PROFESSIONAL DOCTORATES

Why parents and providers choose Applied Behaviour Analysis (ABA) for Autism Spectrum Disorder: Motivations and barriers to implementing ABA in a mainstream school

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Why parents and providers choose Applied Behaviour Analysis (ABA) for Autism Spectrum Disorder: Motivations and barriers to implementing ABA in a mainstream school

Lindsey Roberts

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To my boys!

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Table of Contents

Tables

Chapter 2: Methodology

Chapter 4: Central tensions and barriers to implementing ABA in a mainstream school

Figures

Chapter 3: Motivations - Why parents and providers chose ABA

Chapter 4: Central tensions and barriers to implementing ABA in a mainstream school

Summary

Applied Behaviour Analysis (ABA) has its foundations in the science of behaviour and is used effectively to address socially important behaviours, such as the education of children with Autism Spectrum Disorders (ASD) (Baer, Wolf & Risley, 1968). The evidence to support the use of ABA in behaviourally based interventions with ASD in education settings is growing (Eldevik et al., 2006; Kovshoff et al., 2011; Grindle, 2012; Kasari & Smith, 2013; Peters-Scheffer et al., 2013; Foran et al., 2015; Lambert-Lee et al., 2015 and Pitts et al., 2019). This thesis focuses on the provision of ABA-based education for young children with Autism Spectrum Disorders (ASD) in a mainstream school unit in Wales. More specifically, the research explores some of the factors that influence the decisions that parents and providers make when they choose and commission ABA-based interventions.

The original plan was to conduct mixed methods research to explore the variables around setting up an ABA unit in a mainstream school, and to evaluate the outcomes of the children involved in that project. For reasons that will be explored in more detail in this dissertation, the ABA classroom in the school was not established in the research time frame (from 2015 to 2018). The focus of the dissertation changed to understand four areas: Why parents want ABA for their children; what the school thinks about ABA; how the parents' and providers' views about ABA are informed by evidence, and what the barriers to implementing ABA in a mainstream school are.

Using a qualitative research design a sample of parents and providers from a school setting, including the local education authority (stakeholders) were interviewed to explore their understanding of ABA as an intervention for ASD, and how it could be implemented in a mainstream school. The motivations of the stakeholders to choose and implement ABA, and the barriers that were perceived as a result of that process are analysed in this dissertation. Chapter 1 reviews the evidence in the literature that relate to the thesis, and Chapter 2 presents the methodology used to gather the evidence. Chapters 3 and 4 analyse and discuss the data gathered from the stakeholders. Chapter 3 focuses on the stakeholders' motivations behind their decisions to choose ABA, and Chapter 4 examines

the data on the barriers to implementing ABA-based interventions in the mainstream school. Lastly, Chapter 5 presents an overall discussion of the thesis and outlines implications for this research within the field of ABA and makes recommendations for further study.

Chapter 1: A review of current research

Stakeholder decision making and implementing Applied Behaviour Analysis in a mainstream school

Introduction

Understanding the motivations of behaviour and how these can be used to change learning is of social significance. Applied Behaviour Analysis (ABA) uses the science of behaviour analysis to address these issues and support effective outcomes for children with Autism Spectrum Disorder (ASD). The most recent childhood and adulthood prevalence studies data for the UK show that more than one in every 100 people is on the autism spectrum (1% of children) and 1.1% of the adult population, roughly 695,000 people in the UK (Brugha et al., 2012; ONS, 2011; NICE, 2012 and NAS, 2018). Supporting the education of ASD children and young people is important for social inclusion by developing skills, improving learning and accessing employment. The costs of lifelong education and care is high in the UK, so improved inclusion in mainstream school and adult independence can help reduce those costs. There are over 1,300 commonly used treatment options for ASD in the UK, which is a broad and confusing range for parents and providers to choose from (Green et al., 2006; Matson & Konst, 2014), and to date there is little UK specific evidence to show how these interventions are chosen (Pellicano et al., 2013). There is, however, a growing evidence base for the effectiveness of ABA-based interventions for ASD (Lovaas, 1987, Eikeseth et al., 2002; Eldevik et al., 2012, Lai et al., 2014; Howard et al., 2005). Improved outcomes for children with ASD in Wales is relevant to all stakeholders: parents, teachers, local authorities and researchers. In this dissertation, the term providers refers to those that commission and deliver ASD services and interventions in educational settings; namely the local authority and mainstream school.

There is increasing interest in how ABA interventions can be effectively implemented in mainstream school classrooms. The contribution this thesis makes to this process is pertinent for two reasons; firstly, it examines the motivations behind stakeholder decision making on behaviour interventions; and then explores some of the tensions and barriers

they perceive to their implementation of ABA interventions in maintained schools. The outcomes of the research may inform changes that are made both in mainstream classroom practice, and also the planning of ASD provision locally. In the longer term research such as this can contribute to the discourse on changes in education policy for children with ASD. This is an exciting time for research in Special Education Needs (SEN) and ASD provision as behavioural interventions integrating into mainstream schools in Wales is an emergent practice; it is not only different but innovative. With evidence-based practice supporting stakeholder decisions on behavioural provision, the differences and barriers to implementation can be addressed. Subsequently, improvements can be made to commissioning services processes and potentially, the wider Welsh policy on ASD treatments.

This chapter will explore the literature on a number of areas relating to ASD provision for children and young people and is structured in sections. The first section, education provision for children with ASD will describe both ASD and ABA, and explore generally how ASD provision is chosen for children and young people in the UK. The second section will explore the current and most common types of provision available in the UK, eclectic and behavioural interventions (ABA). The third section will review the literature on the effectiveness of ABA in its application of Early Intensive Behavioural Interventions (EIBI). How behaviour interventions are emerging as effective provision for children in SEN and mainstream school classrooms and units is beginning to show promising results, and this evidence will be discussed in the fourth section. The final two sections explore the literature for evidence on how parents of children with ASD choose behavioural interventions; and lastly how providers choose those ASD interventions.

Education for children with ASD

Autism Spectrum Disorder (ASD) as described in the American Psychiatric Association's Diagnostic and Statistics Manual (DSM-V, 2013) is a neurodevelopmental disorder, biological in nature and characterized by persistent problems in social communication, interaction,

and restricted, repetitive and stereotyped patterns of behaviour, interests or activities (APA, DSM-V, 2013). Autism was a previous umbrella term for four conditions: Autism, Asperger's syndrome (AS), Pervasive Development Disorder-Not Otherwise Specified (PDD-NOS) and Childhood Disintegrative Disorder (CDD). The term ASD is used throughout this dissertation, as an individual's diagnostic definition is not as relevant to this dissertation as is the focus on how their treatment is chosen and delivered.

One percent of children, roughly 695,000 are diagnosed with ASD in the UK (Brugha et al., 2012; ONS, 2011; NICE, 2012; NAS, 2018). For every three children diagnosed in that 1% of the child population, Baron-Cohen (2012), suggests that there are two undiagnosed children who might need a diagnosis during their lifetimes. The number of children diagnosed with ASD rose steadily in the United States (US) since it was first tracked in 2000 (one in 69 children), until 2012 where the prevalence was one in 42 boys and one in 189 girls, approximately five to one (Matson & Kozlowski, 2011; Wright, 2017; CDC, 2020). In 2016 the prevalence was one in 54 children according to estimates from Centres for Disease Control's (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Network (Maenner et al., 2020). The increase in prevalence of ASD until 2012 was believed to come from an increased awareness of the condition from its diagnostic criteria. When these diagnostic criteria were reviewed in 2013 (APA DSM-V, 2013) the US prevalence rates reduced when some criteria for diagnosis were changed, which most likely excluded some individuals from a diagnosis. Debate continues over these changes to the diagnostic criteria from DSM-IV to DSM-V editions, which resulted in the discontinuity of some terminology and diagnostic criteria. Changing the definitions of ASD poses problems for the ongoing provision, appropriate care, treatment and education services for children and adults with ASD symptoms, but without a diagnosis (Volkmar & Reichow, 2013).

Recently, data for the UK on ASD suggests that the costs to the economy are in the region of £3.4 billion per year (Rodgers, 2020; Buescher et al., 2014). If I go back to the definition of ASD where the characteristics are described as pervasive and persistent throughout life, it is important because of the evidence of both prevalence of the condition and the cost, that ASD services are evidenced as meeting the needs of children and their

families for the long term. Education services across the UK demonstrate a shortfall in specialist provision (Lindsay et al., 2005), local authorities are significantly underfunded and furthermore, place approximately 23% of ASD children and young people in expensive provisions out-of-authority (Audit Commission, 2007). Schools in particular would benefit from being more specific and effective in how they teach children with autism in a 'system [that] has failed them' (McNerney et al., 2015; Lenehen, 2018).

How do people choose ASD education for children?

The main aim of this dissertation will explore how parents and professionals make decisions when choosing education services for children with ASD. More specifically it is focused on how ABA-based provision is chosen and then delivered in a mainstream school setting. How both parents and providers choose support and interventions will be discussed in greater detail in (pp.34-40) this literature review, but it is relevant to introduce the topic here.

Choosing from the 1,300 or so options of available education provision is challenging. It is a process made more complex as no single approach can accommodate each child's individual characteristic way of learning that promotes socialization and reduces restricted, repetitive behaviours (Jordan, 1997). For providers (Local Authorities, Health Services and Schools) being informed about the provision choices available is an important factor of any service delivery, and especially so as current UK legislation reinforces parents' rights to have this choice with respect to autism education (DfE, 2015). The responsibility of choosing often falls on the parents to make critical decisions about the education of their children when there is little evidence to go on, amidst varied levels of support from professionals in a system that is not straightforward nor systematic (Romanczyk & Gillis, 2005; McNerney et al., 2015). A decade ago a major review of SEN provision was reported by the Office for Standards in Education (OFSTED, 2010) after scoping all special schools, mainstream full-inclusion, and ASD classrooms or units in mainstream school settings.

Findings suggested that there was no singular model of provision that worked better than any other for children and young people with ASD. Given that there was deficit cited at -7,500 educational places available for ASD children across England alone parents often had no choice but to place their child in mainstream schools. Given that many ASD provisions lacked a rigorous evidence base of effectiveness; combined with limited funding for resources and staff training it makes choosing the right provision for providers to deliver, complex at best; and difficult for parents to know which setting and type of intervention is best for their children (McNerney et al., 2015).

An internet survey of UK parents (Denne et al., 2017) identified that the provision for some children with ASD is typically provided through education services often delivered through a mainstream school setting. Other children will access provision through Special Educational Needs and Disability (SEND) services. Commissioning these services through either route has become a more detailed undertaking than the procurement of provision; where procurement may agree to a provision based on its cost effectiveness. In contrast, commissioning services must account for the recognition of appropriate support, its securing and also it's monitoring for effectiveness. What this means for ASD services is that the process of decision making by provision commissioners is invariably led by those who do not always base their decisions on evidence-based practice. This is despite the SEND Code of Practice (SEND, 2015) specifying that the services and interventions provided should be evidenced as such. Subsequently, support for children with ASD is decided upon according to services' competing demands, priorities, power relationships and the individual perceptions and personal experiences of the commissioners (Rees et al., 2014; Wye et al., 2015). The outcomes of Denne's (2017) study was that commissioners took three different considerations into account when choosing support for autism. Firstly, accountability for the cost, where children were placed in their local authority area, and ideally accommodated in mainstream education provision. Secondly, the child's ASD needs were taken into consideration, and lastly the requests of the parents were a factor. These competing priorities within a commissioning system for any local authority not only creates tension within that system itself, but also a great deal of frustration for all the stakeholders - parents and providers (Denne et al., 2017).

Parents may make choices about which intervention treatments are appropriate for their child's needs based on different criteria of effectiveness and outcomes of those treatments than education and SEN professionals. Parents, by default have to become the principle negotiators in their children's education and treatment throughout life, so their perception on what constitutes effective treatment may differ greatly to those of the providers' and researchers. Local authorities and schools in Wales take a multi-disciplinary approach to commissioning services (ASD Strategic Plan, 2019). However, parents' perceptions of that commissioned treatment's effectiveness often include its cost, its accessibility and its availability to them. When providers are able to address these factors then parents can be better informed to make the best decisions for their children, which may in turn go some way to reducing the frustration stakeholders experience in the commissioning system. Grindle et al., (2009), Dillenburger et al., (2014) and Guldberg (2010) suggested that the stakeholder agents in the commissioning system, work together in the process to improve multi-disciplinary working.

There are a number of issues Dillenburger (2014) suggests that need exploring for effective provision of interventions and practices to be adopted. These are mainly the misconception that professionals in SEN and education services have developed around the science of behaviour studies; and subsequently how these misconceptions are then applied in behaviour based interventions which culminate in a 'category mistake' that professionals and parents make. Briefly, a category mistake in the field of behaviour analysis is when premature conclusions about facts, or behaviours from one situation or category, are made sense of by the observer as explanations for that behaviour as if they belonged to another category (Ryle, 1949; Dillenburger, 2010; Keenan et al., 2015).

With better awareness of misconceptions, providers and parents may change their practice so that more effective interventions can be delivered. Given the paucity of evidence available on how interventions are chosen and implemented, research into how stakeholders in multi-disciplinary teams make intervention choices becomes valuable, which should include how they become more knowledgeable about the interventions they intend

to deliver (Matson & Williams, 2015; Stanislaw et al., 2019). As the focus of this dissertation is on how parents and providers choose ASD interventions, in particular those based on ABA, my aim is to contribute to this discourse.

Providers and parents experience confusion when choosing ASD interventions, as do global governments. Government reports differ in their reviews and recommendations on what the best ASD intervention methods are, citing the two very different models for delivery (McNerney et al., 2015). The behavioural route which includes ABA-based interventions and the eclectic route. The next section reviews the research on the common ASD interventions available in Wales and the UK, which include both eclectic and ABA-based interventions. The eclectic route will be discussed first then the ABA-based interventions.

Common ASD interventions

Eclectic Models of Intervention

In the UK, Ireland and most of Europe, the popular intervention choice for children with ASD is an eclectic approach (Jordan et al., 1998; Dillenburger, 2011). This is an approach that includes a broad range of interventions, and combinations of interventions that are chosen by professionals in schools and SEN settings, which are aimed to improve social and academic skills and promote inclusion. They are chosen because in practice in the classroom they are professed to be 'flexible and child-centred' (Gladwell, 2010). It is internationally agreed that accessing mainstream education is typically the most acceptable form of inclusion for children with special needs, a factor often interpreted as being physically present in a classroom (Dillenburger, 2011). As a result, there is both debate and confusion over which are the best methods that achieve inclusion.

The term eclectic describes a wide range of approximately twenty four methods and commercial packages that are used to support children with ASD (Humphrey & Parkinson, 2006; Osborne & Reed, 2008). These methods are often combined into various approaches, such as – *interactive, communicative* and*, integrative*. Interactive approaches include methods with brand names such as the Social Stories™, Floor Time or activities like music

therapy. Communicative interventions include Picture Exchange Communication System (PECS) (Frost & Bondy, 2002) which is a system of developing communication; or Speech and Language Therapy (SALT). An integrative approach combines a range of different methods that comprise a programme, for example: Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) which uses structured tasks deconstructed into smaller components to learn skills; Sensory Integration or Occupational Therapy (OT). The distinct features of each of these methods is not wholly relevant to my dissertation other than to note that they stem from very different theoretical and education perspectives than behavioural science. As a result, eclectic interventions may not necessarily follow any guided strategy or underpinning philosophy (Reed, 2015). In contrast to behavioural methods, eclectic methods do not have an equivalently robust empirical evidence base that ABA has in behavioural science, which leaves them short on evidence of their effectiveness (Dillenburger, 2011). Whether as individual methods or combinations of methods, the effectiveness of these approaches is cited as being complex to extract. This is exampled further by McMahon & Cullinan (2016) who explored the evidence base of eclectic interventions and found there was a distinct lack in the use of educational theory in their development and methodology to teach children with ASD.

However, more positively, Dillenburger, et al., (2011) and Dillenburger et al., (2012) suggest that some of the individual methods in the eclectic approach have a valid evidence base of effectiveness, and also a small number of studies, according to Howard et al., (2005) and Howard et al., (2015) have examined the outcome effects of blending multiple methods and also found them effective. Whilst eclectic interventions have been shown to be less empirically effective than ABA-based interventions (Howard et al., 2005; Osborne & Reed, 2008) even in the long term effectiveness of interventions (Howard et al., 2015); most of the SEN schools and units in the UK and Ireland continue to promote the provision of an eclectic intervention mix. The eclectic approach most often includes the main interventions of popular choice for ASD such as TEACCH, Sensory Integration, and PECS. Choice, as noted earlier is often based on the collective outcomes of cost, training and abilities of local authority staff to deliver the intervention, alongside the child need, and parent request

(Denne, 2017).

Given that there is a paucity of experimental evidence on the outcome effectiveness of eclectic interventions they are often used in experimental conditions as the method of choice for a control group in comparison studies (Clinical Control Trials - CCTs) with intensive behaviour interventions such as ABA (Osborne & Reed, 2008). The gains achieved by children in these comparison groups is measured against those attributed to ABA and are found to be invariably below those achieved by the ABA-based intervention (Howard et al., 2005 and Sallows & Graupner, 2005). When Osborne & Reed (2008) measured eclectic methods for effectiveness in experimental conditions on 65 children aged two to four years old, where the eclectic method was the only or the primary intervention approach, children made significant improvement (10 points) over a school academic year in intelligence based (IQ) assessments and adaptive behaviour skills. The children took part in reinforcement interventions, structured task interventions similar to those included in the TEACCH method, and SALT. The intelligence gains were comparable to those made by ABA interventions in their earlier studies (Reed et al., 2007), and raised the question of the degree of influence that eclectic methods may have over ABA derived results in IQ and behavioural gains when eclectic methods are used in ABA comparison studies (Osborne & Reed, 2008).

Studies conducted on PECS, Social Stories™, and SALT have shown gains in IQ and adaptive behaviour. For example, within the eclectic intervention study by Osborne & Reed (2008) and later extended by Reed (2015) involving PECS, where improvements were observed in speech and social behaviour. Some children in the study also demonstrated a reduction in problematic behaviour. Furthermore, Social Stories™ used with children in a nursery setting were reported to improve children's adaptive behaviour, reduce disruptive behaviour and increase appropriate social interaction (Osborne & Reed, 2008); and in interventions where SALT is commonly found within an eclectic intervention has shown positive improvement in language skills (Howard et al., 2005; Sallows & Graupner, 2005). What was common to these individual studies was the number of hours of intervention they were implemented for, which averaged 13.5 hours of intensive reinforcement-based

intervention each week, at both home and in school settings. The intensity of intervention delivery was considered an important factor, and is discussed in more detail (p.34).

ABA as an ASD intervention

A sample of key studies are reviewed in more detail from page 25. These examine the empirical research of the effectiveness of behavioural interventions demonstrating that evidence supporting ABA outweighs that available for eclectic interventions as demonstrated by Lovaas' (1987) influential study (Eldevik et al., 2009; Howard et al., 2005; Grindle et al., 2012; Dawson, 2010; Remington, 2007; Reichow, et al., 2012; Barton et al., 2012 and Matson & Lang, 2014). A further example, Eikeseth et al., (2002) compared the outcomes of intensive ABA-based interventions, using a model of early intensive intervention developed by Lovaas (1987), with eclectic methods such as TEACCH-based method and sensory integration. Measures for IQ, language and communication and adaptive functioning were taken at the start of experiment and one year after intervention, for 13 children average age five years. Intervention was intensive, approximately 28 hours per week. Twelve children received eclectic interventions for the same period and same intensity of delivery. Gains were seen across all the measures for the experimental behaviour group that were significantly different for IQ (Increased by 17 points); language (increased by 13 points) and adaptive behaviour (increased by 11 points). In the eclectic group there were gains made in IQ (increased by 4 points), but no increase was seen for the language and adaptive skills measures. They concluded that it was the type of treatment, namely the specific behavioural methods that were important in demonstrating those gains in this study, rather than the intensity of the intervention. This study was extended by Eikeseth et al., (2007) using the same experimental methodology and the same group of children, now with an average age of eight years. The findings were that the experimental behavioural intervention group made gains across the same measures (IQ, language and communication and adaptive skills) IQ gains were statistically significant, which increased by a further 7 points to 25; and adaptive function increased to 12 points. Once more the authors found the intervention method was more important than the intervention intensity in producing gains; but what was indicated in this second study was the that the age

treatment started may not be as important in predicting the outcome gains as had been previously thought by Lovaas (1987).

An important study by Howard et al., (2005) which was replicated and extended in 2015, compared the data on two groups of children with ASD, where one had an intensive behaviour intervention and the other an intensive eclectic over a three year period. Howard et al's (2005) key study demonstrated that an eclectic method was less effective than the experimental behaviour-based intervention used. Outcome gains measured cognitive ability (IQ), language and communication and adaptive skills for 29 children. Both groups were assessed before interventions and compared after one year of intensive behaviour and eclectic intervention for up to 40 hours a week. They found that the behavioural intervention group produced significantly better gains in the aforementioned outcomes than the eclectic intervention group, and these gains were retained after a 14 month follow-up period (details on p.25).

The evidence on eclectic interventions is often based on non-experimental (CCT) designs to substantiate them, which is useful to explore further, particularly with respect to underpinning theoretical approaches that providers use when they choose interventions, as it may contribute to understanding why eclectic intervention choices are being made over evidence based alternatives (Dillenburger, 2011). McMahon & Cullinan (2016) have explored the significance of education theory such as constructivism in the development of eclectic programmes and found them lacking in philosophical underpinning. From a review of available literature on the philosophies of eclectic methods they proposed a strategy where eclectic and behaviour interventions are 'filtered through a lens of constructivism'. Findings recommended that it was important for providers and teachers of eclectic interventions to be aware of, and challenge their own theoretical positions when they created learning plans for children with ASD. When ASD interventions are approached with 'child-centeredness' in mind, educators may be influenced by their own theoretical positions, as eclectic approaches which often use non-experimental designs to evidence their effectiveness may be perceived subjectively. Providers and educators may base their positions on a constructivist approach, and therefore, it is possible that they unknowingly overlook

evidence-based methods. Constructivism is both a paradigm and a theory, which was a concept introduced to education by Dewey (1902), whose beliefs that learning is an active process; that a child's knowledge is constructed, invented and not discovered or passively acquired; and that a child's learning is individual, is sourced from knowledge that is socially constructed, and encourages the child to make sense of the world. For learning to have effective outcomes it should be meaningful, engaging and challenge the learner to solve problems. Dewey forged the constructivism theories that were later developed by Piaget and Vygotsky whose paradigms form the basis of current pedagogical practice (McMahon & Cullinan, 2016).

As a result of providers' theoretical value based positions, McMahon & Cullinan (2016) suggest that eclectic programmes may be misinformed, biased and subject to that individual's interpretation of what is perceived to be in the child's best interest (McMahon & Cullinan, 2016). Providers may therefore approach the choosing of interventions using constructivist paradigm theories and their own preconceived ideas about the process of child development. When instead of judging the methods in terms of their difference, one can be viewed as better than the other. As a result, eclectic models have become are more favourable with many providers (McMahon & Cullinan, 2016). This could go some way to explain why behavioural approaches are sometimes perceived negatively, and are criticised for a variety reasons, such as having a normalizing agenda where skills are generalized, they are teacher-led which are reliant on rewards or aversive penalty that appear to have unclear long term outcomes (Hastings, 2013).

