Developing Effective Structures for Autistic Learners:
Transitions between Education Settings

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DECLARATION

I certify that the whole of this work is the result of my individual effort, and that all sources have been acknowledged.

Signed CMEvans (Student)

Date   6th June 2022

DECLARATION

I am satisfied that this work is the result of the Student's effort.

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ABSTRACT

Transitions between education settings are 'a pivotal moment' (Fortuna, 2014, p.177) for autistic learners. This dissertation considers the successes, limitations, and importance of such transitions while evaluating current practice and the impacts of this on autistic learners, their families, and professionals in this field. Autism as a condition is a complex field and thus requires a person-centred approach to such transitions – 'a brain-by-brain, strength-by-strength basis' (Grandin and Panek, 2014, p.200). To examine this issue, a literature review was conducted to examine research into the area of multi-agency practice and the barriers to effective support. Furthermore, the views of professionals, families and autistic learners have been considered. With the introduction of the Additional Learning Needs Education Tribunal (Wales) Act (2018) (ALNET) following a decade of austerity that has been further compounded by the impacts of the Covid-19 pandemic, it is important to consider the potential impacts of such legislation on current practice as Wales moves into a new framework. Current research indicates two key themes in the limitations of successful transitional arrangements for autistic learners: austerity and inconsistent multi-agency practice. Several distinct disadvantages are already at play for autistic people: increased levels of deprivation (Welsh Government, 2014 cited in Shaw et al., 2016), co-morbid mental health conditions (University of British Columbia, 2021), and typically poorer socio-economic outcomes in adulthood (Shaw et al., 2016). Thus, it is vital that issues in support are addressed to improve these transitional structures for autistic learners and thus positively impact their wellbeing, their families, and future outcomes. In short, this dissertation emphasises the need for a successful ALNET implementation as well as careful consideration of the successes and limitations as time moves on.

ACRONYM

ALN	Additional Learning Needs
ALNET	Additional Learning Needs Education Tribunal (Wales) Act (2018)
ALP	Additional Learning Provision
AS	Asperger's Syndrome
ASC	Autism Spectrum Condition
ASD	Autism Spectrum Disorder
DSM	Diagnostic Statistical Manual of Mental Disorders
HFA	High Functioning Autism
IAS	Integrated Autism Service
ITE	Initial Teacher Education
ID	Intellectual Disability
IDP	Individual Development Plan
LEA	Local Educational Authority
LFA	Low Functioning Autism
WG	Welsh Government

1. INTRODUCTION

Those with Autism Spectrum Condition (ASC; hereafter 'autism' and 'autistic') particularly struggle with social skills, processing information, coping with change and self-organisation (American Psychiatric Association, 2013 *cited in* Lambe *et al.*, 2018). However, these are the exact skills needed to flourish in education (Larney and Quigley, 2006 *cited in* Fortuna, 2014). Most importantly, due to rigid thinking patterns and dislike of change, it is crucial to get the transition period between educational settings right for the well-being and success of autistic learners; as Fortuna (2014, p.177) discusses, transition periods are 'a pivotal moment' in the lives of autistic learners. However, there is a lack of research into programmes offering transitional support for autistic young people (Lambe *et al*., 2018). As such, this dissertation will consider the strengths and limitations of transitional programmes and why such support is so key to autistic young people within the context of education.

Current research and statistics indicate that autistic learners have several distinct disadvantages compared to their neuro-typical peers during, and as a result of, their education experiences. Firstly, they are at increased risk of not only living in deprivation as children (Welsh Government, 2014 *cited in* Shaw *et al*., 2016), but also these circumstances continuing into adulthood due to typically poorer educational outcomes with only 16% of autistic adults finding full-time paid employment (Hodge, 2018). Finally, there is a burden of care placed upon parents and carers who, in the absence of a successful multi-agency model, are required to liaise with and negotiate with numerous professionals with regards to their child's support needs (Abbott, Townsley and Watson, 2005; Ambitious About Autism, 2019; Busby, 2019). Thus, the

impacts of a poor transitional process affect more than just the autistic learner in question.

It is also important to note that autistic people are more likely to experience a co-morbid mental health diagnosis (University of British Columbia, 2021) indicating their increased vulnerability and need for comprehensive support. As such, this dissertation aims to examine the effectiveness of the person-centred and multi-agency model promoted by the Additional Learning Needs Education Tribunal (Wales) Act (2018) (ALNET) which has recently come to play in this field in order to answer the research question posed:

- *RQ: What are the structures for effectively supporting autistic learners in transitioning between education settings?*

In order to examine this issue, a literature review will be conducted considering several important elements of autism in education. As such, a brief background of the history and development of our understanding of autism will be explored, alongside discussion of its strengths and challenges. This will also lead into discussion of labelling of autism as well as theories regarding disability models and societal limitations and changes in this area. There will also be an examination of the strengths and limitations of the multi-agency model following discussion of the lived experiences of not only professionals working in this field, but the parents and carers of autistic individuals. Most importantly, the experiences of autistic learners themselves will be considered. The above will lead into considerations of the limiting factors present in accessing and developing transitional programmes, namely the impact of austere budgets and a lack of availability for autism informed training for professionals working within these

multi-agency models. The introduction of the ALNET is an important consideration throughout this dissertation. As such, it is key to investigate potential pitfalls in the implementation of this model by examining the successes and limitations of similar services rolled out in recent years in Wales. Finally, the characteristics of successful transitions will be considered to inform future practice.

Following this, the results and discussion section will further examine the two key issues raised: implications of austerity and inconsistent multi-agency support. The main issues highlighted throughout the literature review will be considered leading to a series of recommendations designed to improve provision of transitional arrangements for autistic learners throughout their education and thus their educational and socio-economic outcomes in the future. Given that understanding of autism is new and ever evolving, it would be easy to underestimate the impact of successful transitions on autistic learners and their families. It is hoped that this dissertation will explore the positive impacts and characteristics of successful transitions between education settings in order to further inform practice as the ALNET develops on the ground in Welsh education settings.

2. LITERATURE REVIEW

2.1. Introduction

Fortuna (2014, p.178) says that 'transition can have a long-lasting effect on the behaviour and achievement of the [autistic] student.' Put simply, this illustrates the huge need for getting this process right. The National Autism Society highlights the difficulties and challenges found in such 'life changing' transitions (National Autism Society, 2020) while advocating for early planning with the input of autistic learners, their parents/carers, and professionals. As such, this literature review will explore several key areas in this process and evaluate the support currently available for such individuals.

Firstly, the background and diagnostic criteria for autism will be discussed in order to demonstrate the importance of support for such individuals (Fortuna, 2014; Grandin and Panek, 2014) and explain key definitions in the field. Understanding such definitions is critical in developing an understanding of this complex condition as evidenced by the need for autism informed training (Ravet, 2017). Given frequent advice to plan transitions with the input of autistic learners and their parents/carers alongside professionals (Grandin and Panek, 2014; National Autism Society, 2020; Abbott, Townsley and Watson, 2005), a central aspect of such a review is examining the perspectives of those involved in the process. That is: parents, staff and autistic young people themselves. Autistic young people are the experts in their own condition with those close to them providing key insight into their support needs. It is interesting to note that parental and staff views on the success of transitions differ greatly (Fortuna, 2014) and as such this will be explored in more depth. Furthermore, in 2018, the

ALNET introduced a legislative framework for support offered to young people with Additional Learning Needs (ALN) aiming to roll out across Wales in the academic year 2021-2022 (Welsh Government, 2021b). On a basic level, this framework focuses on improving equity and clarity in the education system for learners with any ALN. Specifically, it is hoped to streamline current systems while promoting a person-centred and multi-agency approach while ensuring consistent rights across educational settings, as well as Welsh language rights in this field. A crucial aspect of this legislation with regards to this dissertation is a focus on improving transitional arrangements between education settings (SNAP Cymru, 2022).

A central element of the ALNET is the encouragement of a person-centred and multi-agency approach with improved communication between service users, their parents and guardians and services (ERW, 2018). As such, this submission will critically explore a range of views and opinions from theory, policy, and practice-based sources in order to establish an expansive view of the lived experiences and reality of those under the researchers' gaze (Fortuna, 2014; Lambe *et al.*, 2018; Attwood, 1998). Having said this, while Welsh Government (WG) grants have been issued to support the development of a person-centred approach (ERW, 2018), there has been much concern regarding a lack of funding in Wales. In 2019, research led by the WG discussed this worry in depth describing schools and other educational facilities as 'lack[ing] resources' to properly meet the aims of the ALNET (National Assembly for Wales, 2019a). As such, this literature review will also examine the impact of such budgeting constraints on the availability and quality of autism support.

The difficulties faced by autistic students in education have been proven. Pancer *et al.* (2000, *cited in* Lambe *et al.*, 2018) explained the negative trajectory seen in the mental health of many autistic young people during the first 6 months of their university experience. Furthermore, Lambe *et al.* (2018) found poor outcomes are common for autistic people without an intellectual disability (ID) suggesting a void in support. In addition, the barriers to diagnosis and thus the lack of support for such individuals will be considered. In short, this literature review will delve further into this issue and support understanding of the importance of successful transitional structures and what these might look like, and to do so, we will examine successful interventions for those autistic pupils and students.

2.2. Autism: Changing Definitions

The phenomenon of autism was first described by Leo Kanner, a child psychiatrist, in an article in 1943 (Baron-Cohen, 2015) in which he used the term 'infantile autism.' Coincidentally, the following year, Hans Asperger discussed what can roughly be translated to Autistic Personality Disorder (Attwood, 2015). However, as described by Baron-Cohen (2015), Asperger had actually been lecturing about this condition as early as 1938. Asperger described delayed social maturity and reasoning, impairments in verbal and non-verbal communication, impairments in showing and controlling emotions, and a tendency to obsess over any particular topic (Attwood, 2015). However, while Asperger noted that this condition is also seen in adults (Attwood, 2015), Kanner 'insisted that autism was a condition of infancy' (Baron-Cohen, 2015, p.1330). The concept of autism was not well-known. However, until Lorna Wing published an article in 1981 in which she coined the phrase 'Asperger's Syndrome'

(AS) (Baron-Cohen, 2015). Wing was able to elaborate on Asperger's research to update the definition of the condition. For example, Wing (1981) also found aspects of patients' developmental history showed patterns: babies who showed no interest in babbling and communication, and young children unable to use their imagination to play with others. Additionally, Asperger (1944, *cited in* Wing, 1981, p.117) had argued that older patients with the condition had 'highly sophisticated linguistic skills.' However, Wing concluded that much of this vocabulary was copied (sometimes inappropriately) from other sources. In fact, she found that some individuals may have a better understanding of obscure words than words in everyday use (Wing, 1981). Furthermore, Wing (1981, p.118) found that, rather than how 'Asperger described people with his syndrome as capable of originality and creativity in their chosen field,' that the individuals she encountered were rigid in their thinking patterns, taking a 'narrow, pedantic, but logical, chain of reasoning' (Wing, 1981, p.118). Following Wing's research, the condition AS was added to the Diagnostic Statistical Manual of Mental Disorders (DSM) in 1994. However, some still argued it was a milder form of autism (Autism Society, 2020). In 2013, the DSM-5 was published, and, in this edition, the term AS has been replaced, coming under the banner of 'Autism Spectrum Disorders' (ASD). AS is now considered to be Level 1 of this umbrella term (Attwood, 2015). Attwood (2006, p.18) is concerned that 'the removal of the term . . . will negatively affect the self-identity of' those with diagnoses of [AS].' Furthermore, he worries that the term 'autism' may put some off seeking a diagnosis.

