 times more likely to report a sensory impairment, and over 17 times more likely to report mental health as a primary impairment compared to any other impairments. At the 95% of confidence interval, this group were also statistically more likely to have a primary pain impairment or report pain as a comorbidity than not.

Table 5.1 Intimate domain: association of personal characteristics with barrier profiles

Barrier profiles (Sample size)	**Multiple barriers with health (Figure 5.1b)** (n= 317)	**Multiple barriers without health (Figure 5.1c)** (n=31)	**Time driven (Figure 5.1a)** (n=1,232)
Age (Reference category: 16 – 24 years)			
25 to 44 years	0.80	**0.22*****	1.70*
45 to 64 years	0.74	**0.07*****	**2.04*****
Gender (Reference category: Male)			
Female	0.93	0.93	1.07
Ethnicity (Reference category: White)			
Asian/Asian British	1.05	2.12	0.85
Black/Black British	0.72	**19.88*****	0.70
Dependent child (Reference category: no dependent child)			
Yes	0.85	1.24	1.15
Impairment types (Reference category: impairment not present)			
Sensory	0.86	**5.84*****	0.96
Motor	1.35	1.15	0.71*
Neurodevelopmental	1.34	1.89	0.66*
Breathing	1.48	0.61	0.69
Pain (Reference category: no pain impairment)			
Pain only	0.76	6.78**	0.97
Pain comorbidity	**1.68*****	4.84**	**0.53*****
Mental health (Reference category: no mental health impairment)			
Mental health only	**3.52*****	**16.97*****	**0.24*****
Mental health comorbidity	**2.83*****	4.18**	**0.32*****
Impairment severity (Reference category: Level 1 = least severe)			
Level 2	3.20**	0.54	0.51*
Level 3	**5.51*****	0.13**	**0.34*****
Level 4	**11.45*****	0.26	**0.16*****
Constant	0.04*** F(17, 1544)=11.60, p<0.001	0.02*** F(17, 1544)=4.64 p<0.001	12.40*** (F17, 1544)=11.85 p<0.001

Odds ratios, ***p<0.01, **p<0.05, *p<0.1

5.3. The informal participation domain

This section presents the LCA and regression results describing the types of restricted participation in the life areas of meeting friends and family. For the LCA model diagnostics please refer to Section A 3.2. (p. 298) in Appendix 3.

5.3.1. Barrier profiles: meeting friends

Based on LCA model diagnostics, the 3-class solution had the best classification quality (Appendix 3, Section A3.2.1, p. 298) and it also had good theoretical interpretability. There were three distinct barrier profiles characterising restricted participation to meeting friends: a time driven, a health driven, and a cost driven barrier profile (Figure 5.2).

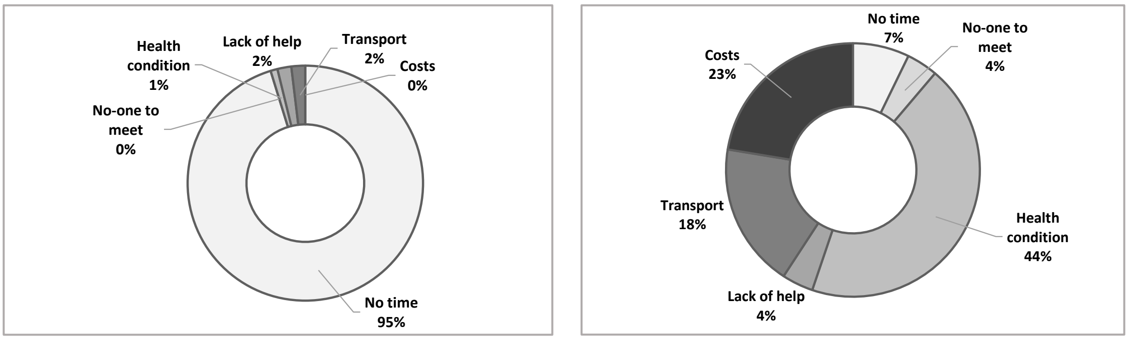
Just under half of respondents (n=980) experiencing restrictions to meeting their friends reported not having time as their primary barrier (Figure 5.2a), representing an estimated 1.2 million disabled people in the UK population at the time of data collection. Environmental barriers (such as ‘difficulty with transport’ and ‘lack of help’) and an existing ‘health condition’ made up only a small (5%) proportion of barriers reported within this profile. Cost considerations, and not having anyone to meet were not reported as barriers by people with this profile.

Nearly a third of respondents with restricted participation in meeting their friends had a health driven barrier profile (Figure 5.2b, n=647) with an estimated population size of over 800,000. Over 40% of the barriers reported within this profile related to a ‘health condition’ as a barrier to meeting friends, followed by ‘costs’ and ‘difficulties with transport.’ Relatively rarely reported barriers within this profile related to ‘no time’, ‘no-one to meet’ and ‘lack of help’.

About a quarter of disabled people (n=478) with restricted participation in meeting friends had a cost driven barrier profile, that was dominated by financial restrictions (63% of total barriers likely to be reported), followed by ‘no time’ (31%) (Figure 5.2c). None of the participants with a cost driven profile were likely to report a ‘health condition’ as a barrier to meeting friends, and a minority reported ‘difficulties with transport’ as restricting their participation in this life area.

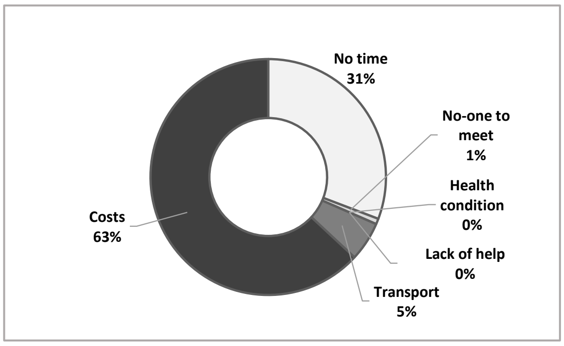
Figure 5.2 Barrier profiles characterising restricted participation to meeting friends

a. Time driven **b. Health driven**



n=980 Estimated population size= 1,267,000 n=647 Estimated population size= 835,700

c. Cost driven



n= 478, Estimated population size= 617,200

*Percentages indicate the relative contribution of a barrier in relation to other barriers reported within a profile.

Personal characteristics

Table 5.2 presents the results of the logistic regression analyses examining whether certain health and socio demographic characteristics were more likely to be observed in different barrier profiles.

Those with a time driven barrier profile (Figure 5.2a) were significantly more likely to be female, half as likely to be of Asian or Asian British ethnicity than White, and significantly less likely to report a motor or mental health impairment or comorbidity than other impairments. They were also significantly more likely to report a mild severity impairment than a high severity impairment.

Those with a health driven barrier profile (Figure 5.2b) were significantly more likely to be of an Asian or Asian British ethnic background (compared to White) and over a third less likely to live with children. They were also significantly more likely to report a motor impairment or a mental health comorbidity than other impairments; and they were 8 times more likely to report a high severity (level 4) of impairment than a mild severity impairment. Respondents with the cost driven barrier profile (Figure 5.2c) were significantly more likely to be young adults (16-24) and they were slightly less likely to be female or to report a primary pain impairment ($p<0.05$). Health characteristics did not significantly predict membership of this latent class.

Table 5.2 Meeting friends: association of personal characteristics with barrier profiles

Barrier profiles (Sample size)	**Health driven** **(Figure 5.2b)** (n= 647)	**Cost driven** **(Figure 5.2c)** (n= 478)	**Time driven** **(Figure 5.2a)** (n= 980)
Age (Reference category: 16 - 24 years)			
25 to 44 years	1.75**	**0.43*** **	1.50
45 to 64 years	1.81**	**0.43*** **	1.46
Gender (Reference category: Male)			
Female	0.98	0.76**	**1.32*** **
Ethnicity (Reference category: White)			
Asian/Asian British	**2.14*** **	1.26	**0.43*** **
Black/Black British	1.46	0.53	1.15
Dependent child (Reference category: no dependent child)			
Yes	**0.65*** **	1.08	1.30**
Impairment types (Reference category: impairment not present)			
Sensory	1.12	0.80	0.97
Motor	**2.22*** **	0.77*	**0.53*** **
Neurodevelopmental	1.50**	0.80	0.72*
Breathing	1.40*	1.02	0.61**
Pain (Reference category: no pain impairment)			
Pain only	0.66**	0.66**	1.34*
Pain comorbidity	1.01	1.07	0.87
Mental health (Reference category: no mental health impairment)			
Mental health only	1.60	1.28	**0.49*** **
Mental health comorbidity	**2.27*** **	1.13	**0.34*** **
Impairment severity (Reference category: Level 1 = least severe)			
Level 2	**2.15*** **	1.45*	**0.55*** **
Level 3	**3.34*** **	1.29	**0.45*** **
Level 4	**8.09*** **	0.99	**0.17*** **
Constant	0.05***	0.68	1.68*
	F(17, 2032)=20.21	F(17, 2032)=2.60	F(17, 2032)=18.34
	P<0.001	P<0.001	P<0.001

Odds rations, ***p<0.01, **p<0.05, *p<0.1

5.3.2. Barrier profiles: meeting family

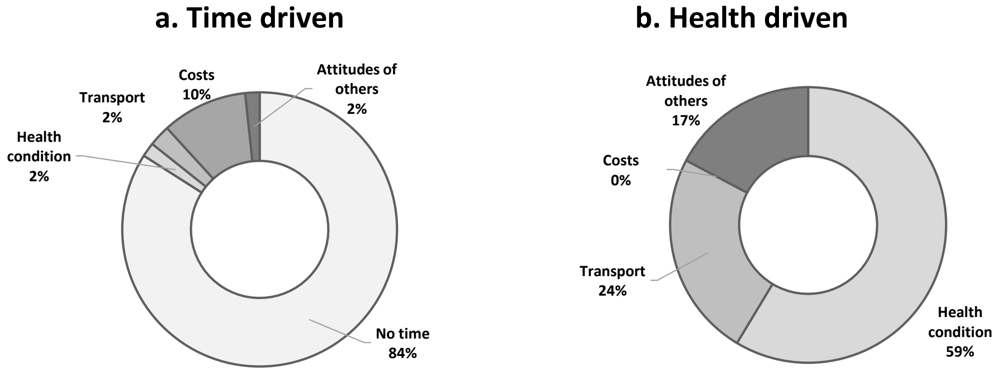
The LCA results suggested that the 3-class solution provided the best classification quality (entropy=0.95, Lo-Mendell Rubin $p < 0.001$) in this life area (Appendix 3, Section A3.2.2, p. 300). The three types of barrier profiles identified, also had theoretical applicability when describing restricted participation to meeting family. One profile was driven by time-related barriers, one by an existing health condition and one by cost considerations.

Over a half of respondents reporting restrictions to meeting their family had a time driven barrier profile (Figure 5.3a, n=982). Lack of time constituted over 80% of barriers reported within this profile, whilst 10% of barriers related to financial considerations and a small minority of barriers related to the 'attitudes of others', 'a health condition', and 'difficulties with using transport'.

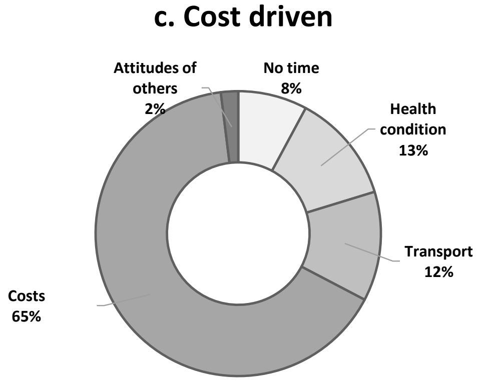
Around a quarter of respondents with restricted participation in this life area had a health driven barrier profile (Figure 5.3b, n=496). People with this profile were also likely to report 'difficulties with using transport' and the 'attitudes of others' as barriers to meeting family. Financial considerations and lack of time were not reported as barriers to meeting family by those with a health driven barrier profile.

About another quarter of respondents reporting restrictions to meeting their family had a cost driven barrier profile (Figure 5.3c). Most (over 60%) of the barriers reported by people with this barrier profile related to 'costs.' A quarter of all barriers comprised of 'difficulty with using transport' and 'a health condition'. Lack of time and the 'attitudes of others' were relatively rarely reported barriers by those in this profile.

Figure 5.3 Barrier profiles characterising restricted participation to meeting family



n=982, Estimated population size= 1,272,000 n=496, Estimated population size= 642,400



n=405, Estimated population size= 525,200

*Percentages indicate the relative contribution of a barrier in relation to other barriers within a profile.

Personal characteristics

Table 5.3 presents the results of logistic regression analyses, testing whether time driven, health driven and cost driven barrier profiles to meeting family were likely to be experienced by people with different demographic and health characteristics.

Being assigned to a time driven barrier profile (Figure 5.3a) was most closely associated with the presence of dependent children in the household. People in this profile were significantly unlikely to report a motor impairment, or a mental health comorbidity and they were also significantly unlikely to have an impairment with a severity level of 3 or above.

Respondents in the health driven profile (Figure 5.3b) were significantly more likely to report a motor impairment, a mental health comorbidity and a high severity impairment than other types of impairments. In terms of demographic characteristics, people with this barrier profile were significantly unlikely to have dependent children.

Respondents in the cost driven profile (Figure 5.3c) were also likely to report a high severity impairment or a mental health comorbidity, but being in this profile was not associated with reporting a motor impairment. In terms of demographic characteristics, the results indicate that people with a cost driven barrier profile were more likely to come from a Black or Black British ethnic background but because of sample size limitations this finding needs further testing.

Table 5.3 Meeting family: association of personal characteristics with barrier profiles

Barrier profiles (Sample size)	**Health driven (Figure 5.3b)** (n= 496)	**Cost driven (Figure 5.3c)** (n= 405)	**Time driven (Figure 5.3a)** (n= 982)
Age (Reference category: 16 - 24 years)			
25 to 44 years	0.93	0.69	1.44
45 to 64 years	1.38	0.68	1.07
Gender (Reference category: Male)			
Female	1.23*	0.85	0.95
Ethnicity (Reference category: White)			
Asian/Asian British	1.83**	1.19	0.52**
Black/Black British	0.86	2.32**	0.50*
Dependent child (Reference category: no dependent child)			
Yes	**0.65*** **	0.92	**1.47*** **
Impairment types (Reference category: impairment not present)			
Sensory	1.29	0.72*	0.96
Motor	**1.76*** **	1.00	**0.58*** **
Neurodevelopmental	1.12	0.95	0.87
Breathing	1.03	0.93	0.99
Pain (Reference category: no pain impairment)			
Pain only	0.86	0.69*	1.19
Pain comorbidity	0.98	0.93	1.02
Mental health (Reference category: no mental health impairment)			
Mental health only	1.49	1.18	0.59*
Mental health comorbidity	**1.98*** **	**1.79*** **	**0.28*** **
Impairment severity (Reference category: Level 1 = least severe)			
Level 2	1.14	1.34	0.81
Level 3	1.78**	1.92**	**0.46*** **
Level 4	**2.94*** **	**2.17*** **	**0.22*** **
Constant	0.13***	0.28***	2.27***
	F(17, 1815)=11.57	F(17, 1815)=3.54	F(17, 1815)=16.71
	P<0.001	P<0.001	P<0.001

Odds ratios, ***p<0.01, **p<0.05, *p<0.1

5.4. The formal participation domain

This section describes the barrier profiles characterising restricted participation in the life areas of education and employment. In the formal domains, participants were more likely to report a larger set of barriers than in the intimate and informal domains, resulting in complex barrier profiles.

5.4.1. Barrier profiles: participation in education

Based on LCA model diagnostics and theoretical sense, the 3-class solution had the best classification performance compared to the 2 and 4-class LCA models (Appendix 3, Section A 3.3.1., p. 301). Figure 5.4 presents the three barrier profiles identified in the disabled sample with restricted participation in education.

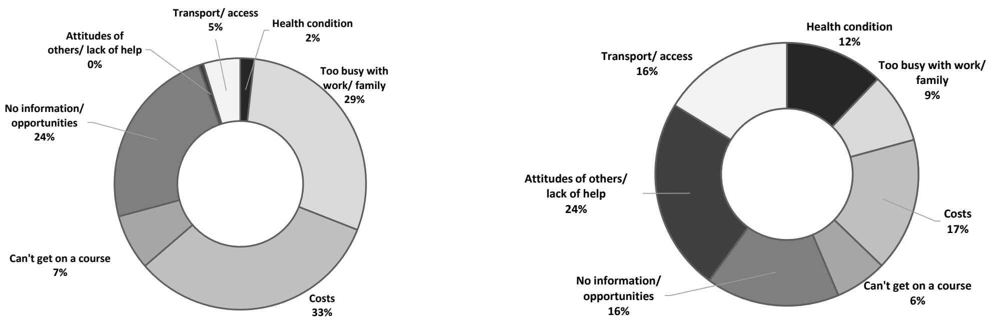
Around 60% of respondents with restricted participation in education had a cost and time driven barrier profile (Figure 5.4a, n=702), representing an estimated number of 928,700 disabled people in the UK. About a third of all barriers reported in this profile related to ‘costs’, another third related to lack of time due to being ‘too busy with work or family’, and another third involved environmental barriers including ‘no information and opportunities’, and ‘difficulties with transport’. An existing ‘health condition’, ‘attitudes of others’ and ‘lack of help’ were least likely to be reported by respondents with this barrier profile.

Around a fifth of respondents experienced a barrier profile driven by multiple environmental barriers (Figure 5.4b, n=223). Respondents with this profile were most likely to report a combination of social and environmental barriers to participating in education. Social barriers included ‘attitudes of others’, ‘lack of help’, ‘costs’ and ‘no information and opportunities.’ Physical environmental barriers included ‘difficulties with transport’ and ‘difficulties with accessing buildings.’ The presence of a ‘health condition’ also played a role in restricting the participation of this group, making up over 12% of all barriers reported. Applying the calibration weight to the data suggests, that approximately 295,200 disabled people in the UK experienced multiple environmental barriers to education at the time of data collection.

Around another fifth of disabled people with restricted participation in education experienced a health driven profile (Figure 5.4c, n=204), representing approximately

270,100 people in the UK population. Respondents in this profile were most likely to report ‘a health condition’ as a barrier to participation in this life area, followed by barriers in the physical environment, such as ‘difficulties with transport’ and ‘difficulties accessing buildings.’ Social environmental barriers, such as the costs associated with education, ‘lack of information’, ‘no opportunities’, ‘lack of help’ and the ‘attitudes of others’ made up around half of all barriers reported by people in this profile. People with a health driven barrier profile were least likely to report ‘too busy with work or family’ as a barrier to participating in education.

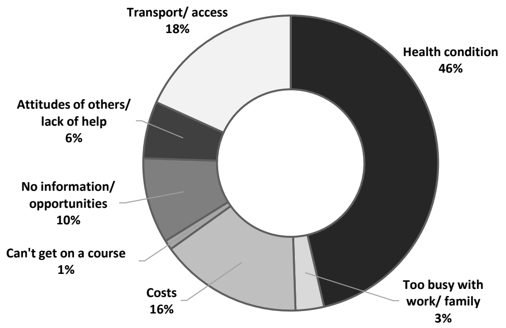
Figure 5.4 Barrier profiles characterising restricted participation to education



a. Cost and time driven **b. Multiple environmental barriers**

n=702 Estimated population size= 928,700 n=223 Estimated population size= 295,200

c. Health driven



n=204 Estimated population size= 270,100

* Percentages indicate the relative contribution of a barrier in relation to other barriers within a profile.

Personal characteristics

Table 5.4 reports the demographic and health characteristics most likely to be associated with the barrier profiles identified above.

Respondents with the cost and time driven barrier profile (Figure 5.4a) were most likely to report mild severity impairments and not to report a motor impairment or mental health comorbidity. Demographic characteristics were not significantly associated with having this barrier profile.

The demographic and health characteristics included in the regression model were not significantly associated with membership of the barrier profile driven by multiple environmental barriers (Figure 5.4b). The results suggest that having a Black or Black British ethnic background, reporting a breathing impairment or a pain comorbidity had a weak association with being assigned to this barrier profile, but the results were only significant at the 90% confidence interval. The low sample size of this group (n=223) limited the robustness of the findings.

The health driven barrier profile (Figure 5.4c) was most likely to be experienced by respondents with a motor impairment and/or a mental health comorbidity compared to other impairments. Respondents in this barrier profile were also significantly unlikely to have dependent children in their household.

Table 5.4 Education: association of personal characteristics with barrier profiles

Barrier profiles	**Health driven (Figure 5.4c)**	**Multiple environmental (Figure 5.4b)**	**Cost and time driven (Figure 5.4a)**
(Sample size)	(n= 204)	(n= 223)	(n= 702)
Age (Reference category: 16 - 24 years)			
25 to 44 years	1.27	1.02	0.86
45 to 64 years	1.90*	0.76	0.85
Gender (Reference category: Male)			
Female	0.82	0.85	1.29
Ethnicity (Reference category: White)			
Asian/Asian British	1.36	0.60	1.17
Black/Black British	0.79	2.13*	0.61
Dependent child (Reference category: no dependent child)			
Yes	**0.45*** **	1.35	1.23
Impairment types (Reference category: impairment not present)			
Sensory	0.92	1.12	0.89
Motor	**2.77*** **	1.13	**0.41*** **
Neurodevelopmental	0.75	1.05	1.10
Breathing	1.10	1.65*	0.52**
Pain (Reference category: no pain impairment)			
Pain only	0.44*	0.55*	1.70*
Pain comorbidity	0.60**	1.54*	0.95
Mental health (Reference category: no mental health impairment)			
Mental health only	0.55	0.92	1.10
Mental health comorbidity	**3.35*** **	1.35	**0.30*** **
Impairment severity (Reference category: Level 1 = least severe)			
Level 2	3.78	1.20	0.66
Level 3	6.33*	1.09	0.55
Level 4	7.81**	2.08	**0.27*** **
Constant	0.02***	0.14***	6.13***
	F(17, 1076)=7.83 P<0.001	F(17, 1076)=3.86 P<0.001	F(17, 1076)=11.09 P<0.001

Odds ratios, ***p<0.01, **p<0.05, *p<0.1

5.4.2. Barrier profiles: participation in employment

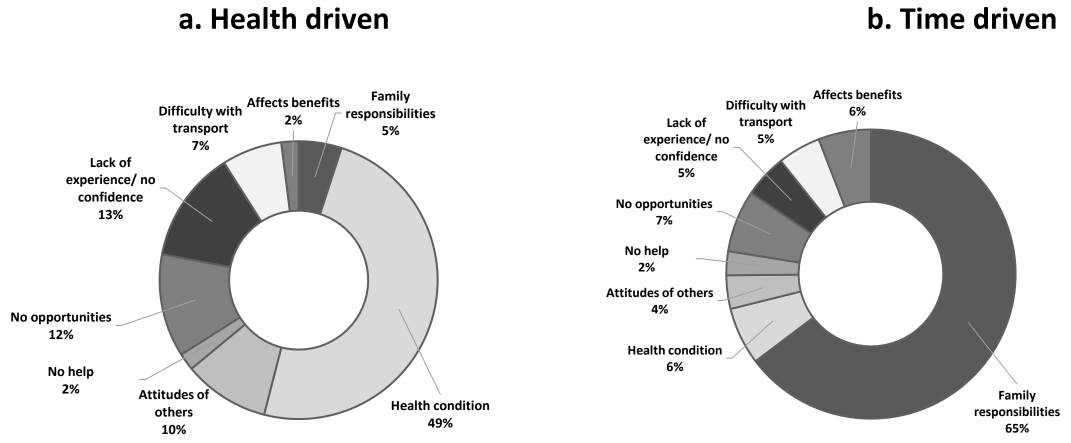
In the life area of employment, the 3-class LCA model had the best fit statistics compared to the 2 and 4-class models (Entropy=0.82, Lo-Mendell Rubin p<0.01) (Appendix 3, Section A 3.3.2, p. 302). The three barrier profiles followed the broad pattern established previously, namely a health-driven and a time-driven barrier profile characterising the restricted participation of relatively large numbers of people, and a smaller group of disabled respondents who were likely to have a more complex, multiple barrier profile. Figure 5.5 presents the three main types of barrier profiles characterising participation restrictions in employment.

Over 60% of disabled respondents reporting restrictions to participating in employment had a health driven barrier profile (Figure 5.5a, n=713), representing approximately 923,100 people in the UK population at the time of data collection. Nearly half of all barriers reported by those with a health driven barrier profile related to a ‘health condition.’ Around a quarter of the barriers in this profile related to social environmental barriers, including ‘attitudes of others’, ‘no opportunities’ and ‘difficulties with transport’; whilst around a fifth related to personal circumstances and attributes, such as ‘lack of experience/confidence’ and lack of time due to ‘family responsibilities.’

About a fifth of respondents with restricted employment participation had a time driven barrier profile (Figure 5.5b, n=264), with an estimated UK population size of over 300,000. For respondents with a time driven barrier profile in the life area of employment, ‘family responsibilities’ constituted the largest proportion of all barriers reported. Respondents in this profile were the least likely to report social environmental barriers such as the ‘attitudes of others’, ‘no help’, ‘affects benefits’ and ‘lack of opportunities’ as barriers to their participation in employment out of the three barrier profiles. ‘Lack of experience’ and ‘no confidence’ were also less prevalent barriers within this profile compared to the other two profiles.

A minority of respondents (ca 17%) reported complex multiple personal and environmental barriers to participation in employment (Figure 5.5c, n=202). Personal attributes, health status and demographic characteristics made up around half of all barriers reported in this profile. Personal barriers included ‘lack of experience and lack of confidence’, ‘family responsibilities' and 'a health condition.' The second half of all barriers in this profile originated from the social environment, including 'no opportunities', 'attitudes of others', and 'lack of help'. Based on weighted data, over a quarter of a million disabled adults were likely to have this barrier profile to employment at the time of data collection.

Figure 5.5 Barrier profiles characterising restricted participation to employment



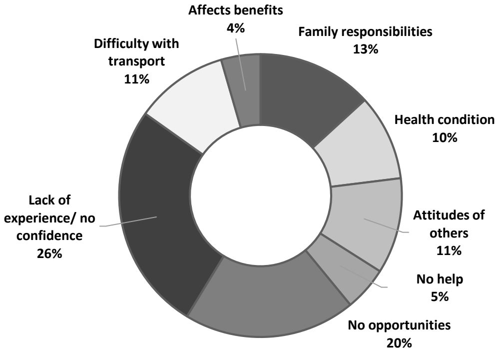
a. Health driven

n=713, Estimated population size= 923,100

b. Time driven

n=264, Estimated population size= 341,900

c. Multiple personal and environmental barriers



n=202, Estimated population size=260,900

* Percentages indicate the relative contribution of a barrier in relation to other barriers within a profile.

Personal characteristics

Table 5.5 presents the results of the logistic regression analyses examining whether certain health and socio demographic characteristics were more likely to be observed in the different barrier profiles described above.

Respondents with a health driven barrier profile (Figure 5.5a) were significantly more likely to be male and significantly less likely to have a dependent child in their household. They were also significantly unlikely to report a neurodevelopmental condition, or a mental health impairment or comorbidity compared to other impairments.

People with a time driven barrier profile (Figure 5.5b) were significantly more likely to be aged 25 to 44 (than under 25), nearly five times more likely to be female and over 10 times more likely to look after a dependent child. People in this group were very unlikely to report a high severity impairment.

Respondents with a barrier profile characterised by multiple personal and environmental barriers (Figure 5.5c), were over twice as likely to have a neurodevelopmental impairment, over four times more likely to report a primary mental health impairment, and twice as likely to report a mental health comorbidity than other impairment types. In terms of demographic characteristics, there was a weak association with being male and younger than 45 years old within this profile.

Table 5.5 Employment: association of personal characteristics with barrier profiles

Barrier profiles	**Health driven (Figure 5.5a)**	**Multiple personal and environmental (Figure 5.5c)**	**Time driven (Figure 5.5b)**
(Sample size)	(n= 713)	(n= 202)	(n= 264)
Estimated population size	*923,100*	*260,900*	*341,900*
Age (Reference category: 16 - 24 years)			
25 to 44 years	0.76	0.64	**4.80*****
45 to 64 years	1.17	0.53**	3.12**
Gender (Reference category: Male)			
Female	**0.52*****	0.65**	**4.85*****
Ethnicity (Reference category: White)			
Asian/Asian British	0.87	1.23	1.06
Black/Black British	0.45	1.96	1.29
Dependent child (Reference category: no dependent child)			
Yes	**0.23*****	0.98	**10.10*****
Impairment types (Reference category: impairment not present)			
Sensory	0.66*	1.08	1.72*
Motor impairment	1.40	0.77	0.73
Neurodevelopmental	**0.50*****	**2.19*****	0.85
Breathing	1.15	0.68	1.28
Pain (Reference category: no pain impairment)			
Pain only	0.64*	1.07	1.79*
Pain comorbidity	0.66**	1.55*	1.25
Mental health (Reference category: no mental health impairment)			
Mental health only	**0.19*****	**4.08*****	1.85
Mental health comorbidity	**0.58*****	**1.97*****	0.98
Impairment severity (Reference category: Level 1 = least severe)			
Level 2	1.21	1.07	0.75
Level 3	1.64*	0.96	0.53**
Level 4	1.85*	1.26	**0.28*****
Constant	5.84*** F(17, 1137)= 11.23 P<0.001	0.25*** F(17, 1137)= 3.34 P<0.001	0.01*** F(17, 1137)= 13.49 P<0.001

Odds ratios, *** p<0.01, ** p<0.05, * p<0.1

5.5. The community participation domain

This section presents the LCA and regression results describing the types of restricted participation in the life areas of volunteering and sport activities.

5.5.1. Barrier profiles: participation in volunteering

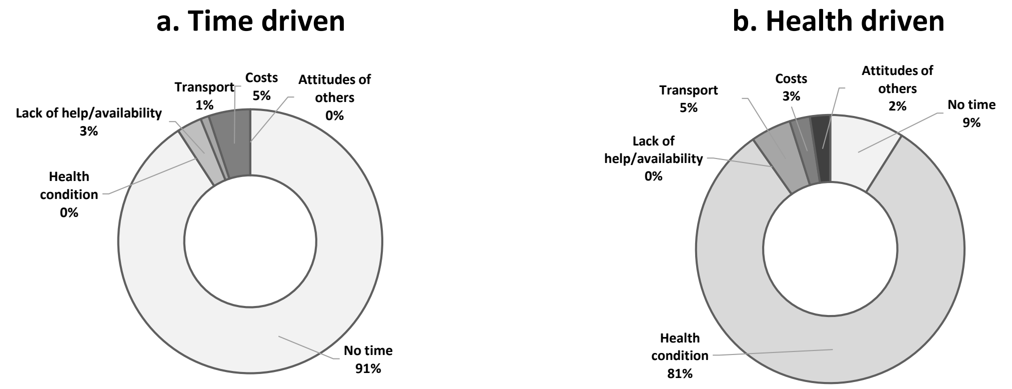
Although LCA model diagnostics for the 2-class solution were slightly better than that of the 3-class solution, based on theoretical applicability, the decision was taken to choose the 3-class solution to represent the final set of barrier profiles in the life area of volunteering (Appendix 3, Section A 3.4.1., p. 304). The 2-class model identified a time- and a health-driven barrier profile, but the 3-class solution also distinguished a smaller, third group of disabled people who were likely to report a complex set of personal, physical, and social environmental barriers to participation. Figure 5.6 presents the three barrier profiles identified in the disabled sample with restricted participation in volunteering.

Nearly 70% of respondents reporting restrictions to participation in volunteering had a time driven barrier profile (Figure 5.6a, n=1,157), representing approximately 1.5 million disabled people in the UK population at the time of data collection. People with a time driven barrier profile were unlikely to report a 'health condition' as a barrier to volunteering and social environmental barriers such as the 'attitudes of others', 'costs', 'lack of help' and 'lack of availability' only made up a small proportion of all barriers in this profile (Figure 5.6).

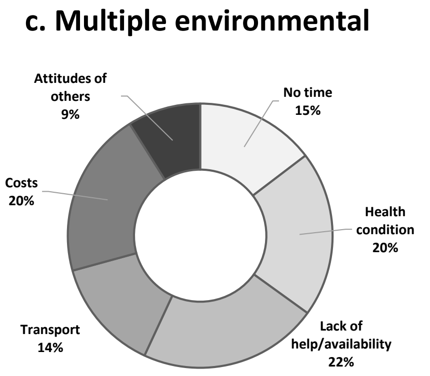
About a fifth of people with restricted participation in volunteering had a health driven barrier profile (Figure 5.6b, n=348), representing nearly half a million disabled people in the UK population. People with a health driven barrier profile were likely to report – besides 'a health condition' – 'no time' and 'too expensive' as barriers to volunteering.

A little over ten percent of those with restricted participation in this life area (Figure 5.6c, n=220) had a barrier profile that was characterised by multiple barriers that were primarily of environmental nature. Around a third of all barriers in this profile related to a 'health condition' and 'no time', whilst approximately two-thirds related to the social and physical environments, including 'costs', 'lack of help/availability', 'difficulties with transport' and the 'attitudes of others.' Although a relatively small number of respondents were assigned to this barrier profile in the disabled sample, applying the calibration weight to the data suggests that approximately 290,700 people in the UK population experienced this combination of barriers to volunteering at the time of data collection.

Figure 5.6 Barrier profiles characterising restricted participation to volunteering



n=1,157 Estimated population size= 1,528,000 n=348 Estimated population size= 459,200



n=220 Estimated population size= 290,700

* Percentages indicate the relative contribution of a barrier in relation to other barriers within a profile.

Personal characteristics

Table 5.6 presents the results of logistic regression analyses, testing whether time driven, health driven and multiple environmental barrier profiles to volunteering were likely to be experienced by people with different demographic and health characteristics.

The results indicate that those with the time driven barrier profile (Figure 5.6a) were significantly unlikely to report a motor impairment or mental health comorbidity and were significantly more likely to report impairments with mild severity. People in this group were likely to have dependent children in their household.

Disabled people with the health driven barrier profile in the life area of volunteering (Figure 5.6b) were significantly more likely to be in the oldest age group (45 to 64), they were over twice as likely to report a motor impairment than other impairments, and they were significantly more likely to report a high severity (level 4) impairment than a mild impairment. People with this profile were also significantly likely to report a pain or mental health comorbidity.

People experiencing multiple barriers to volunteering (Figure 5.6c) were significantly more likely to be aged 16 to 24 years old than in the oldest age category. Some weak associations were found between reporting a mental health comorbidity and relatively high severity levels of impairment and having this barrier profile, but because of the low sample size, these results are not very robust.

Table 5.6 Volunteering: association of personal characteristics with barrier profiles

Barrier profiles (Sample size)	**Health driven (Figure 5.6b)** (n= 348)	**Multiple barriers (Figure 5.6c)** (n= 220)	**Time driven (Figure 5.6a)** (n= 1,157)
Age (Reference category: 16 - 24 years)			
25 to 44 years	1.69	0.59*	1.22
45 to 64 years	**2.66*****	**0.37*****	1.18
Gender (Reference category: Male)			
Female	1.00	0.93	1.05
Ethnicity (Reference category: White)			
Asian/Asian British	1.08	1.39	0.75
Black/Black British	0.27*	1.12	2.15
Dependent child (Reference category: no dependent child)			
Yes	0.73*	0.83	1.40**
Impairment types (Reference category: impairment not present)			
Sensory	**0.51*****	0.99	1.58**
Motor	**2.14*****	0.93	**0.53*****
Neurodevelopmental	0.94	1.23	0.83
Breathing	1.42	0.91	0.70
Pain (Reference category: no pain impairment)			
Pain only	0.54**	0.64*	1.46
Pain comorbidity	**1.66*****	0.80	0.76*
Mental health (Reference category: no mental health impairment)			
Mental health only	2.09*	0.43	0.87
Mental health comorbidity	**2.70*****	1.53**	**0.32*****
Impairment severity (Reference category: Level 1 = least severe)			
Level 2	3.13**	1.86*	0.47**
Level 3	**5.94*****	2.31**	**0.28*****
Level 4	**13.30*****	2.83**	**0.11*****
Constant	0.01*** F(17, 1658)=17.04 P<0.001	0.17*** F(17, 1658)=3.25 P<0.001	7.76*** F(17, 1658)=19.07 P<0.001

Odds ratios, *** p<0.01, ** p<0.05, * p<0.1

5.5.2. Barrier profiles: participation in sport activities

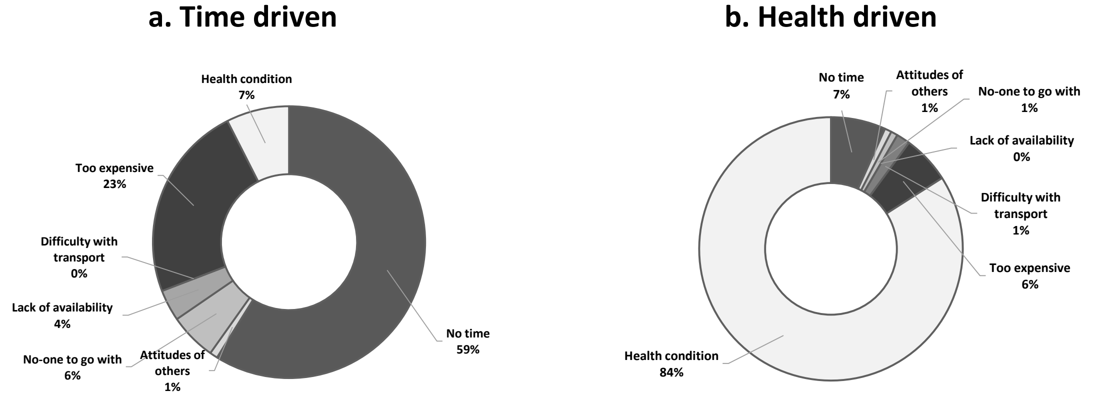
In the life area of sport activities, the LCA model diagnostics suggested similar classification quality for the 2-class and 3-class solutions (Appendix 3, Section A 3.4.2, p.306). After examining the conditional probabilities associated with each class, the decision was taken to choose the 3-class solution because the distribution of barriers across the three classes suggested the presence of three distinct barrier profiles (Figure A.3.7, p. 307). Figure 5.7 presents these three barrier profiles identified across the disabled sample with restricted participation in sport activities.

Over half of respondents with a participation restriction in sport activities had a time driven barrier profile (Figure 5.7a, n=898), representing over 1 million of disabled people in the UK population at the time of data collection. Time restrictions made up over half of all barriers reported in this profile, followed by 'costs.' The presence of a 'health condition' and 'lack of availability' constituted a smaller proportion of barriers. Other people's attitudes and 'difficulty with transport' were the most rarely reported barriers to participation in sport activities in this group.

Nearly forty percent of respondents with restricted participation in sport activities had a health driven barrier profile (Figure 5.7b, n=688), representing approximately 902,000 disabled people in the population. The presence of a 'health condition' comprised of over 80% of all barriers in this profile. Lack of time and cost considerations were the next most often reported barriers, but they only made up just over 10% of the total barriers reported.

Less than 10% of respondents (Figure 5.7c, n=147) experienced multiple personal and environmental barriers to participating in sport activities, representing an estimated UK population size of 192,600. A little less than half of all barriers in this profile related to personal factors, such as 'not having enough time', a 'health condition' or 'no-one to go with'. Social environmental barriers made up around 40% of all barriers, comprising of 'too expensive', 'lack of availability' and the 'attitudes of others'.