Nevertheless, the current growth in the evidence of the effectiveness of behavioural interventions based on ABA in terms of IQ, adaptive skills, language and communication and ASD behaviour improvements is compelling (Eikeseth, 2009; Eldevik et al., 2009; Eldevik et al., 2010; Reichow & Woolery, 2009; Rogers & Vismara, 2008; Virués-Ortega, 2010 and Lai et al., 2014). This body of evidence for the effectiveness of behavioural models and the common use of eclectic interventions as the go-to interventions of choice for ASD in the UK has created a contradiction in practice. For example PECS itself was derived from the science of behaviour, yet is considered by many providers as an eclectic intervention (Frost &

Bondy, 2002). As a result, Welsh, and UK schools traditionally, continue to operate an inconsistent eclectic intervention practice which has some behavioural based provision included (Dillenburger, 2012 and 2011; Simple Steps). Published literature on how behavioural based interventions are being developed in mainstream UK schools is discussed later in this review (p.38); but it is relevant to note here that their long term cost efficiency for local authorities could have a positive effect on how providers choose autism provision (Chasson, 2007).

The point made earlier about constructivism theory underpinning some providers' decision making on behaviour interventions is central to why behavioural interventions can be perceived negatively, be misunderstood and furthermore misrepresented by providers. This is worthy of further analysis, as the resistance to the use of behavioural interventions is thought to be preventing their widespread use for children with ASD (Dillenburger et al., 2010). As noted earlier, choosing ASD interventions in the UK has given rise to confusion for a wide range of providers and parents. This confusion is believed to stem from misunderstanding behaviour based interventions and their scientific relationship with behavioural science. Misunderstanding the science of behaviour mixed with individuals' perceptions has prompted misconceptions that run into misrepresentations of the practice, for example 'as rigid and inflexible' (Jordan, 2001; McMahon & Cullinan, 2016) and are believed to be rooted in a category mistake (p.6) (Chiesa, 2005; Dillenburger et al., 2010). For example, in the UK the term ABA is often misinterpreted as an intervention alongside PECS (Frost & Bondy, 2002) which was developed to address specific communication issues, and is considered an eclectic intervention, yet was derived from the science of behaviour and accepted as a component of an ABA program (Frost & Bondy, 2002; Howard, et al., 2005). Early Intensive Behavioural Intervention (EIBI) and Positive Behaviour Support (PBS) as further examples would fall under the heading of ABA-based interventions, not the other way around. A detailed analysis of EIBI is found on page 28. ABA is not a single methodology but numerous methodologies stemming from the science of behaviour (Eldevik, et al., 2009; Dillenburger, 2011; Gore et al., 2013). Chiesa (2005) explains it not as a bounded intervention but a 'sum' of all the behaviour interventions that constitute it.

Furthermore, she adds to the discourse by saying that making a category mistake diminishes the value of ABA practice as a profession. Training in ABA requires extended higher education training, to at least to Masters level, followed by further rigorous supervised practical experience (1,500 hours) from accredited professional practitioners of the Behaviour Analyst Certification Board (BACB, 2018, https://www.bacb.com/), where the BACB (2018) sets out clear ethical guidelines for qualified practitioners. There remains a dearth of available evidence to support a competency base for mapping professional ABA practice in school settings (Denne, 2011). Differences in training strategies for school staff would need to be addressed for the effectiveness of the programmes to be maintained in the longer term. At the time of writing there has been no clear adoption of their proposed frameworks available for local authorities in Wales to follow. The autism education guidelines for Wales (WAG, 2019) recommend a variety of ABA strategies such as Antecedent-based interventions, Discrete Trial Training (DTT), and PECS, but fall short of actually recommending ABA. Continuing with the understanding of ABA being general and a collective of methodologies based on behavioural science, the next section will review ABA more thoroughly and define what it is and how the early intervention of ABA in the form of EIBIs are applications of ABA, and are more specific.

What is Applied Behaviour Analysis (ABA)?

The earlier section reviewed and discussed how misunderstanding the principles of ABA can lead to its misrepresentation in practice, which in turn may influence the decision making of providers of ASD treatments. ABA is based on the principles of behavioural science and the work of B.F. Skinner (1938). As an umbrella term of behavioural science, the application of ABA has become a useful treatment for a wide range of social problems that include ASD, but also a variety of other special educational needs and addiction (Matson, 2009; Fisher, Piazza & Roane, 2014). ABA has been described by Baer, Wolf & Risley, (1968) as having three strands: a conceptual, an experimental and an applied strand. It is the applied strand of ABA in which this thesis is more interested: a description of an applied science that is used to describe a number of different approaches and interventions to promote inclusion for children with ASD. It is based on the concept that behaviours that

produce favourable outcomes will be repeated when reinforced positively, and behaviours that produce unfavourable outcomes will decrease. ABA refers to the conceptual framework upon which multiple approaches to ASD are based, not simply a package of methods such as PECS, Early Denver Start Model (EDSM) and Positive Behaviour Support (PBS) are specific to the treatment of ASD and its behavioural challenges; EIBIs are therefore an application of ABA (Ringdahl & Falcomata, 2009).

Early Intense Behaviour Intervention (EIBI)

The evidence base for the effectiveness of EIBI is well documented within the literature (Lovaas, 1987; Eldevik et al., 2009; Howard et al., 2005; Grindle et al., 2012; Dawson, 2010; Remington, 2007; Reichow, et al, 2012; Barton et al., 2012 and Matson, 2014); and have proved to be effective and have long term outcome success with children with ASD. The next section will explore the history and evidence behind the early intervention of behaviour interventions, and review the research of a number of key studies by Lovaas, (1987); Howard et al., (2005); Remington, et al., (2007) and Reichow, et al's., (2012) Cochrane Report. These are highlighted to begin this dissertation's exploration of how EIBI has developed, what their limitations are, and how they can be applied in real school settings, which can help reduce the cost of interventions for parents and providers (Jacobson, Mulick, & Green, 1998).

EIBI was first described by Ivar Lovaas in the 1960s, and later in his influential study in 1987 where he applied EIBI as an intervention approach to a broad range of target behaviours in ASD. Specific behaviours were targeted in order to change them by identifying and stabilizing variables in the child's environment to reduce challenging behaviour incidents and reinforce more positive behaviours through a process of discrete trial training DTT (Educate Autism, 2018; Iwata, 1994). Briefly, DTT involves breaking down a complex behaviour or a skill into its smaller components, and then teaching that component through repetition and practice using positive reinforcement to achieve success (Luiselli et al., 2008). Successful outcomes not only benefit the child, but their family, community and local authority, and include life-long skills such as functional skills of dressing, feeding, toileting,

self and personal care, appropriate social behaviours, reduced aggression and self-harm. These can become consolidated and form a base for further learning. EIBI has therefore developed as an approach of more specifically 'packaged' ABA methods devised into programmes of learning that are delivered intensively to children. The programmes aim to fundamentally develop a positive skillset whilst diminishing other possibly challenging behaviours (Matson, 2009).

In experimental situations EIBI has proved to be more effective than the collection of eclectic approaches that are used for ASD (Howard et al., 2005; Howard et al., 2012; Matson et al., 2009; and Fisher et al., 2011, p.4). This is relevant, because not only must interventions be effective, show successful outcomes, and last over time; there is also a need for them to be generalized from setting to setting and be specific to the individual. Improving access to mainstream school inclusion for children with ASD across a range of settings is a desired goal of EIBI (Lovaas, 1987; Eldevik et al., 2009; Eldevik, 2012; Grindle et al., 2012; Dawson, 2010; Remington et al., 2007; Reichow et al., 2011; Matson, 2014; Luiselli et al., 2014 and Pitts et al., 2019). To add further weight to this positive evidence, a review of EIBI studies over the last fifty years has found an emphasis on the earlier the intervention the better the outcome (Beavers et al., 2013); yet there remains a divide between North America and Europe where EIBIs are concerned. In North America, they are the appropriate and first choice educational intervention for young children with autism, where in Europe there is some resistance to behavioural interventions in preference of the eclectic approach (Keenan et al., 2015).

Lovaas (1987) applied behaviour modification interventions as EIBI strategies to an experimental group of young children with ASD for up to 40 hours a week. This was through one to one teaching of DTT by a therapist and or trained parents in the home setting, for almost all of their waking hours. Each intensive programme was designed by behaviour therapists (BCBA®) which accommodated the individual needs of the child, involved reinforcement for the positive behaviours and positive punishment to reduce undesirable behaviours. The practice of aversive reinforcement is not contra-indicated by the BACB®. The intention of the study was to increase their ability to access mainstream nursery /

kindergarten and be functionally and educationally comparable to their peers. The children were on average 3.3 years old at the start of intervention which continued for three years. They were all diagnosed with ASD. There were 19 children in the experimental group and 19 in the comparison group. IQ was measured at the start of intervention, and end of the first, second and third years. The developmental curriculum used focused on reducing self-stimulating and aggressive behaviour in the first year of study; expressive and abstract language and interactive play in the second year, and the third year concentrated on basic skills of literacy and numeracy and appropriate expressions of emotion. Experimental findings showed a 30 IQ point difference between the experimental and comparison group of children, and that 47% of the experimental group (mean IQ of 107) entered mainstream school in Grade 1 (US equivalent to Year 2 - Foundation Phase in the UK). Forty–two percent (42%) entered specific special needs classes for language (mean IQ of 70) and 10% did not progress to mainstream school. By comparison only 2% (five children) of the comparison group achieved the educational and functional ability to progress to mainstream school. There was no significant difference between the two groups at the start of intervention.

EIBI worked well for almost half of the children as they subsequently accessed mainstream school. There were methodological issues posed in the paper, suggesting that the two groups were selected in a biased way; some of the children were not 'truly autistic'; the therapists' approaches differed between experimental and comparison group and that possibly there was some spontaneous improvement to account for the IQ score changes. However, what was useful for future EIBI studies was that the success was based on the early age of starting the treatment and the intensity of the delivery of the programmes. Future studies were recommended to include measurements of both language and communication skills and also play. Lovaas' extended on this study in 1993, and showed that that the gains made persisted at age 11.5 years, and that 90% of those having made those gains were indistinguishable from their peers. Subsequent studies often include measures of communication and adaptive behaviour. Furthermore, and importantly for my dissertation on the rationale of choosing effective interventions for ASD, is that Lovaas highlights the effectiveness of this methodology for the long term benefits of the child. These are in terms

of educational and functional ability but also the impacts on the family and long term lifetime costs of funding education and care for children with autism (Lovaas, 1987).

A further relevant study is Howard et al., (2005) and their extended study in 2015. Both of these papers report on the effectiveness of EIBI, measured against eclectic interventions. The behaviour intervention that was used in both studies was ABA-based and delivered across a range of settings: home, school, treatment centres and community centres between 35 and 40 hours a week. In the second study there were two different eclectic interventions used, one was specific to children with an ASD diagnosis and the other was designed for children with a range of general special needs (including ASD). Interventions in both these eclectic delivery groups were drawn from the TEACCH, Sensory integration and PECS methods. The ASD specific behaviour intervention group had up to 30 hours a week of intervention and the general special needs group had between 15 and 17 hours a week of intensive intervention. In the behaviour intervention group, researchers found that the gains made in the IQ, adaptive behaviour and communication measures after the first year were improved for the following two years, and were twice as likely to score in the normal (higher than 85) range on the stated measures. There were no consistent differences between the outcomes in the eclectic comparison group at the second and third assessment points. Children in both of the eclectic intervention groups made gains, and in some cases achieved scores in the normal range, where they had not at the baseline assessment point.

Whilst this evidence continues to support that behavioural interventions delivered in the early years is more likely to improve cognitive, communication and adaptive skills outcomes than the eclectic intervention group (as in Lovaas, 1987); it is important to emphasise that improvements were also seen in the eclectic intervention groups. It is significant to point out that the comparison groups were also exposed to intensive interventions. The intensity with which interventions are delivered was therefore perceived to be an important factor in experimental research to evidence improved outcomes (Howard et al., 2015). However, to balance the argument of intensity of intervention delivered and highlight some of the potential benefits of low intensity interventions, D'Elia

et al., (2014) investigated a low intensity TEACCH intervention as part of an eclectic strategy. Thirty pre-school children, (15 in the experimental group and 15 in the comparison group) received two hours of TEACCH interventions in school and two at home per week, over a two year period. The findings showed that the children's developmental outcomes of autism severity according to the Autism Diagnostic Observation Schedule (ADOS)(Lord et al., 1999), adaptive behaviour measured by the Vineland Adaptive Behaviour Scales (VABS)(Sparrow et al., 1994), and receptive and expressive language improved significantly more than the comparison group participants over the longitudinal study. What also resulted from this study was a recommendation for further systematic and controlled studies to evaluate the effectiveness of eclectic interventions such as TEACCH, as in this case, to compare the effectiveness of eclectic and behavioural interventions more accurately.

A third prominent study is Remington et al., (2007), who investigated EIBI in 44 pre-school aged children (2 – 3 years old) diagnosed with ASD over a two year period. Children were allocated to the behaviour intervention group because parents had requested EIBI, or were actively seeking it and had up to 40 hours of intensive one to one DTT treatment a week in a home-based setting. Individualised behavioural programmes were designed by BCBA® behaviour therapists and delivered by ABA trained staff. Twenty-three children were allocated to the experimental group and 21 to the comparison group, who received treatment as usual (TAU). The experimental group were assessed before any interventions for cognitive function (IQ), social and communication (language), adaptive behaviours and also autistic behaviours. This study differed from the Lovaas' and Howard et al's (2005) studies in that an assessment of parental mental health, stress levels and perception of their children was included. In addition to the aforementioned methodology, Remington et al., (2007) were careful to consider the methodological limitations that are criticised in behavioural intervention experiments. These are with respect to issues of validity of the results as the usual randomised control trials (RCT) cannot often be adopted in behavioural studies such as these. As a result, comparison groups were used, and inter-group comparison differences pre and post intervention as it was not always possible nor ethical to allocate children to the different groups.

The intention to deliver 40 hours a week of behavioural programmes was in reality more like 25.6 hours a week. The comparison group received a variety of eclectic interventions for the two year period that included, SALT, PECS, TEACCH, Sign Language and Makaton. Most of their interventions were delivered on a one-to-one basis.
At baseline pre-intervention, children in both groups were comparable in IQ, adaptive behaviour and communication and language skills. After one year of intervention 57% of the behaviour group children were accessing mainstream school for approximately 5.8 hours a week; after two years this increased to 74% for 13 hours a week. Twenty-two percent of the children at this assessment period were attending SEN school for nine hours a week, and only one child remained in the home-based programme. The intervention group also received some eclectic interventions during the experimental period, predominantly SLT (65%). This reduced to 22% after one year, and 26% at the end of the second year.
In the comparison group, at the end of the two years of intervention all the children had a school placement. At the baseline assessment point none were in mainstream school; but at the end of year one, 48% were in school for approximately 15 hours a week (42% were in SEN Special Schools for 17 hours a week), and 10% attended a mixture of both settings for up to 15 hours a week.

At the end of the trial period, 26% of the EIBI group showed significant and reliable gains in IQ, and reliable gains in the other measures of language and communication and adaptive behaviours. Of the comparison group, 14% made reliable gains in IQ, yet 14% reliably regressed in their IQ. Parents reported that there was no detriment to their mental health, and stress levels over the test period, and their perception of their children was positively improved. Remington et al., (2007) concluded that EIBI delivered in home-based settings is effective for young pre-school children with no negative impact on their parents, despite the reduced level of actual intervention. This is relevant as it supports that lower intensity interventions (averaging around five hours a day) are producing positive effects, and significant gains.

The last paper reviewed in this section is Reichow et al's., (2012) Cochrane Report: a systematic review of the effectiveness of EIBI for young children with ASD who started

behaviour intervention treatment under the age of six. Earlier studies cited or discussed in this dissertation have indicated that EIBI is a common intervention of choice for these young children, when delivered intensively between 20 and 40 hours a week over a period of years. The outcomes in the studies cited so far in this section have been positive for improved IQ, adaptive behaviour skills and also language and communication ability. In Reichow et al's (2012) report, the outcomes reported that there was some evidence that EIBI was an effective approach for some children with ASD, which sounds less positive than the individual studies commented on so far in this dissertation. It is possible that the rationale for the perceived reserved conclusion is based on the rationale of the review's methodology. When choosing papers for the review, the study used the criteria of the method design being RCTs and Clinical Control Trials (CCTs), where EIBI intervention groups were compared to eclectic TAU interventions, and also that the children participants were under six years old. Five studies were scrutinised, one used RCTs (Smith et al., 2001) and the others used CCTs (Howard et al., 2005; Remington et al., 2007; Cohen, et al., 2006 and Magiati et al., 2007). The average length of study across all the papers reviewed was 26.3 months, and the interventions intensity mean was 24 hours a week for a total of 203 participants. For the meta-analysis a random effects model was used. This was chosen because the parameters being measured are themselves random variables (Higgins, 2002).

The outcome of Reichow et al's (2012) review was that the meta-analysis random effect for adaptive behaviours (0.6), IQ (0.76), communication and language (0.50) and also autism symptoms (0.42) and daily living skills (0.55) were all positive; which meant that EIBI was effective for some children with ASD. Some criticisms of the EIBI studies in general are that CCTs are non-randomised, and as such are open to bias and question the integrity and quality of the evidence. RCTs, according to the National Institute for Health and Care Excellence (NICE, 2012) are a better tool for assessing long term outcomes such as these as they are intended to capture the effect of improvement over a longer period. However, on the basis of their evidence Reichow et al., (2012) suggested recommendations that the methodology applied in future studies' is more robust and uses RCTs, larger samples of participants and ensures that the experimental and comparison group baseline data is more balanced. If the limitations of the evidence because of the choice of methodology is made

more robust it can support providers and commissioners of ASD services to make more informed decisions about EIBI. The review also recommends, to do so on a case by case basis, and use their clinical decision making guidelines – such as ask the family and include previous clinical evidence to help inform intervention choices. Further recommendations that are relevant to include are a rigorous investigation of the impact of the individual components of EIBI, and the educational and behavioural practices of the children in both the experimental and comparison groups.

To summarise the key features and limitations of the papers discussed above, Lovaas' (1987) influential study noted the importance of the intensity of the programmes (40 hours) and the early age (3years) of starting the behavioural interventions for the best improvements in the measures. Howard, et al. (2005 & 2015), highlighted, as did Lovaas, that the intensity of the programme (35 to 40 hours a week) was key to improved outcomes. In addition, behavioural interventions produced better improvements than eclectic interventions over a longer period of three years and across a range of settings - home, school, treatment centres and community centres. They also showed that the gains made were retained 14 months after the end of the experiment, which were developed across that range of settings. Remington et al., (2007) again compared behavioural interventions against eclectic interventions for young children (two to three years old) in the home setting. With this study the intention was to provide intervention for 40 hours a week, but in reality this was more like 25.6 hours a week. Nevertheless, even with the reduced intensity of delivery the results showed positive gains for IQ, language and communication and adaptive behaviour skills, similar to those of Lovaas (1989) and Howard et al., (2005). The studies mentioned so far have all been delivered in the home setting, but Eldevik et al's., (2006 & 2012) design was to make assessments on behavioural interventions being delivered in a school setting for 20 hours a week (see p.37). A different setting and a reduced intensity of intervention delivery time. Again, the results showed that the children made gains in IQ, adaptive behaviour, and daily living skills measures, with the reduced intensity of delivery time of 13.6 hours a week. This was the least intensive behaviour intervention documented in the papers outlined so far. Both experimental and comparison groups were based in a regular mainstream school, which is relevant for my dissertation as

the purpose is to explore the way providers and parents choose ASD interventions and set up a unit in a mainstream school to deliver them.

The last study examined in this section was Reichow et al's., (2012) Cochrane Collaboration Review. This meta-analysis of a range of EIBI studies that included, Howard et al (2005) and Remington et al (2007), measured the effect of EIBIs, and concluded that there is some evidence that EIBI is effective for some children with autism, but there were methodological considerations that needed to be made in future studies to validate the results, i.e. use RCTs for both the experimental and comparison groups; have bigger sample sizes; assess the impact on parents and families and be more specific about the comparative effects of the eclectic intervention that EIBI was compared with. Reed (2015) also suggested a closer analysis of the impact of eclectic interventions. The review also made recommendations that future research investigate the intensity of delivery variable more thoroughly, for example, the minimum hours of intensive delivery for maximum effectiveness. More robust evidence on this factor would be useful to support parents, schools and local authorities in making provision decisions and putting EIBI into widespread practice in schools. Three themes emerged from the research above: the intensity of delivery, the age at which treatment starts and the setting in which the intervention takes place, each will be discussed next.

Intensity of behaviour intervention delivery

The discourse on the intensity of delivery for an effective behaviour intervention programme is worth expanding on further, particularly in light of the data cited in the previous section i.e. that ABA-based interventions delivered in a school setting with fewer hours of intense delivery (approximately 20, but a mean of 13 hours a week in reality) produce similar positive outcome gains as those delivered in home-based interventions for approximately 40 hours a week for young children two to three years old. Matson et al., (2013) and Matson & Konst (2014) reviewed studies on who provides EIBI interventions and in which settings; they suggest that by their very nature programmes need to be intensive in order to achieve successful outcomes. This is reported as being between 20 and 40 hours a

week depending on the starting age of the children, as younger children may not be able to sustain 40 hours a week of intense delivery. Measures of outcomes were noted as consistent for IQ, communication and language, social behaviour and adaptive behaviour which were assessed at the start and after interventions lasting up to two years.

The number of hours of intensive behaviour intervention delivery was highlighted by Matson & Konst (2014), acknowledging that it varied between 4.5 to 40 hours a week, but was most commonly between 20 and 40 hours a week of delivery, which had not changed significantly in the research over the last twenty years. The review noted that there was an absence of evidence on transition strategies for EIBIs from the home-based to the school-based setting. There was however, little evidence presented of efforts being put into the transition from an intensive home-based intervention programme to programmes in school settings. EIBI programmes in home-based settings are reportedly as effective yet more complex and need adapting for a school setting for the gains made to be translated across settings and sustained. They suggest that schools begin to adapt and deliver more EIBI programmes to support the transition from home to school setting. The efficacy of the therapist delivering the intervention is also highlighted, not least the impact on them during intense one to one work with a child.

Intervention Starting Age

The evidence on intervention starting age was not clear in the research and was said to be when the child displays a "readiness" to start (Matson & Konst, 2014). This was explored further in Tiura et al's (2017) research which attempted to predict growth in treatment outcomes according to age, cognitive function (IQ), severity of diagnosis, intensity of intervention and gender. Reichow et al's (2012) Cochrane Review recommended that behavioural practices of the children with ASD in intensive treatments be investigated in relation to outcomes over the long term. There are few studies using longitudinal analyses of child characteristics to predict any rate of outcome improvement of ABA-based interventions (Virues-Ortega & Rodriguez, 2013). Having access to such evidence helps providers and parents choose, manage and plan intervention provision for children's long

term education. Tiura et al's (2017) study comprised of 35 children with a start age of three years, who had one to one intensive ABA-based interventions in home settings for a mean of 15.6 hours a week. Assessments through observation were taken at the outset of the study and every six months for three years for the language and communication, social-emotional, adaptive behaviour, and physical development measures (using the assessment tool - Developmental Profile3). The purpose was to see if age, autism diagnosis severity, cognitive functioning, intervention hours, gender, parent education level (or primary language spoken at home) could significantly predict the intervention outcomes. This was done using a growth curve analysis. Their findings were that a higher cognitive function at the start of intervention showed a significantly faster growth in all the developmental measures. Age at the start of intervention, contrary to Ben-Itzchak & Zachor, (2011) and Eikeseth et al., (2002) was not a significant factor in the growth of the development measures, although improvement in these development measures was found. This was believed to be because the study used a range of predictor variables which influenced the significance. Later age intervention starts producing similar improvements as an early intervention start has positive implications, for example for mainstream classroom inclusion (Remington et al., 2007; Reichow et al., 2012; Eldevick, 2012; Grindle, 2012 and Foran et al., 2015). The value of this particular evidence is useful to behaviour therapists who can plan and track the course of improvement in children over time, and make some projections of the long term effectiveness of intensive behaviour interventions. Needless to say this is valuable evidence for providers when planning ASD provision as it can offer some parameters for how long that interventions should continue which inevitably helps in future cost analysis. The third theme emerging from my review of research relates directly to my thesis of exploring the tensions and difficulties of implementing ABA in a mainstream school ASD unit.

