Transition of autistic school-leavers with complex needs to residential adult services: parent and school professional views, and the implications of those views for transition policy and practice

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Declaration

I declare that the work in this thesis was carried out in accordance with the University of Stirling's Code of Practice: Research degrees, and that it has not been submitted for any other academic award. I confirm that it is my own work and that, where I refer to others' work, it is properly cited and acknowledged.

Bernadette Rowan Casey   28 November 2021

<u>Abstract</u>

This study explores the transition of autistic school-leavers with complex needs from a residential school in Scotland, to adult services, through the views of parents of young people at the school and school professionals from other educational settings across Scotland. The research was initiated by the author's experience as a school professional, realising that outcomes for young people did not always align with the principles of the underpinning education policies in Scotland, GIRFEC (Scottish Government 2018a) and positive, sustained destinations for all young people.

Autistic young people with complex needs face challenges which limit their ability to give their views directly, particularly retrospectively, so parents and school professionals were invited to give their views. Questionnaires and semi-structured interviews were used to elicit views of a convenience sample and generated data from seven parents and five school professionals. Data was analysed using reflexive thematic analysis (RTA).

Parents and school professionals concur about successes and problems encountered, indicating a fragmented and inconsistent approach to transition planning and experience across the country. Findings suggest a lack of collaboration, lack of understanding of complex needs and levels of support required to meet those needs and a lack of availability of appropriate resources. These factors may lead to breakdowns of placements. Sustained destinations are not always positive and positive destinations are not always sustained. The process has a significant negative impact on the emotional wellbeing of parents and families.

The implementation of aspirational Scottish Government policies into practice falls short. The study concludes that there may be no single best practice model due to the complicated and complex nature of the process for this cohort, but that there is scope for improvements to be made to ensure positive outcomes for this cohort of young people and their families.

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List of Abbreviations

AAC	Augmentative and Alternative Communication
ASD	Autism Spectrum Disorder
ASL	Additional Support for Learning
ASN	Additional Support Needs
ATU	Assessment and Treatment Unit
CLN	Complex Learning Needs
CRPD	Convention on the Rights of Persons with Disabilities (United Nations 2006)
CSP	Co-ordinated Support Plan
GDPR	General Data Protection Regulation
GIRFEC	Getting it Right for Every Child
ICD-11	International Classification of Diseases 11th Revision
LA	Local Authority
LAC/LAAC	Looked After Child/ren/Looked After and Accommodated Child/ren
NAS	National Autistic Society
P	Parent
PCP	Person-centred Planning
RIC	Regional Improvement Collaborative
RTA	Reflexive Thematic Analysis
SDS	Self-directed Support
SEN	Special Educational Needs
SIB	Self-injurious behaviour
SLT	Speech and Language Therapist
SP	School Professional
SPICe	Scottish Parliament Information Centre
STF	Scottish Transitions Forum
TA	Thematic Analysis
UNCRC	United Nations Children's Rights Charter
UN	United Nations
YP	Young Person

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Key concepts and definitions:

Additional Support Needs (ASN)

The Education (Additional Support for Learning) (Scotland) Act 2004 replaced, in Scotland, the terminology 'special educational needs' (SEN) with the term additional support needs (ASN) and broadened the term to include support needs that were temporary e.g. illness or bereavement and which could be removed by providing some additional support for learning (ASL).

Adult Service

Post school provision funded by the LA, which may be a tenancy, supported living or care home. The service, including building, resources and support staff may be provided by the LA or a charity or a private company.

Assessment and Treatment Unit (ATU)

ATU is an inpatient unit where people are looked after and assessed while awaiting a more appropriate placement. People may be admitted to an ATU under the Mental Health Act (1983. It should be a temporary admission while future treatment or placement is decided.

Autism

Autism is a lifelong developmental disability that affects the way a person communicates with, and relates to, others and the world around them and is clinically apparent from the first childhood years (Baxter et al. 2015; National Autistic Society (NAS) 2021a). International Classification of Diseases 11th Revision (ICD-11) (World Health Organisation) 2018) uses the term Autism Spectrum Disorder (ASD) to describe a broad classification of autism as being characterised by persistent deficits in the ability to initiate, and to sustain, reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour and interests. In addition, individuals with autism exhibit sensory sensitivities (American Psychiatric Association 2013; NAS 2021a) and difficulties with transitions of any kind (Hume 2008), with transitions causing heightened anxiety (ARC Scotland 2017b). Further explanation of autism is given in sections 1.3.2; 2.1.3.

Guardianship

This is an order made in a Scottish court by the Sheriff [judge], appointing an individual to make decisions and act for an incapable person, once they reach age 16 (Adults with

Incapacity (Scotland) Act 2000). This is usually for a period of 3 years or more and Guardians must reapply to the court after that time. Parents of the young person may apply for a Guardianship order so that they legally have the power to support the young person with finances and issues relating to personal welfare. Sometimes the Local Authority holds the Guardianship order.

Local Authority (LA)

A Local Authority (LA) is a council area. There are 32 LAs in Scotland. In the context of this study, LAs have responsibility for education, social care and housing within their authority and for young people from the LA who are accommodated outside the authority.

Looked after child/ren (LAC)/Looked after and accommodated child/ren (LAAC)

The Children (Scotland) Act 1995) defines 'looked after children' as those in the care of their LA, sometimes referred to as a 'corporate parent'. These are children who are made subject to a Compulsory Supervision Order via the Children's Hearing system, but remain at home with their families receiving support and assistance. Looked after and accommodated children, including those who are the focus of this study, are placed in residential accommodation for whatever reason. This terminology is used by LAs alongside the similar terminology 'care experienced'. 'Care experienced' has no statutory basis. 'Looked After' is statutory. For these children / young people there are legislative requirements around their safeguarding. Children (Scotland) Act 1995: section 17(6). Therefore LAC/LAAC is the terminology used in this thesis.

Transition procedures in Scotland for young people who are LAAC

Transition, in this study, refers to the process for a young person leaving a residential school and transitioning to a residential adult service. Although young people may leave school at any time from age 16, The Children and Young People (Scotland) Act 2014 gave young people 'in care' the statutory right to remain in the same placement until age 21 and eligibility for five years of 'aftercare support', until age 26. For young people with additional support needs (ASN), Scottish Government Guidance relating to Education (Additional Support for Learning) (ASL) legislation (Scottish Government 2017a) states that transition planning should begin "no later than 12 months before the pupil is due to leave school" (n.p.). Advice to parents on *Parentzone* (Scottish Government 2021a) is that "your LA is required to plan for transitions early" (n.p.) if one of a number of factors exist, including attending a residential special school. "Professionals working with you and your child will decide what planning and support is needed" (n.p.). While the school facilitates and supports transition planning, it is the LA's

responsibility to progress that, source, provide and fund the post-school placement. Generally, LAs and families want the young person to return to their home authority on completing school. Sometimes young people are placed outside of their home LA but the home LA still has responsibility for funding.

Variation

A variation is a temporary variation of contract, usually lasting three to six months, which allows an individual young person to remain at school later than the school's upper leaving age. The upper leaving age of the school represented by parents in this study is 21, and is 18 or 19 in the schools represented by the school professionals. A variation is requested by the LA, submitted to the regulator (The Care Inspectorate) by the school and approved or rejected by the Care Inspectorate. A variation may be repeated if an LA requires more time to source a placement.

Young person

Pupil in the study for whom transition planning has begun, usually over 15 years old.

Chapter 1: Introduction

1.1 Introduction

This research was initiated by my own experience as a senior manager in an independent, residential, autism-specific special school in Scotland. I was appointed as a senior manager at the school in 2014, remaining there for just over six years, and had been in post for approximately four years when beginning this research.

The age range of pupils at the school of the study is 8–21. Until 2011 the upper age limit was 18, which allowed young people to remain at school until the day before their 19th birthday. Raising the upper age to 21 was a decision made and agreed between senior school staff, the managing organisation and the Care Inspectorate. This was to allow for longer transition planning as some young people were reaching leaving age with no adult service having been identified and LAs requesting a variation order to allow the young person to remain at school over the age of 19. The upper age of 21 allows young people to remain at school until the day before their 22nd birthday. This was in advance of The Children and Young People (Scotland) Act 2014 (Scottish Government 2014), which gave young people who are Looked After and Accommodated (LAAC) the right to remain in the same placement until age 21.

1.2 Personal reflection

I became aware that, despite the increase in the upper leaving age, variations of contract were still being requested for some young people who were closely approaching final leaving date and for whom no placement had yet been sourced. In some cases, a second or a third variation order was granted while the LA identified an appropriate post-school placement. I realised that there may be a problem and this became something I wanted to explore further.

A number of newspaper reports (Adams 2018; BBC 2018; McNeill 2018; Sweeney 2016) cited breakdowns in post-school placements for autistic young people with complex needs, who had been well supported at their schools, being admitted to hospital or Assessment and Treatment Units (ATUs) because LAs had no alternative suitable provision for them. These reports included reference to some young people who had left the school of the study, two of whom had received more than one variation to provide the LA time to source an appropriate post-school placement. ATUs are often used as emergency care, usually when someone is sectioned under the Mental Health Act (1983). This can happen when someone is in crisis and their families or existing community-based services are unable to cope. The newspaper reports indicated that this was happening to young people who had recently transitioned from

school. This is what led me to wonder about the benefits of variations for some young people. While the extra time is beneficial from the point of view of having ongoing, familiar, specialised education and support, the main reason for the variation is at the request of the LA, so that they could have additional time to find post-school provision. If the process breaks down for some after this, I wanted to consider whether or not this additional planning time had been beneficial.

The publication of reports raising concerns about transition practice for those with additional support needs (ASN) (ARC Scotland 2017b; 2018) and on out-of-area placements and delayed discharge for people with disabilities and complex needs (MacDonald 2018) also added to my interest in carrying out this research. These reports are not autism specific, but autistic people are included in the cohort. MacDonald (2018) states that a significant number of Scottish adults were in out-of-area placements and describes an approach to improvement as involving complex interrelated processes, agencies and services, all of which must work together for better outcomes for individuals. MacDonald (2018) concluded that "a transformational change approach is therefore required to address this issue throughout the sector; this will require an overall change in culture and approach." (p.5).

I wanted to investigate whether the transition process and destination is a generally positive or negative or mixed experience for young people and their families. If the experience is positive for some and not others, I wanted to find out why this is the case and to improve, if necessary, the transition process and procedures, ultimately enhancing the experience of young people and their families throughout the transition process and into adulthood. I wanted to ensure that this cohort of young people had equity of access to opportunity, as their peers, and that their experiences met the aspirations of Scottish Government policies.

1.2.1   Researcher credibility

My background in education, educational leadership and ASL/ASN, provides me with the credibility to carry out this research. I am a trained Primary teacher and, after seven years teaching in mainstream Primary schools, based on my positive experience of working with children with ASN in mainstream classrooms, I applied for a teacher post in a special school. I subsequently received a number of promotions and, prior to becoming a senior manager at the current school, I was a Head Teacher of two special schools, consecutively, in a Scottish LA. In each school, many of the young people had a profile of autism with complex needs. I have achieved further qualifications in the area of ASN and represent the sector on a professional body.

1.3 Context

The school in which the study is based, is a 52-week school, that is, residences open all year with school terms within the year aligned to the host local authority. The host authority where the school is located has no managerial function, although the school is obliged to report any safeguarding concerns that arise to the host authority in addition to reporting to regulators. The school is regulated by Education Scotland for education purposes and by the Care Inspectorate for care and support, including school care accommodation. Education Scotland is the Scottish Government executive agency charged with supporting quality and improvement in Scottish education. Education Inspections occur every four years approximately. Care Inspections take place at least once per year. The school provides education and support for autistic children and young people with complex needs from across Scotland and, occasionally, other areas of the UK.

1.3.1 The pupil population

The young people supported at the school are those whose needs are so complex that they require the specialised education and support provided in a 52-week residential setting. There are detailed assessment procedures to be carried out, by both the LA and using the school's own methods (Appendix 1), before the school is confirmed to be the appropriate place for prospective new pupils. All of these young people are at a much earlier developmental stage than their chronological age, requiring at least 1:1 levels of staffing and support all of the time and 2:1 some of the time (e.g. for personal care routines or for outings to the community). These young people usually prefer very strict routines and structure, finding any kind of transition difficult (Bellini 2006; Hume 2008; Nuske et al. 2018) and most stay at the school all year round without visiting home. While Nuske et al. (2018) provide a systematic review of difficulties and strategies for success on new school transitions rather than transitions to adult services, they provide some insight into how autism affects the transition experience for children and young people. Changing from the routine of school to home could cause severe anxiety for the young people of the study and their family. For most, families come to visit them at the school and the school provides a structure to the visit and overnight facility for parents/family. A small number of young people go home for occasional weekends or short holidays. Most are non-verbal and communicate in different ways using alternative and augmented methods (AAC) which are described in more detail in section 2.3. Young people require to be supported in order to communicate and make their needs known, often by staff who have supported them for some time, who have built up a relationship with them and are

able to interpret and advocate for them (Caynes et al. 2019). The young people will require the same levels of support throughout transition from school to post-school provision and into their adult placement and, almost certainly, throughout adulthood. While young people may be supported to communicate their views at a moment in time, it is much more of a challenge for them to give their views retrospectively or projecting into the future (Fayette and Bond 2018a, 2018b; Reid 2007), such as would be required for this research study. There is further discussion of complex needs in sections 1.3.2 and 2.1.3.

1.3.2 Autism and neurodevelopmental disability

ICD-11 (World Health Organisation 2018) has merged autism, Asperger syndrome and pervasive developmental disorder-not otherwise specified (PDD-NOS) into one - 'autism spectrum disorder' (ASD) – where previously they were separate diagnoses. Terminology has been changed and updated to view intellectual disability from a developmental perspective and to include both intellectual abilities and adaptive functioning (Girimaji 2018). ICD-11 separates intellectual disability and autism spectrum disorders in subsections of neurodevelopmental disability, both with subsections of severity and complexity. The subsection that most applies to the young people in this study is 6A02.5, "Autism spectrum disorder with disorder of intellectual development and with absence of functional language. All definitional requirements for both autism spectrum disorder and disorder of intellectual development are met and there is complete, or almost complete, absence of ability relative to the individual's age to use functional language (spoken or signed) for instrumental purposes, such as to express personal needs and desires." (WHO 2018, np.). The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (American Psychiatric Association 2013) diagnostic criteria for ASD also considers that it is a condition that impairs the individual's ability to communicate efficiently, either with spoken language or via non-verbal communication.

Although, since the 1990s, there has been a "sea change" in awareness of autism and related conditions and a broadening of recognition of autistic people (Rice and Lee 2017, p.515), there is still disagreement about the way autism is and should be described (Kenny et al. 2016). Individuals can be described as: being on the autism spectrum; autistic; having autism; with autism; having or with ASD. National Autistic Society (NAS) advocates the use of language preferred by autistic people (NAS 2021a) citing Kenny et al. (2016) whose study on perspectives from the UK autism community found that the majority of autistic adults in the UK prefer the identity-first term 'autistic'. Autistic people prefer putting the identity first, "an autistic

person", to emphasise that a person cannot be separated from their autism (Autistic Mutual Aid Society Edinburgh (AMASE) 2021, n.p.), rather than the person-first language preferred by some professionals, "a person with autism", in order to de-emphasise the condition. Although many professionals still prefer to use the terminology on the autism spectrum (Kenny et al 2016), this study will present the views and experience of autistic people and their families, so the terminology that will mainly be used in this study is 'autistic'. Other terms will be used and inter-changed when citing others.

1.4 Focus and scope of research

The study focused on the transition experience of young people approaching school leaving, and their families, during a timescale of about six years from 2012–2018. Due to the complexity of the young people involved, their early developmental stage, challenges with communication and social skills, including limited ability to interact with strangers, I intended to approach the parents and families of the young people and have the parent describe the experience from their point of view. As well as struggling with the meaning of their child's special needs, parents and family members tend to advocate for this cohort of young people (Hess et al 2006). While advocating for their child is expected because parents can provide insight into their child's world and experiences (Brett 2002), I wanted to give parents the opportunity to give their views of their own experience too. I also intended to approach school professionals from a variety of settings across the country for their views on transition of autistic school-leavers with complex needs. Pupil voice will be discussed further in section 2.3, parent voice 2.4 and professional views 2.6.

1.4.1 The transition process

Transitions are complex and multi-facted and involve change and uncertainty in the social and cultural world of the individual (Maunder and Crafter 2012). The transition process for those with complex needs requires careful planning (ARC 2017a). Transition has a different meaning and emphasis depending on who is using the term and what their experience and responsibilities may be (Health and Social Care Alliance Scotland 2017): "Some services may focus upon transition as the leaving of one service and transfer to another, like handing on a baton. However, Alliance supports the concept of transition as a complex of interwoven emotional and developmental processes for an individual and their family rather than a single event" (p.10). There may be multiple transfers to multiple services for autistic young people and the nature of their condition makes these changes all the more challenging, with the risk of poor outcomes (Beresford et al. 2013).

In this study the transition process was usually initiated by the study school raising the subject at annual review or LAAC meetings. While the young person, by law, has the right to remain in the placement until age 21, transition planning aims for an earlier leaving date if this is considered by school, parents and LA to be appropriate for the young person. A series of planned letters are sent at regular intervals from age 15 to the home LA, reminding them of the need to plan for suitable post-school placements. The school arranges regular transition meetings which are attended initially by an LA Children and Families social worker until a social worker from the adult team is allocated. Any other relevant professionals eg. health professionals, should also attend along with parents. Usually, the process begins with Person Centred Planning (PCP) facilitated by the school. The overall aim of PCP is good planning leading to positive changes in people's lives and services (Ritchie et al. 2003). Groups of people who know a young person well, focus in detail on them and the vision of all aspects of their future life. This information then guides the transition planning process. Ideally, parents, school, the LA, social worker and any other agencies such as health services, will work together, regularly sharing and updating information about the young person and, based on the needs of the individual young person, a post-school provider and destination will be identified by the LA and agreed by all. Care providers, funded by the LA, may come from within the LA itself, private companies or charitable organisations.

School leavers with complex needs may have to transition across multiple services, including health services (Hall 2019). The LA should progress the transition along with the relevant adult service provider and with support from the school. Depending on the particular needs and cognitive ability of the young person, strategies may include shadowing by staff from the adult service over a period of time in school, visits to new accommodation, overnight stays and social stories, until the transition to the new service is complete. Social stories (Gray 1991) are individualised short stories that depict a social situation that an autistic child or young person may encounter, with strategies to help prepare them for a new experience.

1.5 Aims, objectives and research questions

I wanted to explore further, to find out whether the individual needs of young people are being fully considered in order to meet their support requirements. Guidance on transition exists specifically for young people with ASN (ARC Scotland 2017a, 2019). Therefore, I wanted to find out whether it is implemented effectively and why it may be effective in some cases, but not all. I wanted to discover whether opportunities for these young people are reduced because of the complexity of their individual needs, whether appropriate provision is available

for them, what impact the process may have on young people and their families, and the implications of parent and school professional views of the transition process for policy and practice. Therefore, the research questions are:

1. What are the experiences of autistic school leavers with complex needs, and their families, as reported by parents, during and following the transition to post school destinations? (RQ1)
2. What are the views of school professionals on the transition process for autistic school leavers with complex needs, and their families, during and following the transition to post school destinations? (RQ2)
3. What are the implications of these parent and professional views for policy and practice? (RQ3)

In order to answer the research questions I considered and explored the process further, finding out about planning and collaboration, what resources were available to young people and their families and how the experience impacted them. I relied on parents and school professionals to provide information on behalf of themselves and the young people and I searched appropriate literature to ascertain current thinking and available research. I accessed relevant policies and legislation, relying on the Scottish Government website for updates, and derived key messages and underlying principles from these. The aim of the study was to ascertain whether the experience of autistic school-leavers with complex needs is positive or negative, to assess the impact of this on young people and families, to identify where improvements can be made, and to consider the implications of all of this for policy and practice. The objectives of the study became:

- To collect data on the planning of transition to adult services for those with autism and complex needs as reported in interviews with parents and school professionals (RQs 1 & 2).
- To collect data on the choice and availability of post school options for this cohort and the process of achieving positive destinations, through interviews with parents and school professionals and with reference to current reports (RQs 1 & 2).
- To collect data on the experience of autistic school-leavers with complex needs post transition, as reported in interviews with parents and school professionals (RQs 1 & 2).
- To consider the emotional impact on young people, parents and families as reported by parents and school professionals. (RQs 1 & 2).

- To consider the implications of the parent and school professional views in relation to implementation of the main policy principles into practice, with reference to transition, post-school destinations and opportunities for autistic school-leavers with complex needs, and make recommendations on what actions to take to change and improve practice (RQ3).

1.6 Conclusion

I do have a particular interest in this field of research and I have been influenced by my experience in this area as a practitioner and a senior manager. I had a genuine desire to assess the experience of these young people and their families and, should it be required, to build local capacity, to find ways to improve sustainability and to "help people in their real lives" (Rice and Lee 2017, p. 516). Chapter 2 will review relevant literature and provide further context for the research.

Chapter 2: Literature Review

2.1 Introduction

This chapter focuses on the literature available to support the research topic outlined in Chapter 1, and gives the reader a better understanding of aspects of the research, including autism and complex needs, medical, social and human rights models of disability and the transition process. The Scottish policy context will be explored with particular reference to the overarching policy Getting it Right for Every Child (GIRFEC) (Scottish Government 2017d, 2018a) and the Scottish Government's commitment to positive, sustained destinations for all young people (Scottish Government 2012a, 2012d) followed by parent, pupil and professional voice, the impact on the family and concerns with the transition experience and post school provision for this cohort.

2.1.1 Process of Literature Review

I carried out a search of the University of Stirling library catalogue using Education Research Complete and British Education Index as well as the Directory of Open Access Journals. I used the search terms "autism or autistic or autism spectrum disorder" and "transition to adulthood" to generate initial responses and then included more focused search terms such as "Scotland", "complex needs", "pupil voice", "parent voice", "professional voice", "professional views", "challenging behaviour", "transition experiences", "family stress", "staffing challenges" "policy or policies to generate more specific results for each section of my research. I also used these search terms in Google Scholar. In addition, I relied upon the Scottish Government website for updates to relevant policy and legislation. I am using a mixture of research articles, classification systems, reports, policy documents, newspaper articles, and text-books to ensure as broad a perspective as possible. For example, the classification systems provide definitions, research articles present a number of perspectives on relevant themes from empirical studies, text books from practitioners and professional experts give accessible descriptions, newspapers provide examples of practice concerns and reports provide other perspectives on current policy and practice. These will all add breadth and depth to my own study, tracing developments and providing current and relevant information to inform my research.

2.1.2 Defining 'complex needs'

There is agreement that disability is complex, dynamic, multidimensional and contested (Ghoshal 2018; Rosengard et al. 2007). A "plethora of terms" is used to describe complexity by various disciplines, sometimes specifically and often interchangeably, including, among others, "multiple disadvantage, multiple impairment, dual diagnosis and multiple and complex needs" (Rosengard et al. 2007, p.6). Others have identified complex needs as both breadth of need, where there is more than one need, with multiple needs interconnected, and depth of need, meaning profound or severe needs (Rankin and Regan 2004). There is an implication that those with complex needs are not central to society, but on the edge, as a group and in a variety of circumstances, "marginal, high risk and hard to reach" (Watson et al. 2003, p.10). Ghoshal (2018) recognises that disability is a dynamic phenomenon, undergoing continuous change and believes that a consensus on a definition of disability, although a challenging task, would enhance evaluation and research. The National Strategic Commissioning Group (NSCG) (Scottish Government 2017b, p.6) acknowledges that the multiple factors and specific contexts make it very difficult to agree on a definition and prefers to use a working description instead rather than a definition of children and young people with complex ASN. This includes a number of criteria including children and young people who attend an independent special school.

While the young people in this study have an intellectual disability, autism, their co-occuring conditions (more in section 2.1.3) fit Gillberg and Soderstrom's (2003) definition of learning disability as encompassing many different conditions, usually leading to significant functional impairment and a need for lifelong support and interventions. International literature tends to refer to learning disabilities to include specific learning difficulties including dyslexia, dyspraxia and so on, yet the term "intellectual disability" is increasingly used to refer to people with learning disabilities in British learning disability policy, practice and research (Cluely 2017). MacDonald (2018), uses a definition of a learning disability from the *keys to life* [sic] (Scottish Government and COSLA 2013), that is, a significant lifelong condition that has a significant effect on a person's development. Cluely et al. (2020) agree that the term learning disability covers a diverse range of needs and abilities and that theory, policy and practice have always and continue to "homogenise such people" (p.253), calling for a more inclusive approach to understanding learning disability.

The keys to life strategy (Scottish Government and COSLA 2013) built on *The same as you?* (Scottish Executive 2000a) and recognised that people who have a learning disability have

the same aspirations and expectations as everyone else to live meaningful and fulfilled lives and will need more support than their peers to understand information and lead independent lives. Other features included by MacDonald (2018) to better explain complexity are: severe challenging behaviour, mental health needs and profound and multiple disabilities. Not all in MacDonald's study were autistic but all had a learning disability and complex needs. The complex needs described are often encountered in the cohort of this study. For autistic young people with complex needs, additional difficulties and challenges exist and are outlined in the following section.

2.1.3 Autism and complex needs

There are a number of factors that contribute to complexity for autistic people. Among these are sensory processing difficulties, sensory sensitivity, distressed and challenging behaviours, including self-injurious behaviours (SIB) (Edelson 2011; MacKay et al. 2018; NAS 2021). Autism may also be associated with co-occurring conditions and other features including intellectual or neuro-developmental disability, epilepsy, attention deficit hyperactivity disorder, schizophrenia, obsessive compulsive disorder, Tourette's Syndrome, anxiety and depressive disorders, sleep problems, challenging behaviour, eliminatory disorders and gender identity issues (MacKay et al. 2018). This gives further description to 'complexity' or 'complex needs' as several of these features can occur together, known as comorbidity. All of this can impact on a person's ability to interact with or be involved in society, implying that there is a distinction between 'impairment' and 'disability'. The Disabled People's International (DPI) (1982) defined impairment as the functional limitation within the individual caused by physical, mental or sensory impairment and disability as the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers. This is relevant to the cohort of this study, whose impairment and resulting disability must be considered in the planning and acquisition of appropriate post-school provision.

Difficulties with sensory processing for autistic people is well documented (Kern et al. 2006; MacKay et al. 2018) and levels of sensory sensitivity, either hyper or hypo sensitivity to sounds, colours, smells, textures etc., may also be associated with significantly restricted interests and repetitive behaviours (Schultz and Stevenson 2020). Carter-Leno et al. (2019) found that there are correlations between sensory sensitivity and other neurocognitive functions and challenging behaviour, including self-injurious behaviours. SIB, that is injury to self by, for example, hitting, biting, scratching, head-banging, is very common in autistic people and more common in people who also have learning disabilities (Research Autism 2019, n.p.).

SIB can be short in duration and temporary, while at other times it can continue for months or years. About half of autistic people engage in SIB at some time in their life and it can affect people at any age (NAS 2021a).

The school of this study was familiar with 'complexity' and routinely used a 'scaling tool' (Appendix 1), which had been devised by the Senior Educational Psychologist, in order to assess levels of complexity, pre-admission, of young people who had been referred to the school. The tool outlines autism traits and associated needs under the headings of autism profile, behavioural presentation, health needs, independence/self-care and vulnerability and risk. Some of these traits and needs have been described in the paragraphs above with reference to co-occurring conditions and associated difficulties. Of the needs outlined in the scaling tool, the behavioural profile may be most difficult to describe or understand. Challenging behaviour is a term often used and associated with an individual with complex needs, defined by the Royal College of Psychiatrists (2007) as, when behaviour "is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion" (p.14). Medina et al. (2003) reported that seventy per cent of autistic patients present with SIB and seventy-five per cent of self-inflicted injuries, which either intentionally or not intentionally cause a lesion, are located in the head and neck region. SIB is one of the most challenging behaviours exhibited by people with developmental disabilities (Edelson 2011). The most common forms of these behaviours include head-banging, hand-biting, and excessive self-rubbing and scratching.

Health needs in autistic children and young people are many and varied and may include epilepsy, sleep difficulties, restricted diet, mental health issues. There are often challenges with accessing health services (Cheak-Zamora and Teti 2015). Many autistic young people with complex needs find it hard to tolerate others in their space (Baird et al. 2011) and therefore even have difficulty in tolerating physical support, including support with skills of independence such as toileting, bathing and accessing more mainstream community activities. Jordan (2001) recognises the challenge of this and advises teaching children about independence first before they may exhibit skills of independence. In fact, Jordan suggests that autistic children apparently displaying skills of independence by doing something rather than asking first, may actually be presenting a sign of their difficulty with communication, rather than a strength, therefore increasing their vulnerability.

Vulnerability and risk is included in the scaling tool for this cohort (Appendix 1) as being related to limitations in understanding the environment and limited ability to express themselves, challenging and self-injurious behaviours and requiring constant, high levels of support (Jordan, 2001). This wide range of difficulties makes transition planning for this cohort more complex. Autistic young people with complex needs rely heavily on their medical providers and, along with their parents, often struggle to negotiate the highs and lows of transition from children's to adult services (Cheak-Zamora and Teti 2015). There are likely to be lifelong challenges, and planning for future support should take these needs into consideration (ARC Scotland 2017a). This acknowledges the difference between impairment and disability (DPI 1982) which will be considered further in the following section, presenting the various models of disability and how they relate to societal expectations of, and for, people with disabilities.

2.1.4 Medical, Social and Human Rights models of disability

The language people use to describe individuals with disabilities is important as it influences their expectations and interactions with them (Haegele et al. 2017). This is reflected in the various models of disability. The three models of disability to be outlined are: the medical model, where disability is projected as a personal tragedy with physical and mental deficits (Goodley 2012); the social model, an affirmative model that provided hope for the 'struggling disabled' (Barton 2001); and the human rights approach, which emerged as a challenge to the social model and meant that people with disabilities would be seen as subjects, not objects, and no longer seen as problems, but as rights holders (Quinn and Degener 2002). While a human rights approach to disability is current thinking, it is important to understand how this, and the need to consider children and young people in all their aspects, was reached.

My approach to this study presents aspects from medical, social and human rights models. In the case of the cohort in this study, by defining and explaining complex needs that are unalterable, I am presenting facets of an inevitable medical model of disability. However, the purpose of the study was to consider the experience of autistic school leavers and their families and, if found to be necessary, to improve that experience. Therefore, this research drew on the social model in an attempt to identify and eradicate, where possible, the barriers arising from such factors as the learning environment, health and disability, social and emotional factors and family circumstance (Scottish Executive 2004). A human rights approach was adopted through consideration of the implications of the findings of this study on policy and practice. The human rights approach is "an international issue practiced [sic] at local level" (Rioux and Carbert 2003, p.1).

2.1.4.1 The medical model

According to the medical model, where disability is projected as a personal tragedy with physical and mental deficits (Goodley 2012), the care of children with disabilities has inevitably involved medical intervention, emphasising 'abnormality', disorder and limited function (Brett 2002). This drew increasing dissatisfaction from disabled activists who felt that they were viewed in terms of their physical impairment and that disability was a social construct, a form of oppression making them an oppressed group in society, imposed on them and excluding them from mainstream activities (Oliver 1996; Rioux and Carbert 2003). A shift followed and a social model of disability was developed as a critique to the medical model (Degener 2017).

2.1.4.2 The social model

Allan (2010) charts the emergence of the sociology of disability from the 1980s, "a somewhat troubled and contested field" (p.602). There was a growing movement for change and a desire for transformative change from deficit to affirmative model (Barton 2001). This agenda was taken up by many, and Swain and French (2008) were among those who developed an affirmation model which rejected the idea of disabled people being dependent and abnormal and presented a positive alternative, focusing on affirmation and validity of experiences. The social model took the emphasis away from the physical impairment and concentrated on removal of barriers, attitudinal and structural, that exclude disabled people from society.

Nevertheless, the social model received some criticism. Zarb (1997) found many contradictions and restraints imposed when researching the barriers to exclusion for disabled people, but remained optimistic about potential future "transformative process" (p.64). However, Shakespeare and Watson (2002), while considering the discovery that it is society that needs to change, not them, to be very liberating for disabled individuals, questioned, early in the debate, whether it is already an outdated ideology. They put forward the view that the very success of the social model was now its main weakness, as it became an ideology that could not easily be contested. They claimed that the public face and the private face of the social model may be quite different, suggesting that the physical aspects of disability are discussed privately by activists rather than being publicly acknowledged. They challenged those whom they consider use the words disability or impairment incorrectly and go further to say that the barrier free environment is an unsustainable myth.

Despite the criticism, the social model of disability became the underpinning approach to the Education (Additional Support for Learning) (Scotland) Act 2004, which, rather than focusing

on impairment, considers factors which may prevent a pupil from benefitting from learning and can apply to any pupil throughout their learning career. The Act recognises that barriers to learning do not come from within the child but from other factors, including the learning environment, health and disability, social and emotional factors and family circumstance (Scottish Executive 2004). This will be explored more fully within the Scottish policy context, section 2.2. The 2004 Act moved away from the traditional categorisation, identification and labelling of learners in terms of their difficulties, encouraging the view that ASN may lie in the circumstances in which the learners find themselves (Allan and Catts 2012). The Act signified a commitment to inclusion, reflecting the need to address the inequitable distribution of social capital in our society (Allan and Catts 2012). For the cohort of this study, this means that, despite the difficulties described, a range of post-school options must be explored and placements provided to meet each individual's needs.

While Allan and Catts (2012) attempted to shift the attention away from deficit towards something more positive, MacDonald's (2018) report on out-of-area placements for those with complex needs, appears, eight years later, to support Allan's (2010) contention that the implementation of the sociology of disability has fallen short of aspirations. This raises the question whether the cohort of people with the most complex needs, discussed by MacDonald (2018), is viewed as a collective group rather than as individuals, and completely from a medical rather than a social model of disability. While the medical needs must be acknowledged and considered, they cannot be the exclusive way to define people and the social barriers must be acknowledged and addressed too. It has been argued that the social model was a strong basis for a political movement but an inadequate grounding for a social theory, reflected by Waldschmidt (2017), who states that the ground-breaking impact of the social model has been diluted by many commentators in recent years so that it appears now "a little dusty" (p.21) and in need of amendment. This is significant for the cohort of this study as it suggests that removing barriers for one may create obstacles for another or may implicitly exclude people with the highest support needs (Cluely et al. 2020).

While most writers favoured one of these models over the other, there has been a growing recognition that there are aspects of both models that are important for our understanding of disability (Blustein 2012; Haegele and Hodge 2016; Mitra 2006, 2017). Brett (2002) believed that neither the medical nor the social models recognise the experience and perspective of children with the most profound needs, and their families, and proposed an 'Alliance' model. This is grounded within the experience of disability and purports that "true partnership" (p.837) is the key, recognising the role that parents and professionals have to play in being the voice

of the children, focusing on negotiation, an important aspect to be explored in this thesis. Mitra (2006) presented a capability model in relation to an individual's characteristics, resources and environment, followed by a human development model which discussed disability and wellbeing in terms of resources available (Mitra 2017), also of relevance to this thesis.

Latterly, the social model of disability became almost as strongly criticised as the medical model (Degener 2017) with critics objecting to disabled people not being seen as multi-dimensional people but stripped of their biological and mental attributes and, with only social properties, potentially becoming invisible in society (Anastasiou and Kauffman 2013; Ghai 2006). Oliver (1996), a strong proponent of the social model, had previously called for an end to the criticism until a better model was established. This better model would potentially emerge from the UN Convention on the Rights of Persons with Disabilities (CRPD) (United Nations 2006). Despite the criticism, the social model caused a historic change in the understanding of disability (Russo and Wooley 2020) and greatly influenced the CRPD, enabling the transition to a rights based approach (Kayess and French 2008; Russo and Wooley 2020). While some viewed the human rights model as an improvement on the social model (Degener 2017), others advocated that the two work together to complement and support each other, an interdisciplinary approach (Waldschmidt 2017), what Lawson and Beckett (2020, p.348) referred to as the "complementarity thesis" which they favoured over the "improvement thesis".

2.1.4.3 The human rights approach

The human rights model of disability emerged as a challenge to the social model with a focus on an individual's quality of life (QoL) (Verdugo et al. 2012) and dignity (Lawson and Beckett 2020). The speed with which the CRPD (UN 2006) came into being, compared with other Conventions, "suggests that this was an idea whose time had come" (Stainton and Clare 2012, p.1011). This approach, a human rights framework, is empowering for disabled people as it puts the onus on governments to ensure that societies are inclusive and responsive to the diversity of human needs (Rioux and Carbert 2003). Anastasiou and Kauffman (2013) agreed that politics has the power to transform the world in some ways, recognising that a radical and transformational political strategy must come from the experience of people with disabilities who lived in the past and today. Now is the time to develop responses to the factors that led to the societal exclusion of people with disabilities, with the increasing connectedness of international responses to disability rights and politicisation of disabled people at the heart of these developments (Goodley 2012), and a focus on how rights and relationships can co-exist (Clegg et al. 2017).

Lawson and Beckett (2020) went as far as to say that it is not a model of disability, but a model of disability policy and that, while the social model identified where policy reform is needed, the human rights model provides the guidance and requirements on policy responses to disability, a move to practical, ethical action (Cluely et al. 2020). Models of disability should consider inclusion, citizenship and independence, based on the real life experience of people with a learning disability, and the government needs to support people with learning disabilities and/or autism in workplaces and society (Giri et al. 2021). A Scottish Government report on an independent review into adult social care in Scotland (Scottish Government 2021b) focuses on the human rights approach, promising a new, national approach to improving the system and a shift "beyond the mind-set of existing systems and services" (p.47). [This report was not available during the data gathering part of this study, but is very relevant to the study]. The primary aim of the review was to recommend improvements to adult social care in Scotland, principally with regard to the outcomes for service users, their carers and families, and to improve the experience of people who work in adult social care. A National Care Service proposed by the review describes a system that is "controlled nationally that delivers locally, has the person at the centre and does not cost the earth" (p.38), a move to practical, ethical support as championed by the human rights approach to disability (Cluely et al. 2020).

The influence of the various models and approaches to disability on educational policy in Scotland is discussed in the following section.

2.2 Policy context in Scotland

While this study focused on transition from residential school to post school destinations for autistic young people with complex needs, it is important to have an understanding of the policy context in education in Scotland as it relates to the journey through school and on to adulthood. In this section the main education policies, which set the scene, will be discussed as relevant to this thesis, beginning with the Presumption of Mainstreaming (Standards in Scotland's Schools etc. Act 2000 (Scottish Executive 2000b)) and GIRFEC (Getting it Right for Every Child) (Scottish Government 2017d, 2018a) and associated policies and subsequent reports. This will be followed by a discussion of the policies relating specifically to autism, including the Scottish Strategy for Autism (Scottish Government 2011, 2018c) and the Autism Toolbox (Scottish Government and Scottish Autism, updated 2019a) and, finally, transitions and post school transitions in The *Principles of Good Transition 3* (ARC Scotland 2017a).

2.2.1 Presumption of Mainstreaming and GIRFEC

The basis of current education policy in Scotland is the presumption of mainstreaming as defined in the Standards in Scotland's Schools etc. Act 2000 (Scottish Executive 2000b) and the integral framework of GIRFEC (Getting It Right For Every Child) (Scottish Government 2017d, 2018a) which followed the presumption of mainstreaming. Mainstreaming is the inclusive practice of placing pupils with additional support needs (ASN) in a mainstream school, that is, not a special school. Pupils with ASN will receive the additional support they require in a mainstream class, alongside all other pupils, or in a unit attached to a mainstream school, which may include some integration into mainstream classes. The 2000 Act was the cementing of the Scottish government's strong focus on inclusion and promotion of equality and equity in Scottish education, a move away from segregation of mainstream and special needs education to integration. While mainstream education would not meet the complex needs of the cohort of this study, it is important to understand the context and the under-pinning principles of inclusion and GIRFEC (Scottish Government 2017d, 2018a) that direct Scottish educational policy. Autism specific policies and guidance and those relevant to ASN and LAAC will be discussed in sections 2.2.2 – 2.2.5.

Article 23 of the UNCRC (UN 1990) states that in "recognising the special needs of a disabled child, assistance…shall be designed to ensure that the disabled child has effective access to and receives education…in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development". The term 'inclusion' was subsequently endorsed by the Salamanca Statement and Framework for Action on Special Needs Education (UNESCO 1994) as a radical alternative to 'integration' and adopted in 1994 by 92 countries and 25 international organisations. Inclusion required more than just participation of disabled children and young people in mainstream schools. It asked that schools change culture and practice and remove exclusionary barriers so that children with SEN could participate fully in all aspects of school life, influenced by the social model of disability.

The Standards in Scotland's Schools etc. Act 2000 (Scottish Executive 2000b) then enshrined the right of all children with SEN in Scotland to learn in mainstream schools. While not applicable to the cohort of young people of this study, the criticism of the implementation of presumption of mainstreaming (Allan 2008; Enable Scotland 2016; Morgan 2020; Pirrie 2008), and the wider impact on children and young people with ASN, is relevant. Pirrie (2008) raised concern, about "the presumptuousness of the presumption of mainstreaming" (p.67) and Pirrie

and Head (2007) were scathing of the concept of inclusion in practice, saying that it has never been a natural part of human existence, that it is tokenistic and fragmented. Inclusion, without appropriate resourcing and strong direction from policy, has created some barriers where they did not previously exist and has made issues of inequality in education more, rather than less, difficult to identify and deal with (Pirrie and Head 2007; Stalker and Moscardini 2012). It is possible that, with the emphasis on presumption of mainstreaming and inclusive practices, there is less focus on the requirements of those with more complex needs. For example, the 2000 Act was followed by the Education (Additional Support for Learning) (Scotland) Act (Scottish Executive 2004), which replaced the term special educational needs to the broader term additional support needs (ASN), which included support needs that may be temporary eg. bereavement, teenage pregnancy, hospitalisation. The needs of the small percentage of children with complex ASN, who required significant input from agencies other than education for more than a year, would be addressed through a co-ordinated support plan (CSP) (Scottish Executive 2004). This is a legal document, written with the collaboration of agencies involved, setting targets for the child or young person while they remain in education and reviewing those targets annually. However, despite their legal standing, numbers of new CSPs have declined year on year, even with a significant increase in numbers of pupils with ASN and a previously steady percentage of those who had a statutory plan. The Scottish Government assured that the number of children with a statutory plan would continue to be proportionate, but this is not the case as they are now proportionately fewer (Riddell 2019), suggesting that the requirements of those with more complex needs have become less of a focus. While the significant support needs of the cohort of this study meet the criteria for a CSP, none of the young people included in this study had a CSP. LAs appear to have taken the view that, despite the significant long-term input of agencies other than education, all input can be delivered within the residential education setting.

The Scottish Government includes equality alongside inclusion as a long-standing feature of Scottish education (Scottish Government, 2012a). *Count Us In*, a report by Her Majesty's Inspectorate of Education, (HMIE 2013) defined inclusion and equality as all learners achieving as highly as they can. "Success" means having the knowledge, skills and resilience to maximise one's choices in life, and to "be all you can be" (p.5), all of which applies to every child and young person whether they have ASN or not. GIRFEC (Scottish Government 2017d, 2018a) also, as its name states, applies to every child, and has been "used and tested" since 2006 (Scottish Government 2018a np) and endorsed by the Scottish parliament as a framework in 2009 before eventually being sealed in legislation in the Children and Young

People (Scotland) Act 2014, ensuring a statutory duty on agencies and services to embed GIRFEC (Scottish Government 2017d, 2018a). However, the establishment of GIRFEC (Scottish Government 2017d, 2018a) framework and principles has been inconsistent and fragmented (Hepburn and Belgutay 2012; Stalker and Moscardini 2012). Despite being described as the "golden thread" (Scottish Government 2010a, p.3) that pulled together all policy objectives for children and young people, the fact that the terms "every child" and "all children" are used throughout, and there are no specific references to ASN, meant that it had the potential to inadvertently exclude disabled children and young people (Stalker and Moscardini 2012).

Concern that children with complex ASN are losing out is not new (Dyson (2001) and those with the most complex needs are a significant challenge to policy makers and providers (Pirrie and Head 2007). Stalker and Moscardini (2012) concur and, while it is crucial to see the child as a child, children with complex needs must have their needs highlighted, otherwise they will be overlooked in a culture of collective practices. This is the conflict between the medical and social models of disability (described in 2.1.4) where, to ignore the medical model, or the disability, in the search for social justice, is potentially to do a disservice to the disabled individual. Stalker and Moscardini (2012) identified problems embedded in the current policy and implementation for families with disabled children. While it would take years to overcome these problems, Stalker and Moscardini (2012) believed that many of the problems faced by families and their disabled children could be resolved by a proactive approach and a change of attitude and culture. Morgan (2020) found that support for children and young people with additional needs is overly reliant on "committed individuals" (p.63). This clearly has implications for the quality of transition planning in the later school years and the future direction for autistic young people with complex needs. This was considered in the study.