As previously noted, the National Autism Society says, 'you don't have to be diagnosed to have self-belief' (National Autism Society, 2021) and notes that many who suspect

they are on the Autism Spectrum are happy to stay self-diagnosed. Additionally, given that Baron-Cohen *et al.* (2005) have developed an Autism Quotient for Adults, it can be presumed that Kanner's notion of autism being a childhood condition is incorrect. As such, the autistic children and young adults discussed in this study are still facing the challenges of autism in their day-to-day lives. Such challenges encountered in the lives of autistic individuals are multi-faceted; however, they are listed under two sub-headings in the DSM-5: 'social communication' and 'restricted, repetitive behaviours' (American Psychiatric Association, 2013). Firstly, Attwood (2015) describes individuals who struggle to build and maintain relationships, perhaps in part due to their lack of understanding of non-verbal language and 'impaired pragmatic language abilities' (Attwood, 2015, p.13), and perhaps further inhibited by a lack of understanding as to 'what a friendship entails' (Attwood, 2015, p.13). Such individuals can be 'in an almost constant state of alertness and anxiety' (Attwood, 2015, p.29) as they try to navigate the world via intellect rather than intuition. Furthermore, those with ASD deal with a rigidity of thinking in their day-to-day lives: 'there is a determination to maintain consistency in daily events' (Attwood, 2015, p.14) which can lead to anxiety if not followed. Many with ASD also have special interests about which they may monologue to others or become so focused on they neglect other aspects of their lives. Finally, sensory sensitivity is a great challenge to many with adverse reactions to smells, sounds or even touch (Attwood, 1998). In fact, this can be so overwhelming that it is sometimes the cause of social withdrawal as a coping mechanism (Attwood, 2015). Furthermore, support is complicated by the variable nature of challenges day to day whereby sometimes individuals may cope well and later struggle with the same circumstances (Attwood, 1998). One must note that the challenges faced by each

person with ASD are unique. There cannot be a one size fits all approach (Grandin and Panek, 2014; Fortuna, 2014).

2.3. Autism: Challenges and Labelling

It is clear that the challenges presented by autism are significant and impact heavily upon individuals' lives. However, Baron-Cohen has argued that the term Autism Spectrum Condition (ASC) should take precedence over the more negative Autism Spectrum Disorder (Baron-Cohen, 2017). He highlights the fact that, under certain conditions, autism is not a disorder as it is not disabling. It can, in fact, be an asset to the individual. He believes that the term 'Autism Spectrum Condition' both identifies the challenges individuals face as well as the strengths it can bring. He describes that in an environment which is supportive and autism-friendly, 'the person can function not just well, but sometimes even at a higher level than a typical individual' (Baron-Cohen, 2017, p.746). As such, this clarification between the terms ASD and ASC is critical. The term 'disorder' cultivates a view of autistic people 'as broken humans who are ill and require fixing to enable them to function normally in society' (Robertson, 2009, p.1). However, Baron-Cohen (2017, p.746) identifies that 'there is no single way for a brain to be normal' advocating for a more social model of disability whereby the problem of disability is acknowledged, however, the cause of such challenges in this model is said to be a lack of adaptations offered routinely by society (Oliver, 1990). This change in mind-set is pronounced when reflecting on historic methods of institutionalising autistic people and those with other IDs previously believed to be 'humane' (Grandin and Panek, 2014). Specifically, Baron-Cohen (2017, p.746) stated that the word 'disorder should be used when there is nothing positive about the

condition.' Grandin and Panek (2014, p.200) discussed 'cultivating the autistic mind on a brain-by-brain, strength-by-strength basis' in order to create 'valuable, even essential, contributors to society' – further identifying the positives that the autistic population can create for society when said society is autism-friendly. Consequently, put simply, ASC is a fairer depiction of these individuals. Furthermore, so-called 'functioning labels' are viewed as harmful by many Autistic individuals (Burns, 2019). Typically, autistic people are divided into 'high-functioning' autism (HFA; verbal autistic people without an ID) and 'low-functioning' (LFA; sometimes non-verbal autistic people but always with an ID) (Bottema-Beutal *et al.,* 2021; Lester, 2012). In both camps, autism seems to be described as something negative 'that should be fixed' (Bottema-Beutal *et al.,* 2021, p.18; Hodge, 2018). Stechyson (2021), mother of an autistic child, writes:

> I now understand that "functioning" labels are also ableist, harmful and inaccurate, because how do we really know how well someone is functioning? And what even is "functioning" anyhow – does it mean acting like everyone else?

Given that 78% of autistic children have a co-morbid diagnosis of at least one mental health condition compared to only 14.1% of non-autistic children (University of British Columbia, 2021), it is clear that the autistic experience can have a profound negative impact upon the well-being of autistic people when compared to their neuro-typical counterparts. This brings into question whether those who may be described using the term HFA are actually high functioning at all. Bottema-Beutal *et al.* (2021) argues that such language perpetuates a system whereby 'autistic people are inferior to nonautistic [sic] people' (p.18). Further to this, there are concerns that HFA constructs the idea that individuals in this category are 'savants or worthy of public attention only after

they have overcome their autism' (Osteen, 2008 *cited in* Lester, 2012) relating back to Stechylon's (2021) question 'does [HFA] mean acting like everyone else?' Burns (2019) highlights the concern that a label of HFA could in fact limit support offered. Despite these negative connotations, a study by Ruiz Calzada, Pistrang & Mandy (2012) found that autistic participants did not have a preference when asked to choose between HFA and AS. In fact, some parents preferred to use HFA as they felt that the inclusion of the word 'autism' caused less confusion. However, it must be noted that others preferred AS 'as they felt it holds less stigma' (Ruiz Calzada, Pistrang & Mandy, 2012, p.239). Leekam *et al*. (2000, *cited in* Ruiz Calzada, Pistrang & Mandy, 2012) argued that a label of HFA or AS may be preferable to parents due to the connotations of improved social skills and high intelligence. Nevertheless, more recently, it has been debated whether Hans Asperger's name should be associated with the diagnosis given his links to Nazi Germany and eugenics (Czech, 2018).

Conversely, First *et al*. (2004, *cited in* Ruiz Calzada, Pistrang & Mandy, 2012) state that distinctions such as HFA and LFA are important in allocating support mechanisms and supporting professionals in decision making. While many consider such terms ableist (Burns, 2019; Bottema-Beutal *et al*., 2021; Stechyson, 2021), Kenny *et al.* (2015) found no clear consensus on how best to describe autism in the UK autism community. However, it must be noted that their study included autism professionals as well as autistic people who usually had differing views. Autism research has historically been conducted by neuro-typical people highlighting a gap in autistic informed research and thus such harmful labels being perpetuated by neuro-typical researchers (Bottema-Beutal *et al.*, 2021). Barnes (2003 *cited in* Office for Disability

Issues, 2011) notes the historic failing of including disabled people in research into their own lives and conditions. As such, the Office for Disability Issues (2011) stresses the importance of doing so due to the improved quality of research when such views and experiences are considered. Therefore, it is important to consider autistic views regarding functioning labels and respond accordingly in policy and practice.

Functioning labels and perceptions of autism may stem from the traditional model of disability as described by Robertson (2009, p.1): 'a deficit model has largely dominated most professional and academic discourse on autism over the last century.' Such a standpoint on the condition holds the possibility to limit student development and progression as they are pigeon-holed into preconceived idea of 'severely limited by a disordered neurology' (Robertson, 2009, p.1). As previously discussed, this view ignores possible strengths and talents within the autistic individual that could otherwise be honed and encouraged. Harry and Klingner (2007, p.16) further elaborate, explaining that it is not the language itself that is the issue, but 'the belief system that this language represents.' For example, in order to access support services, one must fall into the bracket of having 'proof of intrinsic deficit' (Harry and Klingner, 2007, p.17) immediately putting these challenges at the forefront of the professionals' view and immediately shifting the discourse away from the potential positives of the neuro-type.

Taylor and Seltzer's (2010) study illustrated the impacts of a lack of support routes for autistic people but specifically without an ID. This subgroup of young people are disabled by their condition but do not meet enough criteria to access more complex

support: their needs are not significant enough to reach the threshold. As a result of such occurrences, 'outcomes in adulthood for autistic individuals without an ID are poor' (Lambe *et al.*, 2018, p1531). Taylor and Seltzer (2010) also identified a group who, while considered to have fewer needs than other autistic young people who were receiving more complex support, were still struggling to live independently at university and beyond. Burns (2019) considers this phenomenon when discussing functioning labels, specifically their HFA label: 'some of the challenges I face are not taken seriously, with whether I am truly struggling being called into question.' It is thus clear that there is a gap in the support available to autistic people who do not fit the standard criteria for support but equally that functioning labels are not the only criteria that should be considered when offering support.

Conversely, most recently, a more positive outlook has emerged which Robertson (2009, p.1) calls 'the neurodiversity perspective' which embraces autistic people's differences and sees such individuals as possessing 'a blend of cognitive strengths and weaknesses.' Hodge (2018) sums up a common view held among the autistic community:

> Ask autistic people what the problem is and they won't answer that it is because there is something wrong with them. Instead they will tell you about how other people don't understand them and so reject and exclude them.

Thus, it is clear that the social model of disability would be a positive step forward in autism acceptance. Robertson (2009) and Hodge's (2018) research into this area has been followed by research such as Bottema-Beutal *et al.*'s (2021). These studies are indicating a shift towards a social model of disability which could help change the

discourse surrounding seeing autism as intrinsically negative by balancing professionals' considerations with strengths and other mitigating factors.

A further challenge in the field of autism is that areas of high levels of deprivation are more likely to have a higher proportion of pupils with ALN. A report issued by the Joseph Rowntree Foundation (Shaw *et al.*, 2016) explains that there are a variety of potential causes for this. For example, complex behavioural difficulties may stem from a challenging home-life or families could have been pushed into poverty by the financial demands of a disabled child (Shaw *et al*., 2016). In fact, the WG has found that Welsh pupils who are eligible for free school meals are twice as likely to also be diagnosed with an ALN (Welsh Government, 2014 *cited in* Shaw *et al*., 2016). However, a study by Durkin *et al.* (2017) challenged this view with data suggesting children from lower economic backgrounds in the USA are less likely to be diagnosed as autistic. Although, this must be read in the context of a country without a health service which is free at the point of access, and thus, such individuals are perhaps less likely to be able to access diagnostic assessments.

Such issues of increased prevalence of ASC among deprived groups may also be exacerbated by 'inter-generational disability' (Shaw *et al*., 2016, p.10) whereby parents with ALN are statistically more likely to be low earners and thus spark a cycle of poverty. Additionally, while navigating a 'fragmented' social support model is challenging for any parent these issues must be compounded by parents' own ALN (Bernardes *et al.*, 2015 *cited in* Shaw *et al.*, 2016, p.19). Data shows that in 2014, learners with ALN were 'three times less likely' to achieve at least 5 GCSEs at grades

A* to C (Grigg *et al*., 2014 *cited in* Shaw *et al.*, 2016, p.13). This issue is further compounded by the figure of 70% of excluded students having ALN and thus unable to sit their GCSE exams (McInerney, 2015). Even small grade increases can have a significant impact upon economic success in the future, performing one grade higher than a fellow student could lead to an increase in lifetime earnings of £200,000 (Department for Education, 2021). Furthermore, the Department for Work and Pensions describes A-Level qualifications as 'a significant protective factor against poverty in later life' (Department for Work and Pensions, 2014 *cited in* Shaw *et al.*, 2016, p.12). Thus, accessing supportive educational opportunities is a clear marker for economic success.

In Wales, there are several areas of the country with small areas of deep-rooted deprivation. The Welsh Index of Multiple Deprivation (WIMD) identifies one such area as Rhondda Cynon Taf where the LEA also has some of the highest concentration of top 10% deprived areas in Wales specifically in the domain of education (Statistics for Wales, 2019). However, it is receiving £725 less per pupil than Ceredigion LEA which is one of three areas with no areas in this top 10% of this category (Statistics for Wales, 2019). Given that the average junior class size in 2021 was 26.2 students (Welsh Government, 2021a), this amounts to £18,995 difference in funding for such a class – an amount which could likely fund an additional Learning Support Assistant's (LSA) average salary in Wales of £16,905.30 (Check a Salary, 2022). As such, it seems that funding does not positively correlate to deprivation and thus likely ALN levels.

These issues are compounded further when combined with an additional protected characteristic such as gender or race. Zuckerman *et al*. (2017) found that Latino community members in the USA experienced more barriers than their white counterparts. Latino children 'had fewer current therapy hours and more unmet therapy needs' (Zuckerman *et al*., 2017, p.1) as well as parents who had less trust in professionals. Additionally, English language skills and cultural perceptions of autism were a barrier to accessing diagnosis and support (Zuckerman *et al*., 2017) linking back to traditional models of disability where autism may be seen as a 'problem' or deficit (Hodge, 2018).