Implementing ABA-based interventions in school settings

In the previous sections I have emphasised the research on the effectiveness of intensive ABA-based interventions for children with ASD in specialised centres or home-based settings, and also presented evidence that it is effective in school settings. Howlin,

Magiati & Charman (2009) in the US; and Reichow, et al's., (2012) in the UK systematic reviews found that indeed EIBI was effective in improving some outcomes for some young ASD children. However, there remains little published research on how these models may be translated and then delivered in SEN and mainstream UK schools. Griffith, Fletcher and Hastings' (2012) UK census of ABA-based school provision found that 14 schools provided ABA-based interventions for 258 children. This figure has now increased to approximately 400 children in 2020, but still only accounts for a small number of the population of children with ASD in the UK (ABAAccess4ALL, 2020). This next section reviews the emerging literature on how ABA-based interventions can be implemented in UK school settings and discusses the effectiveness and limitations of these models. One of the core themes of my dissertation is to explore how a Welsh mainstream community primary school set up an ABA-based unit for young children with ASD.

Reviews and longitudinal studies over the last 50 years in North America, (Beavers et al., 2013) and studies in the UK and North Wales evidence that ABA-based programmes are effective in school settings. There are differences between school-based ABA and traditional EIBI models. Children attending SEN schools or SEN units in mainstream schools often do so to access their right to education rather than for access to any specific behaviour intervention such as EIBI (Griffith et al., 2012). The overall evidence base of improved outcomes for children with ASD in ABA-based interventions in school settings is limited but growing (Eldevik et al., 2006; Kovshoff et al., 2011; Grindle, 2012; Kasari & Smith, 2013; Peters-Scheffer et al., 2013; Foran et al., 2015; Lambert-Lee et al., 2015 and Pitts et al., 2019). These studies will be reviewed for their effectiveness in real-world school settings in terms of the improvements made by children and how they best-fit with school systems, and also how that practice can be replicated for other schools hoping to do the same.

The EIBI model discussed earlier (p.15), of intensive one to one treatment for up to 40 hours a week of individualised behavioural programmes does not fit easily into the current UK mainstream school system. A school day comprises of approximately six hours, over five days a week for 38 weeks of the year. Lesson content is defined by the National Curriculum (NC) and delivered by teachers and support assistants with generalised

education training. This format and structure does not easily allow for EIBI to be delivered without some adjustments and additional staff training. Eldevik et al., (2006) conducted one of the first school based EIBI examples with children with ASD where the focus was on the delivery of the behaviour intervention in a school setting. The intensity of delivery was somewhat lower than that reported by Lovaas, (1989) and the aforementioned EIBI studies. Eldevik et al's., (2006) study comprised of a behaviour intervention group of 13 children, and a comparison group of 15 children receiving eclectic TAU. The behaviour intervention group received on average 12 hours of intervention a week in a mainstream school setting. Assessments on IQ, language and communication and adaptive behaviour measures were made before intervention and after two years of intervention. Briefly, the findings showed that the behaviour intervention group made gains in these measures, but they were not reliably significant; especially when compared to Smith et al., (2001) where significance was shown in the same measures but with a reported 20 to 30 hours of intervention per week, considerably less than Lovaas' (1989) study of 40 hours, but using the same methodology. In Eldevik et al's (2010) meta-analysis review of 38 studies of EIBI with children with ASD, the authors reported that all the studies they interrogated and statistically evaluated showed a large effect improvement for IQ, and a moderate improvement for adaptive behaviour skills across all the research. Recommendations were that EIBI should be the intervention of choice for young children with ASD.

Against previous evidence of the effectiveness of EIBI where most of the evidence had been for behaviour intervention programmes being delivered in the home, Eldevik et al's (2012) paper explored the potential outcomes of delivering behaviour interventions in school settings. This was done within the constraints of mainstream schools' usual funding for educational interventions for SEN children. In the mainstream school this meant using existing staff who may not have been specialized in delivering EIBI, and buying in BCBA® specialized supervision for the staff. In their experimental intervention group 31 ASD children between two and six years old received EIBI in their school settings for 20 hours a week. The comparison (12 children) group received eclectic TAU, which included a mixture of TEACCH, Sensory integration, communication interventions and a small amount of selected ABA programmes. The behaviour intervention group received a minimum of four

hours a day of specific, individualized one to one, DTT intervention. These individual programmes were monitored and revised weekly at staff supervision sessions.
Overall findings were that all the children in the experimental group made significant gains in IQ and adaptive behaviour (daily living skills) after two years of intervention. Interestingly all the children at the start of the study were at a slightly lower than average IQ score for children with ASD of the same age. However, after the behaviour intervention 19% improved IQ by 27 points. The comparison group also made gains in these measures but not reliably so, nor to the extent that the intervention group did. Furthermore, wider analysis of a correlation between the weekly hours of intervention and outcome was not significant however. The researchers questioned whether the programmes could be called intensive as in reality the delivery was only for 13.6 hours a week – an average of three intensive behavioural programmes a day whilst in school, and supplemented with one to one staff support for the rest of the school day. Irrespective of there being no significant correlation between the weekly hours and the outcomes, the positive gains that children made in IQ and adaptive behaviour, and mainstream school inclusion were achieved in a normal school setting with little additional cost to the school and local authority. The recommendations were that this was a viable model to adopt to deliver behaviour interventions in a mainstream school setting, with the caveat that a focus should be on continuity, and building up a staff body with experience to deliver the behaviour programmes (Eldevik et al., 2006; Eldevik et al., 2012).

The next prominent study in a school setting is Grindle et al., (2012) who evaluated ABA-based intervention in a specific autism class in a mainstream Welsh school. Eleven children aged between three and seven years received lower level intensity programmes between 5 and 15hrs of one to one DTT teaching during the school week – a mean of 3.75 hours of intervention a day across a school day (approximately five hours a week for 38 weeks). The intervention group was compared to a group of 18 children who received TAU based on the Welsh National Curriculum. The children in the intervention group made significant improvements (moderate to large effect sizes) on standardized tests for IQ, language and communication and adaptive behaviour after one year of intervention, similar to those of Eldevik et al., (2012). These were continued in the second year of intervention.

When data on adaptive behaviour was measured with respect to the comparison group, the intervention group made significantly higher gains. Overall, these findings indicate that children with ASD can make improvements in a mainstream school with lower intensity behavioural interventions (Grindle et al., 2012).

A further example of ABA-based interventions delivered in a school setting is the study by Peters-Scheffer et al., (2010). Using a similar model of lower intensity behaviour intervention on one to one basis between 4 and 10 hours a week (average 6.5 hours), data from 20 children in the intervention group were compared with 20 children in TAU group. The children from the intervention group participated in the general classroom lessons outside of the individualized intervention sessions. Each child was measured for gains in standardised tests for IQ, adaptive behaviour, and language and communication (receptive and expressive language) skills. The children in this study had a lower baseline IQ before intervention or TAU. The intervention group children made significantly greater improvements in the IQ, adaptive behaviour and receptive language skills after two years of intervention. These results suggest that children with ASD can make effective improvements when lower intensity behaviour interventions are delivered alongside a full time Early Years (EY) school curriculum. The benefits showed that behavioural interventions can facilitate the generalization of skills that support learning.

The examples detailed above are of ABA-based interventions based in mainstream school settings in the UK, except for Eldevik et al., (2012) whose study took place in Holland. All show the effectiveness and the viability of delivering lower intensity behaviour programmes in 'real world' school settings. The following, more recent studies are of ABA-based interventions delivered in Special Educational Needs (SEN) school settings, which were either local authority funded or non-maintained. These differ from mainstream education in various ways, not least curriculum as special schools may choose to adopt the NC, and state schools may not. Staff expertise was also different in the SEN schools, as some staff involved in delivering programmes in these examples are experienced in behaviour therapy. Most likely in a mainstream school few if any staff would have any training in behaviour therapy or be BCBA® therapists.

Firstly, Foran et al. (2015) is the first of three studies that are reviewed here where ABA-based programmes are delivered in a UK SEN schools. Seven children with ASD between five and seven years old, received one to one EIBI programmes for an average of seven hours a week using DTT and also natural environment training (NET) from 10 minutes to 45 minutes bursts. NET is structured learning based on the child's interests and motivation that take place in naturally occurring situations and allow for the generalization of skills taught in DTT to be transferred across a range of situations and settings (Rogers & Dawson, 2009). The interventions took place over one academic school year of approximately 38 weeks. Children made significant improvements in standardised tests for IQ, language and communication, adaptive behaviour and also social play and academic learning skills, also autism behaviours and challenging behaviour decreased. This study is an example of how cost-effective ABA-based interventions could be effectively implemented in a Welsh mainstream school. A limitation of this study is the lack of a comparison group. Most studies included an intervention and a comparison group, and measured within subject changes as a result of intervention or TAU; nevertheless, it is an important first study for Wales (Foran et al., 2015).

The last two studies reviewed here include older children in SEN settings. So far all the studies cited (Mainstream or SEN) involve young children in EY or Foundation Phase (Peters-Scheffer et al., 2010; Eldevick et al., 2012; Grindle et al., 2012 and Foran et al., 2015). My dissertation does not focus directly on ABA-based provision for older children, but the setting up of a mainstream school ASD unit that straddles both Foundation Phase (Key Stage 1) and Key Stage 2 does. Therefore, I have included these studies to balance the view that ABA can be effective for older children. For example, mainstream schools with ASD units where there are intentions that children will transition to mainstream classes partially or wholly, will be delivering the NC at Key stage 2 and will include children from Year 3 to 6 (Aged 7 to 11 years). Having ABA-based strategies in place to support curriculum learning is therefore valuable.

Lambert-Lee et al., (2015) conducted a study of 53 older children (six to eighteen years) in an independent SEN autism day school. Individualised ABA-based intervention plans were devised by behaviour analysts and delivered by school staff trained in ABA. These were individual education plans and function-based behaviour support plans that complemented the NC where appropriate. All teaching was carried out on a one-to-one and small group basis, throughout the school day, so ABA underpinned all the teaching in the school. Eighty-four percent (84%) of the children had additional learning differences, some severe, and IQ was not used as measure of progress. After a year of intervention the children made significant gains in standardised tests for adaptive behaviour and language and also learning to learn skills (Lambert-Lee et al, 2015).

The last example of ABA-based interventions in school settings is Pitts, Gent & Hoerger (2019). The evidence from this study supports Lambert-Lee et al's (2015) earlier suggestion of ABA reinforcing improved gains in learning to learn skills and academic learning for older children in mainstream equivalent of Key Stage 2. Learning to learn skills are fundamental for enabling children with ASD to generalize skills from setting to setting. In Pitts et al., (2019), ABA-based interventions were used in classes across the primary and secondary phases: EY Foundation (Key stage 1), Key Stage 2, and Key Stage 3 (Children aged four to 13 years). Individualised education and behaviour support plans were devised by BCBAs®, and delivered by ABA trained staff. This was for one hour a day (five hours a week) of one to one DTT teaching. All other classroom learning for up to 30 hours a week was supported using the principles of ABA to enable skills to be generalized and transferred from the one-to-one sessions. Assessments were carried out after an academic year of intervention using standardised tests on adaptive behaviour, language and communication, social skills, and academic curriculum. Statistically significant gains were shown in language and communication, and adaptive behaviours, and all the children improved in their 'learning to learn' skills (which included attention, imitation, and following basic instructions). This study has evidenced the positive gains in assessments of 'learning to learn' skills together with research that has shown that children show more academic gains in the second year of intervention (Grindle et al., 2012). This is extremely valuable for future research into the delivery of mainstream ABA-based programmes to evidence the

improvement of academic learning and inclusion to mainstream education. The promising data from this review of school based interventions shows that children in school-based ABA (EIBI) programmes are showing improvements in the broad areas of: IQ, adaptive skills, language and communication skills; learning to learn and also a reduction in autism behaviours. This data supports the use of ABA-based programmes in school settings, but as Eldevik et al., (2012) suggested, sustaining those improvements over time in a mainstream setting is a long term measure that needs further research.

Based on the evidence of the intensity of the ABA programme delivery as well as its early introduction gains can be made that include improved IQ, language and communication skills, improved adaptive behaviour skills and often reduced autism behaviours; all support sustained inclusion into mainstream education (Kovshoff et al., 2011; Lambert-Lee et al., 2015 and Pitts et al., 2019). These studies included data on interventions that had been conducted with children and young people older than the average age cited for most EIBI studies: approximate age 6 years; 6-18 years and 4 to 13 years respectively. To re-iterate, outcome data for the studies all showed positive gains in adaptive behaviours, language and communication, social skills and learning to learn skills. However, in the Kovshoff et al., (2011) paper IQ improvement was included in the data. In addition to the relevance of improvement for children who start interventions later, Kovshoff et al., (2011) made suggestions about the long term effectiveness of EIBI programmes for children once they entered school from home-based interventions, as follows. Theirs was a two year follow up of the Remington et al., (2007) study, where the initial study was a comparison of EIBI for young children with autism in home-based settings. Two years after the end of the intervention period the children who had all transitioned to a school setting were reassessed. Findings were that a 'fixed-dose' of EIBI in early years may not be sustained over time, as gains were sustained in IQ, adaptive behaviour, autism behaviours (were reduced) and language and communication skills, but not consistently significant in the follow up. The outcomes were only statistically significantly for some of the intervention group in the follow up study. On closer analysis of the intervention group data, Kovshoff et al., (2011) found that this was related to the intervention group recruitment which was from two sources. One where the parent

originally commissioned the EIBI, and the second was originally convened by the university investigating the study. The parent commissioned EIBI sub-group children maintained significant gains, whilst the university commissioned sub-group children maintained gains, but they were not significant for the aforementioned measures. The data on the children in the comparison group demonstrated no improvement over the two year intervention and the following two years post-intervention. The differences between the two intervention sub-groups was explained in terms of how the intervention group was constructed. One was delivered by privately sourced (parent or local authority funded) ABA-providers where the delivery was reported to be more intensive and had consistent therapists; and the other which was less intensive and had different therapists from the local authority involved in the delivery. This study is extremely useful in evidencing what the longer term benefits of EIBI may be, and also the considerations that funding early interventions can reduce the longer term education and care costs of ASD as children move through school and into adulthood, not least it highlights a need for a reliable and quality assured practice of delivery. This is particularly relevant for my thesis, as it centres on implementing ABA-based interventions in a mainstream school as a statutory funded service by the local authority. The effectiveness of long-term authority delivered ABA would require further research and rigorous scrutiny.

Furthermore, Kasari & Smith (2013) suggest that EIBIs should be considered as evidence for long-term real-life outcomes for children with ASD in schools, as there is little evidence as yet to support the implementation programmes in schools. They urge researchers to focus on school based ABA rather than home or clinical settings, and encourage children to be flexible to meet the challenges they will face in school settings. The implementation process also needs documenting clearly in a way that is helpful for staff to implement, and other schools to follow. They also recommend reducing the time between research and implementing the practice (Kasari & Smith, 2013). The intentions of my thesis is to explore how parents and providers make decisions about the interventions they choose. I hope to provide a contribution to the context on the issues that parents and providers face during the transition from intensive home-schooling with ABA-based programmes to a lasting engagement with mainstream provision. In addition to improved inclusion as an outcome, the likelihood of there being a reduction in the cost of education

and treatment for these children for the local authority is a factor. At present in Wales, local authorities are funding individualized home-based EIBIs that are usually delivered by external providers. This is in keeping with the practice cited in evidence from other countries and other local authorities in the UK (John, 1988; Howard et al., 2005). The costs to these local authorities can range into the hundreds of thousand per child per year (Keenan et al., 2015). There are logical cost benefits of integrating behaviour interventions into mainstream schools, as are there educational and developmental benefits to children with ASD and their families. How parents and providers choose the best settings and interventions for them has been described as complex, and will be reviewed next (Dillenburger et al., 2011).

How parents choose interventions and ASD provision

There is little evidence available on how parents and providers in the UK choose ABA-based interventions, and the purpose of the next two sections is to explore the existing research for what motivates their decisions. The evidence base for ABA-based interventions being an effective ASD treatment has been established in a range of studies over 25 years, and been reinforced throughout this dissertation (Eikeseth et al., 2002, Chasson et al., 2007; Freeman, et al., 1991; Howard et al., 2005 and Zachor et al., 2010). And, as noted earlier (p.15) the important task of making critical intervention choices for their children invariably falls on the parents of ASD children, a task which is often carried out with little supportive evidence or guidance (Romanczyk & Gillis, 2005; Miller, 2012 ; McNerney et al., 2015). A number of key papers on parents' understanding of ABA and why they choose it will be reviewed next, which include international studies and those from the UK and Ireland.

There are three notable internet surveys on ASD treatment involving UK parents. Whilst they all include UK parents they were not exclusive to them; namely: Green et al., (2006) surveyed 522 parents worldwide to identify the numbers and types of interventions used for children and young people up to the age of 21. Secondly, Salamone et al., (2016) investigated the early interventions for 1,680 families of children up to seven years old across 18 countries in Europe, and thirdly, Denne (2017), whose specific UK study surveyed

176 parents of children with ASD (up to the age of 19 years) about their beliefs on ABA and ASD. The survey was used to devise a scale of parental beliefs about ABA and ASD (P-BAA). This dissertation's focus is on ABA as a treatment for ASD, and as such this latter study is of more specific interest as it makes a valuable contribution to the evidence gap on the beliefs behind the choices of interventions that parents in the UK make. The other two studies are relevant as they explore both the numbers and types of interventions chosen by parents, and offer a worldwide perspective on parental decision making for comparison.

Denne, (2017) analysed survey data from 160 participants of an original 176 sample. The survey identified the types and number of interventions that parents had used and also the parent characteristics, as did Salomone et al., (2016). In Denne's (2017) study, participants came from England, Wales, Scotland and Northern Ireland, across 104 different local authority areas. Eighty-eight percent of the participants were mothers of children with ASD, and just under half of the participants were in the 35—44 years age range category. The level of education was high, as 76% of the participants had undergraduate or post-graduate qualifications; 87% of the families had at least one person in paid employment and half of the sample had a collective income over £45,000. Findings showed that the most popular interventions used by parents (45.6%) were ABA, SALT and visual schedules.

Green et al., (2006) reported that ABA and other skills based interventions were a choice for approximately 50% of the parents they surveyed. Salomone et al. (2016) noted that 18% of parents used behavioural approaches which was associated with a higher parental educational level. However, in their study the data from UK families was only part of the data from 10% of families from six countries. It was suggested that the difference in popularity of behaviour interventions reported in both the Denne (2017) and Green et al's., (2006) studies compared to the Salomone et al., (2016) study, was due in part to the way the interventions were defined in the survey, and that some interventions such as ABA, Lovaas, DTT and EIBI were more distinctly stated in the Salomone (2016) paper. Denne, (2017) included NET, verbal behaviour, ESDM and behaviour modification into the behavioural intervention grouping. What is also relevant is the inclusion of data on previous and currently used interventions. Some interventions such as TEACCH for example, may only

have been used in schools and therefore not included in the parent responses if a child had left school. Also, interventions such as DTT and PECS may have been categorised as Lovaas at the time of delivery, and thus the true use of current and past interventions may not have been reflected in the data. The main interventions parents reported they were 'routinely offered' in Denne's (2017) survey were SALT and visual schedules, but ABA-based interventions were not. There were 27% of children not receiving any interventions at the time of survey, and 6% had never received any interventions. Green et al., (2006) found that ABA tended to be used by those at the more severe end of the spectrum: 80.5 % of children described as severe were reported to be using ABA compared to 56.4% of those described as mild, and 24.2% of those with Asperger syndrome. Salomone et al., (2016) reported that the use of behavioural, developmental and relationship based interventions was associated with the education level of parents, as those parents with a higher level of education were more likely to report using such interventions. What could not be discerned from these papers was whether parents had any choice in the interventions their children received, and whether or not they had shown any preferences for one intervention over another. This is a research area that would benefit from further examination, particularly with respect to identifying who the primary decision makers are, and what considerations influence their decisions. Evidence of the effectiveness of those chosen interventions would also support Kasari & Smith's (2013) recommendation to reduce the time between the research and implementing the intervention in schools.

In Green et al's., (2006) study 30.8% of parents were finding out about ABA for themselves from the internet and books, and 38.5% of parents were relying on experiential and anecdotal evidence to make decisions about interventions. Tzanakaki et al's., (2012) study concerned parents choosing EIBI, and they reported that no parents were given information from health professionals. Only seven percent of parents received information from teachers, and 13% were told that nothing could be done for their children, which inevitably left parents finding out information for themselves. There was an indication that the absence of professional advice on interventions gave parents some unrealistic expectations that their children could be cured, or attend mainstream school within two years (40%) (Tzanakaki et al's., 2012).

Grindle et al., (2009) explored the experiences of parents whose children had been having EIBI at home for approximately two years. In a qualitative study involving 32 families, 53 parents (32 mothers, 21 fathers) the benefits and drawbacks of ABA-based interventions delivered at home were sought using a semi-structured interviews. Overall, parents were positive about the EIBIs they received for their children, yet they experienced some difficulties with the restrictions that intensive home-schooling programmes were placing on them and their families. More specifically, these difficulties were around an invasion of family space and privacy during the intensive therapy sessions. Impacts were felt on their relationships, and the limited 'free-time' parents felt the intervention would afford them (Grindle, 2009). Within Grindle's (2009) findings were examples of perceived biased professional views on behavioural home-based programmes, where 40% of parents interviewed felt that the views of professionals and local authorities were outdated and at times incorrect. As a consequence of this they felt they were being offered interventions other than EIBI for cost effective reasons; and Dillenburger et al., (2010) noted that some parents were dissuaded from using ABA-based interventions.

McPhilemy & Dillenburger, (2013) however, focused on parents' experiences of ABA in Ireland, through a qualitative study of 95 parents and 67 professionals, using two different questionnaires: one for families and the other for professionals. The findings were that 82% of professionals were aware of the distress parents faced when accessing appropriate education for their children. Almost 50% of parents reported to hear about various ASD provisions, whether ABA-based or eclectic from each other, friends and family and from personal research. Little to none came from statutory organisations. In Ireland where the study was based, there were ABA-based schools in the South (Denne, 2017). Twelve government funded Department of Education and Science (DES) pilot projects in Centres of Education (it is unclear whether these are units in schools) had been in operation since 2012/13. Children between two and seven years old with an ASD diagnosis recommending ABA-based treatment were referred to one of these. These centres had been set up as a result of parental lobbying government and tribunal court cases (Autism Ireland, 2018). In Wales, the Special Education Needs Tribunal Wales (SENTW) is a legal forum that

hears and rules on disagreements between parents and or children and young people with ASD and their local authority (NAS, 2018). Seventy three percent of parents cited in Dillenburger et al's earlier (2012) study on parental experiences of home and school-based ABA-interventions, were not near to any ABA-based provision. Just under 10% of the parents in the study had moved house to be nearer to one of these centre schools, and almost 50% had considered moving. Only a quarter of the participants' children were in one of these centres, the remaining (75%) were attending either eclectic special schools or mainstream schools. A small number (6%) of these parents felt their children's provision was never appropriate, whilst 48% said it was 'mostly appropriate', and 45% said it was always appropriate. In contrast to this, 67% of parents whose children attended ABA-based schools said their education was always appropriate; and 30% felt it was sometimes appropriate. Importantly, none reported that it was not appropriate. This is relevant to my dissertation's aim as it shows that parents whose children were receiving ABA in a school setting (67%), felt it was always appropriate and were satisfied, in contrast to none who felt it was not appropriate. Therefore, accessing ABA-interventions through a school setting, even though parents reported a willingness to move home to be nearer the setting, embracing the pressures that would bring to the family, it was a positive decision that parents made. However, parents in McPhilemy & Dillenburger's (2013) paper reported that the majority of parents' surveyed had some unrealistic expectations of their children's abilities as a result of receiving ABA. In contrast to this over estimation of the benefits of ABA, some parents had 'negative' perceptions of ABA. This was also reported in Tzanakaki et al., (2012), for example ABA was perceived as rigid, could not be used with older children, was costly, had a negative effect on family life, it encouraged potential isolation from peers and used aversive techniques. Developing on this idea of parents' contrasting perceptions of ABA, Denne's (2017) conceptual tool for categorising parent beliefs is a useful measure to gather more specific evidence of parent perception of ABA.