2.2.2 Autism specific policies and guidance

The Scottish Government responded to the need for autism specific policies and guidance following studies showing that autistic adults in Scotland struggled to access support (Daly 2008) from their LA or Health Board (Public Health Institute for Scotland (PHIS) 2001). Scottish Executive set up the Autism Spectrum Disorder Reference Group to develop good practice, comprising users, carers and professionals, operating from 2002 to 2008 with a remit to provide information to commissioners about ASD and availability of services, and how to improve services to meet future needs (Kelly 2010). In response to this and their own report on the implementation of the PHIS Report (2001), (Scottish Executive 2006a), Scottish

Government published guidance (2008) focusing on effective partnership working. As a practical resource, the Scottish Government funded the online Toolbox, developed by Scottish Autism with support from Autism Network Scotland (Scottish Government, updated 2019). Scottish Autism, a national autism charity in Scotland, and Autism Network Scotland, an organisation which supports the rights of autistic people, share a vision of a Scotland where autistic people are included and equal in society. This aligns with The Scottish Strategy for Autism's (Scottish Government 2011, 2018c) introductory comment, that a priority is a fairer Scotland, a more equal Scotland, a Scotland for everyone (p.3). The Toolbox presents a section on transitions, acknowledging that transitions can be highly problematic for this cohort, causing high levels of anxiety, which may result in unusual behaviours or responses. The Toolbox provides practical advice in clear language to support with the challenges of transition.

A number of studies and reports over the years have outlined similar recommendations supporting significant action to address inequalities and urgently and thoroughly reform public services for disabled people, including those with complex needs and autism (Autism Network Scotland 2013; Christie 2011; Doran 2012; MacDonald 2018; Scottish Government 2021b). This suggests that the priority of the Scottish Strategy for Autism (Scottish Government 2011) is not yet effected, and that any improvement over the years has not been sufficiently significant, suggesting that autistic people are not fully included and do not yet have a fair and equal standing in Scotland. Doran (2012) recognised that difficulties faced in the implementation of recommendations are not underestimated and states that "complexity can however be used as one of many reasons for doing nothing, moving too slowly to change or not fully including those who use and depend on services" (p.4). On the other hand, Watson (2010) believed that speed, as a common cause of accidents, and acceleration of policy, moving too fast, is a cause of the failure of implementation.

2.2.3 Transition policies

Scottish Government policies over a period of years have promised to address inequalities and improve outcomes for children and young people with ASN as they journey towards transition (HMIE 2006; Scottish Executive 2006b; Scottish Government 2012b). Other reports highlight areas of concern and make recommendations for achieving the desired improvement (Christie 2011; Doran 2012; Pirrie et al. 2005; Scottish Government 2012b). Doran (2012) recognised that others had reached similar conclusions in the past and that there have been repeated failures to improve in key areas, identifying that outcomes for young people with complex needs could be improved if there was better collaboration and less duplication of

services across the range of Scottish Government policy initiatives in education, social work and health services. This was identified more recently too by MacDonald (2018) and Scottish Government (2021b). Social Work Scotland (2018) do not entirely agree and put forward the opinion that integration of services is not necessarily a strength, it is strength of strategic leadership that counts. It would appear that both strong, strategic and distributed leadership are required for successful collaboration, one is not necessarily effective without the other in a co-ordinated form (Leithwood et al. 2004).

Doran (2012) acknowledged the Scottish Government's recognition that the policies and legislation relating to transitions for those with ASN are complicated. There are not clear links between older and newer policies and legislation. As a result, there is considerable confusion among professionals, young people and their carers about young people's entitlements and the roles and responsibilities of those providing the access to these. Since Doran's review there continues to be a growing consensus that there is an increasing need to address the gap between children's and adult services. ASL Guidance (Scottish Government 2017a) outlines the expectations and requirements of LAs in relation to transition. Nevertheless, the transitions for many disabled children and young people in Scotland are often challenging and consistently deliver poorer outcomes than for their non-disabled peers (Jones, 2019).

The overarching principle of the right help in the right place at the right time (Doran 2012; Scottish Government 2019b) still applies into adulthood. Many parents who responded to Doran's review were concerned that all of the services would change and their adult children would not have a package of support and activities that would continue their education and participation in the community. A number of parents were considering giving up work to be at home for young people who needed constant support and supervision. Parents described huge variations and inconsistencies on what services were on offer. Several young people, whom Doran included, did not know what was happening for them when they left school at the end of that month. These issues and stresses for families are widely reported, as identified in section 2.5 of this literature review.

The Scottish Government accepted, or partly accepted, all Doran's recommendations (Scottish Government, 2012c). Six of the 21 recommendations related to funding and commissioning of services and the NSCG produced an ambitious ten-year strategy in response to this (Scottish Government 2017b, 2019b). With regard to transitions, the response to recommendation 11 states:

"We recognise the need to support improved practice in implementing transition duties. Stakeholders consistently express concern in relation to practice in transitions across children and young people's learning experiences, but particularly in relation to post-school transition" (np).

Subsequent to Doran's (2012) review, the Children and Young People (Scotland) Act 2014 delivered statutory duties on LAs in relation to the transition of young people with ASN: "The Act requires education authorities to take specific action to help prospective school leavers with ASN to make the transition from school to post-school life successfully". (Scottish Government 2017a, np.). Guidance on the implementation of ASL legislation states that planning for transition of young people should begin no later than 12 months before the pupil is due to leave school, when the education authority must seek and take account of information from other agencies, and no later than six months before the leaving date, the LA must provide appropriate information to other agencies to support planning (Scottish Government 2017a). While the guidance states 'no later than', which is open to interpretation, this gives a relatively short amount of time for transition planning for those with more complex needs.

In October 2019, in response to concerns raised, a Bill was launched in the Scottish Parliament to ensure that every disabled child with an impairment or a long-term health condition has a right to a transition plan. The consultation for this closed in January 2020 and further progress was delayed by the outbreak of a global pandemic [Covid 19]. There was discussion of the Bill at the Scottish Parliament Education Committee in February 2021, but the Bill fell on the dissolution of Parliament on 5th May, 2021 following the retirement of the Member of the Scottish Parliament who had introduced it.

2.2.4 *The Principles of Good Transition* (ARC Scotland 2017a)

Scottish government policies purport to apply to every and all children and young people all through school years, including transition to post school destinations, which the Scottish Government states, should be positive and sustained for all young people. The *Opportunities for All* pledge (Scottish Government 2012a; 2012d) led, as part of the National Improvement Framework (Scottish Government 2016b) to the terminology "positive, sustained destinations" for all school leavers. A priority within *the keys to life* (Scottish Government and COSLA 2013) is that all adults with learning disabilities, including complex needs, live meaningful and fulfilled lives. Where individuals reside and the services they receive are part of this framework. The *Principles of Good Transition 3* (ARC Scotland 2017a), endorsed by the Scottish Government,

updated from the previous versions to align with the Children and Young People 2014 Act, outline advice, guidance and support required for successful transitions for those with ASN. This updated version includes an autism supplement and a legislative flowchart as well as outlining the seven principles of good transition:

1. Planning and decision making should be carried out in a person-centred way
2. Support should be co-ordinated across all services
3. Planning should start early and continue up to age 25
4. All young people should get the support they need
5. Young people, parents and carers must have access to the information they need
6. Families and carers need support
7. A continued focus on transitions across Scotland (ARC Scotland 2017a, p.v).

While these principles appear clear and straightforward, the challenge is the variability of approaches to implementation across the 32 Scottish LAs. There is not a consistent approach that follows an evidence-based pathway for transitions (ARC Scotland 2018; Who Cares? Scotland 2014, 2017) More consistency is needed so that a transition process in one LA is the same as in another LA (Jacquet 2015, p.38). This would be important for a number of reasons, including the fact that autistic young people may be transitioning across the country and between LAs, and familiarity of services and procedures would be particularly helpful for them, their families and professionals. Strong, strategic leadership that supports collaboration is needed, as identified by Social Work Scotland (2018).

ARC Scotland (The Association for Real Change), a charity that strives to advance knowledge, practice and policy in health and social care for the benefit of people with learning disabilities or other support needs such as autism, mental health problems, sensory and physical disabilities, reported that transitions would be the theme of future Scottish Parliament reports. This was following concerns raised in Scottish Government Advisory Group on Additional Support for Learning (AGASL) (ARC Scotland 2017b). In the 2017 publication, ARC reported that a survey of young people showed that most of them were optimistic about the future and excited about taking control of their own lives, although many were worried about potential lack of support and changes in routine. Parents and carers responded to their survey with a much less optimistic perspective. Of those who responded concerning a young person who was still attending school, a significant majority said that their child did not have a written plan and was not receiving any support. A quarter of those whose child had left school stated that lack of support and information had been the biggest challenge for their child. One parent said

that transition to an ASD specific course was "woefully inadequate" (ARC Scotland 2017b, p.44). Parents asked for an earlier start to the transition process, more honesty about available options, more flexible vocational opportunities for young people and better communication. These are aspects of transition that were explored in this study in the context of residential settings.

ARC Scotland subsequently led a seminar "*Leading the change: Solving the Transitions Puzzle*" (2018) with representatives from LAs, Scottish Government and other agencies including Social Work and Education, to discuss transition support for young people with ASN. Participants raised concerns about the transition process and the most important next steps were identified, including developing a nationally agreed framework for transitions, reviewing current approaches to data gathering and evaluation and ongoing collaboration to develop solutions, share knowledge and resources. Some of the themes identified by ARC (2018) and followed up in their *Principles into Practice* seminars (2019) are reflected in a briefing to the Scottish Parliament (Hall 2019). These are the most important considerations, according to those involved in the transition process from care in children's services to adult service:

- Co-ordination and collaboration between services;
- Person-centred focus, involving the young person and their parents in decision making;
- Starting the transitions planning process early;
- Young people and their parents having a single point of contact;
- Increased information about available options;
- More support for families;
- Dedicated transitions staff;
- Appropriate training for staff (Hall 2019, p.4).

Other studies of cohorts of young people with complex needs, both in and outside of Scotland, have supported these themes and recommendations: it is clear that transition support for young people and their families continues to be patchy and needs further development (Clarke et al 2009; Health and Social Care Alliance Scotland 2017; Murphy and Mackay 2015).

The Scottish Government, in the Ministerial Forward to *the keys to life* (2013) cited some improvements in the quality of life for disabled people since the publication and the implementation of its predecessor, *the same as you?* (2000a):

> "As a nation we can be proud of the some [sic] of the changes in the quality of life for people with learning disabilities since *the same as you?* was published in 2000. People with learning disabilities tell us that they are generally much more accepted and valued in their communities than they ever were before. They are rightly seen as people who can contribute to Scottish society in very positive ways. For some, the biggest change was the closure of long-stay hospitals. For others, having their

own tenancy or being in employment or having good friends and relationships has been transforming" (Scottish Government 2013, np.).

However, the closure of long-stay hospitals may be a reason why MacDonald (2018) found numbers of Scots with complex needs in hospitals in England, suggesting that there has not been such an improvement, rather the creation of a different problem, that is, out of authority and out of country placements. This will be discussed further in section 2.2.5 below.

Following *the keys to life* (2013), the Scottish Government then put forward their delivery plan to 2021 for a fairer Scotland (Scottish Government 2016a), committing to make further changes and remove barriers. It sets out five longer term ambitions and a set of 93 actions, acknowledging that transformational change is needed and promising to do more with the powers and resources that they do have (Scottish Government 2016a). While there have been improvements (Scottish Government 2013), further assurances of support for disabled children and young people and their families continue (Scottish Government 2018b) as well as promised improvements in adult social care (Scottish Government 2021b). This includes a commitment to provide more local planning and delivery of services which is significant for this cohort where there appears to be a problem with lack of services in home LAs across the country (MacDonald 2018).

2.2.5 Post Transition

MacDonald (2018) reported on out-of-area placements and delayed discharge for people with learning disabilities and complex needs and found that a significant number of people in this group had no choice other than to move away from their local community, sometimes out of the country, due to lack of availability of appropriate local services in Scotland. MacDonald reported (2018, p.20) that there were 705 people out-of-area in Scotland from 30 (out of 31) Health and Social Care Partnerships. Although many of this cohort of young people, while at school, are already away from their home environment, the home LAs and families maintain links with a view to the young person returning to the home LA at the end of the school placement. The following statistics, from MacDonald (2018) indicate that, for the majority, this was not their choice to be out-of-area, but imposed upon them due to lack of local availability or choice of service. Of the 705 out-of-area in Scotland, more than one third were autistic and, mostly, a moderate to severely learning-disabled group. Nearly half of the group had been out-of-area for more than ten years, almost another quarter for more than five years. 28% were out-of-area through family choice or their own choice and more than half because no service was available locally. 109 were considered to be priority to return, although MacDonald acknowledged that these figures were likely to be under-reported. MacDonald (2018) also

reported on those who had been admitted to ATUs, with difficulty in managing their challenging behaviour in their placement being the most often cited reason for this. MacDonald concluded that there is a lack of coherent strategy to effectively address the support needs of this group. This suggests, despite the vocal and strategic support of the Scottish Government in initiatives and policies for every and all children and young people, that these are not always effective for this cohort with highly complex needs. The report concluded that this is a human rights issue and that having to move far from home because they were unable to receive support within their local community was "a denigration of their human rights" (MacDonald 2018, p.51).

Eleven years after Rosengard et al. (2007) reported that, overall, while their findings illustrate a variety of excellent practice, "more generally it presents a bleak picture of the quality of responses obtained by people with multiple and complex needs, who continue to be significantly disadvantaged and excluded" (p.v), MacDonald (2018) presented a similar picture, well after the implementation of 2014 legislation. As recently as 2021, the Scottish Government acknowledged further criticism of the system of adult social care, following a review, and proposed a transformational change going well beyond current culture and practice to address gaps in provision through a National Care Service (Scottish Government 2021b). The Scottish Government has now committed to pursuing this and a national consultation process opened in August 2021, with a closing date of 2nd November, 2021. Early in 2022 Enable Scotland launched their campaign, *#MyOwnFrontDoor*, criticising lack of government action since MacDonald's 2018 report, saying that the situation has deteriorated even more since then. The campaign calls on society to address the "human rights scandal (np) facing people with learning disabilities in Scotland, appealing for them to have the right to a home they choose and to live in the community of their choice. A month later the Scottish Government and CoSLA published the *Coming Home Implementation Report* (2022), pledging that, by March 2024, "we want and need to see real change with out of area residential placements and inappropriate hospital stays greatly reduced…only made through individual or family choices…".

2.2.6 Funding

A key issue affecting the social care sector is lack of funding (Scottish Government 2021b). The cohort described by MacDonald are adults with the most complex and challenging needs, a small cohort, but, like the pupil cohort of this study, with very specific and significant support needs and barriers to learning. Although small in number, their support is often expensive due to the very individualised nature of their needs and levels of support required to address those

needs, plus lack of local availability of highly specialised placements. MacDonald (2018) did not doubt that money is being spent with good intentions, but questioned whether it is value for money and whether approaches to collaborative working between authorities may be more effective.

The home LA is financially responsible, even if the young person eventually resides outside of the home authority. The expectation is that, although there may be a number of services involved, including health, social work and education, the home LA will take responsibility for leading the transition process and co-ordinating the process through a Lead Professional, usually from the Social Work Department. There is competition to provide adult services between LA, private providers and charities, which can lead to a focus on cost rather than high quality person-centred care and support and can cause poor terms and conditions, including low pay for social care staff (Scottish Government 2021b).

While these young people attend school, in the context of this research, a residential, autism specific school, high levels of autism-specific education and support are provided. Their right to education and a planned transition to a positive, sustained post-school destination is protected in Scottish Government legislation, policy and frameworks (Education Scotland 2012; Scottish Government 2012d; Scottish Government 2014). Yet, as already evidenced, there are reports and studies identifying recurring themes and significant deficits in transition experiences (ARC Scotland 2017b, 2018; Doran 2012; Hall 2019; MacDonald 2018). While Hall (2019) recognised that policies and legislation in the areas of education, health and social care reflect previous recommendations to some extent, recent evidence suggested that there still remained gaps between policy and practice in transitions between child and adult services (Hall 2019). MacDonald cited cost as being a significant factor in providing appropriate support and, MacKay et al. (2018) concluded that, in autistic people, presence of intellectual disability is the single most important moderator of outcomes and of costs, with major implications for economic estimates and service planning. ARC (2017b) did not refer to cost but reported that the perception among their study participants was that necessary steps to improving transition, where the experience has been reported as negative, are modest and able to be delivered, that there was broad agreement among parents and carers about what would make a difference, and that support should be more joined up and consistent. These views were considered in the empirical part of this study.

2.2.7 Summary of policy context

The range of policy initiatives across education, social work and health, each set within their legislative frameworks and funded from different sources, entail considerable duplication of effort by policy and professional staff in maintaining communication and ensuring cohesion across disciplines and agencies (ARC 2018; Doran 2012; Hall 2019; Murphy and Mackay 2015). The transformational change that MacDonald (2018) called for to address this duplication and lack of cohesion involves "a change of attitude and culture, a new belief in what is possible, resulting in significant changes in structures and systems" (p.46). This is indicative of the findings of the independent review into adult social care (Scottish Government 2021b) which promises to address and improve these same areas, identified as being inadequate by service users and their families. The review promises to provide the transformational change, the overall change to culture and approach requested by MacDonald (2018), and, along with the Coming Home Implementation Report (Scottish Government and CoSLA 2022), promises to ensure the rights of adults accessing social care.

The experience of families varies across the country (ARC 2018; Hall 2019). The purpose of this research was to consider the experience of young people and their families and to consider the implications of this for policy and practice.

2.3 Pupil voice

The challenges with communication, social skills and cognitive ability of the cohort in this study, and therefore potential limitations with their involvement in transition planning, have been outlined in the introduction to this thesis (1.3.1) as well as ways eg. PCP that they are supported to express their views through the transition process (1.4.1). Augmentative and Alternative methods of communication (AAC) are widely used to support young people's communication, ensuring that young people are included in making choices and decisions about situations that affect them. AAC methods include using objects or symbols, signing such as Makaton, an amended form of British Sign Language (The Makaton Charity), social stories (Gray 1998), Talking Mats (Talking Mats Ltd.), PECS (Picture Exchange Communication System) (Bondy and Frost 1985), SPELL (Structure, Positive, Empathy, Low arousal, Links) (NAS 2021b), TEACCH (Treatment of Autistic and Communication Handicapped Children) (TEACCH Autism Program 1971), advocacy, where someone speaks on their behalf, and electronic devices where appropriate. While speech and language therapists support AAC at both school and post-school, transition to adult speech and language therapy services is not always successful (McCartney and Muir 2017). In Scotland, adults with learning disabilities

have found it difficult to access Speech and Language Therapy (Scottish Executive 2003) and, almost two decades later, communication support for people with sensory impairments and learning disabilities can be poor (Scottish Government 2021b).

Article 12 of the United Nations Convention on the Rights of the Child (UNCRC) (United Nations 1989), states that all children and young people should be involved in making decisions about matters that affect their lives. However, for children with disabilities, this is often limited within family settings due to familial norms and values and a desire by families to protect children (Saaltink et al. 2012). Autistic children's views and experiences are particularly underrepresented in decision making at school (Zilli et al. 2020). There are challenges in addressing and effectively intervening with autistic young people of varying abilities, and some forms of research or communications may only be possible with young people who have average or above average cognitive ability (Burke et al. 2019). Burke et al. (2019) acknowledged, while encouraging researchers to find ways to include this group of young people, that the cohort with more complex or significant needs are therefore not widely represented in interventions or programmes that are being designed to improve transition outcomes. For researchers, there is a duty to be a "sensitive researcher" and to carefully manage the emotions of vulnerable participants, so that participants are not left with painful experiences (Liamputtong 2007 p.32). It is, as Burke et al. (2019) outlined, quite a different challenge to seek qualitative information from this cohort as part of a research study, especially if the research requires retrospective thinking or thinking into the future, abstract concepts which many autistic children and young people find difficult (Fayette and Bond 2018a, 2018b; Reid 2007).

Shogren et al. (2012) reported that autistic students with an intellectual disability were significantly less likely than students with other disabilities to take a leadership role in their transition planning and that autistic students were the least likely to attend their meetings, although transition planning does take place and, in many cases, an advocate is present. They may be presenting a limited view of what a leadership role involves for those who have autism and limited cognitive ability, given the methods of communication already mentioned, and they did not account for the fact that some young people may not wish to be involved. This was reported by Beresford et al. (2013) who found that autistic students' level of participation in transition meetings was related to their difficulties with communication and that involvement in the planning was stressful and challenging in itself. Similar findings are reflected by Nuske et al. (2018). Browning et al.'s (2009) study of perceived stress of both neurotypical and autistic young people approaching school leaving appears to provide some context for this.

The autistic participants worried about specific aspects and social relations, they were unable to express their stress and acknowledged that they were not good at dealing with anxiety about either current or potential future experiences. Other studies concur and acknowledge that autistic students are less likely to feel empowered or to wish to participate due to their perceptions of their own autistic traits (Hewitt 2011; Nuske et al. 2018; Wagner et al. 2007). Chandroo et al. (2018) found that autistic students had minimal involvement in the transition planning process and they would seek to redress this lack of empowerment by saying that it is essential that teachers educate autistic students about the transition planning process and support them in improving their self-advocacy skills. This was an Australian study and the policy context may be different. Nevertheless, some clarification of what self-advocacy entails is required. Otherwise, this assumes that autistic students have the capacity to do this in all situations, which is not the case. Gilmartin and Slevin (2010) reflected the views of intellectually disabled participants about being a member of a self-advocacy group. Participants in this study, however, were only those who are able to self-advocate and is likely to exclude the majority of young people in the cohort with the most complex needs and intellectual disabilities.   The nature of transition planning and policy into adulthood is complicated (Burke et al. 2019; Shogren and Plotner 2012) and needs to be designed to address the particular traits of each individual.

Young autistic adults have poorer outcomes than their peers with other developmental disabilities in areas relating to post school provision, such as independent living, further education, and employment (Sosnowy et al. 2018). Sosnowy et al. (2018) investigated how young adults with autism and their families understand and value outcomes, and whether these outcomes matched their goals and aspirations. They reported that participants in their study, both parents and autistic youth, described transition outcomes as more complex than is actually taken into account and planned for. For example, some parents felt that additional support and services to support with study skills, organisation skills and socialising were needed and were frustrated by the lack of understanding of autism by colleges or disability services, even when the service promoted itself as being able to support autistic students. Some parents felt that it was their role to educate the post school provision about their child's autism and associated needs. Overall, what parents considered to be a successful outcome was relative to their child's individual needs. Parent voice will be discussed in the next section, 2.4.

Successful future outcomes in adulthood begin with the transition planning process and this clearly presents many challenges for the cohort of young people in this study and their families. For these young people, when it comes to transition planning in school, they are supported by family and professionals, and are very much included in the person-centred planning process, looking ahead to what will suit them best on leaving school. PCP is recommended by Burke et al. (2019), saying that it empowers individuals to have a major role in decision making about their lives. PCP must take account of and be responsive to autism-specific challenges to transition planning, including anxiety caused by lack of awareness of social norms and aversion to change (Beresford et al. 2013). Depending on individual circumstances, the young person may be represented through advocacy by family and key workers or by some digital representation, outlining their views on pre-recorded audio or video, rather than their physical presence. This is so that the young person can contribute, as far as they are able, while avoiding adding stress and anxiety through an expectation that they will be present and participate in a formal discussion. Autistic children and young people can experience a high level of anxiety every day and many have rigid thought processes and high levels of anxiety when faced with anything or anyone unfamiliar or unknown (NAS 2021a; Nuske et al. 2018). While PCP is an established practice in the school of the study to initiate the transition process, it is not an approach that could be used effectively as a method in this research to seek the views of young people. PCP, as preparation for transition, is focused, with the support of familiar people, on building a future pathway based on strengths and preferences of the young person. The process of eliciting information in a research interview is different and these interview questions are necessarily more open-ended. Obtaining a full picture of the transition process and experience, would require recollection of potentially distressing or negative experiences and a more abstract picture of the future, a skill that autistic people find difficult (Fayette and Bond 2018a, 2018b; Reid 2007).

There has been some discussion of the potential of using of Virtual Reality (VR) technology to support autistic children and young people, including those with learning disabilities (Trepagnier 1999), with lifeskills and with expressing themselves in social situations (Moon 2018; Parsons and Mitchell 2002). VR has the potential to allow the participant some control, improve communication and give the opportunity to practise situations and problem-solving techniques in a controlled environment without having to be face-to-face. However, Parsons and Cobb (2011) found that, although VR appears to be an appropriate method to support autistic pupils, its use and potential is under-researched and requires further exploration. Subsequent research concurs on the benefits of being able to explore virtually before entering

the real world (Newbutt et al. 2020) but empirical studies have been limited in size of research sample (Amat et al. 2021) with very little within educational settings (Newbutt et al. 2020) and presents the benefits more for high functioning autistic people (Qazi and Raza 2019).

Fayette and Bond (2018b) identified a number of studies that supported their findings about the challenges associated with eliciting the views of autistic children and young people and caution that these limitations should be considered when researching. These limitations include the fact that views need to be gathered over time, not seen as a "one-off event" (p.6), but integrated into the culture of the school, that they must be gathered by people who understand autism and are familiar with the young person's preferred communication method(s) and that those supporting young people to make decisions need to ensure true participation and avoid tokenism. Challenges in this area are widely reported (Loyd 2013; Preece and Jordan 2010; Winstone et al. 2014). Struggles with such interactions are due to factors including participants' limited ability to identify and express emotions and their very individualised ways of using language (Preece and Jordan 2010); the potential power imbalance between participants and researcher causing some autistic children and young people to feel that they had to give a certain answer and that only one answer was the correct one (Winstone et al. 2014); and, crucially, the significant challenge of obtaining informed consent (Loyd 2013). Loyd (2013) advised providing and eliciting information by whatever means of communication the participant would normally use, offering the participants the opportunity to discuss their participation with the researcher. This, however, would seem to be more appropriate for those identified by Burke et al. (2019) as being of average or above average cognitive ability, and not appropriate for the cohort of my study who are at a very early developmental stage. Gaona et al. (2019) also state that, despite the significant increase in research on autism, there is a lack of research involving the views of young people contributing to the discussion on transition to adulthood. Their study aims to address what they call this 'paucity in research' (p.340), yet all of their participants are verbal. Nevertheless, Fayette and Bond's (2018a) study of eliciting pupil views in a special school found that modification was also required for pupils who were verbal, due to their other autism traits – difficulty with abstract concepts, social interaction etc. They also concluded that eliciting pupils' views is an ongoing process and that autistic pupils should be taught how to make informed decisions by the experienced staff who support them. Eliciting the views of young people is not an end in itself, but a means to an end of meaningful participation in the decision-making process (McNeish and Newman, 2002).

For this study, taking into account the time passed since transition, the potential upset and the challenges with communication difficulties which prevented data collection, I felt unable to elicit the views of the young people directly, but relied on those who knew them well to speak on their behalf. In addition, I suggest ways that this may be addressed in future studies (6.4.1).

2.4 Parent voice

While Langan (2011) stated that the voices of autistic people, including those less able with additional learning difficulties, have been increasingly acknowledged over the past decade, there has been very little attention paid to the "distinctive contribution" of parental voices (p.193) and this is reflected in the relatively limited literature on the subject. Brett (2002) strongly stated that, by focusing on a social model of disability and ignoring the experience of others, including parents, that the voice, and therefore the experience, of the child may be missed. Burke et al. (2019) acknowledged their own debate about whether to intervene with parents in their study or the young people themselves, and state that most researchers do not have this dilemma as they choose to interact with those who are more cognitively able.

The challenges facing parents with an autistic child are widely discussed (Langan 2011; Neely-Barnes and Dia 2014). Brett (2002) reported that parents voice the need for advocacy and stated that parents hold the key to their child's communication, they are the voice of the child. Families are a critical source of support for children with disabilities (Neely-Barnes and Dia 2014). When a family finds out that their child has a disability, they enter the world of special education which has its own terminology, rules, settings and personnel (Hess et al. 2006). Family support is crucial in supporting autistic individuals for their whole lives (Tint and Weiss 2016). Burke et al. (2019) described parents as the central players in transition planning and support and, in view of the fact that policies are typically written at a reading level that make them inaccessible to those with disabilities, see the involvement of parents as guides through the system. In fact, Hatfield et al. (2017) found that parents believed that the transition planning process was their responsibility. Many parents fear for the future as their autistic child approaches adulthood (Blacher et al. 2010; Cheak-Zamora and Teti 2014; Cheak-Zamora 2015; Doran 2012) recognising that there are gaps in services available and that parents and families will need to fill those gaps. If a thoroughly individualised transition plan is to be produced, then family perspective is critical (Blacher et al. 2010). While parents are key in their child's network and often facilitate transition, there is a lack of information about their hopes and expectations for their child (Sosnowy et al. 2018).

Langan (2011) traces the emergence of parent voice in autism in three phases from the widely held indifference, lack of knowledge and stigma of the 1960s-1980s, to the 1990s onwards with an upsurge in public awareness, and to the 21st century wave of parental activism towards an acceptance of autistic diversity. Langan (2011) attributed parents with half a century of contesting professional theories and practice in autism. Legislation (Scottish Schools (Parental Involvement) Act 2006) has given parents an increasing role and more and better opportunities for partnership since Dale (1996), Case (2000) and Brett (2002) reported that parents perceived that the professionals hold the power by defining how and when parents are involved. Although meeting the complex and highly specialised needs of their child, parents felt that they did not hold an equal relationship with professionals, often lacking the knowledge, expertise or power to influence decisions, participate in interventions or negotiate the services affecting their child (Brett 2002; Case 2000; Dale 1996). Brett et al. (2002) reported that parents perceive that professionals do not see them as people and that they feel that they know their children better than anyone, although Shakespeare (1999) advised caution where parents state that they know best, mooting that a reliance on the parent can ignore the child. Brett too (2002) acknowledged that there is a danger of the child becoming passive if there is too much reliance on the parent but, clearly, there needs to be a balance of input from parent, child and others to overcome this. This is at the heart of Brett's (2002) Alliance model which emphasises dialogue between parents and professionals, although Brett (2002) does acknowledge that some parents prefer a passive role, fearing that they lack expertise or good communication skills. Tensions in relationships between parents and authorities have been reported more recently too with parents indicating that LAs are seen by them as dishonest and inflexible and more concerned with financial implications than with meeting children's needs (Riddell and Weedon 2016). Where this exists, this tension is often carried forward from children's to adult services. This is something that was explored further in the research.

2.5 Emotional Impact

It is reported that many parents and families feel stress and anxiety about their role in supporting their autistic child (Noonan et al. 2018; Nuske et al. 2018; Tint and Weiss 2016). Blacher et al. (2010) found that parents of autistic children worry significantly more than parents of children with other disabilities at the point of transition to adulthood and that a move to a residential setting is often a desirable option for this cohort with severe learning difficulties. Brett (2002) reported that some parents experiencing emotional or psychological stress may actually find it a relief to pass responsibility on to others. This makes Brett's (2002) Alliance

model of "true partnership" which relies on "mutual endeavours" between parents and professionals, if not an impossibility, "perhaps optimistic" (p.837). All parents in Brett's (2002) study expressed feelings centred around their emotional and psychological state and some apologised for being negative. Parents who are stressed and anxious are not able to fully contribute due to feeling "oppressed and disempowered" (Brett 2002, p.840). Doran (2012) focused mainly on the experience of children with complex needs up to the age of 19 but notes that, for parents, preparation for transition to post school provision "loomed large" (p.11). The review team had expected it to concern parents and carers and the young person in the last two years of school, but found that the deep anxieties and concerns about transition arose as early as the later stages of primary school. By far the greatest concern for parents, was the move to adult services and the fear of the young person falling into a "black hole" (p.29) where there was no direct accountability for continuing services.

Studies show too that there should be some caution regarding the role of parents where there are indications that parents often have much lower expectations of the future for their autistic child than the child themselves (Blacher et al. 2010; Chen et al. 2018; Kirby et al. 2018). It should be noted that these studies involved young autistic people who are more able to express their views than the cohort of this research. Holmes et al. (2018) acknowledged a link between parental expectations and outcomes for autistic school leavers where parents associate success with traditional outcomes such as employment, school success and independence, although the study concludes that the causes of this are not clear. Holmes et al. (2018) stated that their results should have some impact on how providers prepare and support families during the transition to adulthood.

2.6 Professional views

The voice of professionals is often heard around the table as part of planning and process in their field. In transition planning, as discussed in this thesis, there is a Lead Professional, usually from social work, who guides and has control of the process and automatic permission to speak or lead and guide the discussion in any meeting about a child or young person. However, their views on the process are less well known. Although reporting on new school transitions rather than transitions from school to adult services, Nuske et al. (2018) found that school staff lacked knowledge about the transition process, lacked understanding of individual needs of autistic pupils and were often time limited, meaning that some transition strategies eg. visiting placements or collaborating with parents, were difficult to implement. For reasons of professionalism, there are limits to how critical or analytical a professional may be of the

system in which they work. Hope and help is what is required for children and families from the professionals (Ariel and Naseef 2005).

Ariel and Naseef (2005) compiled a series of essays devoted to the voice of those who work with autistic children and their parents, mainly therapists, giving their personal accounts and reflections and stating the need for self-determination and patience as well as the necessity to be more than a therapist (Rice and Bellin 2009). The importance of establishing relationships with both the autistic child and their parents, with shared decision-making, is emphasised and echoed by others (Anderson et al. 2017; Hatfield et al. 2017; Kuo et al. 2018).

It is acknowledged that transition of young people to adult services is stressful for professionals as well as parents (Meiring et al. 2016). Problems arise due to multilevel barriers to transition and inadequate interagency and multidisciplinary collaboration (Kuo et al. 2018), what Stalker and Moscardini (2012) refer to as "the old chestnut of poor partnership working including cultural differences between children's and adult services." (p.37). Crane et al. (2021), in their study of education professionals involved in transition of pupils to adulthood, reported that participants worried about being unable to consolidate new knowledge gained from training, due to lack of time. Participants also voiced concern about uncertainty of methods to include pupil voice and inability to support young people due to a lack of available opportunities. There is a lack of advocacy to enable young people to participate more (Meiring et al. 2016).

While these studies identify gaps and needs in the system as related by professionals, Ariel and Naseef (2005) acknowledged the positives and the critical benefit of having the right professional team working together to navigate the complex issues along the spectrum. There is an indication that professionals believe that practices, cross-service communication, collaboration and accountability have improved since the Children and Families Act 2014 in England (Dunsmuir et al. 2019). The same may not be true in Scotland (Enable Scotland 2016; Morgan 2020). Aspects of this will be considered in this study.

2.7 Transition experiences

Transitions have been defined as an ongoing process of psychological, social and educational adaptation, which occurs over time, due to changes in context, interpersonal relationships and identity (Hall 2019). Zittoun (2008) defined transition as the process that follows rupture of usual processes, requiring adjustment and calling for the production of newness. This process can be both exciting and worrying and, for young people with disabilities, requires ongoing support (ARC Scotland 2017a, 2017b). Transitions of any kind can be challenging for autistic

children and young people, who may have difficulty in shifting attention from one task to another or in changes of routine (Hume 2008; Nuske et al. 2018). This may be due to a greater need for predictability (Flannery and Horner 1994), challenges in understanding sequence of activity (Mesibov et al. 2005), or difficulty when a pattern of behaviour is disrupted. For everyone, transitions can be a scary, challenging time but for an autistic person these challenges and fears are often increased and complex (ARC Scotland 2017b) and can often become a period of heightened anxiety and stress for autistic people and their families. It is therefore critical to get transitions right for autistic people (ARC Scotland 2017a).

The transition experience to life beyond school and into adulthood seems to be one of the most problematic times for autistic individuals and their families, often triggering depression and anxiety in autistic people (Bernard et al. 2001; Browning et al. 2009; Osborne and Reed 2008). This may be attributed mainly to their inability to cope well with changes in routine and social situations which require new coping strategies and skills of independence (Bellini, 2006; Nuske et al. 2018). The transition period leaves autistic people vulnerable, and families are faced with fragmented systems of care leading to unsatisfactory outcomes across education, training, employment, social care housing and health services (Friedman et al. 2013). Friedman et al. (2013) suggested that the problem lies in inadequate school-based transition planning. Anderson et al. (2017) also found implications for policy and practice and recommendations for further research. The reasons they offer for poor transition outcomes include lack of individualisation, uncertainty about the role of parents and a shortage of adequate and integrated services.

The call for better and more integrated services is echoed by Cheak-Zamara et al. (2012) who concluded that young people with comorbid conditions are at the highest risk of receiving poor or inadequate health services. The transition from children's to adult health services is particularly challenging, due to "an often complex health and social care landscape and a multitude of different concerns and issues that need to be resolved" (ARC Scotland 2017b, n.p.). Many parents and carers struggle to access the support they believe that their child needs from health and social services post-school and they are often challenged by their child's transition (Health and Social Care Alliance Scotland 2017). A similar picture is reported in England, which is relevant to practice and experience in Scotland:

> "Too often, professionals working with these young people are not encouraged to
> focus on young people's ambitions for adulthood and how best to help them prepare.
> Such poor planning of support is exacerbated by a lack of choice and opportunities

for young people…. In addition, the transition from children's to adult health services is often badly coordinated, which can lead to a deterioration in young people's health" (Department for Education 2011 p.10).

Rydzewska (2012) found that many autistic adults in Scotland struggled to access the support they need and that those who are described as being 'high-functioning' and without cognitive impairment were able to achieve *despite* [writer's emphasis] a lack of appropriate and adequate provision. Other studies of cohorts of young people with complex needs, both in and outside of Scotland, support themes and recommendations outlined by Hall (2019) and ARC Scotland (2017a) in section 2,2,4 - it is clear that transition support for young people and their families is patchy and needs further development (Clarke et al. 2009); transitions for school-leavers with long-term speech, language, swallowing or communication (SLSC) needs usually require a re-configuration of personal support services across health, social care and education, and a move from child to adult services, requiring careful multi-disciplinary and family liaison (McCartney and Muir 2017). There are indications that some of the key aims of the legislation are being addressed as respondents (groups of professionals and managers working in education, health and social care) talk extensively about placing the young person at the centre of decisions on the transition (Dunsmuir et al. 2019). Where there was a sense of collaboration between the individuals, families and the professionals, the experience of assessment was described positively (Mental Welfare Commission for Scotland 2019).

2.8 Post school provision – issues

A number of recent newspaper reports in Scotland may provide some context for the findings of the studies mentioned above and some explanation as to why parents are worried about post-school placements. These refer to autistic individuals with complex needs who were well supported at school and whose post school transition broke down (Adams 2018; BBC 2018; McNeill 2018; Sweeney 2016). This led to significant anxiety for young people and their families and has resulted, in some cases, in a hospital placement for young people, where an appropriate post school placement is not available in their local authority. There are similar reports in England, (Gentleman 2011; Salman 2019). In addition, the independent review into adult social care in Scotland (Scottish Government 2021b) acknowledges that, while there are some positive examples, the majority of responses to the review were critical about the existing structure and design of adult social care, referring to the system as "a guddle" [Scots: complete mess] (p.9), notoriously difficult to access, over-complicated and bureaucratic.

Improvements in some parts of the country are acknowledged, along with the fact that there is much more to be done.

Staffing concerns such as lack of training and high turnover, poor pay and conditions, are reported as contributing to the problem (ARC Scotland 2017b, 2018; Hall 2019; Martin et al. 2011; Scottish Government 2021b; Sulek et al. 2017). The Scottish Government (2021b) acknowledges that staff in the adult social care sector are underpaid and undervalued and promises to address this. Inconsistent staffing, that is high turnover, limited capacity and casual staffing is problematic in organisations supporting children (Martin et al 2011; Sulek et al. 2017), although Sulek et al. (2017) found little evidence specific to an autism setting before their own research. They found that inconsistent staffing leads to lowering of expectations of staff and often to adjustments in programmes of support and interventions for service users and conclude that inconsistent staffing has a detrimental impact on both autistic service users and staff.

There are a number of possible reasons why there is a high turnover of staff in this sector, the impact of challenging behaviour being among them. The prevalence of challenging behaviours among people with ASD is well documented (Edelson 2011; Emerson 2001; MacKay et al. 2018; National Autistic Society 2020). Campbell et al. (2011) report a significant increase in ASD diagnoses since 1999, what Butrimaviciute and Grieve (2014, p.882-883), refer to as "real or superficial 'autism epidemics'". This increase suggests that families and care staff are more frequently exposed to challenging behaviours and that social care organisations are experiencing higher pressures as a result. Butrimaviciute and Grieve (2014), examined care staff's response to being exposed to high levels of challenging behaviours, including SIB. While they noted that previous studies demonstrated that being exposed to challenging behaviour can have a negative impact on care workers, they presented this exposure to challenging behaviour as a "complex, multi-component experience" (p.882) which often resulted in some ambiguity of feelings of failure and achievement and "destructive emotional reactions" (p.882).

The group of individuals who continually self-injure are the most difficult to work with (Fish 2000; Huband and Tantam 1999). Duperouzal and Fish (2010) carried out a study of participants with a mild or moderate intellectual disability living in a medium secure unit, who regularly self-injure. They found common themes in responses from all participants in relation to the actions and reactions of individual staff and organisations. The majority of responses focused on interactions and relationships with care staff. All respondents described difficulties

engaging with staff in relation to their SIB saying that staff would either not discuss it with them or would not understand. Staff response was often reactive rather than proactive, leading to restrictive practices such as close observation, which participants recognised as punitive, causing further stress.

Participants described self-injury as a coping strategy, an emotional release, and felt that they should not be prevented from doing it as this only added to their distress causing them to continue the cycle of self-injury. A very small number said that they had found staff to be supportive, listening, talking personally rather than clinically and helping them to find alternative coping strategies. The participants in the study by Duperouzal and Fish (2010) had a mild or moderate intellectual disability and were able to communicate verbally, unlike the cohort with complex needs and non-verbal communication who are the focus of this research. However, similar accounts are given from non-intellectually disabled people who self-injure (Bosman and Meijel 2008) where self-injury is described as a coping strategy or reaction to emotional stress. Therefore, it is possible to deduce that the same may apply to the cohort with complex needs and that the challenge for staff is likely to be exacerbated by the young person's inability to communicate their needs or cause of distress quickly and easily. Duperouzal and Fish (2010) concluded that staff who work with individuals who regularly self-injure should change their mind-set from trying to fix the problem to supporting them to find alternative, less harmful ways of coping and expressing themselves. This change of mind-set and depth of understanding would require specialised training.

Lack of appropriate training for staff is a concern in supporting autistic children and young people (Enable Scotland 2016; Morgan 2020) and often cited as one of the factors negatively impacting on transition planning and support of autistic young people through that process (ARC Scotland 2018; Hall 2019). Working with autistic children and young people requires specialised training and, as well as knowing and understanding autism, staff should be trained to manage difficult situations that can easily lead to emotional and physical exhaustion (Roncaglia 2012). Roncaglia (2012) considers that training should be a form of coaching, where trainees are involved in challenging situations that require deep reflection of their own practice and solutions that they can bring to the workplace, suggesting a framework that includes a combination of ecological awareness, positive behaviour support, low-arousal approaches, role-play, debriefing and emotional regulation (pp.62–66).

An interdisciplinary, collaborative approach is described by Longtin (2014). The approach includes, as well as clinical and academic support for autistic young people, education and

training for mentors and in-service training for staff, students and other staff, including administrative staff. Evaluations indicated positive outcomes for all participants but, as the project was grant-funded, the author notes that it would not be able to continue in the same way due to lack of funding. Lack of resources and funding is clearly an issue in supporting young autistic people with the most complex needs (MacKay et al. 2018; MacDonald 2018) and in the adult social care sector in general (Scottish Government 2021b).

Chapter 2 has provided some further background context for the research. Research methods and methodology will be explained in Chapter 3.

Chapter 3: Research Methodology and methods

3.1 Introduction

The Literature Review chapter presented information to address the research questions and aims of the study, including autism and complexity, parent, professional and pupil voice, models of disability and the Scottish policy context. This chapter presents the approach, Reflexive Thematic Analysis (RTA), and research methods used, and the rationale for using these methods, and describes the data collection strategy and selection of research instruments and sampling. The chapter ends by outlining the steps involved in data analysis, with a section on researcher reflexivity.