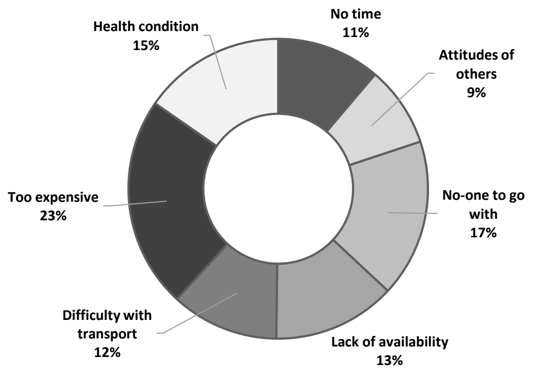
Figure 5.7 Barrier profiles characterising restricted participation to sport


a. Time driven

b. Health driven

n=898 Estimated population size= 1,178,000 n=688 Estimated population size= 902,000

c. Multiple personal and environmental



n=147 Estimated population size= 192,600

* Percentages indicate the relative contribution of a barrier in relation to other barriers within a profile.

Personal characteristics

Table 5.7 reports the demographic and health characteristics most likely to be associated with the barrier profiles identified above.

Respondents with the time driven barrier profile (Figure 5.7a) were significantly likely to be female and to have dependent children. They were also half as likely to have a motor or breathing impairment, or a mental health comorbidity than other impairments, and were significantly more likely to report impairments with mild severity than a high severity impairment.

Participants with a health driven barrier profile (Figure 5.7b) were nearly significantly more likely to be aged 45 to 64 than under 25. They were significantly more likely to be male, and about twice as likely to have reported a motor or breathing impairment than other impairments. Respondents with this profile were also significantly likely to have reported a pain or mental health comorbidity and a high severity impairment compared to a mild impairment.

The minority of respondents who experienced multiple barriers to sport activities (Figure 5.7c) were significantly likely to have reported a neurodevelopmental condition and/or a mental health impairment. In terms of demographic characteristics, the findings suggest that people in the oldest age group were less likely to be assigned to this barrier profile, and that impairment severity did not seem to significantly predict membership of it.

Table 5.7 Sport: association of personal characteristics with barrier profiles

Barrier profiles (Sample size)	**Health driven** **(Figure 5.7b)** (n= 688)	**Multiple barriers** **(Figure 5.7c)** (n= 147)	**Time driven** **(Figure 5.7a)** (n= 898)
Age (Reference category: 16 - 24 years)			
25 to 44 years	1.18	1.01	0.89
45 to 64 years	**1.89*****	0.51**	0.69*
Gender (Reference category: Male)			
Female	**0.70*****	1.13	**1.36*****
Ethnicity (Reference category: White)			
Asian/Asian British	0.78	1.49	1.07
Black/Black British	0.63	1.52	1.30
Dependent child (Reference category: no dependent child)			
Yes	0.75**	0.63*	**1.52*****
Impairment types (Reference category: impairment not present)			
Sensory	0.75	0.77	1.41**
Motor	**2.28*****	0.52**	**0.51*****
Neurodevelopmental	0.69*	**1.93****	1.02
Breathing	**1.94*****	1.10	**0.46*****
Pain (Reference category: no pain impairment)			
Pain only	1.09	0.96	0.90
Pain comorbidity	**1.65*****	1.43	**0.55*****
Mental health (Reference category: no mental health impairment)			
Mental health only	1.09	**3.28****	0.50*
Mental health comorbidity	**1.67*****	1.56	**0.48*****
Impairment severity (Reference category: Level 1 = least severe)			
Level 2	**2.87*****	0.73	**0.49*****
Level 3	**3.23*****	1.02	**0.40*****
Level 4	**3.23*****	1.69	**0.33*****
Constant	0.12*** F(17, 1668)=13.09 P<0.001	0.10*** F(17, 1668)= 3.69 P<0.001	4.13*** F(17, 1668)=13.26 P<0.001

Odds ratios, *** p<0.01, ** p<0.05, * p<0.1

5.6. Discussion

The barrier profiles presented above offer a new insight into the prevalence and patterns of barriers restricting disabled people’s participation across a range of life areas. Overall, the results presented above suggest that restricted participation in each life area is driven by three broad types of barrier profiles, characterised by time driven, health driven and multiple personal and environmental barriers respectively. Although these three broad types of profiles were consistently identified across all life areas, the nature and composition of individual barriers within them varied. There were also differences between the number and characteristics of respondents experiencing each barrier profile across different life areas. Table 5.8 summarises the demographic and health characteristics that were significantly associated with different barrier profiles across each life area, followed by a discussion of the findings.

Table 5.8 Summary of demographical and health characteristics associated with different participation barrier profiles

BARRIER PROFILES	LIFE AREAS						
	Close contacts	Friends	Family	Education	Employment	Volunteering	Sport
Cost/Multiple environmental							
Age	16 – 24 yrs + +	16 – 24 yrs + +				45 – 64 yrs - -	45 – 64 yrs -
Gender		Male +					
Ethnicity	Black + +		Black +				
Dependent children							
Impairment type	Sensory + + MH + +	Pain -			ND + + MH + +		ND + + MH +
Comorbidity			MH + +		MH + +		
Severity of impairment			4 + +			3-4 +	
Health driven							
Age						45 – 64 yrs + +	45 – 64 yrs + +
Gender					Male + +		Male + +
Ethnicity		Asian + +	Asian +				
Dependent children		Yes - -		Yes - -	Yes - -		
Impairment type	MH + +	Motor + +	Motor + +	Motor + +	ND - - MH - -	Sensory - - Motor + +	Motor + + Breathing - -
Comorbidity	MH + + Pain + +	MH + +	MH + +	MH + +	MH - - Pain -	Pain + + MH + +	Pain + + MH + +
Severity of impairment	3-4 + +	3-4 + +	4 + +			3-4 + +	2-4 + +
Time driven							
Age	45 – 64 yrs + +				25 – 44 yrs + +		
Gender		Female + +			Female + +		Female + +
Ethnicity		Asian - -					
Dependent children			Yes +		Yes + +	Yes +	Yes +
Impairment type	MH - -	Motor - -	Motor - -	Motor - -		Motor - -	Motor - - Breathing - -
Comorbidity	MH - - Pain - -	MH - -	MH - -	MH - -		MH - -	Pain - - MH - -
Severity of impairment	3-4 - -	3-4 - -	3-4 - -	4 - -	4 - -	3-4 - -	2-4 - -

Key: p<0.01 Significant positive: + + Significant negative: - -
p<0.05 Weak positive: + Weak negative: -

Abbreviations:
Mental health: MH, Neurodevelopmental: ND

5.6.1. Time driven profiles

The time driven barrier profile was most prevalent across the intimate, informal and community participation domains. Population estimates (using the LOS calibration weight) suggest that over 1 million disabled people experienced a time driven barrier profile across the life areas of meeting close contacts, friends, and family, and participating in volunteering and sport activities, at the time when the LOS data was collected. Respondents with a time driven profile were the least likely to report a ‘health condition’ or physical environmental barriers to their participation out of all barrier profiles.

The relatively high prevalence of the time driven barrier profile across all other types of participation restrictions does not come as a surprise given the findings from the previous chapter. Lack of time was the leading cause of participation restriction in the intimate, informal and community domains, reported by both disabled and non-disabled populations alike (Chapter 4, Section 4.4, p. 115).

The formal participation domains of education and employment were the only life areas where time driven barrier profiles were not the most prevalent among disabled people. The findings in Chapter 4 revealed that in the life areas of education and employment, disabled and non-disabled respondents differed with regards to the frequency with which they reported time related barriers to participation. In the life area of education, ‘costs’ and ‘health condition’ overtook ‘too busy with work/family’ as the most often reported barriers to participation for disabled people. In line with these findings, the most prevalent barrier profile identified by the LCA in this life area was driven by cost and lack of time.

In the life area of employment, the findings from Chapter 4 indicate that ‘family responsibilities’ were the leading barrier to participation restrictions among non-disabled populations, but among disabled people, ‘health condition’ was the most often reported barrier to working restrictions. This finding is reflected in the barrier typology identified in the life area of employment, where most disabled respondents experienced a health driven barrier profile, and the time driven barrier profile was the second most prevalent type of restricted participation.

As discussed previously (Chapter 4, Section 4.5.4, p. 129), time-related barriers to participation were underspecified in the LOS. In the life areas of education and employment, time barriers were defined as ‘too busy with work or family’ and ‘family responsibilities’ respectively, suggesting that the LOS specified ‘lack of time’ in these two life areas. In the intimate, informal and community domains ‘no time’ as a barrier to participation was not further specified and it is likely it takes on a slightly different meaning in each life area. The literature review in Chapter 2 suggests that disabled people use their time differently and spend more time on self-care activities, passive leisure and might take longer to complete activities of daily living (Oi, 1991; Shandra, 2017). Further research is needed to gain a deeper understanding of how the nature of the ‘time barrier’ varies across different life areas and impairment types.

Personal characteristics

Respondents with time driven barrier profiles were the least likely to report a motor impairment or a high severity impairment. Demographic characteristics were only significantly associated with having a time driven barrier profile in the life areas of meeting friends and undertaking employment (Table 5.8, p. 163). In these two life areas, women were significantly more likely to report a time barrier to participation. Having dependent children was also significantly associated with experiencing a time driven participation restriction to employment.

These findings are in line with the literature review in Chapter 2, which suggests that disabled women are more likely to take on the larger share of care giving responsibilities within the household at the cost of participation in employment (Chandola & Rouxel, 2021; Shockley et al., 2017). The LCA results suggest that women’s social participation is not only restricted to the life area of employment, but they are also likely to have a time driven barrier profile to meeting friends. A better understanding of disabled women’s time use and policies targeting family friendly working practices and accessible childcare might be ways of facilitating disabled women’s participation in the informal and formal domains.

5.6.2. Health driven profiles

The health driven barrier profile constituted the second most prominent type of participation restriction across the intimate, informal and community participation domains, affecting between an estimated number of half a million to a million disabled people in the UK at the time of data collection. Employment and sport activities were the two life areas where the health driven barrier profile was the most prevalent among disabled people with restricted participation.

Except in the life areas of volunteering and sport, respondents with health driven barrier profiles were also likely to report social and physical environmental barriers to their participation. Besides a ‘health condition’, ‘costs’ and ‘difficulties with transport’ were the two most often reported barriers to participation by those with a health driven barrier profile, especially in the life areas of meeting close contacts and friends. Disabled people’s financial limitations to participation in leisure is well-documented in the literature (Hastbacka et al., 2016; Merrells et al., 2018) resulting from a higher likelihood of undertaking insecure, part-time, and low-paid jobs (Honey et al., 2014). Physical environmental barriers such as ‘difficulties with transport’ is also documented in the literature as a cause of participation restrictions in a range of life areas. ‘Difficulties with transport’, is a term covering a range of different barriers, including no access to a car, not being able drive and not having available support with using public transportation (Kissow, 2015). Further research is needed to investigate the different types of transportation barriers encountered by disabled people, including the demographic and health characteristics of disabled populations likely to be affected.

In the formal participation domains of education and employment, those with a health driven barrier profile were more likely to report ‘lack of experience and lack of confidence’ and the ‘attitudes of others’ to restrict their participation compared to the other life areas. This finding is concerning, and it reflects previous research which shows that discrimination and negative social attitudes affect disabled people’s confidence and self-esteem, leading to reduced rates of social participation in a range of life areas (Kissow, 2015; van Asselt-Goverts et al., 2018). International studies indicate that improving disabled employees’ working conditions through disability awareness training and the establishment of disability friendly working environments are effective ways of facilitating disabled people’s continued participation (Honey et al., 2014; Nazarov et al., 2019). Future policies that aim to facilitate disabled people’s participation in education and employment in the UK, will need to aim to improve public understanding and perceptions of disability and the development of disability friendly working practices.

Personal characteristics

Experiencing a health driven barrier profile was significantly associated with reporting a high severity mental health, pain, or motor impairment across all life areas except for employment (Table 5.8, p. 163). This implies a need for improvement in health care interventions, especially in the areas of mental health treatments and pain management.

In the life area of employment, men were more likely to have a health driven barrier profile, whilst women were more likely to have a time driven barrier profile which is further evidence of the gendered division of labour discussed earlier (Chandola & Rouxel, 2021; Shockley et al., 2017). The significant association between being male and experiencing a health driven barrier profile in the life areas of employment and sport also reflects the generally higher engagement and participation rates of men in these life areas compared to women (Chapter 4, Section 4.2.1, p. 110).

5.6.3. Barrier profiles consisting of multiple barriers

In each life area, there was a minority of respondents whose barrier profile was neither driven by a health condition or lack of time.

In the informal and intimate participation domains, there was a small group of respondents whose barrier profile was primarily driven by 'costs', with additional time related and transport barriers to meeting close contacts, friends, and family. Those with a cost driven barrier profile were unlikely to report a health condition as a barrier to participation, except in the life area of meeting family.

In the domains of education and employment, an estimated number of nearly 300,000 disabled people had a barrier profile that was characterised by multiple personal and environmental barriers. The personal barriers within this profile were more likely to be related to 'lack of confidence' and the presence of a 'health condition' than a lack of time, whilst the environmental barriers were primarily of social nature. In the community participation domain, those with multiple barrier profiles were equally likely to report a social, physical environmental or personal barrier.

These findings suggests that at least for a minority of disabled people, barriers to social participation operate in multiple contexts which encompass the physical and social environment as well as personal attributes.

Respondent characteristics

Respondents who experienced complex, multiple barriers to social participation across most life areas, were likely to be young and to report a mental health impairment or mental health comorbidity. These results reflect UK government statistics showing an increase in mental health impairment among the younger age groups since 2001 (Office for National Statistics, 2023). Government investment needs to focus on improving the effectiveness and increasing the coverage of mental health interventions for young people to avoid the long-term implications of sustained mental health difficulties for their social connectedness, health, and well-being. In addition, further research is needed to explore the underlying causes of the deteriorating mental health of younger generations and develop preventative measures.

Young disabled adults were also likely to experience a cost driven barrier profile to meeting friends and family which suggests that cost related barriers might be at least partly responsible for the highest rate of participation restrictions reported by this age group compared to all other age groups in the intimate and informal participation domains (Chapter 4, Figure 4.1). There is evidence from the literature that young disabled people are most at risk of unemployment and employment in low-wage, part-time jobs (Honey, 2014). More government initiative is needed to create employment opportunities and to improve the working conditions and job retention of young disabled populations.

Reporting a neurodevelopmental impairment was significantly associated with experiencing multiple personal and environmental barriers to participating in employment and sport. Government statistics and wider research evidence suggest that autistic people and people with mental health difficulties have the lowest rates of employment across all types of disability (Bates et al., 2017; Office for National Statistics, 2022b). The findings of the present study contribute new knowledge about the composition and sources of the drivers of employment restriction in these populations, highlighting the need for a multiagency approach to tackle these, encompassing different policy areas, including health care, transport, and the labour market. It furthermore provides further evidence that the participation restrictions experienced by people with mental health and neurodevelopmental conditions reach beyond the formal sphere of employment. More needs to be done to create inclusive community spaces to facilitate the social integration of this population group.

5.7. Conclusion

This chapter investigated the patterns of barriers reported by disabled populations in different life areas and the demographic and health characteristics associated with these. The findings indicate that the barrier profiles that characterise disabled people’s restricted participation are unevenly distributed across the sample, with some pointing to a more complex range of needs than others.

Across all life areas, the time driven and/or health driven barrier profiles were the most prevalent. Time driven profiles were associated with reporting mild impairment, the presence of dependent children, and (in the life area of employment) being female. Health driven barrier profiles were associated with high severity motor, mental health, or pain impairment. These findings indicate the continued need for investment into subsidised childcare and the development of disability friendly labour market policies and working practices.

There was a small but significant proportion of disabled people who encountered multiple barriers to participation across every life area. Risk factors predicting membership of a multiple barrier profile included being young (aged 16 to 24), coming from a minority ethnic group, and reporting a mental health or neurodevelopmental condition. Limitations of the LOS dataset does not allow for a robust estimation of the size of this population and the exact nature of the social and environmental barriers they encounter. There is a concern, however, that the relative scarcity and vulnerability of this population puts them at risk of being unrepresented by disability rights groups and remain hidden from government interventions. At the same time, the complex personal, social, and physical environmental barriers reported by this group of disabled respondents suggest the need for interventions that cut across a wide range of policy domains.

The analysis presented here was limited to Wave 1 of the LOS dataset. The next chapter explores how disabled people’s participation changed by the time Wave 3 data was collected and the factors associated with these changes.

Chapter 6. Change in restricted participation and barriers to participation in the LOS

6.1. Introduction

This chapter explores the fourth and final research question of the quantitative study, which relates to understanding the factors affecting changes in restricted social participation over time for people with and without disabilities. This includes examining barriers associated with continuing restricted participation, and barriers and facilitators associated with movement into or out of restricted participation at Wave 3. The analyses in this chapter report within subject change in social participation rates, which means changes in participation that were observed in relation to individual respondents.

The chapter consists of three sections. To start with, the study inclusion criteria is defined, and the longitudinal sample sizes are presented. The next section describes the proportions of disabled and non-disabled respondents who reported no change in their social participation in a life area between Wave 1 and Wave 3. These respondents comprised of those who had restricted participation in a life area at both waves and those who did not report participation restriction in a life area in Wave 1 or Wave 3. For sample sizes across different participation patterns (i.e.: restricted at W1 and W3, not restricted at W1 or W3, moved into participation restriction, moved out of participation restriction) please refer to Table A.4.1 in Appendix 4, p. 308.

The final section describes and compares the changes in (restricted) participation between disabled and non-disabled samples. Barriers and facilitators associated with changes in social participation are presented for the disabled sample only. Data on participation rates and barriers/facilitators to participation reported are presented in weighted percentages (for number of observations refer to Appendix 4, p. 308).

6.2. Study inclusion criteria and longitudinal sample sizes

The longitudinal dataset used for this analysis was created from Wave 1 and Wave 3 of the LOS survey data. The time interval between the two waves was on average 3 and a half years, Wave 1 being collected in 2009-2011 and Wave 3 in 2012-2014. The disabled sample for the longitudinal analyses comprised of those working age participants from Wave 1 who still reported the presence of an impairment at Wave 3. The non-disabled sample comprised of those working age participants from Wave 1 who still reported no impairments at Wave 3. Table 6.1 presents the sample sizes of disabled and non-disabled participants. The total longitudinal sample size was 4,296 of which about a third of respondents (33.4%) reported an impairment at both waves.

Table 6.1 Wave 1 to Wave 3 sample sizes (unweighted observations)

	Wave 1	**Wave 3**
Disabled group: disabled at both waves	5,563	1,435
Non-disabled group: not disabled at either wave	17,832	2,861
Total	*23,395*	*4,296*

Table 6.2 presents the break-down of the sample size of respondents who were excluded from the longitudinal analyses. Most respondents were lost at Wave 3 due to a high attrition rate (over 33%) in the LOS (Office for National Statistics, 2015). This resulted in the loss of 17,539 respondents to follow up. A minority (4%) of the Wave 1 non-disabled sample reported to have become disabled by Wave 3. A small group (1.8%) of disabled respondents at Wave 1 did not any impairments that caused functional limitations by Wave 3.

Table 6.2 Wave 1 disabled respondents excluded from longitudinal study*

	Wave 3
Not disabled anymore at W3	827
Became disabled by W3	733
Lost to follow up	17,539
Total excluded from longitudinal sample	*19,099*

*Unweighted observations

Table 6.3 presents the sample sizes of the thesis defined impairment types in the longitudinal dataset. In the longitudinal sample, slightly more disabled people reported a motor impairment and slightly fewer reported a neurodevelopmental impairment compared to the Wave 1 sample (Chapter 4, Table 4.2, p.105).

Table 6.3 Longitudinal sample sizes of thesis defined impairment types*

Impairment type	Impairment present	Single impairment	Comorbidity	Representation in disabled sample
Sensory	208			14.5%
Motor	552			38.5%
Breathing	166			11.6%
Neurodevelopmental	127			8.9%
Pain	1,004	249	755	70.0%
Mental health	280	27	253	19.5%
Total disabled sample	1,435			100%

*Impairments reported at Wave 3 by disabled people who provided data at both Wave 1 and 3.

Table 6.4 presents the number of respondents who provided information about their social participation at both Wave 1 and Wave 3. The available data for different life areas indicate that in some life areas respondents were less likely to answer questions about their participation restrictions than in others. Missing data indicate that the participant either expressed ‘no interest’ in the activity, the question was ‘not applicable,’ or the participant had a missing answer to the question at Wave 1 or Wave 3. The intimate and informal participation domains had the most valid answers to participation questions at Wave 1 and Wave 3 for both disabled and non-disabled people. Less than half of disabled respondents answered questions regarding their participation restrictions in the life areas of employment, volunteering, and sport at both LOS waves. The relatively low amount of valid longitudinal participation data across the community domain for both samples replicate the findings from Chapter 4, which revealed high rates of no interest in volunteering and sport activities compared to meeting close contacts, friends, and family (Chapter 4, Tables 4.4 and 4.5, pp. 110-11).

Table 6.4 LOS W1 to W3 participation data for each life area, N (weighted %)

	Disabled sample		Non-disabled sample	
	Valid data on participation	**Missing data on participation**	**Valid data on participation**	**Missing data on participation**
Intimate	1,362 (94.9)	73 (5.1)	2,508 (87.7)	353 (12.3)
Friends	1,065 (72.4)	370 (25.8)	2,239 (78.3)	622 (21.7)
Family	1,166 (81.3)	269 (18.7)	2,444 (85.4)	417 (14.6)
Education	921 (64.2)	514 (35.8)	1,939 (67.8)	922 (32.2)
Employment	512 (35.7)	923 (64.3)	1,875 (65.5)	986 (34.5)
Volunteering	616 (42.9)	819 (57.1)	1,245 (43.5)	1,616 (56.5)
Sport	587 (40.9)	848 (59.1)	1,387 (48.5)	1,474 (51.5)
Total sample	*1,435* (100%)		*2,861* (100%)	

6.2.1. Sample characteristics

The longitudinal sample had an older average age than the Wave 1 sample (Table 6.5 and Table 4.1, p. 105). The median age of the W1 to W3 disabled sample was 9 years older than the Wave 1 median age, and the median age of the non-disabled sample was 8 years older than the Wave 1 median age sample (Chapter 4, Table 4.1, p. 105). The relatively older age distribution of the longitudinal sample can partly be attributed to the time elapsed between Wave 1 and 3, at the same time, it also points to a high attrition rate among respondents in younger age groups by Wave 3.

Table 6.5 The age distribution of the Wave 1 to Wave 3 sample (unweighted observations)

	Mean	Sd	Median	Min	Max	Count
Non-disabled sample	49.34	13.43	52	19	68	2861
Disabled sample	53.79	11.04	56	19	68	1435
Total	*50.82*	*12.86*	*53*	*19*	*68*	*4296*

The longitudinal disabled sample contained comparatively more women, more respondents with a White ethnic background, and more adults aged over 45, than the Wave 1 sample

(Table 6.6 and Table 4.2, p. 105). There were also fewer single, and more partnered, divorced, or widowed disabled people in the longitudinal sample than in the Wave 1 sample.

Table 6.6 Demographic characteristics of Wave 1 and Longitudinal disabled samples

	Wave 1 Disabled sample		**W1-W3 Disabled sample**	
	Nr	%	Nr	%
Gender				
Male	2,377	*44.3*	600	*41.8*
Female	3,186	*55.7*	835	*58.2*
Total	*5,563*	*100*	1,435	*100*
Age				
16 to 24	394	*7.8*	26	*3.9*
25 to 44	1,840	*35.3*	267	*25.2*
45 to 64	3,329	*56.9*	876	*57.3*
65 to 74	-	-	266	*13.7*
Total	*5,563*	*100*	*1,435*	*100*
Ethnicity				
White	5,120	*90.7*	1,351	*94.2*
Mixed	52	*1.1*	11	*0.8*
Asian or Asian British	223	*4.5*	45	*3.1*
Black or Black British	95	*2.1*	17	*1.2*
Chinese or Other Ethnic Group	71	*1.6*	10	*0.7*
Total	*5,561*	*100*	1,434	*100*
Marital Status				
Single	1,109	*21.8*	229	*16.0*
Partnered	3,494	*60.7*	920	*64.1*
Divorced	798	*14.7*	230	*16.0*
Widowed	162	*2.9*	56	*3.9*
Total	5,563	*100*	1,435	*100*

The following sections present within subject changes in participation rates and associated barriers and facilitators to participation between Wave 1 and Wave 3. To aid interpretation, the results are summarised in figures, representing percentage respondents. Barriers and facilitators to participation that were reported by fewer than 20 respondents are not represented in the figures but are described in Section A 4.3 in Appendix 4, p. 310.

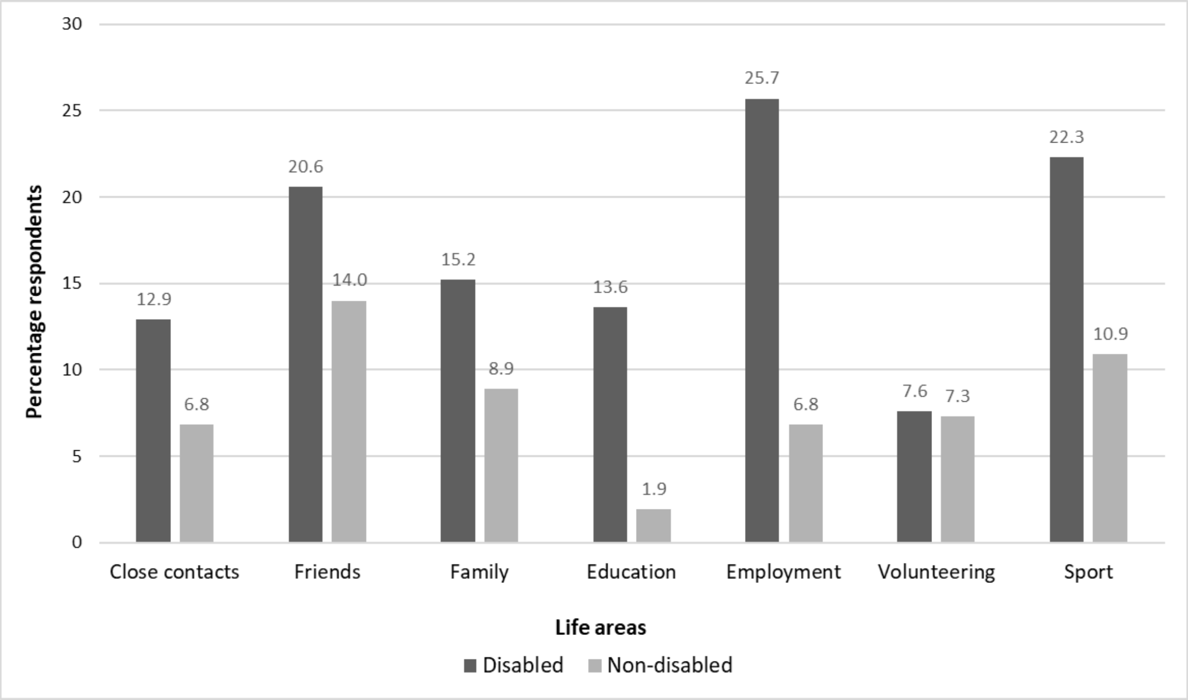
6.3. No change in social participation

The following sections describe, for each life area, the proportions of disabled and non-disabled respondents who reported no change in their participation restrictions between Waves 1 and 3.

6.3.1. Restricted social participation at both waves

The next set of analyses explored, for each life area, the proportions of disabled and non-disabled people who reported restricted participation in the life area at Waves 1 and 3, referred to henceforth as reporting persistent participation restrictions. The sample sizes of disabled and non-disabled people reporting persistent participation restrictions across different life areas are reported in Table A.4.2 in Appendix 4, p. 308. Relatively low proportions of participants reported being restricted in their participation at both W1 and W3 (Figure 6.1). Nearly a quarter of the disabled sample reported persistent participation restrictions to employment, and over a fifth reported restricted participation to meeting their friends and playing sport. Across all activities, less than 10% of non-disabled people experienced persistent participation restriction, except on the domain of meeting friends. The largest difference between disabled and non-disabled people was in the life areas of employment and education, with 11.7% more disabled people experiencing persistent education participation restrictions, and nearly 19% more disabled people experiencing persistent employment restrictions compared to the non-disabled group.

Figure 6.1 Participants reporting restricted participation at both waves



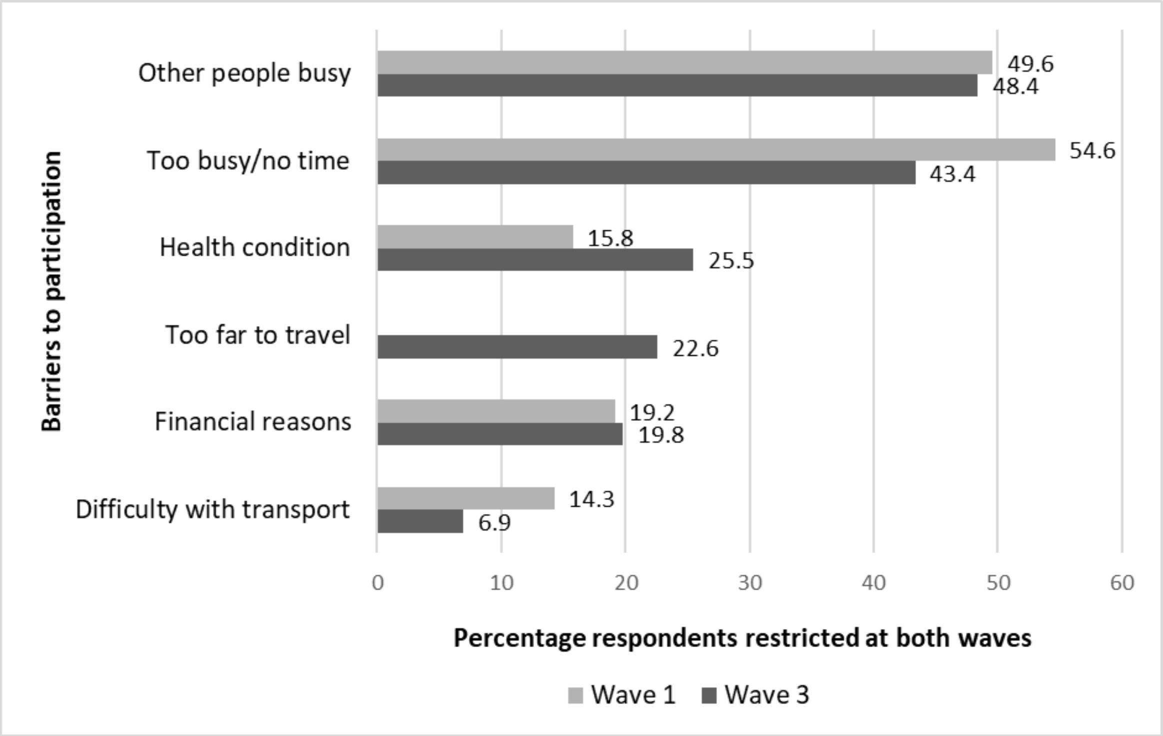
6.3.2. Barriers reported by those experiencing persistent participation restrictions

The following sections looked at whether disabled people reported the same or different barriers to participation in a life area at Waves 1 and 3.

Barriers to meeting close contacts

The time related barriers 'other people busy' and participant having 'no time' remained the most often reported barriers to meeting close contacts at Wave 3 by those experiencing persistent participation restrictions in this life area, although there was a small reduction in the proportion of disabled people reporting these barriers (especially the time barrier) at Wave 3 (Figure 6.2). 'Health condition' as a barrier was reported by 10% more disabled people at Wave 3 compared to Wave 1, a possible indication of deteriorating health during the time elapsed between the two waves. Fewer people reported 'difficulty with transport' at Wave 3, but over a fifth of respondents reported 'too far to travel' which was a new physical environmental barrier added to the LOS at Wave 3, (hence there is not data for this barrier at Wave 1). For the full list of barriers the LOS collected data on in this life area please refer to Table A.4.6 in Appendix 4, p. 311.

Figure 6.2 Meeting close contacts: barriers reported by disabled respondents experiencing participation restriction at both waves*

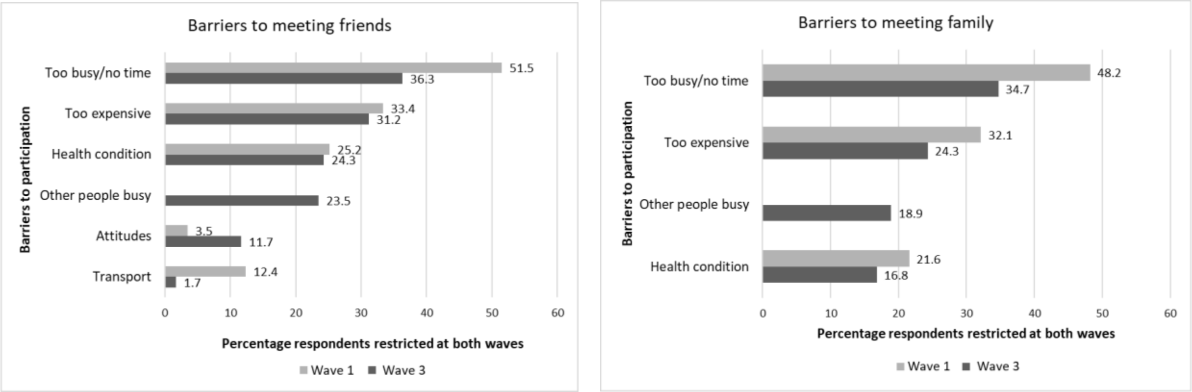


*W1 to W3 sample size for 'meeting close contacts' n=154.

Barriers to meeting friends and family

In the informal participation domains of meeting friends and family, 'lack of time' and 'costs' remained the top two barriers to participation at Wave 3 for disabled respondents with persistent participation restrictions (Figure 6.3). There was however a slight reduction in those reporting these barriers by Wave 3, 'lack of time' being reported by around 15% fewer disabled people, and 'too expensive' reported by 2 to 8 percent fewer disabled people at Wave 3 compared to Wave 1. The proportions of disabled people with persistent participation restrictions reporting 'health condition' as a barrier to meeting friends remained stable between Wave 1 and Wave 3, but slightly fewer respondents reported it as a barrier to meeting family at Wave 3. 'Other people too busy' was a barrier to meeting friends and family that was reported by around a fifth of disabled respondents at Wave 3; the LOS collected no data for this barrier in these life areas at Wave 1. 'Difficulty with transport' was reported by fewer disabled people as a barrier to meeting friends at Wave 3 compared to Wave 1. For the full list of barriers the LOS collected data on in these life areas please refer to Table A.4.6 in Appendix 4, p. 311.

Figure 6.3 Meeting friends and family: barriers reported by disabled respondents experiencing participation restriction at both waves



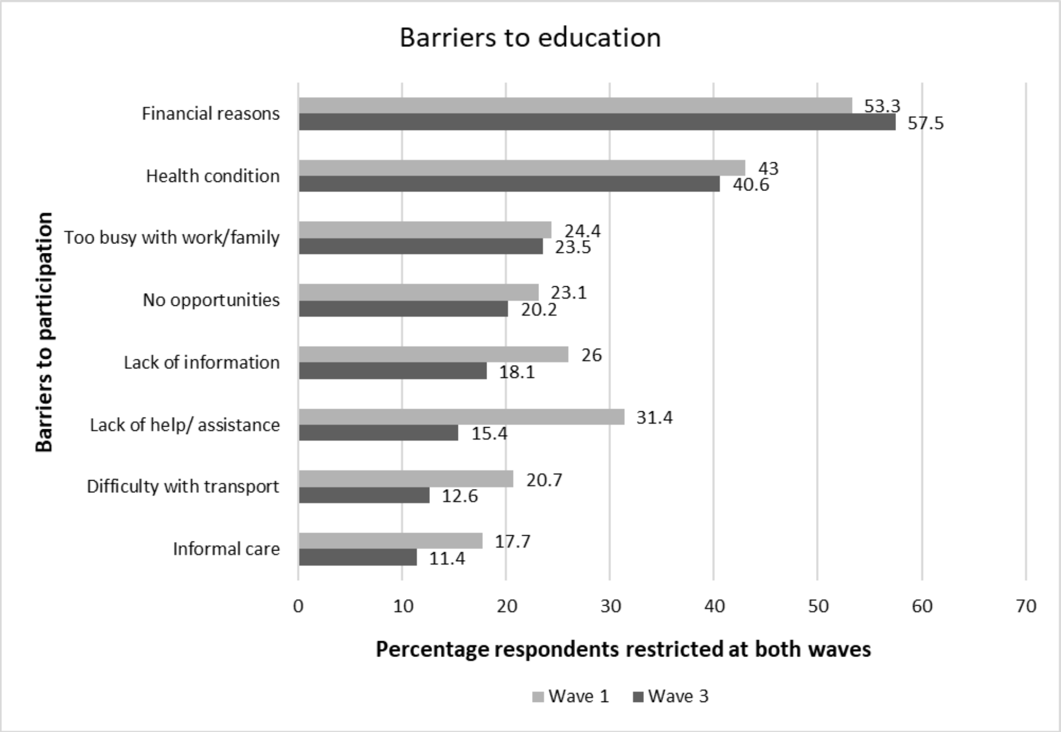
*W1 to W3 sample size: n=201

*W1 to W3 sample size: n= 173

Barriers to participating in education

At Wave 3, the LOS collected no data on barriers to employment. Financial reasons remained the primary barrier to participation in education among those experiencing persistent participation restrictions in this life area, and it was reported by slightly more disabled people at Wave 3 compared to Wave 1 (Figure 6.4). All the other barriers reported at Wave 1 were reported by fewer people at Wave 3 but because of the limited sample sizes it is hard to test how significant these changes are. Around 15% fewer disabled people with persistent participation restriction in education reported ‘lack of help/assistance’ as a barrier to their participation at Wave 3, compared to Wave 1. The barriers that remained most stable (or underwent least change in their prevalence from W1 to W3) were ‘health condition’ and ‘too busy with work/family’. For the full list of barriers to participation in education collected by the LOS at Wave 3, please refer to Table A.4.7. in Appendix 4, p. 312.

Figure 6.4 Education: barriers reported by those experiencing participation restriction at both waves



*W1 to W3 sample size for participation in education: n=110

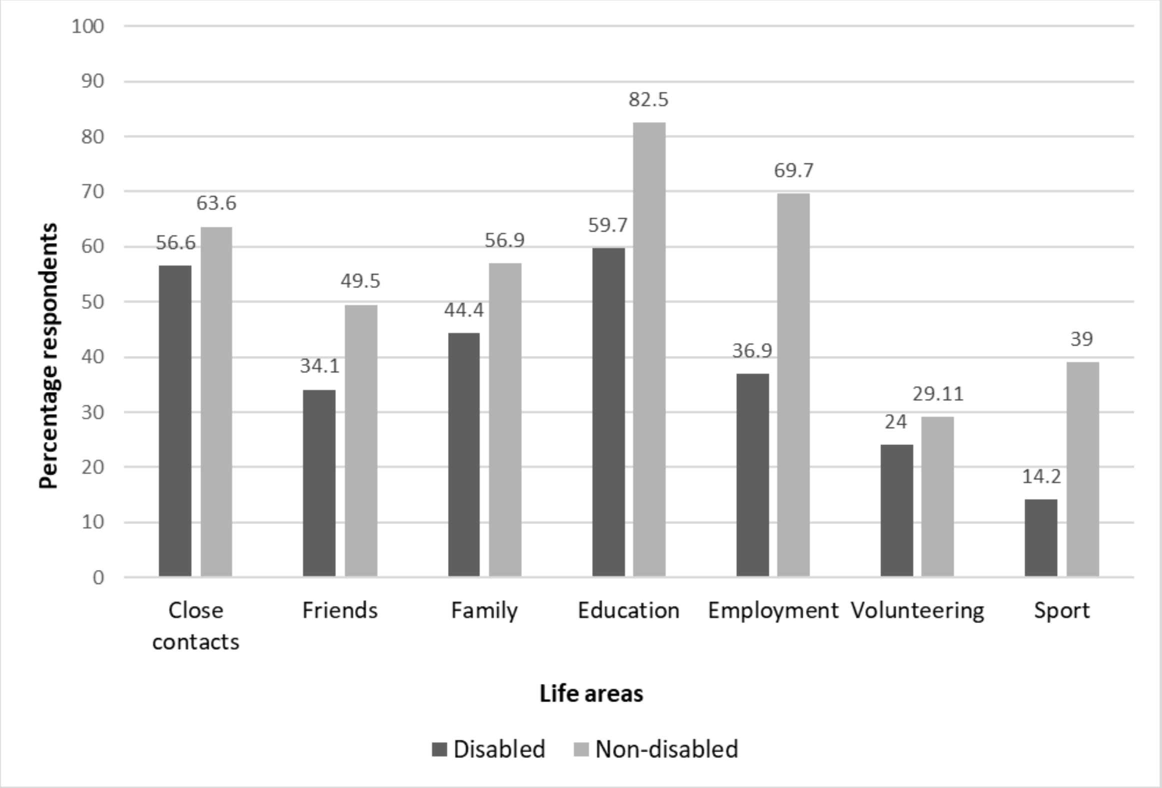
Barriers to participation in volunteering and sport activities

Very few disabled participants reported barriers to volunteering (n=47) and sport activities (n=134) at both Wave 1 and Wave 3 (Appendix 4, Table A 4.8, p. 313). The number of people reporting any barriers to participating in these life areas were too low to report on, except for the top three main barriers to sport activities. 'Health condition' and 'costs' remained the top two barriers to sport activities, reported by 60% (n=85) and 19% (n=23) of disabled people experiencing persistent participation restriction in this life area at both waves. A fifth of the longitudinal sample reported 'no time' as a barrier to sport activities at Wave 1, but only half of these people retained the time barrier by Wave 3 (Appendix 4, Table A 4.8).