Further barriers are seen when considering gender. Lockwood Estrin *et al*. (2020, p.454) describe the likelihood of a 'female autism phenotype' where autistic females may present differently to autistic males. They recognise that autistic characteristics can be masked more effectively in females (Lai *et al*., 2019 *cited in* Lockwood Estrin *et al.,* 2020). As such, one must wonder whether the figures reported for the rates of autism in females are correct as many women and girls may go undiagnosed and thus be missing out on vital support systems. This also suggests that our current perceptions of autism are male focussed leading to stereotypes and misconceptions about the presentation of autism (Happé, 2018). Additionally, recent research by Swansea University found that, on average, girls were diagnosed 6 years later than boys leading to gaps in support as they began their school careers (Thomas, 2022). Attwood and Grandin (2006, p.80) explain that hurdles and difficulties in the young lives of autistic women are 'prolonged and more frustrating' as a result of this lack of understanding and therefore support. It has also been found that 23% of women receiving in-patient

treatment for anorexia also meet the criteria for an autism diagnosis (Ontiveros, 2019) indicating the incredible impact autism can have on one's mental health – especially when undiagnosed. The increased mental health risks present two issues for autistic women and girls. Firstly, when presenting with such issues, due to male autism stereotypes, doctors and mental health professionals are unlikely to identify autism and thus these autistic females miss out on appropriate support (Happé, 2018). Happé (2018) also notes that autistic girls often deliberately copy others' social behaviours and styles in order to hide their autistic traits. Such constant pressure to conform can only increase the risks to their mental health but also potentially limits their access to support as their traits and difficulties are not as apparent to an outside observer.

Such challenges for autistic learners as well as issues deriving from labelling (or lack thereof) support the need for effective transitions between education settings. Thus, the importance of developing effective structures for such transitions cannot be underestimated.

2.4. Autism Educational Transitions: Staff, Parent and Student Perspectives

Bottema-Beutal *et al*. (2021) note that autistic perspectives are increasingly being considered by researchers. However, previous research demonstrates that the perspectives of staff, parents and students can be vastly different. As Topping (2011 *cited in* Fortuna, 2014, p.179) explained, a teacher's perspective often stemmed from academic attainment, whereas 'parents and students...placed greater emphasis on social and emotional issues.' In a study by Dillon and Underwood (2012), it was found that parents consistently scored their ALN children's anxiety at a higher level than staff

during a transition process from primary to secondary education. To be precise, 3 out of 5 parents recorded 'high' or 'very high' levels of anxiety with further high scores in both emotional distress and social difficulties. As Fortuna (2014) explains, this illustrates 'parents' heightened concern' during the transition process. However, one must wonder how often a parent's own concerns are projected onto their child. It has been found that, while parents are sometimes more attuned with their child's socio-emotional state, it is sometimes staff who are more accurate with their observations in this area (Fortuna, 2014). Therefore, it could be presumed that sometimes parent's own concerns skew their perceptions. Parsons *et al.* (2009 *cited in* Fortuna, 2014) found that parents of autistic children found transitions more challenging and stressful when compared to parents of children with other disabilities. For example, Dann (2011 *cited in* Fortuna, 2014) found that parents were anxious about how their child might cope in a new setting – an understandable worry given autistic people often struggle with change and favour routine (Attwood, 2015; Wing, 1981).

Evidence also suggests that staff perceptions are not always accurate. For example, Dillon and Underwood (2012) found that the perceptions of staff were often significantly divergent to parents' beliefs. Furthermore, in one example, a student reported a negative experience while staff had perceived it positively (Fortuna, 2014). Similarly, while parents consistently rated their child's anxiety as high, staff were not good at predicting social rejection that children might face when in a mainstream environment (Jones and Frederickson, 2010 *cited in* Fortuna, 2014) - a common worry for autistic learners (Fortuna, 2014; Lambe *et al.*, 2018). While school staff are on the front line within education, regularly witnessing the successes and stumbling blocks of

these young people during the transitioning process, the socio-emotional state of children is 'less quantifiable' than academic progress (Fortuna, 2014, p.179). Furthermore, young people reported significant anxiety around several issues in a study by Lambe *et al.* (2018) when examining the transition to university level education. It is therefore clear that neither parent nor staff perceptions can be wholly accurate. One must consult the autistic young people in question to gain deeper understanding of the issues which they face in order to improve outcomes and research results (Office for Disability Issues, 2011).

Attwood (1998) notes that many fellow students throughout education, particularly during the teenaged years, are unwilling to tolerate autistic traits. The impact of such intolerance is long lasting. Due to past bullying, it was reported that socialising is considered 'dangerous and exposing' (Lambe *et al.*, 2018, p.1534) and anxiety regarding 'doing or saying the wrong thing and the social consequences of that' (Lambe *et al.*, 2018, p.1535) is extremely heightened during this transition. Ontiveros (2019) quotes one autistic girl: '"I don't have friends mummy, no-one likes me"' further illustrating the enormous impacts of such incidents. Additionally, due to such worries, participants consistently attempted to pre-empt problems and put effort into avoiding social mistakes with unstructured time outside of lessons causing 'high levels of anxiety and discomfort' (Lambe *et al.*, 2018, p.1534). Such behaviour is likely to be more common in autistic women and girls due to their increased probability to mask their autistic traits (Happé, 2018) and increased anxiety regarding obtaining and keeping friendships (Fortuna, 2014). As previously stated, staff often underestimated these concerns in a similar study (Dillon and Underwood, 2012). While autistic people often

struggle to imagine what their future might look like in various scenarios, they are regularly astute 'show[ing] insight into their behaviour, challenges they face, self-guided management strategies and the perception of others' (Lambe *et al.*, 2018, p.1539). Such skills are often overlooked due to assumptions about autism and 'deficits' (Harry and Klingner, 2007, p.17) in keeping with this diagnosis. Such understanding and insight can only feed into the anxiety surrounding transitions as, while the future is unknown, the challenges they face and how others perceive them is not. Again, it seems the social model of disability would support the nurturing and respect of such strengths.

Gurbuz, Hanley and Riby (2018) highlight the importance of social support alongside academic as autistic learners begin their university studies given the increased risks of isolation, bullying and loneliness in this group. Autistic young people were likely to report 'feeling excited about the academic component of university' (Lambe *et al.*, 2018, p.1535) and it is in this area where they might find the most support. However, it is successfully navigating the social world which is the most daunting: 'they spoke about 'looking foolish' or 'stupid,' 'being a terrible person,' 'a nightmare housemate' or 'loner'' (Lambe *et al.*, 2018, p.1535). It is therefore imperative that educational establishments promote social as well as educational support for autistic students as well as ensure all views, including the autistic person's, are considered. This is perhaps best modelled by the multi-agency approach.

2.5. Multi-Agency Approach to Support for Autism

Current educational and social policy 'give a high priority to an integrated approach to service provision' (Abbott, Townsley and Watson, 2005, p.155) following several years of research identifying families' desire for more effective working partnerships between professionals (Mukherjee *et al.*, 1999 *cited in* Townsley, Watson and Abbott, 2004; Townsley and Robinson, 2000 *cited in* Townsley, Watson and Abbott, 2004). Such thinking has been reinforced by the introduction of the ALNET which encourages increased collaboration between social services, education and other agencies involved in the care and support of young people with ALN. Furthermore, Individual Development Plans (IDPs) and Additional Learning Provisions (ALPs) will include clear information about "which agency is responsible for delivering the individual elements" (Welsh Government, 2018a). Having said this, there is a lack of evidence as to how effective multi-agency working is in practice (Sloper, 2004; Townsley, Watson and Abbott, 2004).

Families of those with ALN can have contact with over 10 professionals in the course of a year in the care of their child (Abbott, Townsley and Watson, 2005). Without a multi-agency approach this can quickly become confusing and potentially 'lead to a lack of continuity and co-ordination' (Abbott, Townsley and Watson, 2005, p.155). Such difficulties are summed up by parents in news reports:

> The amount of paperwork you have to read and the amount of phone calls you have to make because you are on a waiting list... it is incredibly time consuming (Busby, 2020).

Busby (2020) reports parents giving up careers in order to support their children through the system: "'it overtakes your life just trying to get that support.'" There is also a worry that not streamlining access to these much-needed services risks children falling through gaps between what each service is able to offer (Sloper, 2004). As such, multi-agency working could have the potential to improve outcomes for the young people involved by simplifying access to what is currently a complicated and overwhelming process. However, Sloper (2004, p.572) discussed that multi-agency working 'challenges existing professional cultures' as well as highlighting the barriers to building such a service, including issues such as time constraints, lack of communication, unclear roles and responsibilities and insufficient funds and resources; findings supported by Townsley, Watson and Abbott (2004). Conversely, a later study found that professionals were highly positive about their experiences of multi-agency working (Abbott, Townsley and Watson, 2005). This is perhaps in part due to their understanding of the limitations of single service operations where it is 'difficult to offer holistic support to a family' (Ball, 2014, p.329).

First and foremost, the improvement in communication between all involved was seen as a key component of a successful multi-agency approach (Abbott, Townsley and Watson, 2005). This also enhanced the relationships between agencies, professionals and families, and gave professionals an increased insight into the lives of those living with a disabled child (Abbott, Townsley and Watson, 2005). However, it should be noted that research to date largely focuses on professionals' perspectives and thus 'cannot provide valid evidence on outcomes for users' (Sloper, 2004, p.575). Although, Abbott, Townsley and Watson (2005) found that families were benefiting from

improved consistency, later media evidence from parents suggests that this barrier has not been overcome to date (Busby, 2019; Busby, 2020) indicating ongoing challenges to such structures and provision.

2.6. Education and Autism: Challenges to Provision

Two main themes emerge when discussing challenges to provision with regards to autism: financial barriers and gaps in professional knowledge or attitudes. Largely, both these strands overlap and interweave throughout the education sector. Attwood (1998) describes teachers who simply do not have enough time to spend providing support and flexibility for these students. Such issues can only be exacerbated when teachers also do not have the necessary understanding of this variable and individual condition, for example, according to Attwood (1998, p.174) there are some teachers who simply 'have no concept of this type of disability.' This issue is perhaps perpetuated by the aforementioned deficit model of disability. Attwood and Grandin (2006) have long promoted a thorough consideration of strengths when developing transition support. However, it must be assumed that such attitudes take not only time but training to filter down into the general domain. Unfortunately, Abbott, Townsley and Watson (2005) found concerns of a lack of funding to support new measures and services. An issue which may prevent access to such training.

Teaching union NASUWT (2018) conducted research into this issue which indicated barriers to accessing training when it is available. They found that not only did teaching and support staff struggle to access quality training for ALN but when they did, they were often required to complete this in their own time. Furthermore, they reported that

schools do not have enough money to pay for what is often expensive training (NASUWT, 2018). It was also found that 40% of respondents to a National Education Union survey stated that their access to continuing professional development had decreased over the previous five years to 2017, indicating a gap in knowledge growth for teaching staff in many pedagogical areas (National Education Union, 2018). However, Attwood (1998) suggests that such experience is not necessary to offer successful support, rather, the learning environment and building relationships should be the focus. Having said this, The National Education Union found that '84% [of respondents] said that workload was manageable only "sometimes" or "never"' in the teaching profession (National Education Union, 2018, p3), and thus, staff are unlikely to have the time to foster such relationships and adapt their classroom environments to specific needs. Given such limitations, it would be difficult for teaching staff to adequately prepare differentiated lessons and resources for those with additional or complex needs with the time available to them for preparation.

A study by Ravet (2017) investigated the support available for students undertaking initial teacher training (ITE) with regards to providing for the needs of autistic learners. It was found that most student teachers in the study felt unprepared for the challenge of supporting autistic pupils: '"But how do I teach them? I don't know about different needs. It's terrifying."' (Ravet, 2017, p.15). It was agreed that autism provision was a necessity and that teachers tried their upmost to support such students. However, a concerning aspect was a clear consensus that often their supervising teachers and tutors had a lack of knowledge on this important issue themselves (Ravet, 2017). Simply put, one student teacher described this missing piece of ITE training as '"anti-inclusive"'

(Ravet, 2017, p.16). This gap in training during ITE further suggests the importance of additional support staff with such knowledge and experience to support autistic learners. Furthermore, two thirds of respondents to NASUWT's (2018) research believed that the support available for learners with ALN had decreased over the previous five years. Both a lack of training and available support leads to the concern that there is not enough funding to properly provide for learners with ALN with the severity of this issue worsening since the implementation of austerity measures.

In 2019, Lewis (2019) reported on the significant decrease in school funding per pupil in Wales over the previous decade. It was estimated that there would be a 'cut of 9% or £500 per pupil in real terms between 2009-10 and 2020-21, if spending plans stay the same' (Lewis, 2019). In the same year, headteachers were quoted as saying school budgets were '"at breaking point"' (Wightwick, 2019) with approximately 70% of schools in a financial deficit with Downe and Taylor-Collins (2019) finding that the current levels of spending on education are not sustainable for council budgets. Downe and Taylor-Collins (2019) furthered Lewis' (2019) argument in regards to the data on school budgets, explaining that, while the budget itself might be protected, it will have declined in real terms due to inflation. As such, concerns have been raised that when school budgets require savings that 'these cuts could hit the most vulnerable children because teaching assistants providing additional support to those children were usually the first to go' (Downe and Taylor-Collins, 2019, p.34). Moreover, the WG recognised that the Covid-19 pandemic had a disproportionate impact on learners with ALN (Welsh Government, 2021c) thus compounding issues already in motion due to austere budgets. In an attempt to alleviate this concern, they pledged £9.8 million to address

such disparities in 2021 (Welsh Government, 2021c) followed by an additional £4.5 million in 2022 (Welsh Government, 2022). While the impact of these funds remains to be seen, there is already a clear inconsistency in budgets across Welsh LEAs. For example, in Rhondda Cynon Taf, spending stood at £5,731 per pupil in 2019 while in Ceredigion it was £6,456 (National Assembly for Wales, 2019b). As such, one must wonder of the difference in support available in each area for those with ALN. However, this disparity does not necessarily correlate with increased levels of poverty in the area and therefore increased likelihood of ALN learners.

Currently, funding for ALN in Wales is not ring-fenced; it is included as part of the entire school budget (National Assembly for Wales, 2019a). As such, decisions regarding its utilisation are made by each local education authority (LEA). Therefore, while statistics are released annually outlining these figures, this data does not necessarily build a realistic picture of the funding available to support individual young people with ALN. There is, however, evidence of young people missing out on vital support. One pupil in Fortuna's (2014) study only had access to a support assistant as another pupil in the class had one. Similarly, news reports discuss parents' long fights for funding to adequately support their children with parents describing a '"battle every step of the way,"' fighting '"bureaucracy"' (BBC, 2020) and giving up careers to support their children without adequate school placements (Ambitious About Autism, 2019; Busby, 2019). Furthermore, despite a 20-week statutory deadline in current legislation for the development and implementation of Education, Health and Care Plans, some parents reported over 18 months for their child to be assessed (Ambitious About Autism, 2019). Finally, exclusions for autistic young people have risen 60%

since 2011 (Ambitious About Autism, 2019) and, in 2014, 70% of excluded children had registered ALN (McInerney, 2015). Both data and media evidence clearly suggest a lack of funding and the significant impact this has on the autistic young people and their families trying to navigate the current system as they suffer the impacts on their mental health with Critchley (2019) reporting that excluded autistic students are at a higher risk of suicide attempts. Furthermore, exclusions lead to a lack of opportunities to sit GCSE exams and continue to further education (McInerney, 2015), thus, protecting their future socio-economic success (Department for Work and Pensions, 2014 *cited in* Shaw *et al.*, 2016). While Townsley, Watson and Abbott (2004) found that the sites in their study were constrained by lack of funding, waiting lists and staffing levels when trying to reach their goals in multi-agency work, such incidents of inadequate funding have worsened since the financial crash of 2008 and an austere budget. More specifically, Ball (2014, p.321) discusses the pressures of inadequate budgets 'undermining efforts to provide multi-agency early intervention for families.' In fact, they go as far to say that such budget constraints are re-enforcing generational class inequalities in the system (Ball, 2014).

Professionals in Ball's (2014) study were greatly concerned by budget limitations and their impact on services provided, waiting lists, collaboration, and rising demand. In short, achieving the aims of multi-agency working was challenging in an austere climate. One social worker described '"fire-fighting"' and '"responding to crisis because we don't have the capacity to respond at an earlier level"' (Ball, 2014, p.325). As such, some aims of multi-agency working are missed while dealing with more urgent and immediate issues. One professional felt that they were teaching their service users

to cope with issues rather than finding solutions (Ball, 2014). Furthermore, the National Audit Office (2013 *cited in* Ball, 2014, p.326) report found that different departments in government had varying distinctions between 'early action' and 'reactive services' thus causing inconsistencies across said services. This standpoint was backed up by Townsley, Watson and Abbott (2004, p.31) where professionals felt unable to 'respond flexibly to the real needs of families and children.' Such issues can only have been exacerbated during and following the Covid-19 pandemic where, not only were vulnerable children feeling more significant impacts from the circumstances than their peers (Welsh Government, 2021c), but professionals were unable to offer practical support with disabled people described feeling '"forgotten"' (Clegg, 2021).

While in the adult social care domain, a report into the launch of the Integrated Autism Service (IAS) in Wales highlights similar issues. The service was created to offer a multi-agency hub to autistic adults and those seeking diagnostic assessments in Wales rolling out from 2017 (Holtom and Lloyd Jones, 2019). Feedback on the service has been extremely mixed across the nation largely stemming from confusion over what the service can offer (Holtom and Lloyd Jones, 2019) and interestingly '"there are major disconnects between what the Welsh Government says the integrated autism service will do and what it does on the ground"' (Mosalski, 2019). Service users have described the support offered as '"post code lotter[ies]"' (Holtom and Lloyd Jones, 2019, p.150) further illustrating the frustration caused by such disparities. Holtom and Lloyd Jones' (2019, p.150) report found 'weakness and inconsistencies' in accessing assessments and support across Wales. Furthermore, many service users and professionals felt that the roll out of the service had been 'too rushed' (Holtom and Lloyd Jones, 2019, p.151)

and that the premature announcement of the service had unfairly raised expectations of what it would be able to offer to autistic people and their families. Importantly, a key complaint was the lack of similar support available for children (Holtom and Lloyd Jones, 2019). As previously stated, levels of support vary across Wales, with extremely variable waiting lists for assessment and support depending on locality and with some service users feeling abandoned post-diagnosis depending on area (Holtom and Lloyd Jones, 2019). Mosalski (2019) noted that funding was an issue for the service with this no doubt compounding the inconsistencies across the hubs. However, when support was received, service users were very positive and Holtom and Lloyd Jones (2019, p.65) report that, while issues were seen in the initial roll out, these issues were 'improved markedly' by 2019. Additionally, the North Wales service was praised for its person-centred approach (Holtom and Lloyd Jones, 2019). Having said this, there is still ongoing concern regarding resources, funding and an overburdened system. The shaky roll out of the IAS for adults illustrates the difficulties in establishing a cohesive and well-run multi-agency model.

It is hoped that the improved legislation in the previous decade may mitigate budgeting worries. In 2017, the WG pledged a £20 million package to quickly implement a person-centred approach in Wales based on the ALNET (Welsh Government, 2017) for children and young people in education. It is hoped that this funding will improve access to support and also improve training prospects for professionals to better understand specific conditions such as autism. Additionally, a further total of £14.3 million has been pledged by the WG to combat the impacts of the Covid-19 pandemic (Welsh Government, 2021c; Welsh Government, 2022). However, as previously

stated, even significant change will take time to filter down and potentially years before the wider effects can be seen. Furthermore, one must wonder how long it might take for this funding to have an impact following a decade of austerity compounded by the Covid-19 pandemic.

2.7. Autism: Educational Transitions that Work

Taylor and Seltzer (2010, p.572) found that there is potentially a group of 'mid-level' functioning autistic young people who fall into a gap in the available support during the transition to adulthood. Furthermore, 'the most pronounced change in symptoms maladaptive behaviours' following an educational transition were seen in young people from lower socio-economic backgrounds (Taylor and Seltzer, 2010, p.572). Such a phenomenon suggests that more support is needed during these transition processes. While an average young person will accumulate life skills 'unthinkingly with increased life experience' (Taylor, 1990, p.79) autistic individuals will need more support through the years. While in the past, such people might have been condemned to life in an institution, many autistic people are now succeeding with support from parents or teachers (Grandin and Panek, 2014). Their needs should be accommodated, and their strengths exploited (Grandin and Panek, 2014). In order to do so, the team around any individual should conduct a person-centred assessment of their strengths and challenges (Elliot, 1990).

The Equality Act (2010) states that reasonable adjustments must be made to allow those with disabilities (among other protected characteristics) to access work, education and services (legislation.gov.uk, 2010). As such, authors such as Attwood (1998), Lambe

et al. (2018) and Fortuna (2014) call for institutions to not only make such adjustments, but to also to consider that 'the type of support that is most successful may well have to be personalised for that particular pupil's needs' (Fortuna, 2014, p.179). As previously discussed, such provision may be hampered by lack of training available to staff in education (NASUWT, 2018) as their knowledge is limited, thus impacting good practice. Further to this, Lambe *et al*. (2018, p.1532) advocate for 'flexible and inclusive practice' with the aim to best support learners while also not 'marking [them] out as different.' Once in place, these reasonable adjustments prevent 'substantial disadvantage' (Lambe *et al*., 2018, p.1532). While transitioning to university level, Lambe *et al.* (2018) found several strategies which make such education more accessible to autistic students. For example, Hastwell *et al*. (2013 *cited in* Lambe *et al*., 2018) discussed quiet hours in university buildings and implementing buddy systems to support autistic students through Freshers' week. Throughout the education system, some adaptations may be learning based, such as typing in exams and working alone rather than on group assignments (Attwood, 2015). Additionally, during school years, where school community and daily routines can be noisy and overwhelming, staff will also need to make adaptations for sensory needs (Attwood, 1998) with children able to skip activities such as assembly or leave lessons early to avoid the busy corridors.

One must remember that any adjustments will need to be on a case-by-case basis given the breadth and depth of the autistic experience and, as such, teachers need not have experience of a similar child (Attwood, 1998). Rather, they must adapt to each individual. As discussed by Layer (2017 *cited in* Lambe *et al*., 2018) such adjustments and adaptations make transitions not only kinder for autistic students, but also benefit

all students and their preferences. Such change, therefore, may also support those on the spectrum without a diagnosis alongside many other learners with undiagnosed ALN. Another hopeful step in this direction is seen in the ALNET Code of Practice: '…where a diagnosis of a particular condition might have been sought but not received - if the IDP can be prepared, then it needs to be prepared.' (Welsh Government, 2018b, p.10). As such, autistic young people on waiting lists for a formal diagnosis can still be recognised as having difficulties which need to be accommodated under the ALN system. In turn, this promotes a fairer system for all involved in the young person's education and begins to address barriers in accessing support.

A key player in such adaptations and support are the teaching and support staff. Attwood (1998) notes that some autistic pupils and their teachers simply are not compatible. This could be due to a myriad of reasons outside of the teacher's control such as classroom size, but a teacher's attitude towards such a child is seen 'reflected in the attitude of other children in the class' (Attwood, 1998, p.174). Unfortunately, due to the aforementioned wide breadth of autistic presentations, many teachers may not recognise the issues at hand with their practice being further hampered by a lack of training as previously discussed. That is to say that the child may be 'considered as simply defiant, wilfully disobedient or emotionally disturbed' (Attwood, 1998, p. 175). Grandin and Panek (2014, p.183) elaborate on the social implications of autism in a mainstream classroom lacking support, explaining that such learners may find themselves 'marginalised.' Such an issues could result in an autistic learner being placed in an unsuitable support setting in response to their unrecognised challenges in a mainstream classroom (Grandin and Panek, 2014). Therefore, it is key from both an

educational and social perspective that solid relationships are cultivated between staff, students and their parents in order to develop the required support. Both educational and social outcomes are dictated by the success of this partnership (Attwood, 1998; Grandin and Panek, 2014).

It is important to remember that skill development is not necessarily age-linear in an autistic young person (Taylor, 1990) and, as such, the development both professional and social skills are critical (Grandin and Panek, 2014). As such, parental support at home and school is key. Lambe *et al*. (2018) found that, when left to their own devices, autistic students did not always develop healthy strategies for coping with the social demands of education. For example, some students planned to isolate themselves at university as a method to insulate themselves from social rejection. To mitigate this, Grandin and Panek (2014) advocate for parents to begin planning for the future from the age of 11 or 12. While this does not need to be a final, lasting decision, parents must at least consider possibilities in order to prepare their child correctly and suitably for life ahead (Grandin and Panek, 2014). Staff, parents, and students working in partnership is seen as key in a successful education and transitional experience and thus a crucial step in such an approach is to outline clear 'expectations and goals for each of those involved' (Fortuna, 2014, p.187). This allows staff, students, and parents to develop positive relationships and thereby work together to find solutions as issues do arise (Fortuna, 2014). These issues echo back to previously discussed successful methods for multi-agency working. Suppo and Floyd (2012) discussed how well-trained parents were able to foster improved outcomes for their children. As such, perhaps the multi-agency model could be further improved with increased training and

support for parents themselves. However, it was noted that no studies have been conducted into families who are unable to access such resources (Suppo and Floyd, 2012) and how this gap in provision might impact them.

Some universities offer support groups for autistic students (Attwood, 2015). Attwood (2006, p.306) hypothesises that, due to the critical and positive support which they offer, that some institutions will become known in the autistic community making them 'first choice of future students and their parents.' This in and of itself highlights the importance placed upon such support and how critical it is to success. A good transition will work well for any student regardless of needs where all involved 'know the student well, communicate effectively and make the reasonable adjustments necessary' (Fortuna, 2014, p.190). However, Attwood and Grandin (2006, p.86) highlight the need to avoid 'charging in to save the day' – a fine balance must be struck between support and independence. Furthermore, Grandin and Panek (2014, p.200) suggest that we 'reconceive' autistic young people as 'valuable, even essential, contributors to society.' That is to say, we move to appreciate their contribution to society regardless of traditional expectations thus moving away from a deficit focused disability model.

2.8. Conclusion

This literature review explored several crucial areas in providing transitional support to autistic young people. It has identified two key issues which impact upon the ability of autistic pupils and students to access support and successfully transition between education settings: inconsistent multi-agency support and the funding constraints which such services and institutions face. Despite clear evidence supporting multi-agency

structures to facilitate transitions for autistic young people, Taylor and Seltzer (2010) discussed the need for more transition services for autistic learners without an ID. They worried that such young people fell through the cracks in existing provision. This is perhaps due to financial constraints as seen with wider reaching multi-agency support services. Nevertheless, it is a clear gap in service provision. Furthermore, while it is clear that attitudes towards autism and other disabilities are developing positively, austerity measures of the past decade have not supported the development of such supportive provision. Current providers struggle to develop transition programmes which meet the needs of autistic young people partially due to funding constraints following national austerity measures.

It is pivotal that practitioners 'prioritise transition planning to ensure better life quality in the school environment' (Fortuna, 2014, p.183) for autistic young people in order to support successful transition. The ALNET's person-centred approach and collaborative transitional planning is hoped to support such change in the near future. Improvements in the two key areas of funding and inconsistent multi-agency support could potentially help to facilitate this change in transitional structures and, as such, these interconnected themes will be discussed in more detail to explore further what this means for transitional support in the field of autism.

3. DISCUSSION OF RESULTS

3.1. Introduction

With co-morbid mental health conditions seen in 78% of autistic children (University of British Columbia, 2021), a key consideration raised by the literature review is the impact of current and planned processes on autistic learners themselves especially with regard to their well-being and general welfare. However, research indicates divergences between the perspectives of staff, learners, and their parents (Dillon and Underwood). Such confusion is exacerbated by austere budgets which limit staff resources – including relevant training – and the availability of practical multi-agency support for families (NASUWT, 2018; Ball, 2014). This discussion will explore the impact of these issues on learners and their educational transitions where clear guidance to prioritise transitional planning in both research (Fortuna, 2014) and policy (Welsh Government, 2018a), while also considering the impacts on staff and families.

3.2. The Implications of Austerity on Support for Autistic Learners

A key issue in this field seen in the literature review is the impact of austerity on the education sector. As discussed, schools have seen a budget decrease of approximately 9% in real terms since 2009 (Lewis, 2019) which has widespread ripples of effect through the education system. Such constraints have limited the support available for autistic learners during their time in state education as teaching staff struggle with the demands of a high workload and little, if any, specialised training (NASUWT, 2018). Most importantly, it has been predicted that such budget deficits will impact those with ALN the most due to cuts on support staffing numbers in schools (Downe & Taylor-Collins, 2019). Outcomes for autistic people are already lower than their neuro-typical

counterparts with a notable gap shown in the outcomes of those described a 'mid-level' functioning (Lambe *et al.*, 2018). Furthermore, it has been noted that maladaptive behaviours are more likely to be seen post-transition in those from lower socio-economic backgrounds (Taylor and Seltzer, 2010). The threshold of 5 GCSEs (A*-C) is less likely to be achieved by ALN students (Grigg *et al.*, 2014, *cited in* Shaw *et al.*, 2016, p.13) with such thresholds and subsequent further education proven to improve socio-economic outcomes in adulthood (Shaw *et al.*, 2016; Department for Education, 2021). Therefore, such cuts are a double blow to those from lower socio-economic backgrounds with ALN who also struggle with such transitions (Lambe *et al.*, 2018). While a disadvantaged group such as this should be the focus of intervention and support this does not appear to be the case. With ALN funding currently not ringfenced in education (National Assembly for Wales, 2019a), it is concerning to think of learners with such needs missing out on vital support in order to help balance budgets.

The first hurdle in the journey to adequate support in education is a diagnosis (Shaw *et al.*, 2016; Zuckerman *et al.*, 2017). The IAS report (Holtom and Lloyd Jones, 2019) illustrates the disparity in waiting times for diagnosis in the adult sector. Given further specialism is required for childhood assessments, this problem can only be exacerbated for young people. In fact, girls are likely to wait six years longer on average for a diagnosis than their male counterparts indicating further inequities in the diagnostic field (Thomas, 2022). Additionally, parents describe fighting for support (Abbot, Townsley and Watson, 2005; Busby, 2019; Busby, 2020) throughout their diagnostic journey and beyond. Put simply, improving diagnostic pathways and support would streamline the process to receiving support in the education sector. Furthermore, as

Zuckerman *et al.* (2017) discussed, perceptions and stereotypes of autism are often a barrier to accessing a diagnosis and therefore support. These hurdles can only add to the stress for autistic young people and their parents (Pancer *et al.*, 2000 *cited in* Lambe *et al.*, 2018). While it would be hard to measure the impact on the well-being and self-esteem of such young people, it is clear that the impact of such compounding issues could be substantial given that 78% of autistic children presenting with a co-morbid diagnosis of a mental health condition (University of British Columbia, 2021). As such, autistic young people are regularly stumbling at the first hurdle despite the best efforts of their parents and caregivers. Additionally, one must wonder about the outcomes for autistic young people with a parent or carer unable or unwilling to advocate for their needs.

The roll-out of the IAS in the adult sector has illustrated the discrepancies in support across Wales (Holtom and Lloyd Jones, 2019; Mosalski, 2019). These '"post code lotteries"' (Holtom and Lloyd Jones, 2019, p.150) create disparities and inequality amongst the already side-lined autistic population and can only add to the frustration felt by autistic individuals. While budget issues have not been the only limiting factor in the success of this programme, the issue of consistency in provision is clear. However, funding this consistency is a challenge given the varying needs of the population across the nation as illustrated by the varying levels of success seen in cities such as Cardiff and rural areas such as West Wales (Holtom and Lloyd Jones, 2019). Having said this, such funding issues do not solely affect rural areas. Data seen in the WIMD shows that, despite being a significantly more deprived area, Rhondda Cynon Taf receives less education funding per learner than the more affluent, yet rural,

Ceredigion (Statistics for Wales, 2019). This would suggest that pupils in Rhondda Cynon Taf are less likely to have access to adequate learning support given their further stretched school budgets. Developing a consistent level of provision across Wales should be a priority when considering diagnostic pathways and multi-agency support in the future (Ball, 2014; Holtom and Lloyd Jones, 2019; Mosalski, 2019). The seeds of such consistency have perhaps been sown with the introduction of the ALNET. However, the strength of this provision, and equitable distribution of allocated funds, is yet to be seen.

It is clear, however, that education staff may struggle to successfully implement ALNET with austere budgets. According to research conducted by the National Education Union, education staff are significantly stressed with a vast majority describing their workload as "never" or only "sometimes" manageable (National Education Union, 2018, p.3); an issue which some consider to be caused by squeezed budgets and staff reductions (NASUWT, 2018). One must therefore presume that this limits their capability to properly support autistic individuals, alongside other additional needs, due to the increased workload that such a task creates through differentiating work, adapting classroom environments, and liaising with other professionals (NASUWT, 2018; National Education Union, 2018). Quite simply, teachers often do not have the time to adequately meet the needs of their autistic learners (Ravet, 2017; NASUWT, 2018). However, austere budgets also lead to a lack of support staff who would previously have plugged this gap. For example, Fortuna (2014) described young people in their study who only had access to learning support staff as they shared a class with another pupil who had designated support. Not only does such a situation impact

upon the thinly spread staff, but also potentially negatively impacts each pupil in question educationally, socially, and emotionally. The support staff member cannot feasibly complete their job to the required standard while expected to support more than their designated child (Fortuna, 2014). Statistics for Wales (2019) figures illustrate the discrepancy between LEA budgets per child which does not necessarily correlate to increased deprivation or ALN. As a result, some schools will have a larger budget to employ the required support staff, while others will be required to risk overburdening support staff, so all ALN pupils sometimes have access to support rather than never – circumstances recorded in Fortuna's (2014) study. As a result, autistic learners across Wales could have vastly different experiences with the amount and quality of support throughout their education, and thus, experience varying impacts upon their educational, socio-economic, and emotional outcomes.

As seen in research conducted by teaching unions (NASUWT, 2018; National Education Union, 2018), their current concern is the well-being of teachers with regard to the volume of planning, data, marking and teaching time. However, given the findings of this literature review, perhaps the demands of ALN students and differentiation needs to have a larger focus. More specifically, it is perhaps pertinent to focus on the impacts this lack of time could have on the ALN learner experience and outcomes. However, even when such staff have the best of intentions, they are unlikely to be adequately trained to support those with such requirements due to a lack of available training to prepare professionals to meet the student's needs (NASUWT, 2018). Professionals in the field of autism have long stressed the importance of

ensuring that education staff have an understanding of autism (Attwood, 1998) and thus this lack of training could have significant ramifications for autistic learners.

Despite this clear lack of training during active careers, Ravet's (2017) research highlights the inadequate level of support for trainee teachers during their ITE. With such a poor foundation to their careers with regard to ALN, it is hard to imagine a well-rounded and educated teaching workforce in the future – especially when continuous professional development in this area is so hard to come by (NASUWT, 2018) and thus unlikely to plug this gap in knowledge. Additionally, the issues seen in accessing training due to lack of funding can only exacerbate the stress and lack of work-life balance currently experienced by teaching staff (National Education Union, 2018) as they try to adequately address ALN in their classrooms with minimal training and understanding. This is compounded by a lack of training during ITE (Ravet, 2017) and an expectation for education staff to access opportunities at their own cost and in their own time (National Education Union, 2018). Differentiating tasks and resources for autistic learners, liaising with professionals, and accessing training increases the workload placed upon these teachers. With budget constraints leading to staff reductions, this places a disproportionate burden on remaining teaching and support staff leading to concern about their ability to effectively implement the ALNET's aims and provision. Furthermore, the adequacy of differentiation must be questioned given the stereotypes often associated with autism (Bottema-Beutal *et al*., 2021; First *et al*., 2004 *cited in* Ruiz Calzada, Pistrang & Mandy, 2012) in the minds of education staff perhaps due to limited autism informed training opportunities.

It is highly important that all professionals involved in education develop a solid foundational understanding of autism, its presentations, and challenges (Attwood, 1998). However, it seems that trainee teachers are being let down in this regard (Ravet, 2017) with a potential negative impact upon autistic learners, their educational attainment and perhaps most importantly, their mental health (Pancer *et al.*, 2000 *cited in* Lambe *et al.*, 2018). This negative impact, however, will not only be felt by teaching staff and autistic learners, but also their parents and caregivers due to the continued fight for support for their child (Abbot, Townsley and Watson, 2005; Busby, 2019; Busby, 2020). Given the difficulties associated with such an impact, it is imperative that training for teachers and other support staff is better implemented and easier to access to ensure a smoother experience for all involved. A potential route to improving educational experiences for autistic learners is improved transitional support between each setting. Transition support is a clear recommendation from several studies in the literature review (Lambe *et al*., 2018; Fortuna, 2014). However, given limited budgets, and the lack of ringfencing of ALN budgets within educational establishments, one must wonder where the funding for such programmes will come from despite the £20 million from the WG for the implementation of the ALNET (Welsh Government, 2017). Following the Covid-19 pandemic, additional funding has been pledged for learners with ALN by the WG. Initially, this was intended to take the form of a total of £9.8 million provided to LEAs to fund additional costs and support specifically for learners with ALN (Welsh Government, 2021c). Disabled people struggled to access many areas of support during national lockdowns – from educational to medical (Clegg, 2021) – and thus the WG recognise that ALN learners are statistically more likely to be impacted by the events of 2020 and 2021 resulting in this additional funding (Welsh

Government, 2021c). In 2022 (Welsh Government, 2022), a further £4.5 million has been made available in addition to the previous year's £9.8 million to aid in repairing the impacts of such gaps in provision. Given the importance of such transitional arrangements, it would perhaps be pertinent for such schemes to be further outlined with clear guidance in policy and legislation with funding supplied to institutions to support better transitional outcomes for their learners, especially in light of the disruption caused by the Covid-19 pandemic.

Having said this, evidence indicates that budget issues pre-date the Covid-19 pandemic with school budgets having decreased in real-terms since 2009 (Lewis, 2019). There are also significant differences in ALN funding offered by each LEA. For example, statistics indicate that a junior class size in Rhondda Cynon Taf is receiving approximately £18,995 less on average than the same class size in Ceredigion (Statistics for Wales, 2019). This is despite Rhondda Cynon Taf being an area identified as having deep-rooted deprivation in the WIMD (Statistics for Wales, 2019). Learners with ALN are statistically more likely to come from a more deprived background – they are twice as likely as their non-ALN counterparts to receive free school meals (Welsh Government, 2014 *cited in* Shaw *et al*., 2016). Thus, it is clear that funding is not reaching those most at need with the current systems. This system therefore risks perpetuating multi-generational deprivation where those with ALN are less likely to achieve a strong set of GCSEs (Grigg *et al*., 2014, *cited in* Shaw *et al.*, 2016, p.13) and a lack of such qualifications indicating increased risk of poverty in later life (DWP, 2014 *cited in* Shaw *et al.*, 2016, p.12). As such, it must be a priority of policies and

legislation to challenge the current status-quo where poor ALN support exacerbates poor economic success in later life.

To conclude, the austerity policy has severely impacted those with ALN, this is especially so for those from a lower socio-economic status given evidence illustrating the significant impact such cuts have on the most vulnerable (Taylor and Seltzer, 2010; Shaw *et al.*, 2016; Lambe *et al*., 2018). The introduction of the ALNET is hoped to mitigate some of these concerns. However, as seen in the roll-out of the IAS for adults in Wales, this is not a straightforward process and must be monitored closely to evaluate successes and limitations. Given the ALNET is entering policy following a decade of austere budgets, it is important to consider whether the £20 million pledged by the WG (Welsh Government, 2017) is enough to successfully implement its aims and objectives especially when the situation has been compounded by the impacts of the pandemic lockdowns.

3.3. Inconsistent Multi-Agency Support: Teaching Staff, Non-Teaching Staff and Families

While austerity is one significant issue in this field, a lack of multi-agency teams, or inadequate multi-agency support where it is available is also a critical hurdle. As seen in the literature review, research indicates that widespread multi-agency support systems could have a positive impact on the attainment and outcomes of young people with ALN – including autism (Abbott, Townsley and Watson, 2005). Without this, autistic young people and/or their parents or caregivers have a huge undertaking in order to manage the multitude of professionals in their lives (Abbott, Townsley and

Watson, 2005; Busby, 2019; Busby, 2020). As such, a multi-agency approach could also improve transitional arrangements between education settings by stream-lining the process of communication between professionals, parents and autistic children and young people throughout the entire experience. The ALNET is a hopeful step in a better direction for those without or awaiting diagnoses as well as the multi-agency approach, as it promotes person-centred practice and careful consideration of the views of the learner in question (ERW, 2018, SNAP Cymru, 2022). The importance of such an approach has long been highlighted by researchers (Attwood, 1998; Fortuna, 2014; Grandin and Panek, 2014). However, in the interim, the impact on autistic learners, their families and educational staff is clear: parents continue to struggle with demands of juggling numerous support workers (Abbott, Townsley and Watson, 2005; Busby, 2020), autistic young people continue to have poorer outcomes (Taylor and Seltzer, 2010; Lambe *et al*., 2018) and stress continues to be seen in educational staff (National Education Union, 2018; NASUWT, 2018).

First and foremost, multi-agency working provides professionals a clear insight into the autistic person's life, wishes, strengths and weaknesses (Abbott, Townsley and Watson, 2005). Such communication is a clear benefit of this method of working with regards to professionals, however, some parents have reported some inconsistency even in areas which use such an approach (Busby, 2019; Busby, 2020). However, given the austere climate, it is perhaps understandable that services are patchy. For example, the rollout of the IAS in Wales demonstrated how services, waiting lists and quality of support can vary significantly across one nation despite funding originating from the same pot. These differences, sometimes called '"post code lotteries"' (Holtom and Lloyd Jones,

2019, p.150), are extremely frustrating for service users and their families. Put simply, this disparity in services is unjust as all autistic people should have access to quality support with such support allocated by need and not location and regional budgets. This issue is further exacerbated by the limitations on accessing support without a diagnosis, something that is increasingly challenging to obtain due to socio-economic and cultural factors (Shaw *et al.*, 2016; Zuckerman *et al.*, 2017). While the National Autism Society support self-diagnosis (National Autism Society, 2021), this is not always useful in practice for many autistic people given the lack of accessible services without a formal diagnosis – especially when such services have limited budgets. However, the ALNET hopes to implement IDPs and person-centred support without the need for a diagnosis which is hoped to somewhat mitigate this issue (Welsh Government, 2021b).

As discussed in Section 3.2, a clear implication of the austere budget is a lack of access to training for professionals in this field as well as the significant demands on professionals' time (Attwood, 1998; National Education Union, 2018; Ravet, 2017). The resulting lack of understanding of the depth and breadth of the autistic experience may have consequences with regard to provision offered. However, funding concerns were a concern before austerity (Abbott, Townsley and Watson, 2005) and continue to the present day (BBC, 2020). Such evidence indicates that little progress has been made in the intervening years with additional pressures coming into play as a result of the Covid-19 pandemic (Welsh Government, 2021c). The positive impacts of multi-agency working are encouraging and thus expanding such programmes is key to improving the experience of autistic young people when accessing support during transitions. The ALNET promotes such thinking and ways of working with ALN learners and contains

clear guidance regarding transitional planning and support (Welsh Government, 2018b). However, as discussed, there is a limit to the progress that can be made in this area with limited funding following austere budgets. One must wonder if the £20 million pledged by the WG (Welsh Government, 2017) is enough to successfully implement multi-agency practice alongside the further demands of the ALNET even with the additional funds pledged since the Covid-19 pandemic (Welsh Government, 2021c; Welsh Government, 2022) following years of budget deficits.

In recent years, teaching unions have been focusing their efforts on staff well-being due to large proportions of the teaching workforce citing considerable stress in their working lives due to workload and high expectations (National Education Union, 2018; NASUWT, 2018). This could cause significant issues as further demands are put on their time via IDPs and other ALNET paperwork and liaison with a variety of agencies. Having said this, smoother transitions and improved support for autistic learners would be hoped to improve such issues with improved behavioural outcomes and increased guidance from other professionals, alongside input from families and the young person in question (Abbott, Townsley and Watson, 2005) which, in turn, would be hoped to ease the hurdles resulting from transitions. In recent years, there has been feeling in professional circles that they are often '"fire-fighting"' (Ball, 2014, p.325) issues rather than pre-emptively offering flexible support and services to meet the needs of autistic learners and their families (Townsley, Watson and Abbott, 2004). Similarly, Ball (2014, p.329) was concerned of the limitations of current systems to offer 'holistic support' to families and, as such, the ALNET's multi-agency and person-centred approach is a welcome step in the right direction. Furthermore, several researchers

have noted that professionals speak highly of multi-agency practice given the benefits the strategy provides to both their practice and outcomes (Abbott, Townsley and Watson, 2005; Sloper, 2004), thus these long-term benefits may outweigh the impact of additional work, training, and processes. Sloper (2004), however, notes that current research regarding multi-agency working does not delve into the perspectives of families of learners with ALN. Evidence in the press (Busby, 2019; Busby, 2020; BBC, 2020) indicates the pressures and stress put upon parents and caregivers of autistic children and young people or those with any ALN or medical need. Abbott, Townsley and Watson (2005) indicate the numerous professionals with whom parents and carers must liaise to ensure care and support needs are met for their child. Such an approach can lead to poor co-ordination of services and young people missing out on support (Abbott, Townsley and Watson, 2005; Sloper, 2004). While the benefits of multi-agency working for families are clearly suggested by research, similar studies investigating the perspectives of families would be beneficial to future planning and evaluating the successes and limitations of the ALNET over the coming years.

There is also a need for clearly defined roles for all practitioners involved in their care as demonstrated by the ALNET's aim for IDPs and ALPs to list responsibilities for each member of such teams (Welsh Government, 2018a). Such a system would avoid conflicting efforts and reduce the pressure on parents and carers to co-ordinate. However, a potential concern of such an approach would be gaining the agreement of several different authorities as to the best course of action for any given learner. Given the lack of training available for such professions, it is possible that there could be a disparity in the quality of professionals involved in a multi-agency approach for autistic

learners. This is illustrated by Ravet's (2017, p.724) study into autism education during ITE where a student teacher stated: "'To be honest I'm not comfortable (with children with autism). I'm a little bit scared to approach them.'" Sloper (2004) also notes the possible conflicts in professional settings as long-standing cultures are challenged. If this were the case, it could lead to major frustrations for families and carers as well as the autistic learners themselves when they are the expert of their own condition or that of their child having spent a vast amount of time advocating for their needs (Busby 2019; Busby, 2020; Ontiveros, 2019; Abbott, Townsley and Watson, 2005).

In a similar vein, there is a lack of research into the benefits of multi-agency working on the autistic learners themselves, with Sloper (2004) noting that research focused on the impacts for professionals before families and the individuals at the heart of the service. Similarly, while there has been significant research into the effects on mental health and well-being of poor transitions (Lambe *et al.*, 2018; Fortuna, 2014), there has been little focus on the positive impacts of good quality work in this area. There has, however, been significant research into the implication of poor support for autistic learners with increased levels of mental health issues (University of British Columbia, 2021; Ontiveros, 2019), lower educational outcomes leading to lower socio-economic outcomes in adulthood (Grigg *et al*., 2014 *cited in* Shaw *et al.*, 2016; Department for Education, 2021), and increased risk of permanent exclusions for learners with ALN in general (McInerney, 2015). Having said this, a key aspect of the ALNET is ensuring that all views are considered including those of the young person in question (Welsh Government, 2018a). As such, it must be hoped that such aspects are considered during the IDP and ALP processes which, if considered carefully, could have a positive impact

on the well-being of these vulnerable learners. Having said this, a key aspect of future research and considerations needs to be the impact of the ALNET's processes on those at the centre of such services: autistic children and young people.

3.4. Conclusion

The key finding of this literature review is that developments to funding and multi-agency working are hoped to improve the welfare of young autistic learners and their families. However, there are substantial hurdles in the path of legislation such as the ALNET in achieving these aims which largely stem from the legacy of austere budgets. It is also important to not underestimate the impact of quality training for professionals working in the field of autism as this will have direct impacts upon the quality of transitions between educational settings, in addition to hopeful improvements in the welfare of autistic learners. The next section will further examine these themes in order to develop recommendations for improvement in practice for educational transitions for autistic learners as the ALNET is rolled out across Wales.

4. CONCLUSION AND RECOMMENDATIONS

This dissertation has examined several key areas of support structures for autistic learners as they transition through education. The Results and Discussion section has identified two key themes which have emerged from the current literature: the impacts of austerity on such support and inconsistent multi-agency approach in current practice. These themes will now be explored in regards to recommendations for improving future practice in light of the ALNET's recent and ongoing implementation across Wales.

The discussion and critique of educational transitions for autistic learners is key in the Welsh Government's aim to provide more inclusive practice for such young people and has recently been written into policy and guidance in terms of the ALNET (Welsh Government, 2018b). Evidence from Wales and further afield clearly suggests a recent gap in provision in providing not only successful transitions, but also general support and guidance for autistic young people and their families (Suppo and Floyd, 2012; Sloper, 2004; Ball, 2014). Furthermore, several barriers to accessing such support when available are apparent such as: perceptions of autism (Zuckerman *et al*., 2017), limited staff training (NASUWT, 2018; Ravet, 2017) and the limitations of austere school budgets on the availability of such services (NASUWT, 2018; Lewis, 2019; Wightwick, 2019). To explore this issue, the following research question has been posed:

- *RQ: What are the structures for effectively supporting autistic learners in transitioning between education settings?*

To undertake this, a literature review was conducted to explore this issue. To begin with, it is important to understand the history of autism and the development of understanding in this field followed by discussion of labels and disability models

prevalent in the field. As noted, there is ongoing debate regarding the use of and potential damage caused by functioning labels (Bottema-Beutal *et al*., 2021; Stechyson, 2021). Additionally, there is ongoing discussion regarding the use of the term 'condition' over the traditional 'disorder' to foster a more accurate view of autism (Baron-Cohen, 2017). This is supplemented by the promotion of the social model of disability in order to create a more inclusive society (Oliver, 1990). Such changes in discourse are key when developing change to current educational systems and the perceptions of autism among practitioners. Another key area to explore was the perceptions and experiences of those in the current systems: namely autistic learners themselves, their families, and professionals (both educational and beyond). Similarly, in light of the ALNET's promotion of multi-agency and person-centred support, it was important to evaluate the effectiveness of current multi-agency support in this and similar areas, as well as the limitations and successes seen in such practice to date. Finally, exploring both good practice in education transitions for autistic learners, as well as the limitations to offering such effective support, was crucial in developing the main themes explored.

Two key themes emerged from the literature review: the implications of austerity and inconsistent multi-agency support across this field. Both themes will be discussed briefly below. Under each theme, initially there will be a resume of the main issues outlined in the discussion. Secondly, there will be an indication of what needs to be developed to improve provision alongside the limitations, challenges, and barriers to improving practice. Finally, there will be recommendations made within each theme

drawn from the literature review and discussion in order to improve future outcomes in this critical area of education support.

The Implications of Austerity

Austere school budgets have created several hurdles for autistic learners as they transition between education settings. This is especially problematic for the members of this group who are also socio-economically disadvantaged (Lambe *et al*., 2018) given that research shows that maladaptive responses to transitions are seen more commonly in this sub-group (Taylor and Seltzer, 2010). Furthermore, issues are seen in accessing diagnoses which are commonly a gateway to support services (Holtom and Lloyd Jones, 2019) with waiting lists and support available being described as '"post code lotteries"' (Holtom and Lloyd Jones, 2019, p.150), and girls waiting significantly longer for diagnoses than boys (Thomas, 2022). Both hurdles add further difficulty in accessing supportive and positive transitions. As such, clear and timely diagnostic and support pathways nationwide are likely to improve transitions for autistic learners as they more easily and swiftly access support. Several proponents of autism informed support throughout education indicate the importance of staff expertise in supporting autistic learners (Grandin and Panek, 2014; Attwood, 1998; Lambe *et al*., 2018). However, research indicates limited opportunities for staff to access training with such issues beginning during ITE and persisting throughout careers due to limited budgets and time (National Education Union, 2018) in addition to poor initial training during ITE (Ravet, 2017). As a result, education establishments may struggle to implement successful transitional schemes without adequately trained staff. This issue is likely to be further exacerbated by autistic stereotypes (Bottema-Beutal *et al*., 2021; First *et al*., 2004 *cited*

in Ruiz Calzada, Pistrang & Mandy, 2012) where staff mistakenly feel informed on this complex topic. Therefore, it is clear that training needs of staff working in this sector should be prioritised in future planning. Thus, these barriers and challenges indicate that change is needed in this area. The following recommendations have been made having been drawn from the critical reflection undertaken in the literature review:

> ***Recommendation 1: An increase in budget for transition arrangements ringfenced at an LEA level.***
> ***Recommendation 2: Prioritising training needs of professionals within autistic learning support to access funded and autism informed training opportunities.***

Inconsistent Multi-Agency Support: Teaching Staff, Non-Teaching Staff and Families

Multi-agency support has been shown to have a positive impact on student attainment (Abbott, Townsley and Watson, 2005) and it is also hoped that effective multi-agency systems would reduce the load on parents and families as they no longer need to navigate a multitude of professionals involved in their child's care and education (Abbott, Townsley and Watson, 2005; Busby, 2019; Busby, 2020). Ball (2014) voiced concerns of staff unable to holistically meet families' needs due to limited staffing and budgets. While the ALNET promotes a person-centred and multi-agency approach (SNAP Cymru, 2020), the lack of training for professionals due to austere budgets and increased workloads (National Education Union, 2018; NASUWT, 2018; Ravet, 2017) indicates a gap in the required professional knowledge to successfully implement such teams. The ALNET promotes clear transitional planning (Welsh Government, 2018b), however, staff may not be able to meet these obligations with current training levels. Thus, improved access to training is critical in a successful rollout of the ALNET's key

aims and should be prioritised and consistent across Wales. This would be hoped to increase the effectiveness and positive impacts of multi-agency teams as they work in this new framework, although this would need to be investigated and measured in due course given the lack of research into this area to date. Having considered these barriers to effective multi-agency support following the literature review's consideration of such issues and the positive impacts of effective multi-agency working, there is a clear need for development in this area as the ALNET is rolled out across Wales. As such, the following recommendation has been made:

> ***Recommendation 3: Undertake audit of how the development of the ALNET has impacted upon on professional multi-agency practice and autistic learners in Wales.***

From this literature review, it is evident that there are a range of key issues in the field of education transitions for autistic children and young people. A number of recommendations have been made with the aim to improve practice and services for autistic learners, their families and professionals moving forward. Overall, it appears that the past decade's austerity budgets have had a significant impact on the ability of schools and multi-agency teams to provide quality transitional arrangements and general support to autistic children and young people and their families. This is as a result of a combination of factors related to unmet training needs, over-burdened teachers and services including the baseline of ensuring timely diagnosis as well as under-developed multi-agency teams to date.

Certainly, while this has been a review of the literature surrounding this complex field, further research, which collects data from multi-agency staff, autistic learners and their

parents or carers would further underpin the evaluation and refining of current policies. Considering such lived experience would also aid in developing future support frameworks for autistic learners during these pivotal transitional periods. Crucially, such research would give a voice to autistic stakeholders in the educational system in Wales. This would be exceptionally vital in evaluating the successes and limitations of the ALNET as the impacts of the new policies and frameworks unfold over the coming years, particularly with regard to its impact on provision and the well-being of autistic learners as they progress through their education.

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6. APPENDICES

6.1. Appendix 1: Ethics Form

SECTION A: About You (Principal Researcher)

1	Full Name:	Clare Marie Evans			
2	Tick all boxes which apply:	Member of staff:	☐	Honorary research fellow:	☐
3	Undergraduate Student	☐	Taught Postgraduate Student	☒	Postgraduate Research Student	☒

4	Institute/Academic Discipline/Centre:	School of Social Justice and Inclusion
5	Campus:	Carmarthen
6	E-mail address:	1402003@student.uwtsd.ac.uk
7	Contact Telephone Number:	07494 261 011
	For students:	
8	Student Number:	1402003
9	Programme of Study:	MA Equality and Diversity in Society
10	Director of Studies/Supervisor:	Dr Caroline Lohmann-Hancock

SECTION B: Approval for Research Activity

1	Has the research activity received approval in principle? (please check the Guidance Notes as to the appropriate approval process for different levels of research by different categories of individual)		**YES**	☒	**NO**	☐
						Date
2	If Yes, please indicate source of approval (and date where known): ***Approval in principle must be obtained from the relevant source prior to seeking ethical approval***	Research Degrees Committee		☐		
3		Institute Research Committee		☐		
4		Other (write in) Dr Caroline Lohmann-Hancock		☒		

SECTION C: Internal and External Ethical Guidance Materials

	Please list the core ethical guidance documents that have been referred to during the completion of this form (including any discipline-specific codes of research ethics, and also any specific ethical guidance relating to the proposed methodology). Please tick to confirm that your research proposal adheres to these codes and guidelines.	
1	**UWTSD Research Ethics & Integrity Code of Practice**	☒
2	**UWTSD Research Data Management Policy**	☒
3		☐

SECTION D: External Collaborative Research Activity

1	Does the research activity involve collaborators outside of the University?		**YES**	☐	**NO**	☒
2	If Yes, please provide the name of the external organisation and name and contact details for the main contact person and confirmation this person has consented to their personal data being shared.as part of this collaboration.					
3	Institution					
4	Contact person name					
5	Contact person e-mail address					
6	Has this individual consented to sharing their details on this form?		**YES**	☐	**NO**	☐
7	Are you in receipt of a KESS scholarship?		**YES**	☐	**NO**	☐
8	Is your research externally funded		**YES**	☐	**NO**	☐
9	Are you specifically employed to undertake this research in either a paid or voluntary capacity?	Voluntary	**YES**	☐	**NO**	☐
10		Employed	**YES**	☐	**NO**	☐
11	Is the research being undertaken within an existing UWTSD Athrofa Professional Learning Partnership (APLP)	If YES then the permission question below does not need to be answered.	**YES**	☐	**NO**	☐
12	Permission to undertake the research has been provided by the partner organisation	(If YES attach copy) If NO the application cannot continue	**YES**	☐	**NO**	☐

Where research activity is carried out in collaboration with an external organisation

13	Does this organisation have its own ethics approval system?	**YES**	☐	**NO**	☐
14	If Yes, please attach a copy of any final approval (or interim approval) from the organisation				

SECTION E: Details of Research Activity

1	Indicative title:	Autism Spectrum Condition: Support in the Field	
2	Proposed start date:		Proposed end date:	

3	**Introduction to the Research (maximum 300 words)** **Ensure that you write for a <u>Non-Specialist Audience</u> when outlining your response to the three points below:** • *Purpose of Research Activity* • *Proposed Research Question* • *Aims of Research Activity* • *Objectives of Research Activity* Demonstrate, briefly, how **<u>Existing Research</u>** has informed the proposed activity and explain • *What the research activity will add to the body of knowledge* • *How it addresses an area of importance.*

4	**Purpose of Research Activity** The main line of enquiry within this research is the personal experiences of those who have an Autism Spectrum Condition (ASC) and their parents/guardians (i.e. their advocates) with regard to the transition between secondary school and further education. In 2016, the National Autism Society (NAS) conducted a report in England which found that half of parents of those with ASC were dissatisfied with the services offered for their children. In fact, nearly three-quarters indicated struggling to even access support (NAS, 2016). Therefore, it is plain to see that further research into such feelings is vital to ensure proper support. Furthermore, as their study focused on England, a study in south Wales under the Welsh Assembly Government's (WAG) devolved Education and Social and Welfare Systems will offer insight into Wales' own specialised support system. Moreover, the NAS's 2016 study did not look into the professionals' viewpoints. However, County Councils were critiqued by parents quoted in the report (NAS, 2016, p.9). As such, I feel that this study will be informative to the field as the professionals' viewpoints and hurdles will also be considered and discussed. Attwood (2007) points out that in the past many young people with ASC could not cope with the transition from school to college with "the need for greater independence skills" (p.304). As such, it is clear that support staff perform a key role in this transition and therefore their lived experience is also invaluable.

Additionally, as of February 2020, the Wales Autism Research Centre (WARC) focuses on topics such as behaviour and diagnosis and familial relationships (WARC, 2020). As such, there is no body of research focusing on this specific issue which all young people with ASC will face as they transition from school into adulthood. It is a key issue in ASC which has not yet been explored.

References:

Attwood, T. (2007). *The complete guide to Asperger's syndrome*. London: Jessica Kingsley Publishers.

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(this box should expand as you type)

5	**Research Question**
	• What are the Perceptions of Educators working with (ASC) and the Individuals and/or families of those who have an Autism Spectrum Condition (ASC) during their transition from Secondary School to Further Education?
	(this box should expand as you type)
6	**Aims of Research Activity**
	• To explore the barriers faced by young people (ASC) when transitioning from secondary school to further education as perceived by professionals, parents and young people with ASC themselves.
	• To identify best practice in regard to young people (ASC) when transitioning from secondary school to further education
	(this box should expand as you type)
7	**Objectives of Research Activity**
	• Explore the perceptions of professionals in this field.
	• Explore the perceptions and lived experiences of parents of and young people who have an ASC.
	• Highlight best practice for supporting successful transition for young people who have an ASC.
	(this box should expand as you type)
8	**Proposed methods (maximum 600 words)**
	Provide a brief summary of all the methods that **may** be used in the research activity, making it clear what specific techniques may be used. If methods other

	than those listed in this section are deemed appropriate later, additional ethical approval for those methods will be needed.
9	**Literature review.**
10	**Location of research activity** Identify all locations where research activity will take place.
11	N/A (this box should expand as you type)
12	**Research activity outside of the UK** If research activity will take place overseas, you are responsible for ensuring that local ethical considerations are complied with and that the relevant permissions are sought. Specify any local guidelines (e.g. from local professional associations/learned societies/universities) that exist and whether these involve any ethical stipulations beyond those usual in the UK (provide details of any licenses or permissions required). Also specify whether there are any specific ethical issues raised by the local context in which the research activity is taking place, for example, particular cultural and/or legal sensitivities or vulnerabilities of participants.
13	N/A *(this box should expand as you type)*

14	Use of documentation not in the public domain: Are any documents **NOT** publicly available?	**NO**	☒
		YES	☐
15	If Yes, please provide details here of how you will gain access to specific documentation that is not in the public domain and that this is in accordance with prevailing data protection law of the country in question and England and Wales. *(this box should expand as you type)*		

SECTION F: Scope of Research Activity

1	**Will the research activity include:**	YES	NO
2	Use of a questionnaire or similar research instrument?	☐	☒
3	Use of interviews?	☐	☒
4	Use of diaries?	☐	☒
5	Participant observation with their knowledge?	☐	☒
6	Participant observation without their knowledge?	☐	☒
7	Use of video or audio recording?	☐	☒

8	Access to personal or confidential information without the participants' specific consent?	☐	☒
9	Administration of any questions, test stimuli, presentation that may be experienced as physically, mentally or emotionally harmful / offensive?	☐	☒
10	Performance of any acts which may cause embarrassment or affect self-esteem?	☐	☒
11	Investigation of participants involved in illegal activities?	☐	☒
12	Use of procedures that involve deception?	☐	☒
13	Administration of any substance, agent or placebo?	☐	☒
14	Working with live vertebrate animals?	☐	☒
15	Other primary data collection methods, please explain in this box For example, 'focus groups'. Please indicate the type of data collection method(s) in this box and tick the accompany box.		
16	Details of any other primary data collection method: (this box should expand as you type)	☐	☒

If NO to every question, then the research activity is (ethically) low risk and **may** be exempt from **some** of the following sections (please refer to Guidance Notes).

If YES to any question, then no research activity should be undertaken until full ethical approval has been obtained.

SECTION G: Intended Participants

1	**Who are the intended participants:**		
		YES	**NO**
2	Students or staff at the University?	☐	☐
3	Adults (over the age of 18 and competent to give consent)?	☐	☐
4	Vulnerable adults?	☐	☐
5	Children and Young People under the age of 18? (Consent from Parent, Carer or Guardian will be required)	☐	☐
6	Prisoners?	☐	☐
7	Young offenders?	☐	☐
8	Those who could be considered to have a particularly dependent relationship with the investigator or a gatekeeper?	☐	☐
9	People engaged in illegal activities?	☐	☐
10	Others (please identify specifically any group who may be unable to give consent) please indicate here and tick the appropriate box.		
		☐	☐
11	Other – please indicate here:		

	(this box should expand as you type)		

12	**Participant numbers and source** Provide an estimate of the expected number of participants. How will you identify participants and how will they be recruited?			
13	How many participants are expected?	*(this box should expand as you type)*		
14	Who will the participants be?	*(this box should expand as you type)*		
15	How will you identify the participants?	*(this box should expand as you type)*		

16	**Information for participants:**	YES	NO	N/A
17	Will you describe the main research procedures to participants in advance, so that they are informed about what to expect?	☐	☐	☐
18	Will you tell participants that their participation is voluntary?	☐	☐	☐
19	Will you obtain written consent for participation?	☐	☐	☐
20	Will you explain to participants that refusal to participate in the research will not affect their treatment or education (if relevant)?	☐	☐	☐
21	If the research is observational, will you ask participants for their consent to being observed?	☐	☐	☐
22	Will you tell participants that they may withdraw from the research at any time and for any reason?	☐	☐	☐
23	With questionnaires, will you give participants the option of omitting questions they do not want to answer?	☐	☐	☐
24	Will you tell participants that their data will be treated with full confidentiality and that, if published, it will not be identifiable as theirs?	☐	☐	☐
25	Will you debrief participants at the end of their participation, in a way appropriate to the type of research undertaken?	☐	☐	☐
26	If NO to any of above questions, please give an explanation			
27	*(this box should expand as you type)*			

28	**Information for participants:**	YES	NO	N/A

29	Will participants be paid?	☐	☐	☐
30	Is specialist electrical or other equipment to be used with participants?	☐	☐	☐
31	Are there any financial or other interests to the investigator or University arising from this study?	☐	☐	☐
32	Will the research activity involve deliberately misleading participants in any way, or the partial or full concealment of the specific study aims?	☐	☐	☐
33	If YES to any question, please provide full details			
34	*(this box should expand as you type)*			

SECTION H: Anticipated Risks

1	**Outline any anticipated risks that may adversely affect any of the participants, the researchers and/or the University, and the steps that will be taken to address them.** If you have completed a full risk assessment (for example as required by a laboratory, or external research collaborator) you may append that to this form.		
2	**Full risk assessment completed and appended?**	**Yes**	☐
		No	☒
3	**Risks to participants** For example: emotional distress, financial disclosure, physical harm, transfer of personal data, sensitive organisational information		
4	Risk to Participant: *(this box should expand as you type)*	How will you mitigate the Risk to Participant *(this box should expand as you type)*	
5	If research activity may include sensitive, embarrassing or upsetting topics (e.g. sexual activity, drug use) or issues likely to disclose information requiring further action (e.g. criminal activity), give details of the procedures to deal with these issues, including any support/advice (e.g. helpline numbers) to be offered to participants. Note that where applicable, consent procedures should make it clear that if something potentially or actually illegal is discovered in the course of a project, it may need to be disclosed to the proper authorities		
	(this box should expand as you type)		
6	**Risks to investigator** For example: personal safety, physical harm, emotional distress, risk of accusation of harm/impropriety, conflict of interest		
	Risk to Investigator:	How will you mitigate the Risk to Investigator: *(this box should expand as you type)*	

	(this box should expand as you type)	
7	**University/institutional risks**	
	For example: adverse publicity, financial loss, data protection	
	Risk to University:	*How will you mitigate the Risk to University:*
	(this box should expand as you type)	*(this box should expand as you type)*

		YES	NO	N/A
8	**Disclosure and Barring Service**			
9	If the research activity involves children or vulnerable adults, a Disclosure and Barring Service (DBS) certificate must be obtained before any contact with such participants.	**YES**	**NO**	**N/A**
10	Does your research require you to hold a current DBS Certificate?	☐	☐	☐

SECTION I: Feedback, Consent and Confidentiality

1	**Feedback**
	What de-briefing and feedback will be provided to participants, how will this be done and when?
	(this box should expand as you type)
2	**Informed consent**
	Describe the arrangements to inform potential participants, before providing consent, of what is involved in participating. Describe the arrangements for participants to provide full consent before data collection begins. If gaining consent in this way is inappropriate, explain how consent will be obtained and recorded in accordance with prevailing data protection legislation.
	(this box should expand as you type)
3	**Confidentiality / Anonymity**
	Set out how anonymity of participants and confidentiality will be ensured in any outputs. If anonymity is not being offered, explain why this is the case.
	(this box should expand as you type)

SECTION J: Data Protection and Storage

In completing this section refer to the University's Research Data Management Policy and the extensive resources on the University's Research Data Management web pages (http://uwtsd.ac.uk/library/research-data-management/).

1	Does the research activity involve personal data (as defined by the General Data Protection Regulation 2016 "GDPR" and the Data Protection Act 2018 "DPA")?	**YES**	**NO**
	"Personal data" means any information relating to an identified or identifiable natural person ('data subject'). An identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person.	☐	☒
2	If YES, provide a description of the data and explain why this data needs to be collected:		
	(this box should expand as you type)		
3	Does it involve special category data (as defined by the GDPR)?	**YES**	**NO**
	"Special category data" means sensitive personal data consisting of information as to the data subjects' – *(a) racial or ethnic origin,* *(b) political opinions,* *(c) religious beliefs or other beliefs of a similar nature,* *(d) membership of a trade union (within the meaning of the Trade Union and Labour Relations (Consolidation) Act 1992),* *(e) physical or mental health or condition,* *(f) sexual life,* *(g) genetics,* *(h) biometric data (as used for ID purposes),*	☐	☒
4	If YES, provide a description of the special category data and explain why this data needs to be collected:		
	(this box should expand as you type)		

5	Will the research activity involve storing personal data and/or special category data on one of the following:	**YES**	**NO**
6	Manual files (i.e. in paper form)?	☐	☒
7	University computers?	☐	☒
8	Private company computers?	☐	☒

9	Home or other personal computers?	☐	☒
10	Laptop computers/ CDs/ Portable disk-drives/ memory sticks?	☐	☒
11	"Cloud" storage or websites?	☐	☒
12	Other – specify:	☐	☒
13	For all stored data, explain the measures in place to ensure the security of the data collected, data confidentiality, including details of password protection, encryption, anonymisation and pseudonymisation:		
	(this box should expand as you type)		
14	**All Data Storage**		
15	Will the research activity involve any of the following activities:	**YES**	**NO**
16	Electronic transfer of data in any form?	☐	☒
17	Sharing of data with others at the University?	☐	☒
18	Sharing of data with other organisations?	☐	☒
19	Export of data outside the European Union or importing of data from outside the UK?	☐	☒
20	Use of personal addresses, postcodes, faxes, emails or telephone numbers?	☐	☒
21	Publication of data that might allow identification of individuals?	☐	☒
22	Use of data management system?	☐	☒
23	Data archiving?	☐	☒
24	If YES to any question, please provide full details, explaining how this will be conducted in accordance with the GDPR and DPA (and/or any international equivalent):		
	(this box should expand as you type)		
25	List all who will have access to the data generated by the research activity:		
	(this box should expand as you type)		
26	List who will have control of, and act as custodian(s) for, data generated by the research activity:		
	(this box should expand as you type)		

27	Give details of data storage arrangements, including security measures in place to protect the data, where data will be stored, how long for, and in what form. Will data be archived – if so how and if not why not.		
	(this box should expand as you type)		
28	Please indicate if your data will be stored in the UWTSD Research Data Repository (see https://researchdata.uwtsd.ac.uk/). If so please explain. (*Most relevant to academic staff*)		
	(this box should expand as you type)		
29	Confirm that you have read the UWTSD guidance on data management (see https://www.uwtsd.ac.uk/library/research-data-management/)	**YES**	☐
		NO	☐
30	Confirm that you are aware that you need to keep all data until after your research has completed or the end of your funding	**YES**	☐
		NO	☐

SECTION K: Declaration

31	The information which I have provided is correct and complete to the best of my knowledge. I have attempted to identify any risks and issues related to the research activity and acknowledge my obligations and the rights of the participants**.**	
	In submitting this application I hereby confirm that I undertake to ensure that the above named research activity will meet the University's Research Ethics and Integrity Code of Practice which is published on the website: https://www.uwtsd.ac.uk/research/research-ethics/	
	Signature of applicant:	CMEvans	**Date:** 12/01/2021

For STUDENT Submissions:

32	Director of Studies/Supervisor:	Dr Caroline Lohmann-Hancock	**Date: 16/01/2021**
33	Signature:	Dr Caroline Lohmann-Hancock	

For STAFF Submissions:

34	Academic Director/ Assistant Dean:		**Date:**
35	Signature:		