3.2 Selecting a research approach

Habermas (1972) and Smyth (1989) outline four stages of approach to critical educational research through reflective practice and this is what this research project aimed to achieve. It involves, through description, an interpretation of the current situation; a presentation of how the current situation came to be; how the situation might change; and, finally, an evaluation through reflexion (Cohen et al. 2011, p.34). There are several potential outcomes of the research in this study - to propose a new understanding of the topic, especially in relation to the context and understanding of 'complex needs'; to improve the transition and post school experience for autistic school leavers and their families by identifying gaps in policy and practice; to address a gap in the literature; to build on existing research and offer opportunities for future research.

I was interested in the experiences of the young people and their families, where reality is subjective. The participants may have had similar experiences, but their perceptions and interpretations of those experiences may differ. Subjectivism recognises that social phenomena are created from perceptions and actions of those social actors concerned with their existence, and that social phenomena may change depending on those actors (Bryman 2012). Therefore, I was focused on an interpretive rather than normative paradigm, as it is concerned with that which is subjective, socially constructed and subject to change. Although social research does not necessarily fit exclusively into one or the other of these approaches, and there may be some overlap, the interpretivist view of the world as developing insights into people's beliefs and their lived experiences through the use of qualitative data (Denscombe 2017) suits this study better than the more scientific approach of positivism which holds that knowledge is based on sense experience and is advanced by means of observation and

experiment (Cohen et al. 2011). As Denscombe (2017, p.8) observes, the social world is regarded as a "nuanced, multi-layered phenomenon whose complexity is best understood through a process of interpretation". Cohen et al (2011) acknowledge that positivism is a less successful approach in the study of human behaviour where the complexity of human nature and the intangible quality of social phenomena are in stark contrast to the order of the social world. The research calls for "an effort to get inside the person and to understand from within" (Cohen et al. 2011 p.18) and, as Phothongsunan (2010) concludes, interpretive researchers seek to investigate how humans perceive and make sense of this world.

I wanted to find out about the experiences of autistic school leavers with complex needs transitioning to adult services and to consider whether and how the experiences reflected the aspirations of Scottish Government policy for these young people. To do this, I wanted to use my own experience to help understand and interpret the data, an interpretivist approach where knowledge is seen as personal, subjective and unique and I, the researcher, understand the social world using my, as well as the participant's', understanding (Al-Saadi 2014). Initially I considered a phenomenological approach. Phenomenology, a philosophical movement which is one of the dominant traditions in 20th century philosophy (Zahavi 2019), is grounded in philosophy, physiology and psychology (Corby et al. 2015; Fischer 2009). It is a range of research approaches that concentrate on the study of consciousness and the objects of direct, lived experience. Hermeneutic phenomenology evolved from this, based on the idea of using one's own experience to help understand the phenomena under investigation, recognising that engaging with the world requires a certain amount of knowledge or understanding of various phenomena and is more easily understood when its relevance is acknowledged (Fischer 2009).

However, phenomenology as a philosophy stresses that only those that experience phenomena are capable of communicating them to the outside world (Parahoo 2006). The aim of descriptive phenomenology is to offer a description of lived experience, as experienced by the experiencer, without any interpretation or explanation (Benton and Craib 2011; Zahavi 2019). As I was relying on parents, as well as presenting their own experiences, to interpret for the young people, I rejected this approach. In addition, phenomenology is a fully qualitative approach, and, as my original intention was to use, although a mainly qualitative study, a mixed methods approach (section 3.4), this would not be appropriate.

I was then drawn to Braun and Clarke's (2006) thematic analysis (TA) approach, which outlines how to identify, analyse and report patterns (themes) in qualitative data. TA is a useful method when investigating under-researched areas (Braun and Clarke 2006), and is used to "identify patterns within and across data in relation to participants' lived experiences, views and perspectives, and behaviour and practices" (Clarke and Braun 2017, p.297), all of which aligned with the purpose of my research and how I hoped to achieve the aims and objectives. TA offers a particular way of working with qualitative data and "is a method, or cluster of methods in its own right" (Braun and Clarke 2021, p.330). Braun and Clarke (2021) acknowledge a number of difficulties or problems in developing a universal quality standard for RTA. One of these problems is the assumption that, due to the relative lack of theoretical prescription intrinsic to TA, it is "atheoretical" (p.337). They maintain that, despite not having inbuilt theory, TA can never be conducted in "a theoretical vacuum" (p.337) and that researchers should specify the philosophical and theoretical assumptions informing their engagement with TA, recognising that RTA is theoretically flexible (Terry et al. 2017), as I have done in the Introductory paragraph of Chapter 1 and earlier in this section, 3.2. TA can be used for analysing a wide range of data types, including interviews and surveys (Terry et al. 2017). In addition, its flexibility and accessibility make it particularly suitable for a researcher, such as myself, new to qualitative research (Terry et al. 2017).

3.3 (Reflexive) Thematic Analysis (RTA)

At the time of writing the paper, Braun and Clarke (2006) wished to fill a gap they had identified, the lack of literature that sufficiently delineated the theory, application and evaluation of TA, as well as making it accessible to students and researchers. Braun and Clarke's (2006) paper received recognition for the ensuing increase in interest in and understanding of TA (Byrne 2021; Terry et al. 2017) and has become one of the most cited papers on *Google Scholar* (Braun et al. 2019). Following this, Braun and Clarke (2013; 2019; 2021; 2022), realised that students and researchers were often misinterpreting their approach or misquoting them, that more guidance was required on the practicalities of engaging in qualitative analysis (Clarke and Braun 2013) and that they wished to prevent engagement in "untheorised mash-ups" (Braun and Clarke 2019, p.589). Since 2006, they have subsequently refined and further outlined their approach to TA, which has evolved to become reflexive thematic analysis (RTA) (2019; 2021; 2022). RTA is a flexible approach that can provide a rich, detailed, and complex account of data (Braun and Clarke 2019; Terry et al. 2017). Braun and Clarke (2022) outline

the variations of RTA as: inductive/deductive; semantic/latent; experiential/critical; realist or essentialist/relativist or constructionist.

In inductive approaches, orientation to data analysis is located within the data, and coding and theme development are driven by the data, while deductive approaches are theory-driven, where data are coded to fit a pre-existing coding framework or codebook (Braun and Clarke 2021; 2022). In inductive coding and theme development, the data is the starting point for identifying meaning and interpreting data, although the researcher inevitably brings their own position and lens to the analysis (Terry et al. 2017). While deductive methods are more commonly associated with positive approaches, using already existing theoretical concepts, and inductive methods are associated with constructionist approaches, generally one approach tends to dominate the other (Braun and Clarke 2012; Terry et al. 2017), but it is likely that coding and analysis will use a mixture of both (Braun and Clarke 2013; 2019; 2021; 2022).

In RTA, focus of meaning may be semantic, where meaning is explicit and explored at a surface level, or latent, where meaning lies below the surface and must be explored at an underlying or implicit level (Braun and Clarke 2021; 2022; Terry et al. 2017). In semantic coding, the researcher does not examine beyond the words spoken by participants, a more descriptive analysis. Latent coding attempts to uncover underlying ideas or meanings. This is an interpretative rather than a descriptive approach, requiring more active engagement by the researcher, aligning with Braun and Clarke's (2006; 2019; 2021; 2022) belief that themes do not emerge from the data but are actively generated by the researcher.

The qualitative framework may be experiential or critical. Experiential captures people's own perspectives and understandings of a phenomenon, while critical analysis focuses on interrogation and unpacking meaning around the topic (Braun and Clarke 2021; 2022). In an experiential approach, the researcher recognises and appreciates the importance of the subjectivity of the participants in data interpretation. A critical orientation does not simply reflect what has been said but delves further into patterns and themes to create a theoretical understanding.

Theoretical frameworks may be realist/essentialist where analysis aims to capture truth and reality as expressed in the dataset, or relativist/constructionist, where analysis aims to interrogate and unpack the realities that are expressed within the dataset (Braun and Clarke 2021; 2022). As a realist/essentialist, the researcher recognises the simple relationship

between language and experience as it is articulated, with meanings and ways of constructing these meanings, mostly un-interrogated, and the interpretative aspects of RTA generally underutilised (Braun and Clarke 2016). On the other hand, the relativist/constructionist approach looks for meaning and meaningfulness beyond the obvious. Codes that occur most frequently are not necessarily the most meaningful or important in the analysis. The researcher must actively seek what is important in answering the research questions.

As Braun and Clarke (2022) outline, there is more than one way to conduct TA. Experiential, inductive and semantic approaches tend to work together, with constructionist, latent and deductive approaches together, although they are not mutually exclusive and operate on a spectrum (Braun and Clarke 2022). RTA requires an active and reflexive researcher, one who engages reflectively and thoughtfully with the data, whose role in knowledge production is at the heart of the research and whose subjectivity is understood as a resource (Braun and Clarke 2019). Researchers bring "their own histories, values, assumptions, perspectives, politics, and mannerisms into research" (Braun and Clarke 2013, p.36). This is why reflexivity is so important, because researchers' interpretations of what they experience during their research is influenced by their own assumptions, values and experience (Braun and Clarke 2013). A truly reflexive researcher will continually "bend back" on them self (Braun and Clarke 2019, p.594) and question their assumptions.

Although Braun and Clarke (2006; 2021; 2022; Terry et al. 2017), outline a six-phase process to RTA: data familiarisation; coding; generating themes; reviewing themes; refining, defining and naming themes; producing the report; they are clear that it is a flexible approach and not about a series of steps or following procedures (Braun and Clarke 2019). RTA offers guidelines, not rules, but a clear process (Braun and Clarke 2022). Rather than being a linear process, it requires the researcher to move, reflectively and thoughtfully, back and forward through the phases as needed, identifying codes and actively generating themes from the data. Braun and Clarke (2021; 2022) are clear that themes do not emerge from the data, nor are they in the data waiting to be discovered, but are "analytic outputs… creative and interpretive *stories* about the data, produced at the intersection of the researcher's theoretical assumptions, their analytic resources and skill, and the data themselves" (2019 p.594).

A fuller explanation of how data analysis was carried out, including the theoretical assumptions informing my engagement with the data through RTA, is in sections 3.9 – 3.9.2.

3.4 Research Design

Cohen et al. (2011 p.17) list some of the requisites of an interpretative approach stating that the researcher is not passive but is intentionally creative in making meanings through their activities; situations are evolving, not static; people define and interpret events so that there are many interpretations of single events; that reality is complex and multi-layered and that we need to examine situations from the viewpoint of the person who experienced them, rather than the researcher. Benton and Craib (2011) discuss how we cannot completely strip back our knowledge. Otherwise, if we ignore our common sense and the concrete objects in front of us, we are left with "a jumble of sense perceptions, colours, sounds and sensations" (p.84). The aims of the study were to ascertain whether the experiences of autistic school-leavers with complex needs are positive or negative, to assess the impact of this on young people and families, to identify where improvements can be made, and to consider the implications of all of this for policy and practice. This will be addressed through the research questions:

1. What are the experiences of autistic school leavers with complex needs, and their families, as reported by parents, during and following the transition to post school destinations? (RQ1)
2. What are the views of school professionals on the transition process for autistic school leavers with complex needs, and their families, during and following the transition to post school destinations? (RQ2)
3. What are the implications of these views for policy and practice? (RQ3)

The objectives of the study were:

- To collect data on the planning of transition to adult services for those with autism and complex needs as reported in interviews with parents and school professionals (RQs 1 & 2).
- To collect data on the choice and availability of post school options for this cohort and the process of achieving positive destinations, through interviews with parents and school professionals and with reference to current reports (RQs 1 & 2).
- To collect data on the experience of autistic school-leavers with complex needs post transition, as reported in interviews with parents and school professionals (RQs 1 & 2).
- To consider the emotional impact on young people, parents and families as reported by parents and school professionals. (RQs 1 & 2).
- To consider the implications of the parent and school professional views in relation to implementation of the main policy principles into practice, with reference to transition,

post-school destinations and opportunities for autistic school-leavers with complex needs, and make recommendations on what actions to take to change and improve practice (RQ3).

A mixed methods approach was originally planned, using both qualitative and quantitative methods, intending to gain information and insights from families about their perception of their child's experience, and their own experience, and information from school professionals (SPs) in a variety of settings across the country, through questionnaires. As I have a particular experience and interest to bring to the research I wanted to ensure that I was checking the findings from one method against the other and "viewing things from different angles" (Denscombe, 2017 p.163). This would also ensure that my beliefs and potential bias would be challenged to a degree, although I do expect my beliefs and experience to help interpret the data (Fischer 2009).

Much has been written on the benefits of one or other approach, and of a mixed methods approach. Kumar (1999) introduces the paradigms of research and says that the advocates of the two opposing sides (quantitative and qualitative) have developed their own values, terminology, methods and techniques to understand social phenomena. Kumar (1999) recognises that both paradigms have their place and that the research purpose should determine the mode of enquiry. Bryman (2012) discusses the distinction between research methods and acknowledges that there are many examples of research which "transcend the distinction" (p.614). While most of the analysis in a mixed method approach is interpretive, some data may be quantified so that researchers are quantifying qualitative data (Strauss and Corbin 1998). I had intended to collect quantitative data from SPs which would potentially support the qualitative data gathered from parents and families. I intended to collect the personal stories from the families and use the quantitative data from SPs, such as numbers of positive or negative transitions, to compare data and gather a picture of transitions for this cohort of young people across the country. Ultimately, I was unable to collect quantitative data from SPs, and this will be explained in section 3.8.2. My intention had been to recognise that the world is not exclusively quantitative or qualitative; "it is not an either/or world, but a mixed world, even though the researcher may find that the research has a prominent disposition to, or requirement for, numbers or qualitative data" (Cohen et al 2011, p.22). Mason (2006) is an advocate of mixed method approach but feels that qualitative research "has the explanatory edge" because it is concerned with explanation in a wider sense rather than measurement or causation (p.16).

For parents, I decided to send a questionnaire to gather initial information and to follow up with an interview where I interpreted from responses that there was a bigger story to tell. This was appropriate for an RTA approach for the reasons explained in section 3.2, that is, the flexibility and accessibility of RTA as a method in identifying patterns in relation to participants' views, experiences and perceptions across a wide range of data types including surveys and interviews, and its suitability for a researcher new to qualitative research (Terry et al. 2017).

I planned the questionnaire with the data analysis in mind (Cohen et al. 2011). The purpose of a research questionnaire is "to discover things" (Denscombe 2017, p.183). I felt that this was an appropriate approach and designed the questionnaire so that it would collect information that could subsequently be analysed through RTA whether there was a follow up interview or not; all respondents would have the same set of questions, allowing for consistency and meaning that a bigger picture of the experiences could be gathered; and that information would be gathered by asking participants directly about the points concerned with the research questions. "Questionnaires work on the premise that if you want to find out something about people and their attitudes, you simply go and ask them" (Denscombe 2017, p.183).

I designed the parent research questionnaire, not to be concerned with statistical procedures but with "persons' lives, lived experiences, behaviors, emotion, and feelings as well as about organizational functioning, social movements, cultural phenomena…" (Strauss and Corbin 1998, p.11). I wanted to attempt to understand the families' lived experiences and their interpretation of their child's experience, questioning whether it follows that, if one has a positive or negative experience, then so does the other. The world I intended to research is a world with which I have some familiarity and I was seeking the deeper insight of the lived experience gathering, collating, visiting and revisiting the data through an RTA approach. I planned to gather information from parent participants through a carefully designed research questionnaire and follow up with a semi-structured interview where I identified that further information or context was needed. I initially planned to gather more statistical information from school professionals in a questionnaire. However, I was subsequently unable to use this approach with SPs and this will be explained in section 3.8.2.

3.5 Participants

3.5.1 Parents

The sample is a convenience sample derived from parents/guardians of 19 autistic school leavers with complex needs who have left residential education in one particular school in

Scotland (where I was appointed in 2014) during six years approximately (2012–2018), and transitioned to adult services. Families of these 19 young people reside in 15 local authorities in Scotland.

3.5.2 Professionals

Through professional links, the researcher had access to a group of school professionals in Scotland who either manage or are senior leaders in residential schools for young people with complex needs and who will have information on transitions to post school placements for individuals in this cohort. The name of the group is being withheld for purposes of confidentiality and anonymity. I wondered whether the experiences of the young people at the school of the study would be typical of the experiences of autistic young people with complex needs across the country and felt that this information could be provided by professionals in a wider context. While the professionals at the school of the study had a wealth of experience to offer, I believed that any recommendations based on the findings of the study may have more impact if there was found to be a similar picture across the country. I chose not to include professionals from the school of the study as, from our work practice, we had had many conversations about the issues that initiated this research and I wanted a broader picture. I felt that professionals at the school of the study may be too close to the issue as they were the people who initiated and facilitated the transition planning process for school leavers. They are likely to have had many conversations over the years with the parents who were participating in the study and I felt that this may have influenced their responses. I was keen to get a broader picture. Although I was the senior manager and had a strategic overview of the process, I was not as operationally involved as the other school professionals. As a researcher, I was conscious of the potential influence of my views and beliefs and the need to be reflexive. This will be explained further in sections 3.7 and 3.11.

3.5.3 Pupils

Although the school leavers are not participants in the research, they are the focus of the research, and the experience of the future cohorts of autistic young people with complex needs will be assessed and potentially improved by the study. The young people whose parents were included in the study were the group who transitioned from an autism specific residential school between the years 2012–2018. To resolve the issue for this research regarding the ability of the young people to participate, consideration was given to the fact that, in my experience, families have been a constant throughout their lives and would be able to advocate for the young person as well as voicing their own views as a parent having been

involved throughout the transition process. For these reasons I chose to interact with parents rather than the young people themselves. Like Burke et al. (2019) I felt that the input from parents would be likely to gather substantial data and subsequently to have more of an impact on improving outcomes for the young people, should that be deemed necessary, than if I attempted to engage directly with the young people themselves.

3.5.4 Inclusion and exclusion criteria

I wanted to examine the experiences of autistic young people with complex needs, transitioning from a particular school to residential adult services in Scotland. Young people would be included in the study if they were residential pupils and had had a planned transition from the school of the study to residential adult services in Scotland. Young people were excluded if they were day pupils or their transition was unplanned or to another educational establishment or outside of Scotland as these criteria would not be relevant to the aims and objectives of the study. The range 2012-2018 was chosen because the early year of the date range, 2012, coincided with a previous decision to raise the upper school leaving age (explained in the introductory paragraph to this thesis) and this seemed to be a good starting point, with the range ending at the current year on beginning the research. I also considered that this would produce a manageable number of participants for research purposes. There were 34 young people who transitioned during the 6-year timescale identified. 15 of these young people were excluded from the study. Three of these came from an LA outside of Scotland, three were day pupils who did not require residential support, five transitioned to an education placement rather than an adult service and four were unplanned transitions. Unplanned transitions may occur when the specialist provision at the school is no longer appropriate or successful for an individual due, possibly, to escalating challenging behaviours and potential safeguarding concerns for the young person and/or others. It then becomes the young person's home LA's responsibility to find another, more suitable, placement. Of the four young people mentioned here, all went to an Assessment and Treatment Unit (ATU) in their LA, that is, hospital provision, due to lack of availability of suitable accommodation in the LA. This can be a devastating experience for young people and families (Aspis 2017) as the future becomes so uncertain. I made a conscious decision not to approach these parents due to the tense and upsetting nature of their child's school leaving and fact that the young person may still be in a medical facility many years later (MacDonald 2018). Researchers need to protect their research participants (Liamputtong, 2007 p.35).

Of the 19 young people identified as eligible for the study using the inclusion and exclusion described above, seven had had a variation order agreed, granting the LA more time to find appropriate post school provision, meaning that they were over the age of 22 on leaving school. Some young people had had more than one variation agreed as is outlined in Table 3, p.85. Five other young people were within a range of just under four months to just under six months of their 22nd birthday. One young person, who had an unplanned transition and therefore is not included in the study, was within two days of their 22nd birthday on leaving the school.

This sample includes families that are known to the researcher through professional involvement at the particular school. There are no additional relationships of a personal nature with the families. Parents were approached using the details held on file in the school. The school's privacy statement advises that personal data may be used for the purposes of research. This policy and statement has been in existence since before my appointment at the school and is available on the school website.

3.6 Instruments

Research questionnaires were used for initial data gathering from parents and school professionals. Parent questionnaires would be followed up with semi-structured interviews where further clarity, explanation or information was sought based on parents' answers to the original questionnaire. Denscombe (2017) advocates using questionnaires to gather information which can be used for data analysis and, importantly, the same questions can be given to each participant, as was the case here. Following up with an interview to explore the respondent's experience further would provide an opportunity to elicit further detail the unique viewpoints and stories, described by Cohen et al (2011 p.267) as "not simply concerned with collecting data about life: it is part of life itself, its human embeddedness is inescapable".

An Introductory letter was composed to be sent to parents (Appendix 3). Two questionnaires were devised, one for parents (Appendix 4), one for professionals (Appendix 5). The questionnaire to parents included sections on the parent's inclusion and involvement in the transition process; the transition process itself; the involvement of the school and local authority in planning and their understanding of the young person's needs; the availability of post school placements and information provided; the experience described in relation to language used in Scottish Government policies; the number of transitions which took place; the impact on the young person and the family; and potential improvements. Professionals were initially approached with a questionnaire with a view to gathering quantitative data.

Information was requested on the number of transitions which took place within the previous six years and whether and why these transitions were deemed to be overall positive or negative.

The questionnaire for SPs requested information about numbers of young people transitioning and whether their destination was considered to be positive or negative from the point of view of the SP, based on their involvement in and knowledge of the transition process and outcome. Questionnaires were accompanied by a detailed information sheet (Parents, Appendix 6; SPs, Appendix 7) and a consent form (Parents, Appendix 8; SPs, Appendix 9).

The information for RQ3 was accrued by considering parent and school professional views as they relate to the key messages and underlying principles of the main Scottish Government policy documents and guidance, primarily accessed through the Scottish Government website, identifying recurring themes of the policies in relation to GIRFEC (Scottish Government 2017d, 2018a), transition and post school destinations and considering how these correspond to parent and professional views.

3.7 Ethical considerations

I first received approval from the school's managing organisation to carry out the research and confirmation from them that they would contribute approximately 50% towards the cost of the study. Then I applied to the General University Ethics Panel for approval and this was granted on 2nd July, 2019 (Appendix 2). To adhere to ethical practices, I followed the British Educational Research Association (BERA) Guidelines (2018).

This raises the question for me about my own potential bias. For the interpretivist researcher, there can be no truly objective position. The researcher becomes part of the research, constructing meanings with the other meaning-makers [participants] (Phothongsunan 2010) and the researcher's thinking is shaped by their own experience within the world in which the research takes place (Denscombe 2017). This is not necessarily a bias, rather an understanding of a subject based on experience as described by Fischer (2009). Being aware of this, I did not influence respondent's answers. During the process of research and analysis, I referred to Tong et al.'s (2007, p.352) 32 item checklist - consolidated criteria for reporting qualitative research – (COREQ) to ensure that I had an external checklist and that all criteria were considered and responded to. When reviewing the data, I actively identified opposing opinions to provide a balanced view.

The potential sensitivity of the research and the vulnerability of the participants is likely to raise ethical challenges around informed consent and anonymity. Mann (2002) raises questions related to ethics and the intentions of the researcher. While this study would seek to act for the good as Mann (2002) outlines, there were questions around risk to participants, consent and confidentiality to be addressed. Karyda et al (2009, p.196) define the "concept of privacy" as each person's ability to control how their personal information is gathered and used and also, the right "to be left alone". To this end, I made clear in information provided to potential participants (Appendices 6 and 7) that the process was entirely voluntary, that they were not obliged to participate in any or all of the process and that they had the right to withdraw at any time. Families were assured of anonymity and confidentiality and all returns were saved using numbers and letters to represent people and places. In addition, in reporting the findings, non-gendered pronouns they, them, their etc. are used throughout to further maintain anonymity. Appendices are redacted where appropriate. In this regard, I am a sensitive researcher, presenting the voices of my participants so that they are not easily identifiable (Liamputtong (2007).

There may be a perception by parents that the senior manager/parent relationship reflects a power imbalance, so I mitigated this by sending an introductory letter (Appendix 3), using contact details on file which is permissible under the school's privacy statement (available online). I explained the ethical considerations to each potential participant, advising them of the purpose of the research, inviting them to participate in a voluntary basis. I explained that this was not part of my role as a senior manager at the school, but separate, as part of research with a view to improving the experience of young autistic people with complex needs transitioning to adult services. Return contact details provided initially were University email address and a mobile phone number rather than school number. However, the school address rather than home address was provided for those wishing to make returns by post, on pre-addressed and stamped envelopes which were marked 'private and confidential/for the attention of the addressee only' and were delivered to me, unopened, by school administrative staff. Participants were offered the opportunity to ask questions before agreeing to participate.

Tong et al. (2007) advise that rigorous attempts to recruit participants and reasons for non-participation should be stated to reduce the likelihood of making unsupported statements. I was as rigorous in my attempts to recruit as I thought was reasonable, seeking guidance from the ethics committee. I was careful to provide detail to ensure informed consent, a cornerstone of ethical behaviour (Howe and Moses,1999). Two parents told me that they did not wish to participate: one expressed clearly that it was due to the negativity of their and their child's

transition experience and I was aware from newspaper reports that others had had a particularly negative experience. I wanted to ensure that no one was either knowingly or "not knowingly coerced" (Liamputtong 2007, p.32). I therefore sent a letter to 12 parents who had not yet replied, apart from the two who had declined, dated 29th October (Appendix 10) offering the opportunity to participate in a telephone or face to face interview rather than a questionnaire. I also advised that this would be the final contact, that I had no wish to raise any painful issues that they wished to avoid. From my experience working with parents of children with ASN who are faced with many challenges, I am aware that there is a possibility that my interview questions may cause some stress or distress for parents reliving adverse experiences (Dickson-Swift et al. 2008). Sensitive researchers must carefully manage the emotions of the participants so that they are not left with painful experiences. (Liamputtong, 2007).

I ensured that I gained consent from each new participant and, at the beginning of recorded interviews, asked participants to repeat their consent, verbally, for the recording. Tong et al (2007) suggest that, generally, audio recording and transcription more accurately reflect the participants' views than contemporaneous researcher notes. Two parent initial interviews and one parent follow up interview were recorded. All five school professional interviews were recorded. Of the two parents who opted for telephone interview for the initial interview, the questions were the same as on the questionnaires.

Professional colleagues were approached via email through the professional group for senior managers of schools which provide education and residential care. An information sheet (Appendix 7) and consent form (Appendix 9) provided information on anonymity and confidentiality and advised that participation was voluntary and that participants could complete the questionnaire but not be interviewed if they did not wish to be. I had to ensure that participants gave informed consent, that I was transparent with them about the purpose of the study and that they were aware of potential risks involved and had the right to withdraw from the study or withdraw comments from the questionnaire or during the interview. Colleagues were assured of confidentiality and that I would not discuss their responses with anyone else and that no school or individual will be named or recognised throughout the study. Members of the group do not all know each other personally but are aware that they share a common interest in improving outcomes for the young people with ASN and complex needs attending their schools. I made it clear that participation is voluntary and that colleagues will be able to withdraw at any time.

None of the young people who would be the subject of professionals' responses were known to me. I was able to assure participants that the professional group, they, their school or any young person will not be named or identifiable from the research.

For security, all questionnaires and interview transcripts were created and stored electronically and encrypted, with only me having access to these. All information was anonymised and only I had knowledge of individual participants. I acquired a tablet to be used solely for the purposes of this research project and this was not shared or accessed by anyone else. All interviews were recorded on an encrypted device. A reputable transcription service frequently employed by the university was used and they assured me of confidentiality. Any paper documents were stored in a locked cabinet and, when being moved, in a lockable briefcase with the combination only known to me. At the end of the study, data will be kept in a secure University of Stirling archive for 10 years as required by University regulations and approved by the Ethics committee (Appendix 2).

3.8 Data Collection Procedures

3.8.1 Obtaining responses from parents

21 Introductory letters (Appendix 3) with information sheet (Appendix 6) and consent form (Appendix 8) were sent in early July 2019 to parents of 19 young people who had transitioned during the period 2012–2018. This included one set of parents who were divorced, both receiving a letter and another where a foster parent and a birth parent had shared responsibility, both receiving a letter. I decided to include these in order to ascertain whether parents of the same young person, living separately, had a similar or different experience and perception of transition. I also included three sets of parents whose child, from the school of the study, had been the subject of a newspaper report following breakdown in post school provision where parents had highlighted issues and concerns. I was aware and considerate of the fact that interview questions could evoke unhappy and stressful memories for parents (Dickson-Swift et al. 2008) but felt that, as these parents had raised the issues so publicly, they may be open to participating in the research.

Parents were requested to return the consent form (Appendix 8) if they wished to participate and the questionnaire would then be sent. Information was included (Appendix 6) on follow up interview, that participants would be chosen for interview based on responses to the questionnaire where I identified that more detail or further investigation was needed. Participants were advised that they may be invited for interview, although they may decline the offer, and, if agreeable to interview, would be asked their preference for the location. This

may be by telephone or Skype or face to face in their home or in the school or another location of their choice. It was advised that interviews would be held in a quiet, private space with care taken that there would be no interruptions.

Initial response to the letter and information was very slow and limited. Two completed consent forms and a third without contact details were received. Questionnaires were sent to the two who had completed consent forms and one of these was returned very quickly. I followed up with a telephone call to all other parents on 31st July. Of those who answered or returned my call, a number voiced a desire to participate but did not subsequently return the questionnaire. Two said that they were not interested in responding, one was too busy, one stated very clearly that their experience had been too stressful and that they did not want to revisit that. Of the parents I spoke to, several said that they had had every intention of participating and that they had not 'got around to it yet' but would do so. Two parents said that they had already sent the consent form although I had only received one without a signature. During these calls, not under interview conditions, some parents gave a small insight into a negative experience, said that they would possibly or would like to contribute, but did not follow up on this. Two of the three parents whose young adult children were the subject of the newspaper reports did not respond to the letter and did not have a facility to leave a voicemail. The third was in the number I spoke to who said that they would return the questionnaire, but did not. As a result of these calls I resent six consent forms and questionnaires.

I checked with members of the ethics committee whether I could approach parents again and was advised that two reminders would be the limit, otherwise this would be considered excessive. I sent a reminder letter (Appendix 10): the phone call had been the first reminder so this was a second reminder. Realising that completing the detail of the questionnaire may be a daunting prospect, I offered parents the opportunity to answer by telephone interview rather than questionnaire if they preferred. As a result of this letter I received two more responses from parents whose preference was a telephone interview. As well as being easier for parents to participate, the telephone method, while asking the same questions with the same wording as the questionnaire, allowed for opportunities to ask subsidiary questions and explore further during the interview. I advised all parents, both written questionnaire and interview, that I may come back to them with further questions for clarification if required during collation and analysis of the data. There were seven responses in total (Figure 1).

Although a relatively small number, seven responses is 37% of the possible participants. Furthermore, this is an idiographic study where a small number of participants is acceptable

"because the purpose is not to generalise, but to explore the meanings which participants place on the social situations under investigation" (Phothongsunan, 2010 p.2). This is a small cohort of similar children overall, across the country, so a small sample size could represent the views of others, although this is uncertain. The smaller the number of cases that there are in the wider, whole population, the larger the proportion of that population that appears in the sample (Krejcie and Morgan 1970). Smaller sample size is more acceptable in qualitative research (Cohen et al. 2011, p.145).

The seven responses received did not include a response from any of the parents whose child had been the subject of a newspaper report, nor the divorced parents or parents with shared responsibility. I numbered the responses randomly from 1 to 7 and saved data electronically under these numbers, password protected. To further ensure anonymity, I assigned the letter P for Parent to each of these and YP for young person, so P1 is the parent of YP1, P2 is parent of YP2 etc. All documents and recordings were password protected as a matter of routine throughout the process. All data was kept secure using locks, passwords and encryption, whether paper documents or electronic.

During collation of the data I requested, via email, further information or clarification from three of the participants who had responded to the questionnaire. Two chose to respond by email and one by telephone.

34 transitions between 2012 - 2018

Excluded 15 young people:
Home LA outside Scotland = 3
Day pupils (not residential) = 3
Move to education placement = 5
Unplanned transition = 4

Included 19 young people
1 set of divorced parents
1 foster parent and birth parent with joint responsibility
= 21 letters sent July 2019

Consent forms returned = 3
1 returned without contact details
2 questionnaires sent

Questionnaires returned completed = 2

31st July: Phone call prompt to parents
No contact = 4
Left voicemail = 8 (1 returned the call)
Spoke to parent = 5
Left message with family member = 2
(Both returned the call)

Questionnaires and consent forms sent = 6
Questionnaires and consent returned = 3

Advice from ethics committee:
1 final letter sent to 12 parents 29th October
Offer of telephone interview rather than questionnaire

Additional consent forms and telephone interviews = 2

Total responses = 7

Figure 1 - outlines all contact made to parents and responses

During the analysis part of the process, in addition to the three parents that I had already contacted for further information, I contacted one parent by email for additional information based on the questionnaire response, and was provided with a lot more detail than expected. This parent provided additional background information in seven emails, including contemporaneous notes from transition meetings, photographs, past and current, of their young adult child engaged in meaningful post school activities. I also contacted again two parents for further clarification of their earlier follow up email responses and received email responses to these. In all cases, I assured them of confidentiality and anonymity and security of data.   All of this is outlined in Table 1.

Table 1	Types and detail of parental response				
Parent	Type of response	Length of interview	Follow up	Type of follow up	Length of follow up interview
P1	Typed response via email		Yes	Recorded telephone interview and email	33 minutes
P2	Hand-written response via post		Yes	Email (Parent voluntarily provided additional information in 7 further emails)	
P3	Hand-written response via post		Yes	Email x 2	
P4	Hand-written response via post		Yes	Email x 1	
P5	Hand-written response via post		No		
P6	Recorded Telephone Interview	25 minutes	No		
P7	Recorded Telephone interview	71 minutes	No – very detailed telephone interview		

3.8.2 Obtaining responses from professionals

For the SPs, an approach was made to an organisation, of which the school of the study is a member, which represents residential special schools in Scotland that are either LA funded, Independent or Grant Aided Special Schools (GASS) which are part funded by the Scottish Government. Initial contact was made by email to approximately 30 members, sent by the group's secretary on my behalf with attached information sheet (Appendix 7) and consent form (Appendix 9), requesting that they respond to the email if they wished to participate, offering the choice of post or email response. Colleagues had the opportunity to ask questions before agreeing to participate. This initiated zero response so I then resent an email to this group, directly from me and requesting their participation in a slightly different way. Realising that a questionnaire is possibly not the easiest way for busy colleagues to respond, and having learned from experience with parents, I offered them the opportunity to speak on the telephone rather than complete a questionnaire. This initiated four responses. I then directly contacted an additional five colleagues known to me from the same group and requested their participation and two colleagues agreed. These were colleagues whom I knew through professional relationships and shared experience in the sector. As a result of all of this, I received five responses agreeing to a telephone call. Responses from school professionals were randomly numbered SP1 – SP5.

These colleagues are from a variety of schools and organisations across Scotland providing a mixture of residential care, respite care and day or residential educational placements for young people with a range of complex ASN (Table 2). The focus of the interviews was autistic pupils with complex needs. Two of the respondents were from similar schools to the school of the study, providing autism specific education and care in a residential setting. As the cohort supported in these establishments is small, and numbers of school leavers are small, professionals were able to remember particular young people and their experiences very well. Most of the discussions were based on experiences from the past two or three years so these are in recent memory. For others, there were some critical incidents which they particularly remembered. While the number of responses from both parents (7) and professionals (5) was not as high as predicted, the quality and experience provided good data for further exploration. While hindsight suggests that initial interviews rather than questionnaires may have produced more responses, ultimately this may have produced too much data, becoming too time consuming for the timescales required to complete the research, especially with the added challenge of a global pandemic [Covid 19]. I made it very clear to all participants that their participation was entirely voluntary, that they did not have to respond and that they could

withdraw at any time. This repetition of the fact that the process was entirely voluntary and that there was no obligation to participate may account in some part for the limited response.

Table 2	Type of school/establishment and interview times		
School Professional	Type of school/establishment	Length of interview (all recorded)	Comment
SP1	Independent residential special school providing day and 38 week places, limited 52 week places – autism specific. Upper age 19.	24 minutes	
SP2	LA funded. Small provision for 52 week residential service; Mainly Short Breaks service (respite); after school and holiday service; Outreach service; all for children and young people with a variety of complex needs. Upper age 19.	41 minutes	Focused only on autistic children and young people.
SP3	Secure care. Children referred through the criminal justice system. Upper age 18.	26 minutes	Focused only on autistic children and young people
SP4	Grant Aided Special School (GASS) Residential special school providing a mix of day and residential places up to 52 weeks – complex needs. Upper age 19.	25 minutes	Not autism specific, the majority of pupils are autistic, only autistic included here
SP5	Local Authority special school aged up to 18 – complex needs, multiple factors	17 minutes	Not autism specific, a large number of autistic pupils, only autistic included here. Not residential although some young people move on to residential care.

3.9 Data Analysis

The interview questions were designed to provide data that would answer the research questions, to address the aim of the study and meet the objectives. Parents were asked about their involvement in the transition process, the process itself, the school and LA's knowledge and understanding of the young person's needs, availability and location of post school destinations, the young person's experience in the destination, the impact on the young person and on the family and potential improvements (Appendix 4). School professionals were asked about positive or negative transition experiences and possible reasons for these outcomes (Appendix 5).

3.9.1 Collation

I considered the data in terms of the objectives.

- To collect data on the planning of transition to adult services for those with autism and complex needs as reported in interviews with parents and school professionals (RQs 1 & 2).

Parent responses to questionnaires and semi-structured interviews provided data for this aspect of the study and these were subsequently analysed using RTA coding methods, which will be described in greater detail later in this chapter. Following the change of direction to use semi-structured interviews rather than questionnaires with school professionals, qualitative data rather than statistical data was gathered from 5 SPs and this provided further insight to address this question.

- To collect data on the availability and choice of post school options for this cohort, through interviews with parents and school professionals and with reference to current reports (RQs 1 & 2).

A number of current reports were sourced through Scottish Government websites (Hall 2019; MacDonald 2018). These and other relevant reports and articles cited throughout the Literature Review chapter, give a picture about the availability of appropriate post school provision for this cohort of young people. Parent and professional responses from questionnaires and semi-structured interviews and responses from professionals were collated to compare the real experience with what is reported elsewhere.

- To collect data on the experience of autistic school-leavers with complex needs post transition, as reported in interviews with parents and school professionals (RQs 1 & 2).

A small number of relevant articles were identified and these have been included throughout the Literature Review. Parent responses from questionnaires and interviews gave rich data for this part of the study, with further input from interviews with professionals. More detail of analysis of this data using RTA will be provided later in this chapter.

- To consider the emotional impact on young people, parents and families as reported by parents and school professionals. (RQs 1 & 2).

Relevant literature is discussed throughout the Literature Review. Data gathered from parents provided a particularly rich account of the impact of this experience.

- To consider the implications of the parent and school professional views in relation to implementation of the main policy principles into practice, with reference to transition, post-school destinations and opportunities for autistic school-leavers with complex needs, and make recommendations on what actions to take to change and improve practice (RQ3).

I identified recurring themes and key messages from Scottish Government policy and guidance, widely available online via Scottish Government websites, Education Scotland website and other related sites. Frequent references included GIRFEC (Scottish Government 2017d, 2018a), every child and all children and young people, inclusion and equity, opportunities for all, positive, sustained destinations and *Principles of Good Transition 3* (ARC Scotland 2017a). I compared that with the key messages, experiences and outcomes relayed to me by parents and professionals in questionnaires and semi-structured interviews in order to ascertain whether or not the lived experience meets the aspirations of the policies and what implications that may have for policy and practice.

3.9.2   Analysis

For the purposes of this research, I adopted mainly an inductive approach in analysing participant responses. To some extent, there was a deductive approach in ensuring that codes and themes were relevant to the research questions. Initially, semantic coding was used, where the words of the participants produced meaning, descriptive analysis. Over time, and being more immersed in the data, latent coding occurred where I, the researcher, interpreted codes and themes to produce underlying meanings and assumptions. An experiential approach was used to consider and interpret the personal and subjective stories and reflections of participants, with some critical orientation to uncover the meanings that lay beneath the words. A mainly realist theoretical framework was used, to capture the reality from

within the data, with some aspects of constructionism, interrogating and unpacking the realities that are expressed within the data (Terry et al. 2017). The majority of analysis was done with inductive, semantic, experiential and realist approaches, and these approaches are often used together (Terry et al. 2017), although there were some aspects of deductive, latent and constructionist theories. One approach is not necessarily superior to another, the most important aspect is that the appropriate approaches are used in relation to the purpose of the analysis and research questions (Terry et al. 2017).

While I was aware that qualitative data analysis software packages are available, I preferred to carry out the data analysis myself, by hand, so that I could immerse myself fully in the data. Otherwise, it would be very difficult to be the active and reflexive researcher that is required for RTA (Braun and Clarke 2006; 2019; 2021; 2022). I carried out a reflexive thematic analysis of the data, referring to the six phases of RTA (Braun and Clarke 2006; 2021; 2022; Terry et al. 2017). Firstly, familiarisation with the data. There were written questionnaires (5 parents), initial phone interview transcripts (2 parents, 5 SPs), follow-up phone interview transcript (1 parent) and follow-up email (4 parents, including the 1 parent who had a follow-up telephone conversation). I listened to all of the recordings again while reading the transcripts to ensure accuracy and made some small corrections, made notes and comments, writing my initial impressions and considering data quality. I got to know the data further by reading, rereading, listening, making notes and reflecting on the process throughout. Appendix 11 includes some examples of the reflexive process, from initial thoughts and ideas to reflections throughout the analysis process.

For the second phase, coding, I separated all questionnaire responses and transcripts into responses from parents and responses from professionals. I began with parent responses. I read and reread these, highlighting, making notes, coding and labelling, organising and summarising the data thinking all the time about the research questions and what I wanted to find out. Coding becomes the basis for developing the analysis and interpretation and a means to label, compile, organise, summarise and synthesize (TCEC 2020b). What is important is that the theoretical framework and methods match what the researcher wants to know, and that they acknowledge these decisions, and recognise them as decisions (Braun and Clarke 2006). I did this over a period of time, coding several at one time, then leaving and returning to them, repeating for others. Appendix 12 shows extracts from two parent responses, revisited over time, indicating both semantic and latent analysis, taking the words of the participant and, later, looking for meaning beyond the words. The process of coding is creating labels, creating a storyline, refining codes and developing patterns into themes to identify the

important messages in the data (Braun and Clarke 2006; 2021; 2022; TCEC 2020b). Revisiting the data helped me to amalgamate codes, or find the more important aspects that would help answer the research questions, not necessarily the most often recurring codes, but "a set of codes that richly and thoroughly captures the analytically relevant aspects of your dataset" (Braun et al. 2016, p.198). I built up a picture over time before moving to the third phase, generating themes.

Once I felt that it was unlikely that anything new would to be discovered from the coding and labelling I began to generate themes and created a file for each parent with responses to each question. I went back to the questionnaire responses and transcripts and rewrote the prominent ideas into the file, question by question. I chose to write them in rather than copy and paste from transcripts as I felt that this would help me remember better and make better connections. I did this for each parent response, writing in one column the key words and phrases that occurred in each question and in the second, patterns or themes that were forming. I began to write notes suggesting a connection, a similarity or a diversity between parent responses. I then created a new document and copied in every parent response to each question. I colour coded this with a different colour for each parent 1 to 7. I then had to consider what this data was revealing in response to the research questions and aims and began to organise and summarise the data, from coding to sub themes, then key themes, identifying patterns within and between categories (Appendix 13). I made correlations by comparing and contrasting the responses and going back to the research questions to ensure that the analysis was relevant to that. I moved back and forward through the data over time, forward and back through phases three and four, searching for meaning, both salient and latent, interpreting the data, generating themes and reviewing themes, reflectively and thoughtfully (Braun and Clarke 2021; 2022). I wanted to be sure that I actively generated the themes, that they were as Braun and Clarke (2019) described "analytic outputs… creative and interpretive *stories* about the data" (p.594). Using mainly inductive approaches, codes were developed from very specific aspects to broader, recurring themes. For example, the broader theme of parent voice was generated from parents' comments about feeling blamed for wanting the best for their child or driving the process. The theme of breakdowns in placements evolved from comments about inappropriate choices of placement by the LA; residential staff commenting on having attended a challenging behaviour course only on the day the young person started, and a parent talking about strategies to support the young person through regular changes of staffing. I sought to find meaning in the words that participants had used and also to search for hidden meanings. As a new researcher, I was initially unsure of what a

theme might look like, but these developed over time and were ultimately edited and refined to reduce wordiness. In phase five, themes were refined further, for example several potential themes were subsumed into one theme "underpinned by a central organising concept, a shared core idea" (Clarke and Braun 2017, p.297) and these became the final themes that are outlined in Chapter 4 of this thesis. I needed to be sure that each theme told a story that was part of a bigger story and included pertinent excerpts from the data that illustrated these stories (Braun and Clarke 2006).