6.3.3. No restrictions to social participation in Wave 1 or Wave 3

Disabled people were less likely to report continued unrestricted participation at Wave 3 compared to non-disabled people in all life areas (Figure 6.5). Across each life area, less than half of the W1 to W3 disabled sample reported no restrictions to their participation, except for meeting close contacts and participating in education. In comparison, the community participation domain was the only life area where less than half of non-disabled people reported unrestricted participation. The difference in unrestricted participation between disabled and non-disabled people was smallest in the life areas of meeting close contacts and volunteering. The largest difference in unrestricted participation rates between the two samples was found in the life areas of employment (32.8%), sport activities (24.8%), and education (22.8%). Unweighted sample sizes of disabled and non-disabled people reporting continued unrestricted participation across different life areas are reported in Table A.4.3 in Appendix 4, p. 309.

Figure 6.5 Respondents reporting no participation restrictions in a life area at W1 or W3*



*Weighted percentages.

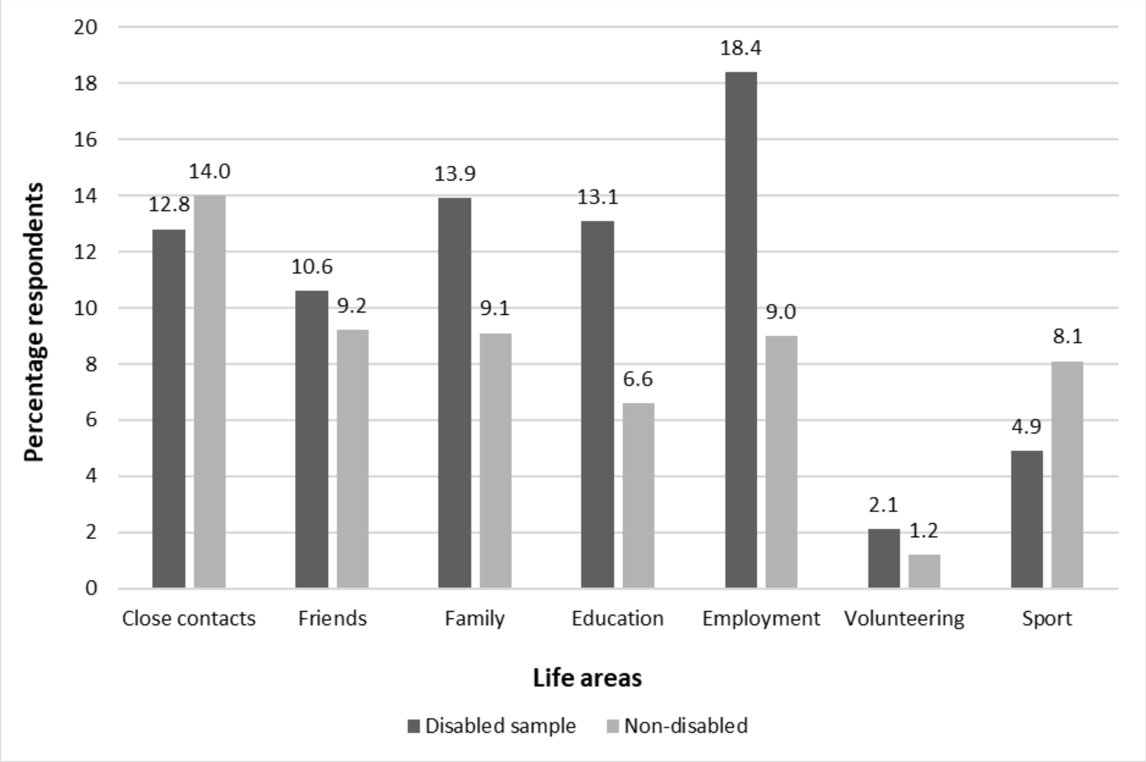
6.4. Change in social participation

The following sections compare changes in social participation between disabled and non-disabled people at Waves 1 and 3, and describe the barriers and facilitators associated with these changes for the disabled sample.

6.4.1. Moved into restricted participation at Wave 3

This section examines the differences in the proportions of disabled and non-disabled people moving into restricted participation in each life area at Wave 3, and the barriers identified by disabled participants as causing this. Similar proportions of disabled and non-disabled people moved into restricted participation in the life areas of meeting close contacts, meeting friends, and volunteering (Figure 6.6). Non-disabled people were more likely than disabled people to report a new barrier to their participation in sport activities and meeting their close contacts at Wave 3. In all other life areas, higher proportions of disabled people reported a new barrier to their participation at Wave 3 than non-disabled people. The biggest difference between the two samples was in the life areas of education and employment, where around twice as many disabled people moved into restricted participation compared to non-disabled people.

Figure 6.6 Participants moving into restricted participation at Wave 3*



*Weighted percentages.

Unweighted sample sizes of disabled and non-disabled people moving into restricted participation across different life areas are reported in Table A.4.4 in Appendix 4, p. 309.

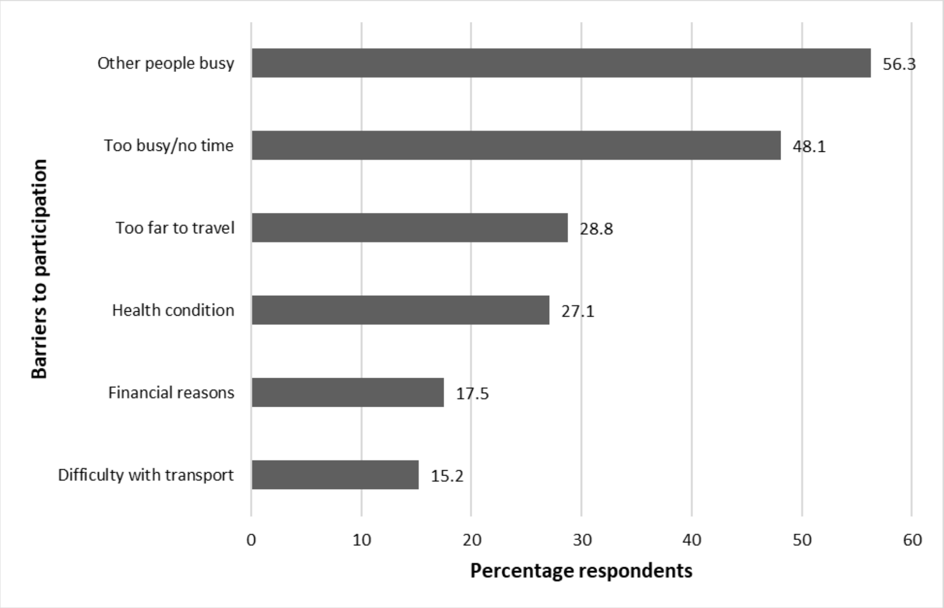
6.4.2. Barriers reported by respondents moving into restricted participation at Wave 3

The following sections describe barriers to participation in different life areas reported at Wave 3 by those disabled people who did not experience participation restriction at Wave 1 in the life area. For the full set of barriers the LOS collected data on at Wave 3 across the intimate and informal participation domains, please refer to Table A.4.9 in Appendix 4, p. 314.

Barriers to meeting close contacts

Figure 6.7 presents the barriers to meeting close contacts reported by disabled people moving into restricted participation at Wave 3. Around half of respondents reported to have encountered a time constraint they did not have at Wave 1, to meeting close contacts at Wave 3. Lack of time was a constraint experienced both by the close contacts and the respondents themselves. Over a quarter of disabled people moving into restricted participation in this life area reported 'the distance to travel' and another quarter reported a 'health condition' as barriers to their participation. Costs and 'difficulty with transport' were reported by a minority of people as new barriers to meeting their close contacts at Wave 3.

Figure 6.7 Intimate domain: barriers reported by disabled people moving into participation restriction at Wave 3

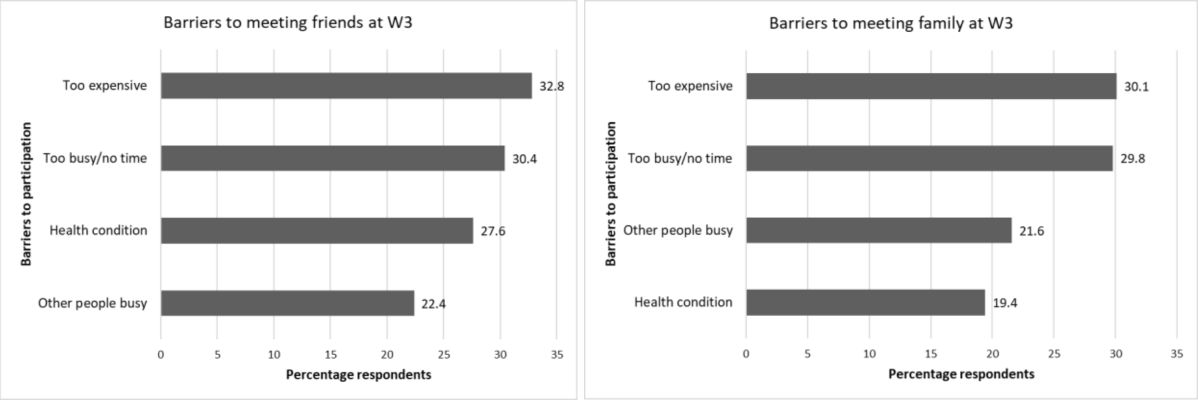


*W1 to W3 sample size for meeting close contacts: n=169.

Barriers to meeting friends and family

People moving into restricted participation in the informal participation domain reported four barriers to meeting friends and family that they encountered at Wave 3 but not at Wave 1 (Figure 6.8). Around a third of people had a new financial or time barrier, and about a quarter to a fifth of people found that a ‘health condition’ or ‘other people not having enough time’ stopped them from meeting their friends and family at Wave 3. ‘Health condition’ was more likely to be reported as a barrier to meeting friends than family.

Figure 6.8 Meeting friends and family: barriers reported by disabled people moving into restricted participation at Wave 3

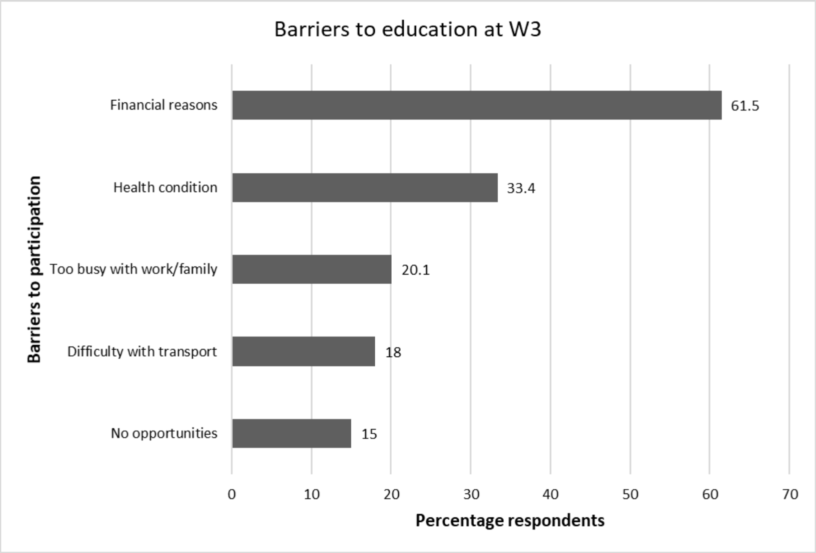


W1 to W3 sample size: n=111 W1 to W3 sample size: n=151

Barriers to participating in education

Over half of disabled people moving into restricted participation in education reported a financial barrier, and a third reported a new or deteriorating health condition as a barrier to participation at Wave 3 (Figure 6.9). Lack of time, and ‘difficulty using transport’ was reported by another fifth of respondents. For the full set of barriers the LOS collected data on at Wave 3 for the life area of education, please refer to Table A.4.10 in Appendix 4, p. 315.

Figure 6.9 Education: barriers reported by disabled people moving into restricted participation at Wave 3



W1 to W3 sample size: n=110

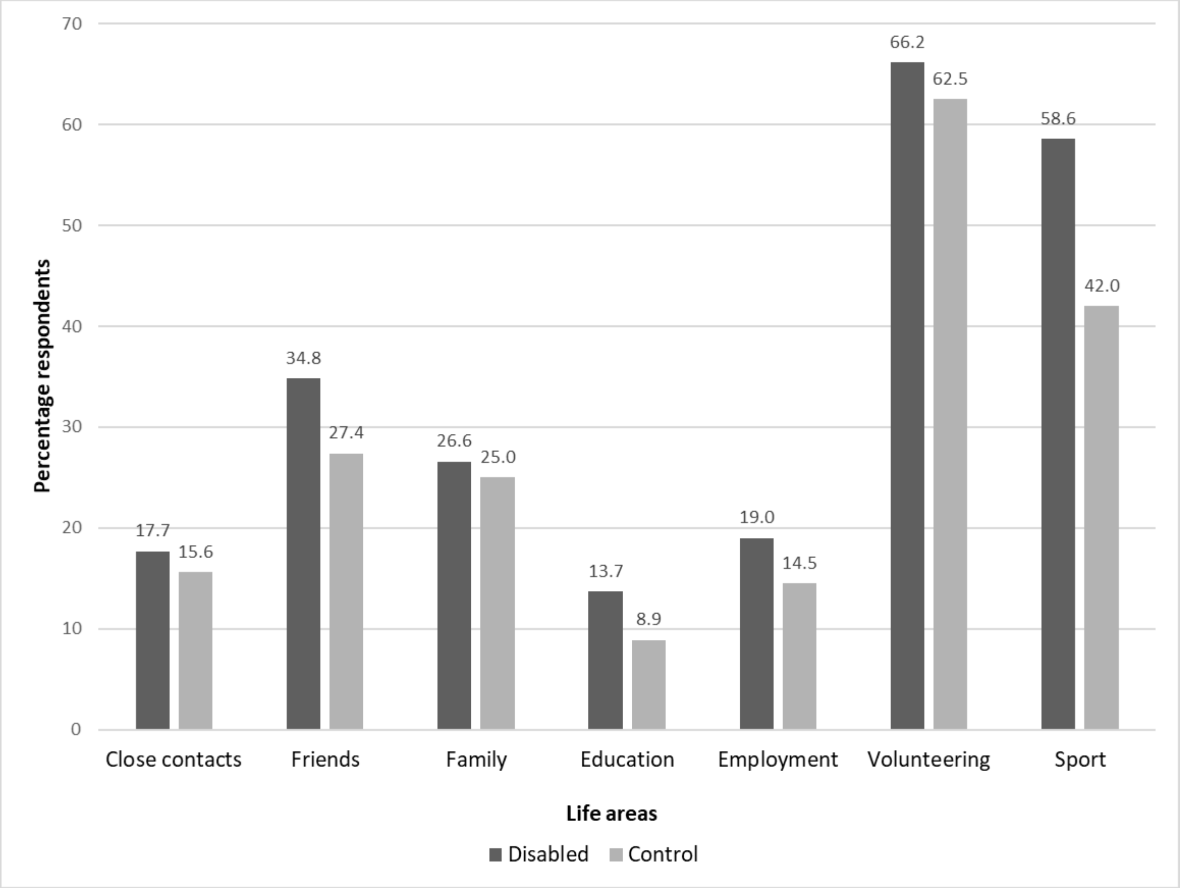
The LOS collected no data on barriers to participation in employment at Wave 3. The sample sizes of those who moved into restricted participation in the life areas of volunteering (n=14) and sport activities (n=33) were too low to be able to present information on.

6.4.3. Moved out of restricted participation at Wave 3

This section summarises the proportions of disabled and non-disabled respondents who moved out of restricted participation in different life areas at Wave 3. Education and employment were the life areas with the least movement out of restricted participation for both samples. The largest proportions of respondents moved out of participation restrictions in the life areas volunteering and sport activities.

Overall, slightly higher proportions of disabled people moved out of participation restriction at W3 in every life area compared to the non-disabled group (Figure 6.10). The largest difference between the two samples was in the life area of sport activities, where over 16% more disabled people moved out of restricted participation compared to non-disabled people.

Figure 6.10 Participants moving out of an activity restriction at Wave 3



For unweighted observations see Table A.4.5 in Appendix 4.

6.4.4. Facilitators reported by respondents moving out of restricted participation at Wave 3

This section presents the facilitators to participation reported at Wave 3, by disabled and non-disabled people. The LOS data on factors facilitating participation in different life areas is limited. The LOS collected no data on facilitators in the life areas of meeting close contacts and education.

Facilitators to meeting friends and family

For both disabled and non-disabled people, having more time was the most common facilitator to being able to meet friends and family at Wave 3 (Table 6.7). This is not a surprising finding, since the most often reported barrier to meeting friends and family was lack of time at Wave 1 (Chapter 4, Figures 4.3 and 4.4). Having 'more money available' to meet friends, was reported as a facilitator by relatively more non-disabled than disabled people (13% versus 2%).

Table 6.7 Facilitators to meeting friends and family at Wave 3

LOS facilitators	**Meeting Friends**		**Meeting Family**	
	Disabled	**Non-disabled**	**Disabled**	**Non-disabled**
Sample size	*365*	*648*	*310*	*584*
More time/not so busy	37 (19.9)	86 (29.8)	28 (22.6)	69 (31.1)
Friends have more time	12 (7.2)	15 (7.2)	13 (10.5)	18 (8.9)
Attitudes of others	3 (3.6)	2 (0.6)	-	1 (0.1)
I now feel welcome	1 (0.8)	2 (1.9)	-	-
Receiving help/assistance	3 (1.6)	2 (2.8)	1 (0.8)	-
Assistance with transport	4 (2.3)	5 (6.3)	1 (0.6)	-
Help with caring resp.	3 (1.3)	3 (0.8)	4 (2.8)	2 (0.8)
More money available	4 (2.1)	19 (13.0)	3 (2.4)	7 (2.2)
Improved health	3 (1.4)	2 (1.4)	4 (2.8)	3 (0.7)

Empty cells denote missing data.

Facilitators to participation in employment

There were very low numbers of people reporting facilitators associated with moving out of restricted participation in employment (Table 6.8). For disabled people, the most important facilitator for accessing paid employment was ‘modified/reduced working hours’ (reported by 15% of the 84 participants in this sample). Receiving ‘tax credits’ was the most important facilitator to employment in the non-disabled group (13% of people reporting it), whilst it was the second most reported facilitator by disabled people (11%). Because of the low longitudinal sample size, it is difficult to estimate the proportion of people in the population who benefited from ‘changes to the work area or work equipment’, ‘modified duties’ and ‘disability awareness training’ when participating in employment.

The LOS collected no data on facilitators to participation in education.

Table 6.8 Facilitators to participation to employment at Wave 3

LOS facilitators	**Employment**	
	Disabled	**Non-disabled**
Sample size	*90*	*252*
Modified hours/days, reduced working hours	12 (15.0)	28 (7.9)
Modified duties	5 (5.0)	4 (1.2)
Employer/staff attended disability awareness training	4 (4.5)	-
A job coach or personal assistant or mentor	1 (1.1)	5 (1.2)
Changes to work area or work equipment	6 (9.2)	8 (2.8)
Building modifications	2 (1.3)	-
Other equipment or services	1 (0.7)	-
Tax credits	10 (11.3)	18 (13.1)

Empty cells denote missing data.

Facilitators to participation in volunteering and sport activities

The number of respondents reporting facilitators associated with their improved participation in volunteering and sport activities is very low (Table 6.9). Having 'more time' was reported as a facilitator for participating in volunteering and sport activities by a minority of non-disabled participants, but sample sizes are too low to gain a clear picture of the facilitators that helped disabled populations to participate in sport activities at Wave 3.

Table 6.9 Facilitators to participation in volunteering and sport activities

LOS facilitators	**Volunteering**		**Sport**	
	Disabled	**Non-disabled**	**Disabled**	**Non-disabled**
Sample size	*393*	*743*	*326*	*611*
More time/not so busy	29 (16.0)	73 (18.1)	5 (3.5)	35 (11.2)
Encouragement from friends/family	4 (2.7)	7 (2.6)	3 (2.9)	7 (3.8)
Attitudes of others	-	-	-	-
I now feel welcome	-	2 (0.3)	-	2 (0.9)
Receiving help/assistance	4 (3.4)	1 (0.7)	1 (1.3)	1 (1.2)
Assistance with buildings	-	-	2 (1.3)	1 (1.2)
Assistance with transport	1 (0.4)	-	-	1 (0.3)
Help with caring resp.	2 (1.1)	-	-	1 (0.5)
More money available	7 (4.0)	9 (2.0)	4 (4.9)	17 (4.3)
Improved health	10 (4.7)	5 (1.8)	8 (6.4)	10 (1.9)

Empty cells denote missing data.

6.5. Discussion

The set of analyses presented in this chapter aimed to explore how restricted participation changed for disabled and non-disabled populations across different life areas between Wave 1 and Wave 3 of the LOS. It also investigated the extent to which barriers to participation were stable or transient across the two time points. The following sections evaluate the findings considering the results from the previous chapters and relevant literature.

6.5.1. Life areas with scarce participation data

Participation data was relatively scarce on the life areas of employment, volunteering, and sport activities, suggesting that relatively high numbers of participants replied with 'no interest' or 'not applicable' in response to survey questions about participation in these activities at one or more waves of data collection (see Table A.4.1 in Appendix 4, p. 308). The high rates of implied disinterest in these life areas at Wave 3, may be partly attributable to the older average age of the longitudinal sample. The investigation of the demographic characteristics associated with 'no interest' in participation at Wave 1 suggested that every year increase in age is significantly associated with less interest in participating in employment and sport activities (Chapter 4, Table 4.6, p. 112).

On the other hand, expressing continued 'no interest' in participation in a life area at both waves may also imply the presence of hidden barriers to disabled people's participation. Further research is necessary to investigate whether disabled people's apparent lack of interest in participation in some areas of life is related to an anticipated of conflict between an impairment and social/physical environmental barriers. Disabled people may not even attempt to participate in an activity if they foresee that participation would come at a considerable personal cost in terms of time, physical and mental exertion, and/or financial resources.

The longitudinal data on participation in the life area of employment contained a large number (over 60%) of missing answers among disabled respondents (see Table 6.4, p. 174), reflecting previous findings from Chapter 4 (Table 4.4, p. 110), indicating that disabled people were more likely to respond with 'not applicable' to questions on participation in employment because of reasons related to their disability at one or both waves. Because of the limited longitudinal participation data in this life area, it is hard to evaluate the effect of the Welfare Reform Act of 2012 (DWP, 2012) on disabled people's participation in employment at Wave 3. The Act required disabled people with Employment Support Allowance to undergo mandatory reassessment of their disability benefits. There is however some evidence from the literature that the activation-based welfare system, founded on conditional welfare payments has not done enough to tackle the social and structural barriers to disabled people's access to the labour market. Instead, the receipt of disability benefits attracted stigma and resulted in adverse mental health outcomes (Barr & Taylor-Robinson, 2016; Garthwaite, 2011; Mehta & Taggart, 2021).

6.5.2. Restricted participation over time and associated barriers

Overall, higher proportions of disabled respondents reported restricted participation across all life areas at both waves compared to non-disabled people. The life area where disabled people were most likely to report a persistent participation restriction was employment. Employment was also the life area in which the largest proportion of disabled people reported a change from unrestricted to restricted participation at Wave 3. In contrast, education and employment were the two life areas where the lowest proportions of non-disabled people reported persistent participation restrictions (Figure 6.1). The LOS did not collect barriers to participation in employment at Wave 3, hence it is not possible to find out if and how barriers to employment changed across the two time points.

Around 12 to 20 percent of the W1 to W3 disabled sample reported persistent participation restrictions to meeting close contacts, friends, or family, and another 10 to 14 percent moved into restricted participation in these life areas at Wave 3. Time restrictions (both others' and respondents' lack of time) and a 'health condition' were the top most often reported barriers to meeting close contacts, whilst cost considerations were a relatively more often reported barrier to meeting friends and family. Research evidence indicates that the 'no time' barrier to disabled people's participation in the context of the informal participation domain could be related to impairment-related time use, whilst financial barriers are more likely to be related to socio-economic circumstances (Hastbacka et al., 2016; Merrells et al., 2018).

Persistent participation restrictions in the intimate and informal domains may lead to a restricted social network and limited access to social and emotional support. There is some evidence that disabled people are likely to have fewer network ties in their informal network layer compared to non-disabled populations (Mithen et al., 2015). Additional research is needed to investigate how impairment affects leisure time use and the prioritisation of social participation across different life areas.

6.5.3. Unrestricted participation

Non-disabled people reported higher rates of unrestricted participation compared to disabled people across all life areas at Waves 1 and 3 (Figure 6.5, p. 181). The life areas in which close to 60% of disabled people maintained unrestricted participation between Wave 1 and Wave 3 were education and meeting close contacts. It is not clear from the LOS analyses performed in this study whether unrestricted participation rates in education and meeting close contacts were the result of disabled people overcoming health and time constraints to prioritise these activities above others, or whether they encountered fewer social and physical environmental barriers when participating in these life areas.

Across all life areas, very few participants provided information about the facilitators that helped them to transition out of restricted participation. This might be due to the LOS not capturing adequately the different types of reasons why disabled people might be able come out of restricted participation.

The most often reported facilitator to meeting friends, family and volunteering was ‘having more time’, which mirrored the findings from Chapter 4, which showed that ‘no time’ that was the highest ranked barrier in these life areas at Wave 1. The longitudinal data also provided some evidence that ‘modified/reduced working hours’ helped some disabled respondents to move out of restricted participation in employment. This finding supports government statistics which showed that reasonable adjustments, like modified or reduced working hours improved the job retention of disabled workers in the UK (Office for National Statistics, 2022b).

6.5.4. Study limitations

The four types of participation patterns across Wave 1 and 3 (i.e.: persistent restricted participation, maintained unrestricted participation, movement into/moving out of restricted participation) had limited sample sizes (Appendix 4, Table A.4.1, p. 308), and only a small proportion of participants provided information about barriers restricting their participation. Low sample sizes meant that it was not possible to perform statistical analyses to test how respondents’ health and demographic characteristics were associated with changes in their participation in different life areas across the two waves and the barriers they reported.

Disabled populations aged 45 or older, and those reporting a pain or motor impairment were overrepresented in the longitudinal sample. This entails that changes in participation and barriers reported at Wave 3 primarily represented older disabled populations. Young disabled adults (especially aged under 25) and people reporting a neurodevelopmental impairment were underrepresented in the longitudinal sample compared to the Wave 1 sample. The findings in Chapter 5 suggest that young disabled adults were likely to have distinct barrier profiles driven by multiple barriers, whilst middle aged and older disabled people were more likely to have a barrier profile driven by time constraints and (severe) health conditions. More work needs to be done to understand the participation trajectories and the stability of barriers to the social participation of young disabled people over time.

6.6. Conclusion

This chapter aimed to improve understanding about how disabled people's social participation in a range of life areas changes over time, and to provide an insight into the factors associated with these changes. The results indicate that changes in social participation between the LOS Wave 1 and 3 surveys were more likely in some life areas than others. Over a quarter of disabled participants reported persistent participation restrictions and nearly a fifth reported a movement into restricted participation in the life area of employment. Disabled people were least likely to report persistent participation restrictions in the life areas of meeting close contacts and education. Non-disabled participants on the other hand, were more likely to report persistent participation restrictions in meeting friends. There was a large amount of missing data on participation across the community participation domains, indicating relatively low engagement rates in volunteering and sport in both disabled and non-disabled samples.

The barriers reported by those experiencing restricted participation remained relatively stable across the two time points, with time and cost related barriers most likely to be reported in relation to meeting close contacts and participating in leisure activities, whilst cost and health related barriers were most likely to be reported in the life areas of education and employment respectively. These findings indicate the need for the development and wider coverage of disability friendly workplace policies and practices because restricted participation in employment imposes financial constraints on disabled people which affect their wider social participation in leisure and community activities (evidenced by the cost barriers they reported in these life areas).

The quantitative study findings reveal little about the exact nature of the time, health, cost, and transport related barriers to participation reported by disabled populations. It is likely that these barriers to participation manifest differently in each life area and across different disability types. In the next part of the thesis, a qualitative study investigates the personal, social, and physical environmental factors affecting the social participation and feelings of social connectedness in a sample of autistic adults.

PART III

AUTISTIC ADULTS' ACCOUNTS OF SOCIAL PARTICIPATION

Chapter 7. Autism in society: diagnosis, perceptions and social participation

7.1. Introduction

The quantitative study presented in Part II used the LOS survey data to explore barriers to social participation reported by disabled people with a range of different impairment types. The results indicated that a small group of disabled people experienced multiple personal, social, and physical environmental barriers to participation in a range of life areas (Chapter 5, Table 5.8, p. 163). Reporting a mental health and/or a neurodevelopmental impairment was associated with having a complex barrier profile. One of the limitations of the LOS meant that it was not possible to differentiate between people with neurodevelopmental conditions, learning and intellectual disabilities in the dataset (Chapter 4, Section 4.5.5 p. 130). This is an important shortcoming of the LOS because government statistics indicate that autistic people have the lowest rates of employment across all disability groups and even when employed, they face disadvantage in the labour market compared to others (Bates et al. 2017; Office for National Statistics, 2022b). There is also evidence from the international literature that autistic people have the worst social connectedness outcomes across the disabled population. This is manifested in high self-reported rates of loneliness coupled with low social network satisfaction and limited social activity in the informal sphere (Billstedt et al, 2007; Orsmond et al. 2013; Gilmore and Cuskelly, 2014; van Asselt-Goverts et al. 2015, 2018).

7.1.1. Rationale for a qualitative study

Part III of the thesis aims to build on the literature review and quantitative study results by employing qualitative methods to further explore barriers to social participation with a focus on autistic people. There were three primary motives for carrying out a qualitative follow-up study with this specific population.

Firstly, as described above, neurodivergent people had a low representation in the LOS dataset with no differentiation between respondents with a learning disability and those with an intellectual disability. The wider evidence suggests that autistic people are at increased risk of social isolation and loneliness compared to other disabled groups. The LOS did not allow for exploration for this.

Secondly, due to the specific traits associated with autism, autistic people may encounter barriers to social connectedness that were not captured by the LOS. Moreover, autistic people may experience or ascribe different meanings to the barriers collected by the LOS compared to other respondents' interpretations. There is currently little known about the social aspects of living and ageing with autism, with the majority of research focusing on children, and on the biological causes and treatments of this neurodevelopmental condition (see Section 7.7). One of the aims of the qualitative study was to contribute to the literature by increasing understanding on how autistic traits interact with social and environmental conditions when attempting to engage in social participation.

Finally, the LOS under-specified several barriers to participation (e.g.: 'lack of time', 'cost' and 'health condition') which might have led to the under-reporting of these barriers by disabled respondents (Chapter 4, Section 4.5.5, p. 130). Hence, the third motive to carry out the qualitative study was to examine in detail the mechanisms through which 'lack of time', 'cost' and 'health' barriers may restrict the social participation of autistic adults. The interviews also aimed to identify barriers to participation reported by this population that were not identified by the LOS and might also be absent from the wider literature.

7.2. Chapter aims

This chapter has three broad objectives. First, it aims to equip the reader with a level of understanding of autism, including its diagnosis, traits and co-occurring conditions that will facilitate the interpretation of the qualitative study findings. Second, it provides a brief summary of what is currently known about autistic people's social participation and how it differs to the participation of people without autism. Finally, the chapter introduces current trends in autism research and the way in which public perceptions and language around the condition have changed in recent years.

7.3. What is Autism?

This section provides a comprehensive overview of what is known about autism, including its diagnostic criteria, traits, and commonly co-occurring conditions.

7.3.1. Diagnostic criteria

In the UK, autism diagnosis is based on the diagnostic manual of the International Classification of Diseases (ICD-11) in conjunction with the Diagnostic and Statistical Manual, fifth edition (DSM-5). Both manuals define autism as a neurodevelopmental disorder that is characterised by (1) persistent deficits in reciprocal social interactions and communications and (2) a range of restricted, repetitive, and inflexible patterns of behaviour. In 2016, atypical sensory processing and integration was included in the diagnostic criteria under restricted and repetitive behaviours. Receiving an autism diagnosis requires the condition to 'significantly limit and impair everyday functioning' (DSM-5). Subsequent sections describe some of the autistic traits related to social interactions and patterns of behaviour that are used to establish an autism diagnosis.

Both manuals provide qualifiers to enhance the specificity of the diagnosis. These are meant to specify the presence and severity of any co-occurring Intellectual Disability (ID) and/or Functional Language Impairment (LI). A clearer demarcation between autism, intellectual disability and language impairment resulted in the unification of 'autism type disorders' under the collective term of Autism Spectrum Disorder (ASD), (henceforth referred to by the more neutral term Autism Spectrum Conditions (ASC)). This new diagnosis replaces several previously distinct but related diagnoses such as 'Asperger's syndrome' and 'Pervasive Developmental Disorder' among others. At the same time, specifying the presence/absence and severity level of co-occurring ID or LI, contributed to the perception of autism as a spectrum condition where a common set of ASC traits vary in their severity and co-occurring conditions across individuals to form a spectrum from 'least affected' to 'most affected' by ASC.

7.3.2. The complexity of autism

As research into the genetic and neurological origins of autism continues to evolve, and as increasing numbers of autistic researchers make their contributions, the picture of autism that emerges is ever increasing in complexity. Neurobiological, social, and behavioural research into autism consistently shows that autistic individuals vary in their “symptom patterns, comorbidities, biomarkers and gene variants” (Waterhouse, 2022). Scientists are starting to believe that ‘autism’ is not a unitary biological entity, but it arises at the intersection of a complex range of biological causes resulting in a wide range of behavioural manifestations (Kuo & van der Merwe, 2022; Waterhouse, 2022). These new insights into autism are also starting to challenge the conceptualisation of autism as a ‘spectrum disorder’. Recently, there has been a shift towards visualising autism on a wheel (akin to a pie chart) composed of ASC traits and co-occurring conditions of differing weights forming a unique pattern for each autistic individual. Future diagnostic criteria of autism are likely to involve trans-diagnostic definitions, accommodating the overlap between autistic traits and other neurological conditions (Happé & Frith, 2020).

7.4. The prevalence and characteristics of the autistic population over time

In recent years, as the diagnostic criteria for ASC broadened and the condition gained better recognition among health care professionals, autism diagnoses rates increased dramatically across Western countries (with a fivefold increase in the UK in the 1990s) (Happé & Frith, 2020). Current estimates of the size of the adult autistic population in the UK are around 1.1% (Brugha & Cooper, 2012; R. Cooper & Cooper, 2021).

There is evidence that autism is not consistently diagnosed across all ages and genders within the population (Loomes & Hull, 2017; Mukaetova-Ladinska & Perry, 2012). Historically, autism was mainly diagnosed in young boys, hence diagnostic tools are still male biased and focus on children (Lai & Kassee, 2019). Recent research indicates that autism manifests itself differently in females, who are more likely to mask their autistic traits and are better able to blend into non-autistic environments than males. At the same time, autistic women often present with symptoms of anxiety, depression and eating disorders (Leedham & Thompson, 2020; Mandy & Chilvers, 2012). As a result, women tend to be diagnosed later in life and large proportions of this population are likely to be either misdiagnosed with other neurological or mental health conditions or to go undiagnosed

(Carpenter & Happé, 2019; Happé & Frith, 2020). Male to female autism diagnostic rates reflect this discrepancy in the presentation of autism between the genders, with a childhood diagnostic ratio of 5 males to 1 female and an adult diagnostic ratio of 2 males to 1 female, suggesting that autism tends to be missed in young girls (Rutherford & McKenzie, 2016).

7.5. Autistic Traits

The following sections describe some common autistic traits associated with its two broad diagnostic criteria, the first, relating to social interactions and communications, the second to repetitive patterns of thinking and behaviour.

7.5.1. Social interactions and communications

One of the primary diagnostic criteria of autism is experiencing difficulties with initiating and maintaining communication and social interactions. There are two broad areas where autistic people function differently to non-autistic people that seem to underlie these difficulties. The following sections briefly review how differences in auditory processing and cognitive preferences affect autistic people's communication and functioning (especially in non-autistic environments) and the consequences of this in terms of social behaviour and psychological outcomes, which affect social participation.

Auditory processing

There is an increased recognition that atypical sensory processing may underlie and/or exacerbate the social and communication difficulties that characterise autism (Gliga & Jones, 2014; Ronconi & Molteni, 2016; Thye & Bednarz, 2018). Sensory processing differences are prevalent in over 90% of the autistic population (Leekam & Nieto, 2007) and they are present across all ages and levels of ASC symptom severity (Baum & Stevenson, 2015; Thye et al., 2018). Atypical auditory processing is one of these sensory traits which includes enhanced perception and sensitivity to high pitched and loud noises, difficulty with auditory orientation, impaired perception of intonation and difficulty with isolating multiple sources of auditory information (O'Connor, 2012; Thye et al., 2018).

Differences in auditory processing have important implications for autistic people's preferred modality of communication and the sensory environment in which social interaction takes place. Research indicates that phone calls are reported to be the worst mode of communication by most autistic people (and a major barrier to accessing health care) because they exclusively rely on auditory processing without the supplementary information provided by facial features and body language (Cummins & Pellicano, 2020; Howard & Sedgewick, 2021). Most autistic people express a strong preference for written communication modes, especially in electronic form such as emails. Written forms of communication are valued for limiting misunderstandings by providing more ‘thinking time’ to formulate messages, as well as a sense of control through following the schemas of established conventions (Cummins et al., 2020; Howard & Sedgewick, 2021).

Differences in auditory processing also place limitations on the types of sensory environments in which autistic people can communicate successfully. Most autistic people find it very challenging to communicate in groups and/or in noisy environments because of sensory overload caused by background noise, and the increased pace and intensity associated with group interactions (Cummins et al., 2020).

Cognitive preferences

Deficit-based explanations of difficulties with social interactions and communication in autism attribute these (among others) to ‘a core impairment in pragmatics’ (R. Davis & Crompton, 2021). Pragmatics refers to the use of context to infer meaning from utterance (Ariel, 2010). Autistic people seem to be less sensitive to the contextual information within a conversation and as a result to have difficulties with decoding implied meaning from language (Wilson & Bishop, 2021). Literal thinking style is a commonly recognised autistic trait that is known to interfere with the interpretation of jokes, sarcasm, metaphor, and irony.