In the development of the conceptual tool for categorising Parental Beliefs about ABA and Autism scale (P-BAA) Denne (2017), included three broad statements to refine and define parent responses: those that reflected a negative view of ABA; those that reflected a positive view and those that could be either, depending on the respondent's perspective.

These belief perceptions were categorised into 43 further statements that could be used to inform how information on ABA was disseminated. Subsequently, the statements were tested against suggestions from responses of stakeholders (comprising of parents and professionals). The scale was then used to quantify parents' beliefs about ABA. The most common responses received from parents was that they 'were (or would be) uncomfortable using ABA because if it [was] not "approved" by the local authority or health boards'. Parents in Grindle et al's study (2009) reported similar responses from parents, due to involvement with tribunals between parents and local authorities to secure funding for ABA interventions. Whilst the scale was useful to identify parents' beliefs about ABA it did not give insight into the factors that truly motivated parents' decisions. For example, whether the cost of ABA was significant in whether they chose it, or whether the additional pressure that ABA-interventions in the home placed on the family was a deciding factor (Tzanakaki et al., 2012).

However, Denne (2017) did identify that having previous experience of ABA was a 'strong predictor' of belief about ABA yet, whether the 'positive belief' about ABA led to the decision to choose it, or whether receiving ABA created the positive belief reported was not evidenced in her data. While this statement seems obvious, it is important to research this concept further as it may hold valuable evidence on what supports the importance that parents place on the anecdotal evidence of others. This can help in making improved intervention choices for parents. There were limitations identified with this particular study; for example, the sample may not have been wholly representative of the ASD parent population, as those of a higher education level with access to the internet, and or some understanding of ABA-based interventions would be more predisposed to participating in the survey. Also, having some understanding or previous experience of behavioural interventions may have factored in their responding and also their orientation of beliefs (Denne, 2017).

The combination of Grindle et al., (2009), McPhilemy & Dillenburger, (2013) and Denne's (2017) findings on the parent experience of behavioural interventions have raised a question about how professionals in the health and education services are viewing ABA, and

subsequently supporting (or not) its delivery to children in home and school settings. Parents had been involved in tribunal court cases with local authorities over ABA-based provision (Grindle et al., 2009) and 50% of the parents in a survey by McPhilemy & Dillenburger, (2013) did not receive any information on ABA from their supporting statutory services. Furthermore, parents in Denne's (2017) internet survey found them 'uncomfortable' using ABA-based interventions if they were not approved of by the local authority. How professionals understand and make decisions about sourcing and funding ABA-interventions requires more research. The evidence on how professionals choose ABA-based interventions will be examined in the next section.

How professionals choose interventions and ASD provision

Professional understanding of ABA has been widely recognised as varied, and has at times been fundamentally misunderstood. How providers may perceive and misrepresent ABA has been discussed (p.6) and referred to using the term category error. Vivid discourse between experts in the ABA field complicates the misunderstanding further, as the diversity of views may not reassure other professionals or parents, and therefore perpetuates the dissent over ABA services by European and UK governments (Keenan, 2015; Jordan, 2001). One suggestion for this has been posited by McMahon & Cullinan, (2016), who suggested that providers may approach the choosing of interventions from their own preconceived understanding of child development. As a result, they may judge eclectic interventions as better than behaviour interventions because they differ from the behavioural interventions in construct and practice. Empirical evidence supporting behavioural interventions may then be overlooked (McMahon & Cullinan, 2016). In Wales and the UK ASD provision is serviced by both the health boards and then, local education authorities when children are able to access the statutory provisions, otherwise specific needs are delivered through SEND services (WAG, 2015). As Denne (2017) notes, accessing provision is a process of commissioning which involves the identification of the provision on a needs base, through statementing, the sourcing and the constant monitoring of interventions for effectiveness. This is in addition to funding that provision. In practice those who make decisions may not

be using evidence of intervention effectiveness to base their decisions on, but are balancing their authority's competing demands for provision and their own perceptions of the value of ABA-based interventions. Three consideration have been identified in this process: Firstly, the cost; secondly the individual ASD needs of the child; and thirdly, parental demand. Competing priorities for authorities has created confusion and tension for both providers and parents (Rees et al, 2014; Wye et al, 2015; Denne, 2017). The benefits of evidence-based practice, and why it may not be considered when choosing interventions are examined in the last section of this literature review.

Local authorities in the UK need to do more than just endorse ABA, they need to fund it if children with ASD are going to have a level education-playing field with their neurotypical peers internationally (Dillenburger, 2011; Denne, 2017). Professionals' knowledge of ABA is related to considerations of best practice, and inclusion for children with ASD. Findings in a recent study by Fennell & Dillenburger (2018) showed that professionals' (in this case SEN Teachers) self-perceived knowledge of ABA exceeded their actual knowledge, and that their ABA knowledge was not related to their statutory training. This is the first empirical study of teachers' knowledge of ABA to date which was gathered in Ireland by survey methods. One hundred and sixty five teachers responded to an online survey that assessed their actual knowledge of ABA against their perceived knowledge. In the sample, 44% had been SEN teachers for approximately 10 years, although only a small number (n=5) had recorded extensive knowledge of ASD. The survey included questions on their training, their self-reported knowledge level of ABA (on a four point scale where 1 = very little and 4= Very good), and eleven detailed questions that assessed the participants' actual knowledge of ABA. The detailed questions included a range of True/False statements; multi-choice questions and open-ended questions. The results showed that only 35% of respondents said they had had any training in ABA, and that 66% of this proportion had received that from statutory government organisations. However, eight percent had no training at all. In terms of self-reported knowledge, 15% said they felt they had a very good knowledge of ABA, 20% had good knowledge, and 50% reported very little to minimal knowledge. Approximately 15% gave no response. What was of interest in this study was that those teachers who were self-reporting 'good to very good' knowledge of ABA - 38.9%,

gave incorrect responses to the eleven questions on actual knowledge. Most of them misunderstood the objective of ABA – to improve socially significant behaviours, as a process to 'eliminate target behaviours', and saw ABA as an intervention that addressed challenging behaviour not programmes to teach new skills and behaviours. Teachers who misunderstand their knowledge levels of ABA could negatively impact on children's outcomes if programmes are not analysed and delivered effectively (Myers & Johnson, 2007). This misunderstanding also has implications for the quality of any ABA-based provision delivered in those teachers' education settings and may also influence staff training required from local authorities (Fennell & Dillenburger, 2018). This is explained further, as certain international regulations must be met to deliver and devise ABA-based programmes. Delivery requires that some teachers and TAs are trained as Registered Behaviour Technicians (RBT®), and devising programmes and supervising RBTs® is the role of a Board Certified Behaviour Analyst (BCBA®). To become a BCBA®, a teacher or designated person must be qualified to at least University degree level, and be awarded by the Behaviour Analysis Certification Board (BABB®) that their training is assured through a minimum of 1,500 hours of supervised practice and their competency bound within strict ethical guidelines (BACB, 2020).

Fennel & Dillenburger's (2018) data on the level of ABA knowledge the teachers were reporting does indicate that further research is needed; firstly, that the assessments of their knowledge of ABA be more rigorously tested, and secondly that the effectiveness of SEN teacher's training be evaluated to meet the requirements of best evidence-based practice. This has a knock-on effect for local authorities as providers of both teachers and provision for ASD, to make training efficient, cost effective and also best-practice. The ABA training that most professionals involved in the diagnosis and treatment (in education services) of children with ASD receive is sparse, which suggests that it is a factor in the root cause of ABA's misrepresentation (Dillenburger, 2014). This is documented further by Alexander et al's (2015) review of literature on the training of teachers in evidenced-based practice of ASD, which indicates a need for teachers in SEN and mainstream schools (in the US) to not only be more experienced in ASD, but also the evidence-based interventions such as ABA to treat it. Deficits in teacher and other professionals' knowledge and experience

falls far short of the quality that parents, and the Board Analyst Certification Board (BACB) guidelines expect from ASD provision (Fennell & Dillenburger, 2018).

Moving this notion of improving teacher's knowledge of ABA by improved training and practice to a wider forum of delivering better services for ASD on, will require providers and policy makers in authorities to address their misunderstandings and improve their own research into evidence-based material (Gillan & Keenan, 2017). These authors suggest that encouraging professional engagement between behaviour analysts and providers of ASD interventions can foster an improved understanding from where comes the category error. In turn, improved communication between professionals can inform ways of changing and improving ABA practice. Their suggestion is that from an evidenced based position of improved knowledge, parents and providers can positively influence policy making to promote ABA interventions in schools (Gillan & Keenan, 2017).

Further evidence from Klein (2016) in the US iterates the importance of good and accurate information about therapies and treatments that is communicated by professionals to parents and care-givers. This is not new, and as reviewed earlier in the section on how parents make decisions about ABA, Grindle's (2009) study explored parental perspectives on home-based EIBIs suggested that parents' experiences could be supportive in improving local authority service provision and informing future policy on the use of ABA-based interventions. One outcome of this study resulted in a need for service providers to deliver home-based programmes that addressed the communication between parent and child that helped parents to manage their children's difficult behaviours. A further key factor that emerged from this paper was that programmes needed to be flexible yet specific, and individual to the child with ASD (Guldberg, 2010). What is of particular note in Guldberg's (2010) theoretically evidenced paper, was the recommendation for a more focused approach to the interventions that are delivered, and also, as suggested by Matson & Konst (2014) to the guidance on how to do so needs to be clearer for providers. This documented process, and clarity can support the transitions for children with ASD from home-based to school-based ABA provision; and as a result, be helpful to parents and providers in making

their provision decisions evidenced-based and from a best practice perspective (Matson & Konst 2014).

The value of parental involvement in multi-agency decision making that informs provision is also rated positively. The involvement of parents in the delivery and maintenance of their child's ABA-based programme(s) as part of the intensive intervention is relational to the child's positive outcomes, and as such, parents play a critical part in that multi-agency delivery (McPhilemy & Dillenburger, 2013). This was evidenced in a mixed methods study of parents' and professionals' experience with ABA (Dillenburger et al., 2012). Ninety-five parents (representing 100 children with ASD) and 67 professionals from a range of multi-disciplines (SALT, ABA Tutor, Additional Learning Needs Coordinator - ALNCo, Teacher, Social Worker, Occupational Therapist, Educational Psychologist to Director of Education) in Ireland. Professionals completed a questionnaire of 29 questions based on their professional background; their training and experience in SEN and ABA; their knowledge of educational provision for ASD and their professional assessment of the future needs for ASD services. A range of participants in their respective parent and professional groups took part in small scale focus groups. Over 30% reported they had some training in ABA, which was believed to be non-accredited, and nearly all the professionals (91%) were aware they needed further training, and 24% were considering a Masters level BACB® accredited training. The study highlighted that there was a distinct gap in the ABA knowledge of parents and professionals. Professionals were less well informed than parents who often gathered their information about ABA anecdotally from other parents of ASD children, friends and their own online research as in Green et al., (2006). Overall, the study showed that there was a general consensus between parents and professionals about the future demand for education services for children with ASD, which was that it was increasing. A recommendation for the future of provision in Ireland was that it should be 'grounded in parent participation and choice' (Dillenburger et al., 2012). In McPhilemy & Dillenburger's, (2013) study, parents supported the need for the wider availability of authority provided ABA-interventions, and some parents suggested as noted earlier, that some professionals were reluctant to recommend ABA.

Evidence of parents influencing the professional decision making process on ABA-based intervention services is an emerging theme in this current dissertation's review of literature. The evidence from parents is emerging as important in making the changes at a professional provider level. Guldberg (2010), conducted a theoretical review of a range of research and policy literature to highlight certain key preconditions for developing best practice in inclusive learning environments for young ASD children. Findings were that best practice is when practitioners adapt interventions to the individual needs of the child, and work in partnership with parents and other professionals. Khanas (2014) conducted qualitative interviews with a sample of parents to measure their perceptions of the support they received during transition between home-based and school-based EIBI settings. Both papers outcomes emphasized the importance of partnership working between parents and professionals. In order to develop better ABA-based practice in home-based and school based settings, it is becoming increasingly more important that providers, whether teachers delivering programmes or commissioners providing them, address misunderstandings around ABA interventions. Both teachers and commissioners of ASD services need to adapt to the individual needs of the child and family at the classroom level, but also work in effective partnership with parents and other professionals in the multi-agency team surrounding that family (Guldberg, 2010; Khanas, 2014).

For a number of reasons related to the long term provision of ASD education and care for children in Wales, a mainstream school has been highlighted as the optimal place for ASD children to access education that has the potential to develop skills and academic work (Eldevik et al., 2006; Grindle et al., 2009; Kovshoff et al., 2011; Foran, et al., 2015; Lambert-Lee et al., 2015 and Pitts et al., 2019). School setting are the cited as the setting of choice for parents (Dillenburger et al., 2012; McPhillemy & Dillenburger, 2013; Denne, 2017), and for local authorities in their provision of their ASD provision. It is the logical setting for academic progression after home-based programmes; and if implemented well ABA in school settings can sustain the outcome benefits of home-based interventions and prove more cost effective in the long term (Eldevik et al, 2012; Kovshoff, et al., 2011; Keenan et al, 2015). The key is to implement ABA-based interventions well. The specificity and quality of behaviour interventions need to be upheld by the BCAB® professional and

ethical standards, and the flexibility of programmes needs to meet the individual needs of children was highlighted earlier (Guldberg, 2010). Decisions relating to intervention choice are often based on the school's ability to provide and deliver them, and the perceived needs of the ASD child according to professionals in multi-agency support teams (Emam & Farrell, 2009; Denne, 2017). To elaborate on this last point, Emam & Farrell (2009) in a mixed methods study observed 17 ASD children (aged six to 16 years) in class and also interviewed teachers, an ALNCo and Teaching Assistants (TA's) in a mainstream school to explore some of the tensions that teachers in schools may face with respect to the inclusion of ASD children. They reported that the tensions, mainly due to difficulties the children experienced in social and emotional understanding had an impact on the quality of the interactions between the teachers and children. TA's were found to be more positive about the inclusion of ASD children, and were more able to adapt to the needs of the children, but were often not trained in managing children with ASD. Thus, delivering best practice ABA-interventions would require a local authority to invest in appropriate staff training for the most effective integration of ABA into mainstream schools. Identifying core factors that are important in implementing evidenced based practice for ABA was the aim of Denne's (2017) research. Findings were that implementing ABA involved different and multi-layered levels of activity between all the stakeholders, the parents and providers; activity that requires further research to identify robust evidence that providers can use to base their decisions on when allocating resources for ABA interventions.

If flexible, specific and unique programmes are in place to meet the needs of the child and the parents, ABA providers and funders could make much more coherent and cost effective decisions about the multi-faceted dissemination strategy for effective ASD interventions (McPhilemy & Dillenburger, 2013; Grindle, 2009). As suggested, (p.3) ASD costs the UK economy almost £3.4 billion a year (Rodgers, et al., 2020; Keenan et al, 2015). The cost benefits in terms of savings to education authorities by providing ABA-based interventions in schools, as outlined in Canada and the US (Dillenburger et al., 2012), could be approximately $208,500 (£162,270) per child per year. There is a robust evidence base available on the changes in policy to provide ABA-based services in schools in North America, yet there is little progress seen in the UK to follow similar guidelines at policy and

provision level (Dillenburger, et al., 2012; Matson & Konst, 2014; Denne, 2017). Thus far the evidence suggests that the ease of intervention implementation, time commitment and perceived effectiveness of an intervention contributes to the decisions parents make when choosing interventions for their child. It is not unique to Wales and the UK. Parallel studies in the US, also suggest that social validation by parents, teachers and administrators of ASD intervention programmes in schools use empirically-based strategies, and encourage active multi-disciplinary collaboration that focus on children's long-term outcomes (Callahan et al., 2008). This points to a need for a more defined evaluation of why and how parents and providers make the decisions they do about the ASD interventions they choose. The qualitative element of my research aims to ask that question, and asks it of the parents, the school and other key stakeholders in the provision of education for children with ASD in Wales. The next section will explore the distinction between evidence-based practice and practice-based evidence, and discuss why evidence-based practice may not be fully adopted by practitioner teachers and commissioners of services for ASD children.

Evidence-Based Practice

There is an intimate link between what we know *of* practice in SEN education interventions and what we *do* in that practice (Nicholls, 2007). It is this link between evidence and practice that I would like to consider next, with a view to evaluating more critically, why more professionals and commissioners do not choose behaviour interventions (Keenan, 2015; Jordan, 2001). I will make a distinction between what I perceive as Evidence-Based Practice (EBP) and Practice-Based Evidence (PBE) in the context of this dissertation; then discuss how teachers make decisions regarding education provision for children in general. This will highlight why teachers may not always adopt evidence-based practice, and what the risks of not doing so might be.

The difference between evidence-based practice and practice-based evidence can be outlined modestly as: practices that integrate the best intervention research evidence and those that gather good quality data from every day practice of delivering those interventions (Margison et al, 2000; Wauburgh, 2007). Ascertaining the value of each in conjunction with the other can be challenging, and especially so when interpreting research

evidence into policy that informs further practice when the outcome data for each paradigm originates from very different domain criteria (RCH, 2001). Three domain levels cited by Biesta (2007) suggest that there can be deficits in an evidence-based practice model of an intervention: at a knowledge level, an intervention's effectiveness, and then at an intervention delivery level. He cautions policy makers and commissioners of services to question the expectations they hold about the value of evidence-based practice in their decision making, as these can be powerful and probably cost driven (Denne, 2017). Furthermore, these expectations can be normalizing in that they in effect, diminish the value of both evidence-based practice and practice-based evidence. It is therefore relevant for policy makers and commissioners to challenge both their unjustified expectations of evidence-based practice and its outcomes, at the same time as question their support of unjustified interventions in teachers' practices (Biesta, 2010).

Evidence-based education is not a solution, but is a set of principles and practices for enhancing educational policy and practice (Davies, 1999). From a contemporary education point of view it is a concept derived from the earlier work of Hargreaves' (1996) and subsequently Reynolds' (1998) government supported reports on evidence-based practice. Amongst others (Hillage, et al, 1998; Tooley, 1998), they suggested that policy and practice should be based on 'what works', and on teacher effectiveness (Atkinson, 2002). Whilst 'what works' may be a sound rationale for taming the autonomy of some earlier education research, and softening the links to policy and cost driven agendas; commissioners continue to choose interventions for ASD children on a basis of cost and parents' critical voice, before the child's education needs (Denne, 2017). However, choosing behaviour based interventions that evidence that they promote positive outcomes, is saying that it works. Then, naturally collecting 'evidence' from a teacher's practice-knowledge base in the classroom, supports the intention that the evidence-based practice chosen is not only the right one, but is having a positive impact. Such practice-based evidence on the back of evidence-based practice goes some way to bridging the practice to research gap (Simons, 2003; DuBois, 2020). This dissertation presents an instance where that research to practice gap between research on effective ABA-based interventions and their successful

implementation in mainstream schools and can be examined.

Why teachers should use Evidence-Based Practice

The benefits of implementing evidence-based practice for practicing teachers are many. Firstly, there is the important and desirable increased likelihood of improved outcomes for children, which is followed by more opportunities for teacher and school accountability - as the data gathered from practice further supports those intervention choices. This can then facilitate support from school managers and commissioners of services, not least parents (Foster, 2014).

Yet, incorporating evidence-based practice and practice-based evidence leaves service commissioners and school managers with the task of piecing together a multi-method, multi-disciplinary evidence-base from which to give precise reasons for an intervention's success or otherwise (RCH, 2011). Whilst this complex process of integrating the two perspectives may go some way to bridging the research to practice gap, the integration necessitates rigorous evaluation if evidence-based practice and practice-based evidence are to be included in parents' and providers' decision making once the question of an intervention meeting a need arises. Sourcing the research, identifying outcomes and strategies to achieve them, appraising the practice-based evidence by incorporating circumstances, values and preferences, then integrating the methods and evaluating the overall process is believed to be a sequence that constitutes such rigour (Denne, 2017; Buysse and Wesley, 2006; RCG 2011). I see it as a given, that we owe it to ASD children to ensure that we can successfully bridge the research to practice gap; or at least make some solid strides into doing so, and deliver effective services in an individualized and context-sensitive manner; only then can we say that we are being evidence-based (DuBois, 2020)

How teachers make decisions regarding education provision for children in general.

When it comes to making decisions regarding education provision for children in general, it is often the school managers or local authority subject leads or practice

specialisms who will decide which provisions will be delivered in the schools. And at a classroom level, it is the individual teachers who are trained to deliver those interventions (Foster, 2014). For example, school-wide approaches to behaviour management that have been successfully implemented in schools in Wales may include an ABC approach (Antecedent-Behaviour-Consequence); Problem-solving approaches; Behaviour agreements and behaviour plans. In line with the Literacy and Numeracy Framework (LNF)(2012), Catch Up® Literacy, Llythrennedd Dyfal Donc and Catch Up ®Numeracy are recommended (Brooks, 2009; Gov Wales, 2010; Foster, 2014). For many schools where individualized programmes of learning are required for SEN children there is neither a unified approach nor formal process for deciding which interventions are used (Jung & Swan, 2011). Teachers, in conjunction with their schools and local authority will generally train and support teachers and support staff on a range of evidence-based practices (Alexander, 2005). However, the decisions made to use certain interventions that work over others is often based on teacher preference, and this is derived from their own research by searching the internet, books and primary resources; or recommendations from others. These choices will then be ratified by their schools and local authorities (Jung & Swan, 2011).

With the increasing numbers of ASD children entering schools and post-compulsory school settings, it is becoming more important to research, rigorously evaluate ASD interventions, train teachers and improve their professional development across all evidence-based practices for ASD, if schools are to meet the growing demands of ASD children and parents (Alexander, 2005). Scheeler (2016) suggests that teacher training providers play a critical role in improving teacher preparation and their 'fitness-for-purpose' so that teachers know and use evidence-based practice in their classrooms (Stormont et al, 2011; Davies, 1999).

Barriers to using evidence-based practice

Two of the most commonly cited barriers as to why teachers do not always adopt evidence-based practice are a lack of time, and an organizational culture that does not support it (McLellan, 2016). Unpacking these barriers further reveals a range of more

complex issues related to misunderstanding and mistrusting research, and generalizing evidence-based practice by teachers (Foster, 2014). Teachers reported that research papers are hard to read because of the unfamiliar terminology often associated with evidence-based practice. Terms such as 'best practice', 'best evidence', and 'research-based', may be seen to be used synonymously with evidence-based practice, despite them having different meanings. A further challenge arises from the differing paradigms from which evidence-based practice is interpreted; especially so where definitions can be described in terms of controlled and randomized studies (Gorard et al, 2016; Foster, 2014). These difficulties serve to highlight that researchers and teachers are very different groups of professionals, and papers are written by researchers who assume they will be understood by all in the subject area, including teachers (Gorard et al, 2014; McLellan, 2016; Foster, 2014). Furthermore, researchers do not have the incentives to translate research for teachers, and may only do so if required by a target audience wanting a practitioner article (McLellan, 2016).