I then repeated these steps for each of the professional responses and, in addition, began to make connections between parent and professional responses. I also carried out inter-rater and intra-rater quality checks as described in the following section, 3.10, and further explained in 3.11, Reflexivity.

Finally, phase six, writing the report. The themes are outlined in Chapter 4 of this thesis, discussed in Chapter 5 with Conclusions and Recommendations in Chapter 6.

3.10 Research credibility

Six LAs were represented in the seven parent responses and five LA areas in the five professional responses with overlap of two LAs between parents and professionals. It should be noted that, although the professionals' schools are located in a host LA, not all are governed by that authority, and some young people referred to by SPs are likely to have come from a wider catchment area, which is the case in the school of the study. Therefore, bearing in mind that this is a small cohort, the data that was collected from at least nine different LA areas, provides a spread of information from across the country.

In order to provide further element of dependability to the analysis, I performed an inter-rater reliability check by randomly selecting two questionnaire responses from parents and one from a professional and asked a psychologist colleague to code separately. This was to check whether the other person agreed or disagreed with my interpretations and whether they found anything new. I believed that this would ensure that a different perspective would give further depth and validity to the findings, although I now question that belief (section 3.11). This check identified almost identical themes. In addition, I carried out intra-rater reliability checks, that is, I checked the consistency of my own interpretations by leaving and returning to the data periodically and frequently to check my own interpretations of the data and codes, which is consistent with reflexive thematic analysis. This ensured that my own engagement with the data was considerable and took place over a long period of time, more than a year, leaving it aside for a time and then revisiting with a clearer mind and focus each time and ensuring

subjectivity checks throughout, being reflexive and considering how the process and analysis may be improved.

3.11 Reflexivity

As a new researcher I ensured that I was reflexive throughout. The research was constantly on my mind and I regularly jotted down thoughts and memos from the beginning of the process and throughout (Appendix 11). This enabled me to consider my assumptions more clearly and to think more carefully about my role in the research process and how I was impacting on the process. The research was prompted by concerns raised during my professional practice and I wanted to investigate these issues further. I was aware of my own views based on experience in the sector and, while I was careful to acknowledge this, I did not bracket my views and beliefs entirely but used them to interpret the findings in an informed way, my subjectivity as a resource (Braun and Clarke 2019). By making clear our own beliefs and biases, we learn about their strengths and weaknesses. The reflective experiences may induce a deeper awareness of phenomena (van Manen 2002) and continuous reflective bracketing can give researchers a greater understanding of themselves (Fischer 2009). Fischer (2009) refers to the "always unfinished business of reconsidering earlier understandings and revising them in light of new understanding" (n.p.).

Even on listening to participants during interview, and on first quick reading of questionnaire responses, some similar responses were occurring from participants. I was already beginning to form connections while still trying to ensure that I was keeping an open mind and not just seeking viewpoints that were similar to my own. It is important to give some externality to the situation by seeing things, not just through my own eyes as the researcher, but also to use a range of data and to ensure that the data include the views of others in the situation (Cohen et al. 2011). The theories we develop to explain the behaviour of the people we study should also, where relevant, be applied to our own activities as researchers (Hammersley and Atkinson 1983). As Tong et al. (2007) outline, when considering researcher reflexivity, "Qualitative researchers closely engage with the research process and participants and are therefore unable to completely avoid personal bias" (p.351). They suggest that researchers should clarify for readers their "identity, credentials, occupation, gender, experience and training", which I have done in the introduction to this paper (1.2; 1.2.1). This allowed my own experience to become to become part of the interpretation of data (Fischer 2009) revisiting the data and, therefore, revisiting my own views and beliefs with a view to creating an understanding of the participants' experiences for the reader.

As a new researcher, possibly naïve, I considered that an inter-rater quality or reliability check would ensure that I was coding accurately from the data. However, as Terry et al. (2017) and Braun and Clarke (2013) point out, there is no one right way to analyse qualitative data and no single truth so inter-rater reliability is not necessary. This type of check suggests that researcher subjectivity is flawed and is not meaningful unless it is done collaboratively (Braun and Clarke 2022). This is what Braun and Clarke (2021; 2022) refer to as small q (qualitative), where there is some "positivism creep" (2022, p.7) into qualitative methods, rather than big Q, fully qualitative approaches. Nevertheless, I carried out these checks at the time. Braun and Clarke (2021) acknowledge that it opens participation for qualitative novices with little research background, which I was at that time. Since then my "qualitative sensibility" has become more developed and I am much more comfortable with subjectivity and uncertainty" (Braun and Clark 2022, p.7).

3.12 Limitations of methodology

With hindsight, an initial telephone interview would possibly have been preferable to questionnaire as the questionnaire responses were limited, even with additional reminders and encouragement, possibly because of the intrusion into privacy or the sensitivity of the questions (Cohen et al. (2011). There was some rapport established during the telephone interviews and telephone follow up conversations which is not possible or apparent from questionnaire responses. Telephone interviews also allow for some spontaneity in asking follow up questions, with the researcher and respondent already engaged together in the conversation with no delay, unlike when responding to a questionnaire. Denscombe (2017, p.186) rightly says that getting people to take part in the research and agree to answer questions is a challenge in its own right.

The decision to send the consent form and information sheet first, then wait for the return of the consent form before sending a questionnaire also created some delays and potential barriers to participants returning the data. It may have been better to send information, consent and questionnaire all at the same time so that potential participants had the opportunity to complete both consent and questionnaire at the same time rather than possibly viewing it as two tasks and losing some momentum between giving consent and receiving the questionnaire.

3.13 Summary

Consideration was given to the research approach and design in relation to the research questions and aims. Data, through a process of reflexive thematic analysis, was gathered,

collated and thoroughly analysed using coding, and checked and double-checked over a period of time. Analysis led to a series of Findings which will be presented in the following chapter.

Chapter 4: Findings

4.1 Introduction

This chapter begins by outlining the findings from the study. The data revealed some important findings, allowing this study to contribute to knowledge and understanding of the unique experiences of young autistic people with complex needs, and their families, during the transition from school to adulthood. The results are evaluated using coding and deriving key themes from the codes. Connections, common themes and differences in the respondents' themes will be highlighted. The findings will be presented in this chapter under key themes from parent responses and professional responses. Individual experiences within those themes will be illustrated with quotes from parents and professionals. While there is a spread of quotations from all participants to indicate their particular experience within the context of the key themes, there are occasions when some participants are quoted more than others. This is a reflection of the prolonged length of time of their transition experience and/or number of transitions experienced.

4.2 Key themes from parent responses

Findings reveal that all parent participants encountered both positive and negative experiences for them and their child throughout the transition journey. There were both contrasting experiences and similar experiences that connected participants throughout the process. An unexpected finding is the paradox that all parents who described a series of significantly challenging and negative experiences involving stress and anxiety for themselves, their family and the young person, ultimately described the overall experience as "positive" if the young person finally achieved a positive destination. This suggests that the outcome for the young person is what is most important to parents and that a positive outcome supersedes a negative process.

4.2.1 Timing of the transition process: "we made it with only a week to spare"

Two of the seven respondents gave a yes/no answer to the question of whether the process started early enough. P6 responded "yes" even though their child had a negative experience following transition and P2 responded "no" despite reporting the most positive scenario of all respondents. P1 recalled that the school had given a "realistic" outlook about potential timescales and, like P2, P3 and P5, had felt at the time that the transition process had started early enough. However, with hindsight, these parents felt that it should have started earlier or that it was rushed in the end (P5) due to unexpected delays or challenges encountered, "I do

feel the pressure was on and it all felt a bit last minute" (P3). For two, school leaving was within days of their 22nd birthday, for two others, one or more variations had been agreed. Table 3 shows the incidence of variations and repeat variations for all pupils during the years of the study. The upper age range at the school had changed from 18 to 21 in 2011 in order for LAs to have more time for transition planning, so the issue of variation requests did not arise in the subsequent two or three years. However, the requests began again in 2015.

The question of timing was irrelevant for P4 as they had used their own knowledge and experience to initiate and "drive" the process and find an appropriate care provider before the LA had even engaged with the planning.

Table 3 Incidence of variations 2012-2018					
Year	Number of variations requested and granted	Number of pupils	Number of variations requesting an extension to previous agreed variation, and granted	Number of pupils and (total number of repeat variations)	Comments
2012	0				These were the years just after the upper age limit had been raised to 21, so there was no necessity for variation requests
2013	0				
2014	0				1 young person left the school 3 days before 22nd birthday
2015	1	1	0		Another young person left the school one week before 22nd birthday
2016	3	2	1	1 (2)	0
2017	8	3	5	2 pupils 2 repeat variations each (3 variations total). 1 pupil 1 repeat variation (2 variations total)	0
2018	2	2	1	1 (4th variation – 3 previously granted in 2017)	2 requests were refused by the school (both for pupils who had previously had variations granted in 2017)

4.2.2 Involvement in the planning process: "I felt I drove much of the process due to my professional background and knowledge"

All seven parent respondents rated highly or very highly the role of the school ("excellent; "9 out of 10"; "100%"), no matter whether there followed positive or negative experiences of post school placements, and believed that the school advocated for the young person and knew their needs completely. P1 also mentioned that their child was involved throughout. P6 believed that the school had "laid the foundations" for their child's future.

Five parents felt that they were involved to some extent or fully involved in the transition planning and choosing a destination. P4 stated that they initiated and "drove" the process. P7 stated that they were not involved in the first transition planning, it was "off the cuff", and subsequently felt "blindly included" while P2 and P3 explained that they knew their own child "better than anyone" so it was most important that they were involved.

Six of the seven respondents rated the transition planning process positively. P7 felt that none of the transitions were planned properly or reflected YP7's needs and level of support required and recounted multiple subsequent breakdowns of placement. Only one parent, P2, had a mainly positive overall experience and described it as "excellent", although notes provided by P2 that were written at the time of transition, indicate that there were some challenges caused by a "frustrating" delay in the Guardianship process. P1 and P6 went on to describe negative experiences where the needs of their child were not met and P5 raised concerns about the suitability of the placement. P3 and P4, although happy with the destination, experienced some challenges, P3 regarding it as "not perfect".

4.2.3 The role of LA personnel: "they were devoted to and fought valiantly for YP"

Three parents referred to individual social workers who had supported them towards and through the process. These were social workers from the children's team with whom they had developed a relationship over a period of time. P1 described the input of one social worker as "invaluable". P2 stated that the social worker "was devoted to… and fought valiantly for" the young person and P3 felt that the process would not have been so successful if it was not for the social worker. P3 recalled having a number of social workers over the years "and I can't say I've had too much of an issue with any of them". The social worker who supported in the lead up to transition showed more of an understanding of autism:

"They painted a picture of a future for YP3 that I didn't think was possible, as my head was full of the bad stories I had heard and my own paranoia. Over time I started to want this picture they painted but I would throw up all my fears…they had this very positive but still staying realistic approach that encouraged me to go along".

P1 acknowledged that they were "exceptionally lucky" with the children's social worker as the lack of communication from the adult social worker proved "somewhat problematic", while P7 stated that they did not have a lot of input from a social worker, recognising that "they are so stretched" and that "everything's based in the LA on paperwork and even that, certainly from [results] it seemed to be well and truly ignored".

P1, P2 and P6, believed that the LA was aware of their child's needs and that LA input was good during the transition process. While P2 described it as "excellent" and had an overall positive experience, P1 and P6 went on to describe negative experiences where the needs of their child were not met. P4 stated that the LA was aware of their child's needs by the end of the process but that this had been a learning curve and that the LA had no clear idea of the needs of the family. P5 acknowledged that the LA was aware of their child's needs but that there were ongoing concerns and problems in the placement. P7's experience was the most negative of all and they maintained that the LA had no understanding of the complexity or needs of their child, that there was no thought put into any of the transitions and that placements were unsuitable. P7 cited lack of understanding of complex needs, "particularly at the higher end of the spectrum" as the reason for this and used language such as "battles" and becoming "despondent" to illustrate their experience. P7 stated, when being informed on lower levels of staffing in adult services, "As YP7 leaves the school gates, the level of care is diminished, you've miraculously found a cure for YP7's condition and the problems around it".

Two parents remarked on the high case-loads of social workers, implying that they are unable to give their full attention to individual cases. P3, P4 and P7 all referred to the hierarchy of LAs as being a stumbling block rather than individual case-workers who could not do anything without the authority of seniors, "although their superiors have been the stumbling block and often the hurdle to get over… workers themselves were kind of helpless and unable to do anything" (P3). P7 clarified that they had never had any difficulty with any individual worker but difficulty had been with "the hierarchy of organisations", that is, those who are responsible for higher decision-making processes and finances. Bureaucracy was cited as a problem, "I have met others…having to negotiate their way through bureaucracy to secure support for their loved one" (P4).

4.2.4 Availability and choice of placements: "I just feel we got lucky, YP got lucky and it shouldn't be like that"

P2 was the only parent who stated that there was enough information on placements available and a choice of placements available to them. Initially P2 had wanted YP2 to return to the family home but the other parent felt that it would be in YP2's best interest to have their own home in the community, and this was sourced and refurbished by the LA without significant challenge.

P1 felt that more time should be given in order for them to consider placements and to compare care packages, although they reported having been offered only one option. The findings show that there was often no choice of placement, "very limited" (P5); "definite lack of resources" (P6) or "practically non–existent", "take it or leave it" (P7) from the LA. "No choice, and that was our issue obviously, and that's why it took us so long to get to where YP7 is". All respondents reported that a building was identified by the LA, then more time was needed for modifications to make it more suitable and several parents mentioned that "timescales wouldn't allow" (P3), or "we made it with only a week to spare" (P5). P1 and P5 were initially happy with the identified destination, but subsequent challenges caused them to question the suitability. A number of parents initially felt involved in discussion and choosing the post school placement, but, in fact, there was no choice other than what happened to be available in the LA at the time. P7 in particular recounted that the stance from the LA, for new destinations after failed transitions, was, "you've not got any other option type thing" or "this is where YP7 should have to go" and likened it to attempting to push square pegs into round holes because LAs had places they wanted to fill, rather than ensuring it was needs-led. P3 mused, "I was told I had a choice, but I suppose I didn't really".

P4 indicated that they had been offered some "unsuitable placements" but dismissed the question about choice of placements available as "not applicable" due to the fact that a "bespoke" option is what is actually required. This would be totally individualised, and P4 set about finding this option them self, identifying the "critical" and "non-negotiable" aspects to present to the LA. P4 felt that the LA was receptive to them because they (the LA) were moving away from a service-led to a needs-led approach.

For all parents, the preferred option was that the young person returned to a destination within their home authority and that visiting family or more involvement with family was a benefit of being close to home. Several mentioned that they would not have to travel so far in order to visit their child and P1 described it as "almost like we need to make up some lost time and not

with travelling – miles to see YP1", although, later, P1 mused that being so close to home was not necessarily a good thing as they were frequently called on to support staff in managing YP1's SIB. P5 was also initially "extremely pleased" to have YP5 close to home but later questioned the suitability of the rural environment and lack of appropriate services. P6 acknowledged that YP6 has embraced a new routine and does not visit family so often, but that having them close makes a big difference. For P7, the important thing was for YP7 to be happy "and if that had to be somewhere away from home, then we would have accepted that". Two young people ultimately found a more positive destination in a neighbouring authority, "the home LA don't have a lot of suitable housing for someone like YP3".

Four parents mentioned being lucky at some point in the process. P1 felt that they were "exceptionally lucky" with the children's social worker when they experienced another who was not as effective. P4 felt "fortunate" that a house became available at the right time when it had been deemed unsuitable for another young person. P6 felt that being in the right place at the right time was a factor in YP6 getting a new destination, "they were so limited for spaces and… if it just so happens that someone at this bit is too old for there so they have to go somewhere else again, or whatever, you know…we were really lucky" and lucky with new staff. After so many failed placements, P7 stated "I just feel we got lucky, YP7 got lucky and it shouldn't be like that".

P7 believed that what is needed for "the higher end of the spectrum" is too expensive for LAs so families have to take whatever happens to be available, even if they do not feel that it meets the needs. P7 stated that this was a false economy. P1 funded autism training for staff from money that was freed up from YP1's care package due to lack of staffing. P4 acknowledged that the LA was moving away from service-led to needs-led provision but that the issue was with the limited budget that would be allocated to meet the very complex needs of YP4.

4.2.5 Breakdowns in placements: "the whole thing went to pot…they made a complete and utter hash of it"

Placements were reported to break down for the following reasons:

- Lack of understanding of need by the LA and the care provider leading to inappropriate provision and levels of support
- Lack of skills, training and experience of staff in the adult service to understand and manage complexity
- High turnover of staff

- Inappropriate physical environment
- Adult services are unable to emulate the good practice of schools.

While five out of seven respondents only had one transition to a post school placement, all of these reported subsequent problems, stress and challenge in that placement. P6 described a significant and stressful breakdown in placement, attributed mainly to poor standards of care, poor management, poor staffing and lack of consistency, and P7 recounted a series of "traumatic" breakdowns in provision resulting in nine transitions in total, outlined here as T1 – T9:

> T1. Lack of planning, move didn't take place
>
> T2."there was a sense that something wasn't particularly right. It was just one of the staff that said, oh, we've been on a challenging behaviour course this morning" [implying a lack of specialised knowledge or training]. P7 providing daily support "just to keep YP7 calm… the support workers there were finding it very difficult to know what to do."
>
> T3. return to school
>
> T4. It became obvious after a couple of visits that this was unsuitable…"placing round pegs in square holes… and I think it's very much about filling beds rather than looking at the person's needs".
>
> T5. " a lot of confusion… a huge problem for YP7 going there and that fizzled out
>
> T6. Issues with staffing, management, structure, levels of care, compatibility with other young people. "As YP7 leaves the school gates, the level of care is diminished, you've miraculously found a cure for YP7's condition and the problems around it".
>
> "…the sort of domestic stuff was pretty awful… huge problems with the building itself… but the staffing issues were desperate… just awful".
>
> The higher the level of need, the less the LAs are able to deal with it
>
> "…and I think that's one of the issues that really came to light is that people's definition of how they can deal with challenging behaviours when they're presented – it appears that everybody has their different definition of that".
>
> T7. Same destination, new provider, lack of trust
>
> T8. Return to home
>
> T9. Current destination – positive [but not permanent]. "instantaneous success…we've found peace for a while".

Low staffing levels and lack of appropriately trained staff is often cited as a reason for challenge or failure in the post school placement. P6 and P7 discussed instances of supporting their child when no staffing was available, P4 agreed to provide additional support hours to supplement the authority's contribution and P1 provided support during particularly stressful

bouts of SIB that care providers were unable to manage. Parent responses indicated that the challenging behaviours provide most stress and difficulty for staff, with SIB causing the most anxiety. Although YP1's placement was sustained, there were problems that P1 attributed to the care provider's inability to support someone "so severely compromised by autism". P5 stated that it would have been helpful if the school had provided some further support for the care provider once the move had been made "just to make sure that they were following the care plan". P7 recounted a number of incidents where the safeguarding of their child was compromised due to low numbers of staff, or inexperienced staff. This led to P7 sleeping over in their child's room or sitting in their car in the carpark outside, so that they would be quickly available to staff if needed.

There are examples of staff turnover being managed positively. P4 described turnover of staff as "a fact of life" and relayed a strategy for gradually introducing new staff and training new staff that is successful, allowing YP4 to "build resilience" and to eliminate unnecessarily high levels of stress and anxiety.

The suitability of the environment is also a factor. P5 questioned the "layout and sturdiness" of their child's environment and furnishings, P4 stated that no move could be made until it was "absolutely right". Of several destinations, P7 regarded that "it was probably the environment was not right…more than anything else, but when you have no choice, when nobody has choice, we end up in scenarios that could be improved but for numerous reasons can't be".

The experiences recounted by all parents indicate some level of anxiety for their child, and those related by P1, P6 and P7 in particular show high levels of anxiety, described variously by parents as "horrendous", "awful", "a debacle", "a bloodbath". P7 reported that YP7 suffered multiple failed transitions leading to them becoming "distraught".

P7 believed that the "higher end of the spectrum" or "the most complex" needs were the most difficult for LAs to support and listed "terrible" failures by several care providers in several destinations and then "instantaneous" success with another. P6 recounted the negative experience with one care provider, then success in the same destination with a different care provider. P7 emphasised that different people have different "definitions" of challenging behaviour and that is why there is an inconsistent approach and outcomes. P1 mentioned an improvement in their child's presentation when medication was prescribed and staff also received quality training and put more structure in place, "it is working".

4.2.6 Relationships with LA: "I totally one hundred percent had the name of being a difficult person"

All parents used language such as "fought for" or "battles" to indicate the intensity of their struggle to achieve a positive outcome. P6 and P7 referred to the broken trust when a preferred care provider failed to deliver on their commitment to support the young people. P3 and P7 felt that speaking up to the LA meant that they were labelled as "difficult". P7 felt that they were "blamed" for strained relationships with the authority or for causing trouble. There was a lack of trust and honesty. P7 also stated that on several occasions they had felt that "because you have a child with additional needs they sometimes take the whole family as if they have that". P7's negative experiences with the LA caused them to lose trust in the authority to the extent that, following resolution of difficulties in Transition 8, they still stayed in their car overnight outside YP7's house, "just in case" [they were needed to support] and subsequently found another out of authority care provider to support YP7. P1 and P3 also indicated that they had lost trust in the hierarchy of the LA.

4.2.7 Parent voice: "knowledge is power"

While all parents felt that they were always advocating in the best interests of their child, there is a sense that parent voice is not effective without knowledge. Parents who had access to specialist knowledge, like P4, and P3 to an extent, were able to steer the process more easily than those who did not. P6 reported that they had a "strong voice", able to speak up for their child, but did not know what was available and therefore did not know what to fight for, especially as they said that the council did not know either. As P3 stated, "knowledge is power".

P3 referred to their strong voice as being both a "gift and a curse", similar to P7's view that it can "add to the pressure". P7 berated LA "attitudes" and said that it is very difficult to advocate for your child to have a home or a space of their own when the LA tells you that, if this happens, you are depriving another young person of a place. P7 stated, "I think it gets to the point where the LA is just sick of me as well. I mean, they've not heard a word from me for the last sort of two, three years, so they're quite happy". It is clear that P7 had a strong voice throughout the transition process although they were not able to prevent a series of failed transitions. It was around the time of the third failed transition, the experience had become "really problematic" and P7 intimated that they had now been labelled as "a very difficult person…which you very quickly get labelled with if you disagree with somebody or you get frustrated". …So, often when you've got a voice it can kick back on you because people don't want to hear it".

On the other hand, P4 found that the LA were receptive to their voice and accepted their "non-negotiable" conditions.

4.2.8 Emotional impact: "…I take no joy in saying this, and I say it with the heaviest of hearts and the saddest of hearts, there were times throughout that experience that I categorically could understand why parents like me take their children and jump off a bridge… that was the strongest I've ever felt like that because I thought there is no future for YP7 and how could I leave them to end up in a place…locked up in a cell, you know" (P7)

Every parent respondent referred to levels of stress and anxiety and the impact on them, their spouse, their autistic child and/or family members. At least three families had a particularly traumatic experience and P7 stated that the interview questions "bring up stuff I've tried to lay to rest" and, as reported (p.66), other parents intimated that they would not participate in the study because they did not wish to revisit the stressful memories of the experience.

There were high levels of stress and anxiety for parents and family throughout the transition planning and process due to breakdowns in communication, lack of availability of placements or information, but the most significantly stressful experiences occurred where the placement was unsuccessful and parents witnessed or perceived lack of appropriate care and support for their child, particularly as recounted by P1, P6 and P7. Even those parents who described an ultimately positive outcome, expressed a horror of ever repeating the experience. Parents described it as "unbearable", "horrendous", "no one could have prepared us for such a traumatic experience" (P1). Others reported the "intense and time-consuming" process, their levels of exhaustion, crying, stress-filled phone-calls and extreme measures they took to care for their own child when they felt that support was inadequate or they had lost trust in the care provider or LA. P7 was "accused of being over emotional" by the LA.

All parents recounted incidents that indicated that their child also experienced some level of distress in relation to the transition process, from presenting with challenging behaviour at home or in the community, withdrawing and becoming introverted to becoming "distraught".

P2 described a mainly positive experience and relayed that the family were "delighted" overall and that YP2 was now "thriving". P3 and P4, with some emotional cost for themselves, felt that the outcome was positive for their child. P4 declared, "I know I would not have the resilience or the emotional resources to take on another major change in YP4's life again". P6 described the change from a negative placement to positive as "superb". Both P7 and YP7 were "distraught" when the final service broke down and P7 described a very challenging time

at home with all their worst fears about the future for YP7 rising to the surface. P7 stated that they "categorically could understand why parents like me take their children and jump off a bridge". When YP7 eventually found a positive destination, "sometimes when I go up there YP7 will take me by the hand and say bye P7" [to indicate that they are happy to be left there without P7] "and somebody actually asked me how I feel about that and I said I feel as if I've won the lottery". P7 admitted that, despite this "fantastic" arrangement, they still fear for YP7's future. The current property is designed to house several young people so YP7 will have to move from there. Although the same care providers will support YP7, this will be another transition to a new environment which has not yet been identified. "I dread the day that I leave them" (P7).

The impact on the family is lifelong and parents, no matter how positive the outcome, still remember the failures and worry about what will happen to their child when they are no longer here to advocate for them. P7 summed up:

> "I think we've a long way to go… that's absolutely for sure. As an individual family… well, you know, we've found peace for a while and we'll just have to take it day by day and that's as good as I could hope for… but I still have huge fears for YP7 as an adult, and I wouldn't be the first parent to say because I certainly know many that have said it – till the day I die there's a part of me that always wishes that YP7 would go [die] before me… that's how all of this makes you feel and to say that about your own child is horrendous".

4.3 Findings from School Professionals

Semi structured interviews were used to ask questions based on the original school professional questionnaires and, due to a lack of available statistical data, were based on professionals' knowledge, experience and understanding rather than facts and figures, producing further qualitative data from SPs rather than quantitative.

Professionals were able to speak about their involvement in and experience of the transition process but, due to data protection considerations, had no or very limited information about sustainability of placements. Some professionals were relatively new to their school and did not have information about all transitions in the previous six years. While professionals were unable to give exact numbers of young people who transitioned nor exact numbers of positive or negative transitions, they gave some particular examples to illustrate the nature of transitions and transition planning that they had experienced and what factors, in their

experience, contribute to either a positive or negative outcome. Types of establishments and upper age are outlined in Table 2, p.75.

4.4 Key themes from professional responses

4.4.1 Timing of the beginning of the process: "The main barrier is not getting the right person around the review table at the right time"

All professionals stated that transition planning begins in school at an appropriately early stage but that LA adult services often do not join the process until later, sometimes having to "hit the ground running", that young people are "lucky" if an adult worker is available early in the process (SP5) and that they are being "failed by the system" (SP1). "The main barrier is not getting the right person around the review table at the right time, so it doesn't start when it should start" (SP1).

4.4.2 Collaboration and the role of the LA: "this young person was lucky because they got an adult social worker early in the process"

Professionals reported that early intervention from the adult social worker, sharing of information and good collaboration between agencies leads to more positive outcomes. However, PCP is patchy and inconsistent for a number of reasons including that young people are "lucky" if they have an adult social worker early in the process. Two professionals referred to high case-loads of social workers meaning that they are unable to contribute consistently to the process or to supporting families, although individual social workers were praised by some for their input. There were examples of poor collaboration between LAs, "not enough of a joined-up approach", meaning that young people missed out on potentially beneficial opportunities. In one example two young people from neighbouring authorities wished to live together on leaving school but bureaucracy meant that LAs "could not make it work" (SP1). Yet, in another example, an adult transition worker was collaborating with a different authority, because of limited opportunities in the home authority, to ensure that the young person's needs were met. SP1 referred to the "diversity aspect" suggesting that more complex young people proved difficult for LAs to place. SP4 and SP5 alluded to this also. SP1 believed that the success of the planning very much depended on individual workers who were allocated to the case "rather than it being a system that works effectively". One SP felt that outcomes were more successful when their own adult service was involved as this presented more effective opportunities for working collaboratively. Lack of information-sharing post-school is a problem. School professionals had limited information on the success or failure of post school destinations due to strict regulations (GDPR) about sharing information. SP2 stated that, due

to lack of information, they were not able to tell whether transitions "could be better or a hell of a lot better", acknowledging that there is often room for improvement.

4.4.3 Availability and choice: "the social worker probably struggles to find out where they're going to put them"

All professionals stated that there is a lack of appropriate post school resources, "the social worker probably struggles to find out where they're going to put them" (SP3), and three referred to parental expectations being "unrealistic" about future provision for their child. There was an account of LA personnel deliberately giving a bleak picture of what would be available, "under-promising" (SP5) so that the parent would be pleasantly surprised when the reality turned out to be more positive that the projection. SP4 stated that the quality of the programme matching the needs of the young person was most important, not whether they went to college or work experience or not. SP2 referred to available services as being "like a salad bowl, a bit of this and a bit of that, rather than a melting pot where services worked seamlessly together". All professionals believed that the needs of the young person must be wholly taken into account during the planning process and that services should be provided to match the level of need.

4.4.4 Breakdowns in placements: "you'll hear of such-and-such went to this place and you just know it's going to be a disaster"

While professionals, in the main, did not have specific information relating to whether or not school placements from their school had been sustained or not, all were aware of placements that had broken down. SPs believed that lack of appropriate support for levels of complexity contributed to this, including lack of specialised knowledge or training for staff and their ability or inability to manage complexity. SP1 advised that the profile of young people attending the school has changed and that social interaction and managing of emotional regulation is becoming increasingly difficult and leading to increasingly "volatile" behaviours. SP4 had experience of placements breaking down where the young people were incompatible together and where very high levels of support were required but not provided. SP3 stated, "you'll hear of such-and-such went to this place and you just know it's going to be a disaster". All professionals agreed that there is good transition planning by schools and an implication that levels of support in schools makes it 'look easy' and that the post school provider is unable to sustain this. SP2 and SP5 referred to adult services being generally less expensive and are therefore believed to be less structured or robust than children's services and unable to emulate the supports that were provided at school. SP2 believed that some placements were

financially motivated rather than needs-led, focusing on cost saving, "there is no bottomless pit of money and no longer care at any cost". SP5 agreed, saying that parents were often shocked by the reduced levels of funding and lack of available adult services.

4.4.5 Relationships: "parents had completely unrealistic expectations"

SPs referred to strained relationships between parents and LAs, with parents being judged as difficult and having "unrealistic expectations" about what is available to them and their child post-school if they spoke up against what was being offered. SP4 remembered some "very, very distressed" parents and a young person "where any discussion about transition work would also be very traumatising". Several SPs mentioned that high caseloads meant that social workers were not always available or up to date on the needs of young people and their families and that this caused frustration. Frequent changes of social workers caused issues for some, with the new social worker not always picking up on previously agreed strategies or information. SP5 stated that a social worker who doesn't know the family or the young person adds stress to a family who are "already experiencing quite a traumatic time". SP2 also commented upon their difficult relationship with the LA, "In terms of social work, the LA, we have found it challenging to work with them…in terms of trying to achieve the best outcomes for young people, it has been a challenge" and SP1 described liaison between the school and the LA as often being "tricky".

4.4.6 Parent voice: "Parents don't know what they don't know"

SP1 and SP4 discussed their LAs' responses to outspoken parents, with SP4 stating that one parent in particular was regarded as "abusive" by the LA. The school had to intervene to provide support for the parent as they were achieving the opposite of what they intended. SP5 believed that parents need support in identifying resources as they do not know what is available. SP1 stated that parents "don't know what they don't know" and that everything has to be "aligned", that appropriate destinations have to be available, otherwise it does not matter how proactive the parent is, or attempts to be. While parents believe that they are advocating for their child, the responses from professionals indicate that this is not always the case, although SP1 believed that parents who are more proactive tended to "push themselves into usually a more successful transition".

4.4.7 Emotional impact: "very, very distressed parents"

All professionals acknowledged that parents and families suffer stress throughout the transition process using language such as "distressed" and "traumatic" to describe this. SP1 and SP5 spoke about supporting families through the challenges of inadequate planning and lack of information and input from LAs. Two SPs recounted stories of particularly emotional experiences for parents, around inappropriate choices of post-school placements and decision-making, which, for the purposes of confidentiality and anonymity, cannot be detailed here. SP4 referred to a young person who was "traumatised" when transition was discussed. There was consensus that families found the entire process to be "traumatic and stressful".

4.5 Summary

Key themes which were generated from professionals' interviews correspond almost entirely to key themes from analysis of parent participants' data. An inter-rater check identified almost identical themes from randomly selected parent and professional responses, including concerns about lack of consultation and collaboration, service-led systems, staffing concerns, breakdowns in trust and emotional impact, both in the present and for the future. Parents and professionals broadly concur on the aspects of transition that are lacking and requiring improvement and the various experiences indicate similar areas for improvement. Professionals, who have experience of both positive and negative transition planning and process, have a clearer idea on what leads to successful outcomes and why some transitions are more or less successful than others. There are some aspects of the transition planning and process that are positive for some young people and their families, but this is not consistent across LAs. The findings from the parent and professional respondents indicate that family and young people's experiences depend on local circumstances including the availability of adequate resources to support those with complex needs and the quality and commitment of personnel. Therefore, it appears that the experiences do not consistently match the aspirations of the policies with regard to GIRFEC (Scottish Government 2017d, 2018a) and positive, sustained destinations for all young people. The findings will be discussed in more detail in the next chapter.

Chapter 5: Discussion

5.1 Introduction

The aim of the study was to examine the transition of autistic school leavers with complex needs, leaving a residential environment and transitioning to adult services, as related by parents and school professionals, and to consider the implications of these parent and school professional views for policy and practice, with reference to GIRFEC (Scottish Government 2017d, 2018a), transition and post-school destinations. I used a reflexive thematic approach, deriving themes from parent accounts of their and their child's experiences through the transition process and beyond and from school professional accounts. While this is a small sample from one setting and may not be typical of other situations, the findings from school professionals supported the parent findings, delivering similar observations and reflecting the thinking outlined in current reports.

I will now show how the findings, outlined in the themes in Chapter 4, relate to the research questions. Examples will be provided with references to the appropriate sections of this thesis. This section begins with a discussion of the relevance of the findings and how they answer the research questions, taking RQs 1 and 2 together, followed by RQ3, and concludes with a reflexive account of implications for my own practice. I will then outline the strengths and limitations of the current study.

5.2 Research Questions 1 and 2:

1. What are the experiences of autistic school leavers with complex needs, and their families, as reported by parents, during and following the transition to post school destinations? (RQ1)
2. What are the views of school professionals on the transition process for autistic school leavers with complex needs, and their families, during and following the transition to post school destinations? (RQ2)

These questions were answered by parents expressing their views on their and their child's experience of transition, and school professionals expressing their views of the transition process. The findings suggest that parent voice is a significant factor in being able to shape and drive the transition process on behalf of their child (4.2.7; 4.4.6), and that those who have some knowledge of the process, through support groups or employment for example, have a stronger voice. As P3 stated, "knowledge is power" and having knowledge of your own and your child's rights gives added confidence. Not knowing what kind of placement or destination

is available to their child (P3), or how to go about securing a positive outcome means that parents are disempowered (Brett 2002). Parents in this study reported that they were well supported by the school during the planning process and that the school knew their child's needs very well (4.2.2). School professionals also reported that they supported parents throughout the planning process (4.4.7). However, the transition journey was unique for each one and parents lacked knowledge of the journey they were about to undertake and potential obstacles which would be presented, such as limited availability of appropriate provision, over which the school had no influence. Sometimes it is only with hindsight, as reported by P1 and P5, that ways to avoid the pitfalls becomes apparent. Increased sharing of information and parental experience may help address this. Parents can shape process if they know how and have the confidence to speak up. Speaking up without knowledge can be counter-productive, meaning that parents may be labelled as difficult or abusive and, in some cases, can achieve the opposite of what they intend (4.4.6) and so become demoralised. This can mean that the voice of the child gets lost (Brett 2002; Shakespeare 1999) and indicates that independent advocacy is required, that is, someone independent of the school or parents who speaks on behalf of the child or young person, putting their needs first.

School professionals appear to be in a middle ground between parents and LA professionals. While SPs express understanding and sympathy for parents, and state their views on the limitations and successes of the transition process, respondents appear almost accepting of some limitations. For example, their experience that adult services often do not join the planning process early enough and that it is "lucky" if they do (SP5), or that it's incredibly dependent on whoever it is that's picked up the case…rather than it being a system that works effectively" (SP1). This endorses Brett's (2002) acknowledgement that a true partnership based on collaboration between parents and professionals is, at best, optimistic, at worst, impossible. The same may apply to some extent to collaboration between professionals in different fields. Parents' perception that professionals hold the power and direct parental involvement, reported by Brett (2002), Case (2000) and Dale (1996), still seems to hold true for the parents who do not have any additional knowledge of the transition process. Those who are empowered by their knowledge, can push towards more successful outcomes (SP1). True partnership cannot be achieved until parents feel involved, accepted and respected by LAs and empowered to steer the transition process alongside others who have an interest in procuring individualised and positive outcomes for young people.

The nature of transition planning and policy into adulthood is complicated (Burke et al. 2019; Shogren and Plotner 2012) and experiences for planning for leaving school can be mixed

(Beresford et al. 2013). This trend appeared in the current study also, showing that, despite positive and proactive involvement from the school of the study reported by all parents, there is a mixed picture of collaboration and practice from LAs and other agencies and a see-saw of positive and negative experience throughout the process for each young person and their family. While all parents expressed that their child was ultimately in a positive destination, the journey to that point was different for each, with P1, P6 and P7 having significantly challenging experiences throughout compared with less complicated, although still described as time-consuming and stressful, experiences of P3, P4 and P5, and fewest levels of challenge described by P2. As participants were geographically spread, this suggests inconsistent practice across the country. While Friedman et al. (2013) conclude that inadequate school-based transition planning is one of the reasons for the fragmented systems and unsatisfactory outcomes, findings here suggest, from both parent and SP responses, that schools' input is strong (4.2.7; 4.4.4) and that LAs are failing in their statutory duties when they do not begin or join planning early (Scottish Government 2017a). There are clearly gaps in the transition planning process and in the practice that follows post-school that account for this. Lack of availability of appropriate provision is a problem (4.2.4; 4.4.3) and sourcing appropriate accommodation may lengthen the time taken for the transition. This is all the more reason for LAs to join the planning process early as advised by Scottish Government guidance (2017a). While high caseloads were acknowledged by parents and SPs, individual social workers, especially in the children's sector, can be committed and have significant positive impact throughout the process (4.2.3; 4.4.2) However, this is not enough without the full collaboration and engagement of adult services and LA personnel who are able to make decisions about allocation of services and funding.

Schools' level of knowledge and familiarity of the young people has built up over a long time of involvement, and enabled good understanding and management of challenging behaviours. P7 recalled challenges and distress when YP7 first started school compared with, some years later, their happiness at returning there following a failed transition, suggesting that YP7 had had an initial unsettled period before being settled and happy at school, probably indicating that the school had to implement and adapt strategies over time to meet YP7's needs. Adult services are at a disadvantage, or putting the young person at a disadvantage, if they are joining transition planning late in the process, having less time to establish relationships and to become familiar with the family, the needs and complexities of the young person and the strategies and supports they require in order to live life. This leads to poor outcomes including lack of individualisation, uncertainty about the role of parents and a shortage of adequate and

integrated services (Anderson et al. 2017) which are apparent throughout the current study (YP1, YP5. YP6, YP7). Doran (2012) contended that outcomes for young people with complex needs could be improved if there was better collaboration and less duplication of services. This, led effectively by strong, strategic, distributed leadership could be key to improvement (Leithwood et al. 2004; Social Work Scotland 2018).

The mixed response from parents and professionals as to whether the LA was aware of the young person's needs (4.2.3), varying from "not at all" (P7), to "by the end of the process" (P4), to "an acceptable level" (P5) to "excellent" (P1, P2), suggests that level of awareness is "incredibly dependent on the [LA] individuals involved" (SP1). Knowledge of autism and its impact on the young person's ability to engage was highly valued by parents and, where this occurred, "painted a picture" of the future as something to aspire towards rather than fear (P3). Too often, provision is identified based on what happens to be available, not what is actually required to fully meet the needs. This was reported by all parents except P2 and by all SPs, and likened to putting square pegs into round holes (P7). Some had more choice than others (4.2.4) or believed initially that they had a choice but realised ultimately that there was no choice (P3). This is neither equitable nor inclusive and suggests that some LAs are not working under the Scottish Government's principles of 'equality and inclusion' (Scottish Government 2012a) or GIRFEC (Scottish Government 2017d; 2018a). While schools facilitate the transition planning, the responsibility for the implementation lies with the LA who maintain responsibility for the young person and fund both the place at the school and the post-school placement. Guidance is available in the form of the *Principles of Good Transition 3* (ARC Scotland 2017a). The process should be driven by proactive and sustained collaboration, embedded in relevant, responsive policy (Lawson and Beckett 2020; Rioux and Carbert 2003), and not by chance.

Challenges in providing appropriate post-school provision and, ultimately, challenges within those placements, leading to the breakdown of some (4.2.5; 4.4.4), indicates that the levels of complexity are not clearly understood or provided for. Some of this may be accounted for by reduced levels of funding between children's and adult services. There is a perception among some respondents (P7, SP2, SP5), concurring with Riddell and Weedon (2016), that LAs are more concerned with financial implications than with meeting needs. There is clearly a lack of funding (MacKay et al. 2018; MacDonald 2018) and this is the key issue affecting the social care sector (Scottish Government 2021b). Some SPs reported having to prepare parents for reduced funding in adult services and that parents were shocked by this (SP2, SP5). Yet, the most important factor in deciding funding and outcomes in this cohort is the presence of

intellectual disability (MacKay et al. 2018). While the inclination to date has been more towards the social model of disability (Allan and Catts 2012; Scottish Executive 2004), the medical factors should not be ignored, but taken into account, along with all other factors, as in the emerging human rights approach to disability.

In order to procure positive outcomes, a fully person-centred approach needs to be in place, to match the resources to the needs of each individual young person. This calls for a true understanding and acceptance of the level of complexity, a consideration of the young person in all their aspects, as promulgated by the human rights approach to disability which focuses on an individual's dignity (Lawson and Beckett 2020) and quality of life (QoL) (Verdugo et al. 2012), a holistic approach to meeting needs. While the social model of disability has gone some way to providing an affirmative rather than a deficit model (Barton 2001), and provides the basis for the attitudinal and structural barriers identified in this study, it has been criticised for its focus on social aspects and ignoring medical and mental attributes of disabled people (Anastasiou and Kauffman 2013; Ghai 2006). Nevertheless, it has identified where policy reform is needed and is a basis for the human rights approach to policy responses to disability (Lawson and Beckett 2020). This puts the onus on governments to provide a policy response to the lived experience of disabled people (Giri et al. 2021; Goodley 2012) that supports the diverse needs of disabled people in society (Rioux and Carbert 2003), all of which is relevant to the findings of this study. Concerns raised in this study, including a lack of understanding of supports required to meet complex needs, and lack of availability of appropriate provision and resources, are similar to those identified in the independent review into adult social care in Scotland (Scottish Government 2021b). The Scottish Government response focuses on the human rights approach, promising a new, national strategy to improving the system and a shift "beyond the mind-set of existing systems and services" (p.47) which, if implemented, will address the concerns raised by this study, that current approaches to transition and subsequent outcomes are inconsistent and fall short of the human rights approach.

A human rights approach would cut across the bureaucracy that currently seems to prevent LAs working together to provide shared opportunities where this would be an appropriate or desired option for young people (4.2.3; 4.4.2). While the school is able to support a cluster of young people from across the country in one place with trained and specialist staff, sharing knowledge, understanding and experience, the approach may be more 'diluted' in the LA. This is such a small cohort, spread across the country, that LAs may not have had the opportunity to consistently build knowledge, experience and resources. A planned and more structured overlap of children's and adult services would help address this. However, school involvement

into the adult placement has the potential to be counter-productive and confusing for the young person already experiencing multiple changes (Madders 2010), unless it is adopted as part of a planned, enhanced transition. This would allow school staff to mentor and train adult services staff and for adult services staff to become familiar with the young person and the family, then taking the lead role following transition, during an assessment period, where levels of support and strategies could be practised and confirmed.