Recent research indicates that the autism specific difficulties with social interaction and communication are not necessarily due to impaired functioning but rather result from a different cognitive orientation in autism which does not align with neuro-typical communication styles (R. Davis & Crompton, 2021). There is evidence that autistic people can decode implied meaning most of the time but seem to require relatively more explicit information in order be certain of the inferences they make (Wilson & Bishop, 2021). There is moreover evidence of an autism-specific communication style which enables autistic individuals to interact more successfully with each other than with the non-autistic population (Catherine J. Crompton & Ropar, 2020; R. Davis & Crompton, 2021; Heasman & Gillespie, 2018). These findings imply that impaired social reciprocity between non-autistic and autistic populations result from differences in cognitive preferences that lead to a communication style mismatch that is bidirectional in nature (R. Davis & Crompton, 2021). This phenomenon has previously been referred to as the 'double empathy problem' (Milton, 2012).

Social anxiety

The communication and social interaction challenges experienced in some social contexts have a critical impact on autistic people's social behaviour, communication preferences and mental health outcomes. The uncertainty derived from not having enough information to establish the correctness of their interpretation of communications with non-autistic people has been reported to be associated with high levels of anxiety in autistic populations. Intolerance of uncertainty is a trait that has been shown to be common among the autistic people and it is a significant predictor of anxiety (Wilson & Bishop, 2021). Social anxiety may either lead to camouflaging behaviours, reduced social participation or complete withdrawal from participation resulting in social isolation.

Camouflaging

Camouflaging, sometimes also referred to as 'masking', is perhaps the main coping strategy used by autistic people to compensate for the communication mismatch they experience in non-autistic environments. Camouflaging primarily involves hiding one's true feelings, preferences, and difficulties, and imitating socially desirable behaviour including gestures and language (Hull & Petrides, 2017). The primary purpose of camouflaging is the masking of autistic traits in order to be able to access non-autistic social spaces and fit into mainstream environments (Bradley & Shaw, 2021; Lai et al., 2019; Lai & Lombardo, 2017).

Long-term camouflaging behaviour has been shown to be detrimental to individuals' physical and mental well-being. Camouflaging behaviour is triggered by feelings of inadequacy, not being accepted and a lack of belonging to society which in themselves increase the risk of anxiety, depression, and suicidal ideation (Hull et al., 2017). In addition, camouflaging requires significant cognitive effort (both self-monitoring and monitoring others) that is described by autistic adults as being mentally and emotionally exhausting, leading to high levels of stress and anxiety, and a diminished sense of self (Attwood, 2007; Lai et al., 2017).

7.5.2. Restricted, repetitive, and inflexible patterns of behaviour

Unlike autistic traits that relate to social interactions with others, the non-social traits, related to restricted repetitive behaviours (RRB) are a relatively under-researched area (Collis & Gavin, 2022; R. Cooper et al., 2021; Grove & Roth, 2016; Kapp & Steward, 2019). RRB may be expressed through the body – in the form of stereotyped motor movements or hyper-/hypo-reactivity to sensory stimuli – or at a conceptual level, in the form of adherence to rigid routines and having intense restricted interests (Collis et al., 2022).

Motor stims

Repetitive bodily movements known as 'motor-stereotypies' have long been a poorly understood autistic trait and are still associated with significant social stigma. Even today, most research focuses on its elimination, modification, and reduction in the form of behavioural therapies (Kapp et al., 2019). As increasing numbers of autistic adults contribute to autism research, there is a growing resistance to the stigmatisation of RRB and the neurodiversity movement has rebranded the phenomenon as 'self-stimulatory behaviour' or 'stimming' (Nolan & McBride, 2015). There is a growing body of literature that points to the vital importance that stimming plays for autistic people's emotional regulation and general welfare. Autistic adults report that stimming enables them to soothe intense emotional reactions (for example to uncertainty, anxiety, or sensory overstimulation) thereby avoiding becoming overwhelmed; it helps to improve focus and task performance; and it provides joy and comfort. Stimming is still not understood widely by the general population, and it is a source of embarrassment to most autistic adults, hence they report suppressing, substituting, or restricting this self-regulatory mechanism in public (Collis et al., 2022).

Interests

RRB manifests itself at the cognitive level in a preference for routine, and intense repetitive thinking around specific topics. Whilst routines are seen as a strategy to manage uncertainty, there is a dearth of research about the role that special interests play in autistic people's lives. There is some evidence that the presence of intense preoccupations predict higher levels of functional impairment and social interaction difficulties in autism (Turner-Brown & Lam, 2011). Research also suggests however, that special interests are often regarded as a source of strength and skill by autistic people and their families (Mercier & Mottron, 2000). Having a special interest is linked with greater self-confidence, a more positive sense of self and an increase in self-esteem; and is seen as of vital importance by autistic people (Attwood, 2007; Grove et al., 2016; Winter-Messiers, 2007). A 2015 study by Grove found that engagement in special interests is intrinsically motivated in autism where the goals are to gain knowledge, or achievement, or to experience a state of flow. Special interests were strongly related to positive affect, benefiting individual well-being, rather than a mere tool to alleviate negative emotion (Grove et al., 2016).

7.6. Commonly co-occurring conditions

There is substantial amount of co-occurrence between autism and other neuro-developmental and mental health conditions. One of the most common neuro-developmental condition that co-occurs with autism is Attention-Deficit/Hyperactivity Disorder (ADHD). Co-occurrence between ASC and ADHD is estimated to be between 20-70% (Brookman-Frazee & Stadnick, 2018; Joshi & Faraone, 2017; R. R. Lee & Ward, 2023; Leitner, 2014). Although ASC and ADHD are distinct conditions, (the former associated with social/communication difficulties and difficulty planning, whilst the latter is characterized by inattention and impulsivity) their co-occurrence is linked to severe impairment in executive functioning (Rosello & Martinez-Raga, 2022).

Mental health conditions that commonly co-occur with autism are anxiety, sleep disorders, depressive disorders, and obsessive-compulsive disorders (OCD) (Croen & Zerbo, 2015; Lai et al., 2019; Mannion & Leader, 2013). Research evidence indicates that at least 70% of autistic people are diagnosed with at least one mental health disorder, which is significantly higher compared to the rest of the population (Lai et al., 2019). Studies on outcomes for autistic adults suggest that persistent mental health difficulties are often accompanied by social isolation, low rates of independent living and occupational underachievement (Hickey & Crabtree, 2018; Hwang & Foley, 2020).

7.7. Autistic people's social participation

Autistic adults participate less often and across fewer major (ICF) life domains, including employment, education, and social, recreational, and community-based activities than the rest of the population (Song & Salzer, 2021). In the UK, autistic people have the highest unemployment rates across all disability groups (ONS 2021), with only 15% in full-time employment in 2008 (Rosenblatt, 2008). Examining autistic adults' wider social networks, research indicates that they have poorer quality peer relationships than the general population, including those with intellectual disabilities (Chan & Doran, 2023). At the same time, there is evidence that autistic adults are more likely to interact and form close relationships with others on the ASC spectrum compared to non-autistic people and they report similar levels of satisfaction with their intimate others as the rest of the population (C. J. Crompton & Hallett, 2020; Morrison & DeBrabander, 2020; Sedgewick & Leppanen, 2019).

Traditional approaches to participation, defined by the frequency of meeting people and the size and quality of social networks were developed with the non-autistic population in mind. Recent autism research, guided by the neurodiversity movement (see Section 7.7.1), acknowledge that autistic people might organise their social activities differently to non-autistic populations, and successful participation might 'look different' in ASC (Baron-Cohen, 2017; Chan et al., 2023; Elmose, 2020). A recent study by Chan investigated autistic adults' participation across a variety of domains and their findings confirmed that most autistic adults have a desire for social connection and that they especially value connecting with others on the spectrum. Moreover, their findings indicate that vocational environments (including volunteering), local communities, common interest groups, autism specific adult support groups and online social networks were the most valued places, both for practising social skills and different social roles; and for building ties of belonging, acceptance and support (Chan et al., 2022).

Social media has been highlighted as a medium that facilitates more effective social interaction between autistic people and others (for example because of the written communication mode and absence of environmental barriers) (K. Cooper & Smith, 2017; Hendrickx, 2015). At the same time, there is some evidence that social media use is not associated with a reduction in perceived loneliness in autistic populations (as opposed to face-to-face interactions), suggesting that it might not be an effective replacement for real world social engagement (Mazurek, 2013).

7.7.1. Factors enhancing autistic adults' social connectedness

Within the context of autistic people's risk of social isolation, researchers are focusing on the protective role of socio-psychological factors that improve autistic people's well-being and social connectedness. Developing a positive identity both in relation to self and to others on the spectrum seems to stand central to mitigating the negative outcomes associated with autism. Research shows that autistic adults often seem to develop a more positive sense of self over the life course, based on increased self-acceptance and the acquirement of higher levels of social competence (Hickey et al., 2018). Autistic people who develop a positive 'autistic identity' which they see as an integral part of themselves are more likely to report higher self-esteem and identify with other autistic people (K. Cooper et al., 2017; Hurlbutt & Chalmers, 2002). Social group membership has been shown benefit physical and psychological well-being (Haslam et al., 2015; Jetten & Haslam, 2012). Autistic people who identify strongly with others in the autistic community experience higher levels of social connectedness, have improved self-esteem and lower anxiety and depression scores (K. Cooper et al., 2017; R. Cooper et al., 2021).

7.8. Perceptions of autism

In parallel with the rising numbers of diagnoses, research into autism has increased significantly over the last 30 years (Happé & Frith, 2020). In the UK, funding into autism research has historically disproportionately targeted biomedical research, investigating autism in terms of its neurology and cognitive characteristics as well as its causes and treatments. There has been comparatively little research undertaken about the effective services for autistic people and their families, including diagnostic services and interventions. Moreover, most autism research focused on children, whilst relatively few studies targeted autistic adolescents and adults (Kenny & Hattersley, 2016). In recent years, applied research into autism has increased, but there is still a considerable gap in knowledge about the lived experiences and support needs of this population. A 2014 study by Pellicano investigating autistic people’s priorities for future UK autism research found that autistic adults, their families and autism practitioners wished to prioritise research into immediate practical concerns which had direct relevance to autistic people’s daily lives. Issues of immediate practical concern related to two main areas: 1) services and supports (including developing skills, evidence-based services, employment and post-diagnostic support) and 2) knowledge about autism (including practitioner training and accurate public awareness about autism) (Pellicano & Dinsmore, 2014). The qualitative study in this thesis aims to address the second of these themes, contributing to accurate knowledge about autism by articulating autistic participants’ experiences of social connectedness.

7.8.1. The neurodiversity movement

As research into and public awareness of autism is increasing, perceptions and understanding of the condition is undergoing continuous change and re-evaluation (Kenny et al., 2016). Recent shifts in the way autism is perceived and referred to, stem from the disability rights movement which aims to de-medicalise disability and emphasises the importance of the lived experience and human rights of disabled people from a societal perspective (Barnes, 2012; Kenny et al., 2016; Oliver, 2013).

The rise of the neurodiversity movement (Singer, 1999) has transformed perceptions of autism which is reflected in current policy making and rhetoric. The neurodiversity paradigm builds on the social model of disability and aims to normalise autism, seeing it as part of mankind’s naturally occurring neurological diversity. As such, it is seen as adding value to society by being a crucial source of evolutionary and creative potential (Chapman, 2019). From the perspective of the neurodiversity movement, autistic people are part of a larger neurodivergent population, whose neurological functioning is different from the mainstream norm in terms of their cognitive orientation, social, learning, and communication preferences. Neurotypical people, on the other hand, are seen to have typical or standard neurological functioning resulting in social behaviours that follow the norm, set by majority values.

Some of those advocating the neurodiversity paradigm believe that autistic individuals are made to feel disabled not because autistic traits are inherently harmful but because of the way these traits interact with neurotypical modes of social interaction, communication, and behaviour (Jaarsma & Welin, 2012; Kapp & Gillespie-Lynch, 2013).

7.8.2. Criticisms of the Neurodiversity Movement

The neurodiversity paradigm has attracted criticism both within the autistic community and among academics because its premise that autism is not a disorder, but a neurological 'difference' seems to refute the intrinsic difficulties that some autistic people experience as a direct result of this condition (R. Cooper et al., 2021). Hughes highlights how the heterogeneity of autism, its wide and complex range of manifestations (together with co-occurring conditions) contradict its perception as a socially constructed disability. Some autistic traits, when presenting with a high degree of severity (e.g.: sensory sensitivities, adherence to rigid routines, difficulties with receptive and expressive language acquisition and impairments in executive functioning) may cause limitations to daily functioning regardless of social context (Hughes, 2021). Acknowledging the significant social and health disadvantage that some autistic traits are associated with, especially for those who are severely affected, is crucial for accessing health and social care services.

7.8.3. Language use

The recent reframing of autism in positive terms as a neurological phenotype that is inseparable from an autistic person's identity (Sinclair & Grieve, 2017) is shaping the language used to describe it. Identity-first or disability-first language sees autistic traits as part of the innate characteristics of an individual (i.e.: 'autistic adult') and does not see autism as a separate (medical) condition which they 'have'. This view aligns with the neurodiversity approach to autism which sees it as an integral and accepted aspect of one's identity (Davidson & Henderson, 2010). Presently in the UK, a large proportion of autistic adults and family members prefer to use 'disability-first' or 'identity-first' language when talking about autism (Kenny et al., 2016). In line with recent research conducted by Kenny et al (2016) about the UK autism community's and their families' preferences for the terms used to describe autism, this thesis will use identity first language to refer to autism and autistic individuals.

7.9. Conclusion

This chapter introduced the rationale for carrying out additional qualitative analyses that build on the quantitative study results presented in Part II of this thesis. It also described the current diagnostic criteria of autism, and summarised common autistic traits which are likely to play a role in social participation. The next chapter sets out the qualitative study objectives and describes the methodology employed in the collection and analysis of the interview transcripts, followed by a personal reflection about my first attempt at qualitative research.

Chapter 8. The qualitative study: methods and reflections

8.1. Introduction

This chapter describes the research methodology of the qualitative study and reflections about my first experience of conducting qualitative research. The chapter consists of three main sections. The first two outline the research methodology and data analysis respectively. The third section is a reflexive piece of writing that describes how the researcher's previous academic and personal lived experience influenced data collection and interpretation.

8.1.1. Study aims

As described in the previous chapter (Chapter 7, Section 7.1, p. 196) people with neurodivergent conditions were poorly identified and under-sampled in the LOS, moreover, the LOS data was limited both in its specificity and coverage of barriers to participation. Autistic populations might encounter different types of barriers to participation than other disabled groups because of the unique challenges that autistic traits pose to social interactions. The main diagnostic features of autism lie in differences in social and communication functioning, and sensory processing, hence it could be expected that barriers to participation for this population will be located around these areas. I therefore decided to extend the knowledge and evidence generated through the analysis of the LOS data by investigating some of the gaps in evidence outlined earlier.

The primary research question of the qualitative study was one of the thesis' main research objectives as set out in Chapter 2 (Section 2.5.2, p.80):

To what extent do existing understandings of social connectedness and disability accommodate and respond to the social participation needs of people with neurodivergent conditions?

Within this broad theme there were several sub-questions:

1. What do autistic people identify as the main factors affecting their social participation across different life areas?
2. What role do autistic traits play in autistic people's social participation?
3. What criteria do autistic people use to evaluate their social interactions?
4. What does 'being socially connected' mean to autistic adults?

The interview topic guide was designed to collect information that would inform these research questions. They covered the following themes:

1. Exploration of the LOS barriers in an autistic population, to investigate:
    a. if the barriers to participation collected by the LOS were appropriate within the context of autism,
    b. what meaning these barriers were attributed to by this population, i.e.: what role they played in their access to participation.
2. Identification of gaps in knowledge:
    a. to explore if there were any additional barriers to participation in this population that were absent from the LOS,
    b. and find out if any of these additional barriers were present or absent from the wider literature;
3. Increasing understanding of social connectedness in autistic populations, to gain insight into:
    a. the value attributed to people and relationships in their social networks,
    b. and the mechanisms underlying social interactions.

8.1.2. Study design and methods

The qualitative study was designed to extend the quantitative study findings in a small sample of autistic adults without intellectual disability. Figure 8.1 locates the research focus of both studies within the conceptual framework of social relations developed in Chapter 2. Environmental and personal factors are the conditions affecting access to the existing social network and social participation in different life areas.

Figure 8.1 Locating the quantitative and qualitative studies in the thesis' conceptual framework of social connectedness (correct

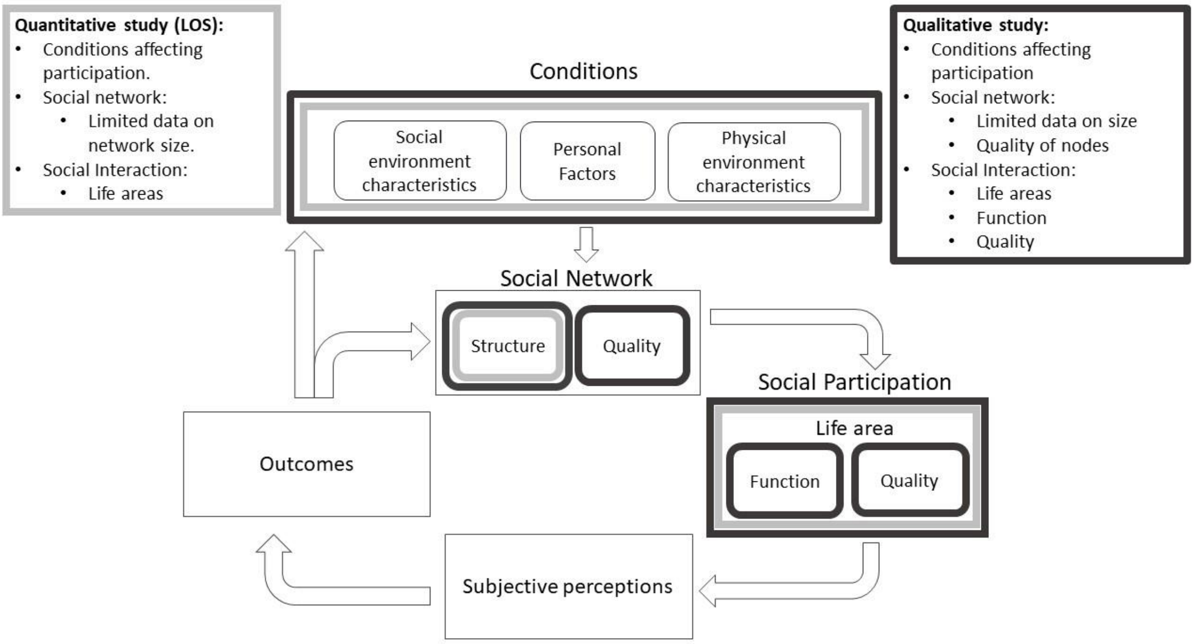


Table 8.1 illustrates how the qualitative research questions aligned with the above goals and locates the qualitative study in the wider thesis framework on connectedness.

Table 8.1 Qualitative research questions in relation to study aims and thesis framework

Research question	Study aim	Location in thesis framework
How do autistic adults access social activities in different life areas?	Aims 1 to 3: exploration of barriers, increasing understanding	• Social participation across life areas • Social network: size and node structure
What are the environmental and personal factors that affect participation and whether a tie can be formed successfully?	Aims 1 and 2: exploration of barriers	• Conditions • Social participation
What are the characteristics of the most valued people in respondents' social networks?	Aim 3: increasing understanding	• Social network: node quality
Is there anything that could be done to facilitate autistic people's social participation and connectedness?	Aims 1 and 2: exploration of barriers	• Conditions • Social participation: life areas

8.2. Methodology

This section describes the qualitative approach, data collection and processing methods and the characteristics of the study sample.

8.2.1. Ontological position

The ontological position of the qualitative study was guided by critical realism (Blaikie, 2007; Hammersley, 1992; Ritchie & Lewis, 2014). This approach assumes, that although there is an objective reality, it cannot be accessed directly because its experience and interpretation is highly subjective. Critical realism values the diversity of interpretations of the social world as they contribute to new insights and a more comprehensive understanding of the subject researched. As opposed to empirical approaches that characterise quantitative methods which strive for uniformity and generalisability, critical realism aims to map the richness and range of experience in relation to a research question (Barbour, 2014).

Within the context of this study, following a critical realism perspective meant exploring how respondents constructed interpretations of ‘barriers’ and ‘facilitators’ to ‘social participation’ within the lived experience of being autistic. The study was designed in such a way as to allow participants to construct their own definitions of the above concepts. Barriers were, for example, referred to in interviews as ‘anything that stops or hinders the person from participation in social activities’, allowing the participant to identify any internal or external factors that inhibited connectedness. Allowing participants to describe their experiences without any pre-defined categories, helped to generate data that lent itself to inductive theory generation.

The research data was collected and analysed within the framework of a social constructionist epistemology. This entailed maintaining an awareness of how my participants’ and my own interpretations contributed to the construction of meaning through each stage of the research: the interview process, designing the coding framework as well as the final analysis.

8.2.2. Qualitative approach

In line with the interpretive approach and constructivist epistemology, the study’s overall methodology followed a generic qualitative approach (Kahlke, 2014). The study aimed to construct a ‘rich description’ (Hoon Lim, 2011) of the barriers and facilitators to social connectedness reported by the study participants. It drew on grounded theory and phenomenological approaches, using inductive methods to generate new knowledge and perspectives about the research topic. The analytical approach was thematic analysis, which used open codes, themes and categories to describe how autistic adults experienced their social interactions and what meanings they attributed to their relationships and their perceived barriers and facilitators to participation. Deductive techniques were employed post-analysis, to verify the findings against existing research.

The study design consisted of cross-sectional data collection through semi-structured interviews. The following sections describe the sampling strategy, ethical considerations, data collection methods and processing.

8.2.3. Sampling strategy

The inclusion criteria of the study were adults over 18 years of age without cognitive impairment and with a diagnosis of autism. During recruitment, the decision was made to also include people who self-diagnosed. This information was not provided in the advert, giving priority to those with an AS diagnosis to come forward. The target sample size was 15, reflecting both the exploratory nature of the study and the fact that this was a smaller, follow-up component of the thesis research. Because of the time constraints placed on the study by the time frame of the PhD, it was decided to obtain a convenience sample, at the same time striving to increase the transferability of the results by selecting approximately equal numbers of male and female respondents (based on their names, since no other data was collected from people who registered an interest). It was considered important to achieve sufficient representation of female participants in the study because of the relative lack of research regarding autistic women and their experiences of social participation.

Recruitment

Recruitment took place online. A directory was drawn up of UK based autism support and advocacy groups, national charities and local social groups for autistic people using web searches. Adverts were placed on social media (primarily Facebook) and on the University of York's internal Slack channel for autistic members of staff and students. National autism organisations were also approached about advertising the study via email, but they either did not support research or had temporarily stopped supporting recruitment to research studies.

An advert/social media post was created that included a visual element (see Appendix 5, Section A 5.1, p. 316) and only a very brief study description. Potential participants could register their interest through an on-line form, upon which they would receive the study information sheet via email and there was a correspondence with them regarding arrangements for the interview. Those who confirmed their wish to participate in the study by email, were sent an online Consent and Background Details form (see Appendix 5, Section A 5.2, p. 317) which collected some demographic information including age (in groups), gender, ethnic background and whether the participant had a formal autism diagnosis and their age at diagnosis.

8.2.4. Data collection methods

Data collection took place between the May and July 2022. The interview mode was decided by the respondents. Respondents could choose between text-based or verbal communication modes and whether they wanted to be interviewed in person or remotely via zoom video, phone or chat. Nine of the semi-structured interviews were conducted via Zoom video call and two in person. Two respondents requested text-based interviews. For these, the Chat function of Zoom was used. The longest interview lasted 1 hour and 51 minutes and the shortest 42 minutes. Most interviews lasted a little over an hour.

8.2.5. Data collection instruments

A draft version of the topic guide was piloted twice, once with an autistic adult, and once with a qualitative researcher. They both provided feedback about the content and flow of the interview. Based on the revised topic guide (Appendix 5, Section A 5.3, p. 320), semi-structured interviews explored autistic adults' quantity and quality of social relationships on the intimate, informal, formal, and community network layers. During the interview we also discussed how these connections were formed in the first place. The questions in the topic guide also aimed to collect additional data on barriers and facilitators to social participation that were not represented in the Life Opportunities Survey.

Written interviews were recorded by Zoom and the transcripts were downloaded to a University of York centrally managed networked computer at the end of the interview. Video interviews were also captured by the Zoom recording tool and only the audio file of the recording was downloaded for transcription. In person interviews were recorded by a digital audio recorder and the audio files transferred to the university managed computer at the end of the interview.

8.2.6. Sample characteristics

Participants were recruited from three sources. The final study sample comprised 13 adults with a varied range of demographic characteristics (see Table 8.2). Age at diagnosis ranged from 13 to 52 years. Eleven participants had been assessed and diagnosed by an autism diagnostic service, and two were self-diagnosed.

Table 8.2 Demographic characteristics of study sample

Gender at birth	Gender identity	Age	Partner	Dep. child	Employment status	Living arrangement	Approx. time since diagnosis
Female	Female	36-45	yes	yes	Carer	independent	2 years
Female	Female	36-45	yes	yes	Student/carer	independent	4 years
Female	Female	56-65	yes	no	FT Employed	independent	7 years
Female	Female	18-25	no	no	Student	with parents	2 years
Female	Female	46-55	yes	no	FT Employed	independent	2 years
Female	Female	46-55	yes	no	PT Employed	independent	2 mnths
Female	Non-binary	26-35	no	yes	PT Employed	independent	5 years
Male	Male	26-35	yes	yes	FT Employed	independent	1 year
Male	Male	26-35	no	no	FT Employed	independent	10 years
Male	Male	46-55	yes	yes	FT Employed	independent	5 years
Male	Male	18-25	no	no	Unemployed	with parents	2 years
Male	Male	18-25	no	no	Student	independent	8 years
Male	Female	18-25	no	no	Student	independent	8 years

There were some marked differences between biological male and biological female respondents with regards to some of their demographic characteristics. Participants who were born female were on average 12 years older at the time of interview (average group age 41 years old) than those born male (average group age 29 years). The average time elapsed since diagnosis was shorter (3 years on average) for biological females than for biological males (6 years on average). These sample characteristics confirm previous findings, suggesting that women are diagnosed with autism later in life than men (Carpenter et al., 2019; Happé & Frith, 2020). Women were more likely to have a partner (5 out of 7) than men (2 out of 6) but this could be related to female respondents being significantly older than male respondents. At the same time, male respondents were more likely to be in full-time employment, whilst female respondents were more likely to look after young children or work part-time. There seemed to be no differences with regards to living arrangements, with a high proportion of the sample living independently.

8.3. Ethical issues

Ethics approval was obtained prior to recruitment from the Social Policy and Social Work Departmental Ethics Committee at the University of York (SPSW/P/2022/01). A project risk assessment was carried out to identify potential risks to the researcher and the participants in line with the University of York's guidelines.

8.3.1. Risks to participants

When designing the research questions and topic guide, I was acutely aware of the sensitivity of the subject I was researching within the context of autism. Autism is a condition that primarily affects social and communication skills, as well as emotional regulation, putting autistic individuals at a considerable risk of social isolation and associated adverse mental health outcomes. Talking to autistic people about their experiences with social connectedness held ethical implications because there was a risk that the interview would elicit painful feelings and traumatic memories. The actions I took to mitigate the risk of causing distress was reminding participants at the beginning of each interview that they could choose not to answer a question, monitoring participants during the interview to see if they were comfortable talking about their experiences, not asking probing questions when participants seemed reluctant to talk about a topic, and being prepared to make follow up emails about autism specific support groups if it was necessary after the interview. I was also prepared to discontinue the line of questioning or pause the interview if I had noticed significant distress in the interviewee or if they requested this.

8.3.2. Risks to researcher

Since all interviews were conducted online or during daytime in the grounds of the university, the interviewing process posed no danger to me as a researcher. With regards to any emotional response I might have had to the content of the interviews, I had my supervisor to debrief with if necessary.

8.4. Data protection

A Data Management Plan was drawn up in accordance with GDPR requirements whereby all interview audio recordings and scripts were stored exclusively on the University of York's password protected and centrally managed file store and on the organisational Google Drive. Each participant signed a consent form before taking part in the interview. The consent form provided opportunity to withdraw from the study and the option of the interview not being audio-recorded. Interviewees also received a Privacy Notice which explained how their data would be used and stored.

8.5. Data processing

Transcription of data was performed by the researcher using Microsoft Word during August and September 2022. All the names referred to during interviews (including respondents' names) were removed from transcripts and replaced with either initials or the role they played in the participant's network, e.g.: wife, daughter, friend. Respondents' job titles and specific community activities and hobbies were removed from excerpts reported in the results (Chapter 9). Transcript files were named by respondent's initials following the interview date and stored on the University of York's managed computer file stores. The interview transcripts preserved as much of the spoken content as possible to reflect the speaking style and character of the speaker. False starts and word/phrase repetitions were only deleted if they would interfere with comprehension of the written text later on. When transcribing, attention was paid to mood, tone, longer pauses and emphatic language. Emphasis in speech was noted in italics, longer pauses (lasting over 5 seconds) were marked with ellipses and notes on mood such as 'laughing' were placed in square brackets.

8.6. Data analysis

Data analysis was carried out solely by the PhD candidate between October 2022 and January 2023. The objectives of the data analysis were to:

1. Define and describe the sample's personal networks and examine and test for patterns in the characteristics of participants in each network type. The creation of the network typology was informed by Fiori et al's work on social network types as described in Section 8.6.1 (Fiori & Smith, 2007).
2. Thematic analysis was used to identify themes and topics around:
    a. Current participation activity in the sample.
    b. Characteristics of valued people in respondents' social networks and how these connections were formed.
    c. Factors affecting access to participation in different life areas.

The process of coding and thematic analysis are described in section 8.6.2.

8.6.1. Constructing social network types

At the first stage of the data analysis, a participant summary table was drawn up in Excel that contained, apart from a brief summary of respondent demographic characteristics (e.g.: age, gender, age at diagnosis, who they lived with and employment status), an indication of their main social activities, their sources of emotional support, self-reported satisfaction with their social network and their main self-reported barriers to participation. The table included a researcher's note section describing how the participant came across in the interview in terms of their overall emotional well-being and the researcher's impression of their extent of and satisfaction with their connectedness.

The participant summary table was used to create a social network typology where interviewees were assigned into one of four types of social network: family focused, friend focused, diverse or restricted. The typology drew on Fiori et al's work on social network types among older adults, where social networks were characterised based on their structural, functional, and qualitative characteristics (Fiori et al., 2007). Fiori's approach to classifying social networks was adapted to the thesis' existing conceptual model of social relations (see Chapter 1, Figure 1.6, p. 50).

Defining network characteristics

Fiori defined the structural aspects of the social network in terms of ‘network size, proximity of network members, marital status, frequency of contact with network members, and participation in social organizations or activities’ (Fiori et al., 2007, p 322). The social network’s structural aspects are captured by the thesis’ conceptual model of connectedness by the number of nodes on each network layer and the frequency of participation in each life area.

Fiori’s measure of functional features of the social network were ‘the exchange of different kinds of support (emotional and instrumental) between network members, as well as the proportion of network members considered to be emotionally close’ (Fiori et al., 2007, p 322). Social network function in this thesis is characterised by tie function (in line with Fiori’s definition) but not by perceived closeness to nodes (a departure from Fiori’s definition).

Fiori assessed social network quality by respondents’ subjective evaluations of their networks. Within the thesis’ conceptual model, social network quality is comprised of three components: the quality of network nodes, the quality of network ties and respondents’ subjective evaluation of whether the social interactions provided by their social network meet their emotional and psychological needs. Node quality refers to the perceived value of a network member based on their attributes and tie quality refers to the perceived value of a relationship based on the resources it transmits and the role relations involved (e.g.: level of reciprocity, symmetry).

Operationalising the network typology using qualitative data

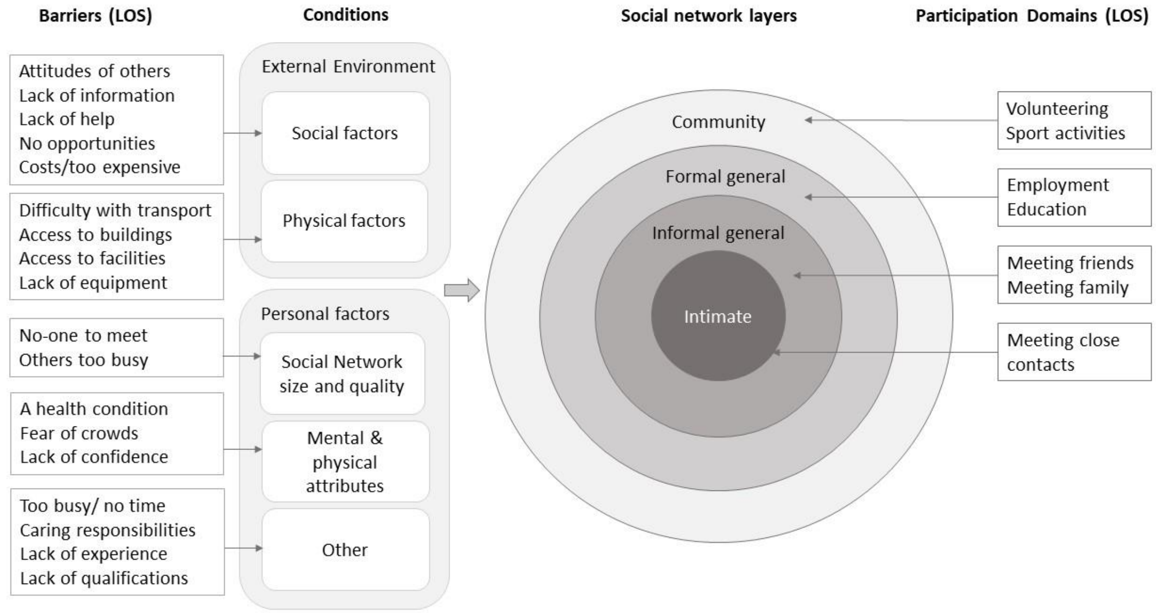
The structural, functional, and qualitative features of interviewees’ social networks were identified from qualitative data gained from interviews. Data on structural features included the number of people in the social network that participants talked about in different social contexts, as well as the frequency with which the interviewee was meeting them. Data on the functional features of the social network was derived from whether the participant reported to have a partner (an indication of intimacy support) and any information they provided about receiving instrumental or emotional support from any other network members. Information about the perceived quality of the social network was gained from several sources: (1) by directly asking participants to evaluate their satisfaction with their social network; (2) by an estimation of the size and diversity of their social network based on the information provided in the interview; (3) and by the researcher's overall impression of participants' contentment with their social network when talking about their relationships. Chapter 9 presents the resulting network typology.

8.6.2. Coding and thematic analysis

The qualitative data was analysed using the framework method first developed by Ritchie and Spencer (Ritchie & Spencer, 1994) and now widely used in applied qualitative research (Furber, 2010; Gale & Heath, 2013; Goldsmith, 2021; Kiernan & Hill, 2018). The first stage of the analysis involved familiarisation with the data, by reading and re-reading the interview transcripts. During this process, themes, subthemes, and topics were identified which were used to create a thematic framework. The creation of the thematic framework incorporated both a top-down and a bottom-up approach.

The initial thematic framework drew on a-priory codes which broadly followed the topic guide and the research questions around which the interviews were built. The themes and topics identified were informed by the model used in the quantitative study, which used the thesis' conceptual model of social relations to map barriers to participation collected by the LOS (reproduced in Figure 8.2). The three core elements of this model were (1) the social network (consisting of concentric network layers), (2) the life areas where the social interaction takes place, (3) and the environmental conditions and individual attributes affecting participation. Regular reference and cross-checking against the LOS barriers helped the initial analysis to retain focus on the research questions.

Figure 8.2 LOS life areas and barriers to participation within the thesis conceptual framework



The theory driven approach to building the initial framework was complemented by inductive, bottom-up methods, which involved looking for new themes and topics in the interview transcripts that represented processes and factors influencing social connectedness that were absent from the thesis' conceptual framework and the LOS survey. The interview transcripts were re-read and participants' language use and phraseology were examined, noting commonly occurring vocabulary used to describe experiences related to connectedness. Words and phrases identified in this way were categorised by topic and formed new in-vivo codes in the revised thematic framework.

Next, qualitative coding took place in NVivo, by applying the thematic framework to the interview transcripts (see Section 8.6.3). This was followed by a process of charting and summarising the initial findings using a matrix in an Excel spreadsheet. In this matrix, each participant was assigned to a row and the themes, subthemes, and topics were organised into columns. Every cell in the matrix contained direct quotes from respondents' interview transcripts to illustrate what the individual participant said about a given theme or topic.

In the final stage of analysis, the Excel matrix was used for interpretation and mapping. Within-case and cross-case comparisons were performed to establish higher level themes and to identify patterns across different themes as well as exceptions to these patterns in participants' accounts.

8.6.3. Provisional coding framework

A provisional coding framework was developed using NVivo (version 20.7.01533) which drew on the initial thematic framework to organise codes around three main themes. These related to (1) participants' existing social networks including current participation rates, (2) factors affecting access to different life areas and a new theme emerging from the qualitative data that related to (3) the features of the social interaction that were reported to play a role in being able to participate in it.

The provisional coding framework was revised as line by line coding progressed, continuously adding to and refining existing codes as working through the transcripts (Appendix 5, Section A 5.4, p. 328). New subthemes and topics were incorporated within the wider coding system. Topics which received large numbers of codes, indicating high density of data, were examined to see if they could be split into subthemes. Some themes which contained sparse data were examined to see if they constituted a 'negative category' that appeared to contradict a commonly reported experience; or if they did not belong to a previously established theme, whether they were an example of the diversity of experience present in the data. Relationships between themes were also explored to identify patterns in the data. Once the qualitative data was exhausted and no more new categories could be identified, saturation was achieved and the coding framework was refined with lesser reference to the transcripts.

8.6.4. Refining the coding framework

During the refinement of the coding framework, a significant shift occurred in terms of the interpretation of the data. This entailed moving away from the topic guide and examining the material coded under each theme, sub-theme and topic, and constructing abstract, higher-level codes which captured factors influencing social connectedness that related to psycho-social processes. These processes often centred around the individual's understanding and integration of their autistic traits or on participants' perceptions of the functional and qualitative elements of the social interaction (e.g.: the effectiveness of communication and the level of reciprocity between participants). This stage of analysis contributed most to the generation of new theory and resulted in a proposed modification of the ICF model of disability, which will be presented in Chapter 10. The final coding framework is presented in Box 1.

Box 8.1 Qualitative study: final coding framework

1. Existing network
    a) How existing connections were made
    b) Regular activities pursued at present
2. Characteristics of valued people
    a) Personal attributes
    b) Definition of friendship
    c) Types of support provided by valued people
3. Factors affecting access to participation
    a) Societal
        i) Autism awareness
        ii) Access to diagnosis
        iii) Opportunities
        iv) Institutional policies and practices
        v) Costs
    b) Environmental
        i) Transport
        ii) Physical environment
        iii) Sensory environment
    c) Individual
        i) Age
        ii) Autistic traits
        iii) Understanding autistic traits
        iv) Interests
        v) Using transport
        vi) Employment
        vii) Caring responsibilities
        viii) Mental health
4. Social interaction
    a) Communication format
    b) Purpose
    c) Qualitative features
    d) Structure
    e) NT vs ND communication styles
    f) Masking

8.6.5. Techniques to enhance trustworthiness

Trustworthiness of analysis was enhanced through the constant comparative method (Barbour, 2014). This involved counting the number of participants within each code of the coding frame, followed by comparing their accounts and looking for any patterns in their answers based on their demographic, personal and other contextual characteristics as well as their network type based on the typology created. Common themes were derived and interpreted within the context of the interviews, and in relation to participant characteristics. The data was charted to compare the relative frequency with which certain themes and topics were talked about during interviews. Analytical notes and summaries were created to describe the data displayed. Attention was paid to recording exceptions to common patterns because of their explanatory value for later theory generation.

8.7. Researcher characteristics and reflections

In this section I reflect about my position in the study as a researcher responsible for all stages and elements of the qualitative data collection and analysis process (Denscombe, 2010; Finlay & Gough, 2003). I am reporting and reflecting on how my personal attributes and life experiences were accounted for in every stage of the research process to both minimise bias and enhance the findings. I was aware of possible bias from two main sources. The first one was my own lived experience of neurodivergence and how that would manifest itself through the assumptions I might be making when constructing meaning from my participants' accounts. The second source of bias was being new to qualitative research and having had virtually no previous experience of interviewing or analysing qualitative data.

8.7.1. Personal experience with autism

I am a white middle-aged woman with no disabilities. At the same time, I have considerable lived experience of autism and its co-occurring conditions (namely ADD and OCD) within my close and extended family. I understood that my close personal experience with autism exposed me to potential bias and emotional reactions during data collection and analysis.

Throughout the research process, I endeavoured to maintain high levels of self-awareness and reflexivity so that my insider knowledge would become an asset in the research process rather than a disadvantage.

8.7.2. Being new to qualitative research

In preparation for the qualitative study, I attended several postgraduate training sessions on research ethics, qualitative interviewing, transcribing and reflexivity in research. I also consulted with senior academics experienced in conducting qualitative research about topic guide development and practical tips about interviewing. I found the interactive training sessions the most beneficial, where students could practice their interviewing skills on each other in pairs. This experience gave me confidence regarding my ability to build rapport and gain insightful information from my interviewees. I found that the training sessions offered limited practical advice regarding qualitative data analysis.

Being new to qualitative research influenced every stage of the research process. It manifested itself primarily in my mind-set and the way I approached data collection and analysis. My previous experience in doing quantitative analysis predisposed me to trying to systemise and 'control' the data by keeping themes and subthemes separate and by building a conceptual model that would guide data analysis. This approach could not be executed 'neatly' and as a result I felt overwhelmed by the volume and 'messiness' of the data. At the start of the analysis, I conceptualised 'social connectedness' as described by my study sample as one large phenomenon comprising of hundreds of micro phenomena that were intricately linked and led to different outcomes for different people. My main difficulty lay in determining the overarching themes that connected singular topics, categories and subthemes together to form a coherent interpretation of the findings.

The sections below describe how my experience of autism and being new to qualitative research affected different stages of the research process.

8.7.3. Topic guide design and participant recruitment

When designing the topic guide, I had to design open ended questions, anticipate different types of responses and the possibility of using prompts. This was a new, inductive method of data collection that was unfamiliar to me. My previous experience with designing survey questions hampered this process because when collecting quantitative data, the goal is to constrain answers to meet a certain set of pre-defined criteria (e.g.: to fit in with categorical or numerical values which do not overlap), whilst when collecting qualitative data, the goal is to generate new knowledge from others' constructed meanings which are often complex with a large amount of overlap. I piloted the first draft of my topic guide with an experienced researcher who provided me with feedback about my interviewing style and advised me about how to start and close interviews, which I had the most difficulty with.

During the recruitment stage, having had previous experience of communicating with autistic people, I had an increased sensitivity and alertness when exchanging emails and setting up interview dates with potential participants. I was committed to be clear and brief in my written communication, and to accommodate requests for different modes of interviewing (for example in person or in writing even though originally interviews were only offered to take place on zoom).

8.7.4. Conducting the interviews

Conducting the semi-structured interviews was the stage of the research process which contained the biggest risk for potential bias. As a general rule, I tried to distance myself as much as possible from my lived experience of autism, keeping an open mind about the responses given in interviews. I also aimed at maintaining empathic neutrality and staying within my role as an unbiased researcher. I failed several times on both counts especially during the first few interviews.

Experiences as a novice interviewer

Collecting qualitative data through interviewing is a unique form of communication exchange. The interviewer needs to establish trust with the interviewee without any significant reference to themselves, providing them a platform to voice their experiences. Being a novice, I had a whole new set of skills to acquire, including building rapport with my respondents, monitoring my interviewees' and my own responses to questions, anticipating potentially sensitive topics, keeping the content of the conversation relevant to the research questions, time keeping and the technical tasks surrounding recording and saving the interview audio files. Learning these new skills involved significant cognitive and emotional demands especially at the start of the interviewing process.

I felt exposed as being an inexperienced interviewer especially during my initial attempts at interviewing, where I was ‘too sympathetic’ towards my interviewees or expressed a value judgement about what was being said (for example: ‘That’s nice!’). This informal approach established positive rapport quickly but at the same time it diminished my control over the conversation, hence my ability to keep it relevant to my research questions or explore topics in greater depth. Being ‘caught up’ in the moment was a mistake I made in my first couple of interviews, especially with respondents who I shared demographic characteristics and life experiences with.

I also became aware of sometimes theorising ‘in situ’. I found myself attempting to map up in my mind where what was being said would slot into my conceptual framework or how it related to previous research. This resulted in theory led assumptions being made and some possibly leading questions. As the interviews progressed, however, I stopped doing this and followed the topic guide more closely. I also paid more attention to where the content of the interview was going and learnt to redirect the conversation to the relevant topics and pursue questions left unanswered. I focused less on being ‘likeable’ and more on what the participant’s account was telling me about my research questions. I learnt that rapport builds naturally through competent communication and being in charge of the interview whilst leaving personality on the margins. My tendency to reflect my interpretation back to the interviewees proved to be a useful technique because it gave my respondents the opportunity to set the record straight when I misinterpreted them.

Modes of interviewing

Conducting the interviews using different methods also provided some challenges. My first two respondents asked for a text-based interview. I accommodated their requests, and their interviews were conducted via the chat function on Zoom. My first interviewee gave me two interview sessions, one in the morning and one in the evening of the same day. This gave me the opportunity to learn from the morning session and adjust my interviewing technique for the evening. The advantage of conducting interviews in writing was that there was more time to think and formulate a question or an answer. There was also no need for ‘image management’ involving monitoring one’s body language and facial expressions which is required when seeing people in person and especially on camera. The disadvantage was that there was a time delay between questions and answers, and it was hard to tell when someone was still thinking or typing or if they were finished with giving the answer because unlike some other messaging apps, Zoom does not display when the other person is typing. It happened several times that we were both typing at the same time and as a result, some answers appeared after a new question or comment had been posted. This was not an insurmountable problem and could be avoided by giving each other more time to respond as well as using some agreed notations in writing. I asked my participant to put an ellipsis (…) to the end of the sentence when she was going to carry on with a thought and was still planning to write more. I started using 'question' to signal when a new question was coming up so that my participant expected me to introduce a new topic. With the second written interview, building on these experiences, my instructions were clearer from the start.

Vulnerable participants

One source of challenge was interviewing participants who reported feeling quite isolated and were dissatisfied with their social networks. Interviews with these participants felt more intense and emotionally demanding. They seemed to require some level of validation, reassurance even, which they expressed either implicitly or explicitly in their interviews. For example, one participant asked me whether 'it was normal not to be invited by others to do things with them'. I found answering this question an ethical dilemma because I did not want to commit collusion by giving her unfounded reassurance, at the same time I could sense her anxiety and I felt that a response was required. The question came up twice during the interview and I gently moved the conversation on, acknowledging that I heard her whilst not providing a direct answer but making a mental note. Later on in the interview, she told me about how all her friends were neurodivergent with most of them experiencing significant levels of executive dysfunction. I felt this was the time to suggest that this may be a reason why they were not good at organising social events and inviting her to them. On reflection, she found this answer to make sense and she could find evidence for this in her experience and as a result she seemed more reassured.

8.7.5. How my lived experience of autism influenced the interviews

With regards to my lived experience of autism, I took the decision not to share this information with my participants. The reason for this was that I aimed to establish empathic neutrality in my conversations with participants and I did not want them to adjust their accounts to what they might have assumed I ‘already knew’. I wanted to put my participants centre stage and allow them to freely recount their experiences to someone with an open and enquiring mind. I succeeded doing this on the most part with some occasional bias creeping in, especially in the beginning. At times I failed to follow up an answer in more detail because I believed I understood what the respondent ‘meant’ with it. Other times, my assumptions manifested themselves in the form of questions or observations, for example: “Was that a sensory issue?” (instead of the more neutral “Why was that?”) or “Sounds like you have a good relationship with yourself.” (which is a statement instead of a question). Making these types of interpretive statements gave participants the chance to correct my ‘constructed meanings’ which they always did. In a sense these mistakes might have in fact enriched the interviews because they revealed a sense of understanding, at the same time allowing participants to correct me or further explore the topic.

Managing the interviews with participants’ needs in mind

I feel that having some insight into autism enhanced the interviewing process primarily because it enabled me to respond quite naturally to my participants. My instinctive knowledge of autism manifested itself in small gestures. For example, when interviewing participants in person, I made sure not to place my laptop anywhere on the table in the interviewing room signalling occupancy of a space. I wanted to make sure my interviewees felt free to choose where to sit. This turned out to be very important to one of my participants, who shared with me that she could not sit with her back to a glass wall/window where others walk behind her (my interview room contained a translucent glass wall).

I also instinctively minimised small talk at the beginning of the interview sessions, only asking questions that were intended to find out whether my interviewees needed any more information about the study instead of ‘to break the ice’ or ‘to put my participant at ease’. I instinctively knew that polite small talk would likely make most of my interviewees feel uneasy. During the interviewing process I did not talk much and aimed never to interrupt. I never spoke more than three sentences in one conversation turn, mostly just one. I also made an effort to allow for silences between utterances to give people enough processing time. I kept my composure very calm and kept my voice at a soft pitch and not too loud, often mirroring the pitch of my participants. My participants might have sensed that I felt very comfortable talking to them which put them at ease and helped them open up.

8.7.6. Reflections about qualitative data analysis

At the stage of analysis, I had to be careful not to allow themes that I felt passionate about (based on my lived experience of autism) to hijack the interpretation of the data. This task was compounded by being a novice qualitative researcher and feeling overwhelmed by the nature and volume of qualitative data. After the initial indexing and identification of some main themes, I had a brief foray into self-determination theory which I felt explained the findings well. Being reminded by my supervisor of my own conceptual framework and the need to complement the quantitative study with regards to barriers and facilitators of connectedness, I redirected the analysis back to the main topic of my thesis. I refined my coding framework twice, each iteration becoming more finely tuned to the research questions.

Data analysis and interpretation continued well into the writing up of the qualitative findings chapter. Having a predefined conceptual model of connectedness and a type of brain that is prone to theorising delayed the interpretation and synthetisation of the results. My attempts at strictly adhering to 'my model' of social connectedness resulted in fracturing the data into disconnected micro-themes which closely resembled to variable descriptions of survey data. An example of this was my attempt to discuss the factors that influence access to different life areas separately, starting with environmental and social conditions and continuing with individual traits and attributes. There is a large amount of interaction between external conditions and individual attributes which made the task of keeping them all in separate boxes impossible and resulted in a lot of cross referencing and repetition throughout the first draft of the chapter. I was also led astray by having to consider participation on several different network layers (4 altogether from intimate to community) and initially attempting to present results for each network layer separately. Learning to 'weave in' contextual information into the presentation of results constituted a major learning curve.

The first break-through in writing up occurred when I realised that the conditions affecting participation (which were neatly categorised in the conceptual model) could not be discussed without reference to each other. The second break-through occurred when my standpoint shifted from talking about ‘participants’ to talking about ‘themes’. This entailed moving from describing respondents’ individual experiences to introducing higher level themes, where respondents’ experiences only served an illustrative purpose. Finding themes on the intermediate level, located between the ‘big picture’ and the micro-level lived experience constituted the hardest part of the write-up.

8.8. Conclusion

This chapter located the qualitative study within the larger thesis framework. It introduced the qualitative study’s rationale and design and described the methods used for data collection and analysis. The chapter also described the researcher’s reflections with regards to conducting the qualitative study and the possible sources of bias that could affect the interviews and interpretation of the data.

Chapter 9. Autistic adults' accounts of their social participation and relationships with others

9.1. Introduction

The focus of the qualitative study was to validate the LOS barriers to participation in a small sample of autistic adults, and to explore if there were any additional, hereto under-researched or unknown factors that might play a role in the social participation of this group. The chapter is divided into two main sections. The first part describes the social network types found in the study sample to help contextualise the rest of the findings. The second section summarises the factors that autistic participants emphasised as playing an important role in forming and maintaining their social networks.

Whilst until now, the thesis focused primarily on the barriers and facilitators to social participation across a range of life areas, the qualitative study also collected – besides current participation activity – data on interviewees' existing social network, the characteristics of their network members and their satisfaction with their current state of social connectedness. The following sections outline how information about participants' social networks was employed in the interpretation of the qualitative data.

9.2. Assigning participants to social network types

At the first stage of the qualitative data analysis, a social network typology was created following Fiori's approach (as described in Chapter 8) that incorporated network structure, function, and quality to distinguish and define the different types of social networks represented in the sample (Fiori et al., 2007). The structural, functional, and qualitative features of interviewees' social networks were identified from the qualitative data gained from interviews. The resulting network typology is presented in Table 9.1.

Table 9.1 Social Network Typology based on the structural, functional and qualitative characteristics of participants' social networks

Network	Family focused	Friend focused	Diverse	Restricted
Structure				
Nodes: - Position in the network: intimate, informal, formal, community layer - Quantity	Network dominated by family, formal and community ties. Informal connections present in the network, with infrequent and primarily online contact.	Little or no contact with family. Extensive informal network contacted regularly both online and in person. Presence of formal and community ties.	Family relationships are present in network but are not attributed significant importance. Presence of several close informal connections. Presence of community ties.	Most network connections consist of family members. Some informal connections are present whose 'closeness' is questioned. Lack of close or intimate connections. Few or no ties to the community.
Frequency and domain of participation	Most social activity in family sphere, followed by community and employment domains.	Most social activity focused on informal relationships.	Regular social activity across all network layers.	Either no social activity, or a lot of effort is expended on 'unsatisfactory' activity.
Function				
Presence of intimate other	Yes	No, or present but not relied on	Yes	No or unsupportive partner
Resources flowing through the network	Instrumental and emotional support *Limited access to informal connections*	Emotional support *Lack of intimacy*	Instrumental and emotional support	Instrumental and emotional support *Lack of reciprocal support*
Quality				
- Overall satisfaction with network - Quality of ties (e.g. reciprocity, duration) - Quality of nodes (e.g. NT vs ND, personal traits) - Researcher's judgement	Broadly (but not quite) satisfied with network. Not actively looking for more connections but open to them. Planning to return to informal activities when children are older.	Broadly satisfied, but some gaps in support. Some sense of loneliness because of lack of significant other or not lonely and shows a degree of emotional self-reliance.	Satisfied with number and quality of social connections. Reporting positive self-image and high level of subjective connectedness/belonging. Good perceived support from partner.	Either explicitly expressing dissatisfaction with network, or seemingly satisfied but planning to make or actively searching for more connections. No intimate connection or difficulties with partner.

Each participant was assigned to a social network type and this information was used throughout the analysis to investigate whether there were any patterns in social, demographic, individual or behavioural characteristics that were associated with having a particular type of network. The following sections describe each network type and how they related to participant characteristics.

9.2.1. Family focused network

Family focused networks were characterised by an emphasis on close, intimate relationships and social interactions which were primarily governed by the domestic sphere. Participants with this network type were all aged under 35 with a partner and had at least one child under 5. Most of the social activity in this type of network, centred on parenting and family life, either within the home or in the local community. Out of all their social relations, participants in this network type placed most emphasis on their relationship with their partner, often described as their 'best friend', who they perceived as their main source of emotional and instrumental support.

> "We've always been there for each other and grown in ways that we've continued to be compatible, and we feel very fortunate about that, I think. … I mean [my partner] is undoubtedly the single most important person in my life." (Participant 4, Male aged 26-35)

Interviewees with a family focused network who were not employed, undertook most of their social participation in the community domain (besides spending time with close connections at home). This involved outings to public spaces, galleries, and museums, as well attending parenting groups and children's activity classes. Despite reporting to have made several connections in their local communities, participants rarely considered them close.

> "But the other mums, I don't know if I would consider them friends. Probably not. I think 'acquaintances'." (Participant 1, Female aged 36-45)

Even when on friendly terms, interactions with other parents were often instigated by and constrained to child-related activities.

> "[Daughter's] best friend's mum is a good friend, but even her I don't see just for myself. It would be related to the children." (Participant 2, Female aged 36-45)

There was a sense that although participants with family focused networks were able to form close informal connections in the past, access to these existing friendships were limited for the time being because of having young children (see Section 9.3.1). The main method participants employed to maintain and expand their existing informal connections was through the use of the Internet. Two interviewees made extensive use of online platforms. One of them talked about enjoying being part of a neurodivergent parent group on social media and she also blogged regularly. Another participant maintained a long-standing friendships online and over the telephone, and created podcasts with a friend.

Wider family ties with parents and siblings were present in this social network type, but were not relied on. Although participants reported to be in regular contact with their family members, some of these relationships were perceived to be either not very close or not to be depended on for substantial support.

> "And there is my family I suppose, re sources of support. But I'm not close to my parents, and my sister have issues of their own, so I don't expect them to support me. But we do talk online regularly and see each other in real life sometimes." (Participant 2, Female aged 36-45)

Overall, participants with a family focused network expressed a sense of satisfaction with their social connectedness, whilst acknowledging that having young children put limitations to their access to informal connections, albeit temporarily.

9.2.2. Friend focused network

Friend focused networks were characterised by an emphasis on informal relationships and relatively fewer numbers of intimate and family relations. Participants with friend focused networks had high levels of participation across the domains of employment, interpersonal activities and the community. Two of the three participants with a friend focused network were young adults aged between 25 and 35 and had no intimate partners. Some of their social activity was directed at finding an intimate relationships which was apparent from their use of dating apps. Not having a partner sometimes resulted in a sense of lacking support in some areas of life, as described by this single parent who highlighted, within the context of parenting, how she had limited access to either instrumental or emotional support.

> "I have some emotional support. Yeah, I do. I have good friends. And I have a therapist. Those are good things. But practically, the day to day type of things, is mostly on me… their Dad is involved, but the emotional labour is all mine really" (Participant 5, Non-binary aged 26-35)

The third participant who was middle aged and did have a partner reported to have little or no need for emotional support. Although she could identify potential sources of support in her social network, she described a preference for self-reliance when it came to resolving emotional problems.

> "I don't really… I've got people who I could call. But I probably… what, for emotional support? Nobody. Because, I don't know, I'm one for sorting things out on my own. I do journal, I do write. And you know, if I'm really, really upset or something, I will write it down. But you won't find me phoning somebody up and say 'Oh I'm in tears and can you come around?'" (Participant 11, Female aged 46-55)

The same interviewee also reported not having female friends and preferring the company of men because she found social interactions with them more straightforward, expressing this as 'what you see is what you get'.

Relationships to family members were rarely mentioned by participants with friend focused networks, or if they were, they were less likely to talk about them (especially parents) in positive terms and did not consider them as a source of support. In one participant's account, the closeness he experienced with his friends was juxtaposed to his relationship with his parents, which he evaluated as problematic.

> "I didn't get emotional support from my parents. I don't really from my mom still so, like that was very important to me while I was a university. They [friends] were my support network because I didn't have anything back home." (Participant 7, Male aged 26-35)

Participants with friend focused social networks who did not have an intimate partner seemed to be lacking the forms of social support that an intimate tie provides. Hence, although they reported overall satisfaction with their network, there was a sense that they were still searching for an intimate relationship.

9.2.3. Diverse networks

Diverse networks were characterised by the presence of nodes on every layer of the social network, social participation in a variety of life areas, and having no caring responsibilities for dependants. Two participants had a diverse social network. They were both married women over fifty years old who were employed and were also active in their local communities. They both reported to have a close, supportive relationship with their partner and several long-lasting friendships. Participants with diverse networks displayed a high level of satisfaction with their connectedness. This was expressed in the way they talked about their friends, appreciating them for their neurodivergent qualities which pointed to a sense of solidarity and belonging. This interviewee’s description of her longest friendships clearly showcases her affection and admiration of her friends, most of whom received an autism diagnosis later in life (like herself).

> “I’d say I have got about half a dozen really, and looking back now, they're all autistic. And it's phenomenal… I would describe them as light bulbs. They're just so creative and knowledgeable in their own fields of expressed interest. That's all they talk about a lot of time, and you can see how enthusiastic and passionate and joyful they are, doing what they love.” (Participant 12, Female aged 46-55)

9.2.4. Restricted networks

Restricted social networks were characterized by either sparse or not sufficient ‘quality’ connections on two or more network layers. Five participants had a restricted network type. Four of these were the youngest participants, whose intimate network layer was dominated by close relationships with members of the family. The younger participants were likely to either live at home or to be in contact with their parents and grandparents on a weekly if not daily basis and they drew most of their emotional support from their families. Four out of the five participants with this network type had no intimate partners, and the one who did have a partner did not feel either understood or supported by them. None of the interviewees with restricted networks reported having close friends except for one who developed a friendship with someone from secondary school over many years.

Participants with restricted network types seemed to find it hard to form reciprocal relationships. They either felt that they could not fulfil the social/emotional needs of others ("I think sometimes I am not very good at like helping him with his problems…" (Participant 8, Female aged 18-25)) or that their own social needs were not quite met ("they won't necessarily invite me to hang out" (Participant 6, Female aged 18-25)). Although one of these young people was socially very active and had a 'friendship group' of about 15 people, she questioned the quality of these connections by doubting whether her feelings towards her friends were reciprocated.

> "I don't know how close I am to all of them, I don't know how close they would describe me as a friend." (Participant 6, Female aged 18-25)

Although participants with a restricted social network were the youngest in the sample, there was one interviewee with this network type who was significantly older and had a partner and a child. Although he did have both formal and informal connections whom he met regularly, he did not perceive any of them as close.

Most participants with restricted networks had a good level of access to emotional support from their close families, at the same time, they seemed to lack reciprocal peer relations. Their accounts of connectedness was dominated by an unremitting search for like-minded others, both on the intimate and informal network layers.

9.3. Factors affecting social connectedness

The qualitative study findings indicate that the (external) factors influencing the social participation of the interviewees in this study operated on three areas, each facilitating the next. These were factors relating to (1) access to the physical environment where the social activity took place; (2) access to the social activity itself; (3) and connecting with other people taking part in the social activity. The way in which the characteristics of the environment, the social activity and other people interacted with and accommodated autistic traits, either facilitated or hindered interviewees' social participation and social connectedness. The physical layout and sensory characteristics of the environment facilitated or blocked access to a social activity. The purpose and format of the social activity facilitated or hindered participants' motivation to engage in it. Other people's awareness and understanding of autistic traits and ability to communicate effectively influenced the success of forming new connections.

In addition there was a fourth factor that played an important role for successful social participation, and this was the degree to which a participant was aware of and understood their own autistic traits and whether they were confident in managing these.

9.3.1. Access to the physical environment

Personal factors determined to a large part participants' ability and opportunities for social participation outside their homes. Personal factors included autistic traits, mental health status, and demographic characteristics (especially age and family circumstances). The sensory characteristics of the environment in which the social interaction took place was another important factor to facilitate social participation. Difficulties with using transport and cost considerations were reported by a minority of participants as barriers to leaving their homes.

Social battery

The majority (10 out of 13) participants talked about having a limited capacity for social participation. The 'social battery' is a metaphor that entered popular usage in the context of health and well-being though it is still absent from the academic discourse (for a web-based article see (Mind Tools Content Team, 2023)). It was a term that was often referred to by participants and it was decided to use it in the analysis and presentation of the findings. The social battery refers to the amount of physical and cognitive energy a person has for social interaction. The capacity to interact with others varies across individuals and it can be drained or recharged by different activities at different rates. The primary means by which social interaction constituted a drain on participants' social batteries, were the cognitive effort involved in communication and masking autistic traits, and sensory overwhelm from the environment.

There were two main ways that the management of the social battery could become a barrier to social participation. The first was the avoidance of social situations because of the anticipation of increased demands on the social battery. The second, was reduced participation in social interactions because of a need to recharge an already depleted social battery.

One of the ways in which the social battery affected participation was by interviewees avoiding social interaction because of the anticipated adverse consequences on the social battery. Having a depleted social battery was described as feeling ‘being overwhelmed’, experiencing ‘burnout and exhaustion’ and like ‘the battery tank is on zero’ (Participant 12, Female aged 46-55). One participant’s account describes how, since recently being diagnosed with autism, he learnt to avoid draining his social battery by reducing social activities and thereby maintaining optimal functioning.

> “So what I’ve actually done over the last months, is I’ve hugely reduced the things that I do. Because of this element of, the time element of everything happening at the same time, and not being able to focus on what work I’m supposed to do and on family and so on. So I was just in a constant shut-down.” (Participant 9, Male aged 46-55)

Managing the social battery was not necessarily seen as a barrier to social connectedness by everyone in the sample. This was apparent from the following interviewee’s account who explained how they ‘were someone who liked a lot of alone time’ and were satisfied with seeing their informal connections no more than twice a week.

> “So seeing a friend, like a different friend, maybe twice a week, is great for me. That's like my social cup all the way. More than that, I’m just overwhelmed and I’ll start getting very frazzled and stuff like that.” (Participant 5, Non-binary aged 26-35)

Recovery time spent on recharging the social battery after taking part in a social activity was a limitation placed on the length and frequency of participation. The cognitive effort involved in concentrating on tasks and interacting with others, especially at work, was an example given by at least two participants as a significant drain on their social battery. Having depleted the social battery by participation in one life area, led to withdrawal from further social activity on others to gain some recovery time.

> “I don't do many things outside of work, especially social things because so much of my social battery is used up at work.” (Participant 7, Male aged 26-35)

The social battery was also managed by limiting the time spent on a social activity. One participant compared their social battery to a clock that ran out after a certain amount of time when she had to temporarily withdraw from further interaction to recharge her battery.

> “So, I will do that [meet friends for a chat]… um… but I think because generally not more than an hour and a half or something. Yeah, I seem to have a cut-off point of about an hour... I’ve just had enough by then. ” (Participant 11, Female aged 46-55)

Four participants described often experiencing burnout and fatigue, which was possibly due to the increased sensory and cognitive demands experienced by autistic people relative to the neurotypical populations (Keville & Meek, 2021). One young interviewee, who was diagnosed with depression, identified fatigue as one of his primary barriers to participation. He described how he experienced fatigue since he started a new job which indicated an increased demand on his social battery.

> “But yeah, now primarily [barrier] it’s just the stuttering and fatigue really if I’m honest with you. I spend a lot of time just feeling quite tired recently. […] I’ve actually spent quite a lot of time lying down, like pretty much like in bed at home. And I think it's getting to the point where it's just a little bit depressing.” (Participant 13, Male aged 18-25)

Although most participants were aware of the ways in which participating in different life areas drained their social batteries, social battery limitations only became a real barrier to participation if it was accompanied by pressures from, for example, work, family life or poor mental health.

Mental health

Experiencing difficulties with poor mental health either at the time of interview or previously were commonly reported in the sample. About half of the sample reported current or re-occurring mental health difficulties. The way in which poor mental health posed a barrier to participation was by increasing the likelihood of experiencing physical (and mental) fatigue and/or heightened levels of (especially social) anxiety which limited social activity outside of the home.

Anxiety around interacting with others, especially with non-autistic people, resulted in withdrawal from social activities for some participants. Three of the youngest participants seemed to be affected by significant levels of anxiety that interfered both with social participation as well as making connections with others. One participant, especially, found it hard to access physical environments outside his home environment because of not feeling able 'to act naturally' around people who did not belong to his family. He talked about feelings of extreme emotional overwhelm when accessing public spaces, describing how 'just walking down the street' was difficult. Although this participant felt socially isolated and was seeking friendship, his anxiety caused him to mask his autistic traits in public which he experienced as a loss of authenticity/identity preventing him from forming genuine connections.

> "People really overwhelm me. So it's like a real battle, because I might want friendship but it overwhelms me, which causes me to not be able to be myself, which means that I'll never find a true connection with anybody." (Participant 10, Male aged 18-25)

Anxiety could also interfere with social interactions and it sometimes manifested itself in stuttering or in a physical inability to speak.

> "Sometimes I just lose the words like I just did there, and then I stim and things in order to get back on track." (Participant 6, Female aged 18-25)

Anxiety was often related to low self-esteem and low levels of self-confidence, where some participants felt that what they had to contribute to the social interaction was of little or no value. This was expressed by one interviewee, who was diagnosed with autism and other co-occurring neurological conditions late in life and by then had developed a negative self-view because of not understanding why he functioned differently to others around him.

> "Whenever I think about going to somewhere and talking about something, I don't think that actually I'm qualified or worthy or, you know, my opinion means anything, because it never has in my mind." (Participant, 9 aged Male 46-55)

Participants with restricted social networks were most likely to talk about ongoing mental health difficulties at the time of interview.

Caring responsibilities

Five participants had a dependent child under 18, and all five reported experiencing constraints on their participation as a result. At the same time, for women who were the main carers of children under 5, childcare related activities in the community were an important source of social connections. The way having children restricted participation primarily manifested itself in a reduced capacity to engage in social activities both in terms of time for self and the ability to work, and an increased demand on the social battery.

> "It's more the case at the moment, I wish I had more time to see the people that you know, I haven't seen for three years in person at this point. I've managed to get to about three dungeons and dragons games since my child was born. But you know these things will sort of change. It's the stage of life I am in." (Participant 3, Male aged 26-35)

Four out of the five parents reported that their children were on the autistic spectrum and some of the older children were experiencing mental health problems which were associated with heightened care demands. Intensified care demands included not feeling able to leave a young child with the other parent in the evenings because of the child's perceived 'clinginess' and need for reassurance, reducing working hours to stay at home with a teenage child who had limited school attendance, or providing significant support to a child to enable them to attend school.

The environment

The sensory and physical characteristics of the social environment played an important role in facilitating interviewees' social participation because of the way they interacted with autistic traits relating to sensory processing. Sensory environmental characteristics are those that affect the senses including hearing, sight, touch and temperature. Of these, differences in auditory sensitivities and processing were highlighted as the biggest factor for accessing the social interaction in at least half of the interviews. Multiple conversations taking place within the same social space was reported to be a major barrier to social participation by several participants because of difficulty with filtering out conversations in the background from the one of interest.

> "I mean, one of the things I struggle with in terms of like sensory things, the main thing for me is audio. So, like […] crowded situations are very difficult for me because other people's conversations don't melt into the background, I'm just hearing 10 different conversations happening as loudly as each other all at once." (Participant 3, Male aged 26-35)

As the account of the following interviewee demonstrates, not being able to follow a conversation resulted in withdrawal from the interaction.

> "I can hear them both and I can't distinguish which sounds are coming from which people, like… and then the conversation obviously makes no sense because I'm hearing two sides of a conversation which aren't related. So in those kind of situations I just sit back and listen to the noise sort of thing." (Participant 8, Female aged 18-25)

Physical environmental characteristics relevant to accessing the social interaction are layout and the personal room it affords to participants. A couple of interviewees expressed preference for conducting social interactions in outdoor environments and in social spaces where they had 'room to move around'.

Public spaces were often described by participants as too noisy and overcrowded. They were often experienced as being overstimulating and 'overwhelming', 'making it impossible to focus on anything' and causing physical distress.

> "That's one of my biggest barriers is, is when I go out to these places, the noises and the visual distraction mean that I can't concentrate on the conversation, on whatever is going on there." (Participant 9, Male aged 46-55)

Social activities in these types of environments were avoided by most participants which entailed restricted access to a wide variety of venues including markets, cafes, restaurants, and sports facilities. The provision of quiet spaces for retreat and recovery were seen as facilitators to participation, allowing participants to ‘gather themselves together’ and carry on with further social interaction.

Using transport

Travelling to places was not reported as a major barrier to participation in the sample, although most participants talked about experiencing some constraints around specific forms of transportation. Participants who had social anxiety were less likely to travel on public transport, especially trains. Being able to drive or cycle enabled these participants to access social activities without having to rely on other forms of transport. One interviewee (who could drive) only used public transport when they were accompanied by someone on the journey.

Two participants reported not being able to drive because of autistic traits. For them, getting to the places where they could participate in a social activity became a barrier, especially if living in a rural location.

> “I mean it's challenging when you live in a rural area anyway, which I do. And it’s doubly challenging because I can't drive.” (Participant 3, Male aged 26-35)

Costs

The cost of leisure activities were rarely mentioned as barriers to participation in the interviews. A minority of participants specifically mentioned having limited spare money to spend on activities but this was not always seen as a problem. Costs were sometimes seen as secondary barriers to accessing social activities because other factors playing a bigger role.

> “I probably would [have problems with costs], if the other barriers didn't stop me before I got to that point. But I don't really notice that, because so many of the other things are in the way before I get to think of that.” (Participant 5, Non-binary aged 26-35)

Students and female participants with children were more likely to report the ‘cost of an activity’ being a barrier to participation. One participant highlighted how their autistic traits related to executive functioning and organisation skills impacted both on access to financial support and on saving money on activities like for example travel; because “last minute tickets cost more than ones booked early” (Participant 2, Female aged 36-45). These results suggest that financial barriers to autistic people’s connectedness are likely to be underreported because other barriers exert their effect at an earlier stage of the participation process.

9.3.2. Access to the social activity

Interviewees appeared to be more motivated to engage in some forms of social activities than others. The features of social activities that participants highlighted to be of particular importance when deciding whether to take part related to their (1) purpose and structure; (2) and their mode of communication.

Purpose and structure

The majority of participants said they preferred to participate in social activities which were task-oriented, had a clear structure, and was predictable in terms of what would happen. Task-oriented social interactions involved doing or achieving things together with others, working towards a common goal or exchanging/learning new information about interests and hobbies. This included a wide range of social activities, for example dancing, playing board games, engaging in team sports, or participating in discussions about favourite topics (e.g.: films, books, games). Activity-based social activities seemed to facilitate participants’ participation through three main ways: (1) they provided ‘purpose’ or ‘meaning’ to the activity, (2) they eliminated uncertainty and (3) they limited or gave a clear focus to verbal exchange.

The perceived purpose of a social activity was considered central to successful engagement by most participants. Eight out of the 13 interviewees highlighted the importance of purposeful social interaction which they saw as their ‘ideal form of socialising’. Perceived purpose lent the social interaction meaning, a sense of achievement and collective success. There was a sense that pursuing the same goal with others facilitated a subjective sense of well-being and connectedness in the participants.

> “I feel good about it because it has a purpose (laughing). There is a start point, there is an end point, and I’m helping somebody else to do something.” (Participant 9, Male aged 46-55)

> “[Role play] is like my ideal form the socializing because you are there to do a thing. It's a specific purpose. It involves a lot of numbers and roles, but also a lot of creativity, in that we ultimately… it's a form of collective storytelling. And we're all there to kind of see where the narrative takes us.” (Participant 3, Male aged 26-35)

Goal-oriented interactions were regarded to reduce uncertainty and facilitated the participation of interviewees who experienced significant social anxiety in unstructured social settings. One participant, who had very limited social interactions outside her family unit, felt very confident teaching and sharing her expertise in a formal institutional setting.

> “So if I am stood up at the front of a room, and I am teaching like maybe 30 people, I can do that fine. If I’m telling people about something that I know about then that’s quite easy.” (Participant 8, Female aged 18-25)

Activity-based interactions were also preferred by participants because they limited the demands on verbal exchange and facilitated the participation of interviewees who reported to finding it hard ‘to carry a conversation’. Attending a social club where structured activities were conducted in small groups enabled one young person’s social participation because she was not expected to talk much.

> “Small groups tend to be easier than one to one, especially with people I have not necessarily spoken too much because I don't need to carry a conversation.” (Participant 6, Female aged 18-25)

Communication mode

The mode of the social interaction was reported to be an important factor for successful communication, particularly when making the first contact with new people. Written modes of communication were employed most often to access the community network layer and to connect with others through online groups. Several participants reported to have met their partner or close friends online via dating apps and interest groups. Most participants voiced a preference for written modes of communication, especially in electronic form, because this was seen as providing more thinking time, enabling participants to ‘formulate their thoughts’ and ‘craft a response’ and providing them opportunities to edit. Communicating in writing was also seen as having the advantage of bypassing the need to manage and read body language, for example by avoiding ‘having to look straight at someone for prolonged periods of time’.

The primary use of online social interactions was to make new connections and to maintain relationships with friends and family who lived some distance away. With respect to making new connections, interviewees stressed that face to face social interactions were valued above all and that ‘online friendships’ did not become ‘real’ until they were consolidated in ‘real life’.

> “Um… I prefer face to face… but it's also a bit scarier. So it was me who suggested, meeting in real life. But that took quite a lot of courage to do that, because it's easier to just hide behind a phone. But I really value the in person stuff.” (Participant 5, Non-binary aged 26-35)

The least preferred mode of communication was reported to be the telephone.

> “Texting and emailing is way better than phone calls quite a lot of the time. Because, when I do phone calls, I find that quite a lot of what I want to say just sort of comes out wrong. For whatever reason. And typing an email or sending a text is much better. But unfortunately it's really frustrating for me that quite a lot of professionals, like people who I need to get in touch with for work and stuff like that, aren’t watching their emails. I have to phone them instead, and it really winds me up because I find it much harder to articulate myself over a phone call.” (Participant 13, Male aged 18-25)

9.3.3. Connecting with others

Not surprisingly, the characteristics of others involved in the social interaction was seen as a key determinant for establishing a relationship with them by most participants. The most important of these were individual traits, including any autistic or neurodivergent traits, followed by their communication style and their level of understanding and acceptance of the participant’s autistic traits. It was not only other people’s traits that had an important role for successful social interaction, participants' own understanding of their autistic traits was also an important factor.

Autistic traits in others

Almost all participants reported that most of their intimate and informal connections were either autistic or exhibited other neurodivergent traits (especially ADHD). Participants described how they instinctively 'gravitated' towards others on the autistic spectrum because they felt 'more at ease' in their company, found them 'more interesting' and had an affinity with the way they 'experienced the world'. Besides seeing the world in similar ways, other autistic people were also considered more 'accepting' of idiosyncratic thinking and behaviour and were reported to be more likely to hold similar ethical principles.

> "But I think, with neuro diverse people I feel a lot more at ease, because I think they've experienced the world in their own way, similar to what I've experienced the world in my own way and we just know it's different to, you know, sort of neurotypical people." (Participant 4, Female aged 56-65)

> "Maybe because their neurology is similar, so we think more alike. Or because we've had similar experiences in life. Also most of the autistic people I know are also vegan; that seems quite common, probably because we are less affected by social norms (eating animal products) and more driven by ethics/justice." (Participant 2, Female aged 36-45)

Although at the time of interview, participants expressed a preference for interacting with other people on the AS spectrum, their accounts revealed that they had tended to form close ties with other autistic people even prior to their diagnosis.

> "My very, very best friend from uni was a girl called [] and we stayed in touch and are still in touch now. We got on sooooo well. Anyway she received her autism diagnosis just a month before me. So all that time we were bezzie mates we were both autistic we just didn't know it." (Participant 1, Female aged 36-45)

Participants described how prior to their diagnoses they formed close relationships with others who were also undiagnosed at the time but received a diagnosis later. Participants talked about how they and their autistic friends were naturally being drawn to each other's interests and personal qualities (especially sense of humour) which were often shaped by autistic traits. Relating to each other through a shared sense of ‘difference’ is apparent from this interviewee’s account describing how he met his best friend at university before they both received their diagnoses.

> “We both knew that we were kind of a bit odd and different and didn't kind of see the world the same way as a lot of other people, but it was a similar kind of odd, and there was kind of a solidarity in that.” (Participant 3, Male aged 26-35)

Communication style

The majority of participants stressed their preference for communication styles that used clear, direct, unambiguous language. Participants expressed a need for ‘directness’ in communication which to them registered as a degree of transparency and honesty.

> “But generally if I could ask NT people to do one thing it would be to be clearer. Be more specific. And be honest.” (Participant 5, Non-binary aged 26-35)

They reported that concordance in communication styles was more likely to be experienced with other autistic people and was seen as a major facilitator to forming a connection. A mismatched communication style was associated with interactions with neurotypical (NT) populations and was seen as a major barrier to understanding each other. As a result, some autistic interviewees experienced NT interactions as ‘quite vague’ and hard to interpret. Interviewees felt that sometimes ‘NT people expect you to be able to read their minds’ and it was hard to tell if they ‘meant’ what they said.

> “I think it's less that I can tell when somebody is neuro-divergent and more that I can tell when they are not. Because there will be a certain way that they'll speak or think things through in a conversation, and something will just twig. I don't know, those interactions go worse. I always get along better with people I suspect to be neurodivergent.” (Participant 7, Male aged 26-35)

Neurotypical people’s understanding of autism

Closely related to autistic traits and communication style was another factor that affected the formation of new connections: the extent to which there was an understanding, accommodation and acceptance of autistic traits by all participants within a social interaction.

Most participants mentioned others' attitudes and awareness of autism and autistic traits as an important factor for their social participation and sense of belonging across a variety of life areas. In the intimate domain, families' understanding and acceptance of autism affected the age at diagnosis and the perceived level of support experienced by the interviewee. About half of participants described how their parents, siblings or partners had very little or mainly negative perceptions of autism prior to their diagnosis. This sometimes manifested itself in a denial or dismissal of their autistic traits which meant that participants were discouraged from seeking an autism diagnosis before reaching adulthood.

> "You know, when you grow up autistic in an environment that punishes you for it; you know my parents were... not accepting at all… of needs different to their own. So, I was told a lot of the time 'don't be silly, it's not too noisy, or it's not too…' You know, so all the things I felt, I was told that's not actually how it is." (Participant 5, Non-binary aged 26-35)

One participant talked about how his partner's difficulty and disbelief of him receiving an autism diagnosis affected his mental health and how their relationship had to undergo a relatively long period of readjustment.

> "She doesn't understand it and what that makes me feel is like 'am I being a fraud in my own home?' because of that." (Participant 9, Male aged 46-55)

Participants who felt most supported by their families and who felt safe to express their autistic traits at home were those who were diagnosed youngest. These participants were also most likely to have a restricted social network type.

The other major life area where social participation was affected by others' understanding of autism was the domain of employment. At least four participants reported having experienced significant work related stress because of discrimination related to their autistic traits. These included being assigned to a different job role after receiving the autism diagnosis (without ascertaining the suitability of this role), being dismissed from a job for 'being too slow' and refusing requests for wearing headphones or increasing the number of days working from home. Others’ negative attitudes and discrimination at the workplace resulted in unemployment for one participant and at frequent job changes for at least three more.

Good practice was also highlighted, where employers consulted interviewees about how their needs could best be met. Managers with high levels of autism awareness often had lived experience of autism within their own social network, or had undertaken autism awareness training and approached autism with an open mind and genuine curiosity.

> “I can always tell with people I work with, whether they've either had the awareness training or whether they know someone like quite close friends or family or somebody with autism. Because it's just their almost like visceral thinking to know how things work rather than seeing it as an extra step to go through, an extra loop.” (Participant 7, Male aged 26-35)

In the community participation domain, when meeting strangers, most participants were ‘selective’ about who to disclose their autism diagnosis to. Superficial, stereotypical, ‘conveyor belt text book’ type of awareness of autism were reported as barriers to social interactions with strangers. Attitudes that hindered social interaction were preconceived assumptions about autistic traits (for example ‘having special interests’, ‘liking trains’) and about what autistic people ‘looked like’. When participants felt that their conversation partner dismissed or trivialised autism, they reported to feel ‘cagey’ and ‘defensive’ and would distance themselves from further interaction with that individual. The following quote exemplifies the negative preconceptions surrounding autism, describing how members of the public tried to ‘reassure’ this participant that they were ‘too nice’ to be autistic.

> “Um, I’m not embarrassed about it I’m quite open about it, and you know some people look quite alarmed, or some people say, ‘Oh no, you're not autistic, you are too nice’ or ‘no, you don't look autistic’.” (Participant 4, Female aged 56-65)

9.3.4. Individual’s own understanding of autism

Participants’ awareness and understanding of their own autistic traits was a factor that cut across all areas of social participation, it influenced access to the environment, the choice of social activity to participate in, as well as the choice of people to make a connection with.

Awareness, acceptance and self-reported competency around managing one’s own autistic traits appeared to be associated with higher quality relationships and better subjective connectedness.

Understanding how autism affected them and the recognition and accommodation of their own autistic traits seemed to act as significant contributors to interviewees’ social participation and overall well-being. There were two main ways in which participants’ awareness of autism affected their social connectedness. The first was the development of self-management strategies aimed at managing the environment and social battery, which affected the frequency and domains of participation. The second was the development of a set of social skills that enabled the participant to safely express their autistic traits in selected social environments. Developing these social skills affected the quality of the ties in the social network.

Self-management strategies

The majority of participants described how discovering they were autistic changed the way they perceived themselves in positive ways. Autistic traits that they previously saw as ‘aspects of their personality’ that was ‘not right’ or ‘not fitting in’ were re-evaluated and attributed to autism instead of seen a personal flaw. This helped interviewees to move away from self-recrimination and allow themselves to acknowledge their previously unexpressed needs.

> “[The diagnosis] has changed things usually. I am much kinder to myself, I’m much more self-compassionate. Because things make sense now. So instead of me trying to ignore all of the things in my body that say this is too much or, I can't do this and squashing it down and being cross with myself; I can do something about it.” (Participant 5, Non-binary aged 26-35)

After receiving their diagnosis, participants developed self-management strategies that helped them not only gain more control of social interactions but also to make more space in their lives for recovery time. Recovery time often meant engaging in a special interest that would recharge the interviewee’s social battery enabling them for social interaction in the future.

> “If I don’t do my interests for a while then my social battery is quite low. So like, I’ve got to have some ‘me time’ and they help like build them, like how much I’m able to go out and do things with people, by falling back on the things that I like to do more.” (Participant 8, Female aged 18-25)

Self-management strategies also played a role when choosing or engaging in a social activity. For example, taking the lead to create appropriate social opportunities that were of interest to the participant (e.g.: establishing gaming groups) or making plans before engaging in a social activity about how to conserve the social battery (e.g.: transport arrangements to leave early) or to avoid sensory overload (e.g.: meeting in outdoor spaces). Participants also used their knowledge of their autistic traits to improve their communication with neurotypical people, either by explicitly asking them to express themselves more clearly or by informing them about how the interviewee’s ‘listening style’ differs from what might generally be expected (e.g.: reduced eye contact or “fidgeting with hands”).

Social skills

Although, all participants employed strategies that were directed either at managing the environmental conditions or the duration of their social interactions, participants with friend-focused, family-focused or diverse social networks were also more likely to be selective about how and who to socially interact with.

> “I mean I’m very comfortable in my own skin now and I know what works for me on a social level and what doesn't. And so I seek out the things that do work and I avoid the things that don't.” (Participant 3, Male aged 26-35)

The ability to make the right choices when it came to social interactions seemed to be founded on the development on a set of social skills that were specialised at integrating the individual’s autistic traits into their (social) lives. All participants with larger and more complex networks were aged over 25 and they seemed to have a good grasp of how their autistic traits affected their social interactions and were confident about how to manage this. They also tended to describe autism in a positive light. Their accounts of being autistic reflected a degree of pride that saw some of their autistic traits as assets (e.g.: “I’m just exceptionally creative, and a little bit eccentric”). For these participants, developing a specialised social skill set and targeting social interactions resulted in high quality reciprocal relationships especially on the informal network layer.

> “I think the friendships that I’m making now are probably a lot more authentic.” (Participant 5, Non-binary aged 26-35)

Younger participants, under 25, with restricted networks seemed less confident about their social skills and were more likely to be either unaware of or hide their autistic traits when interacting with others. They were also less likely to seek interaction with others on the AS spectrum and either did not target their participation or preferred to interact with neurotypical peers. These interviewees reported few reciprocal ties on their informal network layer and they expressed either dissatisfaction with or high levels of uncertainty regarding the strength of these relationships.

> “I don't know how close I am to all of them, I don't know how close they would describe me as a friend.” (Participant 6, Female aged 18-25)

The only middle aged interviewee with a restricted network received his autism diagnosis quite late in life (age 48). He described how he would have made different choices in life had he known about being autistic earlier. He expressed dissatisfaction with his social network which he perceived as one that was built around neurotypical expectations and was unfit to satisfy his interests and social needs.

> “I’m not satisfied. I want to be able to be in an environment – so there is this cocoon that I‘ve created – I want to be able to expand that cocoon to incorporate more people that have inclination just to go off [and pursue my interests with me]…” (Participant 9, Male aged 46-55)

The case of this interviewee illustrates the importance of building social skills around the awareness of autistic traits. Having the social ability to fit into a neurotypical environment (by masking autistic traits and preferences) might lead to an apparent social inclusion (e.g.: some participation and nodes on each network layer), but the resulting social network will not provide the feelings of belonging that are required for psychological well-being.

9.4. Conclusion

The findings presented in this chapter suggest that the social network types typically found in the general population were also present in the autistic sample. Different network types in the sample seemed to be associated with broad demographic characteristics related to life-stage (i.e. establishing a family), and age-related social skill characteristics. Older participants in the sample seemed to be more likely to have a friend-focused or diverse social network, whilst young adults were more likely to have family-focused and the youngest, restricted networks. Age at diagnosis affected the social network of at least one participant who felt that his network lacked authentic reciprocal relationships as a result of him not being aware of his autistic traits earlier.

The findings of the qualitative study suggest that if we want to facilitate the social participation of autistic populations, their access requirements encompass, beyond the physical environment, social activities, and people. For the interviewees in this study, besides the sensory environment, access to transport, and cost considerations, the primary barriers to social participation related to human factors. The features of the social activity itself, its content, structure, and perceived purpose, took a central role in interviewees' accounts of participation. Of equal importance were the personal attributes of the people that the social activity was undertaken with. These included other people's autistic traits, their understanding and acceptance of autism; as well as the participant's own awareness and social skills at accommodating their autistic traits. Since autism is a condition that primarily affects social and communication skills, the finding that the main barriers to participation for this sample related to these same areas does not come as a surprise. At the same time, participants' experiences indicate that increasing (both neurotypical and autistic people's) awareness, understanding and acceptance of autistic traits would enhance the effectiveness of NT – ND social interactions and communications and would benefit the social connectedness of all.

PART IV

FINAL DISCUSSION

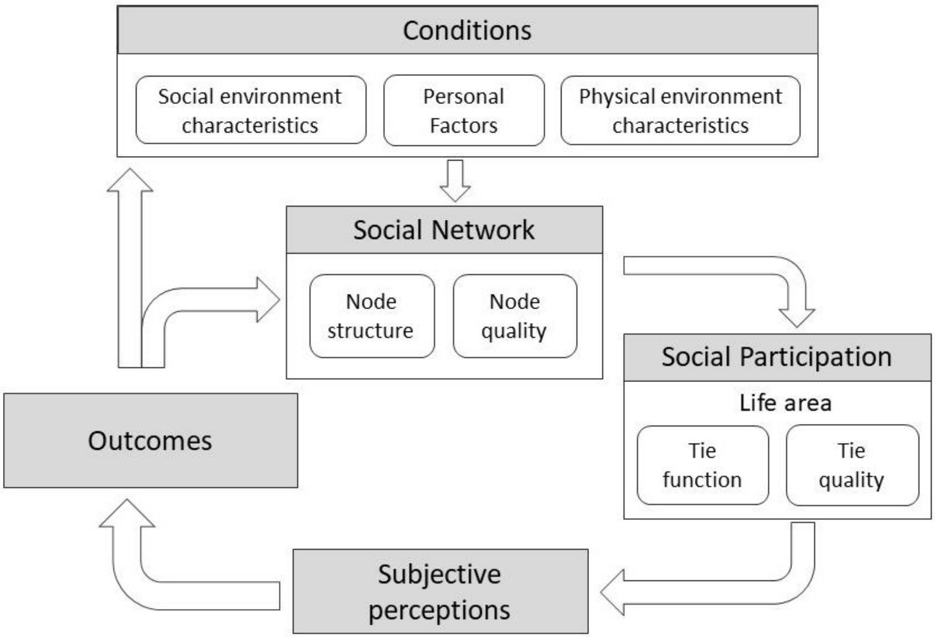
Chapter 10. Final discussion

This thesis used a mixed methods approach to explore factors affecting disabled people's social participation in a range of life areas. The central premise, guiding data collection and analyses throughout, was that participation in different life domains facilitates social connectedness, which has been shown to be vital for people's physical and psychological well-being (Barefoot et al., 2005; Kawachi & Berkman, 2001; Yang et al., 2016). Each empirical chapter in this thesis ended with a discussion of the findings and located those in the wider evidence base. The aim of this chapter is to provide a brief overview of the quantitative study findings and to evaluate how the information gained from qualitative interviews adds to the understanding of barriers to the participation of disabled populations, and what this means for theoretical models of disability. The chapter also evaluates the strengths and limitations of the thesis findings and offers some suggestions for future policy and practice.

10.1. Thesis overview

Identifying barriers to disabled people's social connectedness was the central objective of this thesis, where social connectedness was defined as having sufficient number and quality of relationships in each layer of the social network to make an individual feel supported in every aspect of their lives, and to foster feelings of belonging. Social connectedness was defined as arising through social participation in a range of life areas which facilitated the establishment and maintenance of a diverse set of informal and formal social relationships across the personal network. In Chapter 1, a theoretical framework of social relations was constructed (reproduced in Figure 10.1) which was grounded in a structuralist paradigm, drawing on Network Theory and existing models of social support. It was within this theoretical framework that the thesis definition of social connectedness was located; a definition that synthesised the wide-ranging conceptualisations of the structural and qualitative aspects of social relations in the literature.

Figure 10.1 Thesis conceptual framework of social relations



The thesis' primary research objectives were (1) to explore differences in barriers to social participation reported by disabled and non-disabled people; (2) to discover how health and demographic characteristics were associated with the different patterns of barriers reported by disabled people with restricted participation; and (3) to find out if current understandings of social connectedness and disability accommodated the participation needs of people with neurodivergent conditions.

10.2. Summary of quantitative study findings

The quantitative study used secondary data analysis to compare the social participation rates and barriers to participation reported by disabled and non-disabled adults in the Life Opportunities Survey, a longitudinal study of disability in the UK, collected between 2009-2014. Guided by the thesis conceptual framework, LOS participation data on selected life areas (or participation domains) were linked to social network layers so that the findings could be linked to the structural aspects of social connectedness (Figure 10.2). Restrictions to social participation in a life area were taken to indicate that the respondent was at risk of not being able to establish or maintain social ties at the corresponding layer of their social network, leading to a risk of social isolation (defined as a sparsity of nodes in one or more network layers. See Chapter 1, Section 1.7, p. 54).

Figure 10.2 Locating the LOS in the thesis' conceptual framework

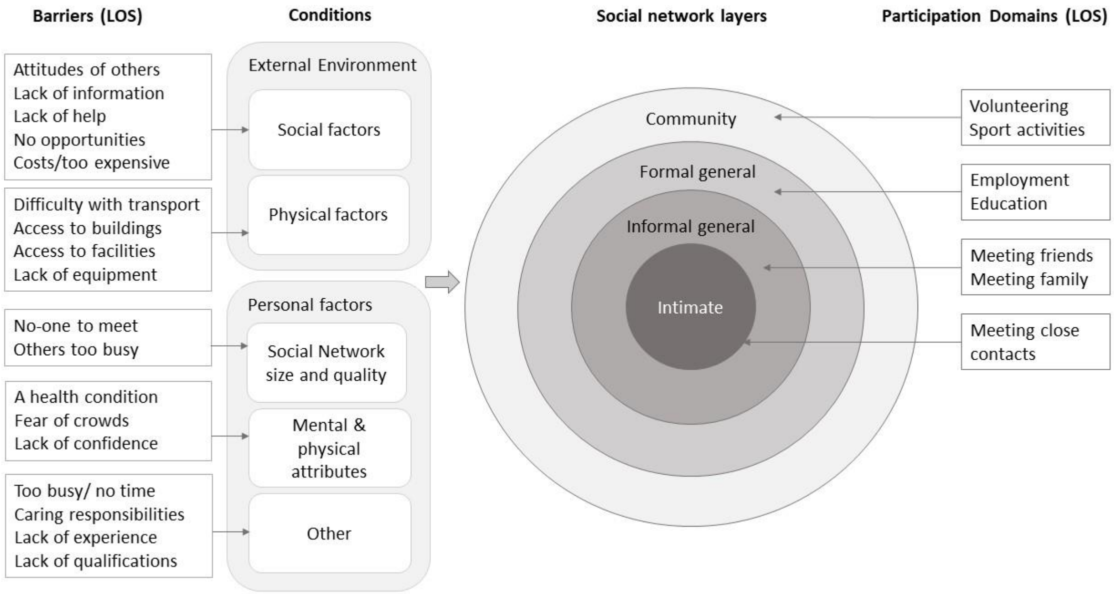


Table 10.1 summarises the headline findings from the quantitative study, which were presented and discussed in Chapters 4, 5 and 6.

Table 10.1 Quantitative study headline findings

Summary of quantitative findings
Chapter 4 Restricted participation and barriers to participation in the Life Opportunities Survey
• Reporting at least one impairment and each year increase in age were associated with expressing less interest in social participation across all life areas in the LOS. • Women were more likely to express interest in participating in all life areas except for employment and sport activities compared to men. • Significantly higher proportions of disabled people experienced restricted participation compared to non-disabled people across all life areas except for volunteering. • The largest difference in restricted participation between disabled and non-disabled people were in the life areas of employment and education. • Young disabled adults (aged 16-24) reported the highest rate of restricted participation compared to all other LOS population groups in the life areas of meeting close contacts and employment. • Non-disabled people were more likely to report lack of time as a barrier to participation, whilst disabled people were more likely to report (besides lack of time), financial considerations and the presence of a health condition as restrictions to their participation. • Significantly higher proportions of disabled people reported social environmental barriers, such as ‘the attitudes of others’ and ‘lack of help’ as barriers to their participation compared to non-disabled people.

Summary of quantitative findings

Chapter 5 Barrier profiles characterising restricted participation in the Life Opportunities Survey

- Latent Class Analysis of barriers to participation reported by disabled people identified three broad barrier profiles which were not equally distributed across the disabled sample.
- Most of the disabled sample had a time driven barrier profile which was significantly associated with the demographic characteristics of being female and/or having dependent children in the household. Disabled respondents with this barrier profile were significantly less likely to report a mental health or motor impairment and more likely to report a mild severity impairment.
- Health driven profiles were the second most common barrier profile. Respondents with this profile were more likely to report a high severity pain comorbidity, mental health, or motor impairment. In terms of demographic characteristics, respondents with a health driven barrier profile were more likely to be male and/or aged 45-64.
- A minority of disabled respondents had a barrier profile that was driven by multiple environmental barriers. Although, the sample size of this group of respondents was small, the results of the regression analyses indicate that disabled people with complex barrier profiles were likely to be young adults (aged 16-24) with a high severity mental health impairment/comorbidity or neurodevelopmental condition.

Chapter 6 Change in restricted participation and barriers to participation in LOS Waves 1 and 3

- Disabled people reported higher levels of persistent participation restrictions (defined as restricted at both LOS Wave 1 and 3) than non-disabled people across all life areas.
- Employment was the life area where most disabled respondents reported persistent or a new participation restriction at Wave 3.
- Meeting close contacts and education were the life areas in which disabled people were least likely to experience persistent participation restrictions.
- Lack of time, and cost considerations remained the most often reported barriers to participation in the informal domain by disabled people experiencing long-term restrictions.

The quantitative study findings highlighted several, previously under-researched factors that impact on disabled people's participation. For example, lack of time as a barrier to social participation has not much been considered in previous literature. The sources and nature of the multiple social and environmental barriers to participation faced by a minority of disabled people is similarly under-represented in the literature. Previous research (influenced by the Social Model of disability and the disability rights movement initiated by people with motor impairments (Driedger, 1989)) tended to emphasise physical environmental barriers to disabled people's participation (Drum et al., 2009). Yet, the quantitative study results point to considerable heterogeneity within the disabled population, both in terms of health and demographic characteristics and how these relate to the barriers to participation encountered. The influence of social environmental, and especially personal factors on social participation have not yet been sufficiently attended to by researchers.

Taken together these findings suggest a need to broaden the scope of research on disabled people's social participation, to include under-represented population groups (both in terms of demographic and disability characteristics) and to explore barriers to participation beyond those relating to access to the built environment.

10.3. Contextualising the LOS barriers to participation for a sample of autistic adults

In the subsequent qualitative study, I chose to focus on autistic adults' experiences of social participation and social network building. This study aimed to fill some of the gaps left by the secondary analysis of the LOS, both in terms of what we know about restrictions to the participation of people with neurodevelopmental conditions (a group poorly identified in the LOS) and the specific barriers to participation they reported. The qualitative study had three broad aims: (1) to validate the LOS barriers in an autistic population; (2) to identify any gaps in knowledge about barriers to participation; and (3) to increase understanding of what social connectedness means to autistic adults.

10.3.1. The nature of time and health related barriers to participation in ASC

The lack of specificity in the LOS of time and health related barriers to participation, raised questions about how time and health related factors affected disabled people's participation in different contexts and whether these barriers meant different things for disabled people with different types of impairments. Autistic adults' accounts of social participation suggest, that in this population, time and health related barriers to participation were closely interlinked, and one was rarely experienced without the other. For autistic adults, time use was primarily determined by autistic traits, mental health status and family circumstances.

Social battery

Autistic participants described how their time use was governed by their perceived capacity for social interaction, referred to in interviews as the 'social battery' (Chapter 9, Section 9.3.1, p. 241). The social battery was described as comprising of finite physical and cognitive resources which placed a time limitation on social interactions. Having to manage a limited social battery required participants to prioritise the social activities they engaged in and to restrict the length and frequency of their social participation in activities and environments that were likely to constitute a significant drain on the social battery. To preserve and maintain their social battery, participants prioritised participation in life areas that were perceived as essential (e.g.: interactions with close family members and employment), and set aside time for recovery, which was often spent on solitary activities.

These findings suggest that the social battery is central to autistic adults' time use. Fatigue and burnout are symptoms that have been shown to co-occur with Autism Spectrum Conditions because of the increased prevalence of sensory and cognitive demands involved in the adaptation to neurotypical ways of functioning (Keville et al., 2021). There is yet scarce research that investigates how the characteristics of the social and physical environments that autistic people navigate during their daily lives affect their social battery, social participation, and ultimately, social connectedness. The way in which health conditions and neurological traits impact on time use is not captured by the LOS which constitutes one of its main limitations (see Sections 4.5.5, 6.5.4 and 10.7.1).

Caring for dependent children

Caring responsibilities were reported as a time barrier to undertaking informal activities by participants with dependent children. Several autistic parents talked about having children with neurodevelopmental conditions who experienced severe difficulties with their mental health and had limited school attendance. Caring for dependants with mental health difficulties increased parental care demands and limited the time and social battery capacity participants could spend on leisure activities.

In the LOS, caring responsibilities were reported as a barrier to participation by a minority of respondents, but because of sampling limitations, analysis of the LOS did not find significant differences in the proportions of disabled and non-disabled participants reporting informal care as a barrier to participation across most life domains (Chapter 4, Table 4.7, p. 128). There is evidence in the literature that autism has a large genetic component, its heritability is estimated to be 70-81% (Bai & Yip, 2019; English & Gignac, 2021; Ronald & Happé, 2005). This entails that autistic parents are more likely to care for autistic children than neurotypical parents. These findings suggest that barriers to autistic adults' social participation could be tackled by holistic, family-oriented policies rather than individualised interventions.

Mental health status

Mental health status was another factor identified in qualitative interviews in relation to time use and social participation by autistic participants. Interviewees attributed reduced social participation outside their homes to symptoms of depression and anxiety. Depression symptoms were associated with experiencing fatigue and a depleted social battery that made social participation difficult. Anxiety symptoms were related to the perceived need for masking autistic traits in social interactions with neurotypical people. Hiding or compensating for autistic traits in neurotypical environments was described as requiring significant cognitive effort, which drained the social battery and resulted in a perceived loss of authenticity and disconnection from others, which made social interaction with unfamiliar people undesirable. Camouflaging behaviour has been linked to lowered self-esteem and increased levels of social anxiety in autistic populations (Attwood, 2007; Hull et al., 2017; Lai et al., 2017).

In contrast, participants who had formed friendships with other neurodivergent people were more likely to actively participate in a range of informal activities outside their homes. They also reported better psychological well-being, and higher satisfaction with their social network than those whose social network was dominated by neurotypical connections. These findings confirm previous research findings which suggest that having high quality relationships with others (especially with those on the ASC spectrum) play as significant a role for autistic people's social participation and well-being as for neurotypical populations (K. Cooper et al., 2017; R. Cooper et al., 2021).

Co-occurring mental health conditions in ASC and associated outcomes of social isolation and loneliness are well-documented in the literature (Croen et al., 2015; Lai et al., 2019). There is however a lack of evidence base around the mechanisms underlying the mental health difficulties autistic people experience. The findings from the qualitative study suggest that mental health conditions prevalent in autistic populations are not necessarily inevitable co-morbidities associated with autism but may partly be attributed to the cumulative negative experiences autistic people encounter in neurotypical environments. Adverse mental health outcomes, such as anxiety and depression may develop and exacerbate over time as autistic people are required to repeatedly overcome social and environmental barriers to their participation (e.g.: negative social attitudes, mismatched thinking and communication styles and unfavourable sensory environmental conditions) that inhibit the formation of authentic connections with others.

10.4. Specifying and adding to the LOS barriers to participation

Table 10.2 describes how the factors described by autistic participants as important for their social participation related to those collected in the LOS. The table also presents additional factors affecting autistic adults' participation identified from the qualitative interviews which were absent from the LOS and other national surveys on social participation.

The qualitative findings suggest that barriers to participation reported by autistic adults can be classified into three broad categories: personal factors, environmental factors, and interpersonal factors. The largest discrepancy between the LOS barriers to participation and those reported by autistic adults are in the areas of personal factors and interpersonal factors. The environmental factors affecting participation reported by autistic participants largely overlapped with the barriers to participation collected by the LOS, except that they were specified within the context of autism.

Table 10.2 Barriers to social participation collected by the LOS compared to those reported in qualitative interviews

Conditions of participation	Barriers collected by the LOS	Barriers/Facilitators reported by Autistic adults
Personal Factors		
Existing social network	No-one to meet	Availability of local friends and family
	Others busy	Others busy
Individual attributes	No time	Limited social battery, mental health status, caring responsibilities
	-	Understanding and acceptance of own autistic traits
	-	Self-management strategies
	-	Social skills
Health related factors	Health condition	Mental health conditions (e.g.: anxiety, depression)
	Fear of crowds	Sensory sensitivities
	Lack of confidence	-
Other	Lack of experience/qualifications	-
	Informal care	Looking after dependent children
Environmental Factors		
Social environment	Attitudes of others	*Under interpersonal factors*
	Lack of information	-
	Lack of help	Access to autism diagnosis and post-diagnostic care
	-	Autism friendly policies and practices in the workplace
	No opportunities	Scheduling and appropriateness of community social activities
	Costs	Costs of transport and activities
Physical environment	Difficulties using transport	Not being able to drive/ anxiety around using public transport
	Access to buildings/facilities	Physical and sensory environment characteristics
	Access to equipment	Access to resources that aid communication needs
Interpersonal Factors		
Function of social interaction	-	Purpose and structure of the social activity
	-	Communication mode
Quality of social interaction	-	Shared traits, interests, experience
	-	Shared thinking and communication styles
	-	Others’ understanding and accommodation of autistic traits

- denotes that equivalent factor was not reported in the LOS/by autistic adults

10.4.1. Personal Factors

Most personal factors affecting autistic adults’ social participation that were not represented in the LOS, related to health related factors and individual attributes. For autistic people, these were largely determined by their autistic traits and any co-occurring mental health conditions. Having dependent children also played a role in the amount of time they could spend on leisure activities. Personal attributes that played important roles for social participation were participants’ level of understanding and acceptance of autism, and their capacity to manage their autistic traits. Participants with diverse social networks and high levels of social participation, integrated ‘being autistic’ into their lives in a positive way, and actively took care of their social and physical needs to maintain high levels of well-being. Their social networks were also likely to contain ties with other neurodivergent people. Awareness of own autistic traits and the development of self-management strategies and social skills seemed fundamental for these participants’ continued social participation, a finding that reflects previous evidence from the literature (K. Cooper et al., 2017; Hickey et al., 2018). Moreover, having informal ties with others on the ASC spectrum seemed to be associated with high self-rated satisfaction with the social network, a finding that echoes previous research into autistic people’s relationship formation (Morrison et al., 2020; Sedgewick et al., 2019). Respondents with restricted networks were the least accepting or aware of their autistic traits, and spent the most time and effort trying to fit into neurotypical environments through masking, and reported lower levels of satisfaction with the social network (see Chapter 9, Section 9.3.4, p. 254). These results raise questions about how to account for the ‘severity’ of a health condition or an autistic trait, given the individual differences in how these conditions/traits are experienced and managed.

These findings may be translated to other disability contexts. They suggest that understanding and developing the ability to manage an impairment or health condition facilitates disabled people’s social participation. There is some research evidence supporting this assumption, which showed that providing self-management training for employees with chronic conditions improved their working capacity and lessened fatigue symptoms (Nazarov et al., 2019).

10.4.2. Environmental Factors

Physical environmental barriers collected by the LOS were similar to those reported by autistic adults with differences in how they were specified. For the minority of autistic participants, ‘difficulties using transport’ entailed not being able to drive because of autistic traits, whilst for others it meant experiencing significant anxiety around using specific forms of public transport. ‘Access to buildings’ was framed in the accounts of autistic participants in terms of the sensory and physical layout characteristics of social spaces which facilitated or hindered their access to the social interaction. Sensory processing differences in autism have been previously shown to place requirements on the types of sensory environments in which autistic people can communicate successfully (Cummins et al., 2020).

Social environmental factors affecting autistic adults’ social participation that were not collected by the LOS, related to access to health care and disability friendly employment policies. The ‘lack of help’ barrier in the LOS, translated to difficulties with accessing autism-specific support, especially within health care and workplace contexts. The LOS ‘no opportunities’ barrier was framed primarily in the context of leisure activities in autistic people’s interviews. Participants described how there were either no social activities of interest in their local area or they were scheduled at the wrong time of day that conflicted with their daily routines and family responsibilities.

The differences in the LOS environmental barriers to participation and those reported by autistic adults relate primarily to differences in how these barriers were phrased in the LOS survey questions versus contextualised within the interviews. Disabled people are a heterogeneous population and the social and physical environmental barriers they encounter are likely to be different in nature, depending on impairment type.

10.4.3. Interpersonal Factors

The LOS collected no data on barriers to social participation that related to interpersonal factors, except for ‘the attitudes of others.’ Autistic participants’ accounts of how they established social relationships stressed the role played by the functional and qualitative characteristics of social interactions. Personal and environmental factors influenced access to the social spaces (life areas) where participation took place, but interpersonal factors determined whether autistic participants could access the social interaction itself.

The functional features of the social interaction that affected forming connections with others related to its perceived purpose, the way it was structured and how it was communicated (see Chapter 9, Section 9.3.2, p. 248). The qualitative dimensions of the social interaction related to the personal traits and demographic characteristics of the people involved, and their level of understanding of autism (see Chapter 9, Section 9.3.3, p. 250). Sharing similar personal traits (including neurodivergent traits), interests, life histories, thinking and communication styles increased the sense of relatedness between autistic participants and others within the social interaction. Relatedness is defined in the literature as the extent to which individuals feel a sense of belongingness and connectedness to others in their social environment and it has been shown to be one of the vital building blocks of intrinsic motivation in self-determination theory (Bartholomew & Ntoumanis, 2011; Ryan & Deci, 2002). Feelings of relatedness seemed to increase autistic adults' motivation for social participation because it removed the social and communication barriers that autistic people often encounter when interacting in neuro-typical environments.

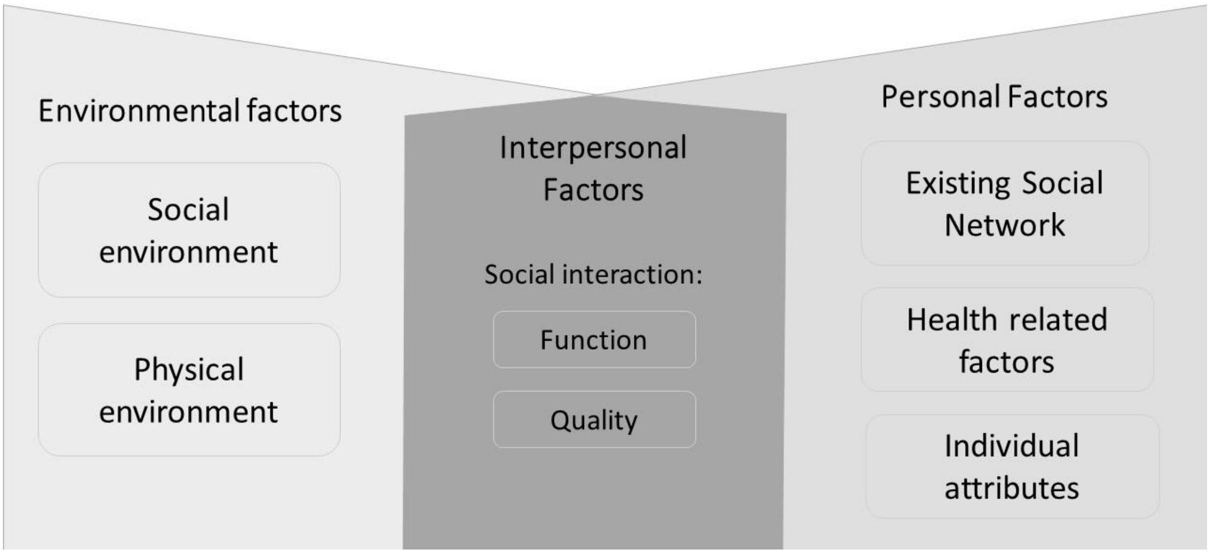
10.5. A new perspective on disability

One of the main findings of the qualitative study was the importance that autistic adults attributed to the functional and qualitative aspects of their social interactions as well as the personal characteristics of the people they were interacting with. These findings have implications for theoretical models of disability because they suggest that beyond the interplay of environmental and personal factors, there is another sub-layer of interpersonal factors which may facilitate or hinder social participation and its outcomes in terms of social connectedness.

The LOS was grounded in the Social Model of disability which emphasises the role of the social and physical environments in the creation of disability. Because of this, the LOS survey did not collect a comprehensive set of barriers to participation which pertained to personal factors. Moreover, the LOS collected no data about barriers *within* social participation, only about barriers of access *to* participation. The ICF model provides a more balanced perspective on how disability arises by acknowledging that functional impairments play a role in the arising of disability when they negatively interact with contextual factors. However, neither the Social nor the ICF Model of disability accounts for the subjective experience of the social interaction which forms the core element of social participation.

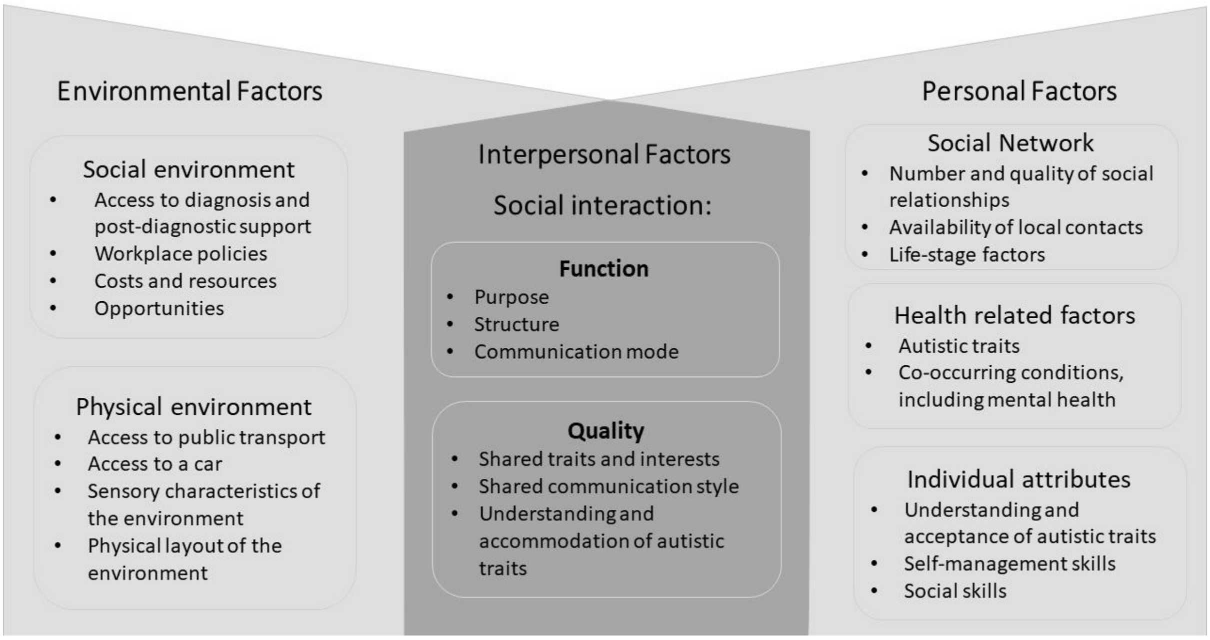
Figure 10.3 introduces a model of disability that extends the ICF model by incorporating the interpersonal factors affecting participation that only arise once the social interaction is taking place. This model illustrates the hierarchical nature of barriers affecting participation. Environmental and personal factors interact in a way that may enable or disable a person's access to the social environment. Once the social environment has been accessed, there is another layer of interpersonal factors which determine whether the social interaction itself can be accessed and completed successfully.

Figure 10.3 A proposed extended ICF Model of Disability



This proposed model of disability can be used to systematically describe the barriers and facilitators of social participation in different populations. Figure 10.4 illustrates how the factors that autistic participants described in relation to their social participation and connectedness is accommodated by the proposed model.

Figure 10.4 Factors affecting the social participation of autistic people



10.5.1. Implications for studies of social connectedness

The proposed extended ICF model of disability does not only provide a tool to map the distribution of barriers to the social participation reported by people with different types of disability, but it also gives an indication of the risks of different social connectedness outcomes. Barriers reported at the levels of environmental and personal factors indicate a risk of social isolation due to not being able to access the social environment. Not being able to participate in one or more life areas is likely to result in a restricted social network containing insufficient numbers of social ties in one or more network layers which are indicators of social isolation (S. Ang, 2019; E. Y. Cornwell & Waite, 2009). Barriers related to interpersonal factors within social interactions would imply being at a risk of experiencing poor subjective connectedness, described in the literature as characterised by lacking a psychological bond with others, resulting in feelings of loneliness (Biordi & Nichilson, 2013; Hare-Duke et al., 2019). The qualitative study findings suggest that social interactions which were lacking in perceived purpose and reciprocity, led to feelings of disconnection and loneliness in the autistic sample (Chapter 9, Section 9.3.3, p. 250).

10.6. Implications for policy and practice

The following sections describe some of the main themes suggested for future policy and practice, based on the thesis findings.

10.6.1. Focus on disabled young adults and disabled parents/carers

The quantitative study results identified groups within the LOS disabled sample, who were at increased risk of restricted participation across certain life areas. Young disabled people (aged 16-24) were most likely to report restricted participation in meeting close friends and family, and employment (Chapter 4, Figure 4.1) putting them at risk of social isolation, low income and adverse mental health outcomes. Young disabled people, especially those with a mental health impairment or neurodevelopmental condition, were also the most likely to have a barrier profile characterised by multiple environmental barriers. The qualitative study built on these findings by showing how the youngest autistic participants (aged 18-25) were the most likely to have a restricted social network, and to experience unemployment compared to others in the sample (Chapters 8 and 9, Table 8.2, p. 217 and Table 9.1., p. 235) Young autistic participants were also more likely to talk about experiencing on-going difficulties with their mental health than participants aged over 30 (Chapter 9, Section 9.3.1, p. 243). Government statistics indicate that a growing number of young adults report a mental health condition as a disability and that young adults with autism spectrum and/or mental health conditions had the worst employment outcomes in 2022 (ONS, 2021, 2023). Taken together, these findings suggest the need for the development of early intervention schemes targeting young adults' social inclusion in the education system and the wider community, and supporting transitions to adulthood and employment. This includes creating suitable supported employment opportunities for young disabled adults and providing support with the development of independence skills and the management of mental health conditions and neurodivergent traits.

The qualitative study results indicate that autistic adults may acquire a better understanding of their own autistic traits, and develop more effective self-management and social skills over time, which enable them to build social networks that suit their needs (Chapter 9, Section 9.2.3, p. 239). Because of the heterogeneity of the autistic population, studies focusing on ageing with autism offer mixed findings regarding social connectedness outcomes later in life and the factors associated with these (Howlin & Magiati, 2017; Sonido & Arnold, 2020). Nevertheless, it could be argued that social connectedness outcomes for young autistic adults could be significantly improved by the provision of early psychosocial intervention in the form of training relating to the recognition and management of autistic traits and social skills development.

The quantitative study found that being female and/or aged between 25 and 64 was significantly associated with experiencing a time-driven barrier profile to participation especially in the life areas of meeting friends and employment. In line with these findings, autistic parents, women in particular, talked about how their caring responsibilities placed time constraints on their participation in informal and community activities. Research studying the determinants of human psychological and physical health outcomes indicates that in order to maintain overall well-being, participation across a range of different life domains is essential (Durkheim, 2006 [1897]; Wray et al., 2011). Social policy needs to attend more to the needs of disabled parents and carers by providing access to support with caring responsibilities, especially in terms financial resources, mental health support and providing opportunities for time spent on leisure.

10.6.2. Improvement of disability awareness training

The qualitative study showed that autistic adults enjoyed participating in a wide range of social activities and they were actively striving to develop emotionally fulfilling social networks. This finding supports previous research which suggests that social relationships are regarded as important and are valued among autistic people just as much as among other populations (Chan et al., 2023; Elmose, 2020). The main barriers autistic participants described that prevented them from forming social connections, related to social, environmental, and personal factors that inhibited the accommodation of autistic traits. Social factors related to others’ attitudes and understanding of autism, its traits, and related conditions. Moreover, autistic participants reported frequent negative experiences involving miscommunication and misunderstandings when interacting with neuro-typical people. There is research evidence that shows that autistic people have different cognitive preferences to neuro-typical people which can result in a communication style mismatch that is bidirectional (R. Davis & Crompton, 2021). These findings suggest that when raising awareness of neurodevelopmental conditions, the training must include information about differences between neuro-typical and neuro-divergent thinking and communication styles and how to bridge these. Disability training needs to move beyond descriptives to providing information about the specific needs that are likely to result from the presence of a certain health condition and equipping people with the tools to accommodate these.

Environmental factors affecting autistic participants' social participation related to the sensory and physical properties of social environments. A lot has been done in recent years to create more neurodivergent-friendly shared spaces, but the qualitative interviews suggest that more needs to be done to improve sensory conditions in public spaces such as restaurants, theatres, and sports venues.

10.6.3. Attention to the drivers of mental health outcomes

The quantitative results revealed that disabled populations experienced higher rates of participation restrictions across all life areas compared to non-disabled people in the LOS. Thirteen to 25% of disabled people reported persistent participation restrictions across different life areas between Wave 1 and 3 (Chapter 6, Figure 6.1, p. 177). Financial barriers, health and time related factors were the most often reported barriers to participation by those reporting persistent restrictions (see Chapter 6, Section 6.3.1, p. 176). In addition, the quantitative study results emphasised the important role that mental health played in disabled people's social participation in the LOS. The absence or presence of a mental health condition or comorbidity was a significant predictor of disabled people's social participation across all barrier profiles and life areas (Chapter 5, Table 5.8, p. 163). The qualitative interviews with autistic adults echoed these findings and pointed to a close link between time use and the management of the social battery and mental health conditions (see Section 10.3.1). There is evidence from the literature that disabled people with psychiatric conditions spend more time on rest and recovery than non-disabled populations (Eklund et al., 2009; Shandra, 2018). It is likely that at least some of the time and health related barriers to participation reported in the LOS, were associated with the presence of a mental health condition. These findings point to the centrality of mental health status for disabled people's social participation.

Restricted social participation exposes the individual to the risk of social isolation. Social isolation and loneliness have been consistently linked in the literature with ill health and adverse mental health outcomes (Berkman et al., 2000; Cohen, 2004). Hence, restricted participation may perpetuate a cycle of low levels of social participation, leading to social isolation, loneliness and ill health. Although improving disabled people’s socio-economic circumstances (through financial benefits and labour market policies) plays an important role in whether disabled people can afford to access social activities, more needs to be done in terms of the prevention of the development of adverse mental health outcomes and the treatment of existing mental health conditions. Creating disability friendly social and physical environments, and following inclusive social practices in a wide range of life areas would be an effective way of reducing disabled people’s exposure to social exclusion and its negative consequences for mental health.

10.6.4. Support with the self-management of health conditions

One of the most striking findings of the qualitative study related to how autistic people’s own understanding and management of their autistic traits contributed to their social connectedness. Participants described how receiving an autism diagnosis and learning about their autistic traits changed the way they viewed themselves and shaped their subsequent choices of social activities and social interaction partners. This finding suggests that receiving an autism diagnosis and post-assessment support, played a vital role for autistic participants’ participation and social connectedness. There is some wider research evidence that psychosocial approaches supporting disabled people in acquiring self-management skills can increase their social participation. For example, providing pain-management training was shown to increase the labour market participation of people with chronic conditions (Nazarov et al., 2019). These findings suggest that investment into high quality diagnostic services and post-assessment support and training would be a cost-effective way to increase disabled people’s participation in a range of life areas.

10.7. Limitations of findings and implications for future research and survey design

This section describes the study limitations and together with the wider findings, what they mean for future research and survey design.

10.7.1. Limitations of findings

The LOS approach to sampling and data collection limited the quantitative study findings in several ways, described in more detail in sections 4.5.5 (p. 130) and 6.5.4 (p. 192). The LOS data overrepresented middle aged and older disabled populations due to following a sampling strategy to reflect population estimates. This resulted in limited the sample sizes for young disabled people and impairments that have higher prevalence rates among younger populations. This entailed that the quantitative study could not provide a comprehensive picture of the differences in the levels of participation restrictions and the barriers to social participation encountered by disabled people with different demographic and health characteristics.

The LOS longitudinal dataset contained very low sample sizes because of an over 33% attrition rate by Wave 3, which resulted in the loss of a large number of young disabled respondents from the dataset. Because of the limited longitudinal sample sizes, it was not possible to perform statistical analyses to examine how being assigned to a specific barrier profile at Wave 1 was associated with changes in participation restrictions and barriers reported at Wave 3. This meant that the thesis could not fully meet one of the quantitative study objectives, which was to identify factors associated with changes in social participation over time.

The LOS data on barriers to participation was underspecified and contained significant gaps. This meant that the LOS data on barriers to participation did not contain enough richness and diversity to build a barrier typology that could account for the heterogeneity of lived experience among different groups of disabled people.

The LOS collected data on functional impairments only which made it problematic to identify people with neurodevelopmental conditions in the dataset (see Chapter 4, Section

4.5.5, p. 130). This limited the reliability of the findings in relation to this group of disabled people.

The qualitative study was restricted to a small sample of autistic adults achieved by convenience sampling, using social media. This meant that autistic people who did not use or have access to the internet could not participate in the research. Moreover, the sensitivity of ‘social connectedness’ as a topic for autistic people meant that those experiencing significant social isolation and disconnect were least likely to be willing to participate in this study. The heterogeneity of the autistic population, coupled with the limited sample size of the qualitative study means that the findings do not offer a comprehensive representation of the varied experience in relation to social connectedness across autistic populations.

In addition, neither the LOS survey, nor the qualitative study collected information about participants’ social network characteristics and subjective evaluations of their social connectedness. If I could repeat this research, I would collect quantitative data about participants’ social networks using a network generator questionnaire (Kogovšek & Hlebec, 2014). I would use this information to link social participation, and barriers to participation to social network outcomes and subjective evaluations of feelings of belonging.

10.7.2. Implications for future survey design

The limitations described above offer learnings for future survey design. The LOS survey questionnaire underspecified barriers to participation, using phrasing that could potentially carry multiple meanings (e.g.: ‘no time’, ‘health condition’, ‘difficulties with transport’). This caused difficulties for the interpretation of the findings and the drawing of implications. Moreover, some of the barriers were reported by very few respondents, suggesting that these barriers to participation were either not experienced by disabled people or they were worded in a way that might not have resonated with respondents. Although the LOS questionnaire was designed with the involvement of a disabled people (Office for National Statistics, 2011a), the data collected suggests that those involved might not have been entirely representative of the heterogeneity found in the disabled population. Care needs to be taken to word future survey questions regarding barriers to participation in a way that reflects disabled people's varied experience, so that survey respondents recognise these barriers when asked about them in the context of the survey.

In addition, the qualitative findings suggest that future surveys of social participation need to include a set of questions collecting information about barriers relating to personal attributes and interpersonal factors that affect the establishment of relationships within social interactions. The qualitative study findings also indicate that survey questions regarding informal care should be designed to differentiate between caring for dependent children with additional needs and caring for adults, because this would help to assess and track changes in parental burden of care and link this back to parents' demographic and health characteristics.

10.7.3. Implications for future research

The thesis findings and limitations point to several new directions for future research. This section introduces a set of research questions and their rationale, building on the work undertaken in this thesis.

1. How does disability impact on time use?

There is relatively little research about how disability affects time management and the prioritisation of social activities. Current literature focuses primarily on factors affecting disabled people's participation in employment and exercise (Chandola & Rouxel, 2021; Christiaens & Brittain, 2023; Firth & Rosenbaum, 2016; Hastbacka et al., 2016). There is not much understood about the implications of living with a functional impairment for the time spent on leisure activities involving others. Having a diverse social network built through participation in a variety of life areas is known to be beneficial for one's health and well-being (Berkman, 2000). More research needs to focus on understanding the types of health-related tasks undertaken by disabled people that consume time. Some of these may for example be time spent on rest and recovery, time spent on planning or completing a task or activity, and time spent on managing a health condition (Oi, 1991; Shandra, 2018). We need to understand how the time requirements of living with a disability affect time use in other areas of life. In addition, more needs to be known about how time use varies based on the nature of the disability and what can be done to design social activities, employment policies and health-care services that accommodate disabled people's time needs.

2. **What is the relationship between social participation, mental health and disability?**

More research needs to focus on the underlying drivers of adverse mental health outcomes in disabled populations. There is research evidence, for example, that there is a high rate of co-occurrence between autism and mental health conditions, often accompanied by social isolation (Lai et al., 2019; Hickey et al., 2018; Hwang et al., 2020). We need to increase understanding of the development of mental health difficulties in disabled populations and the extent to which they are attributable to restrictions in social participation. A health or neurodivergent condition in itself should not necessarily lead to adverse mental health outcomes. If the mechanisms underlying poor mental health outcomes in disabled populations were better understood, interventions could focus more on their prevention, than exclusively on their cure.

3. **What is the prevalence of disabled parents parenting children with additional needs; and how can we assist them in their caring responsibilities and wider social participation?**

The risk of social isolation and loneliness among informal care givers of older adults have been documented in the literature (Perez & Nuccio, 2021). There is less understood, however, about the social participation of parents caring for disabled children (Currie & Szabo, 2020), and even less about the experiences of disabled parents. Evidence about the high heritability of autism (Bai et al., 2019; English et al., 2021), together with autistic parents' accounts in the qualitative interviews (Chapter 9, Section 9.3.1, p. 245) suggest that autistic parents are likely to raise neurodivergent children. More research needs to focus on the exploration of the support needs of disabled parents because they are at increased risk of social isolation due to encountering multiple barriers to participation that are intersectional in nature.

4. **How do interpersonal factors affect the social participation of disabled people?**

The quantitative and qualitative study findings suggest that social and interpersonal barriers make up a large share of the factors affecting the social participation of disabled people. The health driven, time driven and multiple environmental barrier driven profiles identified by the LCA highlighted the important role that the social environment and personal demographic and health characteristics played in restricted participation. The qualitative study findings, moreover stressed the importance of the structural and qualitative features of the social interaction for autistic adults' social engagement (see Section 10.4.3). More research is needed to identify the types of social and communication barriers encountered by disabled people with different types of impairment. It is likely that interpersonal barriers to social connectedness will differ across disabled groups.

5. **What other aspects of the environment affect the social participation of disabled people, beyond physical accessibility?**

Because of the substantial influence of the Social Model of disability on policy and practice, previous policy efforts aiming to facilitate disabled people's social participation focused primarily on removing access barriers to the physical environment (Owens, 2015; Woods, 2017). The interviews conducted with autistic adults highlighted the importance of other aspects of the physical environment for social participation, which related to its layout and sensory characteristics (Chapter 9, Section 9.3.1, p. 245). More research needs to focus on exploring the characteristics of physical/social environments that influence whether disabled people can successfully take part in a social interaction in a given space.

10.8. Thesis strengths

By mapping social participation to different layers of the social network, this thesis provided a new perspective from which to examine the factors that shape disabled people's social connectedness. The thesis definition of social connectedness (i.e.: having sufficient quantity and quality connections on each social network layer) necessitated a research design with a wide scope that encompassed all major life areas. This enabled the quantitative analyses to pinpoint participation domains where disabled people were most at risk of restricted participation. Keeping a wide research perspective also helped to locate gaps in the literature and offer new directions to future research.

The set of latent class analyses presented a new approach to the study of social connectedness, driven by a structuralist paradigm, where model building was driven by the types of barriers reported instead of by the attributes of people reporting them. This approach meant that the same barrier profile could be assigned to disabled people with different personal and health characteristics, uncovering common patterns of disabling barriers across different types of demographics and impairment types. To my knowledge, no previous studies have profiled disabled people based on the barriers they reported to participation. In addition, the quantitative study contributed to knowledge about the relative stability and movement in and out of participation restrictions reported by disabled people in different life areas and changes in barriers to participation.

The qualitative findings broaden current understanding of the factors affecting autistic adults' social participation by emphasising the role that the functional and qualitative features of social interactions play for their social connectedness. Although there is a plethora of research about the social and communication difficulties associated with autism, there is little evidence regarding the mechanisms through which these autistic traits impact on social connectedness. Interventions aiming to raise public awareness about autism and neurodevelopmental conditions still tend to focus on shaping perceptions and creating neurodivergent friendly sensory and physical environments. The thesis findings provide a new perspective from which to approach disability educational campaigns that emphasises the importance of the functional and qualitative dimensions of social interactions.

The thesis makes a significant contribution to theoretical models of social relations and disability. The thesis conceptual model built on previous models of social relations to synthesise concepts of social connectedness which led to the creation of an extended version of the ICF model of disability that accommodates the hierarchical layers of personal and environmental factors that play a role in the construction of disability. This new proposed model accommodates the subjective personal factors affecting participation which were called for by critics of the ICF model (Duchan, 2004; Mitra & Shakespeare, 2019).

10.9. Conclusion

This thesis set out (1) to explore differences in barriers to participation between disabled and non-disabled populations; (2) to discover how personal characteristics were associated with patterns of barriers characterising restricted participation and (3) to examine if current constructions of disability accommodated autistic adults' experiences of social participation. The quantitative study results highlighted persisting differences in restricted participation between disabled and non-disabled populations and succeeded in identifying life areas where disabled people were most at risk of encountering barriers to their participation. Employment and education were the participation domains where disabled people, especially women and young adults, were most likely to report restricted participation, a finding that reflects the historical employment gap between disabled and non-disabled people reported by government statistics (Office for National Statistics, 2022b). After lack of time, financial barriers were most often reported by disabled people to restrict participation in informal social activities, and health barriers were the primary source of restrictions to employment. LCA identified demographic and personal characteristics predicting the likelihood of experiencing one of three broad patterns of barriers. The findings from the qualitative interviews helped to interpret and extend the barriers to participation collected by the LOS within the context of autism.

Disabled people are a heterogeneous population, comprising of diverse demographic groups, with different types and severity of impairment. This thesis made the first step towards charting the barriers to the wider participation of disabled people and contextualising some of these for a sample of autistic adults. It also provided a proposed framework to assist researchers in the mapping and classification of factors affecting the social participation of people with different types of disabilities. Future research needs to focus on linking the barriers to social participation in disabled populations to social connectedness outcomes, which can be measured by indicators of well-being and studies of social network size and quality.

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Appendix 1. LOS Questionnaire on impairments

Derived variable	**Label**	**LOS variable name**	**Question asked of respondent**
DVSee	Whether has vision impairment	IVision	Do you have any difficulty seeing, or wear glasses or contact lenses?
DVHear	Whether has hearing impairment	IHear	Do you have any difficulty hearing, or use a hearing aid? *Include those who cannot hear at all*
DVSpk	Whether has communication/speech impairment	ISpk	Do you have difficulty speaking or making yourself understood, or use aids or special equipment to help you communicate? (Exclude difficulties owning to language barriers)
DVMob	Whether has mobility impairment	IMobil	Do you have any mobility difficulties, for example moving about, walking, climbing stairs; or use special equipment or support services to help you to be mobile? *Include wheelchairs and crutches as equipment.*
DVDex	Whether has dexterity impairment	IDex	Do you have any dexterity difficulties, by that I mean lifting, grasping or holding objects, or use special equipment to help you with these actions?
DVPain	Whether has limiting pain condition	IPain	Do you experience long-term pain or discomfort that is always present or reoccurs from time to time or take medication to manage any long-term pain or discomfort?
DVCond	Whether has condition listed at ICond	ICond	Code all that apply: (1) Asthma or severe allergies (2) Heart condition or disease (3) Kidney condition or disease (4) Cancer (5) Diabetes (6) Epilepsy (7) Cerebral Palsy (8) Spina Bifida

			(9) Cystic Fibrosis (10) Muscular Dystrophy (11) Migraines (12) Arthritis or rheumatism (13) Multiple Sclerosis (MS) (14) Paralysis of any kind (15) Any other long-term condition not already covered (please specify) (16) None
DVBrth	Whether has breathing impairment	IBreath	Do you have shortness of breath or difficulty breathing or use specialised equipment as a nebuliser, oxygen concentrator or cylinder or ventilator to assist with breathing?
DVLrn	Whether has learning impairment	ILearn	Do you have a difficulty learning, for example at school, college, work or in other places? This may be due to a condition such as dyslexia or ADHD…
DVIntel	Whether has intellectual impairment	IIntel	Do you have an intellectual difficulty or developmental delay? This may not have a name but include things like Down's syndrome, autism and other conditions.
DVBev	Whether has behavioural impairment	IBev	Do you have a social or behavioural difficulty, for example difficulty making friends or aggressive outbursts? This may not have a name but may be associated with ADD, autism, Asperger's Syndrome or have no apparent cause.
DVMem	Whether has memory impairment	IMemory	Do you frequently have periods of confusion or difficulty remembering things? *These difficulties may be associated with diseases such as Alzheimer's, dementia or as a result of a brain injury or stroke.*
DVMent	Whether has mental impairment	IMental	Do you have any emotional, psychological or mental ill health conditions that have lasted, or are expected to last, 12 months or more? *These include things like obsessive or compulsive behaviours, anxiety, extreme phobias, depression, schizophrenia, drinking or drug problems or eating disorders.*
DVOth	Whether has impairment not previously mentioned	IOther	Do you have any other difficulties or limitations because of a physical condition, mental health condition or health problem that we have not already covered? Please think of difficulties or limitations that have lasted, or are expected to last 12 months or more.

Appendix 2. Additional tables for Chapter 4

Table A. 2.1 Disabled sample: 'Not applicable' answers to employment status*

	Disabled sample		Non-disabled sample	
	Numbers	**Percentages**	**Numbers**	**Percentages**
Informal carer	349	*23.27*	580	*21.29*
Disabled	665	*44.33*	51	*1.87*
Retired	485	*32.33*	1,002	*36.78*
Student	110	*7.33*	799	*29.33*
Inactive	341	*22.73*	1,644	*60.35*
Total NA on employment	1,500	*100.00*	2,724	*100.00*

*Unweighted observations, weighted percentages. Column percentages do not add up to 100% because one person can report more than one occupation.

Table A. 2.2 Reported barriers to participation in meeting close contacts (weighted percentages)

LOS barriers	**Meeting close contacts**		**Adjusted Chi-Square**
	Disabled	**Not disabled**	
Sample size	*1,580*	*4,081*	**F(1, 5660)**
Too busy/no time	**1,011 (63.6)***	**3,448 (84.6)***	275,56, p<0.001
Attitudes of others	40 (2.6)*	36 (0.88)*	24.00, p<0.001
No-one to meet/ go with	**28 (2.0)***	**26 (0.69)***	15.84, p<0.001
Other people busy	**827 (51.7)***	**1,972 (48.3)***	4.82, p<0.001
Lack of help/ assistance	23 (1.4)*	11 (0.27)*	23.51, p<0.001
Difficulty with transport	**171 (10.8)**	**216 (5.8)**	36.74, p<0.001
Difficulty access buildings	18 (1.1)	1 (0.04)	26.66, p<0.001
Difficulty using facilities	6 (0.4)	1 (0.04)	4.64, p<0.001
Caring responsibilities	**121 (7.3)**	**219 (5.1)**	10.01, p<0.001
Financial reasons	**279 (18.2)***	**415 (11.2)***	41.49, p<0.001
Health condition	**218 (13.9)***	37 (0.8)*	470.5, p<0.001
Fear of crime	17 (1.2)*	5 (0.1)*	22.89, p<0.001
Fear of crowds	37 (2.4)*	6 (0.2)*	60.44, p<0.001

Table A. 2.3 Reported barriers to participation in meeting friends (weighted percentages)

LOS barriers	**Meeting Friends**		**Adjusted Chi-square**
	Disabled	**Not disabled**	
Sample size	*2,104*	*5,899*	**F(1, 8002)**
Too busy/no time	**1,175 (55.5)***	**4,825 (81.6) ***	507.82, p<0.001
Attitudes of others	36 (1.7)*	25 (0.5)*	31.10, p<0.001
Not feeling welcome	28 (1.4)*	21 (0.4)*	24.05, p<0.001
No-one to meet/ go with	**52 (2.6)***	59 (1.0)*	22.90, p<0.001
Lack of help/ assistance	**37 (1.8)***	22 (0.4)*	40.91, p<0.001
Lack of availability	43 (2.1)	92 (1.7)	1.29, p=0.27
Difficulty with transport	**215 (10.1)***	**240 (4.2)***	94.65, p<0.001
Difficulty access buildings	35 (1.7)*	2 (0.03)*	88.58, p<0.001
Difficulty using facilities	19 (0.9)*	2 (0.03)*	42.15, p<0.001
Caring responsibilities	**166 (7.5)***	**334 (5.4)***	11.47, p<0.001
Too expensive	**592 (28.4)***	**1,228 (21.9)***	32.50, p<0.001
Health condition	**404 (19.5)***	42 (0.6)*	1115.84, p<0.001
Fear of crime	21 (1.1)	23 (0.4)	10.57, p=0.001
Fear of crowds	31 (1.5)*	6 (0.2)*	27.71, p<0.001

Table A. 2.4 Reported barriers to participation in meeting family (weighted percentages)

LOS barriers	**Meeting Family**		**Adjusted Chi-square**
	Disabled	**Not disabled**	
Sample size	*1,883*	*5,332*	**F(1, 7214)**
Too busy/no time	**1,022 (53.4)***	**4,132 (77.0)***	332.14, p<0.001
Attitudes of others	**47 (2.7)***	35 (0.7)*	40.01, p<0.001
Not feeling welcome	**41 (2.2)***	31 (0.6)*	36.00, p<0.001
No-one to meet/ go with	23 (1.2)*	19 (0.3)*	18.63, p<0.001
Lack of help/ assistance	19 (1.0)*	14 (0.3)*	16.94, p<0.001
Lack of availability	38 (2.1)	99 (2.0)	0.07, p=0.79
Difficulty with transport	**169 (9.4)***	**167 (3.2)***	96.01, p<0.001
Difficulty access buildings	22 (1.1)*	3 (0.1)*	33.90, p<0.001
Difficulty using facilities	11 (0.6)*	3 (0.1)*	27.03, p<0.001
Caring responsibilities	**89 (4.3)***	**150 (2.7)***	13.29, p<0.001
Too expensive	**552 (29.0)***	**954 (19.7)***	56.85, p<0.001
Health condition	**262 (14.0)***	22 (0.4)*	557.41, p<0.001
Fear of crime	10 (0.5)	8 (0.1)	8.74, p=0.003
Fear of crowds	15 (0.9)*	1 (0.03)*	28.29, p<0.001

Table A. 2.5 Reported barriers to participation in education (weighted percentages)

LOS barriers	**Education**		**Adjusted Chi-square**
	Disabled	**Not disabled**	
Sample size	*1,130*	*1,776*	**F(1, 2905)**
Too busy with work or family	**278 (24.5)***	**753 (42.5)***	81.88, p<0.001
Attitudes of others	**120 (10.3)***	62 (3.6)*	47.67, p<0.001
Lack of information	**255 (22.5)**	**306 (18.0)**	7.30, p=0.007
Lack of help/ assistance	**219 (19.3)***	**188 (11.2)***	27.95, p<0.001
No opportunities	**219 (19.8)**	**301 (16.0)**	6.10, p=0.01
Can’t get on a course	**142 (13.3)**	**195 (10.9)**	3.07, p=0.08
Difficulty with transport	**230 (20.1)***	**151 (8.1)***	86.34, p<0.001
Difficulty access buildings	**52 (4.5)***	2 (0.1)*	52.34, p<0.001
Difficulty using facilities	**45 (3.8)***	9 (0.5)*	36.61, p<0.001
Caring responsibilities	**170 (13.9)**	**272 (14.6)**	0.22, p=0.64
Financial reasons	**608 (53.8)**	**981 (56.7)**	2.08, p=0.15
Health condition	**325 (29.6)***	13 (1.2)*	182.18, p<0.001

Table A. 2.6 Reported barriers to participation in employment (weighted percentages)

LOS barriers	**Employment**		**Adjusted Chi-square**
	Disabled	**Not disabled**	
Sample size	*1,179*	*2,844*	**F(1, 4023)**
Family responsibilities	**350 (28.3)***	**1,315 (43.8)***	79.01, p<0.001
Attitudes of colleagues	**38 (3.1)***	**28 (1.0)***	22.24, p<0.001
Attitudes of employers	**160 (13.6)***	**218 (7.9)***	16.86, p<0.001
Lack of help/ assistance	**72 (5.8)***	73 (2.8)*	18.18, p<0.001
No opportunities	**256 (23.3)**	**528 (19.3)**	6.68, p=0.01
Lack of experience/quals	**198 (17.6)***	**362 (13.0)***	11.83, p<0.001
Difficulty with transport	**161 (13.4)***	**247 (8.6)***	20.90, p<0.001
Difficulty access buildings	24 (2.2)*	12 (0.4)*	25.03, p<0.001
Difficulty using facilities	24 (2.0)*	12 (0.4)*	25.03, p<0.001
Lack of equipment	26 (2.2)*	4 (0.1)*	41.25, p<0.001
Caring responsibilities	**122 (10.0)***	**202 (6.8)***	12.00, p<0.001
Affects benefits	**79 (6.7)***	**100 (3.2)***	21.84, p<0.001
Health condition	**454 (37.9)***	**122 (4.3)***	721.45, p<0.001
Anxiety/No confidence	**118 (10.2)***	70 (2.5)*	101.52, p<0.001

Table A. 2.7 Reported barriers to participation in volunteering (weighted percentages)

LOS barriers	**Volunteering**		**Adjusted Chi-square**
	Disabled	**Not disabled**	
Sample size	*1,724*	*5,318*	**F(1, 7041)**
Too busy/no time	**1,020 (59.1)***	**4,607 (86.4)***	541.98, p<0.001
Attitudes of others	**40 (2.4)***	29 (0.6)*	34.12, p<0.001
Not feeling welcome	**18 (1.1)***	14 (0.3)*	16.96, p<0.001
No-one to meet/ go with	17 (2.0)	88 (1.8)	0.23, p=0.63
Lack of help/ assistance	**58 (4.0)***	90 (1.8)*	18.78, p<0.001
Lack of availability	**57 (3.4)**	150 (2.9)	1.07, p=0.30
Difficulty with transport	**90 (5.2)***	81 (1.5)*	72.99, p<0.001
Difficulty access buildings	24 (1.4)*	9 (0.2)*	24.05, p<0.001
Difficulty using facilities	18 (1.1)	0 (0)	55.24, p<0.001
Caring responsibilities	**142 (7.6)**	**329 (5.8)**	7.10, p=0.008
Too expensive	**152 (8.9)**	**412 (8.0)**	1.25, p=0.26
Health condition	**407 (23.3)***	47 (0.8)*	1016.86, p<0.001
Fear of crime	6 (0.4)	4 (0.1)	7.76, 0.005
Fear crowds	24 (1.5)*	8 (0.2)*	42.44, p<0.001

Table A. 2.8 Reported barriers to participation in sport (weighted percentages)

LOS barriers	**Sport**		**Adjusted Chi-square**
	Disabled	**Not disabled**	
Sample size	*1,732*	*5,027*	**F(1, 6758)**
Too busy/no time	**669 (38.8)***	**3,723 (73.8)***	614.46, p<0.001
Attitudes of others	**44 (2.7)***	33 (0.7)*	40.11, p<0.001
Not feeling welcome	**30 (1.8)***	14 (0.3)*	41.23, p<0.001
No-one to meet/ go with	**136 (8.4)**	**355 (7.5)**	1.14, p=0.29
Lack of help/ assistance	37 (2.2)*	33 (0.7)*	27.21, p<0.001
Lack of availability	**93 (5.8)**	**277 (6.0)**	0.03, p=0.87
Difficulty with transport	**68 (3.9)***	90 (1.9)*	19.98, p<0.001
Difficulty access buildings	17 (0.9)*	4 (0.1)*	22.92, p<0.001
Difficulty using facilities	46 (2.6)*	26 (0.7)*	32.93, p<0.001
Caring responsibilities	**100 (5.4)**	**313 (5.7)**	0.34, p=0.56
Too expensive	**362 (21.8)**	**983 (19.9)**	2.34, p=0.13
Health condition	**774 (44.4)***	**378 (7.4)***	1152.30, p<0.001
Fear of crime	9 (0.6)*	7 (0.1)*	11.41, p<0.001
Fear crowds	29 (1.8)*	10 (0.2)*	52.70, p<0.001

Appendix 3. Latent Class Analyses results and model diagnostics

When selecting barriers to participation across different participation domains for inclusion in the Latent Class (LCA) models, only barriers with at least 50 observations were chosen in order to increase the robustness of the results. For unweighted sample sizes of barriers refer to Appendix 2. The following sections present detailed LCA model diagnostics and latent class probabilities for each participation domain for the disabled sample only. All LCA models are based on weighted samples using the LOS calibration weight.

A 3.1. Meeting close contacts

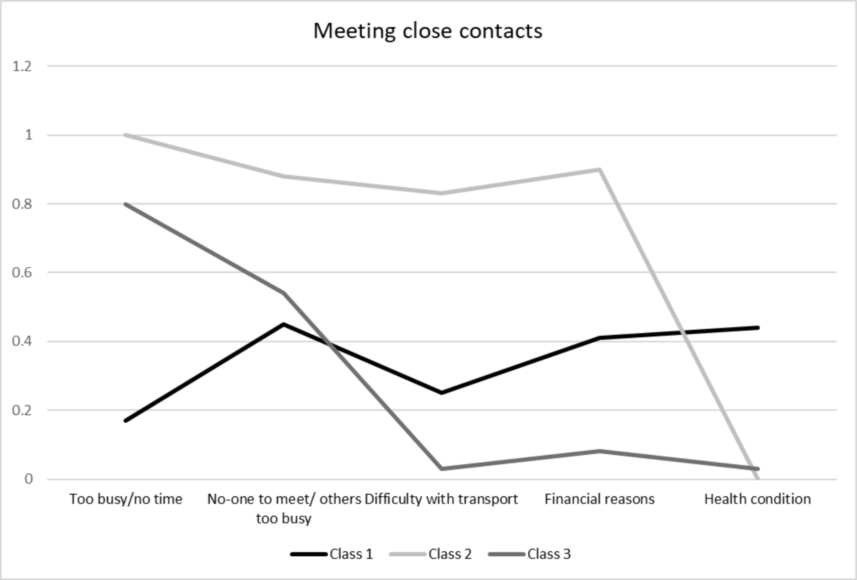
Table A. 3.1 Latent classes: 'restrictions to meeting close contacts'

LOS barriers	**Class 1**	**Class 2**	**Class 3**
Class size (observations)	317	31	1232
Too busy/no time	0.17	1.00	0.80
No-one to meet/ others too busy	0.45	0.88	0.54
Difficulty with transport	0.25	0.83	0.03
Financial reasons	0.41	0.90	0.08
Health condition	0.44	0.00	0.03

Table A. 3.2 LCA Model diagnostics: 'restrictions to meeting close contacts'

Model	L^2	df	p-value >0.05	AIC	BIC	Lo-Mendell-Rubin Adjusted LRT test	p-value < 0.05	Entropy
1 class	367.99	26	<0.001	8120.82	8147.65			
2 classes	95.87	20	<0.001	7831.13	7890.15	295.01	<0.001	0.52
3 classes	47.81	14	<0.001	7795.10	7886.31	46.96	<0.01	0.73
4 classes	30.16	8	0.0001	7787.54	7910.94	19.13	0.27	0.62

Figure A. 3.1 Conditional probabilities 'restrictions to meeting close contacts'



A 3.2. Visiting friends and family

A 3.2.1. Visiting friends

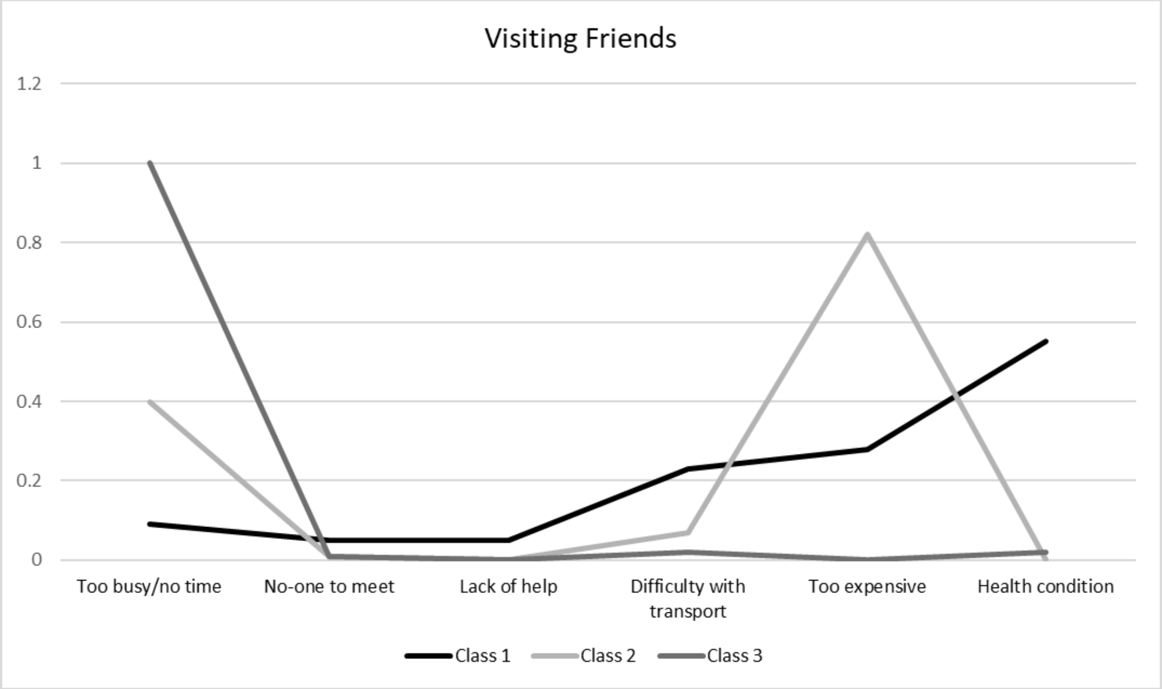
Table A. 3.3 Latent classes: 'restrictions to visiting friends'

LOS barriers	**Class 1**	**Class 2**	**Class 3**
Class size (observations)	647	*478*	*980*
Too busy/no time	0.09	0.40	1.00
No-one to meet	0.05	0.01	0.01
Lack of help	0.05	0.00	0.00
Difficulty with transport	0.23	0.07	0.02
Too expensive	0.28	0.82	0.00
Health condition	0.55	0.00	0.02

Table A. 3.4 LCA Model diagnostics: 'restrictions to visiting friends'

Model	L^2	df	p-value >0.05	AIC	BIC	Lo-Mendell-Rubin Adjusted LRT test	p-value < 0.05	Entropy
1 class	933.37	56	<0.001	9742.52	9776.43			
2 classes	211.19	50	<0.001	8963.04	9036.52	778.93	<0.001	0.84
3 classes	101.40	43	<0.001	8862.74	8975.77	112.21	<0.01	0.75
4 classes	61.33	36	0.005	8831.01	8983.61	44.89	1	0.89

Figure A. 3.2 Conditional probabilities: 'restrictions to visiting friends'



A 3.2.2. Visiting family

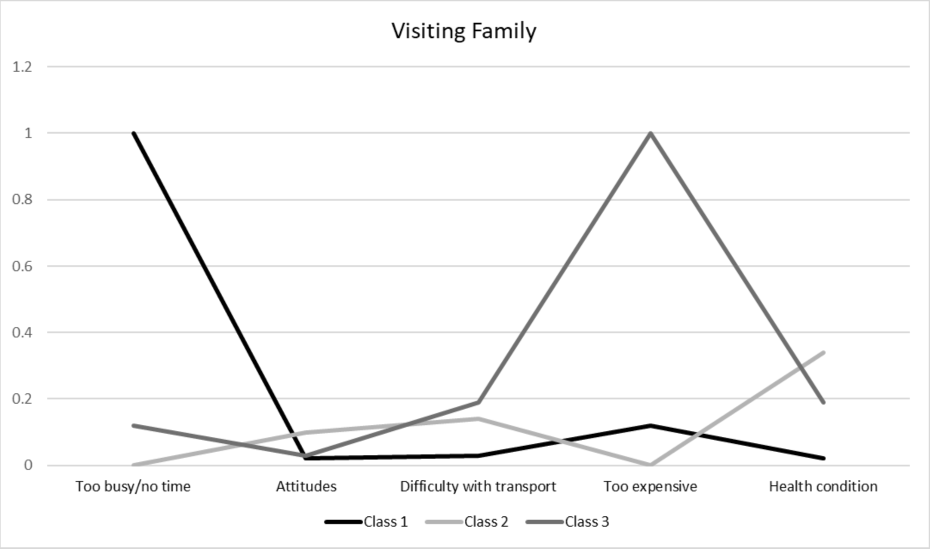
Table A. 3.5 Latent classes: 'restrictions to visiting family'

LOS barriers	**Class 1**	**Class 2**	**Class 3**
Class size (observations)	982	*496*	*405*
Too busy/no time	1.00	0.00	0.12
Attitudes	0.02	0.10	0.03
Difficulty with transport	0.03	0.14	0.19
Too expensive	0.12	0.00	1.00
Health condition	0.02	0.34	0.19

Table A. 3.6 LCA Model diagnostics: 'restrictions to visiting family'

Model	L^2	df	p-value >0.05	AIC	BIC	Lo-Mendell-Rubin Adjusted LRT test	p-value < 0.05	Entropy
1 class	573.33	26	<0.001	8260.87	8288.58			
2 classes	81.93	20	<0.001	7711.91	7772.86	548.33	<0.001	0.85
3 classes	35.58	14	0.001	7671.77	7765.96	51.01	<0.001	0.95
4 classes	15.4	8	0.05	7663.33	7790.76	20.01	0.13	0.70

Figure A. 3.3 Conditional probabilities: 'restrictions to visiting family'



A 3.3. Participation domains of education and employment

A 3.3.1. Restricted participation in education

‘Lack of opportunities’ was excluded from the model because it had low explanatory value. There is no significant difference within disabled groups and between disabled and non-disabled groups with regards to opportunities as a barrier to participation in education.

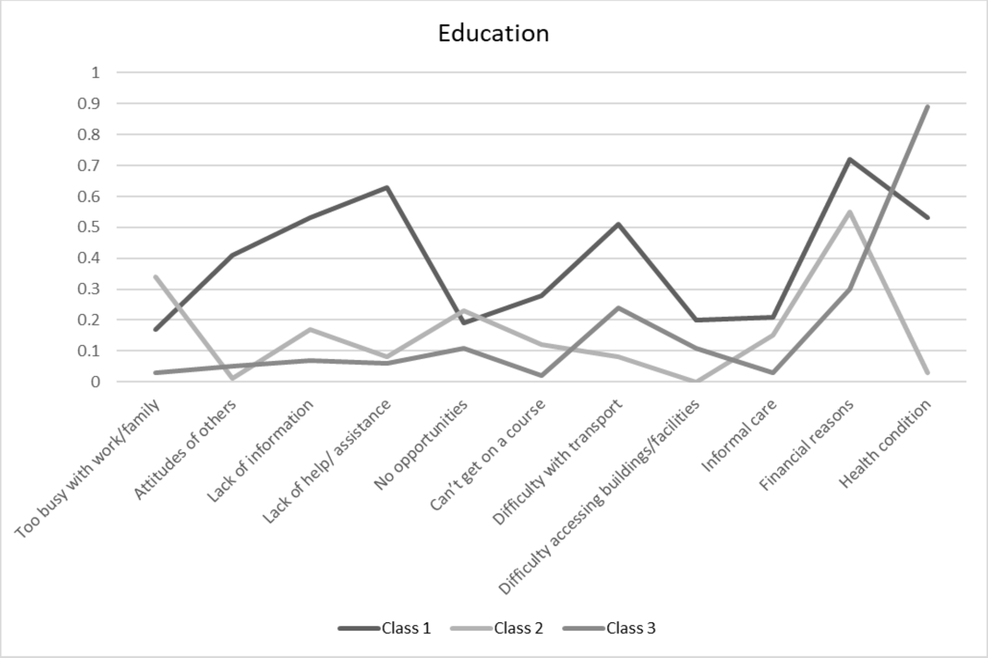
Table A. 3.7 Latent classes: ‘restricted participation in education’

LOS barriers	**Class 1**	**Class 2**	**Class 3**
Class size (observations)	*223*	*702*	*204*
Too busy with work/family	0.17	0.34	0.03
Attitudes of others	0.41	0.01	0.05
Lack of information	0.53	0.17	0.07
Lack of help/ assistance	0.63	0.08	0.06
No opportunities	0.19	0.23	0.11
Can’t get on a course	0.28	0.12	0.02
Difficulty with transport	0.51	0.08	0.24
Difficulty accessing buildings/facilities	0.20	0.00	0.11
Informal care	0.21	0.15	0.03
Financial reasons	0.72	0.55	0.30
Health condition	0.53	0.03	0.89

Table A. 3.8 LCA Model diagnostics: ‘restricted participation in education’

Model	L^2	df	p-value >0.05	AIC	BIC	Lo-Mendell-Rubin Adjusted LRT test	p-value < 0.05	Entropy
1 class	1369.56	2016	1.00	11857.8	11913.1			
2 classes	1157.07	2020	1.00	11451.1	11566.8	425.68	<0.001	0.68
3 classes	1802.57	2010	0.99	11293.4	11469.5	179054	0.18	0.73
4 classes	962.71	1998	1.00	11252.9	11489.3	63.72	0.51	0.67

Figure A. 3.4 Conditional probabilities: 'restricted participation in education'



A 3.3.2. Restricted participation in employment

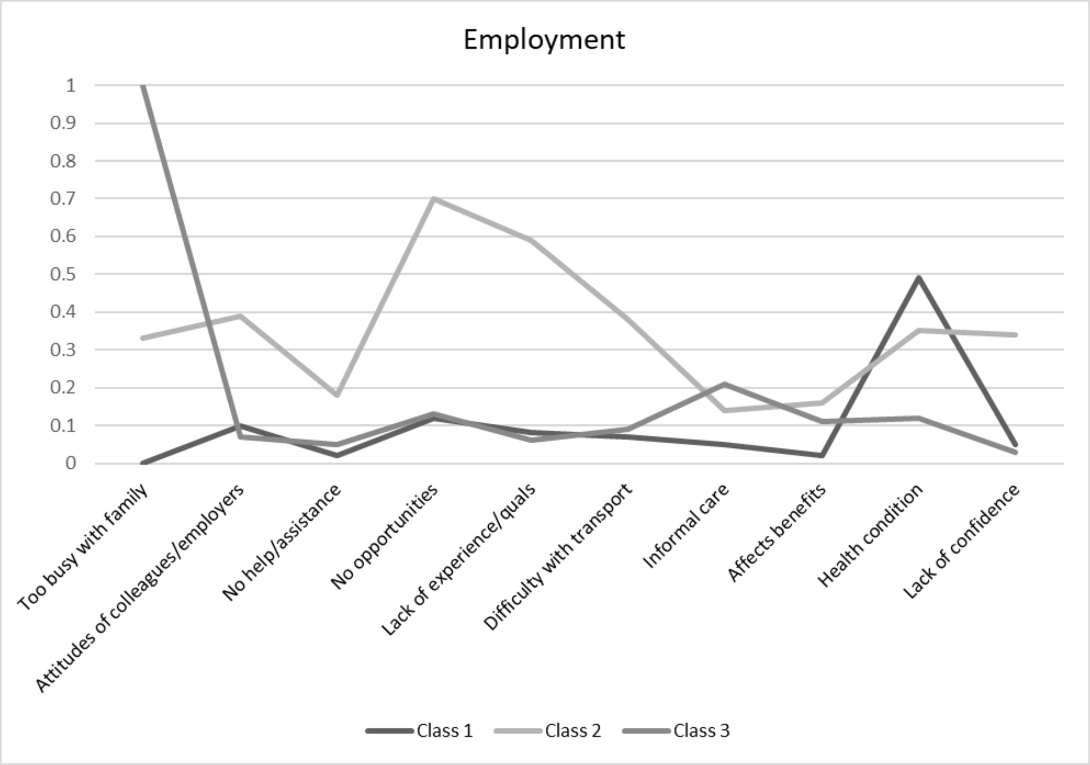
Table A. 3.9 Latent classes: 'restricted participation in employment'

LOS barriers **Class size (observations)**	**Class 1** *713*	**Class 2** *202*	**Class 3** *264*
Too busy with family	0.00	0.33	1.00
Attitudes of colleagues/employers	0.10	0.39	0.07
No help/assistance	0.02	0.18	0.05
No opportunities	0.12	0.70	0.13
Lack of experience/quals	0.08	0.59	0.06
Difficulty with transport	0.07	0.38	0.09
Informal care	0.05	0.14	0.21
Affects benefits	0.02	0.16	0.11
Health condition	0.49	0.35	0.12
Lack of confidence	0.05	0.34	0.03

Table A. 3.10 LCA Model diagnostics: 'restricted participation in employment'

Model	L^2	df	p-value >0.05	AIC	BIC	Lo-Mendell-Rubin Adjusted LRT test	p-value < 0.05	Entropy
1 class	876.1	990	0.99	9932.5	9983.2			
2 classes	817.5	1001	1.00	9604.2	9710.7	345.80	<0.001	0.67
3 classes	643.9	990	1.00	9443.6	9605.9	180.26	0.0002	0.82
4 classes	561.9	979	1.00	9377.7	9595.9	86.78	0.33	0.71

Figure A. 3.5 Conditional probabilities: 'restricted participation in employment'



A 3.4. Participation domains of volunteering and sport

A 3.4.1. Volunteering

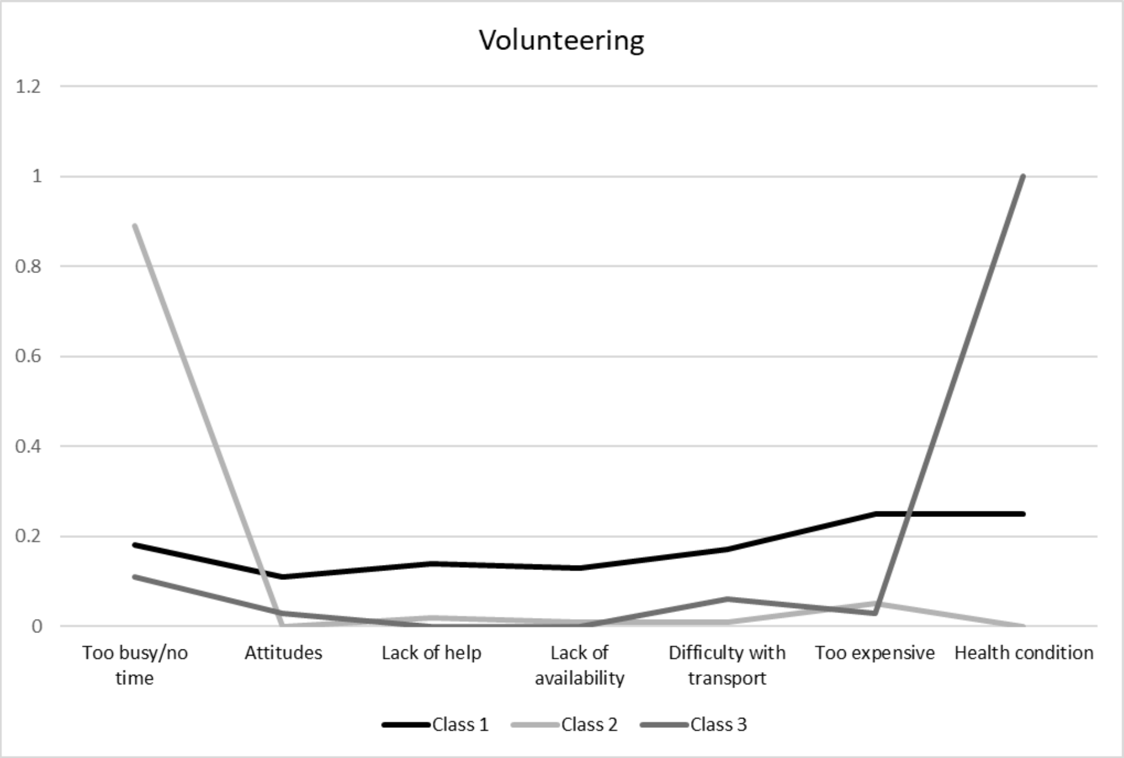
Table A. 3.11 Latent classes: 'restricted participation in volunteering'

LOS barriers	**Class 1**	**Class 2**	**Class 3**
Class size (observations)	*220*	*1,157*	*348*
Too busy/no time	0.18	0.89	0.11
Attitudes	0.11	0.00	0.03
Lack of help	0.14	0.02	0.00
Lack of availability	0.13	0.01	0.00
Difficulty with transport	0.17	0.01	0.06
Too expensive	0.25	0.05	0.03
Health condition	0.25	0.00	1.00

Table A. 3.12 LCA Model diagnostics: 'restricted participation in volunteering'

Model	L^2	df	p-value >0.05	AIC	BIC	Lo-Mendell-Rubin Adjusted LRT test	p-value < 0.05	Entropy
1 class	668.81	113	<0.001	7534.22	7572.38			
2 classes	195.68	109	<0.001	6897.85	6961.64	659.3	<0.001	0.84
3 classes	161.50	104	<0.001	6815.11	6940.51	79.4	0.06	0.74
4 classes	96.33	96	0.47	6757.68	6926.71	72.22	0.02	0.82

Figure A. 3.6 Conditional probabilities: ‘restricted participation in volunteering’



A 3.4.2. Sport

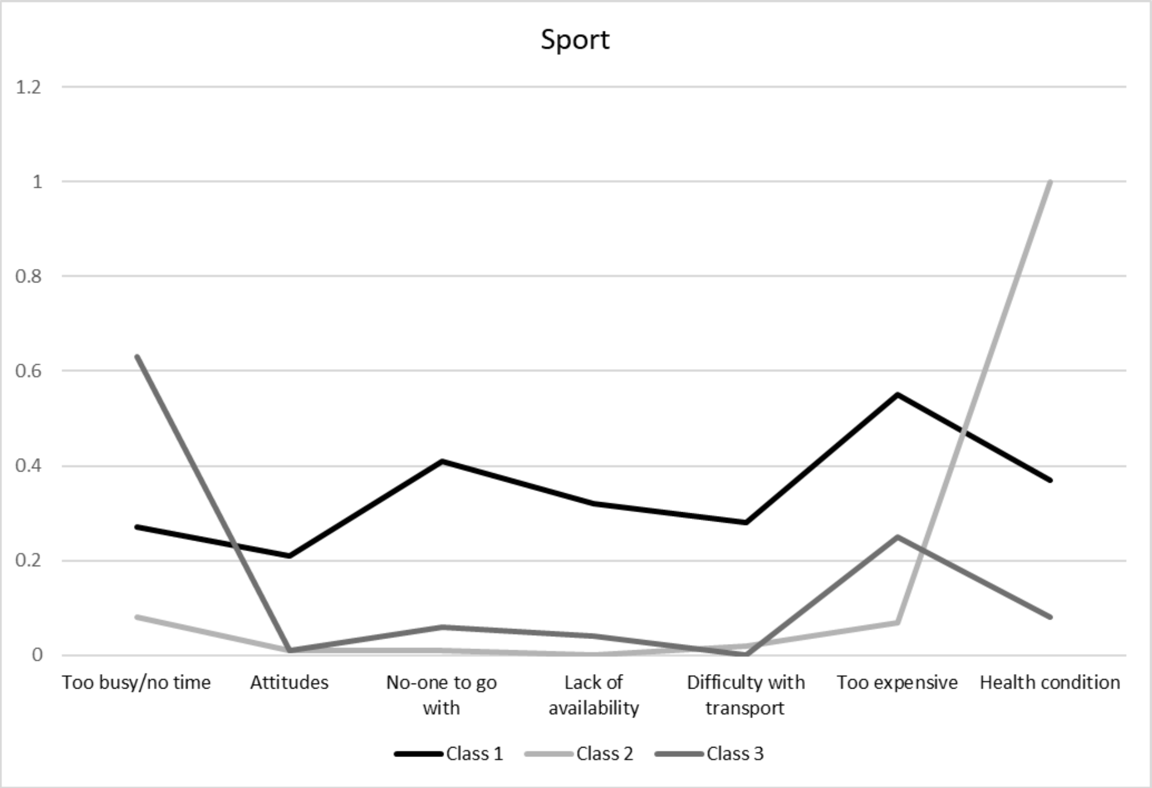
Table A. 3.13 Latent classes: 'restricted participation in sport'

LOS barriers	Class 1	Class 2	Class 3
Class size (observations)	*147*	*688*	*898*
Too busy/no time	0.27	0.08	0.63
Attitudes	0.21	0.01	0.01
No-one to go with	0.41	0.01	0.06
Lack of availability	0.32	0.00	0.04
Difficulty with transport	0.28	0.02	0.00
Too expensive	0.55	0.07	0.25
Health condition	0.37	1.00	0.08

Table A. 3.14 LCA Model diagnostics: 'restricted participation in sport'

Model	L^2	df	p-value >0.05	AIC	BIC	Lo-Mendell-Rubin Adjusted LRT test	p-value < 0.05	Entropy
1 class	755.57	117	<0.001	9389.70	9427.90			
2 classes	330.41	108	<0.001	8900.26	8982.11	497.11	<0.001	0.79
3 classes	175.39	104	<0.001	8661.58	8787.10	250.18	<0.001	0.76
4 classes	134.06	96	0.006	8629.87	8799.04	46.92	0.09	0.74

Figure A. 3.7 Conditional probabilities across: ‘restricted participation in sport’



Appendix 4. Longitudinal sample sizes

A 4.1. Wave 1 to Wave 3 participation patterns: disabled sample only

Table A. 4.1 Sample sizes of participation patterns across Wave 1 and Wave 3*

Life area	Restricted at both W1-W3	Not restricted at W1 or W3	Moved into participation restriction	Moved out of participation restriction	Total sample size in life area
Intimate	154 (12.9)	794 (56.6)	169 (12.8)	245 (17.7)	1,362 (100)
Friends	201 (20.6)	388 (34.1)	111 (10.6)	365 (34.8)	1,065 (100)
Family	173 (15.2)	532 (44.4)	151 (13.9)	310 (26.6)	1,166 (100)
Education	110 (13.6)	582 (59.6)	119 (13.7)	110 (13.1)	921 (100)
Employment	126 (25.7)	202 (36.9)	94 (18.4)	90 (19.0)	512 (100)
Volunteering	47 (7.6)	162 (24.0)	14 (2.1)	393 (66.2)	616 (100)
Sport	134 (22.3)	94 (14.2)	33 (4.9)	326 (58.6)	587 (100)

*Unweighted observations, weighted percentages

A 4.2. Wave 1 to Wave 3 participation rates

A 4.2.1. Restricted social participation at both waves

Table A. 4.2 Participants reporting restricted participation at Wave 1 and Wave 3

	Disabled sample			**Non-disabled group**		
	N	**%**	**Domain sample (100%)**	**N**	**%**	**Domain sample (100%)**
Intimate	154	*12.9*	1,362	156	*6.8*	2,508
Friends	201	*20.6*	1,065	286	*14.0*	2,239
Family	173	*15.2*	1,166	250	*8.9*	2,444
Education	110	*13.6*	921	50	*1.9*	1,939
Employment	126	*25.7*	512	124	*6.8*	1,875
Volunteering	47	*7.6*	616	69	*7.3*	1,245
Sport	134	*22.3*	587	128	*10.9*	1,387
Total sample			***1,435***			***2,861***

*Unweighted observations, weighted percentages. Within subject change.

A 4.2.2. No restrictions to social participation at Wave 1 or Wave 3

Table A. 4.3 Participants reporting no participation restrictions at Wave 1 or Wave 3*

	Disabled sample			**Non-disabled group**		
	N	**%**	**Domain sample (100%)**	**N**	**%**	**Domain sample (100%)**
Intimate	794	*56.6*	1,362	1,659	*63.6*	2,508
Friends	388	*34.1*	1,065	1,113	*49.5*	2,239
Family	532	*44.4*	1,166	1,382	*56.9*	2,444
Education	582	*59.7*	921	1,635	*82.5*	1,939
Employment	202	*36.9*	512	1,338	*69.7*	1,875
Volunteering	162	*24.0*	616	416	*29.1*	1,245
Sport	94	*14.2*	587	558	*39.0*	1,387
Total sample			*1,435*			*2,861*

*Unweighted observations, weighted percentages. Within subject change.

A 4.2.3. Moved into restricted participation at Wave 3

Table A. 4.4 Participants who moved into a participation restriction at Wave 3

	Disabled sample			**Non-disabled group**		
	N	**%**	**Domain sample (100%)**	**N**	**%**	**Domain sample (100%)**
Intimate	169	*12.8*	1,362	282	*14.0*	2,508
Friends	111	*10.6*	1,065	192	*9.2*	2,239
Family	151	*13.9*	1,166	228	*9.1*	2,444
Education	110	*13.1*	921	111	*6.6*	1,939
Employment	94	*18.4*	512	161	*9.0*	1,875
Volunteering	14	*2.1*	616	17	*1.2*	1,245
Sport	33	*4.9*	587	90	*8.1*	1,387
Total sample			***1,435***			***2,861***

*Unweighted observations, weighted percentages. Within subject change.

A 4.2.4. Moved out of restricted participation at Wave 3

Table A. 4.5 Participants moving out of restricted participation at Wave 3*

	Disabled			**Non-disabled**		
	N	**%**	**Domain sample (100%)**	**N**	**%**	**Domain sample (100%)**
Intimate	245	*17.7*	1,362	411	*15.6*	2,508
Friends	365	*34.8*	1,065	648	*27.4*	2,239
Family	310	*26.6*	1,166	584	*25.0*	2,444
Education	119	*13.7*	921	143	*8.9*	1,939
Employment	90	*19.0*	512	252	*14.5*	1,875
Volunteering	393	*66.2*	616	743	*62.5*	1,245
Sport	326	*58.6*	587	611	*42.0*	1,387
Total sample			***1,435***			***2,861***

*Unweighted observations, weighted percentages. Within subject change.

A 4.3. Barriers

A 4.3.1. Restricted social participation at both waves

Table A. 4.6 Intimate and informal domains: barriers reported by those experiencing restricted participation at both waves

LOS barriers	**Intimate domain**		**Informal domain**			
	Close Contacts		**Meeting Friends**		**Meeting Family**	
	Wave 1	**Wave 3**	**Wave 1**	**Wave 3**	**Wave 1**	**Wave 3**
Sample sizes	*154*	*154*	*201*	*201*	*173*	*173*
Too busy/no time	87 (54.6)	72 (43.4)	107 (51.5)	77 (36.3)	81 (48.2)	64 (34.7)
Attitudes of others	4 (3.2)	6 (3.5)	5 (3.5)	22 (11.7)	4 (3.2)	11 (6.1)
Not feeling welcome			3 (1.1)	2 (1.3)	7 (5.1)	1 (0.5)
No-one to meet/ go with	3 (2.0)	4 (3.2)	5 (2.3)	7 (4.8)	2 (0.9)	3 (2.7)
Other people busy	82 (49.6)	76 (48.4)		41 (23.5)		34 (18.9)
Lack of help/ assistance	1 (1.4)	4 (1.9)	5 (3.3)	16 (7.7)	2 (1.5)	14 (6.9)
Lack of availability			6 (3.8)	3 (1.8)	3 (3.6)	1 (0.6)
Difficulty with transport	17 (14.3)	10 (6.9)	22 (12.4)	3 (1.7)	16 (10.9)	1 (0.5)
Too far to travel*		35 (22.6)				
Difficulty access buildings	4 (1.9)	2 (1.2)	7 (2.6)		4 (2.0)	
Difficulty using facilities	1 (0.5)	2 (1.0)	2 (0.7)	4 (2.0)	2 (1.1)	2 (1.0)
Informal care	14 (11.5)	10 (8.1)	18 (8.0)	7 (3.4)	11 (6.2)	8 (2.6)
Too expensive			64 (33.4)	55 (31.2)	51 (32.1)	41 (24.3)
Financial reasons	24 (19.2)	25 (19.8)				
Health condition	22 (15.8)	38 (25.5)	52 (25.2)	49 (24.3)	35 (21.6)	30 (16.8)
Fear of crime	1 (0.5)	2 (0.9)	3 (2.0)	3 (2.9)	1 (0.9)	0 (0.0)
Fear of crowds	2 (2.5)	5 (4.1)	1 (0.4)	3 (3.4)	2 (1.6)	1 (0.5)

Cells diagonally crossed out denote data not collected. Unweighted observations, weighted percentages.

Table A. 4.7 Education: restricted participation at both waves

LOS barriers	**Education**	
	Wave 1	**Wave 3**
Sample size	*110*	*110*
Too busy with work/family	26 (24.4)	28 (23.5)
Attitudes of others	15 (14.8)	10 (10.4)
Lack of help/ assistance	31 (31.4)	15 (15.4)
Lack of information	24 (26.0)	18 (18.1)
No opportunities	25 (23.1)	23 (20.2)
Can't get on a course	14 (13.6)	13 (9.0)
Difficulty with transport	22 (20.7)	16 (12.6)
Difficulty access buildings	7 (6.8)	7 (6.5)
Difficulty using facilities	7 (6.3)	4 (2.8)
Informal care	20 (17.7)	13 (11.4)
Financial reasons	62 (53.3)	62 (57.5)
Health condition	42 (43.0)	43 (40.6)

Unweighted numbers (weighted percentages).

Table A. 4.8 Sport: barriers reported by those with restricted participation at both waves

LOS barriers	**Sport**		**Volunteering**	
	Wave 1	**Wave 3**	**Wave 1**	**Wave 3**
Sample size	*134*	*134*	*47*	*47*
Too busy/no time	30 (19.4)	13 (8.7)	23 (53.3)	18 (45.2)
Attitudes of others	4 (3.5)	7 (5.8)	1 (3.4)	-
Not feeling welcome	2 (1.7)	1 (0.8)	1 (2.3)	-
No-one to meet/ go with	11 (10.0)	4 (4.0)	-	-
Lack of help/ assistance	4 (3.6)	3 (3.6)	-	-
Lack of availability	6 (4.1)	6 (4.5)	-	-
Difficulty with transport	9 (7.3)	-	5 (11.7)	
Difficulty access buildings	2 (1.5)	-	-	-
Difficulty using facilities	6 (5.2)	2 (1.5)	-	-
Informal care	8 (4.7)	4 (2.7)	3 (6.3)	4 (7.8)
Too expensive	23 (19.0)	23 (18.8)	1 (2.9)	2 (3.1)
Health condition	85 (60.7)	87 (62.6)	17 (32.4)	22 (39.3)
Fear of crime	-	1 (0.9)	-	1 (1.7)
Fear of crowds	2 (1.8)	2 (1.8)	-	-

Unweighted numbers (weighted percentages).

A 4.3.2. Moved into restricted participation at Wave 3

Table A. 4.9 Intimate and informal participation domains: moving into restricted participation at Wave 3

	Social Contacts	**Meeting Friends**	**Meeting Family**
Sample sizes	*169*	*111*	*151*
Too busy/no time	78 (48.1)	34 (30.4)	47 (29.8)
Attitudes of others	4 (2.5)	12 (11.3)	14 (9.5)
Not feeling welcome		1 (1.3)	1 (0.9)
No-one to meet/ go with	3 (2.7)	3 (2.9)	1 (0.5)
Other people busy	89 (56.3)	25 (22.4)	32 (21.6)
Lack of help/ assistance	2 (1.3)	14 (11.7)	11 (7.3)
Lack of availability		2 (1.5)	2 (0.9)
Difficulty with transport	23 (15.2)	1 (0.8)	2 (1.6)
Too far to travel*	48 (28.8)		
Difficulty access buildings	1 (0.5)		
Difficulty using facilities	2 (0.9)	0 (0)	4 (2.6)
Informal care	10 (4.5)	3 (2.1)	4 (2.7)
Too expensive		33 (32.8)	38 (30.1)
Financial reasons	28 (17.5)		
Health condition	40 (27.1)	29 (27.6)	33 (19.4)
Fear of crime	1 (0.7)	2 (2.2)	2 (1.3)
Fear of crowds	8 (4.0)	3 (3.2)	2 (1.5)

*Unweighted observations, (weighted percentages).

Table A. 4.10 Education: moving into restricted participation at Wave 3

	Education	
Sample size	*110*	
Too busy with work/family	27	(20.1)
Attitudes of others	13	(15.4)
Lack of help/ assistance	10	(10.3)
Lack of information	14	(13.1)
No opportunities	18	(15.0)
Can’t get on a course	8	(9.0)
Difficulty with transport	20	(18.0)
Difficulty access buildings	8	(6.7)
Difficulty using facilities	3	(1.8)
Informal care	16	(17.8)
Financial reasons	60	(61.5)
Health condition	38	(33.4)

*Unweighted observations, (weighted percentages).

Appendix 5. Qualitative study recruitment and consent forms

A 5.1. Study Advert

How do we find
our tribe?

I am looking for autistic adults for my PhD project to talk about social relationships and autism.

All participants receive a £20 Amazon voucher as a thank you for your time.

For more information or to arrange a meeting:
email: emese.mayhew@york.ac.uk
or register your interest:
https://bit.ly/connect_interest

A 5.2. Consent and background details form

Project title: Talking about social connections with autistic adults

	For text-based interviews	Please mark box
1	I have been told what this research is about and what it involves. I have been given an information sheet dated April 2022 and have had the opportunity to ask questions.	☐
2	I understand that I do not have to take part in the research. I also understand that I can withdraw from taking part up to 2 weeks after my interview.	☐
3	I understand that I will not be named in any research reports, and my personal information will remain confidential.	☐
4	I understand that if the researcher thinks that I or someone else might be at risk of harm, they may have to contact the relevant authorities. But they will try and talk to me first about the best thing to do.	☐
5	I agree for the written interview to be recorded in the Zoom chat box. I understand that I can still take part without agreeing to being recorded.	☐
6	I understand that my words, but not my name or any other information which might identify me, may be used in research reports.	☐
7	I agree for an anonymised version of my data to be kept at the end of the study, and to be used only for publications associated with this PhD.	☐
8	I agree to take part in the research.	☐

Signature participant (please type your name above) Signature interviewer

Information about you

I will use the information I collect here to provide a description of the characteristics of the people interviewed in the research project. I will not report any information if it could identify you.

Gender	**Please mark your answer**
Female	☐
Male	☐
Other/ non-binary	☐
Prefer not to say	☐

Age	**Please mark your answer**
18-25	☐
26-35	☐
36-45	☐
46-55	☐
56-65	☐
66 or over	☐
Prefer not to say	☐

Ethnicity	**Please mark your answer**
White	☐
Mixed/ multiple ethnic groups	☐
Asian/ Asian British	☐
Black/ African/ Caribbean/ Black British	☐
Other ethnic group	☐
Prefer not to say	☐

Have you got an autism diagnosis?	**Please mark your answer**
Yes	☐
No	☐
Prefer not to say	☐

If you have a diagnosis, approximately how old were you when you were diagnosed?

Thank you for filling in this consent form

A 5.3. Topic guide

Talking about social connections with autistic adults

Overall purpose of the interview is to understand:

- How autistic adults form relationships.
- What do they find important/what are the looking for in a relationship?
- What are the main barriers to social interactions/meeting new people?
- What are the main facilitators to social interactions/meeting new people?
- Do they have any suggestions about what could be done to make it easier for them to access social interactions/activities/spaces?

1. INTRO

Thank you very much for agreeing to meeting with me.

- Is this still a suitable time for you to talk? Do you have enough time for this interview? It will last about an hour
- Are you in a place where you will not be disturbed?
- Did you have the chance to look at the information sheet I emailed you about this study? Do you have any questions about it?
- Are you still OK with this interview being audio recorded?

START THE AUDIO RECORDING NOW!

- Press ‘Record to the cloud’
- If wanting to record chat – press ‘save chat’ at the end of the interview

I am going to start the recording now.

a) If consent form not yet filled in

Before we start the interview, I need to make sure that I have your full consent. I notice you haven't filled in the consent form yet. That's not a problem because I can take your consent now. Is that OK?

OK. Now I am going to read a set of statements to confirm you understand about taking part in this study and are willing to take part. Please consider each statement as I read it to you. Then, if you agree, please say 'I agree'. Your consent will be audio-recorded and I will sign the form on your behalf. I will send you a copy of the consent form for your records.

Read the consent form.

Finally, I need to ask you a couple of background questions about you. I need this information to be able to describe the people who took part in my interview, when I write about this study. Read the background questions.

b) Thank you for filling in the consent form.

I am going to start the interview now. If I ask a question you are not comfortable with, you don't need to answer it and you don't need to explain yourself, just tell me to move on to the next question.

How do you prefer to refer to your autism diagnosis?

If they don't have a formal diagnosis: Why do you think you have autism? How do you refer to your autism?

WRITE IT DOWN

2. LIVING CIRCUMSTANCES

WRITE ANY NAME MENTIONED DOWN!

I would like to start with some background questions so that I know a little bit about your circumstances.

- Who do you live with? / Do you live on your own or with others?
- Do you work or study?
- Do you volunteer? Do you do any regular activities outside your home?

3. EXISTING SOCIAL CONNECTIONS

Now I would like to ask you about people you know.

Pick out people on different network layers and find out about them.

***Key topic**: what do they value from each of their relationship. Virtual or face to face? How did you meet? Ever met face to face?*

Are there people in your life you feel close to?

- For example someone you trust to share your feelings or worries with? / someone you could go for advice if you needed to make an important decision.
- How did you meet? / *online or face-to-face*?
- How long have you known them for?
- *Have you got people who you feel close to who are also on the autism spectrum? / How is your relationship different to them than your relationship with neurotypical people*?
- What do you value most about this person/ relationship?

Is there anyone else whose company you enjoy (even if you are not close friends)?

- How did you meet?
- What do you value most about this person/ relationship?

Is there anyone else you meet regularly, for example a colleague or neighbour who you feel you get on with?

You mentioned you were working:

- Are there opportunities to talk to your colleagues at work?
- Do you talk to your colleagues much?/ Meet outside work?
- What do you value most about your colleagues/ being at work?

What they value in a social relationship/ interaction – **KEY TOPIC**

Weave these questions into the previous section whilst asking about the people they know. If we left anyone out, return to them here.

We have been talking about the people you know and talk to regularly. I would like to know:

- *Earlier, you mentioned ...name... What is it about him/her that you value?*
- What is it about this person that makes you feel like you can talk to them?
- What do you value about this relationship?
- What is it that you like about this person?
- What are you looking for in a social interaction? What makes it worth your while to engage in a social interaction? What do you get out of it?
- You said you met xyz during this activity. Do you see them as a source of support?
- How would you define a friend? (as opposed to acquaintance)

Ways of seeking social interaction/activities

Do you do any activities with the purpose of meeting people?

- How did you choose/find these activities? Were they easy to find?

What are your experiences of meeting new people?

- Are you open about being autistic when you meet new people?
- Do you think this information helps people to understand you better or the opposite?
- Do you find that people understand what being autistic means, or are there still a lot of misconceptions around autism?

Would you like to make more friends/acquaintances?

4. BARRIERS (cover LOS barriers too)

Are there things that make social interaction difficult sometimes? For example:

- Some autistic people say that sensory overload can become a problem when socialising in a group. (for example due to a noisy environment or people talking over each other)
- Is the pace of the conversation an issue?
- Do you find the venue important? For example the light conditions and lay-out and the way the space was decorated.
- Some people told me that socialising takes too much effort / energy. Is this your experience?
- Sometimes people just don't have enough time to socialise? Or sometimes activities are at the wrong time of day. Do you find it tricky to make time for social activities?
- Do you need to factor in downtime after a social interaction?
- Do you think there are enough social activities in your area?
- Have you ever been put off doing something because of lack of transport or because the venue was too far away from where you live?
- Has costs ever been a problem for you? For example: have you ever wanted to join a club or do a social activity and you didn't do it because it was too expensive?

Previously, you described … using this word … Can you tell me more about what that means?

This might be very obvious to you, but can you explain me…

5. FACILITATORS (cover LOS facilitators)

Over time, has your experience of meeting people changed? For example, has it become easier? What has changed to make things easier?

Earlier you mentioned you had difficulty with *xyz*, have these difficulties changed over time?

What are the things that helped you making connections in the past?

We were talking about some of the difficulties around socialising. Have you found any solutions to overcome some of these?

- What makes you feel comfortable when talking to someone?
- Well-organised activities led by staff with high autism awareness.
- Asking people to slow down or to write things down when talking to you?
- Quiet, well-laid out venues.
- Small groups, time to engage in one-to-one conversation.
- Engaging in a shared interest with others, for example drama, singing or photography.
- Do you do anything to recharge your 'social' battery? For example taking a break from socialising in a quiet room, listening to some music, reading a book.

LAST 15-10 MINUTES OF INTERVIEW

6. SUGGESTIONS ABOUT HOW TO CREATE MORE AUTISM FRIENDLY SPACES AND ACTIVITIES

(*Move away from personal questions to wider ones but within the context of their experiences.*)

Reflect on their experiences:

I have noticed that you said… do you think that should be something that should be lobbied for?

So thinking about your experiences, what would you like to say to others who want to socialise with autistic people/ who want to organise activities for autistic people?

What do you wish that neuro-typical people knew/understood about autistic people? Especially when meeting them for the first time or when trying to strike up a conversation?

Based on what we have talked about…

Based on your personal experiences…

… have you got any recommendations to people who want to become better at communicating with autistic people?

For example:

- What should people do to make an autistic person feel at ease?
- How can a space be organised to make it easier to be in for autistic people?
- How can activities be organised to make them easier to engage in for autistic people?

(*Move to even broader, society wide questions*)

Based on your personal experiences, what recommendations would you make to organisations who want to plan activities that include autistic people?

- Who needs to hear that? Who needs to make these changes?
- Would you like to see more autism awareness in the media or in government policies?
- How would you describe an autism friendly school or workplace? What are the ingredients?

7. CLOSING QUESTIONS

- Is there anything you would like to add?
- Did you want to say anything before you came to this interview that I haven't asked about?
- How did you find this interview? How was that for you?

8. CLOSING THE INTERVIEW

Many thanks for taking part. I really value your contribution.

I am going to write up and analyse all the interviews over the summer and I expect to write a report in the autumn. Would you like to receive a summary of my findings?

Thank you again, you will be receiving your Amazon voucher via email today.

POSSIBLE QUESTIONS AND SCENARIOS

What’s your definition of autism?

I define autism as a developmental condition that affects especially social, communication and sensory functioning. It’s hard to give a good definition of autism because it’s a very complex condition affecting everyone differently and no two autistic people are the same.

Do you see autism as a disability?

I think it must be acknowledged that autism can become a disability if it has a significant daily impact on a person’s life.

Why are you interested in this topic?

I have experience with autism and neurodiversity in my immediate family and I have seen the impact it has on people’s (social) lives. I would like to raise awareness of autism because I think autistic people have a lot to offer both as personal friends and as members of society.

IF THEY SHOW SIGNS OF DISTRESS

I can see you are finding it hard to talk about this. Would you like to take a break or talk about something else?

If you find this topic difficult to talk about we can move on to the next question.

Would you like me to move on to a different question?

Would you like to take a 10 minute break? You could get a drink, then come back and let me know if you would like to carry on.

If doesn’t want to carry on: It’s up to you if you would like to rearrange the interview or if you just want to leave it at this.

Do you have anyone you can talk to after this interview is over?

Have you tried to join any of the autistic communities online? The National Autistic Society has an online community group and also local branches. I can send you some information about them.

https://www.autism.org.uk/what-we-do/branches

A 5.4. Provisional coding framework

1. The value of social connections: the social network
    a. Close relationships
    b. Wider friendships
    c. The workplace
    d. Meeting new people
    e. Satisfaction with network
2. Access to social spaces: external and personal factors
    a. Societal factors
        i. Access to diagnosis
        ii. Access to healthcare
        iii. Public awareness
        iv. Costs
    b. Environmental factors
        i. Access to transport
        ii. The sensory environment
        iii. The physical features of the environment
    c. Personal factors
        i. Existing social network
        ii. Neurodivergent traits
        iii. Having a diagnosis
        iv. Understanding neurodivergent traits
3. The social interaction: establishing social connections
    a. Functional features of the interaction
        i. Communication format
        ii. Structure
        iii. Language use
        iv. Purpose
    b. Qualitative features of the interaction
        i. Relatedness
        ii. Reciprocity

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