As a result of what makes research difficult to understand, teacher practitioners, their organizations and local authorities commonly generalize evidence-based practice by perpetuating the process with ineffective personal learning and continuous professional development (CPD). The practice of the one-day-workshop culture is useful to provide information and a background to evidence-based practice, but is deemed insufficient to enable teachers to deliver interventions effectively for improved outcomes (Foster, 2014). Some of the feelings that teachers cited about their lack of confidence and self-efficacy of delivering evidence-based practice can be linked to the practice of learning through short training workshops; as just providing information and training is not enough to influence whether they will try new practices, not least adopt them (Foster, 2014).

The continuous professional development of teachers requires a deeper investment from their organizations and authorities to promote evidence-based practice in classrooms. The investment is both financial and fundamentally linked the school's underpinning ethos of practicing from an evidence-based. Overcoming the powerful resistance in the workplace of: "we've always done it this way" requires more than a few keen teachers; or their

managers' recognizing that those teachers' strengths, knowledge and skills are commensurate with what the evidence-based practice is asking of them (Wallis, 2012; Foster, 2014). If those enthusiastic teachers persist in interpreting the research they often give up, or attempt to bridge the research to evidence-based practice gap themselves; which in the ideal world they are perfectly able to do. Gorard (2014) suggests there needs to be a conduit that can translate education research into something practitioners can use more effectively. If what we want is better outcomes for ASD children, then the agenda-setting needs to be more centralized with respect to the content and methods of evidence-based practice, so that it can become more practically relevant (Hargreaves, 1996).

The risks of not using Evidence-Based Practice

The use of evidence-based practice has been shown to improve the learning and behaviour outcomes of students with disabilities such as ASD (Marder & deBettencourt, 2015; Eldevik et al., 2006; Kovshoff et al., 2011; Grindle, 2012; Kasari & Smith, 2013; Peters-Scheffer et al., 2013; Foran et al., 2015; Lambert-Lee et al., 2015 and Pitts et al., 2019), so the risks of not doing so can be detrimental to the development and academic progress of the individual ASD learner. It is recognized that individualizing the provision for each child is challenging, and that adaptations must be incorporated; but when teachers generalize their practice, or adapt interventions, or cut-corners with their delivery it can lead to the provision of that service no longer being empirically supported. Furthermore, if interventions and services are not rigorously evaluated against evidence-based practice criteria and standards, the original intention of providing evidence-based practices is defeated; not least that the individual ASD child does not thrive and funds are wasted (Marder & deBettencourt, 2015; duBois, 2020). Additionally, the overall fidelity and integrity of the provision, school and local authority may be affected (Stormont et al, 2011).

Hargreaves (1996), and subsequent relevant literature (Reynolds, 1998; Atkinson 2002; Simons, 2003; Stormont, 2011 and Foster, 2014), encourages the transformation of both educational research and educational practice to underpin evidence-based practice.

However, the relationship between evidence and policymaking or practice is complex, it involves different ideologies, professional preferences and inter-relationships as much as it does research evidence (Reynolds, 1998; Atkinson 2002; Simons, 2003; Stormont, 2011). My thesis will discuss some of these complex elements throughout this dissertation. They are not only about reproducing an effective model of delivering ABA-based interventions in a mainstream school that can demonstrate improved outcomes, but also about researchers and practitioners accessing the rich critical discourse that can move the discussion forward and go part of the way to addressing the gap between them (Atkinson, 2002; Scheeler et al, 2016).

My dissertation aims to explore the knowledge and understanding of the differences between parent and professional perceptions about ABA as an intervention choice (McPhillemy & Dillenburger, 2013; and Dillenburger; 2012; Green et al, 2006; Denne, 2017) In my study, parents, professionals and teachers of children in a newly established unit for ASD are interviewed to explore and understand their rationale for pursuing ABA-based provisions. Complementing the evidence from the internet surveys (Green et al., 2006; Salamone et al., 2016 and Denne, 2017), my qualitative inquiry could corroborate the findings of earlier parent surveys (Dillenburger et al., 2012). Exploring the tensions that parents and providers experience in implementing ABA in a new ASD unit in a school setting are relevant, and the findings may highlight a deeper understanding of what the difficulties are in relating policy to evidence-based practice. Once the tensions and difficulties are explored, possible recommendations can be suggested.

Chapter 2 presents the methodology used to gather the evidence. Chapters 3 and 4 analyse and discuss the results of a qualitative study on stakeholders' decision making when involved in ASD provision in a new unit in a mainstream school in Wales. Chapter 3 focuses on the parents and providers' motivations behind their decisions to choose ABA, and Chapter 4 examines the data on the tensions perceived and the barriers to implementing ABA-based interventions in the mainstream school. Lastly, Chapter 5 is a general discussion

of the overall thesis and will outline the limitations of this research and make recommendations for further study

Chapter 2: Method

Introduction

This thesis will use a qualitative research approach to explore the motivations and barriers to opening an ABA unit in a mainstream school. Particular emphasis is placed on how parents choose an intervention for their child with ASD and the thoughts and reactions of the school staff and local authority. There are two main project objectives that analyse firstly, the motivations of each the stakeholder groups to choose ABA-based interventions; and secondly how these interventions can be implemented in a mainstream school setting.

I had initially intended to use a mixed method approach to collect the data. Qualitative data from interviews with stakeholders would have complemented data collected from a quantitative method that used a pre and post-intervention test analysis of the effectiveness of ABA-based interventions. This would have been administered to a sample of children in the mainstream unit classroom. However, the school had not implemented the ABA-based interventions at the point of data collection, so the quantitative data could not be collected. However, the qualitative interview data that was collected was thematically analysed to explore the different groups' understanding of ABA and their motivations for choosing it. Due to the absence of ABA in the school, the project objectives were revised to focus more on the stakeholder setting motivations for choosing ABA, and the resultant tensions that were reportedly experienced in the setting up of an ABA-based unit in the mainstream school.

I will provide an overview of the school and unit on which the study is based, and offer a context and timeline before considering in more detail the methodology used in the research. The methodology used a semi structured interview approach and subsequent thematic analysis. This particular method is then discussed and linked to wider research that used the same method and similar analyses by other researchers in the field of ABA; and followed by the details on participants, their recruitment, study procedure, and finally the process of thematic data analysis using N-Vivo 11.4 Pro (2017). N-Vivo is a qualitative data

analysis (QDA) software package that is designed to be used with very rich text-based information, to reach deeper levels of analysis of data (Bazeley & Jackson, 2013)

The study aim

This research study focused on why parents and providers choose ABA-based interventions for children with ASD in a unit in a Welsh mainstream school. More specifically the study explores some of the factors that motivated the decisions that parents, school staff and the local authority make when choosing, and providing ABA interventions. Alongside this, we considered how ABA-based interventions can be implemented in a mainstream school autism unit

Denne, Hastings & Hughes (2017) conducted the UK's first internet survey of parents' beliefs about ABA in the education and support of children with ASD. They and Green et al., (2007), highlighted the need for further research into some of the reasons behind parents' decision making when considering behavioural interventions for their children. Further, Wilson et al., (2018), conducted a systematic review of the factors that influence parental decision making when choosing interventions for their children. Wilson et al., (2018) aimed to combine both the implicit reasons for example; the child or family specific reasons, and the reported reasons that parents of children with ASD cite that influence their decision making when choosing treatments. From this assimilation, Wilson et al, (2018), aimed to identify and understand the significance that parents placed on the factors that influenced their decision making when choosing treatments.

These studies' recommendations and the protocol used by Green et al., (2007) have influenced the direction my research has taken, and the type of questions that participants in my study were asked. These questions were based on a small number of questions that focused on how parents came to learn about ABA, their understanding of it and experience if any; as well as their perceptions about its benefits and drawbacks. My study also explored the difficulties parents had in sourcing ABA and general school provision, and also the expectations they had for their children.

Using a qualitative method, the study's two objectives were, firstly, to analyse and discuss the perceptions that the key stakeholders had about the decisions they make when choosing ABA interventions. This was done to find out more about what influenced their decision making. Secondly, it was to analyse and discuss the process of implementing ABA-based interventions in a mainstream school autism unit. This included the barriers perceived by the stakeholders and the resultant tensions experienced by the providers intending to deliver ABA.

The school

The ASD Learning Resource Centre (LRC) unit, in the school in Wales was newly built in January 2017. The school accommodates in all 243 children aged between 3 and 11 years including 40 children who attend the nursery part-time. At the time of data collection there were three mixed-age classes and seven single-age classes in the mainstream part. Estyn (2017) reported that 20% of the children had additional learning needs (ALN), and 13 children held a statement of special educational needs (Estyn, 2017). Prior to the new build, plans were made in the local authority to create a purpose built unit within the mainstream school that would become a specialist ASD unit. This was part of a bigger county Special Education Needs (SEN) restructure of its existing autism provision, and the plans were to designate this unit as an ABA led ASD provision. Original plans indicated that the unit would take up to twelve children, six in the Early Years Foundation Phase (EYFP) and six in Key Stage 2 (KS2).

Context and timeline for setting up the ABA-based school unit

I have included a context and timeline at this point in this chapter to place the study in perspective with the school and the county's wider education and SEN planning changes. The purpose of including it here is also to make the school unit's position clear as to where it was in the process of introducing ABA-based intervention into the school.

At the outset of this project's timeline, this authority was in the final stages of a review of their SEN provision. The review had been prompted by a number of factors that impacted on the school and local authority's ability to implement ABA in the unit. The

review considered the cost of externally delivered ABA-based programmes, the county's current ASD provision, and the parental requests for ABA-based interventions. These were in addition to planning for the implementation of ABA in the school, the numbers of children admitted to the unit and staffing the LRC unit.

At the time this research was initiated, the local authority was funding ABA provision for a number of children through an external private provider of ABA at a cost of approximately £20,000 per child per year. This funding was predominantly for home-based ABA interventions but a small number of the funded programmes were delivered in schools. Six children in the local authority continued to be funded in this way at the time of data collection. This number of authority funded children receiving ABA provision was fewer than in previous years. The actual number of funded children for the previous years was not forthcoming from the authority. For example, one of these authority funded children was a pupil attending the school and taught separately to his peers on a one-to-one basis by a Learning Support Assistant (LSA). The LSA was qualified as a Registered Behaviour Technician (RBT®), employed by the local authority but facilitating ABA programmes under the guidance of a local external provider of ABA.

Before the county's SEN review, parents had been asking for the local authority to provide ABA in their early year's services provision. At this time a previous head teacher of the school was encouraging the local authority to bring ABA into this mainstream school as part of the 2015 SEND offer. After retirement, this teacher's original planning was subsequently carried forward by the local authority in conjunction with the school's new head teacher.

In 2017, the school relocated geographically and opened as a new community school provision. It was purposefully built to accommodate an ASD unit. On the school's previous site, the school had neither specific ASD unit nor designated SEN provision, and only operated as a mainstream primary provision. As a symbol of full inclusion for SEN pupils attending the unit, the new purpose built unit in the community school was situated in the centre of the main school teaching corridor. This was a significant point according to the school and local authority, as they wanted to demonstrate the level of commitment to inclusion the county was expressing, and also a commitment that the county and school

showed to ABA- based interventions. A new team of specialist teachers and LSAs were employed from outside the community school's current staff team to service the new unit. There was one class teacher who was the unit manager, one higher level teaching assistant (HLTA) and eight LSA's, four for each Key Stage classroom.

At the time of data collection, the local authority reported that prior to, and during the early planning stages for the new school and unit, the local authority perceived that the parents were the driving force for the ABA led provision, and that together with the enthusiasm of the previous head teacher ABA provision was included. At that time, there were a number of tribunal case disputes over ABA provision between parents and the local authority whose outcomes bound the local authority to pay for privately sourced ABA by external providers.

In the early stages of my project planning, the local authority was intending to buy in the services of the external ABA provider that was currently commissioned by some parents to deliver home-based programmes similar to those in Lovaas' study (1987) (See Chapter 1, p.16). However, the authority considered this to be a conflict of interest as they would be paying for the children to have ABA provision in the school's mainstream unit, and paying for the same children to have ABA privately from the same provider.

After consultation with a lead Bangor University ABA researcher for guidance on implementing ABA in school settings; the school's strategy plan changed to one where they would source a BCBA® through an academic institution rather than buy in commissioned services from the local ABA private provider.

Subsequently the new school incorporating the ASD unit was built comprising of two classes. Key Stage 1 (Early Years Foundation Phase: EYFP) and a Key Stage 2 class. Initially the individual class numbers were set at six each, but during the first year of opening this figure year rose to twelve in each class.

During this period, the planning and funding for the delivery of ABA interventions in the new unit was slow to be realised. The unit was in place and children attended from September 2017, but no final agreement had been reached about the sourcing of a BCBA® or RBT® training for the teaching and support staff. The staff group received an introductory one day session on ABA was delivered by external ABA consultants from a University.

It was in the second term of opening that a further class teacher was employed, on a supply basis to cover the KS2 class as the pupil numbers began to increase because of the local authority's additional placements. This post was consolidated by the local authority and later made permanent. An applicant for the post was appointed at the end of the summer term 2017 but left for personal reasons two terms later. The cover-supply teacher was re-commissioned to this role and is now placed in the permanent position.

It is important for the timeline of my project and thesis, to note that when my project started, and right up to the point of data collection the local authority was in the process of sourcing and releasing the funds to commission the services of a BCBA® consultant and associated staff supervision, and arrange RBT® training for LSA's. The local authority and school were also in the process of stabilizing the unit's pupil numbers and its teaching staff. This was nine months after the new school opened in September 2017, and six months since the unit opened in January 2018 when the children were first accepted into the unit. There were still no ABA programmes being delivered in the school unit at the time of data collection in June and July 2018.

Research design

Data was gathered using a qualitative research method based on semi-structured face to face interviews that focused on the two aforementioned objectives. Firstly, there was an exploration of the perceptions of the key stakeholders about the motivations involved in their decision making when choosing ABA-based interventions; and secondly an analysis of their experiences of implementing ABA-based interventions in a mainstream school.

In exploring the first research objective: the parents and providers' motivations that influenced their decision making about ABA-based interventions, the participants were

asked about their understanding and knowledge of ABA. The questions also explored how children made the transition from home-based intensive ABA or other programmes to mainstream school, and what expectations if any, the parents had for their children.

The second research objective examined the stakeholders' experiences of planning and implementing ABA in a mainstream school. This included a review of how ABA was decided upon as an ASD intervention, and importantly how the implementation was executed. Further, there was an exploration of the relationships between the different stakeholder groups.

The data collected in my study used semi-structured interviews with a sample of the stakeholders: parents, school staff and local authority representative. Semi-structured interviews refer to a context where the interviewer asks a series of questions that form a general interview guide, but she has some flexibility to vary the sequence of the questions. This type of interview also allows the interviewer to follow up and ask further prompting or deeper questions to what are seen as significant replies (Bryman, 2016 & Creswell, 2014). It is a method that is used widely in education and social science research as a tool to elicit as detailed a description as possible as a narrative for analysis. Its use can help clarify 'how people make sense of': in the case of this research study, the motivations behind making decision about ABA-based interventions as a treatment for autism; and also, the tensions experienced in setting up a unit to deliver ABA-based interventions (Bryman, 2016). This method uses the premise that both knowledge and evidence are all contextual, situational and more importantly interactional, to allow the participant to create a reality, and that then permits the researcher to gather the most accurate perception overview of the context being studied in that moment (Punch, 2014). Using questions and prompt questions such as '*what do you perceive as…*' and '*what do you think about…*' allowed me to be to use the explicit and implicit rules of interaction and reflexivity. In other words, by being responsive, reflective and flexible in the actual interview-relationship interaction; to construct and ultimately give the data the evidence of a deeper and rich context from which I could then develop themes for analysis (Creswell, 2014). A further and more specific benefit of the semi-structured interview is that I can acquire the data evidence and the context without getting too embroiled in complex description of the process it

uses (Bryman, 2016). For this sample, and the parent group it allowed me as the researcher to access more meaning to the participant's insider perspective, and often their anecdotal retrospective stories about their autistic child was a route to my understanding their motivation to want ABA (Kovshoff et al.,2011). What then emerged from this method of data collection and working with participants was a narrative for analysis, which in turn created data that was rich in evidence of how the stakeholders made sense of their perspective, and for me to understand their perspective (Bryman, 2016).

Generally, the analysis of qualitative evidence as a narrative would complement and strengthen the evidence of quantitative data. For example, in Grindle et al's (2012) two year study of children with autism in an ABA-based intervention class in a mainstream school, the quantitative test data on behavioural improvement after ABA-based interventions showed marginally significantly higher IQ scores in year 1 of the study, and no significant improvement in IQ in the second year. Alongside the quantitative test method Grindle et al., (2012) used the VABS (Sparrow et al., 1994) with parents to make an assessment of changes in behaviour pre and post-intervention to complement the quantitative test data. This is in itself, a semi-structured interview schedule, which according to Hayward, Gale & Eikeseth (2009) in their study on intensive behavioural intervention; is a semi structured interview conducted with parents or main care-givers to assess adaptive behaviours. The VABS is often used amongst researchers in the field of ABA for the purpose of empirical analysis of contextual or improvement changes in behaviour. Eldevik, et al., (2012), in another two-year study of behavioural outcomes in children receiving ABA-based interventions also included the VABS in their methodology. This study, like Grindle et al's (2012) study, evidenced greater gains in the behaviour outcomes than in IQ.

I have taken this to mean that the inclusion of a semi-structured interview to gather data enabled the two previously mentioned studies' not-statistically significant data to be further contextualized, and children's gains across a wider range of behaviour change to be seen more contextually. Remington et al., (2007) also comment on the use of qualitative data from semi structured interviews, saying that interview data allows for the inclusion of a wider range of outcome measures, as seen in the

afore-mentioned studies; and an evaluation of the scope to which these can be taken. To further consolidate the use of the interview and VABS as a semi structured tool for the use in interviews, Kovshoff, et al., (2011) revisited this methodology in a follow up study on two-year outcomes after EIBI interventions had been effective and since finished. They too considered the tool to be one of accessing more meaning to the data collected.

My project's original design planned to include quantitative pre and post-intervention test data, and use the VABS (Sparrow et al., 1994) as part of the quantitative study; but for reasons that were not under my control, ABA was not implemented in the school unit at the time of data collection. The narrative data I collected is rich in content, context and perspective and holds much value on the discourse of why parents and providers are motivated to choose ABA, and why providers want to deliver ABA-based interventions in a mainstream school setting.

Other research more aligned to my objectives of exploring parent motivations and experiences that used semi structured interviews are firstly, Webster et al., (2004). They investigated the parental perspectives of early intensive interventions for children with autism. Their research used the direct face to face form of semi structured method, as did Glazzard & Overall (2012), when exploring the experiences of parents raising children with autism. The latter's findings reported that the accounts were all different, were 'very interesting' and provided rich evidence of the children's characteristic traits. What is relevant to note for my study, is that they found that most parents received little support and that their needs were poorly communicated and understood. This gave rise to a wide range of coping strategies that parents used from 'support from their families to paid help'. It also pointed out a need to improve relationships with the commissioners and providers of the interventions (Glazzard & Overall, 2012).

Green et al's (2007) study investigated similar objectives to mine. She used a combination of both internet survey questions, followed by one to one telephone interviews using a semi structured format in her research on parental experiences with autism. Mine were all face to face interviews. Her findings were that there was a need for parents to receive objective, scientifically validated information about interventions

so that they can make informed choices on interventions. Again, something my method design hoped to expand on.

As I noted above, the semi-structured interview method is well documented as a useful tool to broadly scope themes that in practice encourage participants to give detailed descriptions of their perceptions and understanding of the topic. More specifically it allows an empirical investigation of a concept in depth. Participants can both generalize and expand on the theoretical propositions such as the motivations for choosing ABA-based interventions as in this study, rather than my having to establish a relationship between a dependent and independent variable over a concept (Roll-Pettersson et al., 2016).

The broad scope can then be followed in the analysis stage with more general steps of analysis that build on that scope, so the 'continuum process of concepts' is captured – meaning that the sequence of experiences the participant has, are related to the concept (the interview question) in a way that corresponds to their expectations and how they understand their experiences and expectations (Bulmer, 1979; Creswell 2014; Bryman, 2016). My study does so with scripted, sequenced but not rigid questions, then additional detailed and flexible prompt questions that encouraged more detailed responses from the stakeholder participants.

However, one specific benefit of the semi-structured interview is that it acquires the data and context without overly investing in the process that acquires it (Bryman, 2016). It was empowering as a researcher to gather as accurate as possible an overview of the context behind stakeholder motivations, with its explicit and implicit rules. As the researcher, I was the main collection instrument and subject to minimal standardization (Punch, 2014). This required skill and integrity to work within appropriate bounds of reflexivity: an ability to be in the moment of interaction, reflect and respond to it at the same time - a form of 'reflexive methodological accounting' (Mason, 2002; Creswell, 2014). Kovshoff, et al., (2011) also reported on the care to be taken with personal and potential bias, highlighting the expectation that all sensitive to the participant. Researchers must exercise every caution to obtain reliable and valid data in the qualitative phase of collection. They added that this was in addition to being

My research method needed to explore real-life phenomena of the individual's perceptions, so a non-probability method was chosen. The semi-structured interviews used a purposive sampling method within a non-probability, non-random selection method (Taherdoost, 2016). Moreover, as the sample originated from one particular setting all the participants were included deliberately (Bryman, 2016).

Whilst this purposive sampling was a form of 'convenience sampling' because the participants were available to me through the unit where the research was focused, the participants were able to recommend and make contact with other participants for me. This form of sampling is often called 'snowball sampling' which can be distinguished from 'convenience sampling' in that the participants were more than simply available, they could be used to access other participants (Bryman, 2016). As the parent and stakeholder participants were only accessible through the unit, gaining access to them was done initially by direct request from the unit manager, but then expanded through the snowball method of sampling.

This method both allowed and encouraged other participants to take part in the study, thus the snowball effect within the sample. It is again a non-random one that was useful to recruit the hard-to-reach part of the parent population subgroup in this school who might not necessarily have come forward initially at the unit manager's request. Being encouraged by other parents helped to boost the sample numbers (Taherdoost, 2016 & Bryman, 2016).

The three stakeholder groups in this sample were the parents, the school teachers, support staff and managers, including the head teacher and the local authority SEN lead. Each participant group was different, one consisted of parents of ASD children, a second was professional teachers, support assistants and a head teacher and the third group was a professional service provision commissioner for the local authority. All the participants were considered an authority in their own right, whether that was through their own knowledge base as a SEN teacher, commissioning provider, or as a parent with their experience of their child's autism. In addition to this, each participant within each group was also different, which pointed the data towards a thematic analysis rather than content analysis (Bryman, 2016). My rationale for the use of thematic analysis in favour of content analysis is discussed

more fully on page 72. Within this thematic analysis the themes were not constricted to any specific theoretical framework, but evolved as noted earlier, from the rich data itself.

The purpose of the interviews was to explore the wide-range, depth and quality of the knowledge and experiences the participants had, and as such grounding the themes in the data evidence, from a bottom-up approach (Bryman, 2016).

During each semi-structured interview with the participants, further prompt questions were introduced if, and when necessary, where the responses could lead to a deeper context that could provide further richness for data analysis. For example, when parents were asked about their child's current education and autism intervention provision, if the replies were not clear about whether, and how the parents had a choice in that provision, they were asked 'What choices did you have over the school or education you wanted?'. This was often followed up with 'Why did you make these choices?' (See Appendix E, F & G for Interview Schedules). The benefits of building these tools into the schedule were two-fold: firstly, to ensure that the scope of the subject area was sufficiently covered in as much detail as was possible in the interview; and secondly, in face to face interviews as the interviewer I am acting with awareness and acknowledgement of my part of the interview process with the stakeholders; as I have an implicit role in the construction of the 'knowledge' derived through participants' replies. Further, it refers to my reflectiveness of the implications for the not only the replies that are generated from the interviews, but the methods used, values, biases, decisions and even my presence in the interview (Bryman, 2016). Cresswell (2014), suggests that within this reflexivity, communication can be checked by both parties which refers to the implicit rules of interaction allowing the participant to check within themselves in the interaction that they are responding adequately to the questions. As interviewer, I can then more explicitly request clarification of the participant's responses, and if needed, elicit responsiveness from the participant (Irvine, Drew & Sainsbury, 2012).

Every face to face interview was recorded digitally on an encrypted recording device, then saved and transferred to a safe password protected digital storage area. This protected the anonymity of all participants and safeguarded both the participant's rights to anonymity, privacy and confidentiality, and the evidence for analysis. This is in line with the

Data Protection Act 2018, and the British Educational Research Association (BERA) ethical guidelines for research (2018). At a later date, before thematic analysis, approximately 10% of the interview recordings were verified against their manual transcriptions by a third party researcher. This was to make sure that the integrity of the raw data was maintained; and, that as the researcher actively engaged in the dynamic process of the interview, I did not exert personal bias through the interview questions or gestures of language (BERA, 2018). This is particularly relevant as in semi-structured interviews such as these, the researcher plays a part in the process, and can therefore influence the responses the participant gives as it is up to the researcher what to question and how to probe it further (Punch, 2014; Bryman, 2016).

Participants

Fifteen participants were selected for the face to face interviews during June and July 2018. Seven were parents, and seven were staff from the school. These comprised of teachers, support staff and the school's head teacher. In addition, there was one senior local authority representative included in the sample. All the interviews lasted approximately one hour; and were conducted on the test-school premises. As noted earlier they were recorded using an encrypted digital recorder, stored electronically and then transcribed for thematic analysis.

Recruitment

All the parent participants were contacted directly by the school unit's manager who was also the Foundation Phase (KS1) class teacher. The school uses a home-to-school private and encrypted social communication application called 'See-Saw'. Parents were invited by the unit manager to take part in the interviews using this application, and they responded directly to her. Once they had agreed to take part the manager then compiled a list of parents, and allocated them to interview days and times at the school. The school teachers and LSA staff who worked with the children in the unit who were included in the interviews were asked directly by the head teacher and unit manager to take part in the study. These participants were again allocated an interview day and time. In addition to the interviews that took place, I was invited to attend and observe a number of the unit's

provision planning meetings throughout the 2017/2018 academic year: one in September 2017, one in January 2018 and again in June 2018. These were multi-disciplinary meetings that were convened every academic term to set learning and behavioural targets and to discuss each child's progress. Each child was discussed separately with the team and the child's respective parent(s), and any external providers for example of SALT or ABA. During the meetings, provision, progress and the child's Individual Learning Plan (ILP) targets were discussed and reviewed. It was here that parents were again invited to take part in the research should they wish. The majority of the parent group agreed to participate. The only reason for not including more parents in the interview series was their lack of availability, due to work or other commitments during the interview period. Only one parent declined, but then decided at a later stage to take part. Of the school unit staff, the two class teachers and head teacher and a further four support staff were available to take part during the interview period out of a total of 12 staff involved in the running of the unit. The unit manager, head teacher and local authority SEN inclusion manager were purposefully recruited for their role specificity, and their part in the provision decision making process.

The participants represented the three different stakeholder interest groups in the ABA led unit that was being established in the mainstream school. Tables 1, 2 and 3 below, show the participant and interview information relevant to the reading of this thesis, which explain the abbreviations that are used to represent the different stakeholders in the results sections in Chapters 3 and 4.

Parent Participants

Interview	Code	Length (in minutes)	Parent Participant
Parent Interview 1	P 1	41 m	Mother
Parent Interview 2	Ps 2	58 m	Mother & Father
Parent Interview 3	P 3	21 m	Father
Parent Interview 4	P 4	26 m	Mother
Parent Interview 5	P 5	1h 10 m	Mother
Parent Interview 6	P 6	41m	Mother
Parent Interview 7	P 7	58 m	Mother

Table 1: *Parent Participants*

School Participants

Interview	Code	Length in minutes	Role in the setting
School Interview 1	S1	20m	Learning Support Assistant (LSA)[1] in Foundation Phase Classroom – Learning Resource Centre 1 (LRC1)[2]
School Interview 2	S2	22m	Learning Support Assistant (LSA) in Foundation Phase Classroom – Learning Resource Centre 1 LRC1
School Interview 3	S3	21m	Higher Level Teaching Assistant (HLTA) in Foundation Phase Classroom – Learning Resource Centre 1 (LRC1)
School Interview 4	S4	35m	Key Stage 2 (KS2) Teacher
School Interview 5	S5	56m	Learning Support Assistant (LSA) in Key Stage 2 Classroom (KS2)
School Interview 6	S6	71m	Head Teacher
School Interview 7	S7	82m	Unit Manager and Foundation Phase Classroom – Learning Resource Centre 1 (LRC 1) Foundation Teacher

Table 2: *School Participants*

Local Authority Participant

Interview	Code	Length	Role
LA1	Local Authority Representative Interview	58m	Special Education Needs Inclusion Manager

Table 3: *Local Authority Participants*

Procedure

Prior to the data collection period, an application was made to the University of Bangor's School of Education's ethics committee (CBLESS), and the research project was approved in January 2018 (See Appendix A for ethics approval). At the outset of the interview period, an

[1] LSA = Learning Support Assistant
[2] LRC = Learning Resource Centre (Autism Unit)

information sheet and consent forms were distributed by the unit manager to the interested participant parents and staff either during the school drop-off or pick-up times. They were also circulated during the parent-school planning meetings, and during school briefing sessions. They were subsequently returned to me by the unit manager, as were the interview dates and programme of attendance agenda. In the interest of confidentiality and data protection, the request to take part in the interviews was done in this way by the unit manager through the school's 'See-Saw' app, or through closed planning meetings. Allowing me direct access to the parents and school staff would have required further safeguarding clearance from the local authority. Outside of this method, when parents were being interviewed, they were asked whether they knew of other parents who could be contacted to take part. Contact names were then followed up by the unit manager using the same procedure as outlined above.

All the interviews were conducted by me, and were held face-to-face at the school in a private room. A further consent form and information sheet was offered and completed at the start of each interview, and again consent for the interviews to be recorded digitally for transcription and analysis was requested. Before each interview, each participant confirmed in writing and again verbally, that they gave their consent to take part and to be recorded. All participants were reminded that taking part was purely a voluntary activity, and they could withdraw from the interview at any time during the process, that they could stop the interview and or decline to answer any of the questions without offering a rationale. Each parent was also reminded at the start the interview that their participation and the responses they gave would bear no effect on the educational provision their child would receive, or their job role.

At the point of completing the consent form and verbally agreeing to go ahead with the interview, all the participants were offered a written overview of the purpose of the research project, and the general nature of the questions that they would be asked was communicated to them verbally (See Appendix B).

The interview schedules were used as the primary guide for the nature and sequence of the questions asked during the interviews with each participant from the three

stakeholder groups. Most of the participants were interested in the research topic and were very open with their perceptions and views and talked freely once the interview started. My intention was that the question sequence would be followed, but when asked about their child, as part of the first question on the schedule, the interview evolved into a natural discussion with each participant. These discussions followed the general sequence of the schedule from: information about their child; their expectations for their child prior to any autism interventions; issues arising for the implementation of interventions or any behaviour based programmes and finally, future expectations they may have because of interventions or behaviour based programmes. Only one of the parents was hesitant which was perceived to be because he was nervous being interviewed, and replies were given in direct response to the questions and prompt questions in their ordered sequence. As the researcher, I made sure that all the question areas, and sub-areas were covered during the interview, if not in sequence. None of the participants declined to answer any of the questions, and all gave full and detailed information of their experiences to the best of their ability.

This study's objectives were to explore the perceptions of what motivates the key stakeholders' decision making when choosing or providing autism provision, and their experiences of implementing ABA in a mainstream school. The interviews were the medium for gathering narrative evidence of the participants' perceptions on ABA, their knowledge and understanding of ABA, their experiences with ABA if any, in order to relate this back to their motivations for requesting or providing ABA. Further, they were to investigate the perceptions and the difficulties that stakeholders experienced in setting up the specialist unit for ABA-led interventions.

In exploring the above research questions, parents were also asked about their child, and the current and future provision they were receiving and that which they hoped to receive if it was different. It was followed with an examination of their knowledge and understanding of ABA if any, and any issues that were arising from engaging with ABA interventions.

School staff were asked about their roles and responsibilities within the unit, the interventions they were currently providing and the ABA interventions they hoped to provide. Their preconceptions and knowledge of ABA was explored along with their

perceptions of the benefits and drawbacks to the children and the school. Issues around decisions to provide interventions and ABA-based interventions were asked about as were the data measures that the unit used to monitor and record baselines and progress, and how the aspirations of the school's inclusion policies were perceived.

In addition to the themes of perceptions of ABA, underlying knowledge and understanding of it, the local authority representative was asked about the range of provision that was available for autism across the county and how this was procured, arranged and managed. Of particular interest was how the decision to provided ABA in a mainstream school was arrived at, and what the critical factors of influence in that decision were. Importantly it was valuable to know what difficulties the authority faced in setting up the ABA-based provision which led to further questions about their expectations of ABA in the future.

Qualitative Data Analysis

As mentioned earlier, all the interviews were transcribed verbatim from the digital recordings, and then at the analysis stage these transcripts were reviewed for familiarisation, where initial themes were identified.

At this stage of the data analysis I made the decision to use a thematic analysis over a content analysis method. Both processes follow an iterative procedure and are relevant for qualitative data of this nature. However, thematic analysis is better suited to a small sample which is linked to a phenomenon as in my project, where the objective was to ascertain what the parents and providers of services based their intervention choice decisions on. There were fifteen participants in total, and the respective volume of narrative data produced was relatively small to consider carrying out a systematic identification of messages, words, or a process of interrogation of frequency of words (Bryman, 2016). I wanted to retain some flexibility over the identification of themes and patterns across the whole data set, so that the themes could capture something important of the overall research questions. Both thematic and content analysis tap into the obvious/manifest and the latent/hidden content messages. Thematic analysis required researcher interpretation to seek coherence from participants' diffuse stories that developed through the

construction of codes and interrelating codes that highlighted salient constellations of their individual meanings, which gave rise to a hierarchy of importance (Nuendorf, 2015).

Content analysis on the other hand is very useful for the analysis of large quantities of data, and interrogating messages and images across that data. It is often perceived as a more objective and systematic approach for identifying specific characters, and does so over large data sets and time frames as in longitudinal studies. Nevertheless, coding in content analysis as with thematic analysis is never wholly objective (Bryman, 2016). However, the benefits of using content analysis for this project was considered; as statistical summarization, inherent cross-checking and the potential for triangulation could have offset the absence of quantitative data. I calculated these benefits against those of thematic analysis and my requirement for flexibility, and decided against it. My interview schedule was semi-structured, and I felt the questions did not have the level of specificity that content analysis would require - for example, my interview schedules included several 'why' and 'what' type questions which would be incommensurate with content analysis criteria (Nuendorf, 2015). Whilst there were several instances where the word 'difficult' (p.147) was identified in the data across the three stakeholder groups, the word, as a 'message' could have been used to code using content analysis to garner deeper meaning from participant responses, its use was too infrequent across all the stakeholder groups to yield a relevant theme. Finally, the sample in my study was relatively small, and using content analysis can be problematic when trying to avoid assigning a negative or an undesirable factor to data in smaller samples, as it obscures meaning relating to the research objectives. For example, perceived tension between the school and external ABA providers (Bryman, 2016; Nuendorf, 2015).

Once themes emerged from this process they were further scrutinised, reviewed and refined to create a thematised results report. This is the process I used of actualizing the participants' perceptions using the grounded theory method and referencing the theme to a code for data manipulation and interpretation (Bryman, 2016). Once the original transcripts had been read and reviewed in this way for initial theme identification, it could be coded later. The transcripts were systematically reviewed through N-Vivo 11.4 Pro (2017), and the codes generated. N-Vivo uses the term 'node' to code themes and sub-themes, and later these were developed into tree-diagrams for further analysis and discussion.

Nodes were created within N-Vivo, to categorise the themes from all the data groups. At this stage, each group's data was treated separately to identify any themes that were specific to that group. Later they were cross referenced within the QDA package for any shared themes. A node diagram was created for each group of data, and then each theme and sub-theme was subsequently identified and attached by quotes from the participants. The quotes used in the results Chapters 3 and 4 were identified in this theme and sub-theme synthesis. The tree-diagrams that have been used at the beginning of each theme analysis section in Chapters 3 and 4 (Bazeley & Jackson, 2013) were derived from this process. For example: themes were collated, and placed in a hierarchy or order of perceived importance or due process, such as, knowledge of ABA was placed before perceived benefits and drawbacks of ABA.

Themes, subthemes and resultant quotes were checked once more against the original transcripts to validate as much as possible that the participants' responses were being interpreted accurately. They were also checked so that the responses were related to the relevant question or probe, and subsequently represented as objectively as possible and in an un-biased way (Bazeley & Jackson, 2013).

The core research question that this thesis set out to investigate was firstly, what motivated the parents, the school unit and local authority choose ABA in the first place, and from there provide it as a provision within their wider autism education plans. Secondly, I was interested in the factors that affected the actual implementation of ABA in a mainstream school. I wanted to know what the difficulties schools and local authorities faced when they were planning behaviour based autism provision. This included the barriers they faced to the smooth integration of ABA in the school, and, how ABA-based delivery would be integrated into a mainstream school and whether it worked and improved outcomes for the children. As ABA-based interventions were not in place in the LRC at the time of data collection it was not possible to gather any conclusive secondary data on the pupils' outcomes. Both teachers and LSAs reported on pupils' behavioural and academic outcomes, but the evidence was not analysed formally as part of this study. As the unit was newly opened, some pupils were in an initial six-week screening observation process, after which individual plans would be devised and pupils placed on the school's online assessment tracker SOLAR, which is specifically designed for primary aged children and

those with special needs (SOLAR, 2016). Pupils who had transitioned from their initial six week screening were placed on the system, but there too few and they had only been monitored for a maximum of two terms. This was felt to be too short an assessment period for conclusive data on progress to be gathered.

The evidence that emerged is organised into two data chapters that cover the main themes of what motivated the parents and providers to choose ABA; and then the tensions and barriers the stakeholders experienced in setting up and implementing ABA in a main stream setting.

The first of these data chapters, Chapter 3, presents and discusses the interview data on what the parental and provider perceptions were that motivated them to choose ABA. It then explores their responses that indicate what their perceptions were of their knowledge and understanding of ABA, and the benefits and drawbacks of ABA as they see it. From their responses, I wanted to know what the challenges they faced were; and how these difficulties influenced their decision making if at all, particularly those of the parent group.

The second data chapter, Chapter 4, presents and discusses the data that emerged from the stakeholder interviews relating to the central tensions, and the barriers experienced in setting up ABA in a new mainstream school unit. This chapter expands on what was observed as the LRC unit's current position and practice, and that the promise of ABA being delivered in the unit was slow in being realised. This delay in implementing ABA in the school unit was a source of tension for all the stakeholder groups. A second factor, and possibly the most substantial in terms of evidence is the range of tensions that were created between the stakeholder groups that became barriers to the implementation of ABA. These tensions will be discussed further in Chapter 4. How the stakeholder's understood and interpreted ABA and how they perceived that it should be organized and delivered in a mainstream school was explored with all participants.

The data is explored in more detail through an analysis and discussion of the barriers that were experienced by the different groups in implementing ABA. These were identified as the funding, the training and staffing of the unit to deliver ABA intervention programmes. The chapter also considers the evidence of perceived tensions between the various stakeholder groups, i.e. the parents and local authority; the school and the parents and

those with the private ABA provider. Chapter 4 concludes with an analysis of the impact of these tensions between the different groups because of the delay in implementing ABA interventions.

Chapter 3: Motivations:

Why parents and providers choose ABA

Introduction

I have focused Chapter 3 on one of the two main themes, that which motivated the parents, the school and local authority to choose ABA as an intervention. I have analysed the parent and provider responses as evidence of their perceptions about ABA, and what has influenced their decisions to choose and subsequently provide it. Following this, the participants' perceptions on their knowledge and understanding of ABA is analysed and discussed as were their perceptions on the benefits and drawbacks of ABA. I wanted to investigate what the challenges were that parents and providers face; and how these challenges affected their decisions to choose ABA, if at all, particularly those of the parent group.

The chapter is structured to analyse the parental motivations first; the challenges that influenced their decisions about ABA, the support available to them, their perceptions of ABA's benefits and drawbacks and also the services that are available to them. Then the perceptions of the school and local authority are discussed. The section on school and local authority motivations will cover the local authority's rationale for their decision that was initiated by parental influence and a conflict of interest, then the local authority's and school's perceptions of ABA's benefits and drawbacks. The overall themes, and sub-themes for analysis and discussion are shown graphically by tree diagrams at the start of each section of this chapter, these are developed from the coded responses which were analysed through nodes created by N-Vivo. I refer to the participants by their interview code, which are noted in Chapter 2 (pp. 68-69).

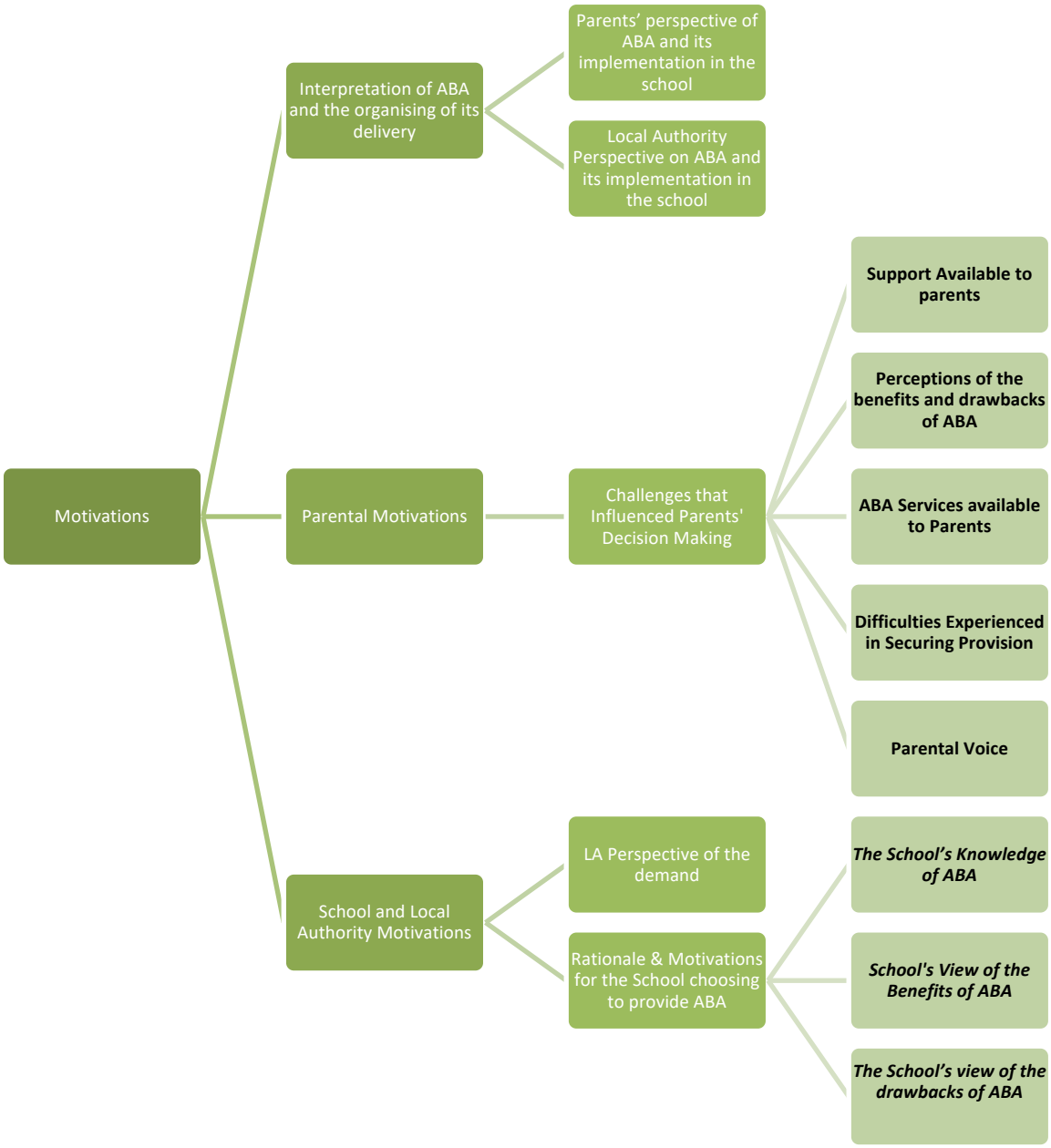

Fig 1: Themes and Sub-themes: Motivations

Why the parent group, school and local authority chose ABA

Fig 2: Themes and Sub-themes: Motivations – Interpretation /Understanding of ABA

The reasons parents and commissioning agents might choose ABA are multi-farious. Evidence from the literature suggests that parents choose interventions for their children based on their own experience, or recommendations from others, in our data the recommendations for ABA had come from non-professionals, which has been seen in other literature (Webster, et al, 2004; Green et al., 2007; and McPhillemy & Dillenburger, 2013). As few of the interviewed parents had any previous experience of ABA, they felt it was '*different*' (P5), or, had heard from their friends that it worked for other children (P1 and P7). From the thematic analysis I carried out, two important sub-themes emerged from the data. The first was that the intention to provide ABA in a mainstream school was initially influenced and driven by the parent group, and then later followed through by the local authority. The second sub-theme emphasised how the stakeholder's perceived they understood and then interpreted ABA. This second sub-theme will be analysed and discussed much more concertedly in Chapter 4, as it plays a part in the central tension that emerged in this study. This tension was centred on how ABA would be implemented in the unit, and what the providers experienced as barriers in doing so. But I will include briefly here, that, how the providers understood and interpreted ABA, emerged from the data as an overestimation of their knowledge of ABA, and an underestimation of their knowledge of how to organise its delivery within a mainstream unit curriculum.

There were many factors influencing the local authority at the time of their decision making about ABA, most notable was the restructuring of SEN provision in the county which was a consuming undertaking. However, the changes being made to the SEN infrastructure seemed to parallel the decision to provide ABA. The SEN inclusion manager for the local authority said in interview that:

> The reality is that we have a unit in [one part of the county], and there is a strong head who likes to introduce her own ideas; and sat alongside that we had the plan that ABA should be introduced because parents are using it, and they wanted that brought into schools (LA1)

This is an important quote to place in this section on motivations, as it reflects the local authority's thinking in their early stages of planning to implement ABA; which was designating one specific unit in the county to deliver ABA. The evidence I gathered suggested that doing this would address many of their ABA issues and the related financial considerations with which they were faced. To elaborate further; in the context and timeline section in Chapter 2, I noted that the local authority was paying on average £20,000 a year per child for home-based ABA programmes. At the time that this data was collected there were six children being funded this way, fewer than in recent years. The local authority was in this position of funding home-based ABA programmes because some parents had taken them to tribunal (SENTW, see p.37) and won their cases. This is an action that many parents across the UK have taken to access funding for ABA after finding out about ABA for themselves and making decisions to choose ABA (McPhillemy & Dillenburgur, 2013; Green et al., 2007; and Tzanakaki et al, 2012; Fazzio, 2014; Keenan & Dillenburger, 2018). Much of the activity underpinning the county's SEN restructure and the introduction of a new ABA-based autism unit was an inherited scenario for both the local authority and the school unit's current head-teacher. Therefore, following the lead of the unit's previous head teacher not only aligned with parent demand for ABA, but would reduce the need for the authority to be drawn into tribunal cases on ABA provision. It also enabled the bigger restructure of SEN provision to happen.

To come back to the first sub-theme in this section, the data showed that the local authority was reactive in following the parent's drive for ABA. The range of EY services and

provision available for ASD children in the county was perceived as being insufficient by this parent group. All the parents in this sample expressed this view, as the following sample of quotes reflect their perceptions of previous placements:

> The impression we got sadly was that they felt that he needed to be elsewhere, but because of the lack of provision or the scarcity of resources it wasn't easy to move him from there (Ps2)

and :

> **Mother**: He was in a little room with no windows, with a lovely lady but she had no experience of autism […] **Father**: She was a qualified teacher but was working there as an LSA, she had no experience of autism (Ps2)

These parents reported that after much communication with their child's school, plans to accommodate SEN provision within the mainstream school would have been put in place, but they felt it was ineffective:

> So, they started on a six week plan, and the next week he would do all day Monday then every afternoons, then a full day; then they would say he can do a full day but can you bring him home for lunch because we can't provide for him at lunchtime, then he wouldn't want to come back to school, and would have melt downs (Ps2).

And in support of their perception of specific SEN EY provision parents said:

> We had meetings with the teacher; this was to be a specifically autism unit – LRC. Where he was before it was general (P3).

> [He went to a] small village school **L** , had no experience with special needs kids, then it was just wait for a unit to come up, it was just such a fight to try and get in, a long draining fight, and ready to jump off the bridge kind of fight (P4)

> His three year funding was running out and I still didn't have answer of where he would go when he was 4, Playgroup were saying his funding was running out, Education were saying there is no space for him to go anywhere, local authority couldn't say where he was going (P6).

> So, what we heard was, so again it was - there's nothing here for us, she went to Special Needs play group and that was 2 hours a week, then the majority of the time by myself (P7)

When asked about her child's EY experience, P6 said that her child had attended playgroup:

> [The] local one, he didn't have any specialized play group […] Because all the units were full in the area, he stayed in the **'XY'** group for an extra year with funding because all the special unit places were full, and the all the nurture groups were full, so they thought he could go in a nurture group in a mainstream classroom, but even they were 'chocca' […] (P6)

These parent reflections of EY services' availability for ABA is supported by the inclusion manager's comment that parents: '[…] *want [an] ABA focus'* made available in the SEN provision that their children received. The inclusion manager believed this to come from an increase in the number of requests for ABA from parents. To expand on this further, the parents were campaigning themselves, through key workers and then the local authority directly, sometimes through tribunals for an autism provision that they felt worked (Green et al., 2007; McPhillemy & Dillenburger, 2013).

Campaigning and pushing for autism provision, and ABA interventions, was a theme in all the parent interviews, as the following range of quotes attests:

> Got to push everywhere (P4)

> Basically it's down to the parents to do the research and do whatever else […] but unless you actually phone yourself and hassle yourself you don't actually get anything (P4)

and

> […] we just kept pushing for it, phone every week, that's how we did it (P5).

P4's child is 7years old, and the campaign for provision had been ongoing:

> Even when I've asked, many a time, over the past three years, someone is supposed to be sorting me out something about his behaviour, because of his anxiety he gets violent, and he's quite strong! I've asked and asked and asked, and been told they will refer me, but I'm yet to see anyone (P4)

> And then from her referring that's when the battle starts, it was in your mind, and you definitely want to get it sorted, and we got letters to say he was on a waiting list. I was one of these people that wouldn't phone people up, I had to change and get more on it, after a year on the waiting list I was on the phone every Monday morning, asking when he was going to be seen, and now I'm like that all the time (P6).

When prompted, 'who were you pushing? P6 said:

> I tried **SE** in Parent Partnership? But she doesn't answer her phone for weeks on end […] then key workers happened to be in a meeting with all the people who would be in a transition meeting. And it was organised for the week before Christmas (P6)

This last quote from P6, highlighted that parents were saying that their child's provision

by the authority was unplanned, and reactive.

Parental motivations for choosing ABA

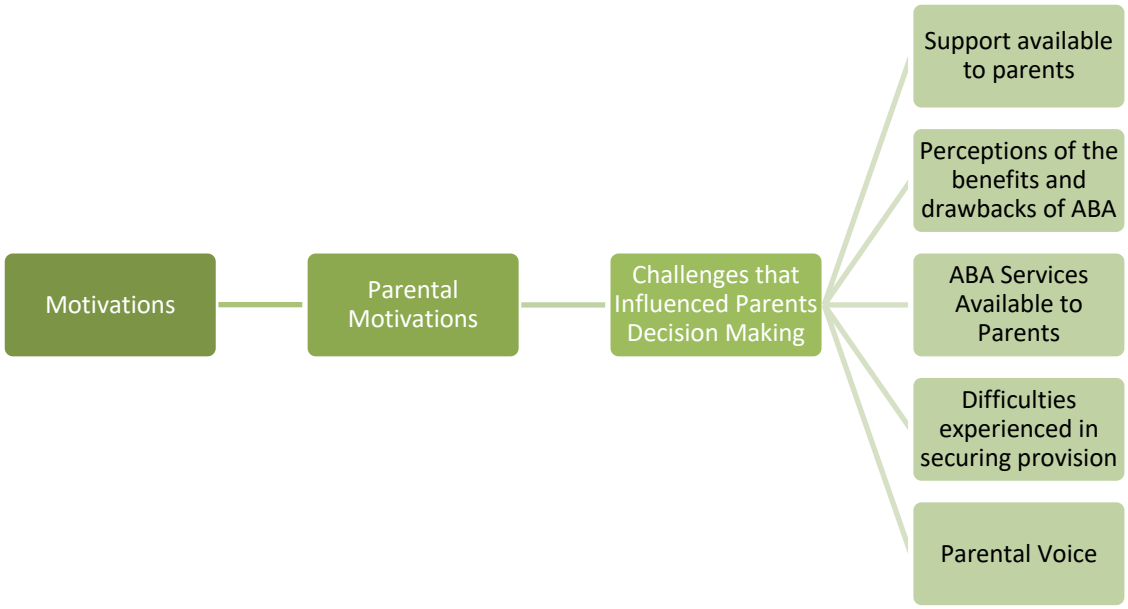

Fig 3: Themes and Sub-themes: Motivations – Parental Motivations

The first of the themes on motivations for choosing ABA is from the parent perspective. Those with previous experience of ABA were motivated by that previous experience, but initially it was based on anecdotal recommendations. As part of this theme, I will discuss those motivations and expand on the challenges that parents felt faced with when making decisions about ABA. These will cover the support that parents felt was available to them; their perceptions on the benefits and drawbacks of ABA; the services available to them; the difficulties they experienced when trying to secure provision and also a brief section on parental voice.

Three of the parents interviewed had first-hand experience of ABA through home-based programmes delivered by an external ABA provider. They were currently choosing ABA because of this previous experience, and they said had actively sought that provision initially after recommendations from other parents. One of those parents wanted ABA

because it represented '*something different*', as she felt that '*nothing else worked'* P5. This in itself reflected a perception that ABA was not only a last resort, but also consolidated that parents felt that existing autism provision was lacking.

Parents 3, 5, and 7, had some previous experience of ABA. They were asked about that experience and how they came to choose it. Parent 7 said that before conducting some independent research she had no experience of ABA at all:

> None, I was introduced to ABA from a friend whose son was autistic and [External Provider] obviously the local company; so with M, I thought she was Autistic and we were going down that path when she was just 14 months old (P7)

These three parents' experiences of ABA was through home–based programmes delivered by an external provider along the lines of Lovaas' intensive intervention (1987) . When P7's child was a few months old she had shown early signs of autism, and by 14months old the family were exploring their options for interventions. At that time, ABA through an external provider was recommended by a friend in a similar situation. P7 had followed that recommendation and subsequently conducted her own independent research online:

> I researched (the external provider) on their website and have them come out to the house (P7)

When asked what ABA was and why they chose it as an intervention P3 said: '*I chose it for my child, [as] I was looking for therapies that were outside the box*' P3. This parent paid privately for ABA from an external provider for home-based programmes before her child started at his previous school. They were actively seeking ABA from the local authority because of a previous, personally funded ABA experience. They saw ABA as different to other mainstream unit interventions as it was outside the usual curriculum interventions that a SEN unit might offer, which places the '*outside the box'* reference into some perspective.

P5 understood ABA as: *'[..] its autism behaviour therapy, helping with speech, food and social issue*s'. P5 quoted that she had the support of another parent at a previous school who had researched and contacted a local private provider of ABA: *'[…] she found them online and contacted them'.* Parents 3 and 6 said ABA was: *'Positive reinforcement to*

behaviour that is desirable' (P3), and that it: *'[…] is a way of analysing behaviour from data*', from P6. This level of detailed response was indicative of their understanding from previous experience with ABA. They demonstrated a greater perception of ABA than those parents interviewed with no previous experience of ABA and that it could be used to help with their children's self-care and functional skills.

P3 said, that as a result of ABA at home by the external provider, her child was now able to use the toilet, would go to the hairdresser and was communicating better: *'He's now toilet trained, will have his hair cut, say some words, there's less frustration for my son and it makes him happy. More structure'.* In addition to these abilities P3's child was now able to engage in social play with his younger sibling: *'On the whole it has worked for my child and for my two children to be able to do a form of play'.*

P5's primary motivation to have an ABA home-based programme was the absence of functional skills such as: '[…] *feeding and toilet training'.* P5 continued by saying that:

> […] it's a chore every day with him because he won't eat; [he's] better than he was, eats a lot more varied now. At one point he was living on porridge, yogurts and raspberry jelly, and digestive biscuits (P5)

After receiving ABA, not only was the child's food range improved, but parents cited an improved flexibility:

> I saw how well it worked for [him], he'd gone from eating 4 -5 things to eating quite a range […] introducing bread, which was a nightmare. Even now he's not great, but he will eat a ham sandwich now; that has taken about a year getting the ham and the bread together. He doesn't really want to eat it but he knows he's got to, so that took a long time, she (ABA therapist) introduced toast and cereal. […] Now he'll eat chips and chicken nuggets, […] that's what she's integrated for him, he'll eat chips, potato waffles, smiles, mash. ABA was an underlying ability to be flexible (P5)

Furthermore, P7 also reported that her experience of ABA had been around functional skills and self-care:

> […] we've managed to get her to use the toilet, she's only just come out of nappies really, so that was a long process for M […]. So with M it's all around self-help things, like she's very good at washing her hands after using the toilet and she will do it to "10". My husband is an ex-nurse so he's really good at enforcing washing the backs of your hands, so she'll do it counting to 10 (P7)

P7 noted that she was applying their family's experience of ABA to other situations within the home and to a range of activities outside, for example: '*It's about thinking around how you are going to do it – and most of it has been done using ABA'.* The benefit of the ABA experience for her was that it could be transferred to other activities, such as going out with parents and therapist into the wider community to work on further developing social skills:

> At the moment we're trying to work on going out into the community – which is a massive thing, she is so young she likes to run, she likes to go her own way […] and again she's got to learn the self-help things in order for us to get out as a family and function; it's all about the functioning (P7)

P7 was convinced that their ABA experience ABA was a positive one: '*She's had a lot of other little interventions, but I can't say that any of them have brought her really on as much as ABA has'.* Parent 3, also expressed an improvement. The improvements were related to functional skills such as self-care, feeding and dressing, attending school and improved social relationships with family.

As a motivator, personal or anecdotal recommendation was an important factor to parents. Some of their comments highlight the strength that anecdotal recommendation had for them over professional advice and guidance. Some parents were specifically choosing ABA over other interventions as noted earlier with P5 and P7's comments. Parents felt that ABA improved outcomes for their children over and above other interventions and methods, and they made recommendations to other parents based on these perceptions and experiences. One parent reported that she had been following professional advice not to try ABA, but on the strength of parental recommendations was persuaded to try it: '*I'm willing to try anything, […] we've just been told not to use it* (P1).

Challenges that influenced parental decision making

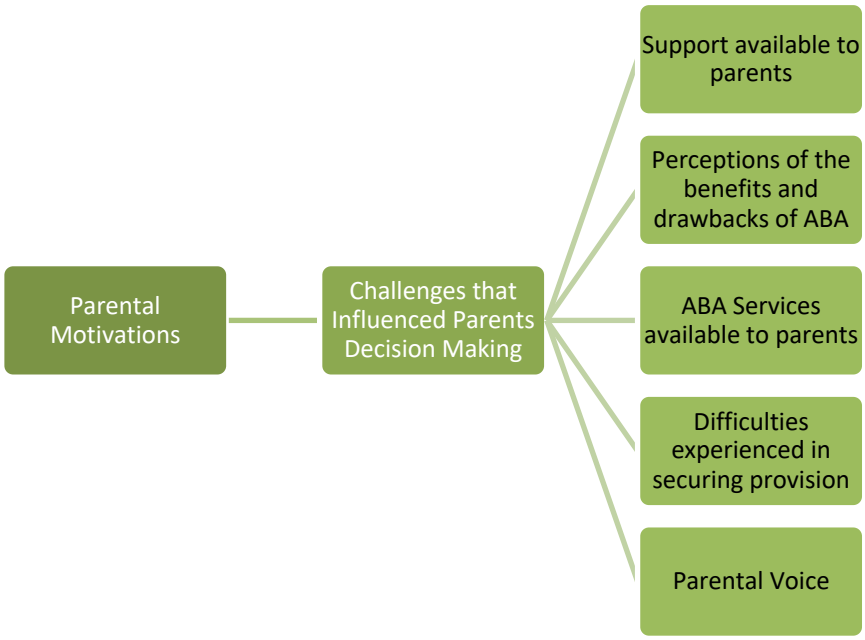

Fig 4: Themes and Sub-themes: Motivations – Parental Motivations: Challenges

Support available to parents

The parents in this study as in Glazzard & Overall's (2012) research, reported on the lack of support that was available to them; particularly in finding and accessing provision autism and ABA. Some parents were guided through the SEN territory by case-workers in the EY multi-disciplinary (EYMD) team, but most were reporting that they researched information on provision, predominantly on-line for themselves, then campaigned for it. They were also accessing non local authority training as a means of overcoming some of the perceived lack of support. Parents were self-motivating and driven to finding the best autism provision that they could for their children, irrespective of their socio-economic standing. In terms of accessing autism provision the difficulties cited were wide ranging: from finding a suitable placement, the timing and the logistics of accessing that placement and also being un-supported in that process. For example, P6 said, after realising her child

was not progressing:

> This was more than a language delay – it was something more than that and I started pushing! And then from her (reference to the Speech & Language Therapist) referring that's when the battle starts, it was in your mind, and you definitely want to get it sorted, and we got letters to say he was on a waiting list, I was one of these people that wouldn't phone people up, I had to change and get more on it, after a year on the waiting list I was on the phone every Monday morning, asking when he was going to be seen, and now I'm like that all the time (P6)

Parents 1 and 6 also said that they had accessed training for themselves: *'I looked these up [….] I put myself on quite a few half day courses to try and learn for his benefit.'* P6. P1 said earlier: '*I went to a PDA conference in Birmingham, […] it's raised my expectations and made me feel a lot more positive'* P1. The point I am making from these quotes is to show that parents were seeking solutions for provision outside of their local authority. A common theme running through all of the parents' interviews was the drive they expressed in finding the best provision that they could for their children. Emotive words such as 'battle' and 'pushing' were often used in the parent interviews and were reflective of their perception of the difficulties they were experiencing. What was valuable to note was that all the parents interviewed were self-motivated when it came to researching, mainly on-line. They were also finding out about their child's needs and sourcing the solutions that they wanted: *'I researched [External Provider] on their website and have them come out to the house to meet her', P5* and: *'Yes, if you keep asking, you have to ask, or it won't be forthcoming'* P4; indicating the drive that parents were developing to get the services they wanted.

Parent perceptions of the benefits of ABA

As indicated earlier, parents of children who had previously received ABA saw improvements in communication, functional skills, family and social life, and the ability to learn new skills and apply them to different situations. This made overall improvements in their lives.

For these parents with previous experience of ABA what they perceived as benefits of ABA were clear: P5 said: '*It's enormous for interacting with family, he could communicate*

with people. It's structured and easy to use, he can learn new skills using ABA more quickly'. P3 said earlier (p.9) that now their child had more functional self-help skills, the child's situation had improved, and for P7 it had been transformational for the family. P7 was positive, saying that the: *'[…] therapy is great. They teach you about the ABCs, apart from the costs I can't think of any negatives at all. [It has], transformed our lives'.* Further, P7 commented on the wide reaching impacts that ABA has had on their family:

> I can't imagine not having it in place! but what we've learnt ourselves from it, what it has opened us up to, is so much more, all the knowledge and understanding, looking at the behaviours and why those behaviours occur – all those things (P7)

Parent 5 also commented on the impact of ABA improving her child's ability to accommodate to the change in school setting, suggesting that ABA therapy developed her child's: '[…] *ability to absorb things easily',* to a point where he can now apply what he has learnt to other settings; adding that:

> […] he knows what he needs to do to get to there, it's more straightforward if he knows what's wanted of him and what is the outcome, which is why I think it works so much better for him, with ABA he can see (P5)

For this parent there were insufficient funds to continue with the home-based programme, and the school ABA unit was an option to maintain the benefits of ABA, without the difficulties of funding and the engagement of external providers. However, some concern was expressed about the continuity of provision, as this quote testifies: '*Not every version of it (ABA) works, and it might work in one place and not another, sometimes he finds it confusing if it's not the same therapist'* (P5). Whilst it was understood that this comment was related to the changes in therapist that the child had experienced through his home-based programmes, it was probed further to see if they related to any issues during the transition from home-based programmes to a mainstream school where there was no ABA. P5 said that: *'[…] he has come on here and they are using a bit of everything, and it's not you can do what you want',* in addition to: *'[…] even if the ABA is mixed in with the other therapies I don't mind so much*', P5. This quote suggests that the parent was satisfied with the school's interventions even though they were not ABA, but the parent may have questioned it had progress not been seen as a result of the previous home-based

programme.

Parent perceptions of the drawbacks of ABA

Amid what was mostly positive feedback from parents regarding ABA, there were drawbacks, the main was cited as the cost, and availability. The only accessible source was through privately funded providers. Parents said that it was difficult for them to accept change and adapt to other interventions after having received ABA; and that their central difficulty was accessing suitable mainstream education provision and support for their children which included ABA. Parents would rather not self-fund and preferred interventions that were available through school or the local authority.

Parent 7 indicated that the main drawback for them was the cost: *'Costs! It's a very big thing',* and in addition to the cost there is, she added, that there was a degree of reliance on the therapy: '*I can't imagine not having it in place!*' *P7.* This parent raised an important issue, that as parents they became reliant on ABA and the external provider to supply it: '*It does become a bit of a crutch I find*' P7.

This was a difficult problem for parents, when they found an intervention that works for them and that provision is not available, nor accessible. When it is accessible it is only available at a price; as evidenced by Parents 5 and 3: *'[We] ran out of funding, […]* and of the charity that *'they had cut funding a lot' P3.* Other parents interviewed said that they: '[…] *did a lot of fundraising for therapists etc. We received a grant from a charity for £3,000 to fund ABA provision at home' P5.* Further, P3 said in support of the difficulties experienced in accessing ABA in a home-programme that: *'My wife fought tooth and nail'.*

The context that emerged throughout the parent interviews was when they found that ABA worked for their child, it was difficult to accept and adapt to other eclectic interventions that were available at the school. Parents were perceiving this as a drawback, not of ABA, but of the school's provision. P7 said: '[…] *like the ABA side of things, I kind of feel a bit let down'.* Adapting to different interventions and incongruence in the continuity of similar interventions used was perceived as a drawback of ABA: *'We use 'Choice Works' at home. But at school they use 'Now and Then', she knows the difference', P7.*

For P5, the transition to the unit in the school came shortly after the funding for the home-based therapy finished, commenting that: *' […] if they are doing ABA here, do we need to have (external provision) coming in as well?', P5*. I assume from this statement that parents would rather not self-fund nor seek funding for interventions that could be accessed through the local authority. Overall, the perceptions of the drawbacks that these parents made about their home-based ABA suggested a real appreciation of the difficulties of accessing ABA in this county. Apart from the cost, and the need for flexibility and continuity in the face of changes in ABA provider, the parents reported few drawbacks to ABA.

Drawbacks of home-based ABA programmes

Home-based ABA programmes generally differ greatly to those available in schools (Grindle et al., 2012; Foran et al., 2015; Pitts et al, 2019). The nature of the ABA therapy provided at home to this parent sample by the external provider was centred on functional skills, feeding, toileting and fundamental communication skills. P7 said that functional skills were worked on first, despite her child being non-verbal at the time of the intervention.

> Focus has been on self-help skills, and getting out in the community, not on Speech & Language [.....] the biggest thing for me was, and her consultant agreed, is around her speech. It's hard because you only have a certain amount of time with Speech & Language, and her ABA therapist isn't a Speech & Language one, it's not something we have worked a lot on, because her interactions sounded more important (P7)

Whilst P7 suggested that the child's 'interactions' were of primary focus she did not question the provider's focus on functional skills. Some context to the priority the parent gave me was that the external ABA therapist was not a Speech & Language (S&L) specialist. S&L therapy is available to the child through the school setting. It was not clear from the interview whether the availability of S&L through the local authority was a factor when the home-based ABA programme was devised. I have taken it to imply that the priority for the ABA provider differed to that of the parent, and the parent saw no reason to question it.

Generally, the frequency and intensity of the home-based programmes were varied according to need, programme, and in some cases funding, as exampled by P5 who was receiving interventions for an hour once a week. This parent was self-funding or accessing charity funding. They received ABA over the course of 18months at a cost of:

> […] about £3,000 and that lasted us for about a year and a half, but we weren't having sessions as regularly as some, like an hour once a week then in the holidays we'd go there for two hour sessions once a week (P5)

When the issue of funding for the intervention was probed, P5 offered that they had sought and were granted funding from a charitable organization, but that: *'[We] ran out of funding, and couldn't afford to pay ourselves as quite expensive. It was funded by the Caudwell Trust?'* P5. Parents were directed to charitable trust funding streams by the external provider which made ABA more accessible for families: *'Recommended by [external provider], they used them a lot so we applied to them, and they look at all your finances, but they would only fund for ABA therapies etc. not equipment' P5.*

This is of interest to this study for two reasons. Firstly, to show the extent to which parents have gone to access ABA; and secondly, it highlights the lever that parents could use to their advantage to get the local authority to fund ABA, if not provide it. This was corroborated by the local authority interview. As noted earlier parents had previously taken the local authority to tribunal over the funding of privately provided ABA therapy: *'We have a had few home programmes, delivered via [External Provider] that have come in about £20,000 a year' LA1.*

ABA Services available to parents:

Before the school ABA placement, parents had privately or local authority funded ABA through home-based programmes. These were based on a very different model to that proposed to be delivered by the school ABA model. They were predominantly focused on functional skills, feeding, and toileting and communication skills. The frequency and intensity of the home-based programmes varied according to the individual child's need and programme, but mainly funding. Parents sought charity and local authority funding for ABA and some were self-funded. This emphasises the extent to which parents would go to access ABA. It appeared to the school and local authority that the external providers made ABA more accessible to families, and having accessed it, parents had reportedly used this private provision as a lever to get the local authority to fund it, or continue funding it after having

taken the local authority to tribunals to fund this ABA externally. However, parents were seeing the ABA led unit in the school as a solution to getting the ABA they wanted, where there were insufficient funds available to continue home-based programmes.

Parents who consciously choose ABA

Further analysis of the sub-theme showed that parents consciously chose ABA. This sub-theme looks at the parent responses of making that choice, followed by a review and analysis of the home-based programmes that parents had experienced. Those parents who had chosen ABA had done so because they had experienced ABA in home-based programmes. As stated earlier, Parents 3, 5, and 7 had received ABA in this format, all delivered by a local external provider. When specifically asked about whether they had chosen ABA, P5 from page 7, said: '*Yes - to enhance his daily living skills, nothing else worked*', made it clear to me that ABA was a conscious choice, and that they were satisfied with it. Whilst P6 had not had any experience of ABA, the response given indicated a willingness to try it. A belief without any experience in ABA's effectiveness was sufficient evidence to inform a decision: '*I didn't choose it initially, but I have the chance to try it. I don't know if it works yet*', P6. This quote supports the position that parents were influenced in their decision making by other parents' recommendations. Parents received the external providers in their homes, where assessments and ABA programmes were delivered:

> When you see other kids coming on, you want to know what they're doing to get those results, another mum put me on to ABA, she found them online and contacted them. They offered me a two hour assessment with him, main issues were feeding and toilet training, they don't come to us now, they used to come to us once / twice a week to do stuff with him at home (P5)

Furthermore, and relevant for this project of establishing ABA in a mainstream provision, P5 added that she was questioning whether it was necessary for the external provider to continue with a home-based programme if ABA was to be available through the school: '*We were having ABA at the time with [the external provider] so [the unit] is going to fit him better because he is doing ABA and it works with him' (P5)*. The assumption was, that having had ABA at home and seen improvements in functional skills that this was going to

be continued in school. The reasons why the external providers were no longer delivering in the home will be addressed in the next section.

Difficulties experienced by parents

One of the central difficulties experienced by the parents was that of securing and accessing suitable ASD provision for their children. This next sub-theme looks at some of those difficulties as they form motivators for campaigning for ABA. Before the children started in the unit accessing provision was a stressful process, where parent pro-activity was a significant marker in accessing any ABA provision for their children. Parents reported feeling unsupported in their search for information and guidance, irrespective of finding ABA privately. All parents interviewed commented that the county's autism service needed improving (p. 4-6); a factor that impacted on their decision making. Often parents were left with little to no choice in the provision they could access.

Parents 2 were examples of parents who expressed more about the value they placed on the recommendations from professionals in their decision making. In their narrative, the parents said that they would have been satisfied had their child stayed at his previous school. They commented that the issues with their child arose from what they perceived as the school being unable to accommodate their child's behaviour: *'[…] he couldn't cope with mainstream school, and I don't think mainstream could cope with him'.* After many discussions and attempts to access provision for their child, the school was not able to accommodate and support him, even with a statement of SEN:

> […] we did manage to get him statemented and some one-to-one for him, but unfortunately they didn't give him anyone who was helpful, […] but because of the lack of provision or the scarcity of resources it wasn't easy to move him from there (P2)

These parents experienced conflicting information from the local authority and the school, they saw that the local authority were providing support for the school to accommodate the child, but they felt it was not successful and that the school was operating inconsistently as attested by the following quote: '[…] *they sent a lot of specialists in to help train their LSA's, but school wasn't responding well to the help'.* The school suggested one course of action and the local authority another. Despite wanting to follow the professional advice offered to them, they found it difficult to do so: '*We are very much*

parents who go along with the professional advice, so we feel that particularly in this area the professionals know better than we do […]'; yet after much involvement with the local authority the parents agreed to move their child to the new ABA led unit. In effect, there was little choice in their decision making.

Parental voice

Furthermore, when parents were asked how they had secured a place for their children at this unit, whether their focus was ABA or not. P4 said that: *'It's been a nightmare. I've only got where I am because I'll quite happily push and phone whatever else. […]'.* Information did not seem to be readily available for the parents of children outside the EY Special Needs Assessment Playgroup (SNAP). P4 added that: *'I was scouring the net and looking for how I could get help, how I could get information'.* This was a parent of an older child in Key Stage 2. The child had been a school refuser for almost two years. This parent went as far as contacting the Welsh Assembly Government (WAG) to express the difficulties she had with the local authority in sourcing and accessing appropriate provision for her child:

> I've done everything I can do – fighting and phoning, there's not much more I could have done, to get somewhere decent I ended up at one point I emailing the Welsh Government in Cardiff and having them send emails back and look at what was going on (P4)

The process of accessing support and interventions in SNAP was not always straight forward, as P5 indicated: *'[…] we just kept pushing for it, phone every week, that's how we did it', P5.* Yet when the parent needs were recognised within the SNAP multi-disciplinary team, the process was less isolating for the parent, and the individual case worker in the team navigated the appropriate provision with the parent: *'SNAP were brilliant they pushed for it […] SNAP were really good, once he started there, they really pushed*' P5*;* and*: 'It was all coming from the Speech & Language (not Health Visitor) as she didn't know*', P6. Some of these issues that parents were facing could have been attributed to the complexities of multi-disciplinary team working in this county. Interview responses showed that having a defined case worker within at least one of the teams was a more effective route to accessing provision that the parents were requesting. This was further corroborated by P4:

> I've only got where I am because […] because I'm so, like I'm in my forty's so I'll quite happily push and phone whatever else, it depends on who you have supporting you as well, who you have assigned to you […] (P4)

All the parents interviewed, whether they had experience of ABA or not had expressed their voice pro-actively about autism provision. P1 had sought a private diagnosis and attended conferences; Ps2 had actively engaged with their child's school and local authority at a senior level; P4 had campaigned at local level for provision and P6 at a national level; and P3, P5 and P7 had all contracted private ABA provision. From the data, the parents' motivation for choosing ABA was based on either their previous experience that ABA worked, or a belief from recommendations of other parents and non-professionals that it would work effectively in autism treatment. Campaigning for ABA and or better EY provision for autism was a clear theme underpinning the parent data. The next section will look in more detail at the school and local authority's motivations for providing ABA.

School and local authority motivations to provide ABA

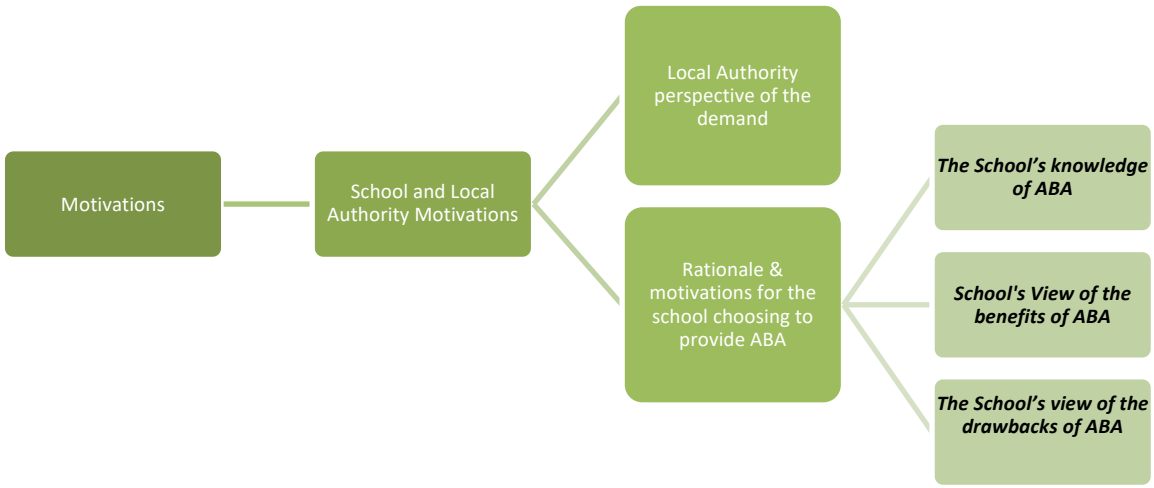

Fig. 5 School and local authority motivations

My study's evidence showed that providing ABA through a mainstream school was fundamentally the local authority's decision. It was a decision that came from both the local authority and the school responding to the demand for ABA from the parent group, and an inherited leadership decision from a previous head teacher. However, that decision was motivated by their high cost of funding of ABA externally and a reported fear of further litigation through tribunals. The local authority was funding a number of home-based programmes delivered by an external provider, and they were justifying future projections of the increasing costs of ABA. In Chapter 4, I will discuss these factors and the potential conflict of interest between the local authority and external ABA provider in more detail, as they comprise part of this project's central tension.

This section's data will present justifications for the introduction of an ABA led unit, namely: the rationalizing and restructuring of its mainstream SEN unit provision, and address firstly the legacy planning of a previous senior manager; secondly, how the providers met the parental requests for ABA and allay fears of future tribunals; and lastly, save on the cost of external ABA provision. I will explore the data from the perspective of the school then local authority as providers respectively.

A bold theme in the school and local authority data showed that they were responding to the parental demand for ABA at the same time as responding to planning legacy from a previous school manager (p.7). Three prominent participants – authority inclusion lead (LA1), the unit manager (S7) and the current head teacher (S6) were the main sources for my evidence on the strategic decision making. Responses from them suggested that senior school staff were aware of the county's rationale behind the unit's inception:

> […] there was a small budget for SEN in the bigger picture of things, and they probably looked at how much these children were getting for ABA outside of the classroom setting and how long does that continue for that child's school life (S7)

This quote referred to the annual cost of funding externally provided home-based ABA; and estimating the long term cost in a climate where the child would at some point enter the statutory education system. When the school head teacher was asked what the main impetus for setting up the unit was, S6 said confidently: '*If I was being cynical I would*

say, litigation initially! The demand from the parent group put: '[…] *the pressure on the local authority to be providing ABA, […]'* S6, and since the opening of the unit that pressure had diminished: *'[…] since we have been set up, the pressure on the local authority has receded massively' S6*. In further attempts to find out why the school chose to provide ABA, S6 was asked about the early planning for the unit. It was apparent that in part, the parent demand was being addressed; but it was also implied that there was a bigger change happening to the county's SEN infra-structure. There was a rationalization of SEN provision, specifically in their unit provision across the county:

> So the decision was taken to divide the existing […] unit (in the South of the county) into two, place one more centrally […] where there was a new school being built, and the [previous] Head there was really open to the idea, so that's how the decision came about (LA1)

ABA was perceived as the *'extra provision' LA1,* and providing it would boost the county's SEN criteria for a new school to be built. Furthermore, S6 indicated that the new-build was also a political decision. This *extra provision* was understood by the stakeholders to be ABA:

> This school was built by him [a local Senior County Councillor] from a political point of view, initially it was going to be built with a youth club at its centre, so to get a new school in [in the centre of the county], and politically we needed an extra provision (S6)

The context and timeline of the provision was presented in more detail in Chapter 2; but it is relevant to re-iterate here that amid wider strategic changes in the county, ABA was an incidental provision that when reviewed by the school and local authority held greater appeal than perceived to be first thought. Firstly, the appeal was that it addressed the growing problem of parental demand, and some potentially escalating costs for ABA: *'We were having, or sensing that there would be more requests coming through for home programmes for ABA unless we provided something in school'* LA1. Secondly, it seemed to feed the political need to create a new build, consolidate provision and add value to the existing provision as the *'something extra'* that S6 quoted, in addition to saving on costs.

For S6, there was the inheritance of previous planning for provision to assimilate: *'I think [previous head] had been given an Autistic Unit and I was left with asking, what do I do*

with this? This? This?' In addition to the infrastructure, the methodology of implementing ABA was also inherited by the current school management, as the following quote reflects*:*

> […] initially we really had pressure (by the local authority) that this would be an ABA provision here at the school. Local authority were telling parents that this was going to be an ABA provision. Parents were under the perception that they were going to get ABA. I think there are a number of parents who were expecting it in the way that they were used to getting it from [External Provider] (S6)

From these quotes it was evident that the school's current management had little influence in the decision making to adopt ABA as a provision, so the reasons why the school chose to provide ABA is more to do with implementing local authority provision planning, and addressing an inherited vision of ABA in a mainstream school:

> I think back to ABA which is the focus of why we had the unit in the first place, it was [the] previous Head's vision of it was for (External provider) to come in and be the lead on this; she was very taken with them, they were coming in like the Speech and Language model, working out the programmes (S6)

The data from both the local authority and school interviews showed that commissioning and implementing ABA through an external provider was not suitable. It was not clear from the evidence whether it was the adoption of a strongly held opinion from a previous senior manager that did not meet the local authority's current direction, or a more informed understanding of implementing ABA in a mainstream school. Allusions to both suggestions were evident though:

> […] it was [the] previous Head's vision of it was for (External Providers) to come in and be the lead on this; she was very taken with them' S6, and 'they [Local Authority inclusion planning team] were quite a way along the way to having [External Providers] to oversee it, but it didn't sit easily with our Head of Inclusion, so she asked me to look around to see if there were any other options (LA1)

Furthermore, LA1 suggested that the local authority were not '*at ease'* with commissioning external services at a substantial cost, because of the conflict between funding services for delivery in the school, whilst at the same time, funding those services for some of the same children in home-based programmes. This conflict of interest weighed heavily in favour of excluding the external provider, as attested to by the comment: '*did we? , almost, commission [The External Provider] to be really heavily involved? were we*

comfortable with that?, and in reality we weren't because it felt to us that it could be a conflict of interest.' LA1. The impression perceived by the unit manager suggested:

> […] to me it looked like [The External Providers] were going to come on board in the beginning and all that fell apart, and [school and local authority] tried to catch up with how things have progressed. Parents were then told they were going to have an ABA led unit. And that upset the apple cart a bit (S7)

Therefore, the justification for the local authority to develop an ABA led unit in the county was four-fold. Firstly the introduction of an ABA lead unit enabled the SEN provision to be rationalized and restructured throughout the county; and placing a unit in an area that was central to the county and more accessible to meet met the SEN need. Secondly, it carried forward the legacy-planning of a previous head teacher and county councillor. Thirdly, it was important to respond to the parental requests for ABA, and in some instances the tribunal outcomes for the local authority to be providing ABA in home-based programmes. This leads to the last justification, which was to save on the cost of external provision of ABA. The school staff and local authority were aware of the need for cost effective provision, as noted in (p.58) that programmes were costing approximately £20,000 each a year:

> I don't know the history but I think [The External Provider] were involved in the initial stages here, when they thought that if having this number of children now seeking ABA through [The External Provider] it was costing the authority a lot of money for this therapy, could we establish a unit where this could take place at a more cost efficient level? (S7)

It was not clear from the school data which were the more significant drivers of change. When all the justifications were considered together, the decision to provide ABA seemed logical to the local authority. S6, for example was in favour of the local authority decision, and offered that: '[…] *the model we decided upon there, was that it needed to be sustainable, how could we take this in-house and be supportive?'.* What was understood by this statement was that firstly; the initial idea of the local authority funding a private provider to deliver ABA in the school lacked a sense of continuity. I took this to mean that the school felt they had a better understanding of the educational continuity that children would need throughout their schooling than an external provider. It also exposed the school's perception of them sustaining the delivery of ABA once initiated.

Secondly, and importantly, out of an absence of knowledge and understanding of how ABA works, S6 openly offered the following, that: '[…] *bringing a Learning Resource Centre, (LRC - unit) into a brand new build is, has been, an inspired way of doing things, but at the start I was really nervous about it, that was my ignorance really, my naivety*'. This quote highlighted some concerns the providers had about their perceived understanding of a number of issues namely; the background knowledge required to plan for an ABA led unit and also, amid that knowledge base, the school's perceptions of the quality of the externally provided ABA therapy.

Moreover, S6 perceived that there were inadequacies that the school had to compensate for in using providers in this way, as evidenced in this quote, *'[…] because what the local authority were perceiving that [Home-based programs from External Provider] those programmes for the pre-school children were being delivered and delivered and were being repeated and repeated'*, S6. S6 was implying that there was little progress being seen in the home-based programmes: '*You would look at charts, showing progress and it amounted to being able to put toothpaste on a (brush) and clean teeth'.* S6 also offered that the '[External Providers were] *the font of all knowledge, saying you need to do this this and this, then disappear and it was left to the school to do it'*. This quote alludes to a perception that the school was losing some control over the ABA provision; but it could also be attributed to a lack of understanding of the way that ABA works in home-based programmes. S6 did not give a clear response of what 'progress' he was expecting, and which measures he was using to assess that progress.

On closer analysis of S6's concerns, the matter of the cost of the private arrangements for ABA, and the influence that the external provider assumedly had over the parents is significant. S6 said: '*I wasn't happy about the level of control that [the External Provider] had, and when you talk about people's values it always comes down to money? It was always about money'* S6. Concern was expressed that vulnerable parents were being taken advantage of by the external provider, but also that externally commissioned ABA services were costly. These cost factors could ultimately impact on the school's budget should ABA be provided by the school.

In exploring this cost element first, LA1 confirmed that some home-based ABA programmes were costing a considerable sum for the county. Parents who were not in

receipt of the authority funding were reportedly self-funding, in particular P5: '*[…] we ran out of funding, and couldn't afford to pay ourselves as quite expensive'* P5. Parents were fundraising and accessing some charity based funding streams (The Caudwell Trust) that were suggested by the external providers. P7 was a self-funding parent who offered that the primary drawback of ABA was the cost. Consequently, the school staff had both knowledge and an opinion on the way that parents were funding their external ABA provision. S7 attested to this: '[External providers] *were very good at, I understand, of finding funding for parents in the beginning and then parents would have to have some respite at home'* and added later in the interview:

> '[…] here were many people doing lots of fundraisers for [External Provider] on social media, and we're in a small place. Fundraisers belonged to other social media groups, and local and wider ASC groups' S7.

Local authority perspective of the demand for ABA

Foremost, LA1 said that parents wanted ABA brought into schools. The school staff perception of the increase in parental demand for ABA was believed to have been influenced by a local external provider. When asked what was driving this need, S7 said that children were receiving intensive ABA and improving (S7); so improvement was the perceived source of the demand for ABA. LA1 responded with: *'Now, whether that would be the same in another county that didn't have such a well-known provider, I don't know, I think they [the External Providers] were only responding to demand'.* These two quotes suggest that the true source of the demand remains elusive. It could be that the external providers were driving up the demand, or that they were responding to it. To paraphrase S7's earlier comment that children were receiving intensive ABA and were improving. Parents of children in EY settings continued to seek ABA solutions for their children's difficulties with challenging behaviour and poor communication skill. These factors affected their ability to attend school and ABA was effective; so naturally they would want it, and they found privately delivered ABA.

ABA in this way was a viable option for parents, as EY funding was available to them through the local authority. With the support of key-workers from the multi-disciplinary EY

team and the external providers, parents were further supported to access additional funding available through charities. S7 said that: '*You could have a grant for it (ABA), [External Providers] were very good at, I understand, of finding funding for parents in the beginning'*. However, once the child entered the school foundation phase, funding and ABA provision through the local authority was more difficult to finance, without going to tribunals. S5, offered an objective response: '[…] *because there are no schools in [the county] using ABA you can see why parents go to [external providers], because there isn't much available'*. This lack of local authority provision of ABA was presumed to have influenced the private demand for ABA.

The local authority's perspective was that it was the parent group who were driving the demand for ABA: '[…] *parents are saying they want the ABA focus',* and done with some persistence as noted in the comment: '[…] *if you listened to some people it would be ABA to the exclusion of all else', LA1.* Therefore, the decision to support and open a new unit in the county with an ABA lead was twofold: firstly, as a result of perceived need and demand from parents as evidenced on page 80, by this quote: '[…] *because parents are using it, and they wanted that brought into schools';* and secondly, the result of the cost implications of providing ABA for children in home-based programs. I evidenced this by LA1's earlier quote suggesting that the cost of individually commissioned ABA could be replaced by a unit that could deliver ABA to more children. The motivation would therefore appear to have arrived from the parents initially, and then from the financial implications of that parental demand, not from an evidence based decision of effectiveness or comparative analysis with other ASD treatments.

In expanding further on the parental demand from the local authority perspective, the data did not specify how many tribunals that the authority had been involved in as a direct result of the demand for ABA. In the unit, there were 24 children, and approximately six of those wanting ABA as part of their SEN statement, and LA1 was open about the fact that the school had promised ABA, but not yet delivered on that promise at the time of data collection. The reasons for that delay and other barriers to the implementation of ABA programmes will be explored in Chapter 4, but there was clarity from LA1, that if ABA was not available the parents would take the authority to a tribunal: *'Five or six sets of parents in that LRC, we're holding them because the children are showing progress, but unless we*

honour what we've said we are going to do we will have six tribunals' LA1. This attests to the strength that the parent group had.

Two relevant opinions emerged from this statement which suggest to me some valuable insight; namely the meaning of *'holding them'* and also the phrase '*showing progress' LA1*. The former suggests that those parents seeking a stable school placement for their children had had their needs met, and were somewhat satisfied. However, the phrase '*showing progress'* needs to be expanded upon further. Progress without baseline evidence is difficult to define, and in this instance, I did not get a clear enough response to evidence what stakeholders considered as progress. Whether progress was perceived by parents, school and local authority that the child attends school regularly, or the children's functional skills, behaviour or academic progress is improving is unsubstantiated in my data. Progress currently relies on the subjectivity of the teacher to assess whether targets have been set, and met accordingly. This will be discussed in the context of barriers to implementing ABA in Chapter 4. It is useful to me to assume that the terms *'holding'* the parents, and '*showing progress'* are terms reflective of the uncertainty that the local authority sense about the situation in the school unit when faced with the parental demands for ABA.

With regard to the second rationale point for ABA that the local authority offered; namely the financial implications placed on the authority: it was given that on average the authority had been funding the provision of ABA by an external provider for approximately four years. With six to eight (approximate numbers cited by LA1) children in receipt of this therapy before the start of the school ABA planning stages, the obvious suggestion was to provide ABA in-house in the school, reiterating what LA1 said: '[…] *funding those (*six to eight children*), then you have got a unit'.* S7 corroborated this plan, which in conjunction with the local authority's future provision planning for children with autism is motivation enough to support the decision to open a new unit:

> […] having this number of children now seeking ABA through [External Providers] it was costing the authority a lot of money for this therapy; could we establish a unit where this could take place at a more cost efficient level? (S7).

As these numbers were indicative of the initial planning decisions responding to parental demand, there were: '[…] *about 4 pre-schoolers at that time, and about another 2,*

2 ½ year olds [that] we were investing very heavily in [the external provider]', LA1. The local authority was, at the time of data collection in the process of planning for such provision, as they were aware of at least six children who would be requiring ABA therapy in the near future. This was based on data supplied to them from the multi-disciplinary SNAP team: '[…] *so there were going to be at least another four coming through and asking for home programs for ABA unless we provided something in school' LA1.* In addition to the approximate cost per child, per year, there were also additional financial reasons associated with children identifying with SEN that the authority took into consideration when opening a specific ABA led unit in a mainstream school. Funds spent on providing home-based ABA programs for EY children could be re-directed into a unit where ABA could be delivered, but also other SEN interventions could be delivered. This could have an impact on the county's accountability of inclusion for children with SEN. When asked how much the ABA strategy is part of the bigger SEN inclusion plan for the county, LA1 responded with: '*It's key to it!*'

Despite that the new unit had opened, there was no clear provider for the ABA-based interventions that the local authority wanted to commission. It was evident from LA1's responses that the local authority had limited expertise and had carried out little research on what ABA is and how it works, notwithstanding how it could be implemented in a mainstream setting. I will discuss this more in the Chapter 4, but it is noteworthy here, that within what appeared to be a dearth of local authority and school knowledge of ABA, LA1 was aware that the knowledge deficits showed across all the stakeholder groups, and said of parents: *'Sometimes parents think there is a "cure", an example [Child X] where a parent wants the child in mainstream for 80% of the time'.* The rationale for why the school chose to deliver ABA is a consequence of the local authority's decision to fund a unit to deliver ABA. So, in effect, it was not so much of a choice for the school, but a directive to implement. Subsequently, the local authority with the head teacher, engaged staff to set up the unit. The following sub-theme will analyse the school's experiences following this decision to set up an ABA unit in a mainstream school.

Rationale and motivations for the school choosing to provide ABA

Fig 6. Rationale and motivations for the school to choose ABA

In this last sub-theme of this chapter, I want to discuss the rationale and motivations the school in particular had about providing ABA. This is in the knowledge that they had little say in the decision making, as the previous section outlined the legacy planning, parent demand and costs elements that were underