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**A study exploring parents' experiences of their young person's transition
from specialist settings to post 19 provision.**

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Abstract

The aim of this research is to explore parents' experiences of their young person's transition from specialist settings to Post 19 provision in the North East of England. The literature in this field is narrow with only a small number of contemporary research conducted into the reality of families with young adults who have learning disabilities, and attend specialist school settings. Furthermore, Biswas et al (2017) state there are there no published studies which explore parents' views of their young person with learning disabilities transition into adulthood. The ontology of this research is seated in social construction; that a person's view and perception of the world is created by the daily social interactions they have with others. While the epistemological position considers the knowledge we hold is interpreted by ourselves; that an individual's knowledge is socially constructed rather than factually determined. Four parent participants were invited to share their narratives on the subject in the form of a recorded interview. An opening question was asked at the beginning of the interview inviting participants to share their experience of transition. Some prompting questions were devised, in case prompting was required, however, the interviews flowed freely. The recorded data was then transcribed, using Braun & Clarke's (2006) method of thematic analysis.

It is hoped information gathered from the interviews will inform good practice when working with families during Post 19 transitions.

Key terms: transition to adulthood, transition, transition to adulthood disability, transition to adulthood learning disability, transition post 19 disabilities, transition parents experience young people, transition parents post 19 young people disability, transition adulthood parent's experiences children.

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Introduction

Transition into adulthood is a developmental phase distinguished by continuing bodily and personal identity growth, social and role exploration, along with goal setting and developing independence (Settersten, Ottusch & Schneider, 2015). There is no clear standard for defining adulthood itself however, young people are also expected to become more independent in assuming positions within employment, education and the community (Gerber, 2012: Settersten et al, 2015). Transition to adulthood for parents is not without difficulty, many parents find their young person's newfound autonomy challenging to accept. This is due to differences in choice, along with parents' wishing to maintain a parenting role; a situation which occurs frequently when a young person has a learning disability (Kloep & Hendry, 2010: Boehm, Carter & Taylor, 2015).

For young people with learning disabilities transition into adulthood is viewed to be a more worrying experience that affects not only the young person but also their family unit. This is largely considered to be due to the lack of adult services available combined with future uncertainty (Kim & Turnbull, 2004.). Also, compared to young adults without disability, transition for young people with a learning disability can often take longer, have substantially more involvement from professionals and result in poor experiences (Dyke et al, 2013).

Certainly, planning for transition to adulthood from specialist education to post-19 provisions are regularly mentioned as an area for concern (DfE, 2014). Recently, the DfE (2014: p 7) stated: "a comprehensive review of what transition should involve for young people with complex needs (Post 19) is urgently required to help restore the confidence of parents and schools". However, interestingly, research within the field of transition to adulthood and/or post-school provision for young people with complex learning disabilities is sparse (Gerber, 2012).

In addition, literature which focusses upon the parents' perspectives of transition to adulthood for their young person with a disability is also scarce. Articles within this area cited "a small amount of literature" which "has focused specifically on the perspectives of parents of students with learning disabilities" (Griffin, McMillan & Hodapp, 2010: p343).

Literature also specified the need for “further research in parent involvement” to be important to ensure that young adults with disabilities receive the opportunities created by law, and benefit from highly knowledgeable professionals and achieve a quality post-school life” (Martinez, Conroy & Cerreto, 2012: p 285). More contemporary research reviewed continued to suggest “very little research exists on the reality of families of young adults with profound learning disabilities” (Gauthier-Boudreault, Gallagher & Couture, 2017: p25). Alongside, “there are currently no published studies within the intellectual disabilities field that explore parents’ views of their child’s developmental transition into adulthood, or how parents adjust and adapt to this transition” (Biswas et al, 2017: p 100).

Parents’ of young people with a disability are also acknowledged to have a poorer Quality of Life, or QL, in comparison to parents of children without a disability (Misura & Memisevic, 2017: Boehm, Carter & Taylor, 2015: Samuel, Rillotta & Brown, 2012: Dervishaliaj, 2013). There is little research within this area, as literature within transition studies generally captures the parents’ perception of their young person’s QL rather than exploring parents’ own perceptions of their own QL.

The improvement of QL for parents is viewed to be an on-going concern due to the nations’ growing dependence on families caring and supporting young people with learning difficulties (Boehm, Carter & Taylor, 2015). Typically, young people with learning disabilities continue to live at home with their families long into adulthood (Boehm, Carter & Taylor, 2015: Kim & Turnbull, 2004). Families of such young people are viewed to play a major role in caring and supporting their young person, due to the limited resources available, alongside the parents’ own anxieties and fears regarding independent living and social care (Boehm, Carter & Taylor, 2015).

As explained above, barriers to transition to adulthood are varied, and the issues do not appear to have changed over time (Gauthier-Boudreault et al, 2019: Thom & Agur, 2014: Wills, Chenoweth & Ellem, 2016: Hoskin, 2017: Bagatell et al, 2017: Gauthier-Boudreault et al, 2017: Biswas et al, 2017), or with the introduction of the Children and Families Act (DfE, 2014). While the introduction of the Children and Families Act (DfE, 2014) increased the age of support from 19 to 25, contemporary research in this field has acknowledged how there is “little or no mention of services for young people over aged 19 years” (Skipp & Hopwood, 2016: p50). Interestingly, Andre Imich (Imich,

2016: p 32) recently acknowledged “transition to post-19 provision is an area identified for further work...”.

At this point, I will share I am the mother of a daughter with Autism, profound and multiple learning disabilities and some physical disabilities aged over 19. I have experienced the transition to adulthood from a specialist setting to a Post 19 provision, and I welcomed the developments in the Children and Families Act (DfE, 2014). I personally found the journey to adulthood and Post 19 provision a challenging experience. Also, as a Trainee Educational Psychologist, I reflected upon my experiences and wondered if families had similar experiences, and how as a future practitioner I could best support families and young people with the transition. My aim for this study was to explore parents’ experiences of their young person’s transition to adulthood, as I considered it important to explore parents’ experiences, and for parents to be supported in all aspects of their young person’s future transition.

Research questions

1. What narratives do parents of young people with learning difficulties tell about their experiences of the transition journey to Post 19 provision?
2. What can EP’s learn from reflecting on the narratives of participants?

Literature Review

Parents’ views and experiences of their young person’s transition from specialist educational settings to Post 19 provision have been rarely researched. The literature in this field is narrow with only a small number of contemporary studies conducted into the reality of families of young adults with learning disabilities within the United Kingdom (UK) (Manthorpe et al, 2015: Hoskin, 2017: Biswas et al, 2017). Generally, research studies within this field explore what life outcomes parents would like for their young person, rather than how they themselves specifically feel about the transition process. Certainly, there is only one published study within the intellectual disabilities field, where the young person has severe intellectual disabilities, that explores parents’ perceptions of their young person’s transition into adulthood (Biswas et al, 2017). As mentioned above, there are presently no published studies within the United Kingdom which explores parents’ views and experiences of their young person’s transition from their specialist setting to Post 19 provision.

This literature review will begin by providing a definition of the term parents' and learning disability; it will then explain transition to adulthood. It will then move onto describing the differences in transitioning to adulthood with a learning disability. An exploration of the literature including Quality of Life, barriers to transition and parents' anxieties related to transition will be discussed. Current Post 19 provision will also be explored, and the review will end with a short discussion regarding Educational Psychology and Post 19 transitions.

Definition of Parents'

"Parents'" are defined within Section 576 of the Education Act 1996 as:

- *All natural (biological) parents', whether they are married or not;*
- *Any person who, although not a natural parent, has parental responsibility for a child or young person;*
- *Any person who, although not a natural parent, has care of a child or young person.*

Parent participation in their young person's education is frequently promoted within the SEN and Disability Code of Practice (DfE, 2014). Parents' should be viewed as "equal partners with expertise" (White & Rae, 2016: p40), in their young person's future and education, and are described as the greatest resource they can have (White & Rae, 2016).

As both a parent of a young person with a disability and a future practitioner I agree with the view of White & Rae (2016) that parents hold vast knowledge of their young person and fully support the inclusion of all parents.

Taking this into account and for the purpose of this research, the term "parents'" reflected the definition above and included; couples, single parents' and stepparents. In this term I felt gender should not be discriminated against; both mothers and fathers, who are parents of young people who are transitioning from specialist school to post 19 provisions were invited.

While I acknowledge mothers and fathers experience the demands of caring for their disabled young person differently (Pelchat, Lefebvre & Levet, 2007); primarily as a higher percentage of mothers are usually primary carers for their disabled young person rather than fathers (McStay, Trembath & Dissanake, 2014: Pelchat). I

acknowledge, and agree, with the view of Pelchat, Lefebvre & Levet (2007: p 125) who, within their literature review of gender differences and similarities of caring for a child with a health need, concluded “acquisition of knowledge is facilitated within a partnership relationship between parents and professionals”. The term parents as outlined above includes both mothers and fathers, also the review suggested more emphasis on the experiences of both genders. As a parent of a young person with a disability, and as a hopeful future Educational Psychologist, I felt including all genders within the term “parents” important as I felt fathers’ points of view are also valuable.

While it would have been useful to examine the differences in experiences between the two genders, this Thesis is focused upon parents’ experiences as a whole. Also, the time constraints of the Thesis did not allow this examination.

Definition of Learning Disability

The International Classification of Diseases 10 (WHO, 1992) categorises Learning Disability under “Mental Retardation” and defines it as:

“...a condition of arrested or incomplete development of the mind, which is especially acknowledged by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor and social abilities”.

In 2016, the UK Government’s definition of a learning disability is a disability which “affects the way someone communicates and understands information”. They go on to further state that individuals with a learning disability may “have difficulties understanding new or complex information, learning new skills or coping independently” (Parkin, 2018: p 4).

There has been a call to further define the term learning disability (Kavale, Spaulding & Beam, 2009), as it has not altered since the 18 descriptions of the term were suggested in the 1960s by Samuel Kirk (Kirk, 1981). Kavale, Spaulding & Beam (2009: p 39) consider while the knowledge and variation in how learning disabilities may affect an individual has developed, the term itself has “remained static”. They go on to propose the term be altered to reflect the knowledge now known about learning disability and to also provide a “richer” description of the term. Similarly, Danforth (2009) considers the term, coined in the 1960s, to be created by Scientists using a mix

of clinical and quantitative methods. Danforth (2009: p 668) views learning disabilities to be less “standardised and uniform” and more fluid. Reflecting on these views and applying it to my own experiences I feel the definition of learning disability fails to capture the essence of how the diagnosis of learning disability affects the person. For example, the definition outlined above by the International Classification of Diseases 10 (WHO, 1992) does little to make sense of how learning disability manifests in the individual. Kavale, Spaulding & Beam (2009: p 40) argue definitions themselves are ambiguous, in that:

“definitions explain the nature of a phenomenon, not the sense of what it really is, but in the way it is conceived to be in different social, political and logical context”.

This is true of the definition of learning disability. While the term is there, how learning disability manifests itself in each individual is different. While, I agree with the views of Kavale, Spaulding & Beam (2009) and Danforth (2009), I wonder how a term would be created to include the individual nuances of each person with a learning disability, if this is needed, or if the individual with the learning disability just has difficulties in communicating and understanding information as outlined above (Parkin, 2018).

This issue aside, learning disabilities are considered to comprise of a diverse group of cognitive disabilities which are situated on a scale of severity, varying from borderline to low average intelligence to those who are considered to have superior intelligence (Gerber, 2012). Estimations suggest approximately 1,087,100 million people in the UK have a learning disability. Public Health England (2016) identified 44%, of individuals as having moderate learning difficulties (MLD), 41% severe learning difficulties (SLD) and 15% as having profound and multiple learning disabilities (PMLD).

Both children and adults may have a learning disability; however, when attending educational establishments, children and young people may also be described as having Special Educational Needs (SEN). In 2014/15 70,065 children and young people in England were noted as having a statement of special educational needs, now an Education Health and Care Plan, with a learning disability being registered as their primary need (Public Health England, 2016).

1. Transition

1.1 What is transition?

Transition into adulthood is a developmental phase distinguished by continuing bodily and personal identity growth, social and role exploration, along with goal setting and developing independence. While, there is no main definition for having reached adulthood, as guides and markers are personal to the individual, it generally marks an on-going change in the roles and responsibilities of a young person (Settersten, Ottusch & Schneider, 2015).

Settersten et al (2015) suggest while there is no clear standard for defining adulthood, there are four clear markers; biological, social, psychological and legal, in which young person is expected to have autonomy. In addition, young people are also expected to become more independent in assuming positions within employment, education and the community (Gerber, 2009). The chronological age in which a young person achieves some markers to adulthood are considered to no longer occur at the traditional age of eighteen due to changes in traditional roles of marriage, employment and education (Settersten et al, 2015: Schulenberg & Schoon, 2012: Kloep & Hendry, 2010). Rather, transition to adulthood is now viewed to span from eighteen to mid-thirties due to extended education, employment routes and high housing costs (Swartz et al, 2011). That said transition to adulthood generally begins with the ending of secondary education and the beginning of a choice of diverse future pathways and experiences which includes a sense of agency on the part of the young person (Schulenberg & Schoon, 2012).

1.2 Parental role in transition to adulthood

During the transition parents often provide support; financial, housing and pastorally, to their young person while they navigate their transition to adulthood (Settersten et al, 2015, Schulenberg & Schoon, 2012: Swartz et al, 2011: Kloep & Hendry, 2010). Swartz et al (2011) suggest support from parents' during this time encouraged self-sufficiency and once the young person had achieved their transition to adulthood, parents took a step back from providing tangible support. Stepping back or "letting go" however according to Kloep & Hendry (2010) for parents' is not without difficulty, many parents find their young person's newfound autonomy challenging to accept due to parents' wishing to maintain their parenting role long-term. This, in turn, creates its

own complications as parents' can tend to find themselves effectively parenting adult children, a situation which occurs frequently when a young person has a learning disability.

1.3 Transition to adulthood with a learning disability

Rehm et al (2012) propose for young people with learning disabilities the definition of transition to adulthood is “functioning as independently as possible with appropriate supports” (Rehm et al, 2012: p 57).

Transition into adulthood for young people with learning disabilities is considered to be a more stressful experience that affects not only the young person but also their family unit. This is due to the lack of adult services available, along with future uncertainty which in turn causes families increased fear and stress (Kim & Turnbull, 2004). In comparison, to young adults without disability, transition for those with a learning disability can often take longer, have substantially more involvement from professionals and result in weakened experiences (Dyke et al, 2013).

As mentioned above, transition through education into adulthood usually spans completion of school, gaining employment, taking part in some form of post 16 education, contributing to the household, community involvement and experiences in social and personal relationships (Hendricks & Wheman, 2009; Dyke et al 2013). However, for young people with learning disabilities, the adoption of such roles can be significantly problematic (Bagatell et al, 2017). The transition from education to adulthood for young people with learning disabilities generally means a move from an environment which is typically a well- supported secure setting to an evolving adult life. This is generally acknowledged by a varied change in roles and environments often concerned with independent living, what activities they will do during the day, education and employment (Dyke et al, 2013).

Hendricks & Wheman (2009) explain transition from school to adulthood, is often an especially difficult time for young people with learning disabilities. For families of young people with learning difficulties; and the young people themselves, the transition from secondary education to further education or employment requires them to “create a new reality”. For the “new reality” to be effective, it should give young people and families a feeling of safety and well-being. However, it can be considered difficult for families and young people to achieve this as the variety of difficulties faced by parents

during transition to adulthood are complex and multi-faceted (Gauthier-Boudreault, Couture & Gallagher, 2017; Dyke et al, 2013; Kim & Turnbull, 2004). The following section will discuss what an effective transition is considered to include.

1.4 What should an effective transition include?

Successful transition planning involves thorough planning, preparation, and implementation. It gives young people the experience to discover and plan for their futures by involving them as an active and respected participant in the process (Hendricks & Wehman, 2009). The aim for a successful transition to adulthood is for the young person to not simply navigate their own way through, however “to make their own choices based on information about available options.....individuals are then empowered to make meaningful choices about desired services” (Bagatell et al, 2017: p 86).

For an effective transition to take place, along with an improved quality of life, transition planning and processes should take into account the whole families perspective on outcomes alongside the consideration of what quality of life means to each individual family (Henninger & Taylor, 2014; Bagatell et al, 2017; Biswas et al, 2017). In doing this the transition process should also consider the ability of the young person to make independent decisions regarding their future, for example, if the young person requires additional support to make a decision. As per the Mental Capacity Act (2005) if a cognitive and/or functional limitation impedes the person’s ability to make a practical decision, people who know the young person well, for example, parents’ or primary carers’, should be on hand to assist in future planning for education or other settings (Kim & Turnbull, 2004; Henninger & Taylor, 2014).

Recent research within the area of transition to adulthood for individuals with learning disabilities explores what life outcomes parents’/carers’ would like their young person to achieve (Henninger & Taylor, 2014). Henninger & Taylor (2014) acknowledge the need for transition planning to consider the young person’s own goals and interests, and to ensure that thinking about future employment, living and learning options are discussed during the process. Henninger & Taylor’s (2014) study, exploring the views of 194 parents of young people with learning disabilities within the US, identified the need for transition to adulthood planning to be collaborative with both services and families to ensure full access to support is available. However, this is not without issue

as young people with a disability approach adulthood, they transition not only from education at 19 but health services at 16 and children's social care 18 resulting in three different transitions (Goodley & Runswick-Cole, 2011). From experience, this can mean three different dialogues with three different services who each have different agendas, criteria, and approaches. This can result in a lack of consideration for the young person's future as each service has a goal to reach in relation to their own service needs. This is especially significant in cases where the young person is looked after and their residential services finish at 18 however, their education at 19. Consideration could be given at this time to future planning for both education and independent living together. For example, further education residential colleges, however, it could be said that the differing agendas and criteria for both social and educational services do not appear to be joined up. For an effective transition to take place, consideration should be given to the gap between the end of child residential care at 18 and education at 19, for a seamless transition to take place.

Families, and parents' are vital contributors when planning for transition, their thoughts and perspectives can be influential in the approaches employed by schools, authorities and service providers (Griffin, McMillan & Hodapp, 2010). In addition, parental involvement is significant in a successful transition to adulthood. When a parent has had considerable participation in planning, outcomes for their young person are considered better (Dyke et al, 2013). Moreover, Henninger & Taylor's (2014) study identified the need for families' perspectives to be captured in order to guide research and professional practice in the future. Gaining parents' and families' views on transition was the foundation of this study.

Family perspectives along with professional views of transition to adulthood are considered by Rhem et al (2012), in their ethnographic study, which explored both sets of views on what they wanted for their young person's future. The study, again based within the US, expressed that, similar to Henninger & Taylor's (2014) study, collaborative support between services is essential as is the need for a focus on the future development of the young person through achievable, realistic support. In addition to this, Rhem et al (2012) acknowledge previous studies regarding transition to adulthood, stating researchers seldom take a holistic overview of the process, rather concentrating on a single support service or a single feature of the process. However, the study did not explore how parents' viewed transition to adulthood from their own

perspectives. This study intends to explore parents' views and experiences of their young person's transition to adulthood, offering a fully holistic overview.

The most contemporary literature within this area cites a "lack of understanding of the needs of young people" (Gauthier-Boudreault, Gallagher & Couture, 2017: pp 16). Gauthier- Boudreault, Gallagher & Couture's (2017) study recruiting 14 parents of young people with a profound intellectual disability, concluded that by being aware of the exact need of the families, there is an opportunity for all services to create and implement support tailored to the families' reality which would assist in an effective transition. The study acknowledged the lack of current research concerning the exact reality of families of young people with profound learning disabilities during transition to adulthood and call for more research in the area in order to support families and young people effectively. Whilst this is an important area for research and one which should be explored further in the future, there is also an identified absence in research within parents' experiences of their young person's transition to adulthood and what would support an effective transition. This research study proposed to explore the experiences of parents of young people with profound learning disabilities during transition to adulthood and in that the realities they may consider for example their quality of life.

2. Quality of Life (QL)

As mentioned above parents of young people with a disability are acknowledged to have a poorer QL in comparison to parents of children without a disability (Misura & Memisevic, 2017: Boehm, Carter & Taylor, 2015: Samuel, Rillotta & Brown, 2012: Dervishalijaj, 2013). While studies within the area of QL have become increasingly popular within the past few decades, there appears to be a lack of focus that captures the parents' own perceptions of their own QL, something which this study aims to uncover (Misura & Memisevic, 2017).

According to Misura & Memisevic (2017, p 43) QL is considered to be a multifaceted perception of which "there is no consensual definition of, and it can mean different things to different people". While there is no agreed definition of QL, there is, however, a consensus that the concept has both objective and subjective aspects related to; personal development, physical, social, material and emotional well-being and

purposeful interests or activities (Misura & Memisevic, 2017: Poston et al, 2003: Boehm, Carter & Taylor, 2015).

In more recent years, research studies have expanded within the field of QL to include families of people with learning disabilities. This is due to the acknowledgement that parents' of young people with disabilities are viewed to hold a poorer family quality of life in contrast to parents' of children who do not have a disability (Misura & Memisevic, 2017: Boehm, Carter & Taylor, 2015: Samuel, Rillotta & Brown, 2012: Dervishalaj, 2013). However, the studies generally capture the parents' perception of their young person's QL rather than exploring parents' own perceptions of their own QL, which are rarely researched, even less so within the UK. Juhasova's (2015) comparison study of 50 families without a disability and 50 families where a young person has a disability within Slovakia, suggested the QL aspect which affects families with a disabled child to be environmental; linked to availability of financial and information sources and health-related services. Misura & Memisevic (2017, p46) explored this aspect further within their parental QL study and explained "keeping good relationships between family members is of the utmost importance" to a whole family QL. Further stating, stronger social and outside support systems lead to an enhanced QL for families of disabled young people.

In the study by Boehm, Carter & Taylor (2015: p 396), families describe the transition as "a window of worry, stress, fear, change and/or uncertainty", which could perhaps be attributed to the challenge of navigating the transition processes. The study, which examined the Family Quality of Life (FQOL) ratings of 425 parents' of a young person aged 13-21 with learning difficulties, recommends various avenues of support which could be suggested to families who are experiencing a transition to adulthood, for example, access to tangible information, advice and support networks. Families within the study reported, "they were generally satisfied with their quality of life" (Boehm, Carter & Taylor, 2015: p 405), however those families where their young person had challenging behaviours or numerous support needs reported a lower FQOL. In these areas, the study suggested that educators and future service/setting providers share information and build relationships with families, along with accurate assessments and suitable realistic interventions.

Similar to Misura & Memisevic's (2017) findings, "service-orientated approaches" including the consideration of accessible support against the family and young person's needs while taking into account a family's quality of life, were also discussed within the study as a positive means of support to families (Boehm, Carter & Taylor, 2015: p 406). The study suggests areas for future research to be concentrated on a more complete picture of the formal and informal support currently accessed by families, in order to effectively improve FQOL during the transition to adulthood. This is an area which this study intends to explore through capturing the parents' narratives within interviews.

Within Dyke et al's (2013) study of 18 Australian mothers of young people with a learning disability, parents' reported while they considered their young person's quality of life to be good or better, they reported their own as "poor" or "very limited" (Dyke et al, 2013: p 154). Similar to Boehm, Carter & Taylor's (2015) suggestions, they felt fearful regarding their "own ageing and ability to care adequately for their son and daughter into the future". Furthermore, they stated a "lack of provision of information during transition, particularly that applicable to severe disability" to affect a family's QL due to the stress levels which increase through not knowing what is readily available after transition (Dyke et al, 2013: p 154). The study acknowledged legislation that advises support and information should be readily available for transition to adulthood, stating that parents are not supplied with such information. The study considers it critical to continue listening to the narratives of parents' of young people with a disability in order to ensure more positive outcomes for themselves and their young person, something which this study intends to explore further.

3. Support

3.1 Peer support

As previously mentioned, seeking support from others in similar situations is viewed as "an important part of the adjustment process for parents' when adjusting and coping with transition" (Biswas et al, 2017: p 106). Biswas et al (2017) consider having support from families and individuals in similar circumstances to provide a feeling of normality, along with a vehicle for parents to express their views and fears in a "guilt-free" environment. Similarly, Yarbrough, Evans Getzel & Kester's (2014: p6) small scale on-line parent survey of 12 parents of young people with learning/developmental

disabilities discovered parents value the emotional support connections with other families provide. Parents also reported they “learn about disability services and how to advocate for their child’s needs”, when accessing support networks. It could be said that Yarbrough et al’s (2014) view reflects that of Biswas et al (2017) in that parents may feel they can speak freely to other parents without the feeling of guilt when discussing their own needs. Reflecting upon my own journey I feel this to be an important observation as parents of young people with a disability can often feel guilt, even within their own family (Goodley & Runswick-Cole, 2011), talking with other parents in similar situations can give a sense of normalcy. This study intended to gather parents’ narrative on their young person’s transition process into adulthood and to also capture the parent’s voices on the aspects related to their own support networks.

3.2 Formal support

More formally, access to support services throughout the EHCP process is acknowledged as “strongly associated with having a more positive experiences” (DfE, 2017: p: 106), parents and young people in the 16-25 year age bracket reported a lack of access to information, advice, and support (DfE, 2017). Similarly, within the Lamb Inquiry SEN Disability Information Review Report (2009) parents expressed the need for information and tailored support through face to face meetings with people who they and their child know well. Also, the report concluded that a range of information regarding how parents and young people may access support services should be made readily available to families. This should be for them to source themselves or through transparent and genuine communication with professionals and services working with them (Lamb, 2009).

DfE Parent Experience Survey (2017) suggests the older the young person the less likely parents and young people are informed of the support available; 74% of parents of children under 5 reported they were told of the support available compared to 57% of young people and parents in the 16-25 age group. Similarly, lack of information during transition regarding the availability of services and support, in particular those related to young people with significant needs, was cited by parents within Dyke et al’s (2013) study on mother’s experiences on transition to adulthood. Also, the study established parents did not have awareness of transition plans which affected their

opportunities for direct input. This could be due to authority staff having a lack of understanding in post 19 transition along with little knowledge of what is available for young people with learning disabilities Post 19 (Harrison, 2016). These views and perceptions reflected my own experience of transition Post 19, there appeared to be a distinct lack of information on the process specifically in what services and provisions were available which lead to difficulty in planning.

Bagatell et al (2017) propose though some young people and their families feel they are able to negotiate school and support systems, barriers still remained due to a lack of information, which is in direct conflict with the person-centred model promoted by the EHCP processes. For services to improve and develop, the shortcomings of the services need to be identified through an exploration of the barriers, facilitators, and needs of the service users. This study endeavored to discover barriers and facilitators to effective transition and the need of the parents who are supporting their young person through the transition to adulthood.

4. Barriers to transition

Barriers to a successful and robust transition are multidimensional; there are several factors that can be considered a barrier to transition, including policy and legislation, an acknowledgement of difficulties and lack of appropriate settings and provision Post 19, these will be discussed here.

4.1 Policy and Legislation

The introduction of the Children and Families Act (2014) was implemented within Local Authorities in September 2014. The Act indicated a major change to the Special Educational Needs (SEN) assessment process for children and young people aged 0 – 25 years with the introduction of Education, Health and Care Plans (EHCP). The EHCP's chief principles are to promote a unified approach between education, health and social care along with handing more control to parents and young people regarding decisions that assure the young person's needs are being met (Children and Families Act, 2014).

The changes to the education system included improving the options for young people aged over 16, by abandoning the statement system in favour of the EHCP assessment which follows through to 25 years of age. The adjustments made the implementation

of Post 19 education for young people with Special Educational Needs and Disabilities (SEND) possible providing an extended period for those young people who require longer to complete their educational outcomes (Long, 2017).

While the changes to the SEND education system provided prime opportunity for the development of young people Post 19, Imich (2016) warns the inclusion of reforms extending the age to 25 to be the most challenging area. He suggests this may take time for organisations and education establishments to be fully aware of their statutory duties and responsibilities (Imich, 2016). Lamb (2016) is in agreement with this statement, suggesting in his Early Review of the new SEN Policy Review Paper (2016), there is much work to be done in changing the culture within the SEN system. Lamb (2016) also suggests while the reforms were attempting to re frame expectations, they are more likely to succeed if the mechanisms are embraced by authority and are acknowledged by staff (Lamb, 2016). Likewise, Harrison (2016) is also of a similar opinion explaining the reforms now require a substantial cultural change to previous working practices, in which LA's now need to establish different; more co-productive, relationships with parents.

4.2 Organisational barriers

In order to explore and develop this field the DfE (2017:p 138) Parent Experience Report suggested that local authorities should consider development in some areas, one of which is recommended to “address the less positive perceptions of the process and impact of plans for those aged 16-25”. In exploring the perception of LA Officers, Harrison (2016) proposes after 18 months of the revised Children and Families Act (2014) that SEN Officers felt one of the main challenges to be “gaining a real understanding of post 16 issues, managing the expectations of families”. Interestingly, Skipp & Hopwood (2016) qualitative research report stated Local Authorities value in depth feedback which provided a deeper level of detail on such issues in order to understand what steps need to be taken to resolve any issues, something which this study intends to do through listening to the narratives of parents.

On the other hand, Harrison (2016) acknowledges were pressures are managed well, a positive picture occurs, families engage, and plans are issued on time and systems processes are understood. Harrison (2016) suggests were LA SEN Officers face pressures; lack of capacity, high staff turnover, to implement the reforms, a less

positive outcome for families emerges. Harrison's (2016) view is reflected by the findings of Skipp & Hopwood (2016) who cite barriers to the successful implementation of an EHC plan to be a skills barrier in SEN staff, staff shortages and a lack of resources to supply provision identified as needed in the plans. That said the Department for Education (2017: p98) Parent Experience Survey reported an overall 82% of parents and young people said they felt the Local Authority staff working with them were knowledgeable about the EHCP process. This is despite SEN Officers feeling one of the main challenges to be "gaining a real understanding of post 16 issues, managing the expectations of families" (Harrison, 2016: p 38). Interestingly Skipp & Hopwood (2016) qualitative research report stated Local Authorities value in-depth feedback which provided a deeper level of detail on such issues in order to understand what steps need to be taken to support families. This study intends to explore through narrative interviews the experiences and perceptions of parents when experiencing their young person's transition, and in that their expectations for their and their young person's future.

This is similar to Biswas et al's (2017) study in which parents outlined significant barriers to engagement with services and organisations to be; exclusion of the parent and young person in decision making, "unsupportive" services and a lack of negotiation between services and parents and young people. Biswas et al (2017) suggest such barriers to "increase parents worries about their child's transition process" (Biswas et al, 2017:p 103), within their study into parents views regarding transition in adulthood for children with a severe intellectual disability (Biswas et al, 2017). The study, which used grounded theory to explore twelve parents views, explored avenues to supporting parents with the transition to adulthood (not in education in life) by applying clinical interventions based upon their transition model of parents views and aspirations which took into account parents perceived barriers to adult v's parent experiences and expectation. The study concluded that parents perceived barriers to adulthood for their young person was affected by their previous experiences with services, professional and organisations. If a parent had a negative experience this appeared to carry over into their perception of adulthood, and vice versa. This perception was also coupled with support if a parent had a supportive network of similar parents or support from organisations their perception of adulthood

transition was more positive than those parents who did not receive support (Biswas et al, 2017).

Similarly, obtaining support from professionals working with families also has its benefits. Manthorpe, Moriarty & Cornes (2015) study comprising of 24 face to face interviews with parent carers of young adults with learning disabilities concluded that parents appreciated support especially in the case where “professional provided support to their adult child was timely, skilled, proactive, experienced and reliable” (Manthorpe, Moriarty & Cornes, 2015: p 98). While parent carers found gaining support for themselves challenging, they felt thankful their young adult had some form of support and reported “this is the best we could hope for in the circumstances” (Manthorpe, Moriarty & Cornes, 2015: pp 99). This study intended to discover, through the parents’ narrative, their perception of support systems; both formal and informal, along with accessibility to information.

Likewise, Gauthier-Boudreault, Couture & Gallagher’s (2017) study of parents of young adults with a profound intellectual disability strengthens the need for robust transition planning, support, and information to be provided to parents and young people. The qualitatively designed study explored the views on the transition of 14 parents of 18-26-year-old male (6) and female (8) young people who have profound intellectual disabilities through semi-structured interviews. The resulting information generated themes of which, similar to Griffin, McMillan & Hodapp’s (2010) & Martinez, Conroy & Cerreto’s (2012) studies, parents identified a lack of informational support, a lack of resource availability and failure in systemic transition planning. Parents within the study recommended avenues for future support, proposing thematic conferences to discuss parents’ and young people’s needs at usefully timed intervals, realistic transition plans, and activities tailored to the individuals which take into account their young person’s profound disabilities.

Bagatell et al (2017) propose by gaining an understanding of the difficulties and facilitators families can encounter in the transition process, coupled with young people and their family’s needs and expectations from their own individual perspectives, would identify inadequacies in the present system. Identification of inadequacies along with positive aspects of the process would enable service providers to improve the process and develop services. This study intended to explore,

through parent's narrative, their thoughts on availability of services and information and their experiences on accessibility to provision and resources.

5. Provision for young people Post 19

As mentioned above, the rejuvenation of the education system for children and young people with SEND provided the possibility for young people aged 19 -25 to continue within education and learning (Long, 2017). While there is “no expectation that all young people with SEND will have an automatic right to continued support beyond 19 or that those with an EHC plan will remain in education until 25”, there is recognition that some young people may require longer to complete their educational outcome and also to learn and develop new skills (Thom & Agur, 2014: P 4). Indeed, Imich (2016: p 29) proposes “central to improving life outcomes is that young people with SEND go on to post-16 education, training or employment”. However, despite the recent changes in the SEND Code of Practice (2014), there is some unease that provision to match this offer is not as well established as it could be, with further work required to develop settings (Thom & Agur, 2014: Imich, 2016: Ofsted, 2010).

Ofsted's 2010 review report described how the “real choice of education and training opportunities at 16 was limited for many disabled young people and those with special educational needs” (Ofsted, 2010: p 11), with “few courses available and low attainment”. This view does not appear to have changed. While local authorities appear to have accepted the essence of the SEN reforms and seem to be committed to joint working with parents, organisations and commissioning groups to improve services, further efforts are required to “translate this consistently into improved experiences” (Imich, 2016: p 32) rather than the negative experiences parents appear to expect.

The Education and Training Inspectorate identified an area for “serious concern”, to be in a small number of young people with multi-agency involvement; health, social care, who wish to transition to post 19 provisions. The evaluation report, into transition arrangements from specialist settings to post-school educational provision, concluded this area required “significant improvement” (DfE, 2014: p 6). The report goes further to suggest post 19 provisions for those young people with such complex needs should begin at aged 14 with dedicated support for parents and young people. Agencies should also work collaboratively to ensure a realistic future plan in which clear choices

can be made. Whilst the report concluded from the parental questionnaires 140 of the 180 returns were largely satisfied with the transition process, 32 of the 40 negative responses belonged to parents of young people with profound learning needs. The dissatisfaction was reported to stem from a lack of provision for this cohort, lack of successful multi-agency working and young people being located with older adults rather than peers of similar ages.

More recently, Gauthier-Boudreault et al's (2019) scoping review of social participation in individuals with profound LD after school life, proposes there are two choices for young people with profound LD after school, day centers or recreational activities. Lacking from this conclusion is further educational opportunities and employment which Gauthier- Boudreault et al (2019) say is not routinely offered to parents or young people. The study, reviewing 33 international articles, concluded that very few individuals with profound LD go on to work opportunities or education due to the significant amount of support the person may require to either complete an educational task or within employment itself along with their cognitive ability. Leisure activities; social, home and physical, appear to be the primary way which young people with profound LD spend their time, that said this is also reported to be dependent upon the personal factors of the young person for example; severity of LD, challenging behaviour and personal care requirements (Gauthier-Boudreault et al's, 2019: Davies & Beamish, 2009). The study commented on their review of the literature that approximately 17% of young people with a profound LD go onto further education after school. Also, the study acknowledged the lack of research internationally within the area of post-education for young people with profound LD and called for further research exploring parents' perspectives and experiences in creating practical resolutions for young people and their families post-education (Gauthier-Boudreault et al, 2019).

Similarly, the Education and Training Inspectorate evaluation report into transition arrangements from specialist settings to post-school educational provision identifies view of concern for Post 19 provision for pupils with complex needs was mirrored by school staff who cited "availability" and "suitability" of provision as areas for concern and development (DfE, 2014: p 6). More recently, The Department for Education Parent Experience Survey reported the second most common complaint with the EHC

process to be “difficulties in getting the help/support needed to meet the needs of the child/young person.....especially in the 16-25 year age bracket” (DfE, 2017: p15).

This view is similar to that of Gerber’s (2012: p 36) who’s review of the literature of the impact of learning disabilities on adults who are in education proposes, the notion that “one size does not fit all” hold true. He explains there are too many individual variables a person holds; cognitive ability, the severity of disability and support, to offer a standard package of support. Through the narrative discussion, this study aimed to take into account the perceptions above regarding the involvement of services within transitions, and parent’s descriptions of their experiences so far.

5.1 Parents perceptions of Post 19 provision for young people with learning disabilities

Parents of young people with learning difficulties are reported to be among the most negative groups concerning transition to adulthood, with one of the primary concerns being what activities the young person will take part in during the day (Gauthier-Boudreault et al, 2019: Wills, Chenoweth & Ellem, 2016: Hoskin, 2017: Bagatell et al, 2017: Gauthier- Boudreault et al, 2017: Biswas et al, 2016). Parents felt whilst professionals offered some pre-selected “realistic options”, these did not match their dreams and desires for their young people, often leaving parents feeling they had made compromises (Griffin, McMillan & Hodapp, 2010). Griffin, McMillan & Hodapp’s (2010) study, which recruited 108 family members of young people with learning disabilities aged 14-25 years old, asked for family’s perspectives on Post 16 education options alongside “it would be better if” questions. Along with a lack of information, parent’s participants also reported “conflicting advice” as to what provision was available (Griffin, McMillan & Hodapp, 2010: p342). The study proposed that for effective transitions in this cohort to be a reality, more support, information and planning should be provided to parents during, and throughout, the transition stages.

Similarly, Martinez, Conroy & Cerreto’s (2012) mixed-methods study exploring parent’s desires and expectations for their young people post-secondary education, suggests parents did not entirely understand what provision was available for their young people. The study, which recruited 136 participants; parents of young people aged 14-22 years with a learning disability, discovered parents wanted more, readily available information regarding provision and services. Parents’ felt while they received some information, this was not adequate for their young person’s needs

which caused confusion as to what options are available. This, according to the parent's responses, left parents feeling "floored and scared to death" (Martinez, Conroy & Cerreto's, 2012: p 284 & 280) about their young person's future. Furthermore, and similar to parents' views within Manthorpe, Moriarty & Cornes's (2015) study, parents also commented on the staff within the settings explaining staff are often not qualified to a level to care for their young people. They also expressed anxieties over the conditions explaining they are often "not homelike and spartan". Adding staff working within the settings are frequently inconsistent in experience and attitude (Moriarty & Cornes, 2015).

This research study intended to explore parent's perceptions of their young person's transition to adulthood and within their narratives, their perception of provision available to their young person.

5.2 Perpetual parents

Young people with learning disabilities (LD) typically continue to live at home with their families long into adulthood (Boehm, Carter & Taylor, 2015; Kim & Turnbull, 2004). Families of such young people are viewed to play a major role in caring for and supporting their young people. Indeed, the term "perpetual parents" (Kelly & Kropf, 1995: p4) is applied to parents who are essentially caring for their older adolescent or adult child who has severe disabilities from birth or childhood. As many of the parents associated with this label provide not only housing and financial support to their young adults, they also often provide personal and basic skills care. Whilst some young people move into supported living settings "perpetual parents" are often called upon to provide assistance with financial matters and as a safety net in the event of negative incidents (Manthorpe, Moriarty, & Cornes, 2015). As a result of this, the improvement of family-orientated outcomes within the transition to adulthood planning is considered to be an on-going concern.

Skipp & Hopwood (2016) in their qualitative research study which interviewed 77 parents and 120 professionals on the Education, Health and Care plan process, report a frequent reoccurring topic to be the availability of suitable provision Post 19 alongside, the provision that was available to not always be full-time. Parents reported this made caring for their young person difficult, due to work or other family commitments. This view is similar to the findings by Gauthier-Boudreault et al (2017)

who suggests parents of young people with a profound disability find it difficult after transition to find appropriate care for their young person as many offers of services post education are on a part-time basis. Parents within the study felt they either had to source “babysitting” or “stop working”, not only parents expressed while services were offered they require a minimum of cognitive autonomy from their young person, which is often not applicable to young people with more complex learning disabilities (Gauthier-Boudreault et al, 2017: p 21).

The single study, discovered to date, which explores transition to adulthood for young people with a severe learning disability within the UK, explored the views of 12 parents of young people through an interview and grounded theory analysis (Biswas et al, 2017). Biswas et al (2017: p 103) investigated how parents viewed the transition to adulthood for their child and considered how the parents made psychological adjustments to cope with the transition. They concluded that the majority of parents engaged in a process which invokes anxiety related to barriers to their child transitioning to adulthood; reliance upon outside support, and “worrying” about possible abuse of their young person whilst in care settings. The study acknowledged the lack of research within the field and called for further research into the perception of parents of young people with a severe learning disability when experiencing transition; the area in which this study is focused.

6. Educational Psychology and transitions Post 19

As mentioned above a major change to the education system was the creation of a clear structure of support for children and young people aged between 0 -25 with SEND. While the age group of 19-25 have not been considered a priority when services are mapped and developed for the future, many service providers feel their current work with Post 16 young people gave them a solid foundation to build frameworks and develop provision for those aged 19-25 (Thom & Agur, 2014).

Amongst such services, Educational Psychologists (EP), according to Atkinson et al (2015) EP’s are “uniquely positioned to support young adults” and are considered “key in working collaboratively with schools, careers services and other agencies” to support transitions to adulthood (Atkinson et al, 2015: pp 160). Atkinson et al (2015) go on to say the addition to the position of an EP in working with young people to the age of 25 signifies a major development to the profession. Also, the Code of Practice

(DfE, 2014) encourages a holistic, person-centred planning approach in which the families and young person's needs, wishes and aspirations are gathered. Harris (2009) considers EP's, to be best placed to discover the voice of the child as they have an established interest in gathering children's views, which also includes young people with learning disabilities.

Similar to the topic of parents perceptions of their young person's transition from Post 19 education, research studies concerning the topic of EP's involvement in transitions for young people aged 16-25 is scarce, with only two studies published to date (Atkinson et al, 2015: Morris & Atkinson, 2018). Atkinson et al (2015) explored the views of 24 EP's through the Delphi technique investigating the development of competencies related to the EP role when working with young people aged 16-25. The study concluded that further training, collaboration with services that provide support to 16-25-year old's and knowledge of services that are available would benefit EP's moving forward. The study suggested that a future review of the literature once the Code of Practice (DfE, 2014) had been embedded into SEND practice.

Following on from the research, Morris & Atkinson (2018) undertook a systematic review of the literature to investigate the current, and future, role of EP's in 16-25 transition work to further education, employment or learning. Using 7 studies, of mixed designs, the review identified that EP's have potentially many skills which could support the transition process for example; continuing an educational and learning focus to the individuals future, gaining pupil voice and supporting and gaining the voice of parents (Morris & Atkinson, 2018). The review highlighted the inconsistencies across transition planning, from the point of view of the parents and called for an evaluation of person-centred practice Post 16. The review also suggested that key themes resulting from the study could inform future EP practice when working with young people and their families Post 16, along with recommending for future research and evaluation of how and if EP's support outcomes at transition reviews. While this study was focused upon the parent's experiences of their young person's transition to adulthood, it would inform EP's of parents' perceptions of transition to adulthood since the changes within the SEND Code of Practice and how EP's could possibly support and assist those transitions.

Methodology

This section will explain the methodological approach used throughout the study when investigating the narratives of the parents who participated. I will begin by defining my insider positionality within the research and follow on to discuss my epistemological and ontological viewpoints. I will then move on to defining the research design and the rationale for using a narrative approach. The section will go on to outline the criteria in which participants had to meet; to be a parent/carer of a young person within a specialist setting who is due to transition in September 2019 or has transitioned in the past two years. It will also discuss the ethical issues surrounding the study, along with how I ensured my interpretations of the narratives were without a level of partiality due to my own personal experiences.

Positionality

Positionality is linked to the values, norms, and beliefs of the researcher and their participants; with that in mind, I felt it important to outline my position as an enmic or insider researcher (Merriam et al, 2001). Insider research is becoming increasingly common in areas related to education as practitioners engage in research within their own settings and organisations. Insider research is described by Greene (2014) as “research is that which is conducted within a social group, organization or culture of which the researcher is also a member”.

For the purpose of this research, I am considering myself as an insider researcher due to my own personal and professional experiences during and prior to joining the Doctoral training course. I myself experienced the transition to adulthood process in 2017 (not in my placement Authority) from a specialist setting to Post 19 education with my own child who has autism, profound and multiple learning disabilities, and some physical disabilities. Furthermore, in my employment prior to the training programme I interacted and supported parents with the transition process in my own Local Authority.

Chavez (2008: p 481) proposes insider researchers to be able to “understand the cognitive, emotional and/or physical precepts of participants”. Reflecting on Chavez’s (2008) view, I consider my position as an insider researcher to possibly be positive due to my personal potential to be able to understand the emotions and perceptions attached to the process.

However, I also acknowledge the view of Greene (2014) who considers “the perception of an insider researcher is narrowed, as too much is familiar”. Insider researchers are viewed to come across ethical and methodological issues which may impact upon their positionality throughout the process of conducting the study (Breen, 2007: Unluer, 2012). For example, more knowledge of the area could lead to potential influence and a lack of objectivity to the data collected (DeLyser, 2001: Hewitt-Taylor, 2002). On the other hand, Unluer (2012) concluded that there appear to be no great benefits to being either an insider or outsider researcher it is simply in how the data is validated. Taking the views in mind, I utilised an Educational Psychologist at my placement to reflect on my data themes and consider any potential influences I may have placed in my interpretation of the data, through regular face to face supervision.

In addition, I have also conducted this research from the position of a Trainee Educational Psychologist (TEP) employed within a Local Authority (LA) that had an interest in the findings of my study. My LA Special Educational Needs Manager who oversees transitions within the Authority wanted to gain “some robust learning points from (my) research in terms of good practice that leads to good transitions for families”.

Ontology

Ontology is how the “nature of reality” (Edirisingha, 2014: Effingham, 2013) is understood, it examines how a particular occurrence, event or happening exists or began. This study’s ontological stance is that of social constructionism, that a person’s view and perception of the world are created by the daily social interactions they have with others. Within this world view, people search for meaning and “understanding of the world in which they live and work” (Creswell, 2007: p 36). Social constructionists suggest social interactions and the language used between people in those interactions stimulate a shared vision or perspective of the world and how we understand it (Burr, 2015). Burr (2015) further explains this suggesting, each interaction with others an individual has, constructs a view or perception of that event. Essentially, our view of the world is constructed through social means and interactions. Miller et al (1990) go on to describe how such interactions, constructions and perceptions ultimately create a sense of self. Similarly, Freedman & Comb (1996, pp 17) explains the sense of self:

“exists in the ongoing exchange with others...The self continually creates itself through narratives that include other people who are reciprocally woven into these narratives...”

I feel this ontology best suited to my own position as a researcher due to my positionality as an inside researcher due to my interactions throughout the years with a diverse range of professionals, parents and young people with LD. I feel this has developed my own sense of self and how I view the world. This view is supported by Creswell (2007) who suggests constructivist researchers to “position themselves” in the research due to their own background shaping their interpretations as they acknowledge how their own personal and historical experiences shape their understandings (Creswell, 2007). In addition, I consider this study to be seated in this ontology as being the parent of a child with a disability we are exposed to a variety of different culturally and socially constructed concepts and institutions for example; schools, health, and social care. Each has been designed to meet the needs of a specific group, it is within these groups’ parents interact and view the world through the lens of such interactions (Dudley-Marling, 2004).

Epistemology

Epistemology is derived from the Greek word “episteme” meaning knowledge. It explores how knowledge is obtained and how it is exchanged, in effect how we know what we know and how we justify such knowing (Wolfe, 1982). It seeks to validate our perceptions, experiences, and awareness of what we see and feel around us into justifiable beliefs rather than unsubstantiated guesses (Audi, 2010). While ontology seeks to identify how a phenomenon originated, epistemology is personal to the researcher or how they view the world around them (Edirisingha, 2014).

Billet (2009) believes an individual develops a personal epistemology through their life and social experiences. Personal epistemologies are defined by Brownlee & Berthelsen (2006) as an:

“individual’s ways of knowing and acting arising from their capacities, earlier experiences and ongoing negotiations with the social and brute world”.

Effectively influencing how a person constructs and views the world around them, personal epistemology is ever-changing through ongoing experiences. This view

reflects the ontology of social constructionism and the view of Creswell (2007) who considers constructionists interpretations are shaped by their own experiences of the social and cultural worlds.

The epistemology used in this methodology is Interpretivist. Interpretivists consider reality to be multiple and relative; that an individual's knowledge is socially constructed rather than factually determined (Lincoln & Guba 1985). Interpretivist researchers steer clear of inflexible frameworks to research and tend to apply more personal and flexible approaches that can capture meaning during interactions with participants (Carson et al, 2005). In addition, interpretivist researchers often have some previous insight into the research topic however are open to gaining new knowledge during the process. Interpretivist research aims to "understand and interpret the meanings in human experiences rather than to predict" (Edirisingha, 2014).

Reflecting upon my position above as an enmic researcher belonging to both a social/cultural and parent group I view my past life experiences have shaped my personal epistemology and how I view the construction of knowledge. Therefore, it was important to me the methodology used in this study acknowledged my potential influence as an insider researcher and enabled me to reflect upon the participants' conversations.

In addition, reflecting my ontological and epistemological position I feel narrative, as a methodology, would be best suited to explore the experiences and perceptions of participants. Narrative is largely compatible in creating an understanding of human interactions, constructions, and perceptions as it reproduces linguistically the route which individuals take to achieve their understanding of events (Miller et al, 1990).

Chosen Research Method

Research methods are described as the "techniques you use" to collect data, (Walliman, 2011: p7) the ways in which participants are identified and acquired, along with how the research data is collected and analysed (Gray, 2009). There are two research paradigms central to research within the social world; quantitative and qualitative. Quantitative research methods aim to explain social phenomena by statistically acknowledging numerical data. While qualitative research "produces findings not arrived at by statistical procedures" (Yilmaz, 2013: p 1) for example meanings and understandings. Qualitative and quantitative methods vary in relation

to their foundations within epistemology and methodology. Quantitative research tends to lean towards objectivist epistemologies and considers reality fixed, while qualitative methods are informed by constructivist viewpoints and reflect that reality is flexible and based upon how reality and knowledge are socially constructed. Qualitative methods also reflect interpretivist epistemologies, asserting the view that many views are applied to knowledge rather than singular perceptions (Bryman, 2012). In comparison, qualitative methods promote collaboratively working with research participants acknowledging their experiences to gain meaning, rather than statistically extracting a single truth from quantitative methods (Bryman, 2012). Qualitative research tends to cover issues within social and human arenas. A feature of qualitative research is the thoughtful interest in issues that can often be emotional and sensitive, a notion of which I share (Creswell, 2007). To reflect my own epistemological and ontological position, qualitative research methods are used within this study as I view it important to gain meaning from parent's experiences and I acknowledge each participant would hold a differing perception of their unique experience.

Literature and research reviewed regarding parents experiences of transitions to adulthood have used for the most part qualitative methods (Hoskin, 2017: Bagatell et al, 2017: Gauthier-Boudreault, 2017: Biswas et al, 2017: Gauthier-Boudreault, Couture & Gallagher, 2017: Manthorpe, Moriarty & Cornes, 2015: Juhasova, 2015). This study also plans to use a qualitative method of data collecting which will allow me to "capture the voice" of participants and "make meaning of their experiences" through narrative means (Rabionet, 2011: pp 563). Qualitative methods are well placed to explore the realities of individuals through the gathering of words or narratives; it is within these narratives' participants present their unique perspectives on their experiences (Creswell, 2007).

Narrative

"scientific and narrative ways of knowing are fundamentally different. Where science concerns itself with the establishment of truth, narratives concern is to endow experience with meaning" (Bleakley, 2005: p 536)

The word narrative is translated as "to know" in which the sharing of experiences through the re-telling of stories embodies the construction of knowledge (Bleakley,

2005: Elliot, 2005) or alternatively an “interpretation of a sequence of events” (Murray, 2003: pp 112). Elliot (2005) explains this in more detail describing narrative as having three distinct features; firstly, they are chronological, secondly, they are meaningful and thirdly, they are social, given that they are created for specific audiences.

According to Wells (2011), the term narrative has varying meanings which are defined by theoretical positioning, the subject of the research and the methodological approach adopted by the researcher. However, while narrative may have varying definitions a dominant theme throughout is that narratives refer to sequential events, experiences or happenings within a person’s life (Wells, 2011). While narrative exists within day to day life for example in books, film, and public speeches, the term “narrative” is usually given to discourse or text which has a particular emphasis on stories voiced by individuals (Squire, Andrews & Tamboukou, 2008: Creswell, 2007). As a research method, the use of narrative within current social and psychological research has increased in recent years. Narrative methods encompass fields of inquiry that offer creative answers to problems, for example, social, personal, and cultural issues (Squire et al, 2014). It proposes enriched opportunities and a fresh angle in applying conversation and discourse to social science policy and practice. Narrative research methods are regularly used amongst minority or discriminated groups or individuals to offer them a platform for their voices to be heard (Knowles et al, 2016). For example, Jones & Lynn (2018) considered narrative thematic analysis to be best placed to analyse the stories told by parents during their child’s stay in intensive care. Narrative thematic analysis was used within this study to analyse parent’s online illness blogs over the duration of their child’s stay in order to identify stressors and coping mechanisms in this minority group.

That said, how researchers approach narrative study differs dependent upon what the researcher is concerned with discovering. Narrative researchers may be interested in the stories individuals re-tell and the meanings behind those stories, or on the other hand, and similar to Jones & Lynn (2018), they could be interested in discovering the *themes* within the stories, either way, narrative can be used either quantitatively or qualitatively (Kohler Riessman, 2008). Quantitative researchers use narrative within social research to apply numbers and statistics to patterns within the story or themes which emerge (Franzosi, 2010). For example, Radzikowski et al (2016) recently utilised quantitative analysis to examine the narratives used within social media to

explain anti-vaccination. When used as a qualitative research method, narrative is grounded in the lived and spoken storytelling of individuals which are then analysed and interpreted by the researcher (Pinnegar & Daynes, 2006). For example, Knowles et al (2016) used narrative methods qualitatively with parents to understand their child's journey into offending behaviours. Recruiting 6 parents, Knowles et al (2016) used narrative interviews asking parents initially for their story using an opening question. The interviewer allowed parents to talk freely, without interruption aside from the interviewer verbally prompting them to expand on parts of their narrative. Resulting interviews were then examined using "an experience centred approach" in which the narratives were used to understand how the parents made sense of their child's experiences (Knowles et al, 2016: p 449). For the purpose of this research study, and similar to that of Jones & Lynn (2018), Radzikowski et al (2016) and Knowles et al (2016) narrative will be used as a method within this study in order to understand parent's experiences of their young person's transition from Post 19 education.

As discussed, this research ontology is seated in social construction, that a person's view and perception of the world is created by the daily social interactions they have with others (Burr, 2015). A constructionist approach to narrative research intends to discover how "meaning is constructed in narratives in relation to the available cultural, social and interpersonal resources" (Squire et al, 2014: p8). Constructionists consider the themes within the narrative, or how the storyteller sees or has constructed the experience, by acknowledging the themes uncovered during recorded spoken narrative interviews (Kohler Riessman, 2008). As mentioned above this study intends to adopt a narrative method of data collection. In keeping with the constructionist approach, the narratives of parents will be gathered via narrative interviews.

Narrative Interviews

Narrative interviews are often used to encourage participants to share their stories during the interview the researcher is positioned as a listener, there to collect the words, stories, and experiences of participants (Creswell, 2007). Within narrative interviews, individuals "remember what we can, and some events are deliberately or unconsciously forgotten" (Muylaert et al, 2014: p 186). The significant point in the interview is that the participant recalls what they perceived as true to them, not just the realities themselves, rather how the person felt and what they experienced. The

resulting narratives taken from the interview are therefore regarded as portrayals and interpretations of the world as viewed through the lens of the participant. Their narratives are not to be taken as fact, or either true or false, however, a perception or point of view of an individual (Muylaert et al, 2014).

Narrative interviews generate person-centred information that can be used to develop whole family holistic support and provide opportunities for the development of recommendations for good practice when working with families (Kendall, et al 2009). Narrative interviews can reveal many aspects of the needs and coping methods of participants in their role of parent and carer. They can also establish participants' perceptions of the experience which may help to inform Educational Psychology practice when working with families who have a young person with LD (Kendall et al, 2009). This research gathered participant's narratives about their experiences of transition through semi-structured interviews. As an interview without consideration to the line of questioning may not have elicited conversation on the topics I wished to cover, having some structure to the interviews allowed me to collect data on areas explored within the literature review (Rabionet, 2011). Additionally, structure and probes allowed me to gather rich information on the topic areas I wished to explore (Richie & Lewis, 2003: Dibley, 2001: Etikan: 2016).

Initially, I aimed to establish a relationship with participants to construct a good line of communication so as to prompt and begin a reflection on their experiences (Richie & Lewis, 2003: Rabionet, 2011: Muylaert et al, 2014). As discussed above, I position myself as an insider researcher as I "studied a group to which I belong" I felt by introducing myself as part of the group to the participants, it enabled me to form a more rapid relationship due to my having an "already established intimacy" (Unluer, 2012: pp 1).

I asked participants an opening question, related to their experience, in order for narratives to flow more freely (Chase, 1995: Elliot, 2005). In establishing the line of questioning, I was mindful of the advice from Holloway and Jefferson (2000) who advised that whilst questions should be simple in nature they should not be rigid enough to focus specifically upon the needs of the researcher as this may stop participants from providing a thorough enough narrative.

Muylaert et al (2014) agree with this suggestion and add interviewers should not interrupt the main body of the narrative, however, use encouragement for the participants to continue by asking questions that do not offer opinions personal to the researcher. I intended to be mindful of this advice during the interview.

As mentioned above, narrative interviews should encourage participants to share their experiences whilst also meeting the focus of the study. The narrative method is mindful of the “examinant questions”, or questions which “refer to the research question or the researcher’s interest that arise from the approach to the study when developing a literature review” (Muylaert et al, 2014: p186). Using this approach, I have reflected upon my area of interest, considered the future recommendations from the literature reviewed above and proposed to use the question below as an initial examinant or opening question.

Can you tell me about your experience of/your transition journey so far?

Furthermore, I identified the following questions as possible probing questions in order to gain information recommended by the review of the literature and pertinent to the study (Chase, 1995: Elliot, 2005: Holloway and Jefferson, 2000).

- 1. Is there anything that made the transition easier or helped you?**
- 2. Was there anything that made the transition more difficult?**
- 3. Is there anything that you think could make the transition easier or could be better?**

Ethics

Ethical approval was sought and granted by Sheffield University Research Ethics Committee (Appendix 1). In addition, and running through the study, I was mindful of the ethical and moral guidelines defined by the British Psychological Societies Code of Human Research Ethics (2014) and those of the Health & Care Professions Council Guidance on conduct and ethics for students (2016).

According to Kvale (2007, p24) interview research is “saturated with moral and ethical issues” this is due to the researchers’ requests for participants to share private aspects of their lives which will effectively be placed into the public eye (Mauthner et al, 2002). I felt this to be especially pertinent to parent participants within this study due to the expectation of sharing stories regarding their young person’s future transition

and the thoughts and feelings this may provoke. Taking this into account the following ethical aspects have been taken into consideration.

All potential participants were provided with the aims and focus for the study within an information sheet. The sheet contained an invitation to take part, and information regarding the nature of the interview for them to make an informed decision about their participation in the research. The information sheet also informed participants that the interview would be recorded with their consent and that names would not be included to ensure confidentiality (Appendix 2).

On the day of the interview, their consent to participate was recorded via a consent sheet (Appendix 3), which outlined their right to withdraw themselves from the research at any time, and reinforced confidentiality and the storing of the recorded and transcribed data collected.

Despite repeated attempts to recruit more parent participants, parents either declined or took the decision to not participate. At that point, I decided to not make further contact to recruit parents as I was mindful of the BPS Code of Research Ethics (2014) which identifies potential participant's right to autonomy and the power/pressure balance between school staff and parents. In addition, and reflecting on the point made above (Mauthner et al, 2002; Kvale, 2007), I was mindful this topic could be deemed as a sensitive subject, to accommodate for this I provided information for parents on how to seek further support in relation to transition and the support of parents/carers through the process by signposting to useful websites, parent/carer support groups and an LA representative.

All participants who responded were then contacted to arrange a convenient date and time for their interview. Participants were given a choice of venue to suit their work commitments and geographical location. All interviews were held in rooms suitable for a private discussion.

Sample

The sample selected for this research study was a purposive sample due to my choosing the sample owing to the specific research question. Owing to such inclusion criteria, the sample could also be considered a homogenous group as I stipulated and specified a particular encounter, I wished the participants to have experienced

(Robinson, 2014). According to Etikan, such purposive chosen sampling can identify “information rich cases” (Etikan, 2016: pp2) which may enable a rich picture to be formed from the data collected. This view is also in keeping with my chosen narrative methodology and that of narrative interviews, both of which generate rich data (Richie & Lewis, 2003; Dibley, 2001; Etikan: 2016). The subject which I explored required participants to have experienced, or are currently experiencing, transition with a young person who has LD and attends a specialist setting.

Initially, a school was chosen within my placement Local Authority. It was selected as I was not directly involved with the school as a Trainee Educational Psychologist and it met criteria as being a specialist setting for young people up to age 19 with LD. The school was also chosen as it often takes part in research-related activities, has a large number of parents/carers to draw upon in comparison to other schools in the area, and its typicality to specialist settings around the country. The school is a maintained specialist setting that provides education and residential care for young people from the age of 2 – 19 years. The pupils have a wide range of difficulties which include complex physical, learning and medical needs. A large proportion of the pupils have Autism Spectrum Disorder and/or severe and profound multiple learning disabilities. Access to free school meals is high and almost all the pupils are from a white British background. The school’s sixth form, where the sample parents were selected, had 18 pupils on roll whose young people are due to transition to Post 19 settings in September 2019.

Initially, I contacted the school’s Senior Leadership Team via telephone to make an appointment to discuss the study. I met with the school’s Sixth Form Head and overall school Deputy Head to explain the purpose of the study and what the resulting information would be used for. An invitation for all 18 parents was extended via the Sixth Form Head, who supplied parents with a cover letter (Appendix 4) and information sheet outlining the aims and intentions of the research.

Two weeks from the date of distribution I contacted the school to collect parent participant consent forms for those parents who wished to participate. Of the 18 invited two parents; the mother and father of Rachael (all names have been changed to ensure confidentiality), responded. A further request for participation was sent out using the same means, again after two weeks I contacted the school and no further

parents had accepted the invitation. I again requested the information be sent out in a reminder email, to which there were again no parents which responded to the invitation. At that point I was mindful of the ethical issues, as discussed above, surrounding freely given consent and made the decision to halt further steps to recruit parents from the school.

As the research area had specific inclusion criteria and was asking for a particular experience, I was aware the sample size would be influenced by this and would most likely be small. Ideally, from the school I would have liked a sample size of 5 parents; however, the lack of replies from parents resulted in only two participants from the identified school.

Participants were then sought via alternative means through parent carer forums within my placement LA and neighbouring LA's. From this, two parents were recruited, and contacted via telephone. All participants were then supplied with the cover letter, information sheet, and consent forms. In all, a total of four parents, three mothers, and one father were recruited to take part in the study.

Owing to the smaller sample I had initially hoped to conduct focus group workshops in which participants would discuss their experiences of their young person's transition to Post 19 settings together as a group. However, due to a low level of response, I made a decision to move from a workshop to an individual, or in the case of Andrew and Bev paired, interviews. Also, participants spread across two counties which meant a focus group would have been difficult to engineer, due to a large amount of distance between participants. This triggered a shift away from focus groups to narrative interviews.

While I acknowledge this may be a small sample for a Thesis, Burmeister & Aitken (2012) suggest the size of the sample to be un-important in qualitative data collection rather the attributes of the participants and how their experience contributes to the depth of the data and the building of a rich picture. This view is also that of Marshall et al (2013) who suggests there are no fixed rules regarding sample size in qualitative research, rather the sample size is dependent upon what information the researcher would like to gain, what the purpose is of the study and what can be achieved taking into account the researcher time. Interestingly, narrative as a methodology is flexible; it does not demand a specific number of participants, rather participants are

determined by the topic of the study and the depth and richness of the data collected (Wells, 2011). Indeed, narrative can be used as a research method using single participants to capture the experiences of individuals to develop practice and gather new knowledge (Hartman, 2017). Narrative research studies using single or few participants are considered to be important to understand stages of processes and to be “the only possible way of obtaining the granite blocks of data on which to build a science of human nature” (Brandell & Varkas, 2010: pp 293). Also, narrative studies that use few participants are used as common practice within social work and clinical research to clarify and explain issues within processes and practice (Wells, 2011: Brandell & Varkas, 2010: Hartman, 2017).

Gathering the narratives

Psychology seeks to understand the individual and to accomplish this we need to understand the social world in which we live. People innately use narratives to explain their perspectives of themselves and others and their experiences of the world around them. As such, narrative approaches to research are considered valuable when studying social and family phenomena (Stephens & Breheny, 2013). That said, using narrative as a way of collecting information does not naturally inform the method of analysis, this is informed by the epistemology and ontology of the study along with what the research intends to discover and contribute to (Kohler Riessman, 2008).

As mentioned above, this studies’ ontology is seated in social construction that a person’s view or interpretation of the world is shaped by their social interactions with others (Creswell, 2007). The Interpretivist epistemological position of this study supports the view that knowledge is socially constructed, as interpretivists view reality to be multiple and relative (Lincoln & Guba, 1985). Narrative as a method of data collection is well-matched to both paradigms as through the re-telling of stories, language influences how we interpret and construct our views (Miller et al, 1990).

There are several approaches that can be applied to analysing spoken narratives. Interactional analysis places importance upon the dialogue or exchanges between the participant or storyteller and the researcher or listener. The analysis is of the narrative and includes all utterances including disfluencies, inflections, and pauses, non- verbal interactions can also be analysed. The method, while also gathering some themes from the data primarily focuses upon the interactions between the researcher and the

participant, including body language and gesture (Reissman, 2005). As this study intended to gain experiences and perceptions, interactional analysis will be discounted as it was not the study's intention to analyse the relationship between the researcher and participants rather the information given during narrative interviews.

Structural analysis places emphasis on the way a story is told or how the narrative is spoken (Reissman, 2005). Viewed to be "the first method of narrative analysis" (Reissman, 2005: p 3) structural analysis has six key components, which neither have to all be present or be in a specific order. While the structure analyses narratives and assists in the recognition of themes, the language within the narrative is considered carefully and speech patterns investigated in order to understand how individuals translate experiences from a personal perspective (Labov, 2006). While this method of analysis can be applied to narrative, this study was concerned with the content or what is said within the narrative rather than how the story is relayed.

The narrative approach I chose is similar to that of Manthorpe, Moriarty & Cornes (2015) who studied the experiences of parent carers where the young adult had LD. The study used face to face interviews and focus groups to gather data which was then reduced into themes that would eventually inform supportive and effective practice in the future when working with parent carers. Similarly, Lithari & Rogers (2017) also explored parents' experiences of transition from primary to secondary school for young people with disabilities. The study adopted a narrative approach and used thematic analysis to analyse data themes from participants, which also included mother/father parent couples. The resulting data were reduced into fewer categories used within the discussion. The study chose to include parent group narratives as they felt that "it is a way to understand caring practices" (Lithari & Rogers, 2017: pp 269). They further stated inclusion from both perspectives is important in effectively supporting young people and their families in a successful transition. Finally, this study acknowledges those of Watson (2018), Coles (2018) and Biswas et al's (2017) whose studies included parent couples within their sample participants. This study also adopted an approach which gathered data from parents either singularly or couple parents with the intention to analyse the data into themes. It is hoped the findings will then inform practice when supporting parents with their young person's transition.

As mentioned above the method of data collection for this study was through narrative interviewing. Narrative interviews as a means of qualitative data collection are considered to “allow the deepening of the research” and the retelling of life stories (Muylaert et al, 2014). Narrative interviews allow time for the participants to talk freely without interruption, as such narrative interviews can often be lengthy. During the recorded interviews, I was mindful of the view that the interviewer may reduce the natural flow of the participant’s dialogue by interjecting with questions or ending the interview early (Mishler, 1986: Elliot, 2005). As such, I followed the advice from Muylaert et al (2014) who suggest interviewers offer positive body language, intonation, and few direct questions during their participant’s narrative. Following this advice, the interviews ranged from 25 minutes to 1 hour and 45 minutes.

Participants

Within this section, the participants to the study will be introduced.

Interview One

Bev and Andrew (pseudonym) are a couple in their sixties and parents of an 18-year-old female; Rachael (pseudonym) who has Down Syndrome, physical and some mobility disabilities, Autism, and severe learning difficulties. Rachael has limited verbal communication; she wears glasses and has hearing aids. Rachael is transitioning to adulthood this current year (2019) and attends a specialist setting. Bev and Andrew’s interview lasted 1 hour and 45 minutes.

Couple Interviews

Researchers are increasingly exploring the advantages of conducting joint interviews when studying experiences which are similar or “lived” within specific social contexts. Noticeably, it is common for individuals who parent young people with additional needs and/or learning disabilities to be married or have a significant partner in which experiences are mutual. Qualitative researchers frequently acknowledge the valuable information both parties hold and as such it is becoming progressively common for “couple interviews” or interview “dyads” to take place (Bjørnholt & Farstad, 2012: Kendall et al, 2010: Sakellariou, Boniface & Brown, 2013). Couple interviews are viewed to have a number of benefits and difficulties. As mentioned above, researchers consider couple interviews to offer an element of shared experiences, alongside the

consideration that if a couple are discussing significant others in their narrative; for example, husbands, wives, offspring, they should be present to inform the “story” as it is told (Sakellariou, Boniface & Brown, 2013). Furthermore, Sakellariou, Boniface & Brown (2013) considers how within couple interviews participants are able to make sense of joint experiences as they are able to interpret their perspectives with someone who is undergoing the same event. On the other hand, researchers identify within couple interviews it may be more difficult to discern individual experiences and perspectives (Kendall et al, 2010). This study is interested in the experiences of parents in relation to their young person’s transition rather than solely focused on an individual’s experience. For this reason, and as a parent and practitioner, I feel it is important to include both parents within the interview as I agree with the view of Sakellariou, Boniface & Brown (2013) above. In addition, I chose to transcribe the data collected from Mr. and Mrs. X as a whole interview and identify them as single participants similar to the analysis within Watson (2018), Coles (2018), Biswas et al (2017), Jones & Lynn (2017), White & Rae (2016).

Interview Two

Jane (pseudonym) is a married woman in her fifties. She is a parent to 21-year-old Donna (pseudonym), who has Global Development Delay and Autism. Donna is non-verbal and requires full-personal care. Donna transitioned from a specialist setting in 2017. Jane’s interview lasted 29 minutes.

Interview Three

Wendy (pseudonym) is a single mother in her forties. She is a parent to 21-year-old Karen (pseudonym), who has Down Syndrome. Wendy describes Karen as a “very vulnerable person” who needs “someone with her 24/7”. Karen has some communication difficulties and transitioned from a specialist setting in 2017. Wendy’s interview lasted 26 minutes.

Trustworthiness

The typical view of trustworthiness within research relates to the credibility of the knowledge learned or found within a study. The trustworthiness of narrative research lies within two distinct areas, the differences in how people make meaning of their

experiences, how they re-tell their experiences through story, and how this is then interpreted by the listener (Polkinghorne, 2007).

Information for this study was collected from parents who had either taken part in a transition from a specialist setting or were going through the process of transition. As such, I believe the information collected will be reliable representations of their views and experiences but also based on what the participants want to share.

Polkinghorne (2007) suggests:

“understanding of human experiences requires evidence in the form of personally reflective descriptions in ordinary language and analyses using inductive processes that capture commonalities across individual experiences” (Polkinghorne, 2007: p 475).

In addition, Nowell, Norris, White & Moules (2017) consider in establishing trustworthiness within research, the researcher should make it clear how they analysed their data. Acknowledging Polkinghorne’s (2007) and Nowell, Norris, White & Moules (2017) suggestions, data collected from the narrative interviews was analysed using thematic analysis to capture the themes and commonalities across the interviews.

To reinforce the importance of the findings from the narrative interviews, this study adopted the framework of Braun & Clarke’s (2006) thematic analysis to analyse the narrative data collected, providing the researcher with a clear framework for analysis.

To also add trustworthiness to my interpretations of the narratives, Mishler (1986) considers narrative interviewers should be mindful of partiality when reporting parts of the interview. Also, while insider researchers are considered to possibly be more understanding of the experiences they are studying, they are also advised to be mindful of how their personal experiences may impact their interpretations of the information gathered (Greene, 2014; Breen, 2007; Unluer, 2012). Finally, taking into account the view of Mishler (1986), Greene, (2014), Breen, (2007) and Unluer (2012), I acknowledge my own personal perceptions of the research subject, and I was mindful my position as an inside researcher could have caused me to place my own personal slant upon the data analysis.

To account for this, Nowell et al (2017: p4) also supply a structure to address the issues of trustworthiness and rigor in qualitative research, by applying a “means of establishing trustworthiness” to each phase of Braun & Clarke’s (2006) thematic analysis. Within each phase, Nowell et al (2017: p4) propose several vehicles for trustworthiness; for example, within Phase 1; Familiarising yourself with the data (Braun & Clarke, 2006), “prolonged engagement with the data” is a marker for trustworthiness. As is “peer debriefing” within Phase 2; Generating initial codes (Braun & Clarke (2006).

Taking this into account I also followed the advice of Nowell et al (2017) alongside the framework of Braun & Clarke (2006) and engaged with the data throughout the process of analysis. Finally, and accepting the views of Mishler (1986), Greene, (2014), Breen, (2007) and Unluer (2012), at the end of Phase 2 and through to Phase 6, I employed my Fieldwork Supervisor within my placement to peer debrief my analysis within my supervisions. My reflections on the supervision are outlined below.

Transcription and Analysis

For the purpose of the data analysis, I used Braun & Clarke’s (2006) guide to thematic analysis as a structure for analysis and transcription (see Figure 1 below).

Phase	Description of the process
1)Familiarizing yourself with your data.	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2)Generating initial codes.	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3)Searching for themes.	Collating codes into potential themes, gathering all data relevant to each potential theme.
4)Reviewing themes.	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic “map” of the analysis.

5) Defining and naming themes.	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6) Producing the report.	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back to the analysis to the research question and literature, producing a scholarly report of the analysis.

Figure 1: Braun & Clarke (2006)

Phase 1) Familiarising yourself with your data

Following Braun & Clarke's (2006) phases of thematic analysis, I familiarised myself with the data by transcribing each recorded interview verbatim (see Appendix 5). I chose to transcribe the narratives verbatim, as the direction given by Braun & Clarke (2006) states to "retain the information..... true to its original nature" (Braun & Clarke, p 88). The transcription encompassed all utterances spoken by myself and participants, including filled pauses spoken by the participants for example "ahm", "erm" and also those spoken by myself to encourage participants to continue speaking for example "hmmm". Incidents of laughing were also noted in the first transcription. I then re-read the transcriptions alongside the recorded interview noting any misses of information in order to produce both a genuine transcription and to further familiarise myself with the data. It was during this phase I began to generate possible patterns and similarities within the data (Braun & Clarke, 2006).

Phase 2) Generating initial codes

Within this phase, I took into account the advice from Braun & Clarke (2006) and avoided analysing the narrative data in relation to the interview questions themselves, rather highlighting narratives which I considered interesting and key to the study. The creation of themes from the data can be approached in two ways; inductive or deductive. Inductive themes are generated from the data, the results of which could have little to do with the research question itself. Whereas, deductive analysis considers the focus of the study and generates themes which attempt to supply an answer to the research question. As this study is an exploration of parent's narratives

of their young person’s transition to adulthood the analysis took an inductive approach rather than a deductive, as there is no specific research question, more an analysis of participants’ narratives (Maguire & Delahunt, 2017). Finally, themes were then constructed through a latent approach rather than a semantic approach, meaning the researcher attempts to make sense and find meaning in what has been said within the narrative interview. Themes were generated in this way as interpretive means of data analyses align with my Interpretivist epistemological position, where I attempt to capture meaning during interactions and the sharing of participant’s narratives (Carson et al, 2005: Lincoln & Guba 1985).

In keeping with the inductive approach above, each transcript was then re-read, and line by line initial codes was manually drawn from each of the narrative interviews and placed in a table sectioning the narrative and the interpretation (see Appendix 6). Figure 2 (see below) displays an example of the data excerpts with coding:

No	Narrative	Interpretation
40 (B)	so our experience of children’s social care was limited and not too impressive in the sense that erm but thought right we have to face this no one likes the idea of having a social worker that I knew no one really likes that intrusion	parents seeking support; lack of support; QOL-intrusion
41 (B)	brief encounters with them were that they treated you as if you might have potentially have abused your child and you were in that same category whether you’re a child in need or not you have the same set of questions as a parent who is doing it because you care for them as the parent who is doing it because she doesn’t so it is very off putting	parents seeking support; parent’s perceptions; QOL-intrusion; system failures

42 (B)	we thought right we have to try again because this piece of information made sense it was going to be better if we got in at 16, so at 16 I rang the number of the county council and asked a few questions blah blah I answered them all obviously far too articulately because six weeks later we get the reply she doesn't qualify for to erm go in for a proper assessment	persistence; lack of support
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Figure 2; an example of narratives and coding interpretation

As advised by Braun & Clarke (2006; p 89) in this phase I allowed for coding each narrative to include as many “potential themes/patterns as possible”, in this I also followed their advice regarding the isolation of the narrative and to keep as much context as possible surrounding the story, the participants are sharing. I felt this especially useful when discussing my interpretations with my Fieldwork Supervisor during supervisions.

Phase 3) Searching for themes

Within Phase 3 I began to develop my initial thoughts as to the emerging areas of possible themes within my interpretations of the narrative extracts, by working methodically through each of the narrative interviews. Using the example of a thematic map by White & Rae (2016), and as advised by Braun & Clarke (2006), strong emerging themes from the Phase 2 were used as headings and areas of similarity were placed under each emergent theme area (see Appendix 7). For ease of narrative identification, each of the themes adopted a colour and related codes were placed beneath each emergent theme. As suggested by Braun & Clarke (2006), it is common for some of the codes to be present within more than one theme and it is also acceptable for some codes do not apply to any theme, these codes are colourless.

Phase's 2 & 3) Reflections with Fieldwork Supervisor

As mentioned above, to establish the trustworthiness of the study I employed the advice of Nowell et al (2017) who suggest peer debriefing during the phases. At the end of Phase 2, I took my initial interpretations to my FWS to reflect upon. We discussed my interpretations, how I had decided upon the codes and any potential

partiality I may have had due to my positionality of being an insider researcher and my own interpretations of experiences of transition. I repeated the process at the end of Phase 3 explaining my decisions on how I had placed the codes into the emergent themes and how they could cross over. Feedback from both debriefs was positive and both instances of debriefing and reflection enabled me to further question my own interpretations of the narrative ensuring I had considered my own potential influences (DeLyser, 2001; Hewitt-Taylor, 2002).

Phase 4) Reviewing themes

During Phase 4 themes can change, be discounted or new emerging themes can be discovered (Braun & Clarke, 2006). Within this Phase themes were refined; areas and codes were reviewed and analysed to either consolidate themes into similar areas or discount themes which do not have enough supporting codes. This Phase as advised by Braun & Clarke (2006) consists of two levels; in level one codes were manually laid out, read and compared individually to identify patterns in the codes. Codes that did not appear to have a place within emerging themes were discarded, and remaining codes formed themes to capture the narratives from participants. In level two, the validity of the themes was checked to ensure they reflected “the meanings evident in the data set as a whole” (Braun & Clarke, 2006; p91). To achieve this, codes were manually moved around to form coherent themes that represented the narratives parents have voiced about their experience of transition to adulthood. At this point, I placed the themes within a thematic map, as advised by Braun & Clarke (2006) (see Appendix 8).

Phase 5) Defining and naming themes

Once the thematic map was finalised, the naming and defining of themes took place within this phase (Braun & Clarke, 2006). Braun & Clarke (2006: p92) suggest “identifying the essence of what each theme is about” within the defining and naming stage. It became apparent within Phase 4 that parent’s narratives focused upon the areas of; planning for the future, provision, negative feelings about the process of transition to adulthood, and parent’s perceptions of what would support a transition to adulthood for themselves and their young person. Within three of the primary themes, there were clear sub-themes or areas for discussion, the final theme stood alone. Sub-themes are considered to be useful in giving coherence to larger themes, the inclusion

of sub-themes also fits with Braun & Clarkes (2006: p92) interpretation of each theme “telling a story”, with the overall story representing the narrative spoken by the participants. The thematic map from Phase 4 was further defined to represent the themes and subthemes in the final thematic map (see Appendix 9).

Phases 4 & 5) Reflections with Fieldwork Supervisor

As mentioned above, and as recommended by Nowell et al (2017), to establish trustworthiness and validity of the resulting data, between Phases 2 to 5, I sought advice and reflections from my Fieldwork Supervisor within my placement. Whilst I had discussed each phase within supervision, I chose at the end of Phase 4 to give my FWS the remaining codes and asked her to manually place them in my primary themes, to see if there were any similarities in interpretation. My FWS undertook the task and then the results were compared to my analysis for validity. The similarities were clear and the feedback positive, and it was felt that the themes which I interpreted from the codes were valid and pertinent to the study. At the end of Phase 5, I again checked with my supervisor my primary themes and how I considered each subtheme to fit in overall with each primary theme telling a story of participant’s narratives.

Phase 6) Production of the report

This section will firstly explain the final phase of the analysis and follow with the report and discussion. The final phase of Braun & Clarke’s (2006) thematic analysis framework concludes with the creation of the report. This study explores the parent’s perceptions of their young person’s transition to adulthood through narrative means. Within the final phase, and in keeping with narrative methods, Braun & Clarke (2006: p 93) advise “embedding” extracts of the narrative within the report to “illustrate the story you are telling about the data”. Also, the report should give sufficient pieces of the narrative to demonstrate the occurrence of the theme. Within this phase, I revisited phase 2 and selected sections of the narratives voiced by the parents which reflected the most prevalent themes and sub-themes.

Report

Theme 1) “it’s like the blind leading the blind”

While parents within the study expressed some positive views regarding their experiences of transition, for the most part, the narratives parents gave were from a negative perception. One of the main themes running through the parents’ narratives was related to the lack of information available before, during and throughout the transition process. All of the parents explained how frustrating they found the transition to adulthood due to the lack of information from schools, transition services, and information regarding provision. All of the parents described how more information should be available to them in order to make realistic decisions about their young person’s future. Due to the lack of information, parents then expressed how they had independently searched for information in order to make informed choices and decisions:

“we knew we’d have to find those things out for ourselves and we’d have to delve into the future by ourselves and I sort of assumed special schools would be geared up to that” – Bev

“it was like the blind leading the blind” – Jane

“But again, we’ve pretty much search it all out ourselves” – Wendy

While looking for support and information, about services and support, parents experienced some confusion over which service would be able to provide support. Bev shared how she attempted to find practical support for their daughter and themselves and found she was signposted to different services:

“Health people said it was a social care problem, social care people said it was a health problem, and we just thought we have far too much to deal with” – Bev

Once practical support was found, there then seemed to be some confusion over the type of support the young people would be allocated. Both Wendy and Jane explained how their young person’s peers were allocated different levels of support:

“other young adults got more time, some got 2 some got 3 years and stayed until they was 22 But my daughter only got 1 year” – Wendy

“some only get two days a week, some get one and some get three” – Jane

This led to parents being unsure of what support their young person would be allocated, and again confusion over who to approach and how much support their young person would receive.

“they treated you as if you might have potentially have abused your child “

One of the sub-themes within parents’ negative experiences appeared to be once support was discovered and services activated, parents perceived they were judged by the system and it’s “labels” for assessments and procedures. Bev and Andrew described how the labels used by the processes which offer support to young people from child services (up until the young person is 18) implied parents are engaging with the systems as they may have potentially abused their child, rather than seeking support to manage with their child’s learning disability and resulting needs:

“they treated you as if you might have potentially have abused your child and you were in that same category whether you’re a child in need or not you have the same set of questions as a parent who is doing it” – Bev

“the other child, child at risk, child in need you could be in jail next week” – Andrew

Similar to feeling judged, parents also explained how they felt their point of view was ignored by professionals when seeking support. Bev and Andrew described how they had approached support services for help, and they had not met “criteria”. When they questioned the decision, they expressed how they were not able to know as they were parents, not professionals:

“we asked the question why and we had a very rude answer which was we can’t tell you” – Bev

“because you’re not another professional we can’t tell you why we haven’t scored enough” – Andrew

The perception of feeling ignored led to parents considering their points of view or experiences with their young people were not heard when talking to professionals. All the parents described how they perceived their voices were not listened to despite being asked their opinion:

“our opinions and thoughts and stuff are, are, are great but they are warm woolly words” – Andrew

“have professionals on board and helping you and saying the right things for you, because they simply do not take parents word for you know for it “ – Bev

“I said no you’re not listening to me” – Wendy

“I think the transition team are very, what’s the word not to sound horrible. They have got no clue basically, they have got no clue. I think they need to have a child themselves to know what it means to some of us” – Jane

This led to parents sharing a narrative of how they felt alone through the process.

You’re on your own...”

As parent’s felt their opinions and life circumstances were not listened too by professionals, parents becoming increasingly independent searching for their own information and support. This led to parents feeling alone:

“Basically, you left school and that’s it now you’re on your own and that’s it now, that’s how we felt and other parents that was with me as well” – Jane

“Basically, it left me with me having to deal with everything that she had to do from then on” – Wendy

While parents spoke about how they felt alone, as far as support from services was concerned, to counteract this all the parents within their narratives explained how they sought support and advice from parents and carers in similar circumstances to them:

“You feel like you’re on your own, you’re not because you’ve got other supportive parents out there and you try and help each other but it shouldn’t be down to that really should it? Just the parents helping out” – Wendy

“I’ve had to deal with all that. I haven’t had any help from anywhere. I have but it’s been other parents we help each other out” – Jane

Within this, all the parents described how they actively supported parents in similar situations. Both Andrew and Bev had links with local parent carer forums and ran a group for young people with learning disabilities, while Jane and Wendy supported other parents with their knowledge of community activities and groups.

Also, parents shared information about their support networks at home. Three of the parents have a partner and one is a single parent. While the data of the couple

participants were analysed separately, all parents with a partner explained they feel supported as they have someone close to talk to.

“we’ve been fortunate in a sense that there are two of us” –Bev

“I am lucky I have a supportive husband” – Jane

While Wendy (the single parent participant) acknowledged how hard it was being a lone parent:

“It can be quite hard because I’m a single parent, it is just me and her” – Wendy

“we have to fight for everything for our guys”

All the parents portrayed how at several points within their young person’s transition to adulthood they had to “fight” for support and services. Andrew also expressed how he automatically braced himself to fight based upon previous experiences, while Wendy shared, she felt she has to fight for everything:

“because you sort of steel yourself for a fight really for all of these things” – Andrew

“we have to fight for everything for our guys” – Wendy

Wendy also considered she had fought continuously since Karen had been born, and that as Karen got older the fight became harder:

“I don’t feel we should kind of just be left to kind of fight I mean we, I fought for 21 years for my daughter for everything in life but yeah it seems to get harder as they get older” – Wendy

Theme 2) “I’m 63 erm so we know realistically we can’t carry on looking after Rachael forever”

Andrew shared within his narrative, both himself and Bev felt it was their responsibility to ensure Rachael was busy during the day while she was no longer in education.

“we know she’s going to move out of full-time education therefore it will be more incumbent on us to sort out what happens to her in the day” – Andrew

“so she’s not at home all day” - Bev

Also, within their narratives, Bev and Andrew shared they were thinking about their own future without Rachael living with them. Both parents explained how they were

realistic about Rachael moving into supported living and how they had planned for the event in advance. They felt they were realistic in their ability to care for Rachael as they aged, and felt as they got older they would find it harder to do so:

“the big transition which we are looking at is for Rachael to be from living with us to be living in supported living that’s the transition that’s the big one” – Andrew

*“I’m 63 erm so we know realistically we can’t carry on looking after Rachael forever”–
Bev*

While Wendy and Jane did not directly share their thoughts about their future plans for support as they aged, Jane described how she wanted her daughter to continue living in the family home. She perceived that as she wanted to keep Donna at home with her the support offered to her was less than it would be if she placed her daughter into full-time care. She felt relied on by adult services to care for her daughter due to her decision, and wondered if she had asked for a residential placement, they would have given more support:

“because at the end of the day if she’s put into a full-time home, they would have to pay for her so why can’t they if she’s at home?” – Jane

While only Bev and Andrew spoke about their future without Rachael, all the parents described how as they age their body reacts to the demands of effectively caring for a young adult. All the parents shared in some form how the demands of caring for a young person with learning disabilities is tiring and challenging:

“Nobody can ever deny the fact that we are getting older and we are not going to be able to look after Rachael” – Bev

“old man and you know you can’t be looking after somebody who effectively not in all respects but in some respects a two-year old you, you err you’re not patient enough and other things so you need, you need to accept you can’t” – Andrew

“You just, the only thing is when you get older it gets harder, some mornings you ache and your body aches but you have to get up who’s there for you have to carry on don’t you it’s the way of life. Take it as it comes and grin and bear it” – Jane

Jane’s daughter Donna was the most severely affected by her disabilities; she is non-verbal and requires full personal care, explaining how she fought day to day with caring

for an adult child. She described how it is similar to looking after a baby in that she has to provide for all of her independence needs:

“It’s just draining sometimes. Some days if you’re not well you still have to get up and change a dirty nappy, you still have to get up and wash her dress her and feed her, it’s like a baby. You can’t just leave it to cry” – Jane

Jane also shared how caring for Donna impacted on her ability to go out and about:

“She didn’t like going out, she didn’t like going to the supermarkets, I couldn’t go shopping, sleeping…… and she just didn’t like coming out of her routine at all which is hard especially going to somewhere”

“It’s it is hard work. If you go out, you’ve always got to be home coz the carers need to be home it’s like having a baby, and you need to care all the time” – Jane

“We can’t do this weekend because we can’t get a sitter or well be there in an hour because I have to sort Donna out first or I have to pack a baby bag basically” – Jane

While Wendy explained she felt she does not have the freedom to go out and about and she has to plan in advance:

“I have to plan everything” - Wendy

Bev and Andrew were both retired, while Jane was a stay at home parent, Wendy was the only parent who worked. While this was her own business and she shared she had some work flexibility, she also expressed how it could be difficult to find people to care for her daughter while she worked, often relying on family and friends:

“I have to rely on someone every week…when I’m working I need someone to be with her” – Wendy

“But it has been hard, it has been hard” - Wendy

Theme 3) “we went to them and we realised that they don’t cater for people like Rachael”

Despite sharing their views and being involved in the Post 19 transition process, none of the parents had a positive experience when initially offered Post 19 provision. All the parents explained the provisions initially recommended to them were not suitable for their young person’s needs; they all described how they visited professional’s

suggestions to find the settings that did not meet the needs of their young people. Also, they described how they had either been offered a limited or only one choice of provision:

“we went to them and we realised that they don’t cater for people like Rachael” – Bev

“I went to and that wasn’t appropriate, and I went to another place and that wasn’t appropriate, I went to another place..... well no she wasn’t going there she might as well have stayed at home to do that” – Jane

“The facilities for children like Donna are disgusting, absolutely disgusting” – Jane

“the only place you could go was...there was no offer of anywhere else or nothing” –

Wendy

“it feels like it breaks all the safeguarding rules to us but there you go”

As well as the provision being unsuitable to their young person’s needs, parents perceived the provisions offered were not safe enough for their young person. Safety of their young person was important to each of the parents; all the parents discussed the safety of their young person within the provision that was offered to them:

“wasn’t appropriate because, erm I mean Donna does do a runner and they had no locked doors or no policies for locking doors, or it wasn’t on camera or anything like that so that was no good” – Jane

“very important that other people from a safety point of view when they are allocating resources again are lookingwhat age she’s working at” – Andrew

The perceived lack of safety within the provisions led to the parents feeling anxious about leaving their young person in unfamiliar places for the first time:

“adult respite we weren’t very comfortable about it and we came away thinking hmmm” – Andrew

“that was the hardest moment ever” – Bev

“I knew there was something wrong because she didn’t want to go” – Wendy

Also, two of the parents; Bev and Jane expressed safeguarding concerns within the provision they were offered. Bev explained how she left Rachael with male members

of staff; while Jane shared the provision she had been sent to had a large age gap and mixed genders:

“it feels like it breaks all the safeguarding rules to us but there you go” – Bev

“Putting her in there with people aged 70, 80, 90 no she’s a young adult. If she strips off way hay, you know what I mean it’s wrong, totally wrong with children and that age gap” – Jane

Also, parents spoke about how they felt worried about leaving their young people with unfamiliar staff within the settings that they did not know or who didn’t know them. Explaining, how this was one of the hardest steps they had to take. Bev and Andrew described how leaving Rachael was difficult:

“we were leaving Rachael with people who didn’t know her, she didn’t know them” –

Bev

“it is quite a big deal letting other people that you don’t know look after her “– Andrew

The issues above generally led to all the parents searching for Post 19 provisions independently. All the parents researched and discovered their young person’s own provision and in the case of Jane, created their own learning environment as they could not find anywhere suitable to meet their young person’s needs:

“so you need to do quite a bit of research to find the places” – Andrew

“When she left school the school helped us put some tables in, we had to do it all as parents” – Jane

“Luckily for me I know all this and I’ve done the research myself or other parents have told me or looking on social media and things and I’ve even googled things” – Wendy

Also, parents shared how they wished for their young people to be close by within their local community rather than in provision out of the county. All the young people attended provision within their local county and all of the young people currently lived at home with their parent/s and one, Rachael, was moving into supported living. Bev and Andrew had settled on a supported living provision within their county and close to their home while Jane expressed her wishes for Donna to remain with her:

“I looked at a couple of places out of town for Donna to be residential but I didn’t want her to be residential I wanted her at home with me” – Jane

“be in some sort of education, not here, but something not dissimilar”

When considering their young person’s Post 19 provision all the parents wanted their young person to continue learning in some form. However, the young people either left school without any form of learning or the provision they were shown was not suitable for their young person’s learning ability.

Andrew acknowledged that he understood Rachael would not be continuing her learning however, he had thought she would be in some form of further learning. Both Jane and Wendy fought for their young people to be able to continue their learning, while Andrew and Bev appeared to accept professional’s advice to discontinue with learning, despite this being their initial wishes:

“Rachael would be in some sort of education, not here, but something not dissimilar”

- Andrew

“I knew she had the capability of doing something like that so I pushed for that to happen” – Wendy

“Donna actually left without an education, any education at all..” – Jane

“will she be happy?”

Within parent’s narratives, they described how they wanted their young people to be happy within the settings they were attending/or going to attend Post 19. All of the parents shared how one of their main priorities was their young person’s happiness:

“objective which is where we are heading is for Rachael to be able to be happy in a supported living environment” – Andrew

“We are always looking to say is it, is it suitable for Rachael? Does it meet her long-term needs, will she be happy?” – Bev

“My daughter she can’t get enough of it. If I could afford to send Karen I would she loves it absolutely loves it” – Wendy

Bev also explained how she “chose” Rachael’s future placement based upon how she had observed support services interacting with young people within her community:

“the group I decided the ones which were the best was the ones which were 100% involved there with the people they were supporting they all looked like they were all having fun together” – Bev

Also, Wendy spoke about how she found her daughter moving to a new provision easier as she was happy there:

“It’s getting easier now because she’s in places she likes” – Wendy

Theme 4) Parental perceptions of what effective support may look like

Parents shared many ideas on how transition to adulthood Post 19 could be made easier for both themselves and their young person. These leaned towards parents using support networks; these were either other parent support networks, seeking support from services through to being informed about what would happen:

“people could do with a mentor to, to who’s not there to save money, who is there to help peoplego with them through the process” – Andrew

“one of the most useful off the cuff remarks from another parent, which is usually who you pick up the most best tips from, was erm you need a social worker while she’s still a child” – Bev

“I just feel that they should be told a lot more, the parents and the young uns, er what’s about to happen” – Wendy

Parents also described how a transition could be made easier for themselves and their young person by beginning transitions earlier or by “buddying up” with a parent who has experienced transition:

“The year or two years before they need to start this transition, but nothing sort of goes into place. You’re just looking at places and talking. That child you need to know, say if you leave school at 18, at 17 they need to get into that transition they need to go there three days a week and then once they actually leave and then that next week they go in five days a week. That’s what I call a transition” – Jane

“From say three months before they leave school to go to college there should be more meets with the parents and even school, or meets with the person they are going to approach next” – Wendy

“it would be nice if you could ask people to buddy up” – Andrew

Jane described how services who provide support to young people Post 19 should work together to support young people across all areas rather than working singularly. Jane explained Post 19 support should be a mixture of all the support:

“It doesn’t have to be full on education, morning education and then access the community but if they got together, education, health and social care together and did something like that I think that would be amazing, wouldn’t you?” – Jane

Discussion

This study was created to explore parent’s experiences of their young person transition post 19 through narrative means. In addition, the study also had three probing questions which were also pertinent to the study, all of which were explored:

- 1) Is there anything which made the transition easier or helped you?
- 2) Was there anything which made the transition more difficult?
- 3) Is there anything which you think could make the transition easier or could be better?

Within the discussion the findings of the research will be considered in relation to the focus of the study, in relation to the research and literature discussed within the literature review. This study also reflects the large amount of valuable information that parents of young people with disabilities hold. It is within this information that the questions above are answered and the findings are discussed in relation to the individual themes and sub- themes identified.

Theme 1) “it’s like the blind leading the blind” – lack of support

All four parents shared their narratives of their young person’s transition to adulthood. Within the stories each of the participants primarily indicated their frustrations regarding the lack of support and information received from transition and adult services. All parents throughout their narratives expressed a lack of information about the process itself, and support and resources available to them and their young person. This is despite recommendations from research and policy that parents and young people should have access to relevant information, before and during, their young person’s transition in order for them to make informed choices (DfE, 2017: DfE,

2014: Lamb, 2009: Dyke et al, 2013: Bagatell et al, 2017). The recommendations from the literature did not appear to be put into place within any of the young people's transitions. Parents appeared to expect services and professionals who were working with them to know what was available to support them.

Also, parents shared how they felt services did not understand their role within the transition with Jane expressing "they don't have a clue", "it's like the blind leading the blind". I agree with the narratives and reflect on how services appear to be unsure of their role within the process. This coupled with the lack of available, realistic services led to parents feeling unsure who to approach for support. I consider parents' narratives and their suggestions within the literature and reflect on the suggestion of Goodley & Runswick-Cole (2011) who discuss parents and young people experience three service transitions within a short time. I wonder if this quick succession of transitions could be responsible for parents being unsure of which service to approach for support as well as professionals being unsure of who may provide support.

Following on from this, despite having access to formal support being associated with a more positive transition (DfE, 2017), parents also shared how they attempted to seek practical support but found they were passed from one service to another. For example; Bev attempted to access practical support however found herself being passed from social care to health care with neither service offering support. Bev's narrative mirrors the thoughts of Griffin, McMillan & Hodapp (2010) who suggest services do not work effectively together and often offer contradictory advice to parents. The experiences of the parents within this study also differ to the recommendations of Hendricks & Wehamn (2009) who explain multi-agency working is essential in Post 16 planning, alongside the knowledge of services required and the resources needed to support the young person. They go on to explain for the transition to adulthood to be successful, both schools and agencies should overlap with each other, be continually re-evaluated and co-ordinated for outcomes to be achieved. Also, Rhem et al (2012), add for transition to be effective in families with multi agencies involved collaborative support between services is essential.

"they treated you as if you might have potentially abused your child"

One of the surprising narratives in relation to this sub-heading was shared by Andrew, who described how the names and labels of assessments, and how he perceived

services to engage with him, was accusatory. Andrew portrayed how “if you’re a child in need or not, you have the same set of questions as a parent who is doing it” (*being abusive*). This issue is considered by Devine (2015, p 75) who describes how “family assessments for the purposes of providing support, are potentially in conflict with assessments for the purpose of investigating child abuse”. The assessments for providing support to families of young people with a disability possibly require a re-think as they appear to be automatically categorised into the same bracket of young people who are experiencing abuse (Devine, 2015). This issue of stigma may discourage parents from accessing much-needed support from social services and contribute to the perceived lack of support once education has finished at 19.

Also, Bev acknowledged that not all parents may want the input from social services as it “can be intrusive”. This is also recognised by the Council for Disabled Children (CDC) (2016) who in their briefing state it is important to “recognise that some families feel there is a stigma associated with social care support”. The CDC report also shared how some local authorities are taking part in a trial to amalgamate the social care aspect automatically into the Education Health and Care plan process to establish the care needs of young people who could otherwise be missed. I consider this a useful trial and one which may quash the fear of social services involvement for parents of young people with learning disabilities.

Parents also felt ignored by services and professionals. The feeling of being ignored is described by Biswas et al (2017) in their study in which parent’s voiced services did not include their points of view and did not support their decisions about their young person’s future. Jane described how she had engaged with services and requested support which was suitable for her daughter but the council disagreed; “they throw it in your face all the time”, while Wendy had directly informed professionals working with her and her daughter they were “not listening to me”. Both Jane and Wendy’s experiences are opposite to what is advised by Lamb (2009) whose report concluded that parents should have access to transparent and genuine communication from professionals and services working with them. Also, White & Rae (2016, pp 140) suggest parents are considered as “equal partners with expertise” and are also viewed as partners in decision making by policy (DfE, 2014). Griffin, McMillan & Hodapp, (2010) share the considerations from the literature above, suggesting families, and in particular, parents, are vital contributors when planning for transition as their thoughts

and perspectives can be influential in the approaches employed by schools, authorities and service providers.

Also, Bev and Andrew shared how they felt unless they had a professional practitioner sharing their point of view their requests were superficial. This mirrors the views of Biswas et al (2017) who suggest a significant barrier to parent engagement with services to be a lack of negotiation and unsupportive services. Again, the narratives appeared conflicting to the opinion of Dyke et al (2013) who advise parental involvement leads to better outcomes for their young person (Dyke et al, 2013).

I consider these issues and reflect back to the previous theme and wonder if as well as professionals bringing their own agenda to the table when discussing transition to Post 19 settings, there is also an element of confusion from service professionals regarding who provides what support. This consideration would fit with the view of Skipp & Hopwood (2016) who, within the literature, suggests barriers to transition to include a skills barrier and a lack of resources. Harrison (2016: p 38) also contributes to this issue, suggesting professionals lack “a real understanding of Post 16 issues”.

“You’re on your own”

One of the significant themes running through all the narratives was how alone parents felt. As mentioned within the report, this appeared to stem from the lack of support from services and the lack of information regarding their future options. All parents appeared to expect services to provide information to them, however, when this did not materialise parents felt alone in their decision making. Parent’s narratives echoed that of Chadwick et al (2013) who described how parents of young people with learning disabilities require timely support at critical times within the transition for them to feel they are not alone. All the parents shared how they felt at one point or another and how support was not timely or adequate. This is despite literature reviewed, suggesting transitions in which parents had been well supported by services, the outcomes for the young people were considered better (Dyke et al, 2013). Also, the DfE (2017: p 106) acknowledged were parents had access to more formal support networks transition is a “more positive experience”. I reflect on this and the views of Wendy and Jane who both had limited formal support and who both had negative experiences in transition. While Bev and Andrew were still immersed in the experience

of transition, they had appeared to replace the formal support with support from other parents in similar situations.

To counteract the feeling of being alone, parents sought support from other parents in similar situations or who had already experienced transition. All the parents felt they received more realistic support from other parents than professionals; as professionals and services either did not have the answers to questions they asked or were not realistic. Their experiences are in line with the views of Yarbrough et al (2014) who suggests there is a high level of value which parents place on the support they receive from other parents in comparison to professionals. Also, Biswas et al (2017) describe how parents may seek support from other parents as this provides an environment that is guilt-free, along with a sense of normality about their life circumstances.

“we have to fight for everything for our guys”

It became apparent from the narratives shared that once parents found a provision which they felt was suitable for their young person, or in the case of Jane organised their own tailored made provision, parents then felt they had to fight for funding or places. This view would align with the literature reviewed from Griffin, McMillan & Hodapp’s (2010), Martinez, Conroy & Cerreto’s (2012) & Gauthier-Boudreault, Couture & Gallagher’s (2017) studies who all suggested that a lack of resources contribute to failures in the transition process.

Also, I reflect on the parent’s perception of “fighting” and I consider if parents perceive they are fighting as their expectations for support Post 19 is in conflict with what is offered to their young people Post 19. This consideration is in line with that of Bagatell et al (2017), Biswas et al (2017) and Harrison (2016) who suggest a challenge for professionals is to meet the expectations of parents. I also reflect that parents generally have their young people in school for five-day schooling until they are 19, this type of support Post 19 is possible, however it is also rare. While the DfE (2017) guidance for young people with special educational needs post 19 reads local authorities “should consider” providing young people who may have access to Education, Health and Care plans support across five days a week from multiple providers; health, education and social care, the reality shared within the parents’ narratives appears not so.

Theme 2) “I’m 63 erm, so we know realistically we can’t carry on looking after Rachael forever” - QL

As mentioned above, parents of young people with a disability are acknowledged to have a poorer QL in comparison to parents of children without a disability (Misura & Memisevic, 2017; Boehm, Carter & Taylor, 2015; Samuel, Rillotta & Brown, 2012; Dervishalija, 2013). The parents within this study shared several aspects of parenting their young person with disabilities and how this affected their day to day life and their future thoughts on their own and their young person’s future.

While all the parents felt it was their sole responsibility to organise their young person’s day activities once leaving school, Andrew identified this specifically sharing they felt “*incumbent*” or responsible in relation to keeping Rachael busy during the day. Through their narratives, each parent explained how they personally had organised the activities their young person accessed during the day, rather than wait for or access support from services. Boehm, Carter & Taylor (2015) and Misura & Memisevic (2017) proposed an approach by services that take into account the parents’ needs alongside the young person’s needs leads to an improved QL during transition to adulthood. This approach did not appear to have occurred within the transitions experienced by each parent, and as identified below, the lack of thought to parents QL has affected their access to work and social aspects.

While all of the parents, spoke freely about how they care for their young people on a day to day basis, only two of the parents shared they had actively planned for their own future. Bev and Andrew spoke easily about their long-term plans in relation to them ageing and who would take care of their daughter. They explained they had planned for Rachael to be living in independent living and how this was their goal or “big transition”. Both Bev and Andrew’s narratives about their ability to care for their daughter as they age appeared to mirror the suggestions of Boehm, Carter & Taylor (2015) who suggest parents often worry about their capacity to care for their young people later in life. Dyke et al (2013: p 154) also considers worry to affect the QL of parents, as while they are ensuring their young person is well cared for and their QL to be “good”, due to the stress and worry of future plans parents described their own QL as “poor”. While parents in this study did not use the term QL specifically, they all

shared how planning either for their young person's future or daily activities added "*stress*" and "*worry*".

On the other hand, Jane and Wendy did not discuss their ageing or future ability to care for their young people, I wondered if this could be due to them being younger than Bev and Andrew. Bibby (2012) however, suggests parents of young adults with learning disabilities avoid planning for their young person's future without them as they have a lack of confidence regarding services available to care for their young person. Bibby (2012: p 41) goes on to suggest for parents of young people with "more severe disabilities and limited communication" to be particularly apprehensive about discussing the future due to the stress related to planning for an unknown future. Reflecting on this view, and the disabilities' the young people have within the study, I consider if Wendy and Jane are indeed apprehensive about considering their own ageing and their ability to manage as both of their daughters fit into Bibby's (2012) category. I also reflect back to the previous themes and consider the view of Bibby (2012), who considers the stress related to future planning to affect parents' QL. I wonder if parents attempt to "avoid" the planning and therefore the stress as their QL is affected enough with the added demands of parenting a young person with high needs.

While only Bev and Andrew shared narratives regarding the future, all the parents described how caring for their young people affects their bodies. Jane discussed how "it's draining sometimes" and Wendy how "it has been hard". This is in line with the literature discussed above which identifies young people with disabilities who continue to live at home is known to negatively affect a family's QL due to the limitations placed upon typical day to day living (Kelly & Kropf, 1995; Bibby's, 2012). Kelly & Kropf (1995) explained how young people with learning disabilities generally continue to live at home with their parents rather than live in alternative or supported accommodation. Reflecting this and as mentioned within the literature review, the term "perpetual parents" (Kelly & Kropf, 1995: p4) is given to parents who are caring for their older adolescent or adult child. Boehm, Carter & Taylor (2015) also discuss this issue and consider the nations' growing dependence on families caring and supporting young people with learning difficulties. This view reflects within the home contexts of the parents who took part in the study as all the parents currently cared for their young person within their home. While Bev and Andrew had a plan in place in which Rachael

would be introduced to supportive living in the future, both Jane and Wendy did not. While this was not discussed directly, both expressed their wish for their young people to remain at home with them.

Also, both Jane and Wendy shared how caring for their young person affected their ability to carry out day to day tasks; shopping and going out at about. Jane, in particular, explained how it was difficult parenting a 21-year-old young adult who required “a *baby bag*”, how you “*can’t just drop everything and go*” and how she had to ensure she had a “*sitter*” in place if she wanted to go out alone. Jane’s experiences are in line with the thoughts of Boehm, Carter & Taylor (2015) who suggest families where the young person has numerous support needs and/or challenging behaviours to have a lower QL than those families where a young person fewer challenging needs. I reflect on this point and the experiences of Jane; my own daughter has a similar presentation to Donna and requires 1:1 care and full personal care. I agree with her narratives regarding how parenting a young adult with extensive needs affects your QL in that you can not “just drop everything and go” and how you require a “sitter” to leave the house independently. I feel this does negatively affect your own QL as, along with the lack of information and support services, such scenarios incite added stress.

I also reflected how during the process there appeared to be very little focus upon my own QL, employment, and social opportunities. The focus appeared to be upon the support my daughter required rather than if I needed to work or access the social opportunities I accessed while she was in full-time education. My experience is similar to the findings of Rhem et al (2012) who suggests research conducted seldom takes a view of parents own QL, rather focusing upon the young person’s QL. Indeed, Juhasova (2015) suggests parents’ own quality of life to be directly related to environmental issues, for example; availability of financial sources as well as the availability of services. It appeared from all the parent’s narratives their QL had been directly affected by issues suggested by Juhasova (2015), so much so Jane expressed she “*wouldn’t wish it on anyone*”, while Wendy reflected upon her ability to access her employment.

I also reflect on the description of transition by Dyke et al (2013) who state transition for young people with learning disabilities symbolises a varied change in roles and environments often related to independent living, day activities, education, and

employment. Considering this description, and applying it to parents, I acknowledge parents also must manage a change in roles and environments once their young person finishes full-time education at 19. I consider, this as for parents their young person may not have a five-day provision as in school. This reflection matches that of the literature reviewed in which one of the parents primary concerns is what activities the young person would take part in during the day (Gauthier-Boudreault et al, 2019: Wills, Chenoweth & Ellem, 2016: Hoskin, 2017: Bagatell et al, 2017: Gauthier-Boudreault et al, 2017: Biswas et al, 2016). This view is also in line with that of Bibby (2012) who suggests parents of young people with a learning disability struggle to continue working and carry out day to day tasks such as shopping while caring for their young person. Wendy directly spoke about this issue within her narrative, sharing she finds care for her daughter so she is able to work.

Also, Hendricks & Wheman (2009) propose families to “create a new reality”, and it is within creating this new reality parents require support and resources from services to continue with their day to day lives. Within the literature reviewed it was discussed that for an improved QL, transition planning and processes should take into account the whole families perspective on outcomes alongside the consideration of what QL means to each individual family (Henniger & Taylor, 2014: Bagatell et al, 2017: Biswas et al, 2017).

I reflect on these issues holistically and I wonder about a transition which considers the three services; education, health and social care, which young people and families are most likely to access, being amalgamated. As mentioned previously I feel this is especially important in cases where the young person is looked after and their residential services finish at 18 however, their education at 19. An approach that considers an amalgamation of the transition to include health, social care, and education together may give more constructive planning for both education and independent living. I continue to consider that for an effective transition to take place, consideration should be given to the gap between the end of child social care at 18 and education at 19.

Theme 3) “we went to them and we realised that they don’t cater for people like Rachael”

As mentioned above, all the parents shared how the choice of provision was limited and in the cases of Jane, Andrew and Bev were initially based upon social care rather than further learning. The parent’s experiences mirror the views of OFSTED (2010), Thom & Agur, (2014) and Imich (2016) who all consider provision Post 19 is not as well developed as it could be and further work to develop suitable provision is required. Their experiences are also in line with the opinion of Skipp & Hopwood (2016) who suggested there is little in the way of development of provisions for those aged 19 and over. It appears from the narratives parents have shared, three years on from Skipp & Hopwood’s (2016) research and five years since the implementation of the SEND Code of Practice (DfE, 2014) the lack of available Post 19 provision continues to stand.

Also, the Education and Training Inspectorate (2014) expressed “serious concerns” regarding the transitions amongst young people with multi-agency involvement; health, education and social care, with difficulties locating support and provision within this group. All of the parents within the study had multi-agency involvement, and all of the parents expressed concerns regarding availability and suitability of provision, along with difficulty navigating which service to approach for support.

As mentioned within earlier themes, all the parents within the study experienced a lack of information about transition, services, and provisions available to their young person. This led to parents sharing within their narratives how they had independently searched for post 19 provision independently of professional’s recommendations. I reflect upon the view of Gerber (2012: p 36) who states services often adopt a “one size fits all approach”, which does not take into account the individual variables young people with learning disabilities possess. I consider this view and reflect if parents within the study may have searched for provision themselves as they had attempted to discuss their young person’s individual needs, however, found themselves not listened to, judged and ignored.

“it feels like it breaks all the safeguarding rules to us but there you go”

Each of the parents expressed fears about their young person’s safety within the post 19 or support provisions they attended or those which they had been asked to consider. All the parents shared within their narratives how they felt their young person

was vulnerable and unable to relay to them if they were unhappy due to their communication needs. This appeared to lead to parents perceiving settings and leaving their young person with staff they “didn’t know” was less than safe. The parent’s fears are in line with Hendricks & Wheman (2009) who suggested that at transition to adulthood parents are to create a new reality, and for that to be effective it should leave parents and young people with a feeling of safety. Kim & Turnbull (2004) also considered how future uncertainty in parents increases fear and stress in families. This view is also mirrored by Boehm, Carter & Taylor (2015) who suggest parents’ stress increases through the lack of information regarding services. Reflecting on these views and the narratives which parents shared, I wonder if the uncertainty of not having an established relationship with staff and being unfamiliar with the settings led to parent’s perceptions of a lack of safety. Robertson et al (2011) discuss this issue, with parents reporting within their study, leaving their young person with staff they, and their young person, did not know caused undue stress and worry.

Bibby (2012: p 41) also discusses not knowing further within their study proposing parents experience stress and anxiety “when their dependent child is among strangers”. All the parents expressed worry over leaving their young person with people they did not know; particularly Andrew who shared it was a “big deal” leaving his daughter with people who didn’t know her. I refer to literature reviewed and particularly the view of Martinez, Conroy & Cerreto (2012: p 284) who states parents are often left feeling “floored and scared to death” during this time. I consider if the issues discussed in the previous themes also contribute to the parents feeling of uncertainty and safety of their young person. Reflecting on personal experiences I feel parents during this time require reassurance and opportunity to build relationships with the settings and staff who are to support their young person (Robertson et al, 2011) which may alleviate some of the parent’s fears towards post 19 provision.

“be in some sort of education, not here, but something not dissimilar”

Within their narratives, all the parents expressed a wish for their young person to continue learning. Each of the parents anticipated their young person would transition from school to a setting that supported further learning skills. While each parent was realistic in that they were aware their young person would not be accessing what is usually considered formal education, for example a typical college education, they

wished for their young person to develop educationally. Their views are in line with the changes to the SEND Code of practice (DfE, 2014) which enabled young people to extend their learning up to the age of 25 years, as policy acknowledged some young people require extra time to develop their skills. While there is no expectation that all young people would require a continuation of educational support to age 25, from the parents' narratives this clearly continues to be a grey area for the young people with learning disabilities transitioning from specialist settings to Post 19 provision.

All parents found it difficult to access further learning opportunities for their young person. So much so that in the case of Jane, her daughter left without any form of further learning despite her requests for this to continue. In the case of Andrew and Bev, they wished for Rachael to continue learning however, were informed by school staff it would not be possible. The narratives shared by the parents mirrored the view of Griffin, McMillan & Hodapp (2010) whose study concluded that parents felt that options offered to them by services they did not match their dreams and desires for their young person.

Also, while policy changed to accommodate young people up to age 25, it appears SEND organisational culture is still to catch up. All the parents described how they were initially directed to social care provision rather than further learning opportunities. The experiences shared by parents within their narratives are in line with those discussed by Imich (2016), Lamb (2016) and Harrison (2016). Gauthier-Boudreault, Gallagher & Couture (2017: pp16) who also discuss the "lack of understanding of the needs of young people" and the need for a culture change in relation to the changes within the Code of Practice (2014). It appears from the narratives there continues to be work to be done in changing the perceptions of SEND and education staff in relation to the further learning opportunities of young people Post 19. I feel this especially relevant within the cohort of young people transitioning from specialist settings to Post 19 provision as historically organisational culture deemed young people with more complex needs to transition to social care rather than further learning opportunities. My view mirrors that of Gauthier-Boudreault (2019) who's review concluded that young people with profound learning disabilities are not routinely offered further learning, rather day centres or recreational opportunities.

Parent's narratives reflected my own experiences, in which my daughter was also not initially offered learning post 19 despite my wish for it to continue and her potential to develop and learn further being made clear. Martinez, Conroy & Cerreto (2012: p285) called for further research within the area of transition to adulthood in order for young people to be well supported in accessing opportunities "created by law". While all parents had significant involvement within their young person's transition to adulthood and requested further learning opportunities, these did not materialise without a perceived fight. I consider this to be possibly due to knowledge of professionals and availability of funding and services, rather than entitlement in law. My view reflects that of Harrison (2016) who considers a lack of staff capacity, skills barriers and a lack of resources to lead to a less positive outcome for families.

Gerber's (2012: p 43) literature review discussing the education of learning-disabled adults also suggests practitioners should have a role in assisting young adults to find their "niche" when progressing onto further education or support. Gerber (2012; p 43) further explains: "successful adjustment to adulthood starts with helping adults with learning disabilities to find their niche", one which matches their skills, interests, and motivations. Within this discussion, practitioners can play a vital role in supporting young people with learning disabilities, and their families, to identify their individual strengths. While all the parents were involved within their young person's transition, and in that expressed their young person's likes and dislikes, strengths and weaknesses it appears this was either not acknowledged or did not match to provision available. It is at this point I reflect upon the involvement of an Educational Psychologist within the transition to adulthood and how with their skill set, they are well placed to offer support within this area (O'Farrell & Kinsella, 2018). This is further discussed below.

"will she be happy?"

In their narratives all the parents' shared how they would like their young person to be happy in their transition environment. Surprisingly, much of the literature reviewed did not appear to include parent's voices regarding their overriding need for their young person to be happy, rather their need for them to be safe and well supported (Bagatell et al, 2017: Henninger & Taylor, 2014: Gerber, 2012: Bibby, 2012: Martinez, Conroy & Cerreto, 2012: Robertson et al, 2011). Reflecting this, Allard et al (2013)

acknowledge happiness to be interrelated with several factors not just as a single achievement. Within their study, which discusses young people with a neuro disability emotional health and well-being outcomes, they reported the perception of happiness to be attained through the achievement of young people being able to acquire more independence, increased social relationships, and increased opportunities. Through the achievement of these outcomes, parents reported their young person appeared happier (Allard et al, 2013). I reflect upon the views of Allard (2013) and of those within the literature reviewed (Bagatell et al, 2017: Henninger & Taylor, 2014: Gerber, 2012: Bibby, 2012: Martinez, Conroy & Cerreto, 2012: Robertson et al, 2011), and consider if parents perceptions of happiness of their young person is through the support and perceptions of safety they consider has been lacking in the themes discussed above. I reflect it would be beneficial to explore parents' perceptions of their young person's happiness and what this looks like to parents; as Bev and Wendy shared their own happiness is dependent upon their young person's happiness within their narratives. I consider Educational Psychologists to be best placed for this exploration as they are suitability trained to consult with parents and young people and work in the best interests of the young people and families as an objective body (Farrell & Kinsella, 2018).

Theme 4) Parental perceptions of what effective support may look like

As mentioned above parents shared many views on how transition to adulthood post 19 for young people who attend specialist settings could be improved. All the parents described within their narratives how they valued the support from other parents and continued to view other parents as an effective means of support after transition had occurred. This is in line with the view of Yarbrough, Evans Getzel & Kester (2014) who explained parents value peer support as other parents who have young people with similar needs share vital information on activities and services. Within his narrative interview, Andrew questioned if a "mentor" system could be established to match parents with other parents who require support through transition. This consideration may be useful as within the literature parents often seek support from those in a similar situation as it provides a sense of normalcy where they may otherwise feel marginalised (Goodley & Runswick-Cole, 2011).

Transition to adulthood is obliged to begin in Year 9 of secondary education (DfE, 2014). It is within this year discussions about the young person's future should take place between the young people and their families and may include services which are supporting them (DfE, 2014). While parents within the study described how their young person's transition did indeed begin in Year 9, they also felt young people should access their transition setting earlier than when they leave school at 19. Parents shared how they felt this would iron out any issues before the young person has left school. Indeed, collaborative support between services is considered essential to a successful transition by Henninger & Taylor (2014), along with a holistic view of support required by Rhem et al (2012). I reflect on parents' viewpoints regarding beginning transition earlier and support Jane's view on the young person accessing their transition setting *"three days a week and then once they actually leave five days a week"* (Jane) as I also feel this would be an opportunity to identify any potential issues with settings and support post 19. However, this would require conversations between families, services and practitioners and again possibly a consideration to the three transitions a young person makes within the space between 18 years of age and 19.

Interestingly, Bev shared how she felt it was important for parents to engage with social services at a young age; *"you need a social worker while she's still a child"* (Bev). Bev reflected how she did not feel she would have support for her daughter post 19 without one; as Rachael was accessing a mix of social care and healthcare support. However, on the other hand, Bev acknowledged not all parents may want social care involvement as it could be intrusive. I also agree with the opinion of Bev regarding social care involvement and note all parents within the study had social care support. Again, I acknowledge the view of the Council for Disabled Children (CDC, 2016) who propose some parents associate a stigma with social care and wonder if earlier collaboration would diffuse this. I also welcome the trial some local authorities are taking part in to amalgamate the social care aspect automatically into the Education Health and Care plan process (CDC, 2016). As a parent who has had social care support for my daughter since she was 13, I consider seeking support from all services for your young person vital for their and parents own successful quality of life.

Following on from this, Jane described how all of the services working together would be most effective. Indeed, collaborative working between services has featured heavily

within the literature reviewed (Hendricks & Wehmen, 2009; Henniger & Taylor, 2014; Bagatell et al, 2017; Biswas et al, 2017). However, I wonder about the points discussed above and propose that if young people and their families lack support from social care and health services pre-transition, they may find it difficult to engage services post 19 due to service dynamics and systems. I consider further research into this area to be important in order to support effective transitions post 19 (Rhem et al, 2012).

Implications for practice

While the questions above were answered within the discussion. One of the research questions remains;

What can EP's learn from reflecting on the narratives of participants?

This question will be answered below;

Within the interview's parents shared their young person did not have any support from an Educational Psychologist within the transition to post 19 settings to identify post 19 learning outcomes, or to advise on recommendations for further learning. Bev and Andrew identified while they had had some educational support during their daughter's later years, they did not give advice on post 19 learning opportunities. Also reflecting upon my own experiences of the transition to adulthood neither the school setting nor my young person had any support during this time. Considering this, I feel input from an Educational Psychologist in relation to further learning post 19, and within the transition meeting, would have been beneficial due to their expertise in consultation and collaborative working (O'Farrell & Kinsella, 2018).

Also, as mentioned above, Gerber (2012: p 43) advises practitioners should have a role in supporting young people to discover their "niche" when leaving education. This view is also supported by Henniger & Taylor (2014) who highlighted the need for transition planning to take into account the young person's goals and interests. This study gained parents' experiences of their young person's transition. Each of the young people has a disability which limits their involvement in the transition process. Parents within the study were advocates for their young person and are vital contributors to post 19 transition planning (Griffin, McMillan & Hodapp, 2010). However, within the themes above parents shared how they did not feel listened to, how they felt ignored by services and professionals and misunderstood. It is at this

point I reflect upon the involvement of an Educational Psychologist within the transition to adulthood and how with their skill set, they are well placed to offer support and mediation within this area as an objective individual (O'Farrell & Kinsella, 2018).

Also, I reflect on the narratives concerning parents' wishes for their young people to continue their learning post 19. While the changes in the SEND Code of Practice (DfE, 2014) provide an opportunity for young people post 19 to extend their learning period to 25, it also provides a platform for Educational Psychologists to extend their own knowledge. I also reflect, similar to Atkinson et al (2015), that the changes to the SEND Code of Practice (DfE, 2014) do indeed signify a development in the profession in an area where Educational Psychologists appear to rarely venture; transitions from post 19 specialist education settings.

Finally, I reflect on the narratives shared above by parents regarding their fears and quality of life, and how parents could possibly be apprehensive about discussing their future in relation to caring for their young adult (Bibby, 2012). I also acknowledge the views of the Council for Disabled Children (2016) that there is a stigma associated with engaging and accepting support from social care. All of the parents within the study had multi-agency involvement; primarily from health and social care. I consider sharing the knowledge resulting from this study with Educational Psychology services will emphasise the need for Educational Psychologists to take into account parent's sensitive feelings in these areas.

Dissemination of research

While I have both a personal and professional curiosity in transition post 19 for young people with learning disabilities from specialist settings, the local authority in which I am employed is extremely interested in my findings. Dissemination of the research is expected within the near future to the Special Educational Need Strategic Lead Team along with the Special Educational Needs and Disabilities Casework team. Also, I continue to work independently with a specialist school for young people with profound and multiple learning disabilities and their authorities' transition, health and social care leads, in order to create a pathway resource from Year 9 for parents and professionals.

Limitations

As discussed throughout, I am positioned as an insider researcher. While this could be considered a benefit, as insider researchers are able to understand the experiences of participants (Chavez, 2008), they are also viewed to possibly apply potential influences to their interpretations (Hewitt-Taylor, 2002: DeLyser, 2001). I also recognised my positionality as a potential limitation in relation to my interpretations of parent's narratives. To acknowledge this, I utilised Braun & Clarke's (2006) method of thematic analysis as a structure along with placing reflection points in the process overseen by my Fieldwork supervisor. While I considered I have taken precautions to avoid any partiality, I also acknowledged this cannot be avoided completely.

Due to insufficient replies from parents invited to participate, and time constraints of completing the research, this study engaged four parents. It could be considered the findings of this study are not generalizable to the population due to the limited number of participants, however, there is viewed to be no minimum number of participants within narrative studies (Marshall et al, 2013: Burmeister & Aitken, 2012: Wells, 2011). Also, the parents from the study lived within two different authorities and shared similar experiences, which it could be argued adds some generalisability to the findings.

Finally, this study explored the parent's experiences of their young person's transition rather than the young person's experiences. This could be viewed as a limitation as it is considered important for young people to have involvement in their transition to post 19 settings (DfE, 2014). However, as mentioned within the literature review, there is a small quantity of research that solely explores parents of young people with learning disabilities views (Griffin, McMillan & Hodapp, 2010). As well as a call for further research within this area from Biswas et al (2017: p 100) who considered there to be "no published studies within the intellectual disabilities field that explores parent's views of their child's developmental transition into adulthood". This study explored this topic and outlines areas for further research below.

Areas for further research

As previously mentioned, literature and research in the area of Educational Psychologists' involvement in transitions for young people aged 16-25 are scarce, with only two studies published to date (Atkinson et al, 2015: Morris & Atkinson, 2018). The most recent study by Morris & Atkinson (2018) suggests further research in this area.

After conducting this study and reflecting upon parent's views, I view the role of an Educational Psychologist to be important within the transition to adulthood in order to support young people and their parents, along with schools, organisations, and agencies. It would also be useful to the Educational Psychology profession for further research related to the specific area of Educational Psychologists' involvement in post 19 transitions for young people from specialist settings. I would suggest this be considered from an Educational Psychologist's point of view in order to develop the knowledge of the profession since the introduction of the SEND Code of Practice (DfE, 2014).

In addition, and as mentioned throughout, transitions to adulthood post 19 have been highlighted as an area for improvement both before the implementation of the SEND Code of Practice (DfE, 2014) and after (Imich, 2016; Skipp & Hopwood, 2016). Also, this study answered the recommendations from Gauthier-Boudreault (2019) who called for further research that explored parent's experiences of transition to create practical resolutions for young people with learning difficulties. Reflecting on my experiences as a parent and researcher, and my subsequent involvement with my own local authority, I view further research in transitions to be important as I acknowledge the suggestion that there could possibly be three different transitions within the space of one year (Goodley & Runswick-Cole, 2011). As mentioned above, health services and children's social care transition young people at 18 to adult services, while education transition at 19 years of age. This can result in three different transitions if the young person is also involved with health and social care (Goodley & Runswick-Cole, 2011). This effectively results in three different dialogues with three different services all of whom each have different agendas, criteria, and approaches.

I feel consideration should be given during the initial health and social care transitions at 18 to future planning for future support which may be required when the young person finishes full-time education at 19. This view is also in line with that of Henniger & Taylor (2014) who suggest collaborative support between services to be essential to focus upon the future development of the young person through achievable realistic support. Reflecting on the narratives shared by parents, and of my own experiences, I do not feel this occurs.

I suggest conducting transition research with all services involved may assist in uncovering gaps in services and support during the transition and within the families' future. This mirrors the view of Rhem et al's (2012) previous research in this field which focused on one service and suggested that a holistic overview would be more effective.

I feel without holistic planning with all services, the young person and their family, a well-supported transition is unlikely to take place. This view mirrors that of the contemporary research reviewed within this study (Martinez, Conroy & Cerreto, 2012: Gauthier-Boudrealt, Gallagher & Couture, 2017: Biswas et al, 2017) all suggest further research in how to support parents in their young person's transition to adulthood. Also, research reviewed (Gauthier-Boudrealt, 2019: Thom & Agur, 2014: Wills, Chenweth & Ellem, 2016: Hoskin, 2017: Bagatell et al, 2017: Biswas et al, 2016) suggests difficulties with transition have not changed over time. I conclude this could possibly be due to the confusion from services over who can offer what support, along with parents continued confusion over who to approach and when. I feel if a more holistic approach to supporting parents, as well as young people, at the point of transitions occur, this could enable transition to be more effective and for parents to avoid the experiences which occurred above.

“but if they got together, education health and social care together and did something like that I think that would be amazing, wouldn't you?” – Jane

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Appendix 1- Ethical Approva



Downloaded: 19/06/2019
Approved: 18/05/2018

Emma Graham
Registration number: 160113932
School of Education
Programme: Doctorate of Educational and Child Psychology

Dear Emma

PROJECT TITLE: Using Appreciative Inquiry to explore parents views on what would support an effective transition for young people and their families from specialist settings to Post 16/19 provision.

APPLICATION: Reference Number 018811

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 18/05/2018 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 018811 (dated 27/04/2018).
- Participant information sheet 1042453 version 2 (16/04/2018).
- Participant information sheet 1042452 version 2 (16/04/2018).
- Participant consent form 1042457 version 3 (16/04/2018).

The following optional amendments were suggested:

Please consider outlining in the information sheet how you will tackle the assumption/hope of parents/carers that involvement in the research will have a direct impact on their young person's transition. Involving young people (even if not been directly part of the research). Clarify how initial contact with parents would be made and if there is permission to use their contact details for this.

If during the course of the project you need to [deviate significantly from the above-approved documentation](#) please inform me since written approval will be required.

Yours sincerely

David Hyatt
Ethics Administrator
School of Education

Appendix 2 – Information Sheet

Exploring parent’s views on transition for young people and their families from specialist settings to Post 19 provision.

INFORMATION SHEET FOR PARTICIPANTS

You are being invited to take part in a research project. Before you make a decision if you would like to take part in the research, it is important for you to understand what the research aims are and what taking part will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact me if there is anything that is not clear to you or if you would like more information. Take the time to decide whether or not you wish to take part. Thank you for reading this.

The aims of the project

This research project intends to explore your current experiences of the Post 19 transition process for your young person. In particular talking about what is working well, what could support you and your young person better and your thoughts on what you feel could best support families and young people in future transitions. It is my intention to discover what best supports parents/carers and their families through this phase and use the valuable information you may share as future learning points for good practice.

Why have I been chosen?

As the project would like to explore parent/carers current experiences of the Post 19 transition process for their young person, you have been invited as you are currently going through the process. Participation is on a voluntary basis, it is up to you if you would like to take part though your participation is valuable and will help to inform future good practice during the transition process for families in the area. You are able to withdraw from the project at any time, however as all information collected within the workshop will be anonymous any information you share will be contributed to the project; this will be non- identifiable to you and will also kept confidential.

What does the project involve?

The project will involve attending a recorded interview as and when you are available. The interview will last approximately 1 hour. The date and time of the interview will be arranged to suit your needs.

Will my taking part in this project be kept confidential?

To be able to capture information I will be recording the conversation on a voice recorder (Dictaphone). This will be kept confidential and will be used to ensure any valuable thoughts; ideas and information shared have not been missed. Once the interview has finished the recorded information will be downloaded and kept on a secure password encrypted file on a password protected computer, the recording on the Dictaphone will be deleted. The voice recordings will not be shared with anyone.

As mentioned above you are able to withdraw your participation at any time however as all information collected within the workshop will be anonymous any information you share will be contributed to the project; this will be non-identifiable to you and will also kept confidential.

This project has been ethically approved by Sheffield University's Research Ethics Committee.

Contact:

If you require any further information, have any questions about the research project, or once the project is complete a copy of the Thesis, please do not hesitate to contact me on: Emma Graham, Trainee Educational Psychologist email: egraham3@sheffield.ac.uk or emmal.graham@lincolnshire.gov.uk or telephone: 01522 553556 or alternatively my Research Supervisor Dr Sahaja Davis, University Tutor and Research Supervisor on email: t.s.davis@sheffield.ac.uk

Thank you for considering to take part.

Debriefing:

Thank you for taking part in the research project. The research project is important to develop an understanding of what best supports families and young people through the transition process from specialist settings to Post 16/19 provision.

While I do not anticipate any negative outcomes or feelings to arise from you participating in this project however, if you feel you would like further support please

contact in the first instance your Transition Worker. Additionally you may also find information regarding the transition to adulthood from <https://www.preparingforadulthood.org.uk/>. In addition, if you have any further questions, either before, during or after the project, please contact Emma Graham, Trainee Educational Psychologist email: egraham3@sheffield.ac.uk or emmal.graham@lincolnshire.gov.uk or telephone: 01522 553556.

Or alternatively for any research related questions please contact my Research Supervisor Dr Sahaja Davis, University Tutor and Research Supervisor on email: t.s.davis@sheffield.ac.uk

Thank you again for your participation in this research project and I look forward to listening to your thoughts and views in the workshop.

Appendix 3 – Consent Sheet

<p>Title of Research Project: Exploring views on transition for young people and their families from specialist settings to Post 16/19 provision.</p>		
<p>Name of Researcher: Emma Graham</p>		
<p>Participant Identification Number for this project:</p>	<p>Please initial box</p>	
<p>1. I confirm that I have read and understand the information sheet explaining the above research project and I have had the opportunity to ask questions about the project.</p>		<input type="checkbox"/>
<p>2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.</p>		<input type="checkbox"/>
<p>3. I understand that my recorded responses will be kept strictly confidential. I give permission for Emma Graham to have access to my 1cknowledg responses. I understand that my name will not be linked with the</p>		<input type="checkbox"/>
<p>research materials, and I will not be identified or identifiable in the report or reports that result from the research.</p>		<input type="checkbox"/>
<p>4. I agree for the 1cknowledg data collected from me to be used in future research</p>		<input type="checkbox"/>
<p>5. I agree to take part in the above research project.</p>		<input type="checkbox"/>
<p>Name of Participant (or legal representative)</p>	<p>Date</p>	<p>Signature</p>
<p>Lead Researcher</p>	<p>Date</p>	<p>Signature</p>

Copies: A copy to be returned to the participant.

Appendix 4 – Covering letter to parents

Dear Parent, Carer or Guardian,

My name is Emma Graham, I am a Year Three Trainee Educational Psychologist from the University of Sheffield and I work for in the office. As part of my Doctorate course I am asked to research an area of interest. My area of interest is in transitions from specialist settings to Post 19 provision.

I am writing to invite you to be involved in a research project about your young person's transition from school to Post 19 provision. I would like to know what your experiences of your young person's transition to Post 19 provision are.

If you would like to be involved please read the information in this pack and contact either myself or your young person's school.

I look forward to hearing from you,

Emma Graham

Trainee Educational Psychologist.

Appendix 5

Signed Consent For

Title of Research Project:
Exploring parents views on transition for young people and their families from specialist settings to Post 16/19 provision in Lincolnshire.

Name of Researcher: Emma Graham

Participant Identification Number for this project: _____ Please initial box

- I confirm that I have read and understand the information sheet explaining the above research project and I have had the opportunity to ask questions about the project.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.
- I understand that my recorded responses will be kept strictly confidential. I give permission for Emma Graham to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.
- I agree for the anonymised data collected from me to be used in future research.
- I agree to take part in the above research project.

Name of Participant or legal representative: W. Robinson Date: 26/11/18 Signature: W. Robinson

Lead Researcher: Emma Graham Date: 26th November 2018 Signature: Emma Graham

Copies: A copy to be returned to the participant.

Lead Researcher: Emma Graham Date: 7.5.19 Signature: Emma Graham

Copies: A copy to be returned to the participant.

Participant Consent Form

Title of Research Project:
Exploring parents views on transition for young people and their families from specialist settings to Post 19 provision.

Name of Researcher: Emma Graham

Participant Identification Number for this project: _____ Please initial box

- I confirm that I have read and understand the information sheet explaining the above research project and I have had the opportunity to ask questions about the project.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.
- I understand that my recorded responses will be kept strictly confidential. I give permission for Emma Graham to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.
- I agree for the anonymised data collected from me to be used in future research.
- I agree to take part in the above research project.

Name of Participant or legal representative: [Redacted] Date: 9.5.19 Signature: [Redacted]

Lead Researcher: Emma Graham Date: 9.5.19 Signature: Emma Graham

Copies: A copy to be returned to the participant.

Title of Research Project:
Exploring parents views on transition for young people and their families from specialist settings to Post 16/19 provision in Lincolnshire.

Name of Researcher: Emma Graham

Participant Identification Number for this project: **Please initial box**

1. I confirm that I have read and understand the information sheet explaining the above research project and I have had the opportunity to ask questions about the project.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.
3. I understand that my recorded responses will be kept strictly confidential. I give permission for Emma Graham to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.
4. I agree for the anonymised data collected from me to be used in future research.
5. I agree to take part in the above research project.

J [redacted] 26/11/18 [redacted]
Name of participant (or legal representative) Date Signature

[redacted] 26th November 2018 [redacted]
Lead Researcher Date Signature
EMMA GRAHAM

Copies: A copy to be returned to the participant.

Appendix 6 – Phase 1 Data Analysis

Appendix One

Transcribed Interviews

Interview One: 26th November 2018 : Bev and Andrew

B: You've ended up without a workshop is that right? Is that because you didn't end up with many responses?

M: That is right, it's because I didn't get many responses I have the two of you and someone else and hopefully another person. I thought it was just too small a number

B: I see it's the case that not many people will be that bothered about doing it.

M: I think that's the case when you do research isn't it, you just err tend get a small amount of people...who would take part

A: Bev ull make up for it don't worry (laugh) B: Oh yeah.

A: Laughing M: Sorry?

A: Bev ull make up for it...

Laughing

B: You can eat the biscuits

M: I bought them because short bread is my favourite and everyone likes shortbread.

A: MMMM

B: They do

B: Ok are you going to sign your bit A: Right

A: Oh what do you know I've signed it in the wrong place but (laughing) B: Ok

M: Thank you

B: Do we have to initial all these.

M: No tick them it would be great thanks

B: Have you signed it? Your signing to say you have read the sheet and you're happy for it to be recorded blah blah blah

B: That's what you were signing B: Here you go

M: Thank you very much

M: Thank you. Well thank you again for coming to talk to me today it is really really very helpful to me. Um and the subject of the chat is is pretty much the same as what it was when it was going to be a workshop. So we are going to talk about transition from school to um to wherever it is your young person is going. Um so I'll start firstly by introducing myself. So my name is Emma Graham. I am from the University of Sheffield and I am a Year Three Trainee Educational Psychologist. I work for and I currently work in Um I am interested in this area because I have a young person that is 21 years old she had profound and multiple learning disabilities and she also transitioned from a specialist school to post 19 provision. So I'm interested in

B: right

M: What other parents think about that process um just sort of their experiences so far. Their thoughts erm and their worries and things that could be made better. So if you could tell me about your young person and her disability and how it affects her that would be great.

B: (laughing) shall I do all the talking while you eat all the biscuits? Yes, this is Andrew

A: the only thing I'm good at is eating biscuits (laugh)

M: you eat the biscuits (laugh)

B: and I'm Bev and our daughter full name is Rachael. She's called Rachael or often Rachael Rachael in places where they have another Rachael so she's used to both. Um she is 18 and she has down syndrome um which was obviously identified um literally the day after she was born and um autism which we eventually got a diagnosis for when she was 17 but we felt she should have had a diagnosis for two or three years. Just took a while to work our way through the system. With the community paediatrician to eventually agree a diagnosis. So she has severe learning difficulties um she also has some physical mobility issues because um when she was 10 we discovered shed got no hip socket on her right hand side and she stopped being able to walk all of a sudden, um she ended up having err two operations on her hip um and wearing a being in a hip spiker for a period of six weeks and then eight weeks and then it was about another month before she was allowed to weight bear.

M: Gosh,

B: So there was quite a long spell from about the June until the January where she couldn't walk at all and then she had to learn to stand and walk so she walks with a limp um so she has some mobility issues as well she can walk but she can't walk forever so it depends on the

A: incentive (laughs)

B: the incentive and how much she has already and everything else. She has loose ligaments, low muscle tone; she has very few teeth, very few adult teeth to come. She wears glasses she has

hearing aids but she doesn't like them and she doesn't really need them for many purposes um if she'd been in a classroom taking instructions from a teacher from the front all the time then she

probably would have needed them but she had a 1:1 working with her all the time so probably didn't need it for that reason. At home where there's no other competing noises she can hear quite well so. Um we have tried to get her used to wearing them in case one day it is highly likely her hearing will deteriorate and she will need to wear them but I think school would always be the place where she wore them she wouldn't wear them at home, um and I think they are struggling at the moment to persuade her, um and that's probably enough of her disabilities.

M: okay thank you very much. I understand that Rachael is going to be leaving in September

B: she is

M: can you tell me um this is about transition. Do you understand the meaning of the word transition? What does it mean to you?

B: um do you want to answer this (Andrew) A: (laughs) oh you mean me (laughs)

M: both of you can answer (laughing) B: we both can answer (laughing)

A: yes, yes um we know she's going to move out of full time education therefore it will be more incumbent on us to sort out what happens to her in the day with financial help from the county council to provide for some care.

B: I mean she's already done a number of transitions as it were so every step is a transition M: hmmm

B: at sort of 2.5, 4, 11, 17 in her case and then again at 19 so, um I think um probably it's fair to say every transition she has undertaken we start preparing for it many years in advance

M: hmmm

B: obviously when she was 2.5 we couldn't start that far in advance because um we started when she was between a year and 18 months I suppose so she was ready with what was then a statement in place for her to start at a preschool, and then as soon as you've done that step you start preparing for the next step, and then you constantly review everything so all the way through her primary school we reviewed and especially from the change from KS1 to KS2 um and um you you always have to be

A: she was in mainstream but we would we would, there was a little bit of pressure from some quarters for her to go to special school, we felt obliged to check them out and that was also the case when she went from primary through to secondary. Thee err the the err advice we listened to was err that if it was possible for her to stay in mainstream...

B: county council wanted her to stay in mainstream... A: yeah, and so it was...

B: because she only

A: because she had a very good 1:1 who was gonna stay with her it was working, it might not work for everybody but it definitely worked for rachael and she's because she had, as anybody would in a way, err err err one person dedicated to her education

B: she was amazing

A: it was she put a lot of thought effort and creativity in to it, Rachael err did do a lot of things beyond what she would have learnt if she in was in if she'd have been at it was fair to say

A: yes. Err because err the individual attention and thee err and thee insistence that she did the work if you like

B: she had to work hard

A: err and err so Rachael learned to read and err which is a great bonus to her so she can err read what's on the DVD and CD labels

M: that's great A: err

B: menus, it's empowered her basically

B: err we was hoping the teaching her of reading would help her speech development that's why we were doing it, but the spin off has definitely been it's empowered her

A: she likes to be able to do that as well, it gives her a sense of independence that she can choose her stuff

M: hmhhh

A: err so anyway that all of these things its it's err helping with her transitions as well because its err means that's she can err take part in more things because she can do more things

M: yeah

A: she's enjoyed coming toshe err I think she'd just about run out of steam at at at secondary (laughs)

B: (laughs)

B: she was working hard

A: she fancies retiring really (laughs)

B: this is much more fun much easier for her A: yeah

A: she enjoys the social side and thee the fact the she's err you know a similar size fish in a smaller pond whereas in mainstream there was certain things that even though the children were very good with her and the staff for that matter err she was still not involved in things like the school play

M: yeah

A: and that were as here she is and she likes doing things like that so B: they didn't do any school plays bar one so

M: I noticed you said earlier on you planned for your transition well in advance so this one from to adulthood

B: adult

M: how have you planned for that? How have you...

B: well I said to Andrew on the way in how long ago did her retire and he was trying to remember and its four years and a bit erm I started going to things like events run by county carers before Andrew retired because I used to go on my own to them so I know since has retired has come with me so, so I started finding out the information for adulthood before we'd done the post 16 transition which she'd done at 17 because the county council let us move from primary school to secondary school a year later each time so they've been they, the county council to be fair have been very adapting to our need which (laughing) is probably unique and erm but anyway so as well as investigating what was going to happen once she came to the end of her time at secondary school, I was picking up information and talking to people about adulthood, erm we do move in some circles although she was in mainstream we've actually run a group for adults with and children with learning disabilities

M: right

B: it's a Christian group which meets every month, we run a special service, and we've been doing that for twelve years so Rachael was only six when that started but she's been part of that with us and as a result we met a lot of adults with learning disabilities and we've met a lot of parents carers who erm support adults with learning disabilities so erm I've we start that process by asking the questions, observing watching looking erm and erm picking up information really because you know you can't pick it up all in one go you kind of it slowly sinks in and every time ..

A: and sort the conflicting ideas from different quarters and then you gradually sift out what's probably accurate and what's, and the other thing is in a way we are probably

more geared up to the big transition which we are looking at is for rachael to be from living with us to be living in supported living that's the transition that's the big one

M: yes

A: so erm the transition between school and some sort of day-care type thing is important that we get that right but thee thee the longer term objective which is where we are heading is for rachael to be able to be happy in a supported living environment with a care package that allows her to do things that keeps her motivated

B: motivated

A: motivated and stimulated during the day so that's thee the probably the first transition is too to once she can't come to school every day is to find other things she can go to everyday but that will morph into probably her sleeping somewhere else rather than sleeping at home

B: yeah and we probably set that as a goal our long term goal, erm I don't know probably by the time she was 14. Probably before then we started writing that into her annual reviews the long term aim that somewhere between the ages of 19 to 25 she would move into supported living so as Andrew said the ultimate target in a sense

M: yeah

B: so we had we have to do that because of our age M: hmmm

B: erm Andrew is A: 64 (laughs)

B: 64 I never get that right A: when I'm 64

B: I'm 63 erm so we know realistically we can't carry on looking after rachael forever and we can't expect our own children, our other children, older ones to do the same erm so we've been steeling ourselves in a sense of that to get used to it the whole process of doing it we've been doing for the past year or so has been helping rachael and us get used

M: yeah

B: new arrangement err um yeah that's been our long term goal so we've been working towards that's in everything we've said and done since then. So as I said we started collecting information

about the trans, post possibilities Post 19 at the same as we were all sort of doing our way through the post 16

A: because we had thought we'd we'd spent a lot of time doing a EHCP plan M: yeah

A: in mind that Rachael would be in some sort of education not here but something not dissimilar but err we've changed our view on that partly because of various professionals' suggestions way of thinking that actually Rachael would go to some sort of college

B: we went to them and we realized that they don't cater for people like Rachael (laugh)

A: yeah and there's some sort of elements of fairy-tale about it anyway in that people are doing vocational courses for things were you think that they there never going to be, there not going to be an IT specialist or something you know. Its its slightly daft anyway but thee err discussion about things like that you know one of them was a bucket list of things, you know you have to be very careful that to phrase things to extract things rachael likes, you can't just sit and have a discussion with her about what she'd like in that league

B: shed have a random answer A: yeah

B: she might say dragon pants A: (laughs)

B: that's her favourite things to say or chocolate that's her current basically what have you done today? Chocolate

A: so you you you would if you worked at it get an idea of what rachael likes and things but you'd get a lot of noise in with that, so you'd the idea of her being in a group learning situation err is not, it's not she's gone about as far as she can with that. She needs to be doing things like dance drama

things shell enjoy doing she doesn't want to sit and do things like basket weaving that doesn't cut it with her err but err finding those sort of places where she's going to get stimulus where it's not going to cost a fortune you find something. Because we've got

an objective in mind to our pleasant surprise because you sort of steel yourself for a fight really for all of these things.

B: we did have one we had one fight

A: yeah but we've found that thee erm, we still, but you still sort of doubt that's what'll happen but it appears to us that genuinely the representatives of the county council have taken on board where we want to be with rachael and are helping with the funding for that's because it's it's because one day we can't just ship her off to supported living its we've we've been given quite a good care package for rachael to go and do residential and all other things and Saturdays someone comes and takes her out

M: yeah

A: it's all paid for we have to it but it's paid for out of funding we get from the county council

B: or the NHS in this case

A: NHS its health care its actually fully funded by them but its by thee thee but that's been very good but assuming we don't get a derailment of that that's seems to be the agreed process that we will get an increase in the package when Rachael leaves school

B: in February

A: that will allow us to pay for the day-care

M: yeah

A: so she's not at home all day

B: could I just go back one step though it's part of the process of building into this bit we've been going round colleges and special schools for a couple of years erm and erm one of the most useful off the cuff remarks from another parent, which is usually who you pick up the most best tips from was erm you need a social worker while she's still a child. They said they'd tried to come in at 19 and had got thee why did you need anything, you didn't need them when they were a child. So that piece of information got lodged in my head so and erm, we had had are only, erm we'd had a visit from a social worker for some sort of assessment when she was 7 who said her need where

being met so she doesn't need anything and you thought ok the fact that's it's me who takes her to brownies and rainbows until she was 11 and I stayed with her and the fact she comes to Sunday school on a Sunday morning and I teach the Sunday school and one of our other children supports her meant her needs were being met so (laugh) so it's case of if we didn't do anything for her you might have stepped in, but obviously as a parent we made sure she had social interaction and opportunities to do things the erm the next they did put us in touch with action for children and thankfully we were then able to access an action for children club which we started probably from about seven right up until she was erm whenever 18, 18, and that was just once a fortnight and that was the hour and a half she could do something without us so that's the only thing she had been able to do without us

A: apart from going to school B: apart from going to school

M: did that stop when she was 18 because she became an adult?

B: yes erm we we'd had some contact when she was 10 with social care assessment when shed had all her hip problems and couldn't move and so someone it was probably the learning disability nurse or _yes, probably_____ someone to come they thought it was a health issue so they arranged for someone the question they asked was would she be on oxygen and the answer was no so its wasn't a health issue and I thought why I have I just wasted two hours of my time at a very very time. Health people said it was a social care problem social care people said it was a health problem and we just thought we have far too much to deal with with a child who was just about to go in for serious op and thank you ok we'll just carry on by ourselves erm so our experience of children's social care was limited and not too impressive in the sense that erm but thought right we have to face this no one likes the idea of having a social worker that I knew no one really likes that intrusion and erm my brief encounters with them were that they treated you as if you might have potentially have abused your child and you were in that same category whether you're a child in need or not you have the same set of questions as a parent who is doing it because you care for them as the parent who is doing it because she doesn't so it is very off putting but we thought right we have to try again because this piece of information made sense it was going to be better if we got in at 16, so at 16 I rang the number of the county council and asked a few questions blah blah blah I answered them all obviously far too articulately

because six weeks later we get the reply she doesn't qualify for to erm go in for a proper assessment

M: okay

B: so we asked the question why and we had a very rude answer which was we can't tell you. You spoke to the lady...(addresses Andrew)

A: yes, yes

B: we wasn't very impressed with her this is the only time I have to say that we have had a bad experience in reality

M: yeah

A: it was err go away we can't B: we are very lucky

A: because you're not another professional we can't tell you why we haven't scored enough err B: so that was it it was no thank you

M: okay

B: fortunately for us we'd also put in for a carers assessment because erm we'd it was one of things I'd never got round to doing so I thought I'd get this emergency plan done and everything else. We wanted it done jointly but you couldn't do that. Jointly on the computer we said can you have a face to face one? And a lady from carers first came and in fact she did it on Andrew basically because she it actually doesn't make any difference if it's one or two of you so. Erm and Andrew at that time was retired and I was still working, so she did it him and erm she was quite sure we ought to have a social worker for rachael and she could see that the long term need was there. Nobody can ever deny the fact that we are getting older and we are not going to be able to look after Rachael so she then knocked on the door as it were of the county council and spent about two hours on the phone.

M: Ok

B: insisting they sent us somebody and um and in the end they gave up and said ok and sent us a student.

M: ok

A: student hey (laughing) it was that bad B: yeah (laughing)

M: (laughing)

B: it was quite bad to begin with. I'm shutting it out of my brain because it's the only time we've had a bad experience the entire time of rachael's existence erm the result was she did get us 24 nights stay at

M: okay

B: from the day she turned 17 until she was 18. She nearly de railed her education process in the process by making some wild actuations of seeing her in school for half an hour and your thinking ahhh which was nearly disastrous but we got over it and fortunately they passed us onto a real social worker as it were and um who grasped the situation she actually came and had err err an afternoon talking to us and we had a very useful conversation because at that point we were trying to make up our minds about where do we go next with her and her comments and thoughts helped in a sense crystallise ours and we thought yes ok , this is it, this is the right way to go.

Unfortunately for us she was promptly ill the next day and couldn't move. I'm sure it wasn't anything to do with talking to me for a few hours (laughing) but err so actually we had a slight hitch and were given another lovely one as well and they err the student had to her credit managed to appear before the panel and got us 24 nights overnight stay so for the last year of her childhood as it were

M: yeah

B: she was able to go to which was absolutely beautiful and wonderful and the staff were great and she was I won't say she's ever been enthusiastic about going to places if you

told her because at that moment in time she's watching her dvd and she don't wanna go anywhere else I'm watching my dvd but when you walked you know walked up the pavement with her and through the door she's there, she's quite happy and its bye and off you go..

M: yeah

B: so you know she's happy. Um and um that was a very that was an important part of the transition that is now going to take place. So I suppose what I'm trying to say is

Rachael's post 16 no sorry post 19 transition we started thinking about and planning for at least by the time she was 14 and the steps we got put into place between then and now have all been part of the grand plan which is taking her to the final transition of moving out of home into supported living so it's an apart from those little hiccups we

A: again the social worker aspect is...I'd forgotten as you do... that that that was an essential link in the chain without that all the other things wouldn't have followed so so in terms of your study I think it's important that people are sign posted or whatever the phrase

M: yeah

A: is to get help early on. If they are going to be in a similar position to us and most people who have got children with special needs are they are not going to be able to look after them indefinitely otherwise its its you know bev knows people who have got you know 45 year old children at home

M: yeah

A: children being effectively children being looked after and they're in their 70's B: they now have emergency care

A: and with you know it's it's not

B: I have a nephew in his forties that's at home with my brother and sister in law and they are 78 you know.

M: You mentioned that each time you did a transition you have questions you ask yourself about err am guessing about what it is you want...what it is your thinking ... and you go through the process you were talking about what type of questions is it you ask yourself?

B: Err err I suppose as I said we are always looking into our long term goal and is this a step that's going to help the long term goal. But obviously we are always looking to say is it is it suitable for Rachael does it meet her long term needs will she be happy, will she be safe. Happy healthy and safe is our chief goal for all our children

M: yeah

B: not just Rachael and erm obviously reaching her potential will contribute towards the happiness as it were err err for all our children we would

A: each of the visit's she's made, like going to when we first went there I have to say we were we were shocked, positively because we thought this you know was sort of you know council run sort of with half-hearted staff and it'll be somewhere where people can park their disabled child and go and have a night out for a change. But it isn't it's it's a really lovely place and err with very caring people and thee err it was you always have that feeling of what's it gonna be is it in our feelings and you can't afford to have them is that rachael gets a series of bad experiences when she's away with other people and that will de rail err and make it very difficult then for us to leave her err we did have one when rachael stayed with some friends of ours overnight and the next time we went there she wouldn't take her shoes off..

B: yeah she didn't want to take her coat of either (laughing)

A: (laughing) so she wasn't going to be dumped there (laughing) B: she thought hang on a minute last time I came here they

A: you sneaked off (laughing)

B: and it was a long time before you came back for me A: so so

B: she usually takes her shoes and socks off the minute she walks in anywhere at home so the fact that

A: (laugh)

B: she usually takes her shoes and socks off and that's it. The fact that she didn't was saying I'm not staying I am going home today

A: (laughing) M: (laughing)

B: yes we and even though she had a great time with them she and loves them

B: she loves to visit them B: it was her

A: so we we wed with that sort of coloured our thinking we want to be very careful and we have Rachael did go to one place where we were first able to send her to respite

B: adulthood

A: adult respite we weren't very comfortable about it and we came away thinking hmhhh

B: that was the hardest moment ever

A: yeah

M: what made it the hardest moment?

B: we were leaving Rachael with people who didn't know her, she didn't know them A: we didn't know them

B: we didn't know them M: hmhhh

A: and we didn't really feel...that they.....I know they B: they were listening

A: I know they made a bit of an effort to listen to us rambling on but thee err it you

B: there were quite a few important things they needed to know that day medically for example her period started just before we arrived so there was things about that that we knew they needed to know

M: yeah

B: because she could be sick and there was a young girl who didn't seem to, she didn't seem, she wanted to tick the boxes on the paperwork and get us out the door she didn't seem to grasp the fact that the television did really need to work in Rachael's bedroom, because she had a bag of CD's and DVD's to play because we needed her to feel at home she was going to a completely strange place ... which you can't explain to herfortunately there was another girl who'd got it under control who she was working with but the one we were leaving her with dunno

A: also when we left there was a bloke...one of the carers where male and she was left alone with

B: another lady with learning disabilities who overnight where staying with a male carer which firstly we were not very comfortable about its not something they had told us when we first signed up to this that that could happen and it was one of those moment where you thought I wouldn't be doing this with any of my other daughters at 18 saying that's fine dear. So whys it suddenly alright for Rachael

A: : she couldn't be alone with if you was in a school classroom or something you'd be leaving the doors open so other people but

B: it feels like it breaks all the safeguarding rules to us but there you go

A: so that was that was a bit so we've err all of these things are we have to we have to be relaxed about were rachael's going as well as rachael being relaxed about it I guess what we're saying so you need to do quite a bit of research to find the places were thee there actually going to meet your fears or void your worst fears as well as the good things and that's another thing Bev's done more than I have we take her to all sorts of things have you come across the?

M: I haven't because I come from err things that are available in are different slightly.

A: its err ay disco for people with B: learning difficulties

A: learning disabilities

B: run at the by someone

A: in err by taking Rachael there because she likes dancing you see B: started taking her on and off by age 14

A: she's a big Hannah Montana fan but she's quite a 118ckno so that sort of environment with flashing lights dark colours and bright

B: and noise

A: and noise she she she can be in that sort of world which is good for her but but but err but the secondary effect of that which you hand thought about at the time is you do notice the other carers the professional carers which you say are bringing their

B: by and large we were always the only parents A: yeah

B: everybody else was on their own or with support so you watch everybody and you look

A: and you notice that they are there tapping away on their phones occasionally having a look to see what their charge is doing

M: hmhhh

A: with whereas with

B: the group I decided the ones which where the best was the ones which were 100% involved there with the people they were supporting they all looked like they were all having fun together and they were fully whatever in the experience with them was the based at we thought right there the ones to talk to because I've looked at the others and I wasn't too impressed so erm and erm we we did look at every other one which was an option around in our wide area

A: but we went as far as to look

M: gosh that's quite a way isn't it? B: just to see what was on offer

A: , which you'll see the signs for coming here

B: and although we are at it's a bit of a trek to we decided it's worth it for the people and she started there the day she was 18 the adult package came into play erm and erm she was given 36 night of respite care and erm 8 hours every weekend of PA support and two lots of 9 hours of PA support which would allow her to go to the daycentre at for every week of the school holidays we sort of bank some of those up so she can go three times in a week or at half term she was able to have respite for the entire Monday to Saturday going to the centre for five days in fact err and once their bungalow came online that they were buying or putting a bid for in January but they weren't getting till April so we couldn't put them down as our preferred provider while we were doing all these forms in January

A: overnight

B: overnights, once that came online we transferred to them which means she's with the staff who know her

A: thee the lady run the affair knows rachael well so which is good coz one of the things we've come to realise that that thee you need carers who are capable of looking after people on a sort of minute by minute basis but you also need people who have got a bigger picture involved especially when you're looking at supported living and someone is going to be living there

M: hmmm

A: so the person might come in for two or three hours or a shift or something but you want somebody who eventually is going to be saying it's about time rachael had a doctor's appointment or a dentists appointment or bought some new shoes or something, that that the the having a structure that were its got somebody in that's got more of an overview I'm not saying they should be taking responsibility of that at the moment but you do feel that that they there is a bit more of a rather than just saying there another 6 hours we will look after her for there more to it than that.

M: by bigger picture do you mean forward thinking those things you just said? A: yeah the

B: they take a positive interest in the persons whole life not just the fact that they are supporting them for a few hours and you've got to have good strong local management of staff basically you can see when it, we do know people who have experienced problems through our circles even then sometimes that problem has occurred because there are no local managers of things going on so when a problem comes there's nobody really there on the ground to sort it for them erm

A: learning these things you know

B: we are learning from other people disasters and mistakes as much as we can (laughs) A: (laughs)

M: is that parents or are you, who's supporting you, what would you say is supporting you well throughout your journey so far whilst Rachael is still in education?

A: well the the they best things was her 1:1 bar the far. B: she had two 1:1's up until she was 11

A: we have had people like here and and other people who have given there the been prepared to make suggestions the social worker we had has been pretty good we had a person who helped us write the EHC or rather we helped her write EHC.

B: we wrote the EHC A: we did, we did,

B: she listened, that was good (laughs)

A: but the the so there's been a number of, once we got into the system M: yeah

A: the the the Dr who was Rachael's Dr community paediatrician who was probably autistic who err err err err bombarded us with you should have put Rachael in a special school earlier and she would have learnt far more than she ever did, we think no you don't know

B: she only saw rachael for about four or five years and she was quite put out that when rachael arrived in her secondary school uniform she promptly sat down on the floor and played with the Duplo and that obviously didn't fit her kind of picture of a child with down syndrome who was obviously attending a mainstream secondary school how could this possibly be right that a child who is playing Duplo on the floor is

A: getting anything else

B: yeah so anyway we had a long battle

A: but she did eventually agree that rachael needed an autism diagnosis and err err so in a sense we have had a result out Dr which will be useful for rachael in the future because these labels what we have found

M: hmmm

B: labels matter

A: our opinions and thoughts and stuff are are are great but they are warm woolly words as far as the systems concerned until

B: a professional says them

A: so yeah what we've found works well is us to write stuff but someone else to sign it off so the EHCP plan which we spent hours writing, so thee Rachael's risk assessment at secondary school which we wrote which and then as a school they adopted as a risk assessment that became then that document fed into other things which meant that they believed....because rachael does have meltdowns now and again

M: okay

A: she's done it here a few times too and she will throw things so they are keeping a record of it here B: the horticulture is the biggest (laughing)

A: (laughs)

M: (laughs) gardening?

B: yeah the watering cans when the parents came round and things. The budgie now is ok it's been on the floor apparently it survived

A: (laughs) A: but thee

B: they are very brave about giving her any animal to look after

A: thee thee the sort of push a little bit to record them because no one wants to really admit by

default that there's things that's gone wrong but we need to know that because we need a log of it from school which will then carry some weight because that then is used to assess our how much support she needs when she's not in from an advice to other people is concerned if you've got stuff that you need to get into other people's thinking when you're thinking how much resources to allocate to you, you need to get that signed off by professionals like, err bad medical issues, autism, because we can say Rachael's got autism traits but that won't count for anything but if Dr says she's got autism then it does count, people will then take that into account when their assessing erm how much money to allocate which in the end in a sense is thee is thee is one of the factors

M: hmhhh

A: I think probably people could do with more help I mean we are prepared to do the research and look into what's available and other things but for a lot of people and again you'll have found this a lot of people who have got in the situation with a disabled child are a single parent

M: yeah

A: coz blokes normally have cleared off because they don't want to stick it out and that erm means that thee poor frazzled lady is left with little capacity to do anything other than get through the day so to go through to do the research to find out then you know is a classic thing of draining the swamp

M: yeah

A: to err find the alligators thee thee haven't got the capacity to do that so thee thee that is a real problem for people.

B: yeah I mean we are fortunate aren't we really A: yeah

B: at the beginning of our journey I initiated a little group of us when rachael was little and we supported each other through the downs syndrome association and err that disappeared as they got older but we sort of moved into action for children one of the ladies that ran the action for children club had a daughter with severe learning difficulties so you could ask her questions and she was ten years down the line so you just ask the people and I've said we've obviously been in some circles err I joined parent carer forum when rachael was fairly young and erm did quite a bit of work with them at one stage but err then I joined when I thought we needed more adult stuff because that's the world we needed to start finding out about you kind of we made the effort in a kind of sense to find the people to support us they haven't coming running to us ever by and large

M: hmmm

B: so it's quite a surprise to move into the adult social care world and find for a start that social workers are very different and they are not interrogating you as if you've abused your child now they are actually looking to support you as an adult...

A: when you go into a meeting with social workers it's called a child in need meeting and B: you think

A: and then you obviously the headlines are you know the social worker missed the clues and the poor kid was getting battered to death by somebody or other, an you you feel you're in one of those sort of meetings where your being looked at to think..

B: the very first time I noticed it when she was seven and we had these people round trying to get some more support with Rachael so she could do things without us really because we knew this had to happen and we just wanted it to be a little gradual by gradual process and I'm explaining about the family you know I've got elderly parents I've also got I'm also looking after and the rest of my family are down south and some of these this is what I'm doing with her and she wrote nothing of that down at all the only comment she made

M: hmhhh

B: was Rachael seems to have a good relationship with her mother she allowed her to blah blah blah and blah blah blah. Thinking hang on a minute what about everything else the information I gave you about our families

A: she was knocking at the door (Interruption from a staff member)

B: erm sorry yeah so yeah that was our first experience of a social worker so I thought hang on a minute she came to judge my relationship with rachael and erm and like I said we get the reply her needs are being met and I thought yeah actually she's got other needs that are not being met but anyway we abandoned ship at that point and thought it's just not worth the hassle persevering..

A: but that's a lot of people come to that, you know what they say it's not our experience but you do feel as though they've they've like bev mentioned her nephew he's he's got special needs he's been in the special Olympics

M: wow

A: but if you asked him if he had special needs he'd say no B: no

A: so when he goes to the benefit the employment benefits thing B: he's in entirely the wrong bit of the system

A: (laughs)

A: because they listened to and not not to his parents so you've got err

B: and the social workers told them years ago your far too articulate and middle class and you'll never get any help bye bye so that's where they are 78 with him at home and err yeah we think oh dear. So having that in mind we probably think it's made us even more determined because we probably couldn't find ourselves in that situation.

A: yeah I mean grumpy enough as it is (laughs) but give me another ten years and I'll really seriously be grumpy old man and you know you can't be looking after somebody who effectively not in all respects but in some respects a two year old you you err you're not patient enough and other things so you need you need to accept you cant..

B: one of the things I've said our little experience of the odd little times we attempted a social worker coming into the children's social worker world but without that lady I don't know what we'd have done id have had to try again but plainly if you've

A: that's another thing

B: to refer yourself they don't want they think there's obviously no problem

M: hmmm

B: but someone else referring you get you there A: yeah

B: so my advice in the transitions would be as Andrew said you have to have professionals on board and helping you and saying the right things for you because they simply do not take parents word for you know for it. So you do need to get support somehow

A: and for not thee thee and another thing we've said is not get discharged from anything, medically, so if you know

B: it's a bit tricky

A: err err that is difficult because people obviously want to discharge you but if B: she was discharged by physios at the age of four or five

A: which was probably a mistake

B: and I err if she hadn't been we wouldn't have ended up at ten with a surprise I had tried the year before to get a physio to look at them and they said you'll have to go to your GP I was trying to get a physio to look at her so I would know whether id need to go the GP because I'm looking at her thinking I'm sure her gaits getting a bit odd, but it was such a hassle to get back in it was like to following June well it was April..

A: but thee but thee reason I mention it is because then if you've got people like the speech and language then err peaditrican and other people who know rachael and are prepared to write a letter that supports ..

B: yeah we had a good speech and language therapist A: yeah

B: from the age of 11 who could

A: probably one of the few people who ... we used that definition you know Rachael usually works functionally

B: functionally

A: functionally at a two to three year old and that then people take that as genuine evidence because when you're out and about it's not good having Rachael or two or three others like her being looked after by one person

M: hmmm

A: you wouldn't take several two or three year olds mobile two or three year old out to a fairground or something if you were err err err as a parent you'd want at least another parent with you so it's very important that other people from a safety point of view when they are allocating resources again are looking at it as sufficiently so all these little things like that which say what age she's working at but it's no good just us saying that its important they thee. Anyway realise that thee what we probably ought to do is let you ask the questions that you...

M: it's okay I'm enjoying listening to you I do have one question... A: yep yep well try and

M: I've enjoyed listening to you A: stop giving long answering

M: no no no its great information thank you. Both of you especially you Andrew have just touched on it a minute ago about the gradual getting used to transitions idea. So you said for both yourself and for rachael you've been planning right the way back from when she was sort of 11, 12 and sort of planning and Andrew mentioned it as well your planning and getting used to rachael going and living in independent living and

B: yeah and other people looking after her most definitely

M: yeah, other people looking after her. Does that help the gradual planning? B: absolutely because it's never been

A: yeah there a number of factors that come into play. One is as a parents you you feel responsible for them and in a sense its nobody else's fault you've got a child

it's your responsibility, like every other parent, to look after that child is one way of looking at it and that's the way we do tend to look at it but you also know that actually if you're looking at what's in the best interests of the child you sooner or later we are not going to be here and it's quite possible that they will be so you've got to have, you've got to have got some sort of exit strategy if you like for not being totally dependent on us. So there's so whilst we might well feel fully responsible for rachael and it's our problem in a sense its that isn't a solution to the long term so we have to look outside and it is, it is quite a big deal letting other people that you don't know look after her trusting and its was not a good experience the one we had

M: hmhhh

A: the first one it's got better

B: thought to be fair she was happy A: Oh yeah she was...

B: and they didn't do anything wrong we found it quite difficult. She seemed resigned she sat on the bed and started watching her things and said bye so you know. She's quite tolerant really in many ways and and

M: yeah

B: and adaptable so she does do these things she might protest A: I'm going to the toilet I'll be back in a minute

B: I suppose you ought to tell someone or do you think you'll be allowed to go on your own (laughs) A: yep (laughs)

B: do you know where ones is

A: yep one near the waiting room

B: thee erm um I've forgotten what I was saying now you have to get used to someone doing things differently and you have to work out what are the things that really matter that we need to say actually blah blah blah or blah blah blah just you know erm and what other things that you think it didn't matter it didn't matter if they did it in reverse order to me or they got her up differently that didn't really matter she will cope with change she wouldn't like to do things differently at home because what you do at home

is how you do it at home but we knew early on because we did have our friends had had her four or five times for the odd night for us

M: yeah

B: erm and they used to do shared care for action for children so they had a wide wealth of experience and house geared up to people with multiple disabilities and things absolutely brilliant couple and we knew she'd be safe and we knew she'd be happy but Wendy always said it doesn't matter what we do here it can be different to what you do there and I knew she knew her stuff she was a trained NNEB and an OFSTED inspector and things and she's a clued up lady and she's dead right in that it doesn't matter you can do something different as long as it wasn't at home erm and um its allowing rachael to have that opportunity to have things done differently so she does get used to that. We said all along we need to know what does she need to communicate is there something we need to work on is there a word you don't understand that you'd like if you say supper our eldest daughter instead of saying supper used to say syrup and you used to think people would think we were giving her calpol for supper every night (laughs)

M: (laugh)

B: and everything because when she was tiny she'd say syrup and wed say supper it's not and then they use that phrase here and rachael doesn't use that phrase its drink and biscuits she says as soon as she's ready for bed she says drink biscuit please

M: laughs

B: and if you'd said to her do you want supper shed probably say no A: does this machine work?

M: it does would you like me to make you a coffee? A: that'd be nice

B: they erm

A: can I have another biscuit (laughs)

M: course you can

B: it's a process of her you know of us helping her and everybody working out what does she need to be able to do to survive and more than survive be happy what does she need to be able to say to communicate all those little steps and erm for us to have that confidence in her and the confidence in the people looking after her

M: yeah. Would you like milk? A: quite a lot I'm a baby

B: erm and for us to get used to the fact she's not just gonna have things done the same way as we might have done them erm the one thing we do try to make about is her diet until we are blue in the face

M: bev would you like a drink? B: no thank you. So erm

A: it's very tempting to give Rachael treats M: hmmm

A: like last night we were at a church service and there was cake at the end of it and we was B: everybody wants to give

A: and err yes everyone wants to give

A: we have the same thing its nice for her to go to choose a piece of cake B: fortunately she chooses the sensible fruit loaf

A: (laughs) M: (laughs)

B: because actually she's not very good at eating cake at all it gets far to cloggy in her mouth because she puts too much in and she spits it out and gets very agitated so I wasn't really wanting her to eat cake at all but thankfully she chose the fruit loaf. So that was good because it was much easier to eat.

M: do you feel as though there is anything... you've mentioned change a couple of times for Rachael. Do you feel as though there is anything which would support parents better to make those changes to their own lives as well as those changes to their young person's lives?

A: I think the thing that what we've said several times is that we've researched this we've found this out erm the people could do with a mentor to to who's not there to save money, who is there to help people not just to sort of say if you did this you could do that go with them through the process.

B: I think especially if you're on your own

A: yeah

B: it would it would have been much harder. I can do the finding out then I've got Andrew to bounce it off and he'll always draw it back to the key things and then when we are writing and what have you err the fact is we are articulate we are both used to writing documents of all kinds I've been in education all my life Andrew's done some education type stuff as well as all his other kind of roles.

A: writing tender responses if you write tender responses you err endeavouring to sell a product basically so you err trying to convey something in the writing thee thee light that is most favourable to your outcome which is to sell the product so thee having that sort of approach is good to think what is somebody going to understand by what we put in, are we saying too much?

M: hmmm

A: because saying too much can be worse than saying too little sometimes we've found that on a number of occasions...

B: PIP

A: yeah PIP form saying that you'll have hear this, the limit of Rachael's ability to make a meal is that under supervision she can cut a carrot up...

B: slowly under supervision she can cut a pre prepared carrot up a pre prepared pear and banana. She can stir a mixing bowl as long as you hold onto the mixing bowl and take it away from her as soon as its finished and they gave her the points for preparing a meal. So you look at it and think. Fortunately she had enough points as she had about 25 points more than she needed but we had a citizens advice bureau friends we've got good friends that can support us so who trained me to fill these forms in several years ago but I double check with him. He scored her into the 70s and she got 50 something or 20 or 12 or whatever but it didn't make any difference...

A: what it is to say this is the limit of what she can do, whereas someone else chose to say B: well I all I should have said was she can't prepare a meal full stop.

A: yeah

B: but I thought I have evidence on my phone of where she's done cookery at school I can't deny the fact that she can very carefully very slowly she's a bit bored by it all

A: (laughs) M: (laughs)

B: ah you know she's just a carrot a thin carrot that's been scraped for her and she's kind of so you yeah you do have to be careful how much you say

A: so I mean B: little I'd say

A: ah yeah err thee thinking on how people are going to react because it is very easy for people I mean it's like the when you go to the doctors they are well by the time they have walked in but their symptoms not as bad as they were but there their not exactly exaggerate but you've certainly got to say, several people have said to us, always but the worst case down. But you need advice

B: yeah we've picked up the advice because we've moved in those circle and we've talked to people your constantly trying to pick up the hints and tips from other parents especially who have been through this process and I try and share them with other people and I've helped several other people with their forms and their things because they think bev ull know because they've done it and had success or whatever so we try to

A: we we the documents we've written because they are all similar B: they probably all shiver when they see us

A: yeah the thee thee EHCP plan was one but then you get the all about me well you'll know

B: the this is me and the all about me and then you go into adulthood and care and you go to children's and you write another set of documents and

M: hmmmmm

B: go into the adult social care and you have to produce another set of document but fortunately the EHCP hasn't made any difference to education but it has been a good contribution to our adult care package and that's been the definitive description of Rachael

A: (laughs) M: hmhhh

B: so the fact it was forty odd fifty odd pages long was good because they've been able to use all that as evidence they needed so, so it came into its own because I did wonder why we'd been bothered actually, so it came into its own when we went into the adult world and we've used that so

A: yeah coz when we came here said sort of you know nonchalantly you know Rachael won't be in education when she leaves here (laughs)

B: (laughs)

A: we thought well you know our plan was that she would be you know B: well I think by then we

A: yeah but it was

B: what was on offer wasn't going to work A: we we

B: starting the EHCP we was told by the educational psychologist who was a lovely lady but we only met her a couple of times when rachael was 15/16 she appeared we hadn't had one until then erm probably when she was about 2 we had one

A: anyway keep going

B: the next time well the fact is an educational psychologist we saw one to get her initial statement we never saw one again until we were coming to the transition sort of post 16

M: hmhhh

B: but she said get everything in there that you want to be covered until she is 25 so I took her at her word and then you think actually she's not going to be in education from 19 because what's on offer educationally isn't suitable for rachael she's actually learning more in the social care world

M: hmhhh A: yeah

B: doing the things that are relevant to her than sitting around with other people at a table for quite some time because I've watched it happen, doing stuff that's totally

irrelevant to her that's not meeting her needs so that was the err advice from the Ed Psych's so we did make it comprehensive in that sense so but it actually it has been useful

A: yeah what we you know the things she like she mustn't be left in the back of the car with things and all these sort of things we've put in but because it's in there now we can refer as per the EHC plan this is the way

B: but thee but I've said we've been fortunate in sense that there's two of us we are used to doing this kind of stuff so we can find out we can pick up these things and we can go and I'll be quite honest we've had the odd little blip with the social workers in the children's sort of areas pleasantly surprised by the fact that it was a seamless transfer from children's into adults err

A: they were expecting Rachael

B: I had told them two or three years earlier at a meeting and they'd written her name down she coming up yes she will be and when Id talked to one of the adults social care people at a meeting and they did know about her by the time we

A: it's all we you did tend to doubt, if you would, that when people said they'd do something they really would

B: so

A: just to get rid of you

B: so they seemed to be expecting her A: but the fact that it seems

B: it was remarkable

B: so we've had a seamless transfer from children's into adults a very good intake worker called comes from area I don't know if you've heard of her

M: no

B: she's very good listens well which is pretty important (laughs) A: (laughs)

B: and taking it on board and puts it into documents and what have you said and err

A: and thee thee nice lady who came and only about a page but

B: it was more than a page dear A: yeah

B: she might have taken out a few key things and put them into another document A:
yeah a really good summary

B: social care assessments. It was an incredibly accurate description of Rachael's
needs and I know we'd given her stuff but she'd actually

A: listened too (laughs)

B: she'd condensed it onto these sections and I thought that is good it is accurate it
was detailed and it was pretty remarkable so because we've not been expecting like
I've said you're more likely well I'm a pessimist well you're more likely to expect things
to go wrong

A: well I think we've we've expected that that you'd have to sort of fight for everything

M: hmhhh

A: in a way

B: we've still got the big hurdle to come

A: dare I say this is part of the problem that a lot of parents have they are so frantic
that they they go in with the sort of fists ready to thump people and and err you know

B: we've met several like that

A: out of Rachael's school in that sort of frame of mind and you know you've got
thinking B: you're not going to get the best out of them if you're going in like that laugh

A: yeah laughs

B: they don't like that

A: and it is hard because you know you've

M: hmhhhhh

A: err I watched the programme lions last night you know the lioness trying to defend
her cubs is thee thee male that's the sort of thing isn't it? Your there defending your
children against all these people who are trying to harm them is the mentality

B: most of them most of the people who I met through the parent carer forum world
where there because they'd had battles and they were wanting to they were ready to
fight and you know if they'd anybody in the meeting had not had any problems with

the statementing and wed had a lot a lot of meetings were they were going to reduce statements and things and it was like ah I'm not if I dare put my hand up because we had a statement for full hours at pre-school when she was two and half which became full hours when she was four which became extended hours they added an extra hour on her day when she moved secondary school they let us move late from primary school to secondary school because of all her hip problems and we didn't know if she was going to be able to walk when she was at secondary school so we stayed an extra year, an extra year at our 11 -16 school so ah we had absolutely no educational battles at all on our journey there was a little moment of doubt were were the lady who was going to be the deputy sort of teacher are you sure bev, but I worked in the school so we could have these conversations are you sure this is the right place so I thought all right well go off and look again and we came back yes were sure and the head said that's great well look forward to welcoming her and then at 11 the lady who again I knew because I taught her boys at a different school that she knew us she'd taught our other children she knew us we've been able to have these conversations probably people don't always have that kind of relationship who says hmm I don't know, ok just give us a try it doesn't work that's fine what we know is we can't ever come back to this if we hadn't tried it because we'd have lost her 1:1 so we always said can we see if it'll work we don't know but it what we says after six weeks and her just getting ready she said its good the county council are not counting her as a year seven until next year so that means she can have another year with us I'm thinking my word six weeks ago you weren't even sure this would work and here you are saying oh this is good she going to be able to have an extra year so you think yes ermm and it had worked by the end of that six weeks

M: hmhhh

B: she'd moved in the June in her year six year, her extra year six year as it where, her year seven year she moved from school in the June which again was unheard of really but again it was a good time to go in a transferred across in the schools point of view so erm

M: flexibility

B: err we have had a tremendous amount of flexibility the county council have backed our choices each time partly because it's what they wanted and erm so we we were we count ourselves fortunate but it's partly because we worked at it

M: hmmm

B: and you have to learn how to deal with people and erm things so as Andrew said people who are not in our position having someone supporting you is probably the thing you're going to need the most I know two other people who used to be part of our little circle one of them now here well he's here some of the time and partly in sand the other one who Rachael's age will be leaving the special school and I know from conversations I've had with both mums recently

they haven't done anything about next step at all and they've not got social workers, and they've got nothing place, and I'm thinking ahhhh you need to start thinking and I'm trying to encourage both of them to think for one their daughter is the eldest in the family and they have two young children so

in a sense they haven't thought about the long term she's not a young mum particularly but they've obviously got two at home so they are not thinking along the lines of they need to be leaving home where for us rachael is the youngest by quite a long way so we are already geared up to the idea that children need to move out erm err but they both in special schools from the age of 11 these two and mainstream primary and I'm surprised their special school haven't given them more input and direction Post 19. But ah we accepted the fact that we were in mainstream school until she was 17

they weren't ever going to grasp, all, everything about Rachael's needs because she was well out of their comfort zone to have a two year old in effect at mainstream secondary school having her own completely curriculum doing everything she needed to do at every minute of the day freedom from the head downwards saying here's the key to the fitness suite go wherever you like do whatever you like for as long as you like do whatever you like

A: she'd she'd join in with some lessons

B: yep she'd join in PE, music, drama, dance, art M: hmmm

B: for as long as it was appropriate and err the kids were wonderful with her she did cookery those sort of things, she didn't do science, she didn't do maths, English she never went near any of those lessons because there wasn't anything she would access there I mean

M: hmhhh

B: she would still be doing art in her way but we have a beautiful drawing she'd done of a face with lines across were they'd been told to put like a marker line for the eyes a marker line for the nose and so one and we got two of these under supervision with saying draw a circle her like this rachael and draw a line here like this rachael and she did it all and its phenomenal that because she was copying everyone else's, if she came here for the first reason now it would wouldn't quite be like this it'd be splash (laughs)

A: (laughs) it was 2 year old art work

B: art so whatever I've got to do to get rid of this so you can see what that level of input makes a difference it had made but obviously there was things they wouldn't know

M: yeah

B: because it wasn't their realm so we knew we'd have to find those things out for ourselves and we'd have to delve into the future by ourselves and I sort of assumed that special schools would be geared up to that

M: hmhhh

B: but looking at my two friends I'm thinking hmm you needed a bit more

A: well there not

B: yeah there not necessarily geared up to that

A: I'm mean one of the things with is is you would want want to say at the end of the day we'd have quarter of an hours conversation or five minutes if it was me twenty minutes if it was bev (laughs)

B: (laughs) well she'd tell me about her family A: she'd like to say which

B: she hadn't talked to an adult all day A: (laughs)

M: (laughs)

B: so we built a relationship with her

A: yeah but it was thee we got feedback everyday B: yeah the good and the bad

A: yeah whereas here it's actually quite hard to get, I mean I'm only saying this by way of illustration

M: yeah

B: good

A: I mean we've got a good relationship with I suspect for a lot of people they don't really have a lot to do with the people in the school the it's not the

B: it's a relief to have your child looked after and given back at the end of the day

A: it's probably a bit more so than if it was a secondary school but err err it's not the sort of thing where somebody could say ah have you thought about getting a social worker I think that's the sort of thing that's not the sort of conversation people are having

B: and as far as I can see to have a successful transition you have to have a social worker M: okay

B: to get into, to have provision for somebody like Rachael post 19 it's going to be a social care package or thee equivalent

A: and its best to get in beforehand that thee thee the need the fact that they've got needs that can't be met exclusively by the parents have been acknowledged while they are still a child

B: there was a play who used to try and get parents to sign up when the children were small

M: yeah

B: it was the children act register M: yeah

B: which was really badly named ermm and I tried to explain to people look the county council want to know what the needs are going to be in five ten years' time they need to know what's coming

that's why they want us to do it but they said they don't want to put my child's name on a children act register because it sounds like you've just become a criminal or you've whatever

A: the other child, child at risk, child in need you could be in jail next week (laughs)

B: so it put people off and she had to work quite hard even the freebie bags that you get given with stuff in weren't even an incentive but you know trying to they need to know our children exists and that they are coming on board and at some point which is why I spoke to the social care the adult social care

A: yeah coz err err thee thee county council doesn't actually know how many disabled children there are when I last asked there's estimates made

B: Andrew's done bits of work with them A: you know there's

B: tendering things as a parent

A: as a token parent laughs thee I'm on various advisory things so there thee err that err you so err unless somebody you've err decided what the ratio of pounds to person is a bit tricky I guess when you don't know and you have to go on national stats

B: right we better go unless you've got anymore A: yeah ask some direct

M: thank you

A: definitely if you feel you can always supplement and ask separate questions by email if you want.

M: err honestly both of you have been a really great help and you've answered I have a few

questions down here and you've answered them all brilliantly. If I do have any more questions then I will email them

B: you can email them M: I will email

A: what do you feel is the outcome of this now?

M: Hopefully the outcome of this now is that I'll write my thesis and qualify as an educational psychologist

A: I like that answer

M: it adds to my area of interest talking to you guys and I also work for the county council and they want to know the barriers and positives they want to know what parents think when they are transitioning from 19 to whichever setting; social care or education they are going to from a specialist school you know parents tend to, in the research, they don't tend to have asked parents who's young people have profound and multiple learning disabilities. And the small amount of parents they do ask, I know the DfE asked small amount of parents whose young people had EHC plans of those who have profound and multiple learning disabilities are a small drop in the ocean and usually they are most complex. It sort of adds to everyone's knowledge really. Is there anything else you guys want to add?

B: No I don't think A: erm

B: I think our biggest hurdle was getting a children's social worker and that seems to be a critical step and if it hadn't been for the lady who did a very good job

A: also talked me into applying for carers allowance which is worth about £3,500 a year which is nice and err so the the

B: it was the first time we thought wow

A: so somebody came along and listened and did something positive, you know not just listen but did something,

B: So came up trumps, they came again to check. Looking back, I'd done somethings to initiate it, but if she hadn't come along at that point I don't know how it would have panned out. So getting into the system as a child was critical to the next steps so it's one of those things you know you think hmmm things could have been very different without that ladies support, you know intelligent support, thoughtful and proactive determination to do what she felt was right for us a family and get it and there are occasionally those pivotal moments where you think hmm things could have been very different we could have been sitting here tearing our hair out if it wasn't for that one

moment where she says right they need a social worker this is ridiculous I'm not going to stop or getting off this phone until you've given her a proper assessment..

A: I think it's how you get advocates it would be nice if you could ask people to buddy up but I think it would be quite a big ask, its erm it really requires funding someone to do it, like are the one outfit that but it er so giving organisations like that to take people through several stages not just a bit of advice and then stand back, would be to do as the in our case, to do something positive that would be a big help for everybody because it can be very draining because there can be people who wouldn't want to do things for themselves and want someone to do everything for them and that would then drain the entire resource..

B: and some people wouldn't want the intrusion, A: no

B: you have to be prepared to allow people into your lives basically and not everyone can cope with that...

A: yeah it depends on the... if someone is physically helping it it it's very important that it's the right person in those roles, if they genuinely want people to, you with all these things there is a danger of encouraging the need by making it hard for people to apply for grants or what have you and that makes it hard for people. It's hard for the county I'm sure to encourage people to get to ask for help because that's going to cost us money so it's not an easy thing to do but if they actually want to help people, especially the ones that are struggling to do it for themselves then erm there needs to be a few more boots on the ground.

M: thank you, thank you both of you. END.

Interview Two:

7th May 2019 – 28 minutes 51 seconds: Jane

R: Thank you very much for agreeing to see me Jane, it's really very kind of you. You have read all of the information and signed the form to say you would consent to participate...

A: Yep

M: so thank you very much. What I am exploring after what you have read is about parent's experiences of transition from secondary school or their sixth form College to post 19 provision or adulthood. In that the sort of experiences that you had, any barriers you faced any support you that had, erm just how you felt about it what it meant for the family. So if you wouldn't mind saying who you are and about your young person and about her disabilities that would be great.

A: My name is Jane my daughter is Donna she's got Global Developmental Delay, she's got Autism and she got an [REDACTED] think that's it (laughs), trying to think, that's the main priority. Donna left school 19 plus because she had a [REDACTED] date and she had an extra year but that was with help from [REDACTED] because I think she missed it by a day or two erm when she actually left school, erm well before she left school we went into transition which you go round and look at all the facilities.

Obviously none of them was good enough, coz as for a mum nothing is good enough. We went to see quite a few and they was umming and arring as to if we would get the funding to take her to erm and then I looked round the Autistic Unit and that wasn't appropriate because, erm I mean Donna does do a runner and they had no locked doors or no policies for locking doors, or it wasn't on camera or anything like that so that was no good. So then erm, Donna during the school days erm so we did a slow transition from to [REDACTED] with the school erm and we set up a classroom in there hoping we would get funding for Donna to come here as it was more appropriate for her erm so this was all going ahead through transitions from school and then Donna actually left without an education, any education at all, because at the time I can't remember what it was that come into practice. It was something just, she'd just missed, so she leaves with a statement but she just missed something that's in now..

M: Education, Health and Care Plan

A: Yes, so Donna had just missed all of that so she wasn't entitled to anything, erm so which was hard. So then erm I went to loads of meetings about what she would get and what she would be entitled to through well it was direct payments. We went to some meetings and they said they would give us 30 hours because obviously Donna needed every day Monday-Friday as she was getting from school and they said the maximum they could give us was 30 hours the rest I'd have to use out of my direct payment package , so we said right ok. So she left school we had to set up a

classroom, find furniture computers to do this on our own, which was hard work. Find a PA that would look after her as well which is really hard nowadays to find a PA.

M: Can you tell me a little bit about how Donna's disabilities affect her please?

A: Donna, it's very much in a routine. Erm she gets up in a morning, she has to have everything just so. It's like a schedule all the time with Donna. She doesn't like change, she didn't like going out, she didn't like going to the supermarkets, I couldn't go shopping, sleeping, erm anyone with a ponytail she used to grab. Erm sleeves up on your jumpers, anything was a distraction to Donna. Anything, doors open, just anything, she used to bite herself, erm and she just didn't like coming out of her routine at all which is hard especially going to somewhere which is bigger environment, she used to do a runner if she wasn't strapped into her chair, she used to do running (morning), erm what else... (Interruption can you let Helen know she has a flat tyre – A: will do), erm

M: you said she was an absconder, she used to run.. A: yeah so she had to have (morning)

A: a wheelchair to stop her from running. At home the house is all secure for her; this is why we actually picked this place for her because it's all secure. And then from there, we came here and set it all up for Donna at and got the package from direct payments to pay a PA for Donna to come here five days a week. Anything above and over that, like transport getting her to and fro from my house we had to sort out, and then we got told she was entitled to education and shed just missed out on an EHC Plan so we went for this, "no she's not entitled to it" and we thought yes she is so then that was a battle from the age of 19 still to date. A battle for education she has actually got three mornings a week education a teacher comes and teaches Donna and she's only been having it a year now because it took us that long to get it all up and running and into place, the council playing the games that they do. It was hard work, draining, mentally and physically, it was hard work and for any parent I wouldn't wish it on any of them and the money its cost us, its cost us an absolute fortune but we wouldn't back down, because at the end of the day she's entitled to it. Finally we got the three days a week, erm we do have days were they can't cover they have not got enough staff. So we jot it all down and when things do blow up again we

have some backfire to help us. We are still in court fighting educationally, we are back again in June erm

M: What are you fighting for?

A: her education still, and health and social care aswell. Erm to give Donna more hours that she deserves because at the end of the day if she's put into a full time home they would have to pay for her so why can't they if she's at home? This is my ploy, and they don't, they don't want to know, erm but since it's been to court I've got more hours and get more help with Donna because it not, it's not, it's just draining sometimes. Some days if you're not well you still have to get up and change a dirty nappy, you still have to get up and wash her dress her and feed her, it's like a baby. You can't just leave it cry (Helen you have a flat tyre)

A: so yes its erm its just totally draining but you have to carry on with it. M: did you have any help and support

A: no,

M: when you transitioned from school to adult services A: none whatsoever

A: None, I dint have a social worker at the time. They just said to the direct payments workers you do the hours and that was it. It was like the blind leading the blind. Basically they didn't want to know, we had to set it all up because we wanted her to come here. Maybe if she'd have gone somewhere else it might have been different but because we wanted her to come here we had to do it all ourselves. When she left school the school helped us put some tables in, we had to do it all as parents. And we weren't the only ones that came there were a couple that came with Donna as well because they liked the facility, and came here because it was secure for them and because there wasn't too many people that you know could interfere with what they were doing. And she was lucky you know because she got five days and we used those hours for that, but some only get two days a week some get one and some get three. Erm but it was hard work if I find a PA and we hadn't have found this facility I don't know where she would be today. She wouldn't have come on as she is now, I can actually take her into a supermarket, she actually packs the shopping. Erm she knows when she's filled her nappy; she's come on in education since she's had it in the last year. We have had a meeting, in how much she has come on and erm she

puts the pots away she'll help putting food away in the cupboards, and she's never done that, never in a million years and it's since she left school she's done all this. And because she's getting 1:1 or 2:1 which she obviously wasn't getting at school which they say they do, and they don't and how much she's improved because she's getting that is amazing it really is.

M: You mentioned before about they offered you different things to go around in the local community, was there much of a choice?

A: No erm there was, Donna, erm I looked at a couple of places out of town for Donna to be residential but I want her to be residential I wanted her at home with me. Because she can't talk I think she's vulnerable and I want her at home with me. If she could then yeah but I, trust,

that's me. I've heard it all before and She went a couple of places out of town and they weren't suited it meant travelling an hour and I'd have had another big fight on my hands with the council to sort it all out because not only would, it would cost her to go there it would cost transport as well, carers there, it would cost a fortune so. And it was out of the boundary so it would have been another fight on our hands and I thought I didn't want her to be travelling an hour and a half every day there everyday and an hour and a half back, 3 hours, she's losing valuable time. If she got education there that's three hours a day she'd have lost she could be learning. So erm I went to and that wasn't appropriate. I went to another place in which had an Autistic unit which wow that was great, it was a square bedroom smaller than hers with a TV and a bean bag in which was a sensory room well no she

wasn't going there she might as well have stayed at home to do that M: hmm

A: they have light room here and everything, and I thought no she's not going there. The facilities for children like Donna are disgusting, absolutely disgusting. And resource, putting her in there with people aged 70, 80, 90 no she's a young adult. If she strips off way hay, you know what I mean it's wrong, totally wrong with children and that age gap. And she won't going there either. So erm the choices no disgusting I wish there would be something here which they are trying to do here but the council just throw it in your face all of the time, because it's ideal it's local to all to

communities. They don't have to get transport all the time to go out to access it all, they can walk go in their wheelchairs, you're at the beach, you're at the shops, you've got bowling, you've got swimming. You don't have to keep going on a bus every five minutes. Surely that's saving money somewhere along the line? And I just thought its ideal for her to access the community here where a lot of places are out in the wilderness and fenced off, and I thought no. No. But as for transition I think I knew what I wanted it was just getting the hours and a PA to find to suit Donna's needs so maybe in that respect I was one of the lucky ones but in others getting education for people is hard

work, really hard work and they don't like parting with their money to be honest but then who does?

M: You mentioned about that you knew what you wanted, was there something that you planned before Donna had left school or?

A: Before transitions, before she left school, because they go through transitions around 15/16 don't they, and through those years I was looking around at facilities because they took you I think they did with everyone. And I knew when I saw them there was nothing out there, nothing whatsoever, for a young girl or a young boy going to some of the places that they send you, there's nothing, there's nothing out there that gives a child that age fun, and life and learning, and obviously Donna can't make it out in the real world on her own but some of them can and they are the fortunate ones I suppose but erm no there's nothing. Some of them were dirty, they weren't clean, the changing facilities were disgusting and you don't want that. And there's more and more vulnerable adults now that what there ever was. And I think they need to change, it's like at the college she could have gone to the college, have you seen how big that place is? She couldn't go there it's an open door policy she'd have been running out, and sorting everybody out with their hair and sleeves and closing doors. It was the same at she needed 1:1 sometimes 2:1 in that place coz there was so much going on, she couldn't cope with it. Even now with people coming in she's out the door checking everybody, it's just constant with her. This place is ideal for people like Donna that's got them needs and they can give them what they want basically.

M: You mentioned there wasn't much support for you when you were transitioning, was that on the part of outside services or did you know other parents that had done it or was it across the board?

A: Across the board. I think the transition team are very, what's the word not to sound horrible. They have got no clue basically, they have got no clue. I think they need to have a child themselves to

know what it means to some of us. Erm basically you left school and that's it now you're on your own and that's it now, that's how we felt and other parents that was with me as well. We had to go for a meeting with health and social care, I keep saying direct payments but its health and social care but it's all part of the same thing isn't it, and they just said we might be able to get you 30 hours and I said you better do because she aint leavin until, basically, you've got to be full on with them, basically she's not leaving until she gets five days a week, and if she doesn't we will take you to court so you've just got to say that constantly. Erm but I think when Donna left there was three of them that got the same as Donna, I think if not we would have had another battle on our hands to get her here five days a week. But erm I think they knew it and I think for Donna's needs and her assessment, obviously they get assessed, and I think they thought oh well we'll give her that amount because she's got to stay in a structured routine like she did at school. So erm I think she left school in the July did the six weeks summer and it didn't start until the end of September so I had her home all of that time, because it wasn't set up for wages for the carers or nothing, so they need to get the plan into gear so as soon as that child leaves they need, a the payment facilities and everything all set up, that time that gap between was hard work and trying to tell someone like Donna she can't go anywhere for that long a period until it all kicks in is disgusting. Erm I think that's it on that, I mean we were lucky because after 8 weeks it all started. But it is stressful, it is tiring it is a joke basically but you'll probably know that (laughs)

M: You mentioned that there is something that they need to do, they need to have some structure in place and to get things sorted or planning, in an ideal world what would it look like for a transition?

A: well I think what they need to do, when she was at I'm not sure how many days a week Donna used to come here, but that's good. So so the year or two years before

they need to start this transition, but nothing sort of goes into place. Your just looking at places and talking. That child you need to know, say if you leave school at 18, at 17 they need to get into that transition they need to go there three days a week and then once they actually leave and then that next week they go in five days a week. That's what I call a transition. I don't call a transition starting at 16 we will talk about it and then at 19 oh we've got nowhere to put her, and nearly at 20 oh yeah we've found somewhere and at 21 you cant have education because your not entitled to it and we've got nowhere to do it, but at 24 you can have it for a year. That's how it is. It's wrong it should all flow like anything and that how it should work, I know in the real world it doesn't but for children like Donna it's got to, its got to flow, because they are out of routine and all that and all the work you've done has gone out of the window.

M: There's been, even in your discussion there you said it's been hard work when she was at home A: hmmm

M: because of her needs going out and about A: Yeah

M: and having a gap erm and its tiring A: yeah

M: there been you know research on parents who have disabilities such as Donna's with families about their quality of life, how does that reflect for you?

A: obviously it's like having a baby, you can't just drop everything and go out you've got to think all the time if I want a night out whose going to look after your daughter? I mean I'm lucky I have a son and daughter in law who lives next door to me so I am lucky like that and I've got a niece who can come and look after her. Erm but they are not going to do it for nothing all the time they want paying as well, erm it's it is hard work. If you go out, you've always got to be home coz the carers need to be home it's like having a baby, and you need to care all the time. And obviously you can't take her to some places because it's not for Donna she likes to run around with kids or she likes to go to the park. She doesn't want to be sat in a pub does she? Or going away for the night, you can't do it. Recently I have just taken her and its took me 11 years to pluck up the courage, took a carer with me, alright we didn't sleep ideally but you get over that because I wanted to do it for her. Erm she is getting better one step forward two steps back. Erm, and it is, I am lucky I have a supportive husband and Donna's our life basically we all work around Donna, our house works around Donna, we've never known no different if you know what I mean so you just get on with it. I

mean to put Donna in with another family, I think, it would be hard, we know it from birth and its life you know we can't do this weekend because we can't get a sitter or well be there in an hour because I have to sort Donna out first or I have to pack a baby bag basically, and make sure you've got everything for her. But I've never known no different. You just, the only thing is when you get older it gets harder, some mornings you ache and your body aches but you have to get up who's there for you have to carry on don't you it's the way of life. Take it as it comes and grin and bear it (laughs).

M: do you think there is much information out there about the transition from education into adulthood?

A: see I never accessed any of it so I'll be honest I never did. Because it was all integrated with school I did it from school. So the transition team sort of sent me to places where they thought was appropriate for Donna see, so I never accessed anything like that I just took their information that they give me and went to look at the places they thought was suitable for Donna. Erm I did have one of the teachers come with me as well and they advised me because they worked with Donna all these years and they erm showed me what was available and they advised me no good for her, so I had that bit of help. So yeah I didn't access it, I just as a mum I believed the transition team in what was available to show me what was available for her.

M: is there any other thoughts or things you want to add about your experiences of transition?

A: I just think there should be a wider spectrum of places for children, not just like Donna but any disability. I think transitions should be easier, than what it was for us. They are lucky now they leave school with an ehc plan because they are entitled to education although a lot of people don't know it. And they are not getting it. Erm but I do personally think there should be more out there for them definitely, and as a parent we are in coming up to a new generation and I think they need to get their arses into gear and get it sorted, for them.

M: how do you think they could do that?

A: well obviously it's going to take money from the government. Maybe build another school that would access children from 19 to whenever. You know what happens after 25 only we will know. But erm if they are entitled to education why not build a school?

19 to 25, you've got a college. Why can't they build a school? You've knocked a few down that would be ideal for children leaving you know, they are still entitled to education fund another school they could stay at home then they don't have to go to respite every night, alright they could still access that. But they've still got the motivation to get up in the morning, they've still got mixing with all their peers, why should they be segregated, from all the kids that they grew up with. I think that would be great and that's what some people are trying to do but they won't have it. They can seem to see beyond it they think 19 ah that it. But I think that would be great another school for 19-25 or when they say education stops. It doesn't have to be full on education, morning education and then access the community but if they got together, education, health and social care together and did something like that I think that would be amazing, wouldn't you? They've knocked enough down, rebuild one (laughs) DIY SOS. (laughs)

M: Thank you very much,

A: Have I answered all of your questions? M: Yes thank you.

Interview Three:

9th May – 25 minutes 46 seconds : Wendy

M: Thank you ever so much Wendy for meeting me and talking about transitions to adulthood for your young person if you could just say who you are and who your young person is, what her disabilities are and how they affect her that would be great, thank you.

D: my name is Wendy Taylor my daughter's name is Karen she has Down Syndrome. Erm and she is very vulnerable erm person. That's all I can think to say, anything else, what else did you ask me sorry.

M: That's ok, how her Down Syndrome affects her. D: ah ok yeah

M: so you mentioned she is a very vulnerable person

D: ah yes, yes she can't be on her own at all she needs someone with her 24/7. M: ok, is that to keep her safe?

D: yeah, yes

M: okie dokie, so what we are going to talk about is transition from Karen's secondary school to adulthood provision that Karen went to or does go to now and your experiences and journey in that.

D: yep, that's fine yep

M: so if you can't start off and remember how that was for you?

D: so when Karen left school, were I felt she was quite safe there, she knew people, she was very happy to go there. Karen joined when she was 7 up until she was obviously 19, erm from there she went onto college erm only doing 1 year where we were informed because she'd stayed at school until she was 19, instead of leaving at 16 she would only get 1 year at college, which to me was nonsense because other children sorry other young adults got more time, some got 2 some got 3 years and stayed until they was 22.

But my daughter only got 1 year and I felt that she needed more but basically I was told she only go the one year, so Karen left at 20 and basically it left me with me having to deal with everything that she had to do from then on . So the transitions from then was looking for places for Karen to go, so she went to a place called services in for a full year a couple of afternoons a week. Again I was informed that if she went there I would be able to get a support worker who would be able to take her to volunteered work out in the public but she would have support with her i.e. costa coffee, a second hand shop. Erm she did a couple of afternoons a week, really not wanting to go but I pushed her to go because I hope she'd get a little job at the end of it maybe. But after asking at certain meetings, they had meetings with me and Karen every three months, and we would ask how it was going. Erm while she was at she got moved about a lot or had different erm young teachers helping her out probably similar age to Karen looking after her, she'd just get used to someone and they gone or they have gone to another room, so she wasn't enjoying going because she had no consistency and Karen like most young uns with down syndrome don't really like change so we really struggled with that but I persevered with it hoping she'd get a job at the end of it. At the end of it when she left last, was that at the end of this year or last year? It was at the end of last year, when Karen left getting upset when I was taking her I thought she was 20 it's not happening, when I spoke to the lady that runs it I said she came here from college on the chances that she'd get a job at the end of it with someone from

your place supporting, her supported work was then to be told orr we don't do that anymore there's not enough money in the pot sorry, so we left there, I then took it on myself to ring the employment mobility services through the parent that told me about it and I rang and spoke to them myself and said I'd love Karen to do some voluntary work because I feel she is capable of doing that. I spoke to a lady called who said, right well bring her in for an interview so I took her in for an interview and told them she'd done a year at college which she is what did she worked at while she was at , she was quite capable of doing it so if she could do something along those lines or a second hand shop because she likes dealing with clothes, she likes to fold clothes ironing and stuff like that.

So when was in the interview and talking I said to the lady, or one of Karen other friends works in costa coffee is there anything like that she can go to volunteering, and she did a list of things that was there but there wasn't anything much for Karen that she could just go in and do. So I said actually Karen goes twice a week to for her dinner because she goes to , which I will tell you about that in a minute also, so I said if was to ask them at to see if she could do some voluntary work there would that be ok? Well said its obviously my job to find her somewhere so I'll get in touch with s and I'll let you know, are well and truly happy to take Karen on because when she goes to have her dinner she helps clearing the plates and stuff anyway.

So she got a job on a Tuesday morning so Karen does that she was doing 1-12 its now changed to 11-1 to fit around everyone if it gets busier she'll take her on for an extra hour and do 10-1 but I think the place shuts at 2 ish anyway. But shes loving it and she works at front of house and she doesn't mind doing the odd pots but she likes to serve, and she loves it and I knew she had the capability of doing something like that so I pushed for that to happen. So every Tuesday she does that and every Thursday and Friday she goes to a place called. Run by at the above , he used to work at but he didn't agree with how the place was being run because it was getting less and less staff and us parents wasn't happy, and he was speaking up for us and he ended pretty much losing his job. So because of that he decided you know I'm going to take it upon myself because these guys need us, people like me, and he's been open a year most people have left quayside to go, my daughter she can't get enough of it. If I could afford to send Karen I would she loves it absolutely loves it, she does Thursdays and Fridays 9-4 and they do all sorts of stuff they do things like they

go collect plastic on the beach for the community, he is a bit of a keep fit freak they go to the gym golf football all of that. He teaches them to eat healthy, but anything they ask, so I was there one day and a young lad said he wanted to send someone who lives away a letter but he didn't know how to start it or even do that, so they all sat that day and did the address in the corner not many people write nowadays but, he always asks them what do you want to know and he helps them massively.

So she, Karen absolutely loves so that's what she does but again we've had to pretty much search it all out ourselves again I knew about that because I'd spoken to them myself, if it wasn't for that or other parents helping me i.e. I didn't know where to go about his voluntary job and another parent said or it's called employ mobility services and give them a ring, and again I wouldn't really know and once Karen left school to go to college, that wasn't the best experience in the world, and then from college to now you feel like you're on your own, you're not because you've got other supportive parents out there and you try and help each other but it shouldn't be down to that really should it? Just the parents helping out, when should have, I don't feel we should kind of just be left to kind of fight I mean we I fought for years for my daughter for everything in life but yeah it seems to get harder as they get older, so

M: you said you didn't have a great experience when she moved from school to college

D: no, no, erm because it was just like they they mistake at the end which I think is why she only got a year, somewhere along the line there was a bit of a mix up, Karen started college she did three days a week, because she named drama, cooking, English maths no English and maths was in it anyway, cooking and drama, she didn't opt for retail. Erm so we did that and so what happened was because Karen did her cooking she was only there three weeks and then they got her a placement and she was going there and they were treating her a bit, and think this particular day Karen just got a bit upset. I did even really know what had gone on, I don't to this day I think everyone was trying to cover it up, I think Karen had stopped working and just sat down and someone a boy had upset he or whatever but a member of staff from had really come down on Karen proper shouted at her made Karen cry and the person who was supporting Karen from said to this woman no more she's not coming back and they pulled Karen out of the café, the lady that worked at, I was grateful for and I kept saying what happened but no one seemed to tell me anything.

Not only that but in the end at the end of all that experience that Karen had every one of those teacher that said to me in this meeting, at the end before Karen had finished college they thought Karen had done some work experience in a café at or whatever but they was all shocked that she'd never done it and she'd been thrown into it that quick. Now when Karen went up from school to college she went with three of her peers that she moved up with not one of them did any work experience in the first year and they were there for three years not one, Karen was straight into it, I didn't know and I thought that's what they had to do and even at the meeting when everyone was appalled that she should have been doing it the second year not the first year, none of them was really there for her I don't believe, it was so hard Karen really struggled in college so I wasn't very happy with it, and me as Karen parent I would recommend it to anybody, I'm afraid so.

M: so when you transitioned from school and went to college, you mentioned a couple of times your support systems where from other parents and you went to find out about things and you went and contacted people. Was it, did you have any other information and advice given to you from say services, or school or anything or was it purely just.

D: ern no just one of the teachers at school was just before they left school to go to college that things was getting tighter and she did say that they maybe will only get one, two or the most that they would get is three years and she'd seen a lot of children transition erm school onto the college.

M: hmm

D: she was the one that did all the transitions and erm and she she probably helped the best she could but that was only bit of advice we got so and they made it sound and when they did the introduction day I thought it sounded good and safe for her being there and there was a few things again and it didn't happen with Karen one of Karen peers who went ended up getting pushed by a peer and he ended up leaving the building and he wasn't found for four hours before everyone didn't know he was there anymore and it just didn't give you that security.

See and it just made me feel I didn't think in a million years my daughter would just up and leave but you never know, I wasn't really, so again for that year. So from 7 – 19 fantastic amazing I felt she was safe she absolutely loved it, but from 19 to now it's

getting easier now because she's in places she likes but I've had to deal with all that, I haven't had any help from anywhere so

M: hmm

D: all I can say is I have but it's been other parents we help each other out. But any other services then no I'm afraid to say haven't, even down to Karen own social worker she got in touch with me three weeks ago and said it's her annual review and I haven't seen her since the last annual review and there's been a handful of times when I've felt I wanted to ask her a few questions and stuff and I can never get hold of her she's always on holiday so even that support network is not really there so its been a bit of a let-down really when it comes to any extra services for our young adults I'm afraid.

M: you mentioned a couple of provisions that Karen has been to and ones that you've been and had a look at is was there choices of provisions for you to choose from when you left

D: no from the only place you could go was college there was no offer of anywhere else or nothing, so it was like and linkage after we had been there a year we got the letter to say she didn't have another year and of course I appealed it and was in a meeting at

college with all these other social workers and people who work at the school and then the transitions and I actually said as far as I am concerned it's all about money if there's not enough money in the pot you won't keep them, that's the way I kind of see it.

And they was saying well look if she'd left school and 16 and come here she would have been here for three years she would have got her three years and I said no you're not listening to me, all the guys that's moved on before Karen went from at 19 and got 2 or 3 years depending on what they needed, she only got 1, she's probably not the only one in the world that got 1 some only got 2 years one of them that went up with her wasn't there for the second year because he was poorly and to me that's just a waste, I know it's not his fault because he had issues but he probably spent four months out of that year at school , I wanted Karen to do an extra year because I felt she needed more help specially with her English and maths and she wasn't given it so I now don't seem to have much faith in it to be honest

M: what was it with, we spoke a bit about her moving from [redacted] to and she went there three days a week and then she's moved from [redacted] to [redacted] and now she helps at one day and she goes to a couple of days when she's at school it's a five day provision and now it's sort of less than five days. How does that affect how you manage with your usual day to day life?

D: it can be quite hard because I'm a single parent, it is just me and her and I run a business so I get one day a week off one and a half two days if I'm lucky. Lucky for me I have a support from family were someone has to look after her on a Monday when I'm at work, someone has to look after her on a Wednesday when I'm at work all day, Tuesday is my day off and Karen can obviously run her about take her to her job and do the jobs I need to do, Thursday and Friday she obviously gets dropped off by me when I go to work, Thursday I finish a bit earlier so I can collect, Fridays I have to rely on someone to collect her, so I have to rely on someone every week and some weeks it can be awkward because I don't know who's picking her up from one Friday to the next and obviously Saturday when I'm working again and I either need someone to be with her or if I'm only at work a few hours she has to come with me unfortunately so, but she can't be left like I said at the beginning she has to have someone with her, so because I have no choice I have to work so yeah erm so yeah.

M: you've mentioned there's not so many provisions around in the area and there's a lack of information you said and support about what's available. If you had any issues or if you wanted Karen to access different activities from going to school and into adulthood, were is it you look for that?

D: Again really I just talk to other parents, I've tried to help out, I met someone who moved from hull to here with two special needs young uns and she said to me what is there around here and luckily for her I said to her there was discos for the guys to go to, there was at the time boxing, there was the special needs gym, drama groups, luckily for me I know all this and I've done the research myself or other parents have told me, or looking on social media and things and I've even googled things. I've even looked one time a few years back I was thinking of moving to even then I looked to see what help there was for Karen in the area, I looked to see if there was a school she could have gone to because she was still at when I looked any services that would be out there for her, obviously I looked for that. There only been a couple of time when

I've looked and wanted to know and I've probably gone to Karen social worker not with much joy but that's who I feel could help us out because she is her social worker, but no, and there is another service, I got a letter other day, there's just an annual thing once a year where they want to talk to Karen and see how she's getting on but apart from that and apart from the social worker we don't really hear from anyone else.

But then I don't really hear from the social worker, the social worker rings me when she wants to do the annual review which is what she has to do, so that's it if I try to get hold of her I get another social worker, because we had a few problems with erm I think it was the college towards the end and I really needed to speak to someone who kind of knew what they was talking about and at that time apparently Karen social worker was off with family problems, she was off for a few months, so they put someone else on Karen case and then in the end it took about 8 weeks just to get an answer back, that's how hard it was and that was just going through the social work system so erm yeah again I just don't have much faith.

I feel that if I kind of need to know anything I ask another parent if they've been through it if you get what I mean so so again I think it's more of a parent network than anywhere else to be honest because I don't really know anyone else, doctor if she's ill, social worker if I have any questions I'm not sure about. But unfortunately I'm quite independent and I try to just crack on with it myself so yeah so I just do, but it has been hard, it has been hard and like I say even now once they go out from school to bigger things like the college and everything and its not just about the education but we have to then find dentist, opticians like at school well they don't always find a dentist but they come into the school so from leaving school we have had to do all that now that sounds easy to a normal parent but when our kids, cant, don't like dentist or don't like doctors its quite hard work to find someone that.

I mean I really struggled to find a dentist that had the time for Karen because she's doesn't like them like most kids don't and we managed to find one lady but she's retiring and moved away now so it's a massive struggle, but everything, so the second they leave education you've got it all to again to fight for. So

M: You keep mentioning the word fighting

D: Coz I just feel that's all we ever do so, yeah.

M: In an ideal world what do you think the transition from school to adulthood would look like?

D: I think personally its from say three months before they leave school to go to college there should be more meets with the parents and even school, then are, or or or meets with the person they are going to approach next because I like I said to you we spoke to at the school whose no longer there now and but she was one who told us how the transition part worked. She was probably the most helpful and she worked at the school. And then when it got to college we had the introductory day and everyone seemed great and it was all sounded amazing but once they are in there it's just not.

But I just believe for our young uns as well as for us parents to feel more at ease yeah more should be done and spoke about before that because it was just it I don't know it just didn't glide, didn't, it all sounded so good and once it started and I just that you know your own young un and Karen gets on with everyone and normally goes in and gets cracking and she never complains about anything but she never really wanted to go to college and after say three months she never really wanted to cook in that café, and I didn't know because nobody was telling me but obviously I think she was either being bullied or there was something not right but she couldn't describe it to me but I knew there was something wrong because she didn't want to go.

Same with the and I had her one day crying saying she didn't want to go and I just thought enough is enough I didn't want to make her do it but I was persevering with her hoping she'd get something at the end of it and I thought why am I putting her through that for a year then I just don't understand. But yeah going back to the transition sorry yeah, I just that there should be more erm I don't know things should just be spoken to and give them a bit more time because our guys need that time.

They can't just come out of one thing and into another they can't do that we just deal with it we do, I think they need more. It's like anything in life, like tonight my daughter will ask me what's going on tomorrow mum, she needs to know the night before and er I have to plan everything and if it's something she's not happy about I do obviously try to avoid talking about because I know I'll never get her there (laughs) but we yeah I just don't think they can jump in from one thing to another so yeah I do feel that perhaps they should have had one visit from the college maybe two or three and I just feel that people should just talk more to the parents and the young uns from where

they are transitioning to and from, I think that might help, I think, but apart from that I'm only going on my experiences but I think that's what maybe should happen because I think that was the biggest thing for Karen.

I kept telling her she was moving to a bigger thing and we looked round, oh is great and that but it's alright seeing it but doing it is two totally different things. Like I say, our guys don't like change she's not keen on change and I do have to forewarn her about certain things like she pretty much knows she's coming to work with me for a few hours on Saturday and we are not at Saturday yet but I have to tell her because otherwise she can't get her head round it, hmm so yeah they need pre warning really and like I say jumping out of one thing into another is just not easy for them so I just think personally if they could add a few more visits than normal spoke about it a bit more rather than just expecting them to slot in, I think that would help apart from that I'm not really sure but, yeah going back to your fight I feel we have to fight for everything with our guys it's just not there anymore, everything education for them to do fun things, yeah, form filling all the time, I feel like I spend all my time filling in forms and erm so yeah that's what I meant by fight (laughs)

M: is there anything else you think you might like to add, bearing in mind this is about parents experiences of transition to adulthood?

D: erm no like I say I just feel that they probably should be told a lot more, the parents and the young what what's about to happen next especially from the transition side, erm from a parents point of view erm it's an hard one it would take me days to tell you this rather than a few minutes or hours. I dunno I just get up every day and get on with it, it's quite an hard one to answer that, it is very hard for our guys to deal with a lot of things in life I just feel that they need a lot more time than they get that's the only way I can really express it, like I say we can go on forever really couldn't we so... but yeah my daughters experiences wasn't that great and I just didn't feel we got any support or help at all so I just felt like we was left and you just get on with it because that's what you've got to do so yeah

M: Okie dokie thank you very much D: your welcome.

Appendix 7 – Phase 2 Data Analysis

Phase 2: generating initial codes

Bev and Andrew's Interview

Number	Narrative	Interpretation
1 (A)	we know she's going to move out of full time education therefore it will be more incumbent on us to sort out what happens to her in the day with financial help from the county council to provide for some care.	QOL; parents searching for care; acknowledging the future; thinking about the future
2 (B)	I mean she's already done a number of transitions as it where so every step is a transition	Lots of transitions in life
3 (B)	at sort of 2.5, 4, 11, 17 in her case and then again at 19 so, um I think um probably it's fair to say every transition she has undertaken we start preparing for it many years in advance	Preparing in advance for transitions
4 (B)	as soon as you've done that step you start preparing for the next step, and then you constantly review everything so all the way through her primary school we reviewed	Preparing in advance for transitions
5 (A)	so anyway that all of these things its it's err helping with her transitions as well because its err means that's she can err take part in more things because she can do more things	Independence, thinking about the future
6 (B)	erm I started going to things like events run by county carers before Andrew retired because I used to go on my own to them so I know since has retired has come with me so, so I started finding out the information for adulthood before we'd done the post 16 transition which shed done at 17	Transition to adulthood; preparation; finding information; support from partner ; being proactive
7 (B)	the county council to be fair have been very adapting to our need which (laughing) is probably unique	Support from services; flexibility
8 (B)	as well as investigating what was going to happen once she came to the end of her time at secondary school, I was picking up information and talking to people about adulthood	Transition to adulthood; parents searching, parents talking to others
9 (B)	we met a lot of adults with learning disabilities and we've met a lot of parents carers who erm support adults with learning disabilities so erm I've we start that process by asking the questions, observing watching looking erm and erm picking up information really	Transition to adulthood; parents searching, parents talking to others
10 (B)	because you know you can't pick it up all in one go you kind of it slowly sinks in and every time ..	Transition to adulthood; thinking about the future over time,
11 (A)	and sort the conflicting ideas from different quarters and then you gradually sift out what's probably accurate	Transition to adulthood; thinking about the future; collecting relevant information

12 (A)	other thing is in a way we are probably more geared up to the big transition which we are looking at is for rachael to be from living with us to be living in supported living that's the transition that's the big one	Transition to adulthood; future thinking; planning for the future; planning for life without the young person
13 (A)	so erm the transition between school and some sort of day-care type thing is important that we get that right	Right type of care/provision; peace of mind
14 (A)	but thee thee the longer term objective which is where we are heading is for rachael to be able to be happy in a supported living environment with a care package that allows her to do things that keeps her motivated	Happy in the provision; keeping young person motivated/interested
15 (B)	Motivated (<i>in agreement with A importance of motivation in supported living</i>). Motivated and stimulated during the day	Being motivated/interested
16 (A)	so that's thee the probably the first transition is too to once she can't come to school every day is to find other things she can go to everyday but that will morph into probably her sleeping somewhere else rather than sleeping at home	Transition to adulthood; provision; parents searching; forward planning
17 (B)	yeah and we probably set that as a goal our long term goal, erm I don't know probably by the time she was 14. Probably before then we started writing that into her annual reviews the long term aim that somewhere between the ages of 19 to 25 she would move into supported living so as Andrew said the ultimate target in a sense	Transition to adulthood; goal setting; forward thinking;
18 (B)	so we had we have to do that because of our age (<i>focus on supported living</i>)	QOL; realistic forward thinking; parenting adult children
19 (B)	I'm 63 erm so we know realistically we can't carry on looking after rachael forever and we can't expect our own children, our other children, older ones to do the same erm so we've been steeling ourselves in a sense of that to get used to it the whole process of doing it we've been doing for the past year or so has been helping rachael and us get used	QOL; realistic forward thinking; parenting adult children
20 (B)	new arrangement erm um yeah that's been our long term goal so we've been working towards that's in everything we've said and done since then. So as I said we started collecting information about the trans, post possibilities, Post 19 at the same as we were all sort of doing our way through the post 16	Transition to adulthood; parents collecting information; QOL; realistic forward thinking;
21 (A)	Rachael would be in some sort of education not here but something not dissimilar but erm we've changed our view on that partly because of various professionals' suggestions way of thinking that actually Rachael would go to some sort of college	parents hopes/wishes; education and learning; professionals unrealistic perceptions
22 (B)	we went to them and we 1cknowle that they don't	Post 19 provision; suitability of

	cater for people like Rachael (laugh) (<i>college</i>)	provision
23 (A)	yeah and there's some sort of elements of fairy-tale about it anyway in that people are doing vocational courses for things were you think that they there never going to be, there not going to be an IT specialist or something you know.	Post 19 provision; suitability of provision; realistic options
24 (A)	you would if you worked at it get an idea of what rachael likes and things but you'd get a lot of noise in with that	Young person's wishes; young person's voice
25 (A)	She needs to be doing things like dance drama things she'll enjoy doing she doesn't want to sit and do things like basket weaving that doesn't cut it with her err but err finding those sort of places where she's going to get stimulus where it's not going to cost a fortune you find something	Post 19 provision; parents hopes; suitability of provision; cost of provision
26 (A)	Because we've got an objective in mind to our pleasant surprise because you sort of steel yourself for a fight really for all of these things.	Forward thinking; fighting
27 (A)	but you still sort of doubt that's what'll happen	Lack of faith; pessimism about receiving provision
28 (A)	genuinely the representatives of the county council have taken on board where we want to be with rachael and are 1ckno helping with the funding for that's because it's it's because one day we can't just ship her off to supported living its we've we've been given quite a good care package for rachael to go and do residential and all other things and Saturdays someone comes and takes her out	Transition to adulthood; other services; flexibility; being listened to
29 (A)	it's all paid for we have to 1cknowle it but it's paid for out of funding we get from the county council (<i>NHS</i>)	Funding for services/provision
30 (A)	<i>NHS</i> its health care its actually fully funded by them but its 1cknowled by thee thee but that's been very good but assuming we don't get a derailment of that that's seems to be the agreed process that we will get an increase in the package when Rachael leaves school	Funding for services/provision; support from services
31 (A)	that will allow us to pay for the day-care	Finances
32 (A)	so she's not at home all day	Being cared for in the day
33 (B)	it's part of the process of building into this bit we've been going round colleges and special schools for a couple of years	Transition to adulthood planning; parents looking at provision
34 (B)	erm and erm one of the most useful off the cuff remarks from another parent, which is usually who you pick up the most best tips from was erm you need a social worker while she's still a child. They said they'd tried to come in at 19 and had got thee why did you need anything, you didn't need them when they were a child. So that piece of information got lodged in my head so	Transition to adulthood; forward planning; what's helpful; parents supporting parents; other services
35 (B)	we'd had a visit from a social worker for some sort of	Other services; lack of support

	assessment when she was 7 who said her need where being met so she doesn't need anything and you thought ok the fact that's it's me who takes her to brownies and rainbows until she was 11 and I stayed with her and the fact she comes to Sunday school on a Sunday morning and I teach the Sunday school and one of our other children supports her meant her needs where being met so (laugh)	and understanding from other services about young person and family life
36 (B)	so it's case of if we didn't do anything for her you might have stepped in, but obviously as a parent we made sure she had social interaction and opportunities to do things	Other services; lack of support and understanding from other services; parents parenting
37 (B)	the next they did put us in touch with action for children and thankfully we were then able to access an action for children club which we started probably from about seven right up until she was erm whenever 18, 18,	Other services; signposting; support
38 (B)	and that was just once a fortnight and that was the hour and a half she could do something without us so that's the only thing she had been able to do without us	Independence of the young person
39 (B)	Health people said it was a social care problem social care people said it was a health problem and we just thought we have far too much to deal with with a child who was just about to go in for serious op and thank you ok we'll just carry on by ourselves	parents seeking support; lack of support; being passed around services
40 (B)	so our experience of children's social care was limited and not too impressive in the sense that erm but thought right we have to face this no one likes the idea of having a social worker that I knew no one really likes that intrusion	parents seeking support; lack of support; QOL-intrusion into your life with services involvement
41 (B)	brief encounters with them were that they treated you as if you might have potentially have abused your child and you were in that same category whether you're a child in need or not you have the same set of questions as a parent who is doing it because you care for them as the parent who is doing it because she doesn't so it is very off putting	parents seeking support; parents perceptions; QOL-intrusion; system failures; feeling judged
42 (B)	we thought right we have to try again because this piece of information made sense it was going to be better if we got in at 16, so at 16 I rang the number of the county council and asked a few questions blah blah I answered them all obviously far too articulately because six weeks later we get the reply she doesn't qualify for to erm go in for a proper assessment	parents being persistent in seeking support; lack of support
43 (B)	so we asked the question why and we had a very rude answer which was we can't tell you. You spoke to the lady..	lack of support; systems
44 (A)	because you're not another professional we can't tell you why we haven't scored enough err	lack of support; systems

45 (B)	Nobody can ever deny the fact that we are getting older and we are not going to be able to look after Rachael	Parents parenting older children; QOL; looking to the future; realistic
46 (B)	it was quite bad to begin with (<i>social care</i>). I'm shutting it out of my brain because it's the only time we've had a bad experience the entire time of rachael's existence from the result was she did get us 24 nights stay at the	Other services; lack of support; bad experiences; positive outcome
47 (B)	She nearly de railed her education process in the process by making some wild actuations of seeing her in school for half an hour and your thinking ahhh which was nearly disastrous but we got over it	Other services; professionals misunderstanding
48 (B)	fortunately they passed us onto a real social worker as it were and um who grasped the situation she actually came and had err err an afternoon talking to us and we had a very useful conversation because at that point we were trying to make up our minds about where do we go next with her and her comments and thoughts helped in a sense crystallise ours	Other services; support from professionals; discussions and thinking helping solidify choices
49 (B)	which was absolutely beautiful and wonderful and the staff were great and she was I won't say she's ever been enthusiastic about going to places if you told her because at that moment in time she's watching her dvd and she don't wanna go anywhere else I'm watching my dvd but when you walked you know walked up the pavement with her and through the door she's there, she's quite happy and its bye and off you go..	Provision happiness;
50 (B)	so you know she's happy. Um and um that was a very that was an important part of the transition that is now going to take place	Provision happiness;
51 (B)	Rachael's post 16 no sorry post 19 transition we started thinking about and planning for at least by the time she was 14 and the steps we got put into place between then and now have all been part of the grand plan which is taking her to the final transition of moving out of home into supported living	Transition to adulthood; planning; forward thinking;
52 (A)	that that that was an essential link in the chain without that all the other things wouldn't have followed so so in terms of your study I think it's important that people are signposted or whatever the phrase (<i>social services</i>)	What makes it better; signposting (<i>social services</i>)
53 (A)	is to get help early on. If they are going to be in a similar position to us and most people who have got children with special needs are they are not going to be able to look after them indefinitely otherwise its its you know bev knows people who have got you know 45 year old children at home	What makes it better; seeking help and support; being proactive; asking for help
54 (A)	children being effectively children being looked after and they're in their 70's	Parents parenting adult children

55 (B)	I have a nephew in his forties that's at home with my brother and sister in law and they are 78 you know.	Parents parenting adult children
56 (B)	I suppose as I said we are always looking into our long term goal and is this a step that's going to help the long term goal. But obviously we are always looking to say is it is it suitable for Rachael does it meet her long term needs will she be happy, will she be safe.	Looking to the future; goal setting; suitability of provision; happiness; safety
57 (B)	Rachael and erm obviously reaching her potential will contribute towards the happiness as it were err err for all our children we would	Happiness; reaching potential
58 (A)	each of the visit's she's made, like going to [redacted] when we first went there I have to say we were we were shocked, positively because we thought this you know was sort of you know council run sort of with half-hearted staff and it'll be somewhere where people can park their disabled child and go and have a night out for a change.	Respite provision; parents apprehensions, perceptions and expectations
59 (A)	But it isn't it's it's a really lovely place and err with very caring people and the err it was you always have that feeling of what's it gonna be is it in our feelings (<i>respite</i>)	Respite provision; parents apprehensions, perceptions and expectations
60 (A)	you can't afford to have them is that rachael gets a series of bad experiences when she's away with other people and that will de rail err and make it very difficult then for us to leave her err we did have one when rachael stayed with some friends of ours overnight and the next time we went there she wouldn't take her shoes off..	Parents fears; staying away from home
61 (A)	that sort of coloured our thinking we want to be very careful and we have Rachael did go to one place where we were first able to send her to respite	Parents fears; staying away from home
62 (A)	adult respite we weren't very comfortable about it and we came away thinking hmmm	parents worries about leaving their young person with people you don't know
63 (B)	that was the hardest moment ever (A: yeah)	leaving young person with people you don't know
64 (A, B)	B: we were leaving Rachael with people who didn't know her, she didn't know them A: we didn't know them B: we didn't know them	leaving young person; fear of the unknown
65 (A)	and we didn't really feel...that they.....I know they	no knowing
66 (B)	they were listening	people not listening
67 (A)	I know they made a bit of an effort to listen to us rambling on but thee err it you	people not listening; parents feeling judged?
68 (B)	there were quite a few important things they needed to know that day medically for example her period started just before we arrived so there was things about that that we knew they needed to know	passing on information; other people not knowing information
69 (B)	because she could be sick and there was a young girl who didn't seem to, she didn't seem, she wanted to tick the boxes on the paperwork and get us out the	passing on information; other people not knowing information; workers being

	door she didn't seem to grasp the fact that the television did really need to work in Rachael's bedroom, because she had a bag of CD's and DVD's to play because we needed her to feel at home she was going to a completely strange place ... which you can't explain to her fortunately there was another girl who'd got it under control who she was working with but the one we were leaving her with dunno	"good enough"
70 (A)	also when we left there was a bloke ... one of the carers where male and she was left alone with	gender of carers; feeling uncomfortable
71 (B)	another lady with learning disabilities who overnight where staying with a male carer which firstly we were not very comfortable about its not something they had told us when we first signed up to this that that could happen and it was one of those moment where you thought I wouldn't be doing this with any of my other daughters at 18 saying that's fine dear. So why's it suddenly alright for Rachael	gender of carers; feeling uncomfortable
72 (A)	she couldn't be alone with if you was in a school classroom or something you'd be leaving the doors open so other people but	gender of carers; feeling uncomfortable
73 (B)	it feels like it breaks all the safeguarding rules to us but there you go	gender of carers; feeling uncomfortable; lack of information??
74 (A)	so that was that was a bit so we've err all of these things are we have to we have to be relaxed about were rachael's going as well as rachael being relaxed about it I guess what we're saying so you need to do quite a bit of research to find the places were thee there actually going to meet your fears or void your worst fears as well as the good things	parents expectations on themselves; parents researching the settings; having fears acknowledged
75 (A)	secondary effect of that which you hadn't thought about at the time is you do notice the other carers the professional carers which you say are bringing their charges	Parents thinking about the future; suitability of provision; parents expectations
76 (B)	everybody else was on their own or with support so you watch everybody and you look	Parents thinking about the future; suitability of provision; parents expectations
77 (A)	and you notice that they are there tapping away on their phones occasionally having a look to see what their charge is doing	Parents expectation, perceptions and fears about their young persons future
78 (B)	the group I decided the ones which where the best was the ones which were 100% involved there with the people they were supporting they all looked like they were all having fun together and they were fully whatever in the experience with them	Parents noticing other provisions and making decisions
79 (B)	So we thought right there the ones to talk to because I've looked at the others and I wasn't too impressed so erm and erm we we did look at every other one which was an option around in our wide area	Parents searching for provision; suitability of provision;
80 (B)	and although we are at [REDACTED] it's a bit of	Parents searching for provision;

	a trek to [REDACTED] we decided it's worth it for the people and she started there the day she was 18	suitability; safety; happiness
81 (B)	once that came online we transferred to them which means she's with the staff who know her	Relationships; parents feeling safe
82 (A)	the lady run the affair knows rachael well so which is good coz one of the things we've come to realise that that thee you need carers who are capable of looking after people on a sort of minute by minute basis but you also need people who have got a bigger picture involved especially when you're looking at supported living and someone is going to be living there	Relationships; parents feeling safe
83 (A)	so the person might come in for two or three hours or a shift or something but you want somebody who eventually is going to be saying it's about time rachael had a doctor's appointment or a dentists appointment or bought some new shoes or something, that that the thee having a structure that were its got somebody in that's got more of an overview I'm not saying they should be taking responsibility of that at the moment but you do feel that that they there is a bit more of a rather than just saying there another 6 hours we will look after her for there more to it than that.	Relationships; safety; being with staff that have an investment in the person
84 (B)	they take a positive interest in the persons whole life not just the fact that they are supporting them for a few hours	Being with staff that have an investment in the person
85 (B)	you've got to have good strong local management of staff basically you can see when it, we do know people who have experienced problems through our circles even then sometimes that problem has occurred because there are no local managers of things going on so when a problem comes there's nobody really there on the ground to sort it for them erm	Good management of provision to sort problems
86 (A,B)	A: learning these things you know B: we are learning from other people disasters and mistakes as much as we can (laughs)	Parents searching; learning or knowledge from others.
87 (A)	we have had people like [REDACTED] here and [REDACTED] and other people who have given there the been prepared to make suggestions the social worker we had has been pretty good we had a person who helped us write the EHC or rather we helped her write EHC.	Support from services; positive support; working with professionals
88 (A,B)	B: we wrote the EHC A: we did, we did, B: she listened, that was good (laughs)	Parents involvement in education; being listened too
89 (A)	bombarded us with you should have put Rachael in a	lack of understanding;

	special school earlier and she would have learnt far more than she ever did, we think no you don't know	professionals viewpoints not matching parents
90 (A)	but she did eventually agree that rachael needed an autism diagnosis and err so in a sense we have had a result out Dr [redacted] which will be useful for rachael in the future because these labels what we have found	Meaning of labels to parents; labels provide access to support for the young person
91 (B)	labels matter	Value placed on labels; labels to access support?
92 (A)	our opinions and thoughts and stuff are are are great but they are warm woolly words as far as the systems concerned until	Systems preferring professionals viewpoints over parents
93 (B)	a professional says them	value placed on professionals opinion versus parents opinions
94 (A)	so yeah what we've found works well is us to write stuff but someone else to sign it off so the EHCP plan which we spent hours writing, so thee Rachael's risk assessment at secondary school which we wrote which and then as a school they adopted as a risk assessment that became then that document fed into other things which meant that they believed	value placed on professionals opinion versus parents opinions
95 (A)	default that there's things that's gone wrong but we need to know that because we need a log of it from school which will then carry some weight because that then is used to assess our how much support she needs when she's not in from an advice to other people is concerned if you've got stuff that you need to get into other people's thinking when you're thinking how much resources to allocate to you, you need to get that signed off by professionals like, err bad 1cknowle or medical issues, autism	realistic information; value placed on professionals opinion versus parents opinions
96 (A)	because we can say Rachael's got autism traits but that won't count for anything but if Dr [redacted] r says she's got autism then it does count, people will then take that into account when their assessing erm how much money to allocate which in the end in a sense is thee is thee is one of the factors	value placed on professionals opinion versus parents opinions; funding
97 (A)	I think probably people could do with more help I mean we are prepared to do the research and look into what's available and other things but for a lot of people and again you'll have found this a lot of people who have got in the situation with a disabled child are a single parent	What would make things better; help and support; transparency
98 (A)	coz blokes normally have cleared off because they don't want to stick it out and that erm means that thee poor frazzled lady is left with little capacity to do anything other than get through the day so to go through to do the research to find out then you know is a classic thing of draining the swamp..... to err find the alligators thee thee haven't got the capacity to do that so thee thee that is a real problem for people.	QOL; family dynamics; lack of available family support; better support with a partner

99 (A,B)	B: yeah I mean we are fortunate aren't we really A: yeah	QOL; support from partner
100 (B)	at the beginning of our journey I initiated a little group of us when rachael was little and we supported each other through the downs syndrome association and err that disappeared as they got older	Parents supporting parents; support networks
101 (B)	one of the ladies that ran the action for children club had a daughter with severe learning difficulties so you could ask her questions and she was ten years down the line so you you just ask the people and I've said we've obviously been in some circles	Parents supporting parents; support networks
102 (B)	parent carer forum when rachael was fairly young and erm did quite a bit of work with them at one stage but err then I joined [redacted] when I thought we needed more adult stuff because that's the world we needed to start finding out about you kind of we made the effort in a kind of sense to find the people to support us they haven't coming running to us ever by and large	Support networks; changing support circles to suit need and journey
103 (B)	so it's quite a surprise to move into the adult social care world and find for a start that social workers are very different and they are not interrogating you as if you've abused your child now they are actually looking to support you as an adult...	Other services; systems faults; parents perceptions
104 (A)	when you go into a meeting with social workers it's called a child in need meeting and	Name and labels of the process and how they are interpreted by parents
105 (A)	and then you obviously the headlines are you know the social worker missed the clues and the poor kid was getting battered to death by somebody or other, an you you feel you're in one of those sort of meetings where your being looked at to think..	Systems; labels of process and their meaning; parents negative interpretations
106 (B)	the very first time I noticed it when she was seven and we had these people round trying to get some more support with Rachael so she could do things without us really because we knew this had to happen and we just wanted it to be a little gradual by gradual process and I'm explaining about the family you know I've got elderly parents I've also got I'm also looking after and the rest of my family are down south and some of these this is what I'm doing with her and she wrote nothing of that down at all the only comment she made	Trying to access support and assistance; feeling judged; parents feeling prepared, giving yourself time
107 (B)	was Rachael seems to have a good relationship with her mother she allowed her to blah blah blah and blah blah blah. Thinking hang on a minute what about everything else the information I gave you about our families	Not being listened to; feeling judged; ignored
108 (B)	erm sorry yeah so yeah that was our first experience of a social worker so I thought hang on a minute she came to judge my relationship with rachael and erm	Not being listened to; feeling judged; perceptions of professionals; giving up

	and like I said we get the reply her needs are being met and I thought yeah actually she's got other needs that are not being met but anyway we abandoned ship at that point and thought it's just not worth the hassle persevering..	
109 (A)	because they listened to [redacted] and not not to his parents so you've got err	Not being listened to, listening to professionals rather than parents
110 (B)	and the social workers told them years ago your far too articulate and middle class and you'll never get any help byebye so that's where they are 78 with him at home and err yeah we think oh dear. So having that in mind we probably think it's made us even more determined because we probably couldn't find ourselves in that situation	Professionals perceptions; inequality; parents looking for support; parents fears
111 (A)	yeah I mean grumpy enough as it is (laughs) but give me another ten years and I'll really seriously be grumpy old man and you know you can't be looking after somebody who effectively not in all respects but in some respects a two year old you you err you're not patient enough and other things so you need you need to accept you cant..	QOL; parenting adult children, being realistic; forward thinking
112 (B)	so my advice in the transitions would be as Andrew said you have to have professionals on board and helping you and saying the right things for you because they simply do not take parents word for you know for it. So you do need to get support somehow	Not being listened to; parents versus professionals; support
113 (A)	and for not thee thee and another thing we've said is not get discharged from anything, medically, so if you know	Value of labels and diagnoses; value of professional views
114 (A)	but thee but thee reason I mention it is because then if you've got people like the speech and language then err paediatrician and other people who know rachael and are prepared to write a letter that supports ..	Value of labels and diagnoses; value of professional views; support from professionals
115 (A)	very important that other people from a safety point of view when they are allocating resources again are looking at it as sufficiently so all these little things like that which say what age she's working at but it's no good just us saying that its important they thee.	Parents perceptions of safety; parents not feeling listened to; parents versus professionals
116 (B)	and other people looking after her most definitely	Worry about people other than the parents looking after their young person
117 (A)	yeah there a number of factors that come into play. One is as a parents you you you feel responsible for them and in a sense its nobody else's fault you've got a child it's your responsibility, like every other parent, to look after that child is one way of looking at it and that's the way we do tend to look at it but you also know that actually if you're looking at what's in the best interests of the child you sooner or later we are	Feeling responsible for their adult child; worries about when parents are no longer there

	not going to be here and it's quite possible that they will be so you've got to have, you've got have got some sort of exit strategy if you like for not being totally dependent on us. So there's so whilst we might well feel fully responsible for rachael and it's our problem in a sense its that isn't a solution to the long term so we have to look outside and it is, it is quite a big deal letting other people that you don't know look after her trusting and its was not a good experience the one we had	
118 (B)	thought to be fair she was happy	Happiness
119 (B)	and they didn't do anything wrong we found it quite difficult. She seemed resigned she sat on the bed and started watching her things and said bye so you know. She's quite tolerant really in many ways	Parents fears; fear of leaving the young person
120 (B)	now you have to get used to someone doing things differently and you have to work out what are the things that really matter that we need to say actually blah blah blah or blah blah blah just you know erm and what other things that you think it didn't matter it didn't matter if they did it in reverse order to me or they got her up differently that didn't really matter she will cope with change she wouldn't like to do things differently at home because what you do at home is how you do it at home	Other people looking after your young person; worrying other people look after your young person correctly
121 (B)	its allowing rachael to have that opportunity to have things done differently so she does get used to that. We said all along we need to know what does she need to communicate is there something we need to work on is there a word you don't understand	Acceptance; parents fears; apprehensions; planning for the future
123 (B)	it's a process of her you know of us helping her and everybody working out what does she need to be able to do to survive and more than survive be happy what does she need to be able to say to communicate all those little steps and erm for us to have that confidence in her and the confidence in the people looking after her	Happiness; planning for the future; parents fears apprehensions
124 (B)	and for us to get used to the fact she's not just gonna have things done the same way as we might have done them	People doing things differently
125 (A)	I think the thing that what we've said several times is that we've researched this we've found this out erm the people could do with a mentor to to who's not there to save money. Who is there to help people not just to sort of say if you did this you could do that go with them through the process.	What would help; planning for the future; support
126 (B)	I think especially if you're on your own..... it would it would have been much harder. I can do the finding out then I've got Andrew to bounce it off and he'll always draw it back to the key things	Talking to partner; support; what would help

	writing documents of all kinds I've been in education all my life Andrew's done some education type stuff as well as all his other kind of roles.	Parent
128 (B)	we've picked up the advice because we've moved in those circle and we've talked to people your constantly trying to pick up the hints and tips from other parents especially who have been through this process and I try and share them with other people and I've helped several other people	Talking to other parents; helping others; what helps
129 (B)	the this is me and the all about me and then you go into adulthood and care and you go to children's and you write another set of documents and	Having to tell your story more than once
130 (B)	go into the adult social care and you have to produce another set of document but fortunately the EHCP hasn't made any difference to education but it has been a good contribution to our adult care package and that's been the definitive description of Rachael	Telling story more than once; systems and supporting documents
131 (B)	so the fact it was forty odd fifty odd pages long was good because they've been able to use all that as evidence they needed so, so it came into its own because I did wonder why we'd been bothered actually, so it came into its own when we went into the adult world and we've used that so	Systems and supporting documents
132 (A, B)	yeah coz when we came here said sort of you know nonchalantly you know Rachael won't be in education when she leaves here (laughs)... We thought well you know our plan was that she would be you know B: well I think by then we A: yeah but it was B: what was on offer wasn't going to work	Transition to adulthood; education; misinformation; difference to parents hopes
133 (B)	starting the EHCP we was told by the educational psychologist who was a lovely lady but we only met her a couple of times when rachael was 15/16 she appeared we hadn't had one until then erm probably when she was about 2 we had one	Educational psychology
134 (B)	the next time well the fact is an educational psychologist we saw one to get her initial statement we never saw one again until we were coming to the transition sort of post 16	Educational psychology
135 (B)	she said (EP) get everything in there that you want to be covered until she is 25 so I took her at her word and then you think actually she's not going to be in education from 19 because what's on offer educationally isn't suitable for rachael she's actually learning more in the social care world	Educational psychology; supporting documents; advice; learning and type of learning
136 (B)	doing the things that are relevant to her than sitting	Post 19 provision; learning;

	around with other people at a table for quite some time because I've watched it happen, doing stuff that's totally irrelevant to her that's not meeting her needs so that was the err advice from the Ed Psych's so we did make it comprehensive in that sense so but it actually it has been useful	educational psychology; suitability of provision
137 (A)	yeah what we you know the things she like she mustn't be left in the back of the car with things and all these sort of things we've put in but because it's in there now we can refer as per the EHC plan this is the way	Parents sharing information; documents and usefulness
138 (B)	I've said we've been fortunate in sense that there's two of us we are used to doing this kind of stuff so we can find out we can pick up these things and we can	Support from the partner
139 (B)	I'll be quite honest we've had the odd little blip with the social workers in the children's sort of areas pleasantly surprised by the fact that it was a seamless transfer from children's into adults err	Transition to adulthood; positive experiences; other services
140 (B)	I had told them two or three years earlier at a meeting and they'd written her name down she coming up yes she will be and when I'd talked to one of the adults social care people at a meeting and they did know about her	Transition to adulthood; positive experiences; other services; sharing information
141 (A)	we you did tend to doubt, if you would, that when people said they'd do something they really would	Lack of faith
142 (B)	so we've had a seamless transfer from children's into adults a very good intake worker	Transition to adulthood; positive experiences
143 (B)	she's very good listens well which is pretty important	Parents feeling listened to
144 (B)	taking it on board and puts it into documents and what have you said and err	Parents feeling listened to; acknowledged
145 (B)	she'd condensed it onto these sections and I thought that is good it is accurate it was detailed and it was pretty remarkable so because we've not been expecting like I've said you're more likely well I'm a pessimist well you're more likely to expect things to go wrong	Parents feeling listened to; acknowledged; lack of faith
146 (A)	well I think we've we've expected that that you'd have to sort of fight for everything	Fighting; expectation of fighting
147 (A)	dare I say this is part of the problem that a lot of parents have they are so frantic that they they go in with the sort of fists ready to thump people and and err you know	Fighting; barriers
148 (B)	you're not going to get the best out of them if you're going in like that laugh	Parents working positively with professionals
149 (A)	I watched the programme lions last night you know the lioness trying to defend her cubs is thee thee	keeping your children safe; being protective of your adult

male that's the sort of thing isn't it? Your there defending your children against all these people who are trying to harm them is the mentality	child
most of the people who id met through the parent carer forum world where there because they'd had battles and they were wanting to they were ready to fight	Fighting; parents supporting parents
we have had a tremendous amount of flexibility the county council have backed our choices each time partly because it's what they wanted and erm so we we were we count ourselves fortunate but it's partly because we worked at it	flexibility; parents working with services
you have to learn how to deal with people and erm things so as Andrew said people who are not in our position having someone supporting you is probably the thing you're going to need the most	Having another person to help you if you are alone
I know from conversations I've had with both mums recently they haven't done anything about next step at all and they've not got social workers, and they've got nothing place, and I'm thinking ahhhh you need to start thinking and I'm trying to encourage both of them to think for one their daughter is the eldest in the family and they have two young children so in a sense they haven't thought about the long term she's not a young mum particularly but they've obviously got two at home so they are not thinking along the lines of they need to be leaving home	Planning for the future
where for us rachael is the youngest by quite a long way so we are already geared up to the idea that children need to move out	Future planning; parents accepting young person being more independent
we knew we'd have to find those things out for ourselves and we'd have to delve into the future by ourselves and I sort of assumed that special schools would be geared up to that	Parents seeking information; parents assumptions/perceptions of provision
it's a relief to have your child looked after and given back at the end of the day	Having a break
it's not the sort of thing where somebody could say ah have you thought about getting a social worker I think that's the sort of thing that's not the sort of conversation people are having	Not talking about sensitive subjects
and as far as I can see to have a successful transition you have to have a social worker	Access services for support
to have provision for somebody like Rachael post 19 it's going to be a social care package or thee equivalent	Post 19 provision; acknowledgement of type of provision
and its best to get in beforehand that thee thee the need the fact that they've got needs that can't be met	acknowledgement of young persons needs by services

	exclusively by the parents have been acknowledged while they are still a child	
161 (B)	the county council want to know what the needs are going to be in five ten years' time they need to know what's coming that's why they want us to do it but they said they don't want to put my child's name on a children act register because it sounds like you've just become a criminal or you've whatever	Future planning; what would help; support from services
162 (A)	the other child, child at risk, child in need you could be in jail next week	Systems; parents perceptions; barriers
163 (B)	they need to know our children exists and that they are coming on board and at some point which is why I spoke to the social care the adult social care	Future planning; what would help; services knowing about young people in advance
164 (A)	yeah coz err err thee thee county council doesn't actually know how many disabled children there are when I last asked there's estimates made	Planning in advance
165 (B)	I think our biggest hurdle was getting a children's social worker and that seems to be a critical step and if it hadn't been for the carers first lady who did a very good job	Future planning; positive support from services
166 (A)	so somebody came along and listened and did something positive, you know not just listen but did something,	Parents feeling listened to; what would help; positive experiences
167 (B)	Looking back, I'd done somethings to initiate it, but if she hadn't come along at that point I don't know how it would have panned out. So getting into the system as a child was critical to the next steps so it's one of those things you know you think hmmm things could have been very different without that ladies support, you know intelligent support, thoughtful and proactive determination to do what she felt was right for us a family and get it and there are occasionally those pivotal moments where you think hmm things could have been very different we could have been sitting here tearing our hair out if it wasn't for that one moment where she says right they need a social worker this is ridiculous I'm not going to stop or getting off this phone until you've given her a proper assessment..	Future planning; what would help; parents seeking support; barriers to services
168 (A)	advocates it would be nice if you could ask people to buddy up but I think it would be quite a big ask, its erm it really requires funding someone to do it,	What would help; parents supporting parents
169 (A)	take people through several stages not just a bit of advice and then stand back, would be to do as the ██████ in our case, to do something positive that would be a big help for everybody because it can be very draining because there can be people who wouldn't want to do things for themselves and want	What would help; parents supporting parents; realistic

	someone to do everything for them and that would then drain the entire resource..	
170 (B)	and some people wouldn't want the intrusion,	QOL; family privacy; barriers
171 (B)	you have to be prepared to allow people into your lives basically and not everyone can cope with that...	QOL; family privacy; barriers
172 (A)	if someone is physically helping it it's very important that it's the right person in those roles, if they genuinely want people to,	What would help; suitability of professionals
173 (A)	with all these things there is a danger of encouraging 1cknowledg need you can 1cknowle the need by making it hard for people to apply for grants or what have you and that makes it hard for people	What would help; realistic options; support
174 (A)	It's hard for the county I'm sure to encourage people to get to ask for help because that's going to cost us money so it's not an easy thing to do but if they actually want to help people, especially the ones that are struggling to do it for themselves then erm there needs to be a few more boots on the ground.	What would help; realistic options; support; funding

Jane's Interview

Number	Narrative	Interpreted meaning
1.	Donna left school 19 plus because she had a July birth date and she had an extra year but that was with help from because I think she missed it by a day or two erm when she actually left school,	Support; support from school
2.	...erm well before she left school we went into transition which you go round and look at all the facilities. Obviously none of them was good enough, coz as for a mum nothing is good enough.	Post 19 provision; parent perception; not good enough; wanting it to be good enough
3.	We went to see quite a few and they was umming and arring as to if we would get the funding to take her to Hull,	Post 19 provision; lack of funding
4.	...then I looked round [redacted] t the Autistic Unit and that wasn't appropriate because, erm I mean Donna does do a runner and they had no locked doors or no policies for locking doors, or it wasn't on camera or anything like that so that was no good.	Post 19 provision; safety
5.	... we set up a classroom in there hoping we would get funding for Donna to come here as it was more appropriate for her	Parents sorting/1cknowledg provision by themselves
6.	Donna actually left without an education, any education at all..	No education; no support
7.	...because at the time I can't remember what it was that come into practice. It was something just, she'd just missed, so she leaves with a statement but she just missed something that's in now....(EHCP)	Transitions; post 19 education; lack of information; misinformation

8.	So Donna had just missed all of that so she wasn't entitled to anything, erm so which was hard.	Transitions; post 19 education; misinformation
9.	So then erm I went to loads of meetings about what she would get and what she would be entitled to through well it was direct payments. We went to some meetings and they said they would give us 30 hours because obviously Donna needed every day Monday-Friday as she was getting from school and they said the maximum they could give us was 30 hours the rest I'd have to use out of my direct payment package, so we said right ok.	Support from other services (social); parents expectations of support
10.	So she left school we had to set up a classroom, find furniture computers to do this on our own, which was hard work. Find a PA that would look after her as well which is really hard nowadays to find a PA.	Transition to adulthood; Post 19 provision; parents searching, feeling alone; going it alone
11.	She didn't like going out, she didn't like going to the supermarkets, I couldn't go shopping, sleeping, erm anyone with a ponytail she used to grab. Erm sleeves up on your jumpers, anything was a distraction to Donna. Anything, doors open, just anything, she used to bite herself, erm and she just didn't like coming out of her routine at all which is hard especially going to somewhere which is bigger environment, she used to do a runner if she wasn't strapped into her chair,	QOL; difficulty managing day to day life; going shopping; keeping young person safe
12.	At home the house is all secure for her; this is why we actually picked this place for her because it's all secure	Safety; security in the home
13.	And then from there, we came here and set it all up for Donna at and got the package from direct payments to pay a PA for Donna to come here five days a week. Anything above and over that, like transport getting her to and fro from my house we had to sort out,	Transition to adulthood; parents going it alone; lack of support
14.	then we got told she was entitled to education and she'd just missed out on an EHC Plan so we went for this, "no she's not entitled to it"	Post 19 education; misinformation
15.	We thought yes she is so then that was a battle from the age of 19 still to date. A battle for education she has actually got three mornings a week education a teacher comes into and teaches Donna and	Post 19 provision; fighting
16.	she's only been having it a year now because it took us that long to get it all up and running and into place,	Post 19 education; parents going it alone; lack of support
17.	The council playing the games that they do.	Parent's feeling not listened to; 1cknowledge1p1 systems barriers
18.	It was hard work, draining, mentally and physically, it was hard work and for any parent I wouldn't wish it on any of them and the money its cost us, its cost us an absolute fortune but we wouldn't back down, because at the end of the day she's entitled to it.	QOL; costing parents money/ finances, feeling like your fighting; affecting health and well-being
19.	Finally we got the three days a week, erm we do have days were they can't cover they have not got enough staff. So we jot it all down and when things do blow up again we	Feeling as though they have to fight; fighting for education

	have some backfire to help us. We are still in court fighting educationally, we are back again in June erm	
20.	M: What are you fighting for? A: her education still, and health and social care as well.	Fighting for health and social care
21.	more hours that she deserves because at the end of the day if she's put into a full time home they would have to pay for her so why can't they if she's at home? This is my ploy, and they don't, they don't want to know, erm but since it's been to court I've got more hours and get more help with Donna	Fighting; lack of support; inequality due to young person being at home cared for by parents
22.	It's just draining sometimes. Some days if you're not well you still have to get up and change a dirty nappy, you still have to get up and wash her dress her and feed her, it's like a baby. You can't just leave it cry	QOL; parenting adult child; no choices
23.	It's just totally draining but you have to carry on with it.	QOL; tiredness; no choices
24.	M: did you have any help and support A: no, M: when you transitioned from school to adult services A: none whatsoever	Transition to adulthood; lack of support; feeling alone
25.	None, I didn't have a social worker at the time. They just said to the direct payments workers you do the hours and that was it. It was like the blind leading the blind. Basically they didn't want to know, we had to set it all up because we wanted her to come here. Maybe if she'd have gone somewhere else it might have been different but because we wanted her to come here we had to do it all ourselves.	Transition to adulthood; lack of support; parents finding provision; professionals not supporting parents choices
26.	When she left school the school helped us put some tables in, we had to do it all as parents.	Post 19 provision; school support; parents finding provision
27.	And we weren't the only ones that came there were a couple that came with Donna as well because they liked the facility, and came here because it was secure for them and because there wasn't too many people that you know could interfere with what they were doing	Safety;
28.	And she was lucky you know because she got five days and we used those hours for that, but some only get two days a week some get one and some get three.	Transition to adulthood; support; perceived inequality; parents talking to parents
29.	Erm but it was hard work if I didn't find a PA and we hadn't have found this facility I don't know where she would be today. She wouldn't have come on as she is now	Post 19 provision; school support; parents finding provision
30.	I can actually take her into a supermarket, she actually packs the shopping. Erm she knows when she's filled her nappy; she's come on in education since she's had it in the last year. We have had a meeting, in how much she has come on and erm she puts the pots away she'll help putting food away in the cupboards, and she's never done that, never in a million years and it's since she left school she's done all this	Post 19 provision; making progress; independence for the young person/helping out
31.	And because she's getting 1:1 or 2:1 which she obviously	Post 19 provision; higher

	wasn't getting at school which they say they do, and they don't and how much she's improved because she's getting that is amazing it really is.	Staff ratio leads to progression
32.	No erm there was, Donna, erm I looked at a couple of places out of town for Donna to be residential but I didn't want her to be residential I wanted her at home with me	Post 19 provision; choice; parents preferences; keeping young people close by in their community
33.	Because she can't talk I think she's vulnerable and I want her at home with me. If she could then yeah but I, trust, that's me. I've heard it all before and I wouldn't.	vulnerability; trust; safety
34.	She went a couple of places out of town and they weren't suited it meant travelling an hour	Post 19 provision; suitability, being closer to home
35.	and I'd have had another big fight on my hands with the council to sort it all out because not only would, it would cost her to go there it would cost transport as well, carers there, it would cost a fortune so. And it was out of the boundary so it would have been another fight on our hands	Fighting; lack of funding
36.	I thought I didn't want her to be travelling an hour and a half every day there every day and an hour and a half back, 3 hours, she's losing valuable time. If she got education there that's three hours a day she'd have lost she could be learning	Post 19 provision; suitability;
37.	So erm I went to [REDACTED] and that wasn't appropriate, and I went to another place and that wasn't appropriate, I went to another place in [REDACTED] which had an Autistic unit which wow that was great, it was a square bedroom smaller than hers with a TV and a beanbag in which was a sensory room well no she wasn't going there she might as well have stayed at home to do that	Post 19 provision; suitability;
38.	The facilities for children like Donna are disgusting, absolutely disgusting.	Post 19 provision; unclean; parents preferences;
39.	And [REDACTED] resource, putting her in there with people aged 70, 80, 90 no she's a young adult. If she strips off way hay, you know what I mean it's wrong, totally wrong with children and that age gap. And she won't be going there either.	Post 19 provision; not age appropriate; parents preferences;
40.	So erm the choices no disgusting	Post 19 provision; choice; suitability
41.	I wish there would be something here which they are trying to do here but the council just throw it in your face all of the time, because it's ideal it's local to all to communities. They don't have to get transport all the time to go out to access it all, they can walk go in their wheelchairs, you're at the beach, you're at the shops, you've got bowling, you've got swimming. You don't have to keep going on a bus every five minutes. Surely that's	Post 19 provision; parents wishes; something close to home in their local community

	saving money somewhere along the line?	
42.	I just thought its ideal for her to access the community here where a lot of places are out in the wilderness and fenced off, and I thought no	Post 19 provision; choices; community living
43.	But as for transition I think I knew what I wanted it was just getting the hours and a PA to find to suit Donna's needs so maybe in that respect I was one of the lucky ones	Post 19 provision; parents choices, knowing what you want; feeling grateful
44.	Others getting education for people is hard work, really hard work and they don't like parting with their money to be honest but then who does?	Post 19 education; lack of funding
45.	And I knew when I saw them there was nothing out there, nothing whatsoever, for a young girl or a young boy going to some of the places that they send you, there's nothing, there's nothing out there that gives a child that age fun, and life and learning, and obviously Donna can't make it out in the real world on her own but some of them can and they are the fortunate ones I suppose but erm no there's nothing.	Post 19 provision; lack of provision
46.	Some of them were dirty, they weren't clean, the changing facilities were disgusting and you don't want that	Post 19 provision; safety, cleanliness,
47.	She couldn't go there it's an open door policy she'd have been running out, and sorting everybody out with their hair and sleeves and closing doors.	Post 19 provision; unrealistic options; safety
48.	I think the transition team are very, what's the word not to sound horrible. They have got no clue basically, they have got no clue. I think they need to have a child themselves to know what it means to some of us.	Transition to adulthood; lack of understanding from services
49.	Erm basically you left school and that's it now you're on your own and that's it now, that's how we felt and other parents that was with me as well.	Transition to adulthood; feeling alone
50.	they just said we might be able to get you 30 hours and I said you better do because she aint leaving until, basically, you've got to be full on with them, basically she's not leaving until she gets five days a week, and if she doesn't we will take you to court so you've just got to say that constantly.	Transition to adulthood; other services; fighting
51.	I think if not we would have had another battle on our hands to get her here five days a week	Transition to adulthood; fighting
52.	I think they knew it and I think for Donna's needs and her assessment, obviously they get assessed, and I think they thought oh well we'll give her that amount because she's got to stay in a structured routine like she did at school.	Transition to adulthood; the needs of the young person same as in school
53.	I had her home all of that time, because it wasn't set up for wages for the carers or nothing, so they need to get the plan into gear so as soon as that child leaves they need, a the payment facilities and everything all set up, that time that gap between was hard work and trying to tell someone like Donna she can't go anywhere for that long a period until it all kicks in is disgusting.	QOL; parenting adult child; work life balance; support not timely
54.	But it is stressful, it is tiring it is a joke basically	QOL; stress and tiredness; no choice

55.	The year or two years before they need to start this transition, but nothing sort of goes into place. You're just looking at places and talking. That child you need to know, say if you leave school at 18, at 17 they need to get into that transition they need to go there three days a week and then once they actually leave and then that next week they go in five days a week. That's what I call a transition.	What would make it better; staggered visits until in full time
56.	I don't call a transition starting at 16 we will talk about it and then at 19 oh we've got nowhere to put her, and nearly at 20 oh yeah we've found somewhere and at 21 you can't have education because you're not entitled to it and we've got nowhere to do it, but at 24 you can have it for a year. That's how it is.	Transition to adulthood; misinformation; support not timely
57	It's wrong it should all flow like anything and that how it should work I know in the real world it doesn't but for children like Donna it's got to, it's got to flow, because they are out of routine and all that and all the work you've done has gone out of the window.	Transition to adulthood; what would make it better; staying in routine; seamless
58.	it's like having a baby, you can't just drop everything and go out you've got to think all the time if I want a night out whose going to look after your daughter	QOL; parenting adult child; life balance
59.	I mean I'm lucky I have a son and daughter in law who lives next door to me so I am lucky like that and I've got a niece who can come and look after her.	FQL; support from family
60.	Its it is hard work. If you go out, you've always got to be home coz the carers need to be home it's like having a baby, and you need to care all the time. And obviously you can't take her to some places because it's not for Donna she likes to run around with kids or she likes to go to the park. She doesn't want to be sat in a pub does she? Or going away for the night, you can't do it.	QOL; parenting adult child; finding cognitive age appropriate activities
61.	Recently I have just taken her and it's took me 11 years to pluck up the courage, took a carer with me, alright we didn't sleep ideally but you get over that because I wanted to do it for her.	QOL; parenting adult child; wanting to do "normal" family things
62.	she is getting better one step forward two steps back	Progress in the young person
63.	I am lucky I have a supportive husband and Donna's our life basically we all work around Donna, our house works around Donna, we've never known no different if you know what I mean so you just get on with it.	QOL; support from partner; getting on with it
64.	I mean to put Donna in with another family, I think, it would be hard, we know it from birth and its life	QOL; 1cknowled family difference
65.	we can't do this weekend because we can't get a sitter or well be there in an hour because I have to sort Donna out first or I have to pack a baby bag basically, and make sure you've got everything for her. But I've never known no different	QOL; parenting adult child; residing yourself
66.	You just, the only thing is when you get older it gets harder, some momings you ache and your body aches but you have to get up who's there for you have to carry on	QOL; harder to parent adult child as you get older; age of parent

	don't you it's the way of life. Take it as it comes and grin and bear it	
67.	See I never accessed any of it so I'll be honest I never did. Because it was all integrated with school I did it from school. So the transition team sort of sent me to places where they thought was appropriate for Donna see, so I never accessed anything like that I just took their information that they give me and went to look at the places they thought was suitable for Donna.	Transition to adulthood; taking professionals at their word; relying on their expertise
68.	I did have one of the teachers come with me as well and they advised me because they worked with Donna all these years and they erm showed me what was available and they advised me no good for her, so I had that bit of help.	Transition to adulthood; visiting places with someone who knows the young person well
69.	I just as a mum I believed the transition team in what was available to show me what was available for her.	Transition to adulthood; taking professionals at their word, relying on their expertise
70.	I just think there should be a wider spectrum of places for children, not just like Donna but any disability. I think transitions should be easier, than what it was for us	Transition to adulthood; post 19 provision; what would make it better; more choices
71.	They are lucky now they leave school with an EHC plan because they are entitled to education although a lot of people don't know it. And they are not getting it.	Transition to adulthood; access to education
72.	I do personally think there should be more out there for them definitely, and as a parent we are in coming up to a new generation and I think they need to get their arses into gear and get it sorted, for them.	Transition to adulthood; post 19 provision; availability; what would make it better; more choices
73.	well obviously it's going to take money from the government	Transition to adulthood; funding; what would make it better
74.	Maybe build another school that would access children from 19 to whenever. You know what happens after 25 only we will know. But erm if they are entitled to education why not build a school? 19 to 25, you've got a college.	Transition to adulthood; post 19 provision; availability; what would make it better; entitlement to education; build more provision
75.	But they've still got the motivation to get up in the morning, they've still got mixing with all their peers, why should they be segregated, from all the kids that they grew up with. I think that would be great and that's what some people are trying to do but they won't have it.	Transition to adulthood; post 19 provision; availability; what would make it better; being with friends and similar ages of peers
76.	But I think that would be great another school for 19-25 or when they say education stops. It doesn't have to be full on education, morning education and then access the community but if they got together, education, health and social care together and did something like that I think that would be amazing, wouldn't you? They've knocked enough down, rebuild one (laughs) DIY SOS. (laughs)	Transition to adulthood; post 19 provision; what would make it better; more flexible provision to meet the needs of the young person

Wendy's Interview

Number	Narrative	Interpreted meaning
1	She is very vulnerable erm person	Safety Vulnerability
2	Ah yes, yes she can't be on her own at all she needs someone with her 24/7	Safety Vulnerability
3	R: ok, is that to keep her safe? W: yeah, yes	Safety
4	So when Karen left school, were I felt she was quite safe there	Safety
5	She k [REDACTED]	Relationships
6	She was very happy to go there	Happiness
7	We were informed because she'd stayed at school until she was 19, instead of leaving at 16 she would only get 1 year at college	Misinformation Disappointment
8	Which to me was nonsense because other children sorry, other young adults got more time, some got 2 some got 3 years and stayed until they was 22	Inequality More education
9	But my daughter only got 1 year and I felt that she needed more but basically I was told she only go the one year, so Karen left at 20	Parents hopes More education
10	Basically it left me with me having to deal with everything that she had to do from then on	Lack of support Feeling alone
11	So the transitions from then was looking for places for Karen to go	Searching for places
12	Really not wanting to go but I pushed her to go because I hope she'd get a little job at the end of it maybe	Independence for their young person
13	She got moved about a lot or had different erm young teachers helping her out probably similar age to Karen looking after her. She'd just get used to someone and they gone or they have gone to another room	changes to staffing
14	So she wasn't enjoying going because she had no consistency and Karen like most young uns with Down syndrome don't really like change so we really struggled	change to provision
15	I persevered with it hoping shed get a job at the end of it	Independence
16	Was then to be told after a year of being there or we don't do that anymore there's not enough money in the pot sorry, so we left	Disappointment Lack of funding Loss of provision
17	I then took it on myself to ring the employment mobility services through the parent that told me about it and I rang and spoke to them myself	parents searching for provision.
18	But she's absolutely loving it	Happiness in the provision
19	She loves it	Happiness in the provision
20	I knew she had the capability of doing something like that so I pushed for that to happen	Independence

21	He used to work at [REDACTED] but he didn't agree with how the place was being run because it was getting less and less staff and us parents wasn't happy, and he was speaking up for us and he ended pretty much losing his job	Post 19 Provision; lack of funding
22	My daughter she can't get enough of it. If I could afford to send Karen I would she loves it absolutely loves it	Post 19 Provision; happiness More of what makes YP happy
23	He always asks them what do you want to know and he helps them massively	Post 19 Provision; parents hopes/supportive provision
24	Karen absolutely loves [REDACTED], so that's what she does	Post 19 Provision; happiness
25	But again we've had to pretty much search it all out ourselves	Post 19 Provision; parents searching for provision; lack of support
26	I knew about that because id spoken to them myself	Parents own knowledge
27	If it wasn't for that or other parents helping me i.e. I didn't know where to go about this voluntary job and another parent said	Parents supporting parents, information
28	Once Karen left school to go to college, that wasn't the best experience in the world	Transition; negative experiences
29	You feel like you're on your own	Transition; feeling alone
30	You're not because you've got other supportive parents out there and you try and help each other but it shouldn't be down to that really should it? Just the parents helping out	Transition to adulthood; parents supporting parents
31	I don't feel we should kind of just be left to kind of fight I mean we I fought for 21 years for my daughter for everything in life but yeah it seems to get harder as they get older	Transition to adulthood; fighting for provision
32	They 1cknowle their mistake at the end which I think is why she only got a year, somewhere along the line there was a bit of a mix up	Post 19 Provision; lack of communication,
33	She was going there and they were treating her a bit, and think this particular day Karen just got a bit upset	Post 19 Provision; fears, safety, vulnerability
34	I did even really know what had gone on	lack of communication; safety
35	I don't to this day, I think everyone was trying to cover it up	lack of communication; safety
36	A member of staff from [REDACTED] had really come down on Karen proper shouted at her made Karen cry and the person who was supporting Karen from [REDACTED] said to this woman no more she's not coming back and they pulled Karen out of the café	lack of understanding of the young persons needs in the provision; safety; vulnerability
37	The lady that worked at [REDACTED], I was grateful for and I kept saying what happened but no one seemed to tell me anything	Post 19 Provision; lack of communication
38	They thought Karen had done some work experience in a café at [REDACTED] or whatever but they was all shocked that she'd never done it and she'd been thrown into it that quick	Post 19 Provision; lack of communication
39	Now when Karen went up from school to college she went with three of her peers that she moved up with not one of them did any work experience in the first	Transition; lack of communicating young person's needs between provisions

	year and they were there for three years not one, Karen was pushed straight into it	
40	None of them was really there for her I don't believe. It was so hard Karen really struggled in college so I wasn't very happy with it, and me as Karen's parent I wouldn't recommend it to anybody, I'm afraid, so	Post 19 Provision; suitability of provision
41	Erm no just one of the teachers at school was just before they left school to go to college that things was getting tighter and she did say that they maybe will only get one, two or the most that they would get is three years and she'd seen a lot of children transition erm [redacted] school onto the college	Support from school transition to adulthood; Post 19 Provision availability
42	She was the one that did all the transitions and erm and she she probably helped the best she could but that was only bit of advice we got so	Support from school; transition to adulthood
43	When they did the introduction day I thought it sounded good and safe for her being there	Safety; college
44	There was a few things again and it didn't happen with Karen one of Karen's peers who went ended up getting pushed by a peer and he ended up leaving the building and he wasn't found for four hours before everyone didn't know he was there anymore and it just didn't give you that security	Safety; college
45	So [redacted] from 7 – 19 fantastic amazing, I felt she was safe	Safety; school
46	She absolutely loved it	Happiness; school
47	It's getting easier now because she's in places she likes	Post 19 provision; happiness
48	I've had to deal with all that, I haven't had any help from anywhere	Support; feeling alone
49	I have but it's been other parents we help each other out	Support; parents supporting parents
50	But any other services then no I'm afraid to say haven't	Support; lack of support from services.
51	Karen's own social worker she got in touch with me three weeks ago and said it's her annual review and I haven't seen her since the last annual review and there's been a handful of times when I've felt I wanted to ask her a few questions and stuff and I can never get hold of her she's always on holiday so even that support network is not really there so, it's been a bit of a let-down really when it comes to any extra services for our young adults I'm afraid	Lack of support from other services; feeling alone
52	No, from [redacted] the only place you could go was [redacted] college there was no offer of anywhere else or nothing	Provision; lack of choice
53	After we had been there a year we got the letter to say she didn't have another year and of course I appealed it and was in a meeting at [redacted] with all these other social workers and people who work at the school and then the transitions and I actually said as far as I am concerned it's all about money if there's not	Post 19 Provision; lack of funding

	enough money in the pot you won't keep them, that's the way I kind of see it	
54	And they was saying well look if she'd left school and 16 and come here she would have been here for three years she would have got her three years	Transition to adulthood; misinformation
55	I said no you're not listening to me	Not feeling listened to
56	All the guys that's moved on before Karen went from at 19 and got 2 or 3 years depending on what they needed, she only got 1	Post 19 Provision; perceived inequality
57	I wanted Karen to do an extra year because I felt she needed more help especially with her English and maths and she wasn't given it so I now don't seem to have much faith in it to be honest	Lack of faith; more education; more support
58	It can be quite hard because I'm a single parent, it is just me and her	Feeling alone; lack of support
59	Lucky for me I have a support from family	Support from family; family network
60	I have to rely on someone every week and some weeks it can be awkward because I don't know who's picking her up from one Friday to the next and obviously Saturday when I'm working again and I either need someone to be with her or if I'm only at work a few hours she has to come with me unfortunately so, but she can't be left like I said at the beginning she has to have someone with her, so because I have no choice I have to work so yeah erm so yeah	Quality of Life; working commitments; juggling commitments
61	Again really I just talk to other parents, I've tried to help out	Support parents supporting parents
62	Luckily for me I know all this and I've done the research myself or other parents have told me, or looking on social media and things and I've even googled things	Finding information – parents searching
63	There only been a couple of times when I've looked and wanted to know and I've probably gone to Karen's social worker not with much joy but that's who I feel could help us out because she is her social worker, but no	Trying to find support but support isn't available
64	There is another service, I got a letter other day, [REDACTED], there's just an annual thing once a year where they want to talk to Karen and see how she's getting on but apart from that and apart from the social worker we don't really hear from anyone else	Lack of support from other services
65	I don't really hear from the social worker, the social worker rings me when she wants to do the annual review which is what she has to do	Lack of contact from services
66	If I try to get hold of her I get another social worker	Support – lack of relationship

	how hard it was and that was just going through the social work system so erm yeah again I just don't have much faith	
68	I feel that if I kind of need to know anything I ask another parent if they've been through it if you get what I mean so so again I think it's more of a parent network than anywhere else to be honest because I don't really know anyone else	Support; parents supporting parents
69	Unfortunately I'm quite independent and I try to just crack on with it myself so yeah so I just do – support	Going it alone
70	But it has been hard, it has been hard	Difficulty managing (QOL)
71	Even now once they go out from school to bigger things like the college and everything and it's not just about the education, but we have to then find dentist, opticians. Like at school well they don't always find a dentist but they come into the school so from leaving school we have had to do all that now that sound easy to a normal parent but when our kids, cant, don't like dentist or don't like doctors its quite hard work to find someone that	Transition to adulthood; lack of holistic support; parents searching
72	So the second they leave education you've got it all to again to fight for	Fighting
73	R: You keep mentioning the word fighting, W: Coz I just feel that's all we ever do so, yeah -	Fighting
74	From say three months before they leave school to go to college there should be more meets with the parents and even school, or meets with the person they are going to approach next	Transition what would help; relationship building; being familiar with provision
75	She was probably the most helpful and she worked at the school	Transition to adulthood; positive school support
76	And then when it got to college we had the introductory day and everyone seemed great and it was all sounded amazing but once they are in there it's just not	Post 19 Provision; not as it first appears
77	But I just believe for our young uns as well as for us parents to feel more at ease yeah more should be done and spoke about before that because it was just it I don't know it just didn't glide, didn't, it all sounded so good	Transition; not seamless
78	I, just that you know your own young un	Parents knowledge of their own young person
79	She never really wanted to go to college and after say three months she never really wanted to cook in that café, and I didn't know because nobody was telling me. But obviously I think she was either being bullied or there was something not right but she couldn't describe it to me but I knew there was something wrong because she didn't want to go	Post 19 Provision; lack of communication; not safe; not happy
80	Same with the and I had her one day crying saying she didn't want to go and I just thought enough is enough she's 21 I didn't want to make her do it but I	Post 19 Provision; lack of communication; not safe; not

was persevering with her hoping she'd get something at the end of it and I thought why am I putting her through that for a year then I just don't understand	happy
Things should just be spoken to and give them a bit more time because our guys need that time. They can't just come out of one thing and into another they can't do that we just deal with it like we do, I think they need more	Lack of understanding from professionals in provision
I have to plan everything	Quality of Life; planning for future events
I just don't think they can jump in from one thing to another so yeah I do feel that perhaps they should have had one visit from the college maybe two or three	What would make transition better ; more frequent visits to provision
I just feel that people should just talk more to the parents and the young uns from where they are transitioning to and from, I think that might help	What would make transition better; more communication
I think that was the biggest thing for Karen I kept telling her she was moving to a bigger thing and we looked round, oh its' great and that, but it's alright seeing it but doing it is two totally different things	Transition to adulthood – Post 19 Provision; reality of moving to a new provision
Our guys don't like change she's not keen on change and I do have to forewarn	(QOL) need to be aware of change
So yeah they need pre warning really	What would make transition better; taking into account the young person's needs
Jumping out of one thing into another is just not easy for them so I just think personally if they could add a few more visits than normal spoke about it a bit more rather than just expecting them to slot in, I think that would help	What would make transition better; more visits to transition provision
Back to your fight I feel we have to fight for everything with our guys it's just not there anymore, everything education for them to do fun things, yeah, form filling all the time, I feel like I spend all my time filling in forms and erm so yeah that's what I meant by fight (laughs)	Fighting for education, fighting for activities, justifying yourself and young persons needs
I just feel that they probably should be told a lot more, the parents and the young 1 know what what's about to happen next especially form the transition side	What would make transitions better; more information for young people; forewarning
From a parents point of view erm it's an hard one it would take me days to tell you this rather than a few minutes or hours. I dunno I just get up every day and get on with it, it's quite an hard one to answer that	QOL; getting on with it
It is very hard for our guys to deal with a lot of things in life I just feel that they need a lot more time than they get that's the only way I can really express it	What would make transition better; more time for the young person to process the transition
My daughters experiences wasn't that great and I just	Transition to adulthood; lack of

Appendix 8 – Phase 3 Data Analysis

Phase 3; searching for themes

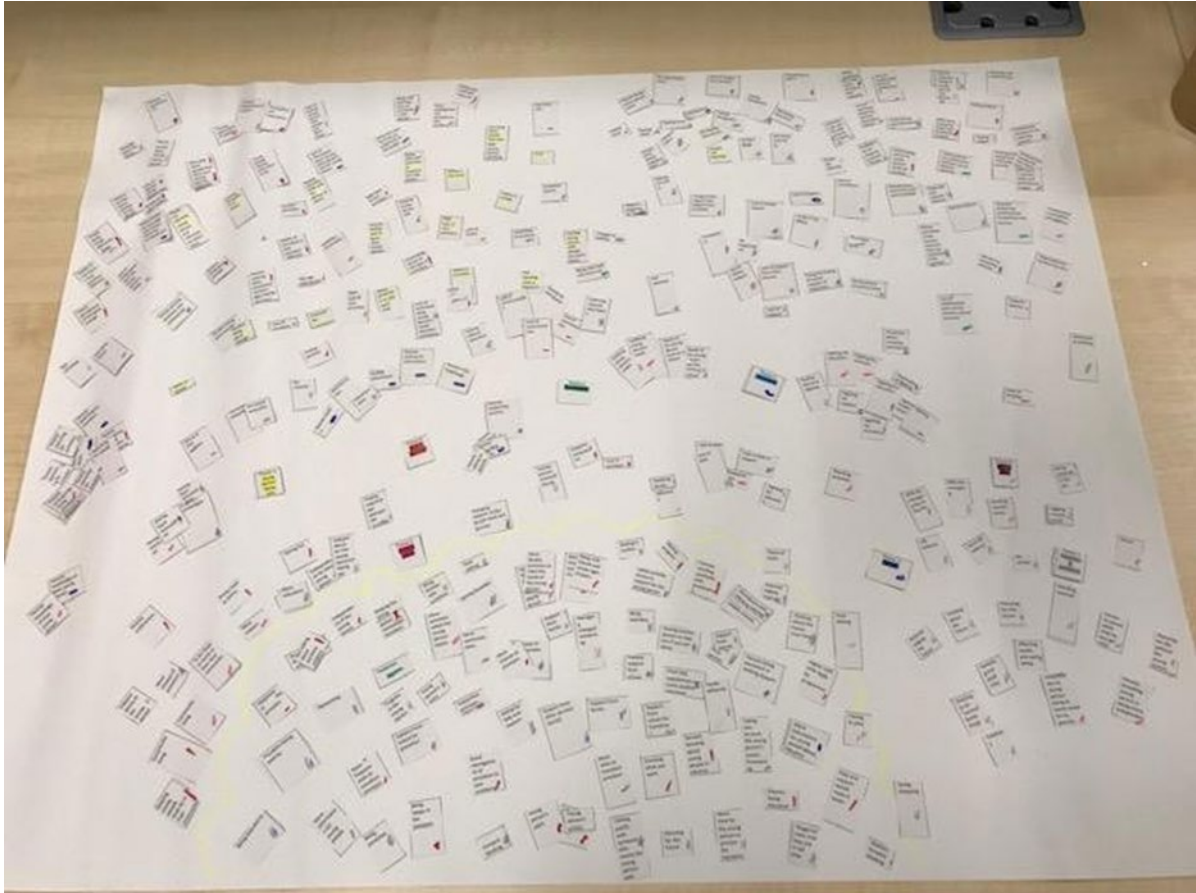
Theme 1: Young person being safe	Theme 2: Relationships	Theme 3: Information	Theme 4: Parents' wishes	Theme 5: Support	Theme 6: Post 19 Provision	Theme 7: Transition to adulthood	Theme 8: Quality of life
Vulnerability	Happiness	Misinformation	Disappointment	Lack of support	Lack of funding	Negative	Feeling alone
Safety in school	Changes to staffing	Feeling alone	More education	Feeling alone	Loss of provision	Feeling alone	Lack of support
Safety in college	Not feeling listened too	Searching for places	Independence for their young person	Parents doing it alone; going it alone	Parents searching for provision	Fighting for support	Support from family
Safety in provision	Loss of relationships with service workers (social services)	Parents searching for provision.	More provision which the young person enjoys	Parents supporting parents	Searching for places	Lack of communicating young person's needs between provisions	Family networks
Safety in the home	Workers being good enough	Parents own knowledge	Lack of faith	Support from school for transition	Happiness in the provision	Support from school for transitions	Working commitments
Trust	Being with staff who know her	Parents supporting parents	More support	Not feeling listened to	Supportive provision	Misinformation	Juggling commitments
Right type of care provision	Being with staff that have an investment in the person	Lack of knowledge	Parents knowledge of their young person	Trying to find support but support isn't available	Fighting	Perceived inequality	Going it alone (being independent)
Leaving young person with people you don't know	Professionals viewpoints not matching parents	Parents looking for information	Fighting for education	Lack of support from other services	Lack of understanding of the young person's needs	Lack of holistic support	Difficulty knowing
Not knowing what is happening	Values placed on professional opinions versus parents opinions	Parents knowledge of their young person	Fighting for activities	Lack of contact from services	Lack of communication	Parents searching for provision	Having to plan
People not knowing young person and information about them	Systems preferring professionals viewpoints over parents	Lack of knowledge	Justifying young persons needs	Lack of consistency	Suitability of provision	Knowledge building	Managing change/rewarning

People not listening	Feeling ignored	More information for young people about transition	Parents sorting/organising provision themselves	Lack of faith in support	Availability of provision	Being familiar with provision	Fighting for 1cknowledge n
Workers being good enough	Parents working positively with professionals	Finding information	Parents expectation of support	Not timely	Lack of choice	Positive support from school	Fighting for activities
Feeling uncomfortable with the gender of carers		Passing on information	Inequality due to young person being at home cared for by parents	Lack of holistic support	Misinformation	Not seamless	Justifying young person's needs
Parents feeling safe to leave their young person		Other people not knowing information about the young person	To be closer to home in their local community	No help; feeling alone	Perceived inequality	More communication	Getting on with it
Being with staff that have an investment in the person		Lack of information about having other genders care for young person	Community living	Just getting on with it	Not as it first appears	Reality of moving to a new provision different	Difficulty 1cknowledge g day to day life
Parents 1cknowledge ns of safety		Professionals viewpoints not matching parents	Needs of the young person same as in school	Support from other services (social)	Lack of communication	Taking into account the young person's needs; forewarning	Going shopping
Worrying other people look after your young person correctly			Being with friends and similar ages of peers	Parents expectations of support	Not being safe	More visits to transition provision	Keeping young person safe
Being 1cknowledge g e of your adult child			More flexible provision to meet the needs of the young person	Organisational systems barriers	Not being happy	More 1cknowledge g e n for young people	Costing parents money/finances
			Professionals unrealistic perceptions	Support not timely	Lack of understanding from professionals	More time for the young person to process the transition	Feeling like your fighting
			Reaching potential	Support from family	More frequent	No help/supp	Affecting health

					visits to transition provision	ort	and well-being
			Having fears 1cknowledged	Having flexibility	Reality of moving to a new provision different	Getting on with it	Parenting and adult child
			Good 1cknowledgment of provision to sort problems	Right type of care provision	Parent perceptions of not good enough	Leaving without education	No choices
			Difference in parents views and professional s views	Being listened to	Parents sorting/organising provision themselves	Going it alone	Tiredness
			Parents accepting young person is being more 1cknowledged	Provision being paid for	Fighting for education	Not being listened to	Independence for the young person/helping out
				Lack of understanding of young person and family life	Fighting for health and social care	Organisational systems barriers	Work life balance
				Signposting	Safety	Professionals not supporting parents choices	Stress
				Being passed around services	Making progress	Parents talking to parents	No choice
				Systems failures	Higher staff ratio leads to progression	Lack of 1cknowledging from services (transition teams)	Life balance
				Feeling judged	Parents preferences	Needs of the young person are the same as in school	Finding cognitive age appropriate activities
				Parents being persistent in seeking support	Keeping young people close by in their community	Staggered visits until they are in full time	Wanting to do "normal" family things
				From bad experiences can come positive outcomes	Being closer to home	Being seamless	Progress in the young person
				Professionals misunderstandi	Unclean provision	Staying in routine	Support from

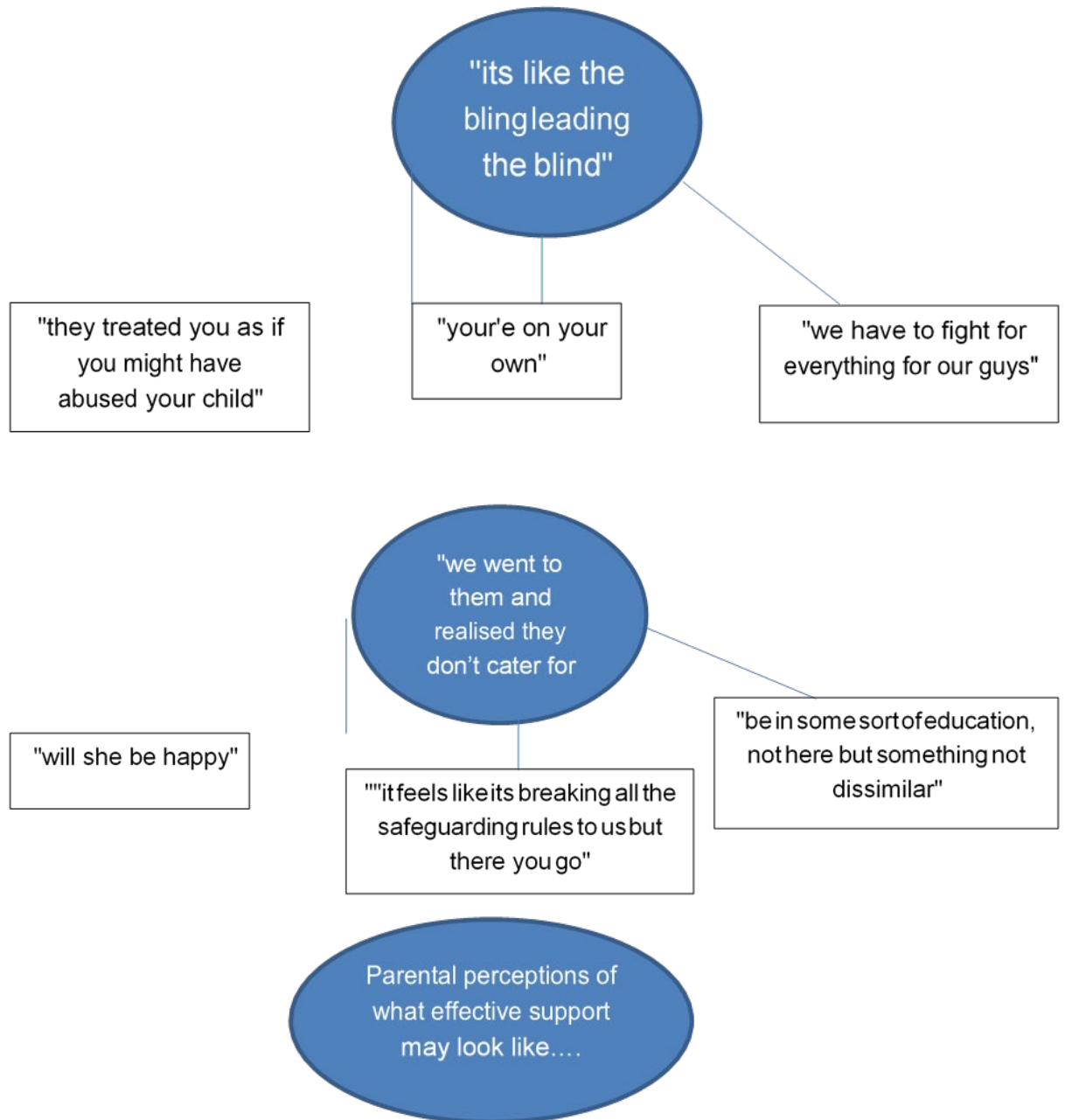
Appendix 9 – Phase 4 Data Analysis

Phase Four: reviewing themes



Appendix 10 – Phase 5 Data Analysis

Phase 5) Defining and naming themes and sub themes



Appendix 11 – Summary of findings and recommendations

Key findings from the study

- Parents continued to feel frustrated through the lack of available and timely support, and information available from transition and adult services.
- Parents independently researched and sought out settings/provisions for their young person due to the lack of timely support and information.
- Parents felt alone through the process of transition, due to untimely or inadequate support.
- When parents replaced the support they expected from professionals with support from parent groups, they felt well supported during the transition.
- Parents felt professionals did not understand their own role in the transition process, and this led to parent's feeling they were passed from service to service and left without answers.
- Parents felt judged by both professionals and the systems and procedures in place to support them and their young people.
- Parents felt ignored and not listened too. They felt as though their viewpoints were not valuable, as they were "not professionals".
- Parent's felt as though they had to "fight" for support or funding for their young people during, and after, the transition to adulthood.
- Parents often felt confused about what their young people's entitlement to Post 19 support would be or look like.
- Parents felt they would like their young people to continue learning and be happy within their Post 19 setting.
- Parents felt the choice of the Post 19 provision was limited and often un-suitable. They sometimes felt it was unsafe to leave their young people due to a lack of communication.
- Parents felt worried when leaving their young person with people they did not know.
- Parent's felt a continued responsibility to plan, care, and support their young person despite them being an adult.
- Parents found it difficult to discuss or plan for their own future without their young person.
- Parent's acknowledged their aging and the negative effect of caring for their young person had on their well-being, bodies, and QL.
- Parents felt that caring for their young person affected their ability to carry out day to day tasks for example; shopping and also working.
- Parents wanted their young person to live or be supported in their local area.

Key recommendations related to parents for Post 19 transitions

- Make contact and seek advice and support from parent support groups, family and friends.
- When your young person is in Year 9 begin to consider what support and/or provision would look like after they leave school. Write this down.
- From Year 9 to when your young person is in Year 11 begin to research provisions, settings and services. Explore all options; day services, learning provisions, independent living settings, which are realistic and appropriate choices for your young person.
- In Year 11, arrange a meeting with your local Adult Social Care when you have gathered your information. Take a friend, advocate or member of staff from your young person's school with you.
- In Year 11, ask for an assessment of needs for your young person and for yourself. Ask how much statutory support you and your young person may receive. Keep in mind your young person may have to contribute financially.
- Be aware the amount of statutory support, you, and your young person could receive may not be the same amount as of time as being in school full time. There could be a difference. Begin planning how you may fill the time, especially if you have work commitments.
- In Year 12, begin planning transition to your, and your young persons, preferred choice/s of Post 19 provision by asking for a meeting with Education, Healthcare and Social Care professionals. Asking for as much information as possible on the new setting, its services and staff.
- Ask professionals to arrange transition sessions/days and review your young person's progress frequently.
- Throughout the process continue seeking support from parent support groups, family and friends.

Key recommendations related to Educational Psychology and Post 19 transitions

- The involvement of Educational Psychologists in Post 19 consultation and planning is beneficial in assisting parents to be heard within meetings and to assist the young people to find their niche.
- Opportunities for Educational Psychologists to be included in Post 19 consultation and planning would allow Educational Psychologists to further develop their own learning and expertise in both consultation skills with parents of young people with complex additional needs and planning for young people with complex needs.

Key recommendations related to professionals and Post 19 transitions

- Give timely, realistic and relevant information, beginning at Year 9, and throughout the transition process.
- Give information about local and on-line support from parent support groups and advocate services.
- Be sensitive to the individual needs and circumstances of each young person and their family. Bear in mind that statutory assessments of need are often a “one size fits all” and some questions and/or options may not be appropriate and cause offence or upset.
- Give all statutory and non-statutory options for parents and young people to consider including; day services, learning provisions, independent living settings. Make it clear what type of service and support each setting, service and provision offer. Be mindful parents often want their young person to be local rather than out of their local area.
- Listen to parents, they offer valuable information on the young person. Make them feel they are heard.
- Offer support to visit provisions, settings and services, during Year 11.
- In Year 11, offer an assessment of needs for the young person and for the parent. Make it clear how much statutory support the young person, and parent, may receive. Inform parents the amount of statutory support, they, and their young person could receive may not be the same amount as of time as being in school full time. Also, inform the parent the young person may have to contribute financially.
- Keep in mind parents do not legally have to care for their over 18-year-old young person. Ensure the support offered Post 19 is proportionate to the need of the family, and sensitive to the parents own needs to work and to have a Quality of Life.
- In Year 12, begin planning transition to the preferred choice/s of Post 19 provision by asking for a meeting with Education, Healthcare and Social Care professionals. Give

parents and young people as much information as possible on the new setting, its services and staff.

- Ask professionals to arrange transition sessions/days and review the young person's progress frequently.