It appears that adult services are not always able to emulate the supports provided in children's services and some of the reasons for this are acknowledged in the independent review into adult social care (Scottish Government 2021b). Fragmented systems of care lead to unsatisfactory outcomes (Friedman et al. 2013). The young person needs to be supported to acquire new coping strategies and skills of independence, otherwise they will be unable to adapt and become vulnerable (Bellini, 2006). The reasons cited by parents as contributing to the breakdown of placements are interrelated (4.2.5) and reported by Adams (2018), BBC (2018), McNeill (2018) and Sweeny (2016). The chain of reduced levels of staffing caused by reduced funding (Scottish Government 2021b) and/or lack of understanding of the complexity of need, can lead to young people not being supported appropriately. This can then lead to higher incidents of challenging behaviours, including SIB (Edelson 2011; NAS 2021), which can lead to anxiety for staff (Butrimaviciute and Grieve 2014) who are not well paid (Scottish Government 2021b), and not always well trained (Roncaglia 2012). This may result in high turnover of staff (Martin et al. 2011; Sulek et al. 2017), which can lead to inconsistency and unfamiliarity for young people, which can in turn lead to increased incidents of challenging behaviours (Douperouzal and Fish 2010; NAS 2021), and the cycle is repeated. As well as the complete breakdowns of provision reported, multiple times by P7, there are examples cited throughout the study of: lack of understanding of need (P1, P5, P6, P7); reduced levels of staffing requiring support from parents (P1, P4, P6, P7); increased levels of challenging behaviour, including SIB, indicating levels of anxiety of the young person and causing anxiety for staff (P1, P5, P6, P7); and inappropriate physical environment (P1, P5, P7). Some or all of these factors combined can lead to negative outcomes for young people, staff and families.

Parents expressed that the preferred option is that the young person returns to a destination within their home authority (4.2.4; MacDonald 2018), but appropriate services are limited (4.2.4; 4.4.3; MacDonald 2018) and access to information generally about supports available can be restricted through bureaucratic and over complicated systems (Scottish Government 2021b). While out-of-area placements may be an appropriate choice for some, the Ministerial Foreward to MacDonald's (2018) report acknowledges that out-of-area placements are

seldom in the best interest of those with complex needs, or their families. Positives reported in this study and by MacDonald (2018), about a placement close to home, include being nearer to family and having more interaction with family. For some, this is non-negotiable (P2, P4). However, the reality does not always live up to the expectation and hindsight raised questions, for some, subsequently, about the suitability of placements and whether returning to the home authority had been the best option when potentially better services are available elsewhere (P1, P5). For others, the young person adopts a new routine and voluntarily dismisses the input of the family, preferring their own space and environment (P6, P7). This raises the question whether it is necessary or feasible to have placements available in all areas or whether there should be a concentration of placements in accessible locations across the country. For example, rather than providing placements in rural areas with limited access to other services, transport and leisure facilities, it may be more advantageous to have a concentration of services in various locations, possibly in neighbouring authorities where resources could be combined to provide options either in, or close to, the home LA. While parents want their child to be as close to home as possible, P7 remarked that the important aspect was that the young person was happy, wherever that would be. The home authority would continue to finance the placement so it would be their responsibility to ensure that it is appropriate and that nothing more suitable could be procured within the LA. This would call for more and better collaboration between services and LAs and for an end to bureaucracy. All of these issues are acknowledged in the independent review into adult social care (Scottish Government 2021) with a pledge that they will be addressed through a transformational change of the current system. Some of this could be addressed if LAs adopt a more regional approach to transition support, allowing more movement and collaboration between authorities. Regional Improvement Collaboratives (RICs) were established in Scotland in 2018/19. The purpose is to improve outcomes in education by working across disciplines, including health and social care, and authorities. One of the areas of focus is positive, sustained destinations for school-leavers. This appears to be an appropriate platform for an individual to have regional responsibility for the co-ordination of services for this small cohort of young people across the country.

For some, it was not a matter of choice of placements, but a bespoke placement only was required (P3, P4), although none of the placements was entirely bespoke. Bespoke placements are thoroughly individualised (Blacher et al. 2010), needs-led, designed, sometimes including a purpose-built property, to address and support the physical, social, emotional and health needs of an individual young person, rather than attempting to fit a young

person into an already established service, or attempting to partly modify the service to meet needs. MacDonald (2018) recommends the designing of bespoke environments that best meet the sensory needs of this cohort rather than simply using available housing. If a bespoke option is what is required for these young people, and findings suggest that this is the case, then the planning should begin early, well in advance of any proposed leaving date, and ongoing, with proper collaboration between children's and adult services over time, to assess the needs of the young person as they change and develop. Providing bespoke options would require increased funding from LAs but, if implemented properly, would improve outcomes for this cohort and, ultimately, lead to potential savings as the false economy of perceived cheaper, but ultimately less effective, options is eradicated (P7). This aspect is also addressed by the independent review into adult social care in Scotland (Scottish Government 2021b), which recognises that the sector is affected by lack of resources, and promises to increase future funding through a National Care Service.

Parental disappointment and feelings of being let down by post school destinations offered or provided to their child (4.2.4), are echoed by SPs (4.4.3) who referred, in several cases, to unrealistic parental expectations (SP1, SP4). The instance of an adult worker 'under-promising' in order to manage a parent's expectations indicates that the LA is aware that they are unable to meet the expectations and provide a bespoke or appropriate choice of destinations. There is a gap between parental expectations and what the LA is able to provide, not that the parental expectations are necessarily unrealistic, but what the LA is offering may be unrealistic, either because they do not have the appropriate resources available or they do not understand what resources are needed. While some LAs indicate that they are moving towards a needs-led rather than a service-led approach, in line with a human rights approach to disability, the outcomes do not always reflect this. For example, P4 stated that the LA was moving towards a needs-led service, but reported that the process was time-consuming and stressful for them and, despite an overall positive outcome for YP4, P4 emphasised that they would not have the resilience or emotional resources to cope with another major change for YP4. For all others except P2, there were issues with the post school provision. The problem appears to be less the parents' expectations, more the LA's inability to meet those expectations. It seems that the parental expectations are unrealised rather than unrealistic. Availability of destinations or inability of LAs to provide a bespoke option is one part of this issue. The experience in that destination is another and consideration needs to be given to why some destinations have positive outcomes and some negative.

This study concurs with others that concerns relating to inconsistent quality and ability of staff and fluctuating staffing levels causes anxiety (Sulek et al. 2017) as the incidence of challenging behaviours tends to increase under these circumstances (Edelson 2011; Emerson 2001; MacKay et al. 2018). Staff find challenging behaviours difficult (Butrimariciute and Grieve 2014) particularly SIB (Fish 2000; Hubard and Tantam 1999) and find the role difficult without appropriate training and safeguarding. Participants in other studies, both without and with intellectual disability (Bosman and Meijel 2008; Douperouzal and Fish 2010) describe SIB as a coping strategy, so, where this takes place among the most complex cohort, it is possible to deduce that they are not coping with their situation and, unable to communicate verbally, display their anxiety and distress through SIB. Participants in the other studies valued understanding, supportive, approachable staff, (Bosman and Meijel 2008; Douperouzal and Fish 2010), so, again, it is possible to deduce that this is what is required for the most complex young people too, with specially trained, competent staff using consistent approaches. P1 wanted to advise prospective new staff, at interview, of the level of challenge, particularly SIB, and felt that the care provider did not want this information shared at that time. Yet this means that staff are unprepared and lack adequate expectation, experience or training of what their support role entails. There is evidence that care staff feel under-valued and underpaid (Scottish Government 2021b). There was little evidence in this study of the interdisciplinary, collaborative approach to training (Longtin 2014), or the coaching approach where trainees are involved in challenging situations that require deep reflection of their own practice and solutions that they can bring to the workplace (Roncaglia 2012). This justifies P7's concern about the statement from a member of care staff on day one in a new placement for YP7, "we've been on a challenging behaviour course this morning", indicating a lack of depth of specialised knowledge or training. Quality Induction training and ongoing training for staff is one way to address this. There is currently early engagement of a Scottish Government working group considering a national approach to regulation and deployment of Pupil Support Staff. This was initiated in response to Morgan's (2020) review of the implementation of ASL legislation in Scotland and includes the development of a skills framework and training programme for pupil support staff in schools. A national approach to workforce planning and development has been identified for the adult care sector too through a National Care Service (Scottish Government 2021b). Some of the current deficiencies in transition planning and procedures could be addressed if these two national groups work collaboratively with a shared purpose.

The stories of fluctuating positivity and negativity in post-school destinations in this study, influenced one way or another by change of provider, levels and quality of staffing, suitability of accommodation or support strategies used, highlight fragmentation and a lack of consistency of approach, and concur with others (Friedman et al. 2013; Scottish Government 2021b). There is underestimation by some of the level of support required to meet the needs of these very complex young people at the "higher end of the spectrum" (P7) and differing understanding and definitions of challenging behaviour. As P7 exclaimed, "well, God Almighty, why can't people look at this and for the higher end of things see how this works, and why can't we work towards duplicating that?...If you have a model of care that works then surely people should work together and adapt that… if organisations tended to work more together". P4 recognised changes of staffing as a "fact of life" and strategies to build resilience in the young person were successfully used.

There must be some accounting for the multiple challenges and breakdowns of placements reported by parents and SPs. Young people who were miserable in one placement had a completely different experience in another or with a different provider, from "terrible" failure to "instantaneous success" (P6) when a new care provider adopted a different approach and showed understanding of their complex needs. A focused approach, appropriate autism training and increased structure and routine led to improvement. These are the resources and strategies that should be made available and implemented to avoid the stressful experiences reported.

Parents and families of an autistic child experience significant stress (Begum and Mamin 2019) and this is reflected in the current study where the emotional impact is clear. Parental anxieties about transition may arise years in advance of the process (Doran 2012) as parents fear that their child will be lost in adult services without anyone taking proper responsibility or accountability for continuing services (Blacher et al. 2010; Cheak-Zamora and Teti 2014; Cheak-Zamora 2015). The findings of this current study reflect the findings of others, that parents of autistic children worry significantly more than parents of children with other disabilities at the point of transition to adulthood (Blacher et al. 2010) and that the more complex and challenging the young person and their needs, the more significant is the parents' worry (Wong et al. 2020), as is reflected by parent participants in the study (4.2.8) and supported by views of the professionals (4.4.7).

It was apparent during the study, by the nature of the responses during interview, or language used in both written and verbal presentation, that parents' emotions were stirred when

recounting some of the negative experiences, both from the parents who stated that they did not wish to take part and those who did: the questions "bring up stuff that I've tried to lay to rest" (P7). This underlines the strength of negative feeling that parents experienced. Beresford et al. (2013) also report very low response rates from parents and autistic young people in their study on transition to adult services, although no reasons are given for this. As a sensitive researcher (Liamputtong 2007), I had a responsibility to be aware that participants may be "vulnerable to their own emotions being stirred by taking part in the research" (Dickson-Swift et al. 2008, p.39) and to manage emotions appropriately through sensitive approaches to questions and questioning, providing detailed information and offering the opportunity to withdraw.

As evidenced in the current study, the transition process can present some challenge and stress or anxiety to all families and autistic young people (Bernard et al. 2001; Browning et al. 2009; Osborne and Reed 2008). The impact of poor outcomes on these young people can have a devastating effect (YP1/P1, YP6/P6, YP7/P7), leaving them vulnerable (Anderson et al. 2017; Bellini 2006; Friedman et al. 2013). While parents experienced stress and trauma throughout the entire process (4.2.8), young people may be more sheltered during the transition planning as they are likely to have a more passive role (Beresford et al. 2013; Browning et al. 2009; Shogren and Plotner 2012) but the transition process itself can trigger anxiety and depression (Bernard et al. 2001; Browning et al. 2009; Osborne and Reed 2008). This may lead to significant bouts of challenging and self-injurious behaviours. If the environment is unsuitable and staff are unable to manage the behaviours, it can escalate causing prolonged distress to young people (YP1/P1,YP5/P5, YP6/P6, YP7/P7), staff and families.

The impact of unrealised expectations caused some parents to fall into a dark and despairing mind-set, as starkly described by P7 (p.88). The impact on the family is lifelong and parents continue to worry about the future for them and their child. The more stressful the transition journey, the more likely parents are to have concerns about the future (P6, P7). Feelings of being let down and breakdowns in placements cause parents to lose trust in the future. As noted in section 4.2, if a placement is ultimately positive, despite previous negative experiences, parents describe the overall experience as positive. A positive outcome overtakes the challenge of the journey to that outcome. This is similar to findings in Balubaid's (2017) comparative study of the transition experience from childhood to adulthood for autistic young people in the UK and Saudi Arabia, that, regardless of challenging experiences reported, half of the UK respondents reported a positive childhood experience.

5.3 Research Question 3:

What are the implications of these parent and professional views for policy and practice?

The language of these documents and policies, as discussed in section 2.2, is aspirational and, rightly, assures a positive experience, for every and all children and young people. To recap, "Equality and inclusion has long been a strong feature of Scottish education and continues to be so…" (Scottish Government, 2012a) and the purpose of GIRFEC (Scottish Government 2010a; 2017d; 2018a) is to support children, young people and families by making sure children and young people can receive the right help, at the right time, from the right people. The policies outline a supportive and progressive journey through the education system to adulthood that should be available to every child and young person in Scotland. There is frequent repetition of 'every' and 'all', throughout the policies and guidance, in reference to equal and inclusive opportunities and positive outcomes for all children and young people.

The experiences and outcomes of the participants in this study do not align consistently with the aspirations of these policies, concurring with Pirrie and Head (2007) that those with the most complex needs are a significant challenge to policy makers and providers. Despite previous reports, reviews and legislation, there continues to be a fragmented approach (ARC 2017b; Hall 2019) and not equity, equality and inclusion for all and every one of this cohort. This does not mean that everyone should be treated the same, but that there is equity of access, equality of opportunity and inclusive practices allowing young people with complex needs to be considered in the same way as their non-disabled peers. Currently, where there is a successful outcome, it is sometimes attributed to luck in availability of housing or personnel (P1, P4, P6, P7, SP5) or advocacy by a knowledgeable parent (P3, P4, SP1, SP4) or committed professional (P1, P2, P3, SP1) rather than consistent and thorough application of policy and principles. The transition process identified here is lengthy and stressful for most, (4.2.8; 4.4.7). For some (P6, P7), a positive destination follows a period of challenge and negativity, getting it wrong before getting it right and, for others, sustained destinations which, with continued challenge, are not always positive (P1). LAs may mistakenly use a 'one-size fits all' approach when addressing the needs of the most and the least complex young people, considering, erroneously, their needs to be similar (Bawden 2005). For all parent respondents there is stress and anxiety at some point or continually throughout the process and, for most, concern or fear for the future (4.2.8; 4.4.7). The aspirations of these policies are partially

fulfilled for some, or eventually fulfilled, although still with apprehension for the future, and that is not good enough.

Verdugo et al. (2012), based on the assessment of quality of life-related outcomes, proposed three strategies that can be used to improve the human rights of disabled people. These are to use person-centred planning, advertise provider profiles and implement a system of support, which seems a straight-forward approach and aligns with the findings of this study and others (ARC 2017a; Hall 2019). The human rights approach is "an international issue practiced [sic] at local level" (Rioux and Carbert 2003, p.1). The National Care Service proposed by the independent review into adult social care in Scotland (Scottish Government 2021b) proposes a system that is "controlled nationally that delivers locally, has the person at the centre and does not cost the earth" (p.38). If LAs adopt a more national or regional strategy towards transition planning and support, allowing the development of expertise, movement and collaboration between authorities at a local level, this could be a move to practical, ethical support as championed by the human rights approach to disability (Cluely et al. 2020).

The Scottish Government endorses the *Principles of Good Transition 3* (ARC 2017a) and these are almost identical to the recommendations of the SPICe briefing (Scottish Parliament Information Centre) (Hall 2019), so the requirements are already known and understood. It is the implementation of these principles that is lacking and should be addressed. Christie (2011), Doran (2012), MacDonald (2018) and Scottish Government (2021b) all make similar recommendations, several years apart, about transforming services through better approaches, collaboration and a rights-based approach. This suggests that there is a problem with implementation, not with knowing what needs to be done. The solution to that problem must be found, to ascertain why these recommendations are not being implemented thoroughly, even with Scottish Government endorsement. The GIRFEC framework existed for several years before being included in the 2014 Act. It was enshrined in the Act due to inconsistent and fragmented approaches to GIRFEC across the country (Hepburn and Belgutay 2012; Stalker and Moscardini 2012) and the Act was intended to enforce implementation of the GIRFEC principles. This study suggests that these are not yet fully implemented. There is no need to introduce new policies and legislation, just to thoroughly embed the ones that already exist, with the recognised principles, and avoid either moving too fast, which is a potential cause of the failure of implementation (Watson 2010) or, using complexity as a reason for moving too slowly or doing nothing (Doran 2012).

While it is important to have aspirational policies, it is imperative that the right resources are available for implementation and that all actors are proactively meeting roles and responsibilities in order that the experience for all children and every young person matches the aspirations. Transformational change is required (MacDonald 2018; Scottish Government 2021b) although some small changes can quickly and easily be delivered to have an impact (ARC Scotland 2018). Parents have expectations that the policies and legislation will deliver the promised outcomes. These expectations should simply be expectations, never unrealistic expectations and, with everything aligned, the deep-rooted problems addressed and the policies properly resourced and enacted, the expectations can be realised (Stalker and Moscardini 2012). The Scottish Government (2021b) has promised transformational change in the shape of the National Care Service and it remains to be seen whether that will be implemented more effectively than previous recommendations.

There are also implications for my own practice because of this study. While this is an area that I am already familiar with, and have an understanding of, I am now even more aware of. possible gaps in the process, of ways to potentially improve outcomes, and of the depth of emotion and levels of stress that accompany this process for parents (Blacher et al. 2010; Wong et al. 2020). I will use my professional contacts where possible to raise awareness of these issues and to consider ways of addressing them, both locally with LAs, and nationally through professional bodies and with the Scottish Government in relation to revisiting the Transition Bill (Scottish Government 2020)..

I will aim to engage more proactively with LAs and encourage greater collaboration on transition planning, seeking early or earlier engagement from adult services where needed, as is their duty within the legislation (Scottish Government 2017a). To date, there has perhaps been a tendency to see each professional or agency as a separate part of the whole transition planning process. In future, a more collaborative approach is required (ARC 2017a; Hall 2019) with recognition of the importance of all roles and responsibilities and a communication plan that is agreed, shared and enacted by all. I will influence this as far as I am able within the limits of professional boundaries.

I will support parents by providing more information to them about the process and encouraging the same from LAs, through a more structured and collaborative approach to transition planning. I will encourage parents who have lived the experience to share information with other parents about their experience, particularly those from the same or a neighbouring LA.

Furthermore, I will support parents in communicating the needs of their child and levels of complexity to the LA more effectively. While this is already part of my practice, I am now more aware that the communication is not always successful. There is often a gap in the handover between children's and adult services in the LA, noted by Friedman et al. (2013) and described by both parent and SP participants in this study, over which I may have limited influence. However, I will raise awareness of this through my professional conversations and raise more formal concerns with the LA if appropriate, offering potential solutions and actively seeking to cut across bureaucracy where that is possible. In addition, I will procure the services of independent advocacy to represent young people and ensure that their needs are heard and acted upon.

Moreover, I will encourage more structured handovers between school and adult services, allowing time for knowledge and understanding of the young person and strategies for their support to be shared and embedded and to consider ways, within the law, to continue to share information and strategies post transition.

When beginning this study I believed that there was a problem that I needed to solve. Throughout the study I have become more aware that the transition planning and process is complicated and that there may be no best practice model. However, structural and attitudinal barriers have been identified and can be addressed to remove barriers and improve outcomes. A more consistent and forward thinking approach with a focus on human rights is required (Scottish Government 2021b) The policies are good, the implementation needs to get better in order to improve practice.

There will be further discussion of the implications of the study and for future research in section 6.2.

5.4 Strengths of the study

Although a small sample of parents from one setting, the study included representation of almost one third of LAs across the country between participant parents, young people and school professionals, with the likelihood of a broader representation from schools whose catchment areas include LAs outside of their host authority. Parents and professionals produced very similar findings, giving credibility to the results, and these in turn echo what is being reported currently (Codd 2018; MacDonald 2018; Morgan 2020; Scottish Government 2021b). In addition, some of the more extreme examples of negative destinations and experiences reported by parents, are reflective of others reported in newspapers in both

Scotland and England (Adams 2018; BBC 2018; Gentleman 2011; McNeill 2018; Salman 2019; Sweeney 2016).

Parents, through questionnaires and semi structured interviews, gave authentic accounts of their perspective of their child's experience, and this was supported by what was reported at school level by SPs, building up some typifications of those experiences (Benton and Craib 2011). This is a reference to Schutz's (1962, 1964) notion of 'typification'. No matter what we experience in the world, we have built up enough knowledge to recognise even the unfamiliar and we must acknowledge that. For example, we may not know individual types of trees, but we recognise a tree as a tree (Zahavi 2019). Benton and Craib (2011 p.84) describe how we build up 'typifications' of other people and that "the social world is built up from a complex multitude of typifications which we organise into 'meaning contexts'". Through our own experience and interactions with others we gather information that builds up a picture of typical phenomena and that is how we acquire and recognise types.

Although parents of school leavers across a period of six years were approached, the parents of most recent leavers did not respond to the invitation to participate. For some, who intimated in phone-calls that their experience was negative, this suggests that they did not yet feel able to speak about it. The parents who responded from the earlier years of the research limits were able to recount experience over a number of years, giving a fuller picture of the post-school experience and their child's journey into adulthood, providing rich data for the study.

Data was checked and analysed thoroughly, including an inter-rater check and an intra-rater check. Thematic analysis guidelines were followed (Tong et al. 2007) taking breaks and revisiting over time in order to reconsider with a fresh viewpoint. Written drafts were sent regularly to supervisors and responded to with written feedback and discussion in video calls, with feedback noted and acted upon for re-drafts.

5.5 Limitations of the study

Although first-hand accounts were not given by young people, parents provided powerful commentary. I relied on the parents to give a true picture as I was unable to interview the young people. Parents presented subjective information, recalling and speaking on behalf of their child and interpreting their child's behaviours and presentation. During transition, while young people were unable to tell their parents how they felt, they communicated their feelings through established patterns of behaviour, and parents were able to construe this. The paucity in research involving directly the views of autistic young people (Gaona et al. 2019) are reflected by this study, and some of the reasons for this are discussed.

Not all parents who were approached wished to participate. Some indicated that they did not want to relive the experience indicating that some strong data has potentially been missed out. However, their reluctance in itself indicates an alignment with the findings of the study.

There is limited information from school professionals on what happened in post school placements, relying in some cases on informal information or hearsay.

Doctoral restraints, such as word count, limited more detailed reporting of the experiences. However, a redacted transcript of one parent account (P7) and one SP account (SP1) are included in the appendices to give the reader a flavour of the stories told (P7 Appendix 14; SP1 Appendix 15).

On reflection, with hindsight, I would have approached some aspects of this study differently if I had to do it again. As outlined in section 3.12, I would have changed some of the methods, using interviews from the beginning rather than questionnaires, which some parents found daunting and which took too much time, both to be returned after first giving consent and for participants to complete. Going straight to interview would, I believe, have given more and even better data. In addition, I would have asked more specific questions about the young person's experience and for more evidence of their emotional state and how they expressed their happiness or unhappiness. There is evidence of some of this in parent responses and there were some powerful and telling anecdotes, but I feel that some of the questions could have explored the experience of the young person more deeply and I wish that I had taken the opportunity to examine this more.

The conclusions and recommendations drawn from the study will be outlined in the following chapter along with implications of the research and for future research.

Chapter 6: Conclusions and Recommendations

6.1 Introduction

The study set out to examine the experience of autistic school leavers with complex needs and their families, as told by parents and school professionals, when transitioning from a residential school setting to adult services, and to consider whether the experiences meet the aspirations of Scottish Government policies. The conclusions and recommendations, followed by implications of the study, including the contribution to new knowledge and understanding, and for future research, are discussed in this chapter.

6.2 Conclusions

The similar experiences reported in this study by parents and school professionals, indicate a picture of inconsistency of approach and experience across the country. This has been recognised too by previous studies (Hepburn and Belgutay 2012; Stalker and Moscardini 2012). While there are some examples of good practice, there is an overall impression of challenge and anxiety caused by a process that is bureaucratic and difficult to manage (MacDonald 2018; Scottish Government 2021b). This is in contrast to the aspirations of Scottish Government policies which present GIRFEC, positive, sustained destinations and positive experiences and outcomes as the expectation for every and all children and young people.

The timing of the beginning of the transition process is not necessarily an issue, and input from schools is timely and valued, but the late engagement of LA adult services is an issue and a failure of a statutory duty. Lack of collaboration and partnership leads to an approach which is fragmented, inconsistent and not person-centred, service-led rather than needs-led and far from the reality of a human rights approach. Inappropriate choices are offered to young people due to, variously, a lack of understanding of need, lack of appropriate resources, lack of funding. Placements can break down because young people are not appropriately supported, the environment is not suitable to their needs, all staff do not have the required training and skills, there is high turnover of staff. It may be a combination of any or all of these factors and there may be other factors, but these are the ones most often reported. According to the findings, there is a lack of overall co-ordination of services, with bureaucracy preventing collaboration between LAs. Parents often feel powerless, disempowered and unable to fully advocate for their child. There is an emotional toll on young people, parents and families and always apprehension about the future. These are factors that have appeared in previous

studies (Anderson et al. 2017; Burke et al. 2019; Christie 2011; Clarke et al. 2009; Doran 2012; MacDonald 2018; McCartney and Muir 2017).

Lessons may be learned from these experiences, which participants expressed a horror of ever repeating. If a placement can go from "horrendous" to "instantaneous success" in the same location from a different provider, the reasons for this should be investigated, identified, documented and shared in order to improve the experience for others.

The Scottish Government assures positive, sustained destinations for all (Scottish Government 2012a; 2012d). The findings of this study suggest that a sustained destination does not always mean a positive destination and a positive destination does not always mean sustained. Although all young people in the study ultimately achieved a positive destination, negativity and challenge permeated the process for almost all and there was some emotional cost for every parent participant and their child. Parents continued to worry about the future, the potential unsustainability of placements and what would happen to their child when they were no longer around to fight for them (ARC 2017; Doran 2012).

Addressing these shortcomings will require commitment and a financial investment. The transition planning process, quality and availability of destinations and meeting individual complex needs all need to be improved, which will, in turn, ease the pressure and stress for parents and families. While there may be no best practice model because of the varying needs and complexities of both the transition planning and the individuals involved, there is a need to develop a more consistent approach and to consider what may be required in future years. The Scottish Government (2021b) has announced a plan to improve adult social care in Scotland, through a National Care Service, and this may go some way to tackling some of the issues outlined in this study. Recommendations for improvement from previous reports (ARC 2017; Christie 2011; Doran 2012; Hall 2019; MacDonald 2018) have not been fully implemented so there is also a necessity to address the barriers to implementation.

6.3 Recommendations

Recommendations arising from the study are listed below.

- ASL Guidance should be clarified regarding timescales for appropriate transition planning for young people with more complex needs, ensuring that there is no ambiguity or openness to interpretation with statements such as "no later than 12 months before the pupil is due to leave school", and clarity about reasons why an LA should begin transition planning early.

- An enhanced transition planning process is required, with longer and more collaborative input between children's and adult services with contingency planning in place for sharing of information when key staff leave. LA adult social work staff should join the planning process earlier and parents should be included, supported and meaningfully involved throughout. Advance planning is required on the part of the LA, predicting when young people are likely to be transitioning and ensuring that the current and future needs of the young people are known and understood and that services will be available to meet those needs.

- Post school destinations must be appropriate to the needs of the young person, to be established through person-centred planning to meet the full needs of the young person, and resources and funding made available to provide the required level of support.

- Independent advocacy should be provided for young people in order to represent their best interests throughout the entire process.

- A regional approach to co-ordination of available services for this cohort should be considered, overseen by bodies such as the Regional Improvement Collaboratives and/or proposed National Care Service, in order to break down bureaucratic barriers between LAs, and provide a more collaborative approach to the provision of services.

- Training in ASD and associated conditions and the implications of that for daily life and independence must be provided for all who work with, or are responsible for, services for this cohort. The Scottish Government is currently considering a national Skills Framework for pupil support staff and a National Care Service for adult social care. This promises a system, controlled nationally, that delivers locally.

- Transition planning should include a planned overlap of staff shadowing between children's and adult services, including ongoing sharing of staff between the services after the transition is complete. In addition, a means to provide some level of follow-up between school and adult service for a designated time period, sharing information within the law, should be devised.

- Information and guidance should be provided for parents and families, to include advice from parents who have already negotiated the process and can provide examples of lessons learned and successful outcomes as well as more formal guidance from LAs in a written, digital and/or infographic format. A range of appropriate and informative support services for parents, such as carers' centres or signposting

from charities, should be made widely available to families so that all have access to adequate support.

- Records should be kept of possible reasons for breakdowns of placement for individual young people, along with detail of successful outcomes, so that lessons for the future can be learned and good practice can be shared.

- Barriers to implementation of policy need to be identified and eradicated through appropriate monitoring and follow up of new systems.

- The Transition Bill (Scottish Government 2020) should be revisited by the Scottish Parliament to ensure that the principles of good transition are implemented into practice and protected within legislation.

6.4 Implications of the study

The study has contributed to knowledge and understanding of the experience of autistic school leavers with complex needs during the transition process, particularly in a residential setting, as well as the impact on families, and has identified gaps in policy and practice and reasons for both the success and failure of post school placements. The study has built on existing research into the transition experience of autistic-school leavers (Anderson et al. 2017; Burke et al. 2019; Friedman et al. 2013; Pirrie and head 2007). There are implications from this research for planning and resources, for parents, operational staff in education and social care, wider professionals and managers, LAs and for the Scottish Government in terms of implementation of legislation, policy and practice and the improvement of practice.

The main implications of the study are the responsibility of the Scottish Government and LAs, in that the structural and attitudinal needs require to be addressed and improved. The supply of resources, including funding, appropriate provision, staffing and training are likely to require significant financial input from the Scottish Government and commitment from LAs. In particular, acquisition of appropriate housing/accommodation or funding for future bespoke provision that takes into account all the potential complexity of young people should be made available. Monitoring of policy recommendations and practice should be undertaken at both a national and local level to ensure a good transition experience and positive destination for young people that matches the aspirations of current policy, which is positive and outlines an appropriate journey through school and into adulthood for all children and young people. The application and implementation of policy into practice needs to be enacted. At local level this could be translated into a 'transition procedures' protocol that outlines a step-by-step approach including clear roles and responsibilities.

Some of the implications of this study rest with the professionals whose day-to-day practice has a significant impact on the experience of families and young people. Methodical training and staff development opportunities in knowledge and understanding of autism and complex needs should be part of professional induction. Professionals need to find a voice that challenges others whose practice falls short of the policy recommendations and standards. There should be appropriate and robust methods of communication and collaboration between professionals in all fields and parents. Professionals need to recognise the role of parents as active participants and establish realistic ways to ensure they are supported included in the planning and process.

Information and support services for parents have to be upgraded. While the experiences and possible challenges are unique, parents who have previously been through the process should be encouraged to give advice and information to parents who are about to embark on the transition journey. This would give parents some idea of the obstacles and barriers that they may encounter and some support in overcoming these, as well as potentially offering challenge to LAs with the objective of improving the process and services, so that there is less difficulty for others in the future. Similarly, the successful outcomes could be shared and strategies adapted to suit the needs of others. LAs could provide other support services, such as written or infographic guidance or support from voluntary sector or charities, or signposting to *Parentzone* website (Scottish Government 2021a).

Young people should be included in the planning and process as far as they are able. Training in person-centred planning and knowledge of alternative methods of communication should be provided as part of professionals' induction. Specialised advocacy services should be established and used to support young people to have their views and voice heard.

The experience of young people beyond the transition process needs to be monitored and reviewed through an annual review process to ensure that the destination remains appropriate and positive. Where challenges arise, these should be addressed timeously and, where the provision is deemed no longer appropriate, following an honest and robust appraisal, alternative provision that meets the needs should be found. Reasons for breakdowns of placement should be recorded for lessons learned. Similarly, good, successful outcomes should be published and shared among providers.

This study has the potential to improve practice and outcomes for young people, parents and families and professionals. A financial and attitudinal commitment is required. The Scottish Government has already made this commitment and promises transformational change

(Scottish Government 2021b). This is what is needed to turn the recommendations of this study into reality.

6.4.1   Implications for future research

Other reports have indicated similar findings and made similar recommendations to this study (Christie 2011, Doran 2012, Hall 2019; MacDonald 2018; Scottish Government 2021b) suggesting that there is a problem with the implementation of research recommendations. Future research could investigate why the implementation of previous recommendations has fallen short and monitor the progress of the implementation of the National Care Service (Scottish Government 2021b).

There is potential for future research to ascertain the views of young people directly to further influence improvement of the transition process. This would require a longer period for research than was available in this study, in order to establish relationships and appropriate methods of communication with potential participants. Further exploration of access to participation of autistic pupils using Virtual Reality methods would be useful (Parsons and Cobb 2011), using bigger studies (Amat et al. 2021) and including those with more complex needs. In addition, longer-term studies to monitor and track young people's communication through patterns of behaviour and the connection between certain behaviours and the young person's experience would be worth pursuing.

The experience of wider professionals as participants in the transition process, including, for example, health service personnel and speech and language therapists, could be investigated to ascertain where other gaps exist and need to be addressed.

6.5 Dissemination

The findings and recommendations of this study will be disseminated via various appropriate networks including relevant autism charities and organisations, education and social care professional bodies and regulators and government advisory groups. Participants will receive a summary of findings and recommendations. The researcher has access to a wide range of contacts through their professional connections with these groups. A range of social media platforms will also be used to share appropriately. The researcher will seek to publish in appropriate journals.

References:

Adams, L. (2018) Learning disabilities care 'far from home'. *BBC Scotland News*, 02 October. Available: https://www.bbc.co.uk/news/uk-scotland-45666103 [Accessed: 06 November 2021]

Adults with Incapacity (Scotland) Act 2000. Available: Adults with Incapacity (Scotland) Act 2000 (legislation.gov.uk) [Accessed: 10 June 2021].

Al-Saadi, H. (2014) Demystifying Ontology and Epistemology in research methods. School of Education, University of Sheffield.

Allan, J. (2008) Inclusion for all? In: T. G. K. Bryce and W. M. Humes, eds. *Scottish Education: beyond devolution.* Edinburgh: Edinburgh University Press, (np).

Allan, J. (2010) The sociology of disability and the struggle for inclusive education. *British Journal of Sociology of Education*, 31 (5), pp.603-619.

Allan, J. and Catts, R. Eds. (2012) *Social Capital, Children and Young People.* Bristol: The Policy Press.

Am I Included? (2016) Am I included? [Television Broadcast] BBC1 Scotland. Available: http://www.bbc.co.uk/programmes/b0868n19 [Accessed: 28 November 2021].

AMASE (Autistic Mutual Aid Society Edinburgh) 2021 Available: https://amase.org.uk/glossary/ [Accessed: 11 September 2021].

Amat, A. Z., Zhao, H., Swanson, A., Weitlauf, A. S., Warren, Z. and Sarkar, N. (2021) Design of an Interactive Virtual Reality System, InViRS, for Joint Attention Practice in Autistic Children. *IEEE Transactions on Neural Systems and Rehabilitation Engineering*, 29, pp.1866-1876.

American Psychiatric Association (APA) (2013) *Diagnostic and Statistical Manual of Mental Disorders.* 5th ed. Arlington, VA: APA.

Anastasiou, D. and Kauffman, J.M. (2013) The Social Model of Disability: Dichotomy between Impairment and Disability. *Journal of Medicine and Philosophy*, 38(4), pp.441–459.

Anderson, K. A., Sosnowy, C., Kuo, A. A. and Shattuck, P.T. (2017) Transition of Individuals With Autism to Adulthood: A Review of Qualitative Studies. *PEDIATRICS*, 141 (4), pp.318-328.

ARC Scotland (2017a). *Principles of Good Transitions 3.* Edinburgh: STF and Scottish Government. Available:

https://scottishtransitions.org.uk/blank/wp-content/uploads/2017/01/complete-POGT3_A4-version.pdf [Accessed: 06 November 2021].

ARC Scotland (2017b) *Facing the Future Together: A national survey of young people with additional support needs and their parents and carers about their experiences of leaving school.* Edinburgh: ARC Scotland.

ARC Scotland (2018) *Leading the change: Solving the Transitions Puzzle: Recommendations and actions from a national seminar on improving transitions for young people who require additional support.* Edinburgh: ARC Scotland. Available: http://scottishtransitions.org.uk/blank/wp-content/uploads/2019/09/Solving-the-Transitions-Puzzle-Seminar-Report-Dec-2018.pdf [Accessed: 06 November 2021].

ARC Scotland (2019) *Principles into Practice*. Edinburgh: STF and Scottish Government.

Aspis, S. (2017) *Assessment and Treatment Units – young people with learning difficulties and autism: Overuse and abuse of sectioning of Disabled people (including young people with learning difficulties and autism).* Blog. Available: Assessment and Treatment Units - young people with learning difficulties and autism - Allfie [Accessed: 06 November 2021].

Autism Network Scotland (2013) *Summary Guide to Employment Policy, Structures and Initiatives in Scotland*. Glasgow: Autism Network Scotland.

Baird, G., Douglas, H.R. and Murphy, M.S. (2011) Recognising and diagnosing autism in children and young people: summary of NICE guidance. *British Medical Journal*, 343(6360), n.p.

Barton, L. (2001) Disability, struggle and the politics of hope. In: L. Barton, ed. *Disability, politics and the struggle for change*. London: David Fulton, pp.1- 10.

Bawden, A (2005) Anger over Warnock's criticism of special schools. *The Guardian* 10 June 2005 Available: https://www.theguardian.com/education/2005/jun/10/schools.uk [Accessed: 06 November 2021].

BBC (2018) Family's anger over detention of woman with severe autism. *BBC Scotland News*, 30 November. Available: https://www.bbc.co.uk/news/uk-scotland-highlands-islands-46404478 [Accessed: 06 November 2021].

Begum, R. and Mamin, F.A. (2019) Impact of Autism Spectrum Disorder on Family. *Autism Open Access*, 9(4), pp1-6.

Bellini, S. (2006) The development of social anxiety in adolescents with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 21, pp.138–145.

Benton, T. and Craib, I. (2011) *Philosophy of Social Science.* 2nd ed. London: palgrave macmillan.

Beresford, B., Moran, N., Sloper, P., Cussworth, L., Mitchell, W., Spiers, G., Weston, K. and Beecham, J. (2013) *Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions.* University of York: Social Policy Research Unit. Available: http://www.york.ac.uk/inst/spru/pubs/pdf/TransASC.pdf [Accessed: 06 November 2021].

Bernard, J., Harvey, V., Potter, D. and Prior, A. (2001) *Ignored or Ineligible? The reality for adults with autistic spectrum disorders.* London: NAS.

Blacher, J., Kraemer, B. R. and Howell, E. J. (2010) Family expectations and transition experiences for young adults with severe disabilities: does syndrome matter? *Advances in Mental Health and Learning Disabilities*, 4(1), pp.3-16.

Blustein, J. (2012) Philosophical and ethical issues in disability. *Journal of Moral Philosophy*, 9, pp.573–587.

Bondy, A. and Frost, L. (1985) *PECS (Picture Exchange Communication System).* Delaware: Pyramid Educational Consultants, Delaware Autism Program.

Bosman, M. and Meijel, B. (2008) Perspectives of mental health professionals and patients on self-injury in psychiatry: a literature review. *Archives of Psychiatric Nursing,* 22, pp.180–189.

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology,* 3, pp.77-101.

Braun, V. and Clarke, V. (2012) Thematic analysis. In: H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf and K. J. Sher, eds. *APA handbook of research methods in psychology, Vol. 2. Research designs: Quantitative, qualitative, neuropsychological, and biological.* American Psychological Association, pp. 57–71.

Braun, V. and Clarke, V (2013) *Successful Qualitative Research: A Practical Guide for Beginners.* Thousand Oaks: Sage Publications.

Braun, V. and Clarke, V. (2014) Thematic analysis. In: T. Teo, ed. *Encyclopaedia of Critical Psychology*, New York: Springer, pp.1947-1952.

Braun, V. and Clarke, V (2019) Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, 11(4), pp.589–597.

Braun, V and Clarke, V (2021) One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*, 18(3), pp.328-352.

Braun, V. and Clarke, V. (2022) *Thematic Analysis: A practical guide*. London: Sage.

Braun, V., Clarke, V. and Hayfield, N. (2019) 'A starting point for your journey, not a map': Nicky Hayfield in conversation with Virginia Braun and Victoria Clarke about thematic analysis. *Qualitative Research in Psychology*, doi: 10.1080/14780887.2019.1670765

Braun, V., Clarke, V. and Weate, P. (2016) Using thematic analysis in sport and exercise research. In B. Smith and A. C. Sparkes eds. Routledge handbook of qualitative research in sport and exercise. London: Routledge pp.191-205.

Brett, J. (2002) The Experience of Disability from the Perspective of Parents of Children with Profound Impairment: is it time for an alternative model of disability? *Disability & Society*, 17(7), pp.825–843.

British Educational Research Association [BERA] (2018) Ethical Guidelines for Educational Research, fourth edition, London.

Browning, J., Osborne, L., and Reed, P. (2009) A qualitative comparison of perceived stress and coping in adolescents with and without autism spectrum disorders as they approach leaving school. *British Journal of Special Education*, 36, pp.36–43.

Bryman, A. (2012) *Social Research Methods*. 4th ed. Oxford: Oxford University Press: Oxford.

Burke, M., Waitz-Kudla, S. N., Rabideau, C., Lounds Taylor, J. and Hodapp, R. M. (2019) Pulling back the curtain: Issues in conducting an intervention study with transition-aged youth with autism spectrum disorder and their families. *Autism*, 23(2), pp.514 – 523.

Butrimaviciute, R. and Grieve, A. (2014) Carers' experiences of being exposed to challenging behaviour in services for autism spectrum disorders. *Autism*, 18(8), pp.882-890.

Byrne, D. (2021) A worked example of Braun and Clarke's approach to reflexive thematic analysis. *Quality and Quantity*. https://doi.org/10.1007/s11135-021-01182-y

Campbell, C.A., Davarya, S. and Elsabbagh, M. (2011) Prevalence and the controversy. In: J.L Matson and P.Sturmey, eds. *International Handbook of Autism and Pervasive Developmental Disorders.* New York: Springer, pp.25–35.

Carter Leno, V., Vitoratou, S., Kent, R., Charman, T., Chandler, S., Jones, C. R. G., Happé, F., Baird, G., Pickles, A. and Simonoff, E. (2019) Exploring the neurocognitive correlates of challenging behaviours in young people with autism spectrum disorder. *Autism*, 23(5), pp.1152–1164.

Case, S.P. (2000) Refocusing on the parent: what are the social issues of concern for parents of disabled children? *Disability & Society*, 15(2), pp.271–292.

Caynes K., Rose T.A., Theodoros D., Burmester D., Ware R.S. and Johnston, L.M. (2019) The Functional Communication Classification System: extended reliability and concurrent validity for children with cerebral palsy aged 5 to 18 years. *Developmental Medicine and Child Neurology*, 61, pp.805–12.

Chandroo, R., Strnadová, I. and Cumming T. M. (2018) A systematic review of the involvement of students with autism spectrum disorder in the transition planning process: voice and empowerment. *Research in Developmental Disabilities*, 83, pp.8-17.

Cheak-Zamora, N. C., Yang, K., Farmer, J. E. and Clark, M. (2012) Disparities in Transition Planning for Youth with Autism Spectrum Disorder. *PEDIATRICS*, 131(3), pp.447-456.

Cheak-Zamora, N. C., and Teti, M. (2015) "You Think It's Hard Now… It Gets Much Harder for Our Children": Youth with Autism and Their Caregiver's Perspectives of Health Care Transition Services. *Autism*: *The International Journal of Research and Practice*, 19(8), pp.992–1001.

Cheak-Zamora, N.C., Teti, M. and First, J. (2015) 'Transitions are Scary for our Kids, and They're Scary for us': Family Member and Youth Perspectives on the Challenges of Transitioning to Adulthood with Autism. *Journal of Applied Research in Intellectual Disabilities*, *28* (6), pp.548-560.

Children and Families Act (2014) Available: https://www.legislation.gov.uk/ukpga/2014/6/contents/enacted [Accessed: 28 November 2021].

Children (Scotland) Act (1995) Available: https://www.legislation.gov.uk/ukpga/1995/36/contents [Accessed: 28 November 2021].

Christie, C. (2011) *Christie Commission on the future delivery of Public Services*. Edinburgh: Scottish Government. Available: https://www.gov.scot/publications/commission-future-delivery-public-services/pages/4/ [Accessed: 06 November 2021].

Clarke, V. and Braun, V. (2016) Thematic Analysis. In: E. Lyons and A. Coyle, eds. *Analysing Qualitative Data in Psychology*, 2nd ed., pp. 84–103. London: Sage.

Clarke, S., Sloper, P., Moran, N., Cusworth, L., Franklin, A. and Beecham, J. (2009) Multi-agency transition services: greater collaboration needed to meet the priorities of young disabled

people with complex needs as they move into adulthood. *Journal of Integrated Care*, 19(5), pp.30-40.

Clegg, J., Murphy, E. and Almack, K. (2017) Liberal Individualism and Deluzian Rationality in Intellectual Disability. *Philosophy, Psychiatry and Psychology,* 24(4), pp.359–372.

Cluely, V. (2017) From "Learning disability to intellectual disability" - Perceptions of the increasing use of the term "intellectual disability" in learning disability policy, research and practice.British *Journal of Learning Disability*, November, pp.1-9.

Cluely, V., Fyson, R. and Pilnick A. (2020) Theorising disability: a practical and representative ontology of learning disability. *Disability & Society*, 35(2), pp.235-257.

Codd, J. (2018) *The experiences of parents who have a child with an intellectual disability.* PhD, University of Oxford. Available: https://ora.ox.ac.uk/objects/uuid:a82af99b-3c2a-4b42-bb52-6e7fe6060f69 [Accessed: 06 November 2021].

Codd, J. and Hewitt, O. (2020) Having a son or daughter with an intellectual disability transition to adulthood: A parental perspective. *British Journal of Learning Disabilities*, 49(1), pp.1-13.

Cohen, L., Manion, L. and Morrison, K. (2011) *Research Methods in Education.* 7th ed. London: Routledge.

Corby, D., Taggart, L. and Cousins, W. (2015) People with intellectual disability and human science research: A systematic review of phenomenological studies using interviews for data collection. *Research in Developmental Disabilities,* 47, pp.451 – 465.

Crane, L., Davies, J., Fritz, A., O'Brien, S., Worsley, A., Ashworth, M. and Remington, A. (2021) The transition to adulthood for autistic young people with additional learning needs: the views and experiences of education professionals in special schools. *British Journal of Special Education*, 0(0), pp.1-24.

Dale, N. (1996) *Working with Families of Children with Special Needs: partnership and practice.* London: Routledge.

Daly, J. (2008) *I exist: the message from adults with autism in Scotland.* Glasgow: National Autistic Society Scotland.

Degener T. (2017) A New Human Rights Model of Disability. In: V. Della Fina, R. Cera, G. Palmisano, eds. *The United Nations Convention on the Rights of Persons with Disabilities.* Cham: Springer, pp.41-59. Available: https://doi.org/10.1007/978-3-319-43790-3_2 [Accessed: 07 November 2021].

Denscombe, M. (2017) *The Good Research Guide*. 6th ed. London: Open University Press.

Department for Education England (2011) *Support and aspiration: A new approach to special educational needs and disability, A consultation*. London: The Stationery Office Ltd. Available:http://www.educationengland.org.uk/documents/pdfs/2011-green-paper-sen.pdf. [Accessed: 07 November 2021].

Dickson-Swift, V., James, E. L. and Liamputtong, P. (2008) *Undertaking Sensitive Research: Managing Boundaries, Emotions and Risks*. Cambridge: Cambridge University Press.

Doran, P. (2012) *The Doran Review: The Right Help at the right time in the right place. Strategic Review of Learning Provision for Children and Young People with Complex Additional Support Needs*. Scottish Government. Available: https://dera.ioe.ac.uk/15988/1/00408307.pdf [Accessed: 28 November 2021].

Disabled People's International (1982) Constitution of Disabled People's International, preamble. Available: http://dpi.org/document/documents-of-reference/dpi-constitutionen.pdf [Accessed: 15 August 2021].

Dunsmuir, S., Cline, T., Crafter, S. and Lang, J. (2019) Challenges in planning transition to adulthood for young people who have special educational needs and disabilities: professional and managerial perspectives. *Journal of Research in Special Educational Needs*, 20(1), pp.27–37. Available: https://doi.org/10.1111/1471-3802.12459 [Accessed: 07 November 2021].

Duperouzel, H. and Fish, R. (2010) Hurting no-one else's body but your own: People with intellectual disability who self injure in a forensic service. *Journal of Applied Research in Intellectual Disabilities*, 23(6), pp.606-615.

Dyson, A. (2001) 'Special needs as the way to equity: an alternative approach?'. *Support for Learning*, 16(3), pp.99-104.

Edelson, S. (2011) Understanding and Treating Self-Injurious Behaviour. *Autism Research Institute*. Available: https://www.autism.org/self-injury/ [Accessed: 07 November 2021].

Education (Additional Support for Learning) (Scotland) Act 2004. Scottish Executive. Available: http://www.gov.scot/Topics/Education/Schools/welfare/ASL [Accessed: 28 November 2021].

Education (Scotland) Act 1980. Available: http://www.legislation.gov.uk/ukpga/1980/44 [Accessed: 07 November 2021].

Education Scotland (2012) *Supporting learners from early years to positive sustained destinations.* Education Scotland. Available:

https://www.education.gov.scot/Documents/supporting-learners-framework.pdf [Accessed: 28 November 2021].

Emerson, E. (2001) *Challenging Behaviour: Analysis and Intervention in People with Severe Intellectual Disabilities.* Cambridge: Cambridge University Press.

Enable Scotland (2016) *#IncluED in the Main?! 22 steps on the journey to inclusion for every pupil who has a learning disability*. North Lanarkshire: Enable Scotland. Available: https://www.enable.org.uk/wp-content/uploads/2017/08/IncludED-in-the-Main-22-Steps-on-the-Journey-to-Inclusion.pdf [Accessed: 28 November 2021].

Enable Scotland (2022) *#MyOwnFrontDoor* North Lanarkshire: Enable Scotland. Available: https://www.enable.org.uk/myownfrontdoor-campaign-launches/ [Accessed: 26 February 2022].

Fayette, R. and Bond, C. (2018a) A qualitative study of specialist schools' processes of eliciting the views of young people with autism spectrum disorders in planning their transition to adulthood. *British Journal of Special Education*, 45(1) pp.5-26.

Fayette, R. and Bond, C. (2018b) A systematic literature review of qualitative research methods for eliciting the views of young people with ASD about their educational experiences. *European Journal of Special Needs Education*, 33(3), pp.349-365.

Flannery, K. and Horner, R. (1994). The relationship between predictability and problem behavior for students with severe disabilities. *Journal of Behavioral Education, 4*, pp.157-176.

Fischer, C. T. (2009) Bracketing in qualitative research: Conceptual and practical matters. Psychotherapy research: *Journal of the Society of Psychotherapy Research*, 19(4-5), pp.583-590.

Fish R. (2000) Working with people who harm themselves in a forensic learning disability service: experiences of direct care staff. *Journal of Learning Disabilities* 4, pp.193–207.

Friedman, N., Warfield, M.E., and Parish, S. (2013) Transition to adulthood for individuals with autism spectrum disorders: current issues and future perspectives. *Neuropsychiatry*, 3(2), pp.181-192.

Gaona, C., Palikara, O. and Castro, S. (2019) 'I'm ready for a new chapter': The voices of young people with autism specrum disorder in transition to post-16 education and employment. *British Educational Research Journal*, 45(2), pp.340-355.

Gentleman, A. (2011) Where's the support for autistic young people? *The Guardian*, 11 October. Available: https://www.theguardian.com/society/2011/oct/11/where-support-autistic-young-people [Accessed: 28 November 2021].

Ghai, A. (2006) Disability in contemporary India. In: G. L. Albrecht, ed. *The Encyclopaedia of Disability*, Sage Publications, pp.437-440.

Ghoshal, S. K. (2018) Concept of Disability – The Dynamic Trend. *International Research Journal of Commerce Arts Science*, 9(4), pp.233-245.

Gillberg C., and Soderstrom H. (2003) Learning disability. *Lancet*, 362 pp.811–821.

Gilmartin, A. and Slevin, E. (2010) Being a member of a self-advocacy group: experiences of intellectually disabled people. *British Journal of Learning Disabilities*, 38 (3), pp.52-59.

Giri, A., Aylott, J., Giri, P., Ferguson-Wormley, S. and Evans, J. (2021) Lived experience and the social model of disability: conflicted and inter-dependent ambitions of people with a learning disability and their family carers. *British Journal of Learning Disability*, 00, pp.1-9.

Girimaji, S., Jayendra, A. and Pradeep, V. (2018) Intellectual disability in international classification of Diseases-11: A developmental perspective. *Indian Journal of Social Psychiatry,* 34(5), pp.68 – 74.

Goodley, D. (2012) Dis/entangling critical disability studies. *Disability and Society*, 28(5), pp.631-644.

Gray, C. (1998) Social Stories and Comic Strip Conversations with Students with Asperger Syndrome and High Functioning Autism. In: E. Schopler, G. Mesibov, and L. Kunce, eds. *Asperger Syndrome or High Functioning Autism?* New York: Plenum Press, pp.167 – 198.

Habermas, J. (1972) *Knowledge and Human Interests* (trans. J. Shapiro). London: Heinemann.

Habermas, J. (1984) *The Theory of Communicative Action. Volume One: Reason and the Rationalization of Society* (trans. T. McCarthy). Boston, MA: Beacon Press.

Haegele, J. A. and Hodge, S. (2016) Disability Discourse: Overview and critiques of the medical and social models. *Quest*, 68(2), pp.193-206.

Haegele, J., Zhu, X. and Davis, S. (2017) Barriers and facilitators of physical education participation for students with disabilities: an exploratory study. *International Journal of Inclusive Education*, 22(2), pp.130-141.

Hall, A. (2019) *Transitions of young people with service and care needs between child and adult services in Scotland.* Edinburgh: Scottish Parliament Information Centre (SPICe). Available: https://digitalpublications.parliament.scot/ResearchBriefings/Report/2019/3/29/Transitions-of-young-people-with-service-and-care-needs-between-child-and-adult-services-in-Scotland [Accessed: 07 November 2021].

Hammersley, M. and Atkinson, P. (1983) *Ethnography: Principles in Practice.* London: Routledge.

Hastings, R. P., and Petalas, M. A. (2014). Self-reported behaviour problems and sibling relationship quality by siblings of children with autism spectrum disorder. *Child: Care, Health and Development*, *40*, pp.833–839.

Hatfield, M., Falkmer, M. and Falkmer, T. (2017) "Leaps of faith": parents' and professionals' viewpoints on preparing adolescents on the autism spectrum for leaving school. *Journal of Research in Special Educational Needs*, 17(3), pp.187–197.

Health and Social Care Alliance Scotland (2017) *Experiences of Transitions to Adult Years and Adult Services.* Edinburgh: Scottish Government.

Hepburn, H. and Belgutay, J. (2012) Still left in the shadows. *Times Educational Supplement Scotland (TES online),* 28 September. Available: https://www.tes.com/news/still-left-shadows [Accessed: 28 nOVEMBER 2021].

Hess, R. S., Molina, A. M. and Kozleski, E. B. (2006) Until somebody hears me: parent voice and advocacy in special educational decision making. *British Journal of Special Education,* 33(3), pp.148-157.

Hewitt, L. E. (2011) 'Perspectives on support needs of individuals with autism spectrum disorders: transition into college'. *Topics in Language Disorders*, 31, pp.273–285.

HMIe (2006) *Missing Out: A report on children at risk of missing out on educational opportunities.* Livingston: Her Majesty's Inspectorate of Education.

HMIe (2013) *Count Us In: Success for All.* Livingston: Her Majesty's Inspectorate of Education.

Holmes, L. G., Kirby, A. V., Strassberg, D. S. and Himle, M. B (2018) Parent Expectations and Preparatory Activities as Adolescents with ASD Transition to Adulthood. *Journal of Autism and Developmental Disorders*, 48, pp.2925-2937.

Howe, K. R. and Moses, M. S. (1999) Ethics in educational research. *Review of research in education* 24(1), pp.21-59.

Huband, N. and Tantam, D. (1999) Clinical management of women who self wound: a survey of mental health professionals' preferred strategies. *Journal of Mental Health,* 8, pp.473–487.

Hume, K. (2008). Transition Time: Helping Individuals on the Autism Spectrum Move Successfully from One Activity to Another. *The Reporter* 13(2), pp.6-10.

Jacquet Consultancy (2015) *Where next? – Evaluation of the Scottish Transitions forum.* Edinburgh: Jacquet.

Jones, G. (2019) Transition support bill launched. *Third Force News*, 10 October. Available: https://thirdforcenews.org.uk/tfn-news/transition-support-bill-launched [Accessed: 28 November 2021].

Jordan, R. (2001) *Autism with Severe Learning Difficulties*. Guernsey: Souvenir Press.

Kayess, R. and French, P. (2008) Out of Darkness into Light: Introducing the United Nations Convention on the Rights of Persons with Disabilities. *Human Rights Law Review* 1, pp.1-34.

Kelly, P. (2010) *Towards an Autism Strategy for Scotland*. Edinburgh: Scottish Government.

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C. and Pelicano, E. (2016) Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), pp.442-462.

Kern, J. K., Trivedi, M. H., Garver, C. R., Grannemann, B. D., Andrews, A. A., Savla, J. S., Johnson, D. G., Mehta, J. A. and Schroeder, J. L. (2006) The pattern of sensory processing in autism. *Autism: The International Journal of Research and Practice*, 10(5), pp.480-494.

Kirova, A. (2002) When a child feels left alone. In M. van Manen, M. Ed. *Writing in the dark: Phenomenological studies in interpretive inquiry*. London, ON: Althouse, pp.155-167.

Krejcie, R. V. and Morgan, D. W. (1970) Determining sample size for research activities. *Educational and Psychological Measurement*, 30(3), pp.607–610.

Kumar, R. (1999) *Research Methodology. A step-by-step guide for beginners* London: Sage.

Kuo, A.A., Crapnell, T., Lau, L., Anderson, K.A. and Shattuck, P. (2018) Stakeholder Perspectives on Research and Practice in Autism and Transition. *Pediatrics*, 141(4), pp.293-299.

Langan, M. (2011) Parental voices and controversies in autism. *Disability and Society*, 26(2), pp.193–205.

Lawson, A. and Beckett, A.E. (2020) The social and human rights models of disability: towards a complementarity thesis. *The International Journal of Human Rights,* 25(2)*, pp.348-379.* Available: https://doi.org/10.1080/13642987.2020.1783533 [Accessed: 07 November 2021].

Leithwood, K., Jantzi, D., Earl, L., Watson, N., Levin, B. and Fullan, M. (2004) Strategic leadership for large-scale reform: the case of England's national literacy and numeracy strategy. *School Leadership and Management*, 24(1), pp.57-79. Available: https://doi.org/10.1080/1363243042000172822 [Accessed: 28 November 2021].

Liamputtong, P. (2007) *Researching the Vulnerable*. London, Thousand Oaks, New Delhi: Sage.

Longtin, S. (2014) Practice Brief: Interdisciplinary Support Services for Students with Autism Spectrum Disorders. *Journal of Post-Secondary Education and Disability*, 27(3), pp.333-342.

Loyd, D. (2013) Obtaining Consent from Young People with Autism to Participate in Research. *British Journal of Learning Disabilities,* 41(2), pp.133–140.

MacDonald, A. (2018) *Coming Home: A report on out-of-area placements and delayed discharge for people with learning difficulties and complex needs*. Edinburgh: Scottish Government. Available: https://www.gov.scot/publications/coming-home-complex-care-needs-out-area-placements-report-2018/pages/5/ [Accessed: 28 November 2021].

MacKay, T., Knapp, M., Boyle, J.M., Iemmi, V., Connolly, M., and Rehill, A. (2018) *The microsegmentation of the autism spectrum: Economic and research implications for Scotland*. Edinburgh: The Scottish Government.

Madders, T. (2010) *You Need to Know*. Bexleyheath: The National Autistic Society, Marstan Press.

Martin, K., Hart, R., White, R., Sharp, C. (2011) *Young People with Special Educational Needs/Learning Difficulties and Disabilities: Research into planning for adult life and services*. LG Group Research Report. Slough: NFER.

Mann, C. (2002) Generating data online: ethical concerns and challenges for the C21 researcher. Keynote lecture, *Nordic Conference on Internet Research Ethics*. Trondheim, Norway June 1-2, 2002.

Mason, J. (2006) Mixing methods in a qualitatively driven way. *Qualitative Research* 2006(6) pp.9-25.

Maunder, R. and Crafter, S. (2012) Understanding transitions using a socio cultural framework. *Educational and Child Psychology*, 29, pp.10-18.

McCartney, E. and Muir, M. (2017) School leavers with learning disabilities moving from child to adult Speech and Language Therapy (SLT) teams: SLT s' views of successful and less successful transition co-working practices. *Journal of Research in Special Educational Needs*, 17(3), pp.168–178.

McNeill, A. (2018) Couple's care plea over autistic son. *The Stirling Observer*, 10 January. Available: https://www.pressreader.com/uk/stirling-observer/20180110/281513636548965 [Accessed: 28 November 2021].

McNeish D, and Newman T. (2002) Involving children and young people in decision making. In: *What Works for Children*? D. McNeish, T. Newman and H. Roberts, eds. Buckingham: Open University Press.

Medina, A. C., Sogbe, R., Gomez-Rey, A. M. and Mata, M. (2003) Factitial oral lesions in an autistic paediatric patient. *International Journal of Paediatric Dentistry*, 13, pp.130–137.

Meiring, M., Seabi, J., Amod, Z., Vorster, A. and Kern, A. (2016) Transition for Adolescents with Autism Spectrum Disorder: South African Parent and Professional Perspectives. *Frontiers in Psychiatry*, 7(93), pp.1-6.

Mental Health Act (1983) Available: Mental Health Act 1983 (legislation.gov.uk) [Accessed: 09 June 2021].

Mental Welfare Commission for Scotland (2019) *Person centred care plans: Good practice guide*. Edinburgh: Mental Welfare Commission for Scotland.

Mesibov, G., Shea, V., and Schopler, E. (2005). *The TEACCH® approach to autism spectrum disorders.* New York, NY: Plenum Publisher.

Mitra, S. (2006) The Capability Approach and Disability. *Journal of Disability in Policy Studies,* 16(4), pp.236-247.

Mitra, S. (2017) The Human Development Model of Disability, Health and Wellbeing. In: S. Mitra, ed. *Disability, Health and Human development*. London: Palgrave, pp.9-32.

Moon, J. (2018) Reviews of Social Embodiment for Design of Non-Player Characters in Virtual Reality-Based Social Skill Training for Autistic Children. *Multimodal Technologies and Interaction,* 2(3), 53.

Morgan, A. (2020) *Review of additional support for learning implementation: report*. Edinburgh: Scottish Government. Available: https://www.gov.scot/publications/review-additional-support-learning-implementation/ [Accessed: 28 November 2021].

Murphy, J. and Mackay, M. (2015). *Will anyone listen to us? What matters to young people with complex and exceptional health needs and their families during health transitions*. Edinburgh: CEN. Available: https://www.talkingmats.com/wp-content/uploads/2015/11/20151027-CEN-report.pdf [Accessed: 28 November 2021].

National Autistic Society (2021a) Available: https://www.autism.org.uk/ [Accessed: 07 November 2021].

National Autistic Society (2021b) *SPELL (Structure, Positive, Empathy, Low arousal, Links).* Available:https://www.autism.org.uk/advice-and-guidance/topics/strategies-and-interventions/strategies-and-interventions/spell [Accessed: 28 November 2021].

Neely-Barnes, S. L. and Dia, D.A. (2014) Families of children with disabilities: A review of literature and recommendations for interventions. *Journal of Early and Intensive Behavior Intervention*, 5(3), pp.93-107.

Newbutt, N., Bradley, R. and Conley, I. Using Virtual Reality Head-Mounted Displays in Schools with Autistic Children: Views, Experiences, and Future Directions. *Cyberpsychology, Behavior and Social Networking*, 23(1), pp.23-33.

Noonan, H., O' Donoghue, I. and Wilson, C. (2018) Engaging with and navigating limbo: Lived experiences of siblings of adults with autism spectrum disorders. *Journal of Applied Research in Intellectual Disabilities,* 31, pp.1144-1153.

Nuske, H.J., McGhee Hassrick, E., Bronstein, B., Hauptman, L., Aponte, C., Levato, L., Stahmer, A., Mandell, D.S., Mundy, P., Kasari, C. and Smith, T. (2018) Broken bridges- new school transitions for students with autism spectrum disorder: A systematic review on difficulties and strategies for success. *Autism*, 23(2), pp.306-325.

Oliver, M. (1996) Defining Impairment and Disability: Issues at Stake. In: C. Barnes and G. Mercer, eds. *Exploring the Divide.* Leeds: Disability Press, VII XI X111 pp.39-54.

Osborne, L. A. and Reed, P. (2008) Parents' perceptions of communication with professionals during the diagnosis of autism. *Autism*, 12, pp.259–274.

Parahoo K. (2006) *Nursing research principles process and issues.* 2nd ed. Hampshire: Palgrave McMillan.

Parsons, S. and Cobb, S. (2011) State-of-the-art virtual reality technologies for children on the autism spectrum. *European Journal of Special Needs Education,* 26(3), pp.355-366.

Parsons, S. and Mitchell, P. (2002) The potential of virtual reality in social skills training for people with autistic spectrum disorders. *Journal of Intellectual Disability Research*, 46(5), pp.430–443.

Phothongsunan, S. (2010) Interpretive paradigm in educational research. *Galaxy: The IELE Journal,* 2(1), pp.1-4.

Pirrie, A. (2008) Through a Glass, Darkly: Reflections on the 'Presumption of Mainstreaming' in Scottish Education. *Scottish Affairs* 62(winter), pp.63-79.

Pirrie, A. and Head, G. (2007) Martians in the Playground: Researching Special Educational Needs. Oxford Review of Education, 33(1), pp.19 -31.

Pirrie, A., Head, G. and Brna, P. (2005) *Mainstreaming Pupils with Special Educational Needs: an evaluation.* Edinburgh: Scottish Executive. Available: https://dera.ioe.ac.uk/5907/1/0021334.pdf [Accessed: 28 November 2021].

Preece, D., and Jordan, R. (2010) Obtaining the Views of Children and Young People with Autism Spectrum Disorders About Their Experience of Daily Life and Social Care Support. *British Journal of Learning Disabilities,* 38(1), pp.10–20.

Public Health Institute for Scotland (PHIS) (2001) *Autistic Spectrum Disorders – Needs Assessment Report.* Edinburgh: NHS Scotland.

Qazi, S. and Raza, K. (2019) Towards a VIREAL Platform: Virtual Reality in Cognitive and Behavioural Training for Autistic Individuals. *Advanced Computational Intelligence Techniques for Virtual Reality in Healthcare,* 875, pp.25-47.

Quinn, G., and Degener, T. (2002) *Human rights and disability: The current use and future potential of United Nations human rights instruments in the context of disability.* Geneva, Office of the High Commission for Human Rights.

Rankin J. and Regan S. (2004) *Meeting Complex Needs: The Future of Social Care.* London: Turning Points/ Institute of Public Policy Research (IPPR).

Reid, B. (2007) *Moving on Up? Negotiating the Transition to Adulthood for Young People with Autism.* London: National Autistic Society.

Research Autism (2019) Available: https://www.autism.org.uk/directory/r/research-autism [Accessed: 08 November 2021].

Rice, C. E. and Lee, L-C. (2017) Expanding the global reach of research in autism. *Autism*, 21(5), pp.515 – 517.

Rice, K.M. and Bellin, M.H. (2009) Review of Voices from the Spectrum: Parents, Grandparents, Siblings, People with Autism, and Professionals Share Their Wisdom, by C. N. Ariel and R. A. Naseef, eds. *Social Work in Health Care*, 48(5), pp.555-557.

Riddell, S. (2019) Additional Support Needs and the use of Co-ordinated Support Plans in Scotland. *Centre for Research in Education Inclusion and Diversity (CREID),* [Blog], 16 January.Available:https://www.ed.ac.uk/education/rke/centres-

groups/creid/projects/autonomy-rights-sen-asn-children/project-blogs/riddell-blog-csp
[Accessed: 20 September 2021].

Riddell, S. and Weedon, E. (2010) Reforming special education in Scotland: tensions between discourses of professionalism and rights. *Cambridge Journal of Education*, 40(2), pp.113-130.

Rioux, M. and Carbert, A. (2003) Human Rights and Disability: The International Context. *Journal on Developmental Disabilities*, 10(2), pp.1-14.

Ritchie, P., Sanderson, H., Kilbane, J. and Routledge, M. (2003) *People, plans and practicalities: achieving change through person centred planning.* Edinburgh: Scottish Human Services Trust.

Roncaglia, I. (2012) Working With Individuals on the Autistic Spectrum Disorder: Training and Support for Staff Practitioner. *Psychological Thought*, 5(1), pp.60-68.

Rosengard, A., Lang, I., Ridley, J. and Hunter, S. (2007) *A Literature review on Multiple and Complex needs: Closing the Opportunity Gap Approach: Multiple and Complex Needs.* Edinburgh: Scottish Executive.

Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists (2007) *Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices*. College Report. CR144. London: Royal College of Psychiatrists. Available: https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr144.pdf?sfvrsn=73e437e8_2 [Accessed: 28 November 2021].

Russo, J. and Wooley, S. (2020) The Implementation of the Convention on the Rights of Persons with Disabilities: More Than Just Another Reform of Psychiatry. *Health & Human Rights: An International Journal*, 22(1), pp.151-161.

Ryan, G. W., and Bernard, H.R. (2000). Data Management and analysis methods. In: N. K. Denzin and Y. S. Lincoln, eds. *Handbook of Qualitative Research* 2nd ed. Thousand Oaks, CA: Sage, pp.769 – 802.

Rydzewska, E (2012) Destination unknown? Transition to adulthood for children with autism spectrum disorders. *British Journal of Special Education*, 39(2), pp.87–93.

Saaltink, R., MacKinnon, G., Owen, F. and Tardif-Williams, C. (2012) Protection, participation and protection through participation: young people with intellectual disabilities and decision making in the family context. *Journal of intellectual Disability*, 56(11), pp.1076-1086.

Salman, S. (2019) Simon Baron-Cohen: Neurodiversity is the next frontier. But we're failing autistic people. *The Guardian*, 02 October. Available: https://www.theguardian.com/society/2019/oct/02/simon-baron-cohen-autism-neurodiversity-brains-money [Accessed: 28 November 2021].

Schultz, S. E., and Stevenson, R. A. (2020) sensitivity and sensory reactivity in relation to restricted interests and repetitive behaviours. *Autism*, 24(1) pp.121–134.

Schutz, A. (1962) *The Problem of Social Reality: Collected Papers I*. The Hague: Martinus Nijhoff.
Schutz, A. (1964) *Studies in Social Theory: Collected Papers II.* The Hague: Martinus Nijhoff.

Scottish Executive (2000a) *The same as you?* Available: *https://lx.iriss.org.uk/sites/default/files/resources/The%20same%20as%20you.pdf* Edinburgh: Scottish Executive. Available: [Accessed: 28 November 2021].

Scottish Executive (2000b) *Standards in Scotland's Schools etc. Act 2000*. Scottish Executive. Available: http://www.legislation.gov.uk/asp/2000/6/pdfs/asp_20000006_en.pdf [Accessed: 28 November 2021].

Scottish Executive (2002) *Guidance on presumption of mainstream education. Circular No 3/2002*. Scottish Executive. Available:

https://www.gov.scot/binaries/content/documents/govscot/publications/advice-and-guidance/2018/07/standards-in-scotlands-schools-etc-act-2000-presumption-of-mainstreaming/documents/standards-scotlands-schools-etc-act-2000-guidance-presumption-mainstream-education-pdf/standards-scotlands-schools-etc-act-2000-guidance-presumption-mainstream-education-pdf/govscot%3Adocument/Standards%2Bin%2BScotland%2527s%2BSchools%2Betc%2BAct%2B2000%2B-%2Bguidance%2Bon%2Bpresumption%2Bof%2Bmainstream%2Beducation.pdf [Accessed: 28 November 2021].

Scottish Executive (2003) *A Scottish Executive review of speech and language therapy, physiotherapy and occupational therapy for children and speech and language therapy for adults with learning disabilities and autistic spectrum disorder*. Edinburgh: Scottish Executive. Available: https://www.webarchive.org.uk/wayback/archive/20150220021104/http://www.gov.scot/Publications/2003/08/18065/25750 [Accessed: 28 November 2021].

Scottish Executive (2006a) *Autistic Spectrum Disorders Needs Assessment Report (2001). Scottish Executive report on implementation and next steps*. Edinburgh: Scottish Executive.

Scottish Executive (2006b) *More Choices More Chances: A strategy to reduce the proportion of young people not in education, employment or training in Scotland.* Edinburgh: Scottish Executive. Available: https://www.yumpu.com/en/document/read/44699365/more-choices-more-chances-scottish-government [Accessed: 28 November 2021].

Scottish Government (2008) *Commissioning Services for People on the Autism Spectrum. Policy and practice guidance*. Edinburgh: Scottish Government. Available: https://sid.usal.es/idocs/F8/FDO22179/autism_spectrum.pdf [Accessed: 28 November 2021].

Scottish Government (2010a) *A Guide to Implementing Getting it right for every child: messages from pathfinders and learning partners*. Edinburgh: Scottish Government. Available: https://lx.iriss.org.uk/sites/default/files/resources/GIRFEC.pdf [Accessed: 28 November 2021].

Scottish Government (2010b) *A Working Life for all Disabled People*. Scottish Government. Available: https://www.gov.scot/Publications/2012/11/7084 [Accessed: 07 November 2021].

Scottish Government (2011) *The Scottish Strategy for Autism*. Scottish Government. Available: https://www.gov.scot/publications/scottish-strategy-autism/ [28 November 2021].

Scottish Government (2012a) *Opportunities For All - supporting all young people to participate in post-16 learning, training or work*. Edinburgh: Scottish Government. Available: https://www.gov.scot/publications/opportunities-supporting-young-people-participate-post-16-learning-training-work/ [Accessed: 28 November 2021].

Scottish Government (2012b) *Supporting Children's and Young People's Learning: A report on progress of implementation of the Education (Additional Support for Learning) (Scotland) Act 2004 (As Amended).* Scottish Government. Available:

https://dera.ioe.ac.uk/13902/1/00387992.pdf [Accessed: 28 November 2021].

Scottish Government (2012c) Response to the Doran Review. Available: https://www.gov.scot/publications/meeting-needs-scotlands-children-young-people-complex-additional-support-needs/pages/3/ [Accessed: 07 November 2021].

Scottish Government (2012d) *Post-16 transitions Policy and Practice Framework Supporting all young people to participate in post-16 learning, training or work.* Edinburgh: Scottish Government. Available: https://www.webarchive.org.uk/wayback/archive/20150220023258/http://www.gov.scot/Publications/2012/11/3248/0 [Accessed: 28 November 2021].

Scottish Government (2014) *Children and Young People (Scotland) Act 2014.* Scottish Government. Available: http://www.legislation.gov.uk/asp/2014/8/contents/enacted [Accessed: 28 November 2021].

Scottish Government. (2016a) A Fairer Scotland for Disabled People. Available: https://www.gov.scot/binaries/content/documents/govscot/publications/report/2016/12/fairer-scotland-disabled-people-delivery-plan-2021-united-nations-convention/documents/00510948-pdf/00510948-pdf/govscot%3Adocument [Accessed: 07 November 2021].

Scottish Government (2016b) National Improvement Framework. Available: National Improvement Framework for Scottish Education - 2016 Evidence Report - gov.scot (www.gov.scot) [Accessed: 10 June 2021].

Scottish Government (2017a) Additional support for learning statutory guidance. Available: Additional support for learning: statutory guidance 2017 - gov.scot (www.gov.scot) [Accessed: 08 June 2021].

Scottish Government (2017b) *The right help at the right time in the right place. Scotland's Ten Year Strategy for the Learning Provision for Children and Young People with Complex Additional Support Needs 2017-2026.* Edinburgh: National Strategic Commissioning Group, Scottish Government. Available: https://www.gov.scot/publications/right-help-right-time-right-place-scotlands-ten-year-strategy-learning-provision-children-young-people-complex-additional-support-needs/ [Accessed: 28 November 2021].

Scottish Government (2017c) *Included, Engaged, Involved Part 2 Preventing and Managing School Exclusions.* Edinburgh: Scottish Government. Available: https://www.gov.scot/publications/included-engaged-involved-part-2-positive-approach-preventing-managing-school/ [Accessed: 28 November 2021].

Scottish Government (2017d) *Getting it right for Every Child (GIRFEC) Policy Update.* Scottish Government. Available:

https://www.webarchive.org.uk/wayback/archive/20180529151707/http://www.gov.scot/Topics/People/Young-People/gettingitright/publications/girfec-policy-update-July-2017 [Accessed: 28 November 2021].

Scottish Government (2018a) *Getting it right for Every Child (GIRFEC).* Edinburgh:Scottish Government. Available: https://www.gov.scot/policies/girfec/ [Accessed: 28 November 2021].

Scottish Government (2018b) *Supporting Disabled Children and their Families*. Edinburgh: Scottish Government. Available: https://consult.gov.scot/children-and-families/supporting-disabled-children/#:~:text=The%20Supporting%20Disabled%20Children%2C%20Young%20People%20and%20their,is%20available%20here.%20Results%20Updated%205%20Jun%202019

[Accessed: 28 November 2021].

Scottish Government (2018c) *The Scottish Strategy for Autism: Outcomes and Priorities 2018 - 2021*. Edinburgh: Scottish Government. Available: https://www.gov.scot/publications/scottish-strategy-autism-outcomes-priorities-2018-2021/ [Accessed: 28 November 2021].

Scottish Government (2019a) *Autism Toolbox*. Edinburgh: Scottish Government, Education Scotland and the National Autism Implementation Team. Available: http://www.autismtoolbox.co.uk/ [Accessed: 28 November 2021].

Scottish Government (2019b) *The right help at the right time in the right place – Scotland's Ten Year Strategy for the Learning Provision for Children and Young People with Complex Additional Support Needs – September 2019*. Edinburgh: Scottish Government. Available: https://www.gov.scot/publications/right-help-right-time-right-place-scotlands-ten-year-strategy-learning-provision-children-young-people-complex-additional-support-needs/documents/ [Accessed: 20 September 2021].

Scottish Government (2020) *Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill.* Edinburgh: Scottish Government. Available: https://www.parliament.scot/bills-and-laws/bills/disabled-children-and-young-people-transitions-to-adulthood-scotland-bill [Accessed: 28 November 2021].

Scottish Government (2021a) *Parentzone website.* Education Scotland. Available: https://education.gov.scot/parentzone/additional-support/how-schools-plan-support/planning-for-transitions/ [Accessed: 09 June 2021].

Scottish Government (2021b) *Independent Review of Adult Social Care in Scotland*. Edinburgh: Scottish Government. Available: https://www.gov.scot/groups/independent-review-of-adult-social-care/ [Accessed: 28 November 2021].

Scottish Government and COSLA (2013) *the keys to life*. Edinburgh: Scottish Government. Available: https://www.gov.scot/binaries/content/documents/govscot/publications/strategy-plan/2013/06/keys-life-improving-quality-life-people-learning-disabilities/documents/keys-life-improving-quality-life-people/keys-life-improving-quality-life-people/govscot%3Adocument/00424389.pdf [Accessed: 28 November 2021].

Scottish Government and CoSLA (2022) *Coming Home Implementation: report from the Working Group on Complex care and Delayed Discharge*. Edinburgh: Scottish Government. Available: https://www.gov.scot/publications/coming-home-implementation-report-working-group-complex-care-delayed-discharge/ [Accessed: 26 February 2022].

Scottish Government Education Committee (2017) *Additional Support Needs, Submission Pack.* Scottish Government: Edinburgh. Available: http://www.parliament.scot/S5_Education/General%20Documents/20170222ESASNSubmissions.pdf [Accessed: 28 November 2021].

Scottish Schools *(Parental Involvement) Act 2006* Available: Scottish Schools (Parental Involvement) Act 2006 (legislation.gov.uk) [Accessed: 10 June 2021].

Shakespeare, T. (1999) *Life as a Disabled Child: a qualitative study of young people's experiences and perspectives*. Leeds: Disability Research Unit.

Shakespeare, T. and Watson, N. (2002) The social model of disability: an outdated ideology? *Research in Social Science and Disability*, 2, pp.9-28.

Shogren, K.A. and Plotner, A. J. (2012) Transition Planning for Students With Intellectual Disability, Autism, or Other Disabilities: Data from the National Longitudinal Transition Study-2. *Intellectual and Developmental Disabilities,* 50(1) pp.16–30.

Smyth, J. (1989) Developing and sustaining critical reflection in teacher education. *Journal of Teacher Education*, 40(2), pp.2-9.

Social Work Scotland (2018) *Integrating Health and Social Care in Scotland: The Impact on Children's Services, Part 1: Literature and policy review.* Available: https://socialworkscotland.org/wp-content/uploads/2018/06/LiteratureReview-IntegratedChildrensServicesinScotland.pdf [Accessed: 28 November 2021].

Sosnowy, C., Silverman, C. and Shattuck, P. (2018) Parents' and young adults' perspectives on transition outcomes for young adults with autism. *Autism*, 22(1) pp.29-39.

Stainton, T. and Clare, I.C.H (2012) Human rights and intellectual disabilities: an emergent theoretical paradigm? *Special Issue: Human Rights and People with Intellectual Disabilities*, 56(11), pp.1011-1013.

Stalker, K and Moscardini, L. (2012) *A critical review and analysis of current research and policy relating to disabled children and young people in Scotland: A report to Scotland's Commissioner for Children and Young People.* Glasgow: University of Strathclyde. Available: https://pure.strath.ac.uk/ws/portalfiles/portal/80861367/Stalker_Moscardini_2012_Critical_review_and_analysis_of_current_research_and_policy.pdf [Accessed: 28 November 2021].

Strauss, A. and Corbin, J. (1998) *Basics of Qualitative Research.* 2nd ed. London: Sage.

Sulek, R., Trembath, D., Paynter, J., Keen, D. and Simpson, K. (2017) Inconsistent staffing and its impact on service delivery in ASD early-intervention *Research in Developmental Disabilities*, 63, pp.18-27.

Swain, J. and French, S. (2008) *Disability on equal terms*. London: Sage.

Sweeney, V. (2016) Complaint over care for severely autistic daughter. *The Inverness Courier*, 17 April. Available: https://www.inverness-courier.co.uk/news/complaint-over-care-for-severely-autistic-daughter-150881/ [Accessed: 28 November 2021].

TCEC (Tobacco Control Evaluation Centre (2020a) *Analysing Qualitative Data.* University of California, Davis: UCDavis. Available: 2018-05-17-TT17-Analyzing_Qualitative_Data.pdf (ucdavis.edu) [Accessed: 28 November 2021].

TCEC (Tobacco Control Evaluation Centre (2020b) *Coding Qualitative Data.* University of California, Davis: UCDavis. Available: CodingQualitativeData_0.pdf (ucdavis.edu)) [Accessed: 28 November 2021].

TEACCH (1971) *TEACCH (Treatment of Autistic and Communication Handicapped Children).* University of North Carolina: TEACCH Autism Program.

Terry, G., Hayfield, N., Clarke, V. and Braun, V. (2017) Thematic Analysis. In: C. Willig and W. Stainton Rogers, eds. *The SAGE Handbook of Qualitative Research in Psychology*. 2nd edition. London: SAGE Publications, pp.17-37.

Tint, A. and Weiss, J. (2016) Family wellbeing of individuals with autism spectrum disorder: A scoping review. *Autism*, 20(3), pp.262-275.

Tong, A., Sainsbury, P., Criag, J. (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal of Quality Health Care*, 19(6), pp.349-357.

Trepagnier, C.G. (1999) Virtual environments for the investigation and rehabilitation of cognitive and perceptual impairments. *NeuroRehabilitation*, 12(1), pp.63–72.

United Nations (1989) *Convention on the Rights of the Child* (UNCRC). New York: United Nations.

United Nations Convention on the Rights of the Child (UNCRC) (1990) Article 23. New York: United Nations.

United Nations (2006) *Convention on the Rights of Persons with Disabilities* (CRPD). New York: United Nations. Available: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html [Accessed: 16 August 2021].

United Nations Education, Scientific and Cultural Organisation (UNESCO) (1994) *The Salamanca Statement and Framework for Action on Special Educational Needs*. Salamanca: UNESCO. Available: http://www.unesco.org/education/pdf/SALAMA_E.PDF? [Accessed: 16 August 2021].

Van den Hoonaard, W. (2008) 'Inter- and intracoder reliability'. In L. M. Given, LM ed. *The Sage Encyclopaedia of Qualitative Research Methods.* Thousand Oaks, CA: Sage Publications Inc, pp.446.

Verdugo, M.A., Navas, P., Gómez, L.E. and Schalock, R.L. (2012) The concept of quality of life and its role in enhancing human rights in the field of intellectual disability. *Special Issue: Human Rights and People with Intellectual Disabilities*, 56(11), pp.1036-1045.

Wagner, M., Newman, L., Cameto, R., Levine, P.and Marder, C. (2007) *Perceptions and Expectations of Youth with Disabilities. A special topic report of findings from the National Longitudinal Transition Study-2 (NLTS2) (NCSER 2007–3006)* Available: http://files.eric.ed.gov/fulltext/ED498185.pdf [Accessed: 16 August 2021].

Waldschmidt, A. (2017) Disability Goes Cultural. In: A. Waldschmidt, H. Berressem and M. Ingwersen, eds. *Culture - Theory – Disability*. Bielefeld: transcript Verlag, 2017, pp.19-28.

Watson, C. (2010) Educational Policy in Scotland: Inclusion and the Control Society. *Discourse Studies in the Cultural Politics of Education*, 31(1), pp.93-104.

Watson, L., Tarpey, M., Alexander, K. and Humphreys, C. (2003) *Supporting People: real change? planning housing and support for marginal groups.* York: Joseph Rowntree Foundation/York Publishing Services.

Who Cares? Scotland (2014) *Care Experienced Young People's Views: Interpreting the Children and Young People Act 2014.* Available:

https://www.whocaresscotland.org/wp-content/uploads/2018/05/Report-Interpreting-the-Children-and-Young-People-Act-2014-care-experienced-young-peoples-views.pdf [Accessed: 16 August 2021].

Who Cares? Scotland (2017) *Continuing Care, Continuing Concerns.* Available: https://www.whocaresscotland.org/wp-content/uploads/2018/05/WCSreport-on-Continuing-Care-Dec-17.pdf [Accessed: 16 August 2021].

Winstone, N., Huntington, C., Goldsack, L., Kyrou, E. and Millward, L. (2014) Eliciting Rich Dialogue Through the Use of Activity-oriented Interviews: Exploring Self-identity in Autistic Young People. *Childhood,* 21(2), pp.190–206.

Witte, D.L. (2002) Remembering the childhood loss of a mother. In M. van Manen, M. Ed. *Writing in the dark: Phenomenological studies in interpretive inquiry.* London, ON: Althouse, pp. 167-178.

Wong, V., McGrew, J. and Ruble, L. (2020) Predicting the Outcomes of Parents of Transition-Age Youth or Young Adults with ASD. *Journal of Autism and Developmental Disorders.* 50, pp.2723–2739.

World Health Organisation (2018) *International classification of functioning, disability and health: children and youth version*: ICF-CY. World Health Organisation.

Zarb, G. (1997) Researching Disabling Barriers. In: C. Barnes and G. Mercer, eds. *Doing Disability Research.* Leeds: The Disability Press, pp.49-66.

Zahavi, D. (2019) *Phenomenology: the basics.* Oxon: Routledge.

Zilli, C., Parsons, S. and Kovshoff, H. (2020) Keys to engagement: A case study exploring the participation of autistic pupils in educational decision-making at school. *British Journal of Educational Psychology*, 90(3), pp.770-789.

Zittoun, T. (2008) Learning through transitions – the role of institutions. European Journal of *Psychology of Education*, 23(165), pp.165-181.

Appendices:

Appendix 1 – 'Scaling tool'

Scoring 1 – 4, relating to the intensity of need:

1   = Low level

2   = Moderate level

3   = High level

4   = Very high level

The majority of young people attending X School would score high or very high on the five areas covered by this scaling tool. It is our experience that where a young person's presentation merits a high or very high score (3 or 4) in more than one of these areas, then consideration for a placement at X School may be appropriate.

	1	2	3	4
AUTISM PROFILE	☐	☐	☐	☐

May include difficulties with communication,

social skills, sharing space, obsessive rituals,

coping with change, sensory stimulation, etc.

BEHAVIOURAL PRESENTATION	☐	☐	☐	☐

May include violence to others, damage to property,

self-injurious behaviour, inappropriate social behaviours,

etc.

HEALTH NEEDS	☐	☐	☐	☐

May include epilepsy, sleep difficulties, restricted diet,

mental health, difficulties accessing health services, etc.

INDEPENDENCE / SELF CARE

☐ ☐ ☐ ☐

May include developmentally young individuals,

in particular difficulties with toileting, bathing,

tolerating support, as well as needing support

to access more mainstream community activities,

work experience, etc.

VULNERABILITY AND RISK

☐ ☐ ☐ ☐

May include risk to self or others, in relation to

behavioural presentation, or need for high levels of staff

support, as well as vulnerability to abuse or exploitation, etc.

Appendix 2 – ethics approval from the University

UNIVERSITY of STIRLING

Bernadette Casey
Faculty of Social Sciences
University Of Stirling
FK9 4LA

General University Ethics Panel (GUEP)
University of Stirling
Stirling
FK9 4LA
Scotland UK

E: GUEP@stir.ac.uk

2 July 2019

Dear Bernadette

Re: Eliciting preferences for risk communication strategies, risk perceptions and consumers' attitudes towards food safety – GUEP 648 R

Thank you for submitting the revisions to your submission of the above to the General University Ethics Panel. The ethical approaches of this project have now been approved by GUEP.

Please note that should any of your proposal change, a further submission (amendment) to GUEP will be necessary.

Please ensure that your research complies with the University of Stirling policy on storage of research data which is available at:
https://www.stir.ac.uk/about/faculties-and-services/information-services-and-library/current-students-and-staff/researchers/research-data/plan-and-design/our-policy/

If you have not already done so, I would also strongly encourage you to complete the Research Integrity training which is available at: https://canvas.stir.ac.uk/enroll/CJ43KW

If you have any further queries, please do not hesitate to contact the Panel by email to guep@stir.ac.uk.

Good luck with your research.

Yours sincerely,
Pp.

Jackie Hamilton

On behalf of GUEP
Professor Catherine Hennessy
Deputy Chair of GUEP

Appendix 3 Introductory letter (parents)

Dear X,

I am ------- of --------- School where your son/daughter attended school. I am contacting you because your son/daughter transitioned from school to Adult Services within the past 6 years. I got your contact details from our records (which is permissible under our privacy statement). I am contacting all parents whose son/daughter had a planned transition from school to Adult Services as I am carrying out some research in this area and I would be very pleased to hear about your and your son/daughter's experience. I would like to invite you to take part in this research. It is entirely voluntary and you do not need to participate if you do not wish to do so. However, I do think that parents' input could improve the transition experience for autistic young people with complex needs.

I am carrying out this research as a part time student at the University of Stirling. It is separate from my role as ---- of the school.

I am enclosing an information sheet which should answer any questions you may have. Please do not hesitate to contact by phone, email or post using the contact details provided if you have any further questions.

If you choose to participate, please return the enclosed consent form in the stamped addressed envelope provided and I will send you a questionnaire. You may, if you wish, get a family member to help fill in the questionnaire. Once I receive your questionnaire responses I may invite you to an interview to answer some further questions based on the information you have given. You do not have to complete a questionnaire or participate in an interview if you do not wish to do so and you may withdraw from the process at any time.

All of this is explained fully in the information sheet.

I look forward to hearing from you.

Yours sincerely, Bernadette Casey (Researcher)

Appendix 4 Parent Questionnaire

Post school transitions for autistic school-leavers with complex needs. **Research questionnaire – questions for parents/guardians about transitions to post school destinations.** **Please answer the questions below to indicate the experience of your son/daughter and your family during transition to post-school destination. Please give as much detail as you wish and use additional paper at the end of the questionnaire if you need to.** **You may ask someone to help you complete the questionnaire if you wish.**	
In which Local Authority do you live?	
Firstly, please describe the place where your son/daughter transitioned to from school. What type of provision was/is this and in what Local Authority area?	
1. **Your inclusion and involvement**	
1.1	How far did you feel included and involved in the transition process for your son/daughter?
1.2	Why did you feel like this?
2. **The transition process**	
2.1	Do you think that the transition process began early enough?
2.2	Please give reason/s for your answer.
3. **The Local Authority**	
3.1	Did you feel that the LA was fully aware of the needs of your son/daughter?
3.2	How would you rate the Local Authority's involvement in the transition process for your son/daughter?

4. **The school your child was leaving**	
4.1	Did you feel that the school was fully aware of the needs of your son/daughter?
4.2	How would you rate the school's involvement in the transition process for your son/daughter?
5. **Availability of placements and information**	
5.1	Was there enough information on possible placements available?
5.2	Were there enough placements available?
5.3	Did you have a choice?
6. **Post school destination**	
6.1	Was your son/daughter offered a post school destination close to your home?
6.2	If not close to home, why not? Was this through choice or because there was no choice?
6.3	What were the important factors that influenced this?
7. **Scottish Government Policy – positive destination**	
7.1	Scottish Government policy refers to "positive, sustained destinations". Did your son/daughter move to a "positive" destination?

7.2	Please explain your answer. What factors made it positive or not positive?
8. **Scottish Government Policy - sustained destination**	
8.1	Scottish Government policy refers to "positive, sustained destinations". Is your son/daughter still in the same "sustained" destination?
.	
8.2	If not, why not? What happened to prompt this move to a different provision?
9.	
9.1	Was the initial transition process an overall positive or negative experience for your son/daughter? Give reasons for your answer.
10. **Evaluate your and your family's experience**	
10.1	Was the initial transition process from school to first post school destination overall a positive or negative experience for you and your family? Give reasons for your answer.
10.2	Did this experience have any additional impact on your family? How would you describe or evaluate that?
11. **Potential improvements**	
11.1	What would have made this transition process a more positive experience?
I	
12. **Subsequent transitions (if applicable)**	
12.1	What about any subsequent transitions? Were these positive or negative experiences for your son/daughter, you and/or your family? Please give reason/s for your answer.
12.2	Is there anything which would have improved this/these experiences overall?

Please use this box to write anything else that you feel is relevant.
Thank you very much for participating in this research. Your time and effort is appreciated and your views are much valued. I will contact you before the end of October if you are invited to participate in the follow up interviews. Many thanks.
Please provide up to date contact details, telephone and email. Many thanks.

Appendix 5 Professional Questionnaire

	Post school transitions for autistic school leavers with complex needs. Please base your answers on planned transitions during the past 6 years (2013 – current)	
1.	How many such transitions took place?	
2.	How many of these transitions were positive? i.e. that a successful transition was made to a positive destination?	
2b.	Please give reasons why these transitions were deemed to be "positive"	
3.	How many of these transitions were not positive? i.e. no transition to a positive destination	
3b.	Please give reasons why these transitions were deemed to be "negative"	
4.	How many (if known) of these young people moved on to another provision from the initial destination?	
4b.	What reasons were there for moving to a new destination?	
5.	Is there any other information you wish to provide that may be useful to the researcher	
Sincere thanks for your time and effort in completing this questionnaire. Your views are much valued. Thank you.		

Appendix 6 Information sheet (parents):

Dear X,

I am contacting you because you are the parent or guardian of a young autistic person with complex needs who transitioned from school to Adult Services within the past 6 years. I am carrying out some research in this area and I would be very pleased to hear about your and your son/daughter's experience.

I am --------- where your son/daughter attended school. I got your contact details from our records which is permissible under our privacy statement. I am contacting all parents whose son/daughter had a planned transition from school to Adult Services. I am carrying out this research as a part time student at the University of Stirling. It is separate from my role as ----- of the school.

I am currently participating in part-time studies at the University of Stirling which will lead to a qualification as Doctor of Education (EdD). The area I am researching is the transition of young autistic people with complex needs to post-school destinations. Scottish Government policy documents consistently refer to "positive, sustained destinations" for school-leavers and "Getting it Right for Every Child" (GIRFEC). GIRFEC is the Scottish Government's approach to supporting children and young people. Achieving "positive, sustained destinations" is a key priority in the Scottish Government's National Improvement Framework (www.gov.scot). I want to find out if your son/daughter's experience matched the language of the policies.

I am inviting you, as the parent or guardian of a young person who experienced transition within the past 6 years, to be a participant in this research by answering questions in writing about your family's experiences of post-school transitions. The process is entirely voluntary. You are not obliged in any way to do this. If you do decide to take part, you can withdraw your participation at any time without needing to explain and without penalty, by advising the researcher of this decision.

I will choose some participants for a follow up interview based on questionnaires. Participants for interview will be chosen in order to obtain a variety of responses and also to gain further detail about relevant experiences. This is likely to be based on either very positive experiences

or very negative experiences, or if you tell me something that I would like to explore further. I will contact you in writing by ----date------ if you are invited for interview and we will arrange a suitable time and place for this to happen. Interviews can take place by phone or Skype or in a place of your choosing. Interviews are likely to last approximately 45 minutes to 1 hour and will be audio recorded. The recordings will be saved and password protected and will be transcribed. Recordings will be referred to by the researcher in the course of the research to clarify what was said or tone of voice or anything that the researcher wishes to confirm, and will not be shared other than with the transcriber. If you are willing to answer the questionnaire and prefer not to participate in an interview please indicate this on the consent form. The interview is entirely voluntary and you are not obliged in any way to participate. You can withdraw from the process at any time without needing to explain and without penalty, by advising the researcher of this decision.

The transcriber will be chosen by the researcher on the advice of the University and will be from a reputable company known to the University. Transcribed interviews will be seen only by the transcriber and the researcher and will be encrypted before being sent from the transcriber to the researcher. All audio recordings will be encrypted before being shared with the transcriber and passwords will be shared separately. The researcher will change both audio and transcriptions passwords on receipt of transcriptions from the transcriber.

There will be no payment or reward for participation but you will be contributing to research and current thinking on these themes and hopefully improving the transition experience for young autistic people in the future.

I want to assure you of confidentiality and guarantee that I will not discuss your comments or answers with anyone else. Information recorded and used in the research will be anonymous and I will not disclose any of your answers to anyone else. Your son/daughter will not be identifiable. All data will be stored electronically as per the University of Stirling Guidelines, password protected and encrypted. Data will be stored, as per University requirements, for ten years in a University of Stirling research archive.

Your time and effort would be appreciated and your views much valued. You would be making an important contribution in this area to improve the experience of autistic young people with complex needs when transitioning from school to Adult Services.

At the end of the project I will provide, on request, a summary of the main findings. This will be anonymised and will not contain any reference to individuals.

This research has been reviewed by the General University Ethics Panel (GUEP), University of Stirling.

In the event of any complaint please contact the Dean of the Faculty, Alison Bowles,

Faculty of Social Science (FoSS)

Iris Murdoch Building

University of Stirling FK9 4LA

If you are interested in participating please return the consent form in the enclosed stamped addressed envelope and I will contact you.

If you have any questions please contact me and I will be happy to answer your questions. Please contact me in one of the following ways:

Telephone: 07---

Email: -----

Post: ------

Sincere thanks for your participation. It is much appreciated.

Appendix 7 Information sheet (professionals)

Dear X,

I am ------- which is a residential school for young autistic people with complex needs. I am contacting you through --------- as we are members of that group which represents residential special schools in Scotland and works to improve outcomes for young people in such settings.

I am currently participating in part-time studies at the University of Stirling which will lead to a qualification as Doctor of Education (EdD). The area I am researching is the transition of young autistic people with complex needs to post-school destinations. Scottish Government policy documents consistently refer to "positive, sustained destinations" for school-leavers and "Getting it Right for Every Child" (GIRFEC). I want to find out if the experience of young people in our schools matches the policy.

I am inviting you, as a senior manager of a residential special school, to be a participant in this research by answering questions in writing about the experience of young people transitioning from your school to Adult Services in the past 6 years. The process is entirely voluntary. You are not obliged in any way to do this. If you do decide to take part, you can withdraw your participation at any time without needing to explain and without penalty, by advising the researcher of this decision

There will be no payment or reward for participation but you will be contributing to research and current thinking on these themes and hopefully improving the transition experience for young autistic people in the future.

I want to assure you of confidentiality and guarantee that I will not discuss your comments or answers with anyone else. Information recorded and used in the research will be anonymous and I will not disclose any of your answers to anyone else. Your school will not be identifiable. All data will be stored electronically as per the University of Stirling Guidelines, password protected and encrypted. Data will be stored, as per University requirements, for ten years in a University of Stirling research archive.

Your time and effort would be appreciated and your views much valued. You would be making an important contribution in this area to improve the experience of autistic young people with complex needs when transitioning from school to Adult Services.

At the end of the project I will provide, on request, a summary of the main findings. This will be anonymised and will not contain any reference to individuals or schools.

This research has been reviewed by the General University Ethics Panel (GUEP), University of Stirling.

In the event of any complaint please contact the Dean of the Faculty, Alison Bowles,

Faculty of Social Science (FoSS)

Iris Murdoch Building

University of Stirling FK9 4LA

If you are interested in participating please email me and I will send you a consent form and the questionnaire. For returning the consent form and questionnaire, I will provide a stamped addressed envelope which is marked "private and confidential" and will be opened by me only.

If you have any questions please contact me and I will be happy to answer your questions. Please contact me in one of the following ways:

Telephone: 07---

Email:----

Post: --------

Sincere thanks for your participation. It is much appreciated.

Appendix 8 Consent (parents)

Experiences of autistic school-leavers with complex needs. Consent form for participants

Consent: Y/N

I confirm that I have read and understood the above information sheet and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary, that I may choose not to answer any question if I feel uncomfortable.	
I understand that my responses will be kept anonymous and entirely confidential and that my data will not be shared with anyone else.	
I am aware that I will not be named in any research outputs and that all reasonable steps will be taken to avoid me and my son/daughter being identified by people I know through the stories I tell.	
I give permission to be quoted anonymously in the research report.	
I give my permission for my data to be anonymised and used in future research.	
I agree to being invited for interview in response to the answers I give.	
If invited for interview, I agree to be audio recorded.	
I agree to take part in this study.	

Name

Date

Appendix 9 Consent (professionals)

Research into transitions of autistic school-leavers with complex needs to post school destinations

Consent form: **Please tick ✔ each box to give your consent or X to disagree**

I confirm that I have read and understood the information sheet and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary, that I may choose not to answer any question if I feel uncomfortable and that I may withdraw from the research at any time without penalty, by informing the researcher.	
I understand that my responses will be anonymised and confidential and that my data will not be shared with anyone else.	
I understand that any paper copy of my questionnaire responses will be opened and read only by the researcher and will be stored securely in a locked cabinet or case and will subsequently be stored according to University regulations.	
I am aware that I will not be named in any research outputs and that all reasonable steps will be taken to avoid me and the school I represent from being identified.	
I give permission to be quoted anonymously in the research report.	
I give my permission for my data to be anonymised and used in future research.	
I agree to my data being stored according to University of Stirling regulations, for ten years in a secure archive.	
I agree to take part in this study.	

Name

Date

Appendix 10 Reminder to parents

28th Oct, 2019

Dear Parent,

Apologies for another reminder. I may have a solution if you wish to complete my questionnaire but have not had time to do so.

I've had a low response rate to the questionnaire and I'm wondering if you would rather speak to me directly about your son/daughter's and your experience of transition to Adult Services, either face to face or by phone. I know that completing a long questionnaire can be time consuming and a chore, so a 'one-off' conversation may be the solution.

I do not want to dwell on what, for some, may be a negative experience and I will treat you and your responses with tact and sensitivity and absolute confidentiality. I am keen to improve outcomes for young autistic people with complex needs and your help with this would be so valued and appreciated.

If you would like to participate in this way rather than completing the questionnaire, you can contact me at the school or by email to ---------- or on my university email b.r.casey@stir.ac.uk or by phone 07442531449. **Please contact me by Sunday 10th November if you wish to take part** and we will agree a convenient time for our conversation.

Your participation would be much appreciated and valued and you would be contributing to improving the outcomes for this cohort of young people.

If I don't hear from you by 10th November, I wish you and your family all the very best in the future.

Yours sincerely,

Bernadette Casey

Appendix 11 Examples of reflexive process

Appendix 11a 31st January 2019 – Researcher's initial thoughts and ideas, with reflections highlighted – excerpts

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Ethics: what is needed?

Introduction to project – I think there is a problem, actually I am sure there is a problem. Need good data. I think their stories will back me up. Look and listen out for the unusual, something that needs to be explored. If invited to interview, I must hear their stories, anything that goes against what I am thinking. Need to be aware and be open to that.

Who?

What questions? Need to ensure questions cover positive and negative.

Background – Some knowledge of circumstances, must be open to broader view.

Relationship – in managerial control of school and pupil transitions…hope that will encourage people to respond. Same relationship with all. May be a barrier for some? Ensure all detail in cover letter.

Approach all and ask all to take part…how many times?

Contact by phone initially, previous addresses (privacy statement and policy)

Methods - Questionnaires, interviews, document review – open questions, allow for follow up

What happened after transition? Search for positive as well as negative

Professionals group – point of transition – get ethics – Questionnaire

2 sets of participants

Questions – indicative questions Manage 7 – 10 interviews invited from questionnaires

Questions for interviews – needed for ethics – why was it successful or otherwise? Moved on… why?

Timing – parents may have much to say – allow an hour and ask if they want to continue. Active listening, no interruptions. I can sometimes jump in if I recognise something or make a connection, so I must try not to do this. Let them talk, it is their story. What if they get upset? There is potential for this. What difference if face to face or Skype? It is easier to comfort in F2F. Skype could be abrupt ending. If so, check in later. Reassure in advance, remind them of the purpose. Allow them to stop at any point.

Transcriptions – verbatim or grammar conventionalised What does research say about types of transcriptions? How to anonymise – check literature. Deleted or kept for a time? Check ethics.

Triangulate between parent and document/ questionnaire and interview.

Willing volunteers – how much 'encouragement is allowed? Check with ethics

Deadline – 15 March

Appendix 11b 24th January 2020 – Reflections on beginning analysis

The slow response rate from both parents and professionals and the worry that there will not be enough data, or enough strong data, still niggles. I know that the interviews will provide at least some of this, the stories were so real, but, now that I am about to begin the analysis, I have a fear that I will discover that I haven't enough and will need to redo or start again. I am kicking myself that I didn't offer interviews from the start. This may have been a better offer for participants. Thinking…what would I prefer to do, interview or questionnaire? Questionnaire sometimes seems the better option, until it is there looming there in front of you, a job to be put off until another time. An interview, there is a time and place and it is done. I will know the next time. For now, I need to make sure that I take time with what I have, revisit, look for the meanings - obvious and those I have to search for… the stories are in there.

Appendix 11c 20th August 2020 – reflections on a parent's words following a reading about "depth of experience that may lie behind the simple words" (Kirova 2002).
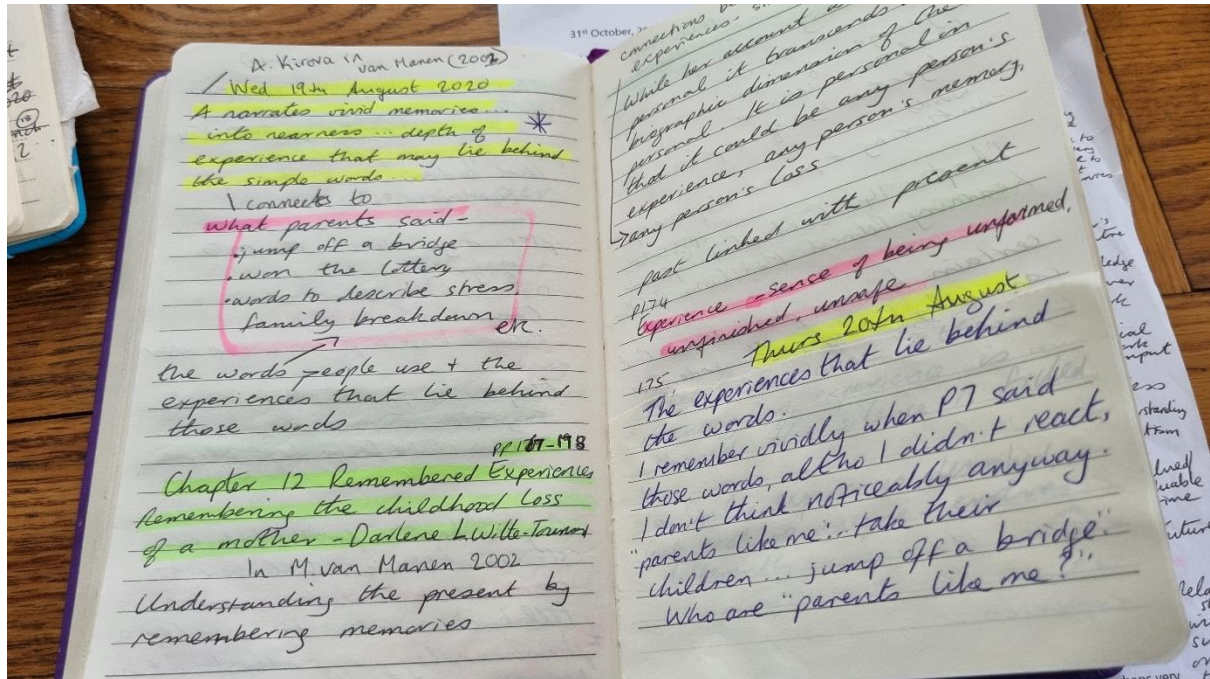
What experiences did I "dredge up"? Who I had "laid to rest"? What emotions must she have had to recall? Was I really a "sensitive researcher"?

I thought I knew + understood parental anxiety. I have always known - at this level - that there is stress associated with the transition process for parents. I have referred to it 'sympathetically'. Now, for P7 + the other parents, the language they used, has opened my eyes to the depth of their pain. Stress now seems almost flippant way to describe.

* Look for the depth of experience that may lie * behind the simple words

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Appendix 12 Analysis phase 2, coding – 2 excerpts (questions 5 and 10)

Questionnaire for parents

Parents put their faith in care delivery — TRUST – broken trust

Parents put their faith in care delivery to meet the needs of the vulnerable person, not the case, seriously disappointed

Seriously disappointed. Let down.

Guardianship

Guardianship

SIB

We recently had our guardianship for ___ replaced for a further 5 years, the sticking point was ___ staff when this happens made a request to the court ___

Questionnaire for parents

Page | 13

Recurring – Staff training (lack of)
Staff scared, hiding, leaving (MESS)
Stress words – meltdown, upset x 3 aggressive
→ Staff unable to cope. One close, caring friendship
Protect. Intervention (SIB)
traumatic (yet positive overall? FOR YP?)

Constant phone calls

12.
Subsequent transitions (if applicable)   Only one transition but subsequent problems.

12.1   What about any subsequent transitions? Were these positive or negative experiences for your son/daughter, you and/or your family? Please give reason/s for your answer.

Prior to transition process
Since ___ moved into ___ own property   Experience of transition was positive   Emotions   traumatic experience (previously said positive)

No one could have prepared us for such a traumatic experience   TRAUMATIC

Problems started within weeks of ___ moving into ___ house, concerned that ___ would be returning to school, self injury +++ aggressing towards staff, constant phone calls asking for ___ to come over to the house to calm ___ down, staff scared of ___, staff member phoned the police, ___ arrived, staff member running out of he house saying: I need to get out of here: ___ left to sort out the mess, other member of staff hiding in a room, ___ calmed ___ very quickly, Self injury damage cleaned by ___, carer did not return for a week — Staff training, This behaviour continued for quite sometime, ___ receiving constant calls, early hours of the morning/late at night

Police

Staffling

because Dad was in the vicinity + willing

Complex needs – SIB behaviour

Neighbours – location

Staff spoke about getting medication to ___ if ___ was upset, what I didn't expect was a member of staff sticking a plastic medication cup to a broom handle so ___ could give ___ medication from a distance, then the staff were told to wear caps so ___ could not access their hair
Staff receive BSS training, main issue is to protect themselves and basically let ___ self harm go on without any intervention, ___ has inflicted quite serious facial injury during these episodes.

Police were called by a concerned neighbour at 3am one morning, loud screams heard coming from the house, ___ was in a major meltdown, the carer, male, and ___ had a very close and caring friendship, carer had no idea the police had been contacted until the flashing blue lights appeared, ___ had begun to settle prior to their arrival, all settled, no police action required, further episode requiring police attendance a few weeks later, I arrived before them, other parent there, upset, carers upset, ___ in a very aggressive state, ___ calmed ___ down, police were very good, reassuring everyone that ___ was now calm and with ___, again no police action required

Questionnaire for parents
B Casey June 2019

Staff scared, running, hiding, upset
Parent upset, clean
self injury damage
Screams   police
YP major meltdown aggressive.

Emotions
IMPACT

traumatic experience (previously said positive)
Police ?
Staff lacking confidence
Medication
Police x 2
Staff emotions/ training

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Transition 6 (school had ... ...)

domestic stuff
ie. happening in the house

R: We had food in the house that was out of date...the sort of domestic stuff ~ LA responsibility
actually but there were huge problems with the building
... responsibility. But the staffing issues

Questionnaire for parents

P1, P3 also mention importance of good social worker.

Each one has a set of individual / unique circumstances — Circumstances

2. The transition process	TIMESCALE — longer due to

2.1	Do you think that the transition process began early enough?

Timescale

No. This was probably due to (Circumstances.) Timescale
Social Worker became ill and the — Why could someone else not take over? Social work input
transition process was delayed for six months
We did not have a problem with this as — and — health
always fought valiantly for — and — health — delay — challenges with sanisation
had to take precedence. The S.W. dealing with — Error
the Guardianship for the courts made a mistake Guardianship

fighting language
sw input strong

2.2	Please give reason/s for your answer.

Timing

Language

Took time to realise the mistake Why?

with the paperwork for the court so this had
to be sorted out. Once the paperwork
was resubmitted to the court again we — Guardianship
were granted Guardianship and the
transition could take place. The S.W. — Social worker — overwork
cited overwork as the reason for the
mistake for the paperwork. This added at
least 3 months onto the transition process.

So there was at least 9 months added
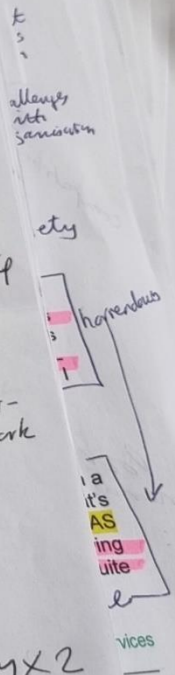onto the transition process.

harrendous

S.W. – overwork. Others mention high
case loads – implication – cannot
spend the time needed.
2 S.Ws here – 1 "fought valiantly" – became ill
Language sw health had to take precedence – no one to
take over? Guardianship sw – mistake. overwork.
halo effect? Process stopped – no one to
take over? Guardianship sw – mistake. overwork.

Delay x 2

Appendix 13 Analysis phases 3 and 4, generating and reviewing themes (extracts)

Post school transitions for autistic school-leavers with complex needs.
Research questionnaire – questions for parents/guardians about transitions to post school destinations.

Analysis - combined answers -all parents

Overview:
1. Positive transition process, appropriate destination (parent's view, in authority) but major challenges and problems subsequently
2. positive overall, both process and destination
Delay in Guardianship led to delay in transition but they knew yp coming home and so were able to tolerate this
3. Overall positive transition process (would have been better if started earlier) and positive destination for yp, but not without challenges including for family
4. Positive transition process and positive destination with some challenges. Strong parental voice here, based on knowledge and experience through own employment
5. Suggests positive overall but problems, so is this an appropriate destination? Challenge of rural authority – can stay at home for up to 7 days at a time - any inclusion in the community is limited or non existent – is this a positive outcome?
6. good transition process, poor destination, "horrendous". LA took over care provision and there was an improvement "superb". 1 destination, change of provider (potential to compare with parent 8 whose child attended same provision at one point, but moved on to new provider)
7. Overall negative. 8 transitions planned. Several failed transitions, returned to school, others stopped, transitioned to provision, failure , new provider took over, some improvement but moved to new service. Many challenges en route but now in positive destination. Cannot remain in this house, will have to move but provider will stay the same.
Compare negative language with positive
Lots of detail – relevant quotes
Series of poor transitions and series of negative and un-sustained destinations

In which Local Authority do you live? Six LAs represented	
5. **Availability of placements and information**	
5.1	Was there enough information on possible placements available?	
1.Only 1 option - tenancy SW input very good	Choice of placements – no choice, 1 option

		SW input important
2. Yes		
3.In hands of LA		Funding Finding appropriate accommodation
4.Parent says NA. Required commissioned bespoke service		Bespoke – parent can drive the process
5.No		Contradicts 1.2?
6. Definite lack of resources I worried that we didn't know what places were available but at the same time neither did the council		Luck/chance – something turning up at the right time Privileged to have been able to get young person into school Positivity about school
7.No		
5.2	Were there enough placements available?	
1.No		No choice
2. Yes		
3.No		
4. As above 5.No		Bespoke is needed
6. LA came to us when they had decided on destination – they picked one, yp would be a good candidate for it Had to wait while modifications were done – school aren't going to shove them out with nowhere to go sort of thing		Variation – LA required more time Reliance on goodwill of school Trust
7.No, a series of unsuitable transitions, not properly planned		
5.3	Did you have a choice?	
1.No		

2. Yes	
3. There was one option, so no choice, but it had to be right I insisted	Parent voice – parent ability in shaping the process, or driving it forward (also P4)
5. Limited – either adult service of school or back home – is this a choice?	Is this a choice? Appropriate or convenient (Parent 5, availability versus suitability)
6.That was the only one	No choice
	P 26 – there was nothing up here
7. No, as 5.2 That's why it took us so long p 26	The choice was practically non existent Luck, what was available (P4, P6 said this) Shocked by lack of opportunity p 27 Funding Cost Care sector staff – remuneration, retention p 27/28 Pay and conditions p 28 Complexity "…particularly the higher up the spectrum you go…"

From parents

- Lack of availability of choice – sometimes it is what happens to be available in the LA, not needs-led
- When is a choice not a choice?
- Proximity to home is an important factor
- Luck/chance often plays a part, being in the right place at the right time, for example when a space in a house becomes available
- Tension in relationships between parents and LAs/ Lack of trust in authority
- Perception among some that finances are more important than finding appropriate provision.
- Parent voice – knowledge is power – parents can shape the process if they know how or have the confidence to speak up. Parents sometimes feel that they have to take whatever is available, others fight for more.

From professionals

- Lack of appropriate post school provision – available services that the young person is made to fit rather than personalised to meet individual needs
- Lack of understanding by the new service provider of complex needs and levels of support required
- Adult services have less money available so there is a significant drop in level of support provided between children's and adult services

10. **Evaluate your and your family's experience**		
10.1	Was the initial transition process from school to first post school destination overall a positive or negative experience for you and your family? Give reasons for your answer.	
1.Positive 2.Positive 3. Positive for yp but an exhausting and emotional roller coaster for family 4. Very positive outcome, home 5.Positive 6.Positive 7.Negative for all reasons above		Family stress – emotional Rollercoaster Proximity to home is influencing factor
10.2	Did this experience have any additional impact on your family? How would you describe or evaluate that?	
1.Subsequent change Staff unable to deal with challenge Phone calls to parents Challenging behaviours Arguments – family Increased stress		Increased stress for family – negative impact on family (see 12.1 and follow up interview for more detail) Emotional impact Staffing – challenges and challenged

	Complex needs – challenging behaviours Negative emotions – stress for family and staff– language used
2. YP coming home, we were delighted	Returning to family and community
	Stress Bereavement Struggles Issues with fuel bills – significant (unusual circumstances)
4. Intense and time consuming Stressful Deterioration in health 1:1 family time	Emotions Stress Funding Support – 24/7 Parent health Parent contribution to support package Family time, holidays, relaxed (Can go on holiday with family. Less complex than some?) Routine
5. Happy to have yp home – visit yp and yp visits	Family visits Proximity to home
6. See p 9 for negative effects – couldn't sleep etc Positive - Importance of routine Complex needs	Compare positive and negative experiences p 9 Parent didn't describe specific incidents, but language emphasises negative experience Proximity to home Family Social opportunities Routine

7. Detailed information provided on negative impact Horrendous, horrendous situation Flaws desperation P 21 blackmail I thought we'd hit the jackpot Optimistic – new start fresh start – transition from within an organisation Battle Desperate Shambles Challenge Unresolved Horrendous Disgusted Awful Distraught Most horrendous Sacrifice Collapsed Denial Impossibility Survival mode Exhausted Unforgiveable	P 19 "I categorically understand why parents like me take their children and jump off a bridge…there is no future forthem…how could I leave them to end up in a place that we were talking about was on the telly, locked up in a cell, you know". Parent voice p 21 I am outspoken and people get offended by that, you know….I can't be worried about how you feel about me…if anything, it (strong voice) can add to the pressure P22 it can often kick back on you because people don't want to hear it Fight for my kid

From parents

- As 9.1, even with subsequent problems, parents may view the overall process as positive if there is ultimately a positive, or mainly positive outcome for the young person.
- Having the young person close to home is important for most.
- Can be exhausting and an emotional roller coaster for family – language used to describe this.
- When things go wrong for the yp in their placement, it can have a devastating impact on parents and family – language used to describe this, stark

From professionals

- High levels of stress and anxiety for families and carers due to break downs in communication and lack of opportunity and/or appropriate care and support for their child
  - Impact on the relationships among those involved (parent/ authority/ providers) – strained
- Parent voice is only effective when there is knowledge; organisations prefer parents to be submissive

Appendix 14 P7 redacted transcript

I: …and if you can just confirm your consent for having the conversation recorded.

R: Yes, I confirm the consent.

I: Okay. Thanks very much for taking part, P7, I really appreciate it,

R: Oh, you're welcome.

I: Okay, that's fine. I'm going to obviously record the conversation but I'll type some bits of it, …So we'll go through the questionnaire and if there are any other things that you want to add as we go along just, you know, do that wherever you feel that you want to do it, okay.

R: Okay.

I: So which LA do you live in again, P7?

R: It's…well, YP7 lives in --- LA.

I: Okay. So with YP7's first transition from school where did they go to and just tell me a wee bit about that.

R: Well, the first one that actually took place…I think it was in about 2012 – my timeline might be a wee bit out…

I: That's okay.

R: Before that there actually was a suggested move that…the LA took me into a meeting and told me that they were leaving X school and moving. I had no concept of that at all; it was a straight off the cuff news to me. I was really very angry about it actually.

I: Yeah.

R: So it ended up that that didn't take place. So it was about a year later, I think, that a place was identified for them up in LA and, yeah, that was in about 2012 I think it was. So we identified that was a supportive one and had accommodation for them to go to.

I: Supported living.

R: With three…I think three other people in the house.

I: Okay. Is this the one that didn't work out?

R: Yes, uh-huh. This is the one that they went to and then they came back to X school.

I: So tell me about that then; what happened that they had to come back and how long was they there?

R: YP7 was only there…again, this is just a kind of vague recollection – they were only there certainly no more than a couple of months. But they went there…and initially I was quite pleased; I knew the service provider and I was quite pleased of the identified house that they were going to.

I: Yeah.

R: Obviously the biggest thing for me was that it was really close to home; it was in an area that YP7 grew up in and so they knew it really well as well. So that was a big thing for me. And, as I say, I knew the service provider. So the thing I was a wee bit concerned about was that it was a very small room that they were going into, a very small bedroom, but then the one at X school was not, you know…was comparable to that anyway and obviously it was a shared…you know, just with the use of the house. So even from the onset, the first day, there was sense that something wasn't particularly right.

I: Okay.

R: It was just one of the staff that said, oh, we've been on a challenging behaviour course this morning. But it kind of drew a… There were things that led up to that, you know, discussions at meetings and things, but certainly I got a sense at the time that even…just even with my experience of the local authorities that it was this is where YP7's going, but thankfully I kind of agreed with that at the time. It was a kind of you've not got any other option type thing. But, as I say, the positive seemed to outweigh that sort of issue. But, as I say, the first day there was a certain feeling straight away. And I tried like most parents in these circumstances…it's a very anxious time, you know, and you're concerned with how… And YP7, I think, had been having quite a bit of difficulty before they left, and I think that…you know, it's obviously a highly anxious emotive time for the family.

I: Yeah.

R: But it was very soon discovered that the new service provider had difficulty in understanding YP7 and YP7's responses, I think, were through anxiety and stuff which were difficult for them to handle. We then discovered that there was somebody in the house, which I wasn't aware of…and I think this is one of the big problems of the transition issues…I wasn't aware that it was somebody in the house that was very vulnerable as YP7 had got really anxious and, therefore, it was actually putting someone else in danger. So when that was…like came to light and the fact that YP7 was obviously

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having a lot more difficulty in settling than was anticipated that the LA, because of the vulnerability particularly of another housemate, was quickly identified as having to leave, you know, and the only choice at that time obviously was to come back to X school. And that had its issues.

I: Yes, yeah, because that would be quite unusual to go back to the school.

R: Yeah, and I have to say when YP7 went back…I always kind of…you'll need to kind of reel me in, B, because I do tend to sort of go off at a tangent.

I: No, it's okay, I'm interested.

R: When YP7 first…like any parent, when YP7 went to X school it was an exceptionally difficult time, I mean it was awful, not only because of the lead up to that decision and the way YP7 was presenting,their behaviours and everything and how it was affecting…I was a single parent with my daughter and YP7, and, you know, it was, you know, very, very problematic. It was a ridiculously emotive time. And when YP7 went down there…I'll always classify that as one of the worst days of my life…

I: When they came back?

R: No, when they first went to X school.

I:

R: And the reason I'm telling you that is because when I left that day all I heard was YP7's voice booming out, you know, P7, P7, very, very upset – it was awful. When they went back after going to the first transition and F, after about six or eight weeks it was I think they were there – when they went back their face was an absolute picture. they were standing up beside the tree waving and…

I: Yes.

R: It was the complete and utter opposite, you know. So they were very happy to go back because they were really very miserable where they were, they ended up being in their room most of the time; I ended up going in nearly every day just to help keep them calm, you know, because of the vulnerability with this other person and because of what highlighted…the support workers there were finding it very difficult to know what to do.

And I think that's one of the issues that really came to light is that people's definition of how they can deal with challenging behaviours when they're presented – it appears that everybody has their different definition of that.

I: Yes.

R: And I think that became very obvious when that happened. I see YP7 now to what they were going through then; they were just full of such terrible anxiety, you know, they really was. So, you know, that then proved to be very difficult that they were going back in the sense…

I had had some issues with X school before YP7 had moved and I have to say that when we had the meeting for them to come back I was put in the most awful of positions by ---.

I: What happened?

R: Well, I'll say this, and the social worker witnessed it as well, but I had put in a complaint to the care inspector who I have huge views about as well, because we had some problems and when YP7 left I had decided that that was that, I'm closing the door and I just want to move on. And obviously for YP7 to go back…it was basically said at a meeting for them to go back that…there would be difficulty with YP7 coming back to X school if I was to proceed with the complaint which I thought was absolutely atrocious because it was…I felt, and I'm saying how I felt, it was like blackmail…

I: Yes

R: …that YP7 wouldn't be allowed back and, of course, YP7 had nowhere else to go. If it hadn't been for YP's response I think that would have been…and that was the only thing I had to focus on rather than the difficulty for me, for them going back. I found it very…I was just…I think it was probably in retrospect now having experienced further problems with ---and our own personal experiences...it was…I wouldn't say the start, it was probably the middle of the problems. But yeah, that made it way more difficult for us. But it was to ensure that we could then try and find somewhere else for YP7 to go, and there was somewhere that had been identified quite quickly by the LA, a second place for them to go, to the point that it even was that we left a lot of the stuff in X school so that we could move it directly to the next place if that was going to be successful.

R: Again, it was very apparent that the place wasn't suitable in my opinion for YP7 and I think that's one of the difficulties, you end up…you know, the LA are like, no, this is where they should have to go and I had then to battle with them about it. We did start a bit of a transition with YP7 there and YP7 went up for a couple of visits. It just became quite obvious quite quickly that it wasn't suitable for him.

I: Uh-huh.

R: But the LA weren't happy about that and I think that just goes back to putting people…you know, placing round pegs in square holes sort of thing, and I think it's very much about just filling beds rather than looking at the person's needs. In an idealistic world that's the way it should work; it should be

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listening to what the person's needs are, who they're going to live with, where they're going to live. But unfortunately I have no idea why they've never really got to that point yet.

I: Yeah.

R: And it makes it very difficult for a lot of…particularly at the higher end of the spectrum it makes things very, very difficult.

I: Yes.

R: So that experience then became really problematic. By then I had totally, a hundred percent, had the name of being a very difficult person which you very quickly get labelled with if you disagree with somebody or you get frustrated.

I: Yes.

R: I think the one thing I've always said, and I think now this was from one worker in particular – I've never had any issues with any individual social worker, my issues have always probably been with the hierarchy or organisations.

I: Yes.

R: Similarly with any on the ground staff, there's very few times I've had any particular issue with anybody. But the difficulty is, as I've always said, my viewpoint personally is that honesty is the best policy and as soon as that trust has gone, you know, we're all hitting problems then and people get very defensive of their own organisations and people tend it easier to blame other people. I certainly could look back in time and say that, you know, there were probably times I could have handled things better more than likely but, you know, you're in an awful scenario and very, very emotional and worrying scenario about your child's future – present and future.

R: So the second attempt at the transition really, really highlighted all of that and I was becoming quite despondent, to be quite honest, about what the options were. We then came up with a reluctant scenario of moving YP7 down to --- and we then started…and that just turned out to be a bloody nightmare as well… That wasn't the ideal for me because it meant YP7 still living down there, nowhere near home, but if it was best for YP7 then that we would have to done and I would have done that gladly if it had been best for YP7. But again we hit problems at X school who were going through some…

I: Yes, that's right.

R: …things as well – one minute they were going to be a care home and the next minute they were going to be something else.

I: Yes, that's right.

R: So there was a lot of confusion going on, there was a lot of change of faces, there was refurbishment meant to be going on. And, in fact, I had seen --- school when YP7 first started and I thought it looked really good but by the time YP7 was intending to go it was like definitely in need of an update. But that again…cosmetics don't bother me, it's about YP7 and their quality of life is what really matters.

I: Yes.

R: But it then became a huge problem for them going there and that fizzled out until we got the offer of YP7 moving to another place that the LA were developing actually in the town that YP7 grew up in, in a place across the road from where my parents lived, and it was meant to be a bespoke set-up for three or four young adults and I thought we'd hit the jackpot, I really thought we'd hit the jackpot with this one. There were still, I think, at that point when we were told about it at a LA meeting, we were told, I think, if I recall correctly, that I don't even think the service provider had commissioned yet but it did end up ---

I: Was this ---?

R: That's it, yes. That then became the worst time of all. But I have to say the lead up to it…it took about a year for that transition just, I think, mainly because of trying to get the staff and for the building to be completed. They were just doing a refurb of an existing building. And, you know, we were getting involved in that; we went up and visited the place, and when staff were being recruited we even got involved in some of the interviews and stuff – that felt very inclusive and I was very pleased with all of that; it felt really quite refreshing. And although I had some issues with ---] that was taken over here, I am a great believer…it's about…you know, you can't brand a whole organisation by the people in it, by the experiences.

R: So it's, you know, a new start, a fresh start, you know, new team of people and certainly a new… I was very, very optimistic about it, I have to say, because I thought, well, at least with YP7 it'll be the same sort of model of care that will be happening, you know, and obviously the transition from within an organisation would seem to be a positive thing and --- were very high with that.

I: Yes.

R: But, I have to say, I was…within weeks it was very obvious that…but actually even before that it was very obvious that things weren't as they seemed. There were staffing issues prior to the place opening.

       YP7 was meant to have a 1:1 which was an argument that first arose, or a discussion – I'll say that politely – that first arose with the LA when YP7 was transitioning, just in the general area of transitioning when they were looking at moving YP7 from X school. I kept getting told that the adult services really they don't do a 1:1 scenario. I think that's more like what happened in ---, it was not an identified like 1:1 scenario, it was basically more people supervising. I said, well, really what you're telling me is that as YP7 leaves the gates of X school, their level of care is diminished, you know, you've miraculously found a some cure for YP7's condition and problems around it.

I: Yes.

R: That was an ongoing battle with LA which was very difficult, but we got there and that was identified when we went to ---. It was meant to be that YP7 would have the 1:1 and certainly when they were in the house there would also be a floating staff member there and when YP7 went out it would be 2:1, and I was happy with that, that was fine. Anyway, it was very obvious from the onset that --- had major staff issues and it just wasn't going to work, it was just not going to work. And again we then went back into the… I could tell you some stories of things that happened there that really are quite incredulous and how it was responded to, and again I then got the blame for standing…

I: Give me an example of one of those.

R: One of the examples about the staffing levels, and it was said and noted at meetings that anybody that works with YP7 should have a transition, you know, time with them to get to know them and stuff, and I found out that agency staff were getting brought in and literally given a book to read, a dossier saying what their care support plan was, what they needed, there was no management in the house and they were then told to look after YP7, they were on shift with YP7 without having met him, without having any management supervision or support or anything. I mean we had issues of YP7 waking up in the morning covered in toiletries and they had bleach in their bed, because they got up during the night at some point and had accessed all this stuff.

I:

R: We had food in the house that was out of date…the sort of domestic stuff was pretty awful actually but there were huge problems with the building itself which was the LA's responsibility. But the staffing issues were desperate. I don't know how many times I asked for meetings and they

weren't forthcoming, and getting the truth out of what was happening in there was just awful. And it ended up I got a phone call from, I think it was ---, somebody who was based down in…

I: Yes

R: I got a thumbs up to say that they didn't have anybody to put on shift with YP7. I thought, what do you mean you've got nobody on shift? So I thought I'll go in; I'm obviously going to go in. And then it just disintegrated completely for me. That actually…when we took this up with the chief exec and the directors denied all that stuff ever happened – it was just absolutely ridiculous.

So basically then YP7 had very intermittent staff. The whole place was now mainly filled with agency workers because staff had just bailed. I was going in looking after YP7 and some of the staff were just distraught. It was just awful. I couldn't believe what I was witnessing. It was awful, it was the most horrendous experience. I categorically could not believe that that was happening - in an organisation like that, that this would happen. And then the denials and the accusations all started. I was sitting there going what the hell is going on. Literally, I ended up bringing YP7 home because one I would not leave them with agency staff. And when I tried to broach it I was shut down and then I was… on a daily basis emailing the LA and saying, you know, what's happening and all the rest of it. I think the bottom line was that --- turned round and actually blamed myself for them withdrawing from the service – it was lovely. How I got the blame for that I'm not quite sure.

I: Oh

R: I did actually ask to see the letter and they were going to let me see it, the LA, because of The Freedom of Information Act. I thought, what the hell, I mean what's the point of that. It was just…it was beyond understanding, the responses. If they had, you know…the service was breaking down very obviously, very quickly, and there was a denial that that was going on. But the agency staff were brought in almost immediately and practically they were used totally.

I: Yeah.

R: And there were difficulties within the house because the behaviours of…there were only three people including YP7 in the house, and YP7 included plus particularly one other person had very difficult behaviours at times and you can't expect people to go in from agencies that have just worked in care homes with the elderly.

I: Yeah.

R: Well, one of the people actually used to be at YP7's old school. And there was a young lady and YP7 and her should never have been in the same place with people who didn't know how to work that.

I: Yeah.

R: I mean I think that's the biggest… I mean I think I was even asked did I think this would even work, and I'm like, well, how do I know, that's not my job. I don't know this person, I don't know what presentations there are, I've got no idea whether this will work. There seemed to be enough space in the house that it could have been managed. But we ended up in a shut-down scenario, you know; they were putting locks on doors and goodness knows what. I got attacked once and YP7 was constantly wandering in rooms and parents were threatening things…I mean it was a blood bath, not literally as in physically, but it was just ridiculous. I mean I've got copies of the emails where I requested meetings with --- and, you know, they never materialised. Obviously there were discussions going on with the LA with them. The LA from what I was told was very disgusted but, as I said, well, you're equally to blame, you know, where's the solution to this? and it's like… So, as I say, I ended up taking YP7 home. And it was awful because they were so distraught.

I: Yes.

R: I was the worst person to have YP7 at home then because I was distraught. I thought what's the future here for them, what are we going to do? I'd spent my whole life with YP7; I'll just quickly recap that. When YP7 was young I had a conversation with a professional once about how my difficulties and coming to terms with what life was presenting for them and, you know, where would it all end up. And that person told me, well, the one thing…the worst thing that they encounter is like older adults, you know, being at home and something happening to them, their parents and carers and then, you know, that person then has to be taken out with no previous separations from these people, their parents or carers.

I: Yes.

R: So I had made a promise to myself that that would never happen with YP7, and so I was very proactive in getting them respite when they were younger and the way I dealt with that is I had to look at my daughter was going away to stay with her friends, so YP7 was going away – that was the way I'd cope with it sort of mentally.

I: Yes.

R: But I was determined that YP7 would never be like that. And, you know, unfortunately came to X school it was because YP7 had had the most

horrendous lead up time to that and that's why that decision had to be made.

I: Yeah.

R: I had to even source it; I mean I had to source a place for them to go. It was, you know, I found out about --- online or something; I think that's how it happened and, you know, put forward to the LA – there was very little choice and especially, you know, all year round choice. There's always some residential schools but they close in the… I don't know what the situation is now because obviously I'm not involved in all that.

So when we got to the stage that YP7 was coming home it was like, you know, I've done all this and it's been the most horrendous…and I use the word sacrifice, for me, really – and for YP7. And we're now back at the point where YP7's back at home and it's like all that issue around…that became really quite ingrained in me that, because it had been so…you know, we'd got used to it, if you know what I mean.

I: Yes.

R: We'd got used to YP7 not living at home by this time obviously, not all the time, because even when they were at X school they used to come home regularly every week.

I: Yes.

R: But anyway, the whole thing collapsed. Then the LA took over the care…it took a bit longer than I would have thought it should have considering what was going on. So we took YP7 back when they had staff on. I mean I used to sit outside in the carpark when the LA had employed staff to take over. And there were still a couple of people that had been down at X --- with who had then moved over to work for the LA, so there were a couple of people who had come back that still knew YP7. They had done it kind of funny in ---. they'd kept like the [gender] team as the [gender] team, and that's something I couldn't…I thought initially the staff were meant to work with all three people so that there would always be that coverage.

I: Yeah.

R: But it didn't work out that way so that also created issues. But certainly when the LA took over… What we used to do just to sort of support the staff was sit out in the carpark in the car on a Saturday night trying to watch something on the laptop, so that we were there and, you know, more often than not they'd come out and say YP7's having a bit of a difficult time, and we'd go in and help.

Having said that, even like when --- are having problems, like we're here to help; I mean I want the best for my child.

I: Yeah.

R: I want the best for the people that are looking after them so if there's anything I could do, you know, if there was gaps I am more than happy to go and help out until everything's sort out. But when things don't get sorted out and, you know, when things keep declining and there's a lot of denial going on then it becomes an impossibility.

I: Yeah.

R: We kind of hoped at that point we maybe were going to get there.

I: But just the very idea of you sitting in your car on a Saturday night waiting to help.

R: That's what we did. And after the incident overnight I never left YP7 alone, I mean they either came home to stay at night or I stayed at night with them – I moved in practically. So, you know, we'd be in through the day or we sat out in the car and then I would go in and stay the night with them – they were having a lot of seizure activity during the night, a lot of terrible seizure activity during the night. And I thought I can't…I can't leave YP7, one with people that have not got the experience to look after this and the confidence – which takes time and that's fine, but certainly I couldn't leave them with agency staff that had, you know, absolutely no experience of this.

I: Yes.

R: And unfortunately the nightshift tended to… even when the LA took over. But particularly I know who was responsible for it, and the response from… When that incident happened I got a phone call from…you know, the bleach and the toiletries and stuff, and YP7 – actually their pyjamas could stand up alone when they came out of them because they were covered in this stuff and thankfully they didn't manage to open the the safety bleach thing or cleaning fluids. But the response from --- was atrocious; I never even got an apology for it, never even got a recognition. I think when I pursued it they said they did an investigation but the person concerned said that they acted appropriately really, so it was their word against YP7's.

I: Yeah.

R: And then they were expecting me to let that person to still look after YP7 overnight, you know, and I was like… And actually I could tell you…I won't even go into it because it's not what this is about, but I could even go into telling you the things that I discovered when I was there. And I just thought, och, do you know, it's just…

My focus solely then went into survival mode and it was like…we were exhausted and my partner, they used to come in in the morning with cups of coffee for everybody. And, you know, we went through…I still remain friends with people from that time; we're still in touch with some of the people that worked for that last month or so with YP7 before they finally moved on because they were very supportive and they were learning and, you know, I know a few of them still work there.

But, yeah, I'm afraid --- organisation let us down, in my opinion, exceptionally badly and it wasn't just me, there were other people that witnessed it and couldn't understand how it could have been done so badly.

I: Yeah.

R: And it's not even it being done…it was the attitude that I just… Oh, I tell you, I don't think I could ever forgive that; I really can't forgive that, it was terrible.

I: Yes.

R: So it brings up stuff that I've tried to lay to rest.

I: Yes.

R: The positive is that YP7 was then offered…well, actually at one point the LA…I discovered that YP7's behaviour was getting the blame for most of the issues within the house but it then transpired that it wasn't YP7. I mean, they were having difficulties without a doubt, but it was…it was a strong combination of unsuitability and bad management and that actually just created a situation that should never have been created. But when we identified an organisation that one of my friend's daughter is being looked after by for a long time and they had come in, I think with the hope from the LA to actually take over the running of --- but they weren't keen on doing that – just through events they actually had said that they would be willing to take YP7 under their wing. So it ended up YP7 moved – again, at that point I was like how many times have we got to do this.

I: Yeah.

R: It's like I'm so ingrained in how long people need to get to know YP7 – because I kept getting told how bad my son was…I mean I literally was getting told constantly how destructive and how difficult my son was that I didn't even know what to believe anymore. And all I can say is that when this organisation came in and took over and started…within an instant – instantaneously, YP7 started going out every day, they now…they had a few small behavioural issues, I would say, in the first year – nothing major, throwing a cup of juice or, you know, a wee bit anxious about this – but

every day now my child goes out to the shops, the parks, museums, everywhere.

I: What's the organisation?

R: Well, it's a small organisation in LA. They did run a sort of day service for a while, till quite recently, and have a couple of residential, but they were mainly running as a day service.

I: And how did you find them again?

R: Well, they looked after my friend's daughter for a long time. She went to their day service for a long time.

I: Right.

R: When her daughter was looking – she had had difficulty again of placements under different organisations and because they were looking after her during the day my friend fought for them to look after her residentially.

I: Yeah.

R: And the LA gave in to that and it's proved extremely successful. So that's, as I say…instantaneously YP7's life changed completely.

        Honestly, this is the one thing that I think really, really frightens me, frightens is probably the right word, in the sense of if you have a model of care that works then surely people should work together and adapt that, rather that this… I think from my own personal experience, and again I don't like to generalise because I think it's too easy to generalise and lay blame; it's not about that, it's about what's positive and going forward, and I think if organisations tended to work more together…

        And I think I kind of found that out when YP7 first…you know, I felt with YP7's first move to X school, I felt that X school…--- was their team leader at the time and I think was very efficient and I had always got on very well with them and they were patient with me, and I think I felt it was done very well. There was a lot of information passed over, there was a lot of visits and they were very accommodating. And then, of course, the receiving service provider…it all seemed to be kind of working. But the day it started it was just so obvious that it hadn't been working. And I think sometimes, and it goes back to the reality and the interpretation… Like see just now where YP7 is, the support workers will say, you know, YP7's a breeze compared to some of the…I'm never told anything personal, it's not about that, it's just about YP7 himself because they don't present, you know, exceptionally challenging behaviours which some of these guys are used

to being with. Similarly I think that can happen…when you are dealing with very challenging behaviours your definition of challenging behaviours can vary and for people that don't deal with challenging behaviours as we would see it, you know, have a different definition. When those two meet there's going to be a clash and some just get lost in translation.

I: Yes.

R: That's very much highlighted, you know. And the other thing that I found was that because of the way services are contracted, you know, some of the…well, I'm going to say again from my own personal experience, that it became obvious and was actually verbally said to me that, you know, if a service provider refuses to take on somebody they can have arm-twisting done with threats of losing their contracts.

I: Yeah.

R: So, you know, I lay a lot of fault with the LA in their attitudes towards all of this. But there is this thing between service providers that somehow it's not gelling and, you know, I think there could maybe be an improvement on that to help those that are going through all of this.

I: Yes.

R: Anyway, that's really what's happened from YP7's point of view. And they're now in the happiest place that I've ever seen them.

I: That's great.

R: I actually feel now…I think, oh my God, what is this, why is…? You know, maybe the scenario down at --- was not…but I think it was probably the environment was not right for YP7 more than anything else.

I: Yes.

R: But when you have no choice, when nobody has any choice, you know, we end up in scenarios that could be improved but for numerous reasons can't be. But certainly improvements could be made if people were a bit more open-eyed and a bit more honest and a bit more accepting that they can make mistakes. As parents we're expected to be, you know, accused of being over-emotional or over this or over that and yet, you know, we're not allowed to tail that back.

I: Yeah.

R: And I think, you know, it's a very, very vulnerable situation, I think, sometimes, as a family that everybody else is trying to control what you're doing. And I don't know how many times I've had to say look I'm not just

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YP7's mum, I'm their legal guardian and I have a legal right, a legal obligation here to try and get the best for my YP7. It's so distressing when you see that the attempts at doing this are awful – I mean you only have to see what was on the telly the other night there about that young girl incarcerated in a blooming NHS…and that was threatened to me as well by a LA person – if I don't accept this, well, YP7 will have to go to an NHS hospital or whatever, probably down south. I've had that thrown at me as well, because you don't think something's suitable for them. I don't take any joy in saying it but I was right, do you know what I mean?

I: Yes.

R: And in fact the one time I actually thought it was going to work it turned out to be the worst one – I'm certainly not always right.

Anyway, I think there are a lot of lessons that have yet to be learned and I think some of it is probably pretty easy but just people can't see the wood for the trees sometimes.

I: Yes. That's a lot of things that happened in a relatively short time.

R: Yeah. And I think, you know, YP7's probably more the exception than the rule – I would like to think, but I've a nagging suspicion YP7's not. I've a couple of friends that have had difficulties. But I think obviously it becomes more difficult the higher up the needs are, you know.

I: Yes, and that's part of the focus of my research about complex needs – do people understand what that means and what level of planning needs to go into a transition for that. And it's not just a case of we've done a course in challenging behaviour, we can do it.

R: Yeah, which is scary, isn't it?

I: Yeah.

R: And I think that's it. But in a sense you have to look at the focal point of who are making a lot of these decisions and that's the LAs and until they stop, you know, sort of looking at the square pegs into the round holes or whatever and actually looking at how… And I think, you know…at one of the last meetings…thankfully now our review meetings are few and far between and very brief, but I really have not had an issue; I've had nothing to make any complaint about. And people who have known me in the past will think that's unbelievable, but it's actually true. From things even like wearing their own clothes to people being honest why things can't happen or are happening. And I think some of these steps are quite easy if people…or organisations changing their mind of how they're going to do things.

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I: Yes.

R: The trouble is you're all fighting from money to survive and contracts to survive. It doesn't mean to say…I mean, down at --- I met some wonderful people; I met some really nice, nice people.

I: Yes.

R: I also came across some people that were very, very difficult for me personally because I knew they weren't relaying the correct information to me, just at certain times with certain things. And then, of course, it didn't help when the head of --- organisation just would not admit to anything, do you know what I mean?

I: Yeah.

R: I just can't understand that, you know; we're not all here to try and be the best…

I: Yeah, yeah.

R: I'm a great believer it's the person at the top that makes the difference, whether it's like --- at the school… I mean, I think I met --- about once or twice in the whole of the time that YP7 was there.

I: Yeah.

R: I always thought that was very strange in that there was not any sort of contact like that. I understand that people are busy and people have their remits but I think it is about what organisations portray and how they… Again, where YP7 is at the moment if I have any issues I can pick up the phone and say…there's been a couple of very minor things but as soon as something's been done, it's done, accepted and that's it, you know.

I: Yes.

R: It's about people working together to make sure…nothing's perfect, but…YP7's by himself now. they weren't meant to stay where they are now for this length of time; the initial move…it's actually a house that was meant to have two people in it – I think maybe years ago it was meant to be three. It's not owned by the LA but they rent it.

I: Yeah, and is it close to home as well?

R: Yeah, I mean I go and see YP7 twice a week. We go out, take them out down to my daughter's for tea and stuff. They took fireworks and had a firework party up there the other night and stuff, you know. And it's very much like a home; I mean, it is YP7's home. And even when we've got YP7

out and I'll take them home and YP7's like… When I go there, their relationship with the staff is brilliant. I mean they goes to the staff before they comes to me, which I always joke about and people find quite funny. But sometimes when I go up there, you know, YP7 will take me by the hand and say bye P7, because they don't need the mother.

I: Yes.

R: And somebody actually asked me how I felt about that and I said I feel as if I've won the Lottery. Now that to me is just…fantastic.
But I still have fears for YP7's future. I mean this is a private organisation and I don't know what the longer term scenario is going to be – it's not like a big charity that hopefully will keep going forever. There's always a fear for the future.

I: Yes.

R: And YP7's health at the moment is fairly stable; they still have their daily seizure activity and people don't pick up on all their… and things; that's fine, that's not a thing for me. As long as I know YP7's safe and YP7's enjoying themselves and YP7's happy – that's the thing that I never thought when they were at --- I could ever think of…

I'll be honest with you, I think that what that scenario at --- did to me, and I take no joy in saying this, and I say it with the heaviest of hearts and the saddest of hearts, but there were times throughout that experience that I categorically could understand why parents like me take their children and jump off a bridge.

I: Yeah.

R: And that's, you know…I've felt that…that was the strongest that I've ever felt like that because I thought there is no future for them and how could I leave them to end up in a place that we were talking about was on the telly, locked up in a cell, you know.

R: And it's the most horrendous, horrendous situation to be in. So when you have organisations that don't understand that and they're meant to I just…or people within that organisation…obviously I'm taking about the people running ---… It's not what you're meant to be doing.

I: Yes.

R: It's not what you're meant to be doing. And I'm not singling out…I can only say about --- is that's our experience.

I: Yes.

R: I think, you know, there are flaws which is a real big thing and we've been through a few now and that was the desperation issue for me – where is this going to end and why are people saying they can do things and they don't and why is the LA not recognising that. Now that YP7 is in somewhere that YP7's settled and happy is…well, God Almighty, why can't people look at this and for the higher end of things see how this works, and why can't we work towards duplicating that, you know; organisations that maybe don't have the experience or… You know, --- have the experience of looking after autistic kids but I really questioned the experience of how it is protected and then how it is sort of denied when it's not working.

I: Yes, yes.

R: There's not an answer you know. And I think everybody has to open up and start talking to each other.

I: Yeah.

R: If we don't, you know, nothing's changed. I sit and think YP7's now, what, --age---, what's changed, and really not a lot. I just feel we got lucky. YP7 got lucky and it shouldn't be like that.

I: No.

R: Everybody should be in a place like YP7. It took them a long time to get lucky and I think that's where I put the --- thing behind me because we had to go through that to where they are and if we hadn't gone through that we probably wouldn't be where they are. So that's the kind of reasoning now and I'm just thankful that we got here because at that time I thought, you know, we'd had two or three attempts to end up in the most horrendous… I actually think at --- I thought there was no hope left for him.

I: Yeah.

R: And it was this portrayal that YP7 somehow was this monster and causing havoc. And everybody that knows YP7 now are like YP7's a gentle …., you know.

I: Yes.

R: And I think that's about the responses…It's a combination of things but it is about, you know, YP7's in a place, an environment that YP7's happy and it's quiet which is vitally important which became much more…

I: Yeah.

R: I never wanted YP7 to have a single tenancy; I always kind of thought, no, no, no, YP7 would be better in an environment…as long as they had their

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own space, but I was so wrong, so wrong. I mean YP7's much better... Now that's what I'm fighting for because they will be moved from there. We'll be retaining the same care providers but because the house is actually meant to be for more people then YP7's obviously just a single tenant in there at the moment and YP7's got a lot of space for one person. But again they've got no idea where they're going to move him.

I: Yeah, and I'm sure that worries you.

R: Well, it doesn't worry me so much...as I think as I've said earlier on as long as they retain the same care provider.

I: Yeah.

R: The other thing that I'm just adamant on is that they have their own space; YP7's not just moved into a house with other people. I think, you know, realistically I have to accept that...I mean I've been accused in the past of, well, you know, if we give YP7 this then you're denying other families that. I can't take that responsibility on – that's your responsibility.

I: Yeah.

R: I'm responsible for YP7 and I have to fight for YP7. It's like when I was asking for more respite or whatever we were doing it was always a kind of battle. And all that stuff should never happen. But it does unfortunately. I think because I am outspoken people get offended by that, you know, and that's...I think, well, I can't be worried about how you feel about me.

I: Yes.

R: I've got to worry about what happens with YP7.

I: A thing as well that I notice when speaking to parents...certain parents have a strong voice; you're obviously one of those parents, and things happen because you keep at it...

R: And if anything it sometimes can add to the pressure.

I: Yeah.

R: You then get, as it was even down at ---, you know...I was accused of being a difficult... There was stuff in YP7's room...and YP7 was sleeping on a mattress that I wouldn't put a dog on. I mean I sat down on it and you sat on the bare box. And that was on top of all the plans they were doing to renovate the house which they'd never discussed with me. I mean I literally found out things because I took YP7 up and down, because I physically was present at ---. You'd come in and you'd see things that were going on.

But the reason that I actually welcomed that was because I got to meet some of the guys that were looking after my son.

I: Yes, yes.

R: You have a wee chat and you're kind of this, that and the other. But obviously physically there were things going on and I was always very conscious about crossing lines and stuff like that. That's important. But it's also important from a parental point of view to be as friendly as possible with the people that are looking after your child, you know, to build some sort of relationship with them – I think that's probably the better term.

I: Yes.

R: So I put a complaint in and then I got a letter, you know, sort of accusing me of how I'd been aggressive to staff and how I'd been this and how I'd been that. And I categorically remember one time when I would absolutely have…to my shame I would put that label on it…I won't go into the details of it but I had had enough and I actually had raised my voice quite loudly and in an environment that I should never have done it - that I absolutely take responsibility for. But as far as anything else is concerned I generally…I've got a loud voice anyway, so maybe some people feel that's a bit…a bit kind of intimidating. But I don't care, you know; at the end of the day I should be accused of that in the circumstances of…you know, I wasn't going round beating up people, you know, and I think that's what they make you feel like. So often when you've got a voice it can sometimes kick back on you because people don't want to hear it.

I: Yeah.

R: And they certainly don't want to hear what you have to say. And it does come back to that really silly thing about…I've felt it several times…that because you have a child with additional needs they sometimes take the whole family as if they have that.

I: Yes.

R: And certainly families can be impacted for many reasons on it but I've still got my faculties about me and I can still fight for my kid if I see something's going wrong, and certainly if people are not telling me the truth it angers me greatly to the detriment of my child if that's what's happening.

I: Yeah.

R: But there were things there that were not right, and then you get accused of even being vocal. But these are small pockets of things over a long period of time.

I: Yes.

R: But I felt that at --- as well. You then get this label upon you. I didn't lose sleep over that, I was losing sleep over the fact of what was happening to YP7. And I thought, well, you can label me all you want but you're the one that's failing my child dreadfully.

I: Yeah.

R: And it's that old thing, isn't it, it's… And I remember one person down the road, – again, there's no need to say names, but I remember one person had said to me, that they understood a lot now what I was going on about, a lot of stuff about the personal care more than…because their parent was now in a care home and they had a lot of the same issues. And I thought, well, that's nice and I appreciated the comment but there's still a lot of stuff you think, oh God,

I: Yeah.

R: But that's a different issue to what you're wanting to talk about, I know. But certainly I think labels carry with you and that makes things more difficult for everybody around.

I: Yeah.

R: I think it's just about everybody accepting that we can all have difficulties and I think that's what I've always said – I don't expect perfection for YP7, I never have; the reality is that it doesn't exist. It doesn't exist for any of us in life, but I can't stand when people are not being honest with me…

I: Yes.

R: …particularly around the issues of a vulnerable young person and I think that's the first and foremost thing that it's the local authorities or the organisations have to make happen, without a doubt.

I: Yeah.

R: I think the one thing in retrospect that I think…I do believe that there is a place for advocacy in all of this and I think, you know, when things become…particularly when they become a bit difficult, and again it's a lack of availability…

I: Yes.

R: Relationships that form from where the person's coming from and then where you're going to…you're trying to re-establish that. And I think, you know, whether you're like me and carry a label of whatever you are around

with you or…YP7 carries the label of how they present and the effects of their condition, then it would often be good, I think, to have somebody that is completely neutral that can come in and offer the support to both sides, just be that missing link.

I: Yes.

R: I think that…you know, until we manage…and I don't think this out of human nature, I don't think it would really occur to be this big unified sort of set up of different organisations helping each other, it should be that you need a bit more of a kind of impartial viewpoint, I think, when things are difficult. Even when things aren't, you know, I think sometimes it might be nice to have an offset when you're feeling a bit frustrated…for people that don't have the voice it would be a good thing as well.

I: Yes, exactly, yeah, okay. I'm just a wee bit conscious of time…

R: Okay. I told you once I start this…

I: No, but it's great from the point of view of the kind of information that I need....

        So I think you've actually answered most of the questions in that whole first section. I'll just go through the other ones. … about how did you feel included and involved in the transition process – I think you had quite a strong voice there but some of the time it was out-with your control, but did you still feel involved in the initial process from school?

R: Yeah, but I think certainly from…when they were moved from X school, as I said, I think there was, yeah, a lot of information and it was shared with me, it was getting passed over, and there were certainly numerous meetings.

I: Yes.

R: No, I certainly felt included in that respect. I think being blindly included…I think because what then comes up is that, you know, you don't really know the information from the other side.

I: Yes.

R: But certainly from leaving X school there was certainly…I don't have any personal complaints about that.

I: Yeah.

R: I think the information was there and it was done the way that I would have thought it would be done certainly.

I: Yes. And do you think that the transition process began early enough?

R: Yeah, I was very vocal about how long transitions should take for YP7 and X school agreed with me at the time; it certainly was over numerous months rather than sometimes what was being suggested was numerous weeks. Yeah, certainly the time should be totally dependent on what the needs of the individual are and the complexities of the needs to make sure that the receiving organisation understands that.

I: Yeah.

R: Then again, that does create a wee bit of an issue because of that sort of defence mode of what people's understanding of what individual things are – it's kind of a strange thing and it gets lost in translation when so much information is passed.

      Again, I think just…just to reiterate that one, I think X school would have seen YP7 as they had known them and, you know, I think some people get accused of painting too good a picture.

I: Yeah.

R: And I didn't think that was true; when that was suggested to me I thought X school, what I saw of the paperwork and what was being said…

I: Was fair, yeah.

R: So I would probably think the receiving organisation was not fully understanding of it, that viewpoint.

I: Did you feel that the LA was fully aware of YP7's needs?

R: No, not at all… there was no thought put into any of the transitions, to be quite honest.

I: Although they would have been involved in the transition process.

R: Oh, absolutely, and obviously they were involved in the meetings. I mean I think everything's done by paperwork that --- will read and they will read about YP7. You know, social workers now are so stretched. How often did YP7 see their social worker? I remember when we first went there there was one that used to come down once a month or something or once every two months or something, but latterly I don't think anybody ever came down. I think that's it; they're so stretched now that that becomes an impossibility. Yeah, everything's based on the LA on paperwork and even that certainly from results it seemed to be well and truly ignored.

I: Yes.

R: And LA involvement is [inaudible] with me, yeah.

I: And you mentioned already the school was aware of the needs and knew them well.

R: Absolutely, yeah.

I: Do you think there was enough information on possible placements or were there enough placements available?

R: No, and that was our issue obviously and that's why it took us so long to where they is, I think. The information about placements was very sparse because there wasn't really anything.

I: Yeah. So you didn't really have a choice, did you?

R: Oh, the choice was practically non-existent. That's why we ended up initially back to shall they stay down ---.

I: Yes.

R: Because there was nothing here. One of the ones that they had tried, that was outside of where we live – that was up in ---, so that wasn't near home either. Certainly that's why the whole thing from the age of like eighteen to YP7 eventually left there was because the choices were practically non-existent.

I: Yes. The next bit you've more or less answered about the destination close to home and… what was available…YP7 being lucky now…what you said about putting square pegs into round holes is just – we've got this place and this young person's going to go there….

R: Yeah, mm-hmm. And I think that absolutely… I mean there would be a denial about that but I think that became very obvious as soon as we got involved in the transition issues and it's us trying to get fighting… Again, I don't know what I kept getting surprised all these years. I was really shocked by the lack of opportunity but I was really shocked because of that lack of opportunity the stance the local authorities take and instead of looking at developing services over the last ten, fifteen, twenty years, you know, it's like there's always a reason not to and I know particularly now it's obviously because of the financial aspects. Again, as I say, well, look, if you don't do it it's going to cost you more.

I: Yes, uh-huh.

R: And it causes a lot of distress. I don't know, common sense seems to go out the window.

I: That's the first time you've mentioned the financial aspects. Do you think that has a big sway on what happens?

R: I think it's quite complex. I think it's easy to blame solely the financial aspect; it's obviously a huge part of it because looking after somebody like…a care package for YP7 is very expensive and that's really shocking for people when they hear that. So again if that is the main reason then you think, well, why is that not then being…is there anything… you would address any financial issue.

I: Yes.

R: But it's more complex than that and it's about how people perceive a job in the care sector. I think it's how care workers are remunerated, I think it's about working opportunities, I think it's how people perceive that kind of job. I think it's a very complex thing. Retention of staff, as you will know, is very…it's a difficult thing to attain. Certainly, I think now people have to be pushed forward to go to jobs that…the care sector is a classic place that people come to. So you get a variation of quality of staff for different reasons and certainly pay for the staff is a big thing. You know, it's not the first time you'll hear the story of people leaving a care job to go and work in a supermarket and get paid more.

I: Yes.

R: So until you address some of that…

I: Yeah.

R: You can plough as much money into buildings and into ideas but until you address how you're going to be paying your staff… I've always said, and I say it to the guys that have got YP7 now as well and I've said it to some of the X school lot when we were there – as a parent I am so appreciative of what these people do, you know; I'm so appreciative that people… Whether they fall into it, whether they choose…and I don't think that too many people really choose to go into it, but when they fall into it and end up getting satisfaction out of it these people should be hung on to, do you know what I mean?

I: Yes.

R: Until they're appreciated… And, as I said, as a parent I often get quite appalled at how support workers or care staff are treated and how they're perceived because they're looking after the most important thing in my life.

I: Yes.

R: So why can't that be recognised? And I'd say that about the elderly caring scenario as well – we're just not very good at this, you know; we're not very good at recognising what people do and how it is.

I: Yes.

R: And often how difficult, particularly the higher up the spectrum you go. I mean who goes to work expecting to get punched or kicked, you know, for the minimum wage, and before then it wasn't even that, you know, and very little prospects, and certainly a lot of times very little appreciation. I think that can be quite soul destroying.

I: Yes.

R: Long hours and, you know, often difficult hours or long periods of things that are maybe very quiet to things that become ridiculously difficult, you know.

I: Yes.

R: It's a very mixed job to have.

I: Yeah.

R: But I think until there's an appreciation of that… Yeah, to answer your question it's a complex scenario definitely.

I: Okay. The next couple you have answered already about positive and sustained destinations…And then you said that YP7 may have to be moved on. So it's not sustained in that it's the same house but it's going to be sustained in that it's the same provider.

R: Yes, uh-huh, there's certainly no indication that that would change and unless the care provider stopped providing care, but I can't see that happening.

I: Yeah.

R: I think it gets to the point where the LA is just sick of me as well. I mean they've not heard a word from me for the last sort of two, three years so they're quite happy.

I: Yes, maybe.

R: Don't need to put up with me.

I: Uh-huh. Next it's about evaluating YP7's experience…you've talked about their anxiety and distress... you said some really quite significant things about the impact on the family and the distress that it causes. Anything you want to add…

R: I think I've probably covered it all. I think just for me it just completely highlights as a society that we're just not getting it right, you know.

I: Yes.

R: It is in life until it directly affects you we're not very good at recognising it and I think that's probably why the elderly care is coming more into the focus of things because we're living longer and more families are experiencing the problems.

I: Yeah.

R: But, yeah, I think we've got a long way to go, that's for sure, that's absolutely for sure. As an individual family I have to sit here and think, well, you know, we've found peace for a while and we'll have to just take it day by day and that's as good as I could hope for, you know. But I still have huge fears as YP7 as an adult and I wouldn't be the first parent to say because I certainly know many that have said it – till the day I die there's a part of me that kind of always wishes that YP7 would go before me, I think. That's how all of this makes you feel and to say that about your own child is horrendous.

I: Yes, but you're saying it from a place of…it's about YP7, yeah.

R: And having experienced what you've experienced and seeing what you've seen and met who you've met there are positives and negatives. We're still there, you know; I think that's the issue – we're still at the point of…I dread the day that I leave him.

But I had a cousin pass away younger than me and she has a son with fragile X and she has several other children. One of her many, many sadnesses leaving this world was that, and she had a husband, but she was distraught about what was going to happen to her son.

I: Yeah.

R: And I think that's what people probably don't really get when you're sitting at these meetings, you know, that I have all this.

I: Yes, I know, I know.

R: And I totally understand the states that these organisations have to try and survive under and that again shouldn't be happening either.

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I: Yeah.

R: But unfortunately it's a very expensive scenario.

End of transcript

Appendix 15 SP1 redacted transcript

I: Okay. I'm recording SP1, so are you happy for that to happen?

R: I'm happy for that to happen.

I: Okay…So, if we use the questionnaire as a starting point, and don't worry if you don't have the answers to the data…because I'm actually more interested in the stories and what actually happens.

R: That's fine.

I: So, I'm looking at transitions from here…planned transitions…from here to adult services and whether those have been positive sustained destinations in the way that the language of the policies talk about. So, do you know how many or, kind of, in the region of how many took place from your school in the past six years?

R: I mean I would expect at least seven off the top of my head, and I'm thinking about the ones that I know that have gone well and are still going well. But I'll go back and check that for you, get the right figures. Where it has worked most positively is been when one of our ---adult services teams have picked up the transition.

I: Okay.

R: So, there's also the diversity aspect in that population that influences things a little bit, because what I've got at the moment, for example, is a cohort coming through into the senior phase now who will be able to go on, and access some form of a, sort of, college destination. But that becomes trickier to, sort of, track and manage when I don't have the liaison points within the LA.

I: Yes.

R: So, I'm finding there is a lot of leaning on me to say, well, you know, you need to organise college for this young person in ---, for example, but I'm actually needing the LA to liaise with me about what that might look like, so I can get him ready and plan for that. So, that's a, kind of, growing area that I think will come through a little bit more, whereas historically the young people that were here. And we do still have probably half our population that are, you know, very early communicators, so are going to need a huge amount of support for the rest of their adult life. And the majority of them have gone onto a, sort of, supported living arrangement, accessing adult day centres across…that type of model has been predominantly where they have gone. I mean we have…I can remember in my time here, although not as head, where we had two young people that were leaving here, and

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should have gone into that type of arrangement. But actually, ended up having to go home for at least a year, because there wasn't anything in place, and the authority hadn't moved fast enough to organise that.

I: Yes…it is very, very challenging for them to go home, and sometimes what we find is local authorities apply for variation.

R: Yeah. We've got that at the moment. I mean two of our young people are over 19 and are still with us. And actually, last session I had two nearly 21-year olds still with us. They should have been part of a planned transition. But we had started those conversations when they were 16, but nothing was moved on, or something was attempted by one social worker…not picked up by the next one…not picked up. So, that was a fail, like, they were failed by the system, and then therefore as a result had nowhere else to go if we couldn't keep them. So, the two that we have have arrangements.

I: What's your age range?

R: Well, we are five to 19 technically, but yeah, our youngest at the moment is 8, and our oldest is 19…I mean the majority of our population are, kind of, between 12 and 16 really. It's unusual for us to get eight. But the two that are now…we are now in the process of looking more like they've got something set up. One will go to our adult services out in ---, and the other will be picked up by X school. But that's been toing and froing, and their transition has been quite a difficult process. It's been…there was a merge…we were hoping at one point, they would move to live with another yp that they live with here. And we were going to transition them together, but we couldn't get the two authorities to, kind of, make that work. So, one transition…

I: …so that approach was made to the authorities and why did they not…

R: I don't know, we didn't get any reason from…I mean the reason I got from the adults for the transition worker was we just couldn't get the two authorities to cross the red tape to make it work. Because actually that could have been really appropriate, the two yp live together here, you know, they are two young [gender]…the compatibility for one of them is particularly difficult to, kind of, find the right environment that wouldn't be restrictive to another person they're living with. So actually, this model of those two yp worked incredibly well, but it just for no reason that has made any logical sense didn't come to. Interestingly one of those yp had a film made about them ---. I don't know if you saw that. Did you ever see that film?

I: I don't think so. No.

R: So, it was a film about yp, that actually they got a BAFTA for it in the end. But interestingly the film maker has just come back to approach me,

because they've got permission and funding to setup a film based purely around transitions. …I mean they're trying to take the yp's story and the difficulty of the family in terms of how the transition has been managed…

So anyway, they are now going back to the area and they've got to be picked up by ---, but they still haven't got staff in place, and they still haven't allocated a property. And they were set to move in Christmas, so they've now set to move in January. But I mean that marker has just continually moved for a year and a half.

I: Yeah… So, you said earlier that some of the more positive ones have been where your own adult teams have picked up the transition.

R: Yes.

I: And is that because you are able to do the planning together more easily? Or why is that?

R: I think so. I think it is a logistical scenario. I mean we've got one leaver who is planning…we are planning for them to go in the summer, and at the moment their adult social worker is advocating greatly that they stay up here. Because they are, you know, very much included within this local area, and it's coinciding with…it's likely will have a property within essential services that they can move into. So that team are now starting the, sort of, transition work with that young person now. So, I think it's almost…it removes I suppose a layer of that red tape of trying to get different organisations and teams working collaboratively. Because we can start to do the information sharing, whilst all of the other bits are going on, and I think that's probably what makes it most successful.

I: How do you get your team involved? …how do you introduce that to families or to LAs?

R: We're quite careful about that too. And it's just another option. So, we just lay it on the table at our review meeting. Usually our partners already are aware, because we are the only school and we are predominantly an adult service organisation.

I: Yes.

R: So, they usually are already aware and often ask the question, well what services might there be that you could pick up in that area? So, I then sometimes link them into that regional manager of that particular area. So, we are…but very carefully in terms of how we…it's an offer on the table and it's by no means something they need to take up. But I think often with some those children that are more complex it does, kind of, suit the family, but it also suits the LA when it's particularly an area like ---, for example, that have, you know, very little provision in place that would meet the needs.

They almost certainly know that they have got to be out of area for that placement.

I: Yes. Yeah. Okay so, that's one of the things that makes transition positive. What about some of the ones that you can think of that have been negative? Like the two that you are talking about that had to go home for a year. Can you tell me a wee bit about that?

R: I think that the main barrier to the negative is not getting the right person around the review table at the right time. So, it doesn't start when it should start. And so, what happens is waiting lists are too long. Parents aren't made aware of, okay, where are the places I could go and look at, or I can go and see? And unless you've got a parent that's pushing and advocating and has a, kind of, awareness of the world…of this world, you know, they don't know what they don't know. You know, and I feel as though it's the parents who, no, okay I need to go and see this, I need to go and do that, I need to ask for this, I need to ask for that. They manage to push themselves into usually a more successful transition, but for the parents that just need to, sort of, wait and see, often then, you know, unless we are saying, where's the adult social worker? Where the transition worker? What's happening with the young person who needs guardianship? Have you thought about that yet? You know, it feels as though often, there's not one person leading that process.

        And parents are anxious about that. You know, they want that information. They want to be able to go and say, okay, I've gone to see X, Y and Z. That's a no, because I don't like that type of thing, that won't work. But this would work, something like that. Okay, let's build something like that and start from that process. But it feels as though it's incredibly dependent on whoever it is that's has picked up the case. And rather than it being a system that works effectively. It seems to be very much almost case-by-case of an individual worker is particularly good. You know, I find myself in a position of saying, oh that's great, they've really pushed that forward. But it's reliant almost on those individual people doing that and when they are not there, things just don't move fast enough. And before you know it, they are coming on 17 and, hang on, what's happening next? You know.

I: Yes. Even a couple of parents as well in their responses have talked about the invaluable input of the social worker…So absolutely, individual people seem to be key.

R: So, that's a classic case of that the yp you'd like to eventually…last year, I mean when they were 21, that was a classic case of that. Social workers continually changing and a different social worker picking it up in a different way. And then nobody being aware of what had come before. You know, it's like we've been here before, why are we doing this again? You know

that, kind of, repetition of mistakes or just nobody seeming to do anything that was moving it forward.

I: Yeah…these are familiar things…

R: Yeah. I mean certainly when I was at the last X Group meeting, we were talking about, you know, just that difficulty of the lack of coordination between different authorities or approaches and things. And interestingly we also had a conversation about appears more… looking at pulling day placements on the 18th birthday rather than carrying it through for the 18th year, which was an interesting caveat.

I: Yes. And who was saying that?

R: I was having that conversation with X in --- school. Because they had found that's happening more and more frequently that there's, sort of, well it's turned into that 18th birthday and that's it now. But hang on, these children have missed years of education. And actually, if you had a thriving young person who was turning 18 in mainstream, you wouldn't pull them out of school at their 18th birthday.

I: Yes. Well exactly.
        Okay. Let me think if there is anything else. Yes, we were talking about positive or negative destinations. What about sustained destinations? Do young people go from you to a service or wherever it is that they are going and stay there happily? Or do they move on somewhere else? Either for a positive or a negative reason.

R: It's hard to know that information completely. I usually hear, if it that's…within our services that's easier to track, and they would tend to stay. Although we have had one yp that wasn't managing within the adult service that we set up for him here. And they ended up gong I think to --- [out of country]. I wasn't involved in that transition but it sounded to me like they just didn't identify the appropriate space for him actually, it seemed to be the, sort of, trigger. I'm not sure how or what happened around that transition. So, the ones…they tend to…when they get into whatever that…because it is a supported long term tenancy they then usually would remain in there from what I know, but it can also be hard to keep hold of that information, because we wouldn't necessarily go back and ask, you know, check in on a families that leave, I suppose.

I: Yes. And quite often, service providers are not allowed to give you that information…because of data protection and everything…

R: Exactly. It does make it difficult to track.

I: That young person that you talked about moving out of country, do you know what, kind of, place it was or why? Was there a choice involved there?

R: I don't know. I mean I could find out more about that…Because we've got a service manager that ran that service, so I could ask. Essentially it got to crisis point here. Really harmful behaviour. And I actually think it was probably a short-term psychiatric stay. And then I think they will have found from that. I don't know why it was ---. I will see if I can find out a little bit more about that particular case. Because when they were here and at school, they were incredibly happy and settled. So, something…there was an impact of something within that context.

I: Okay. That's really good SP1because it, kind of, matches up with what I've been hearing from parents, and other professionals…

R: Yeah. I mean I think the landscape…there's an interesting change in the nature of the young person that we are getting referred. I mean if I think five years ago, we would have a lot more of the, sort of, learning disability profile. Now I feel we have much more of the more cognitively able in a lot of areas, but actually, the social interaction and the managing of emotional regulation is where it is difficult. And I can't help but feel…and it would be a guess, but the, sort of, presumption of mainstream aim being, well okay, you know, these children whilst there needs might not be being met within this particular authority unit, they're not actually destroying anything or harming anybody or themselves, and so that's okay, you know. So, the children that we are getting are far more volatile in that respect. And I think that's the nature of why we are getting them. I mean that's me, totally surmising.

I: Well, I understand where you are coming from with that, yeah.

R: Because there certainly has been a change in that profile and there must be a reason for that, you know.

I: One of the things that I'm going to touch on in the research as well is what is or what are complex needs? …And it's a completely different, kind of, planning for that transition to adult services than it is for most other young people.

R: Totally. And particularly if it's not a, sort of, autism specific provider, you then have that difficulty of generic versus autism specific. And I think that has a real impact. I think where you see it most successfully is when it is somebody that really understands the autism developmental level. You know, and not about actually, we are just generically provide. And you see the lack of understanding, through the lack of training when that happens.

I: Okay. Is there anything else you can think of you wanted to add or tell me about?

R: Not that's coming to my mind but if there is, I'll phone you…

I: Yeah. If you are able to tell me a wee bit more about numbers that would be good. I don't mind, even a, sort of, whether they're more positive or negative or, you know, anything about that. I'd be interested as well why that young person went to ---.

R   Yeah

I: I'm going to turn off the recorder first of all SP1 because we have finished the research conversation. So, I will just switch that off.

End of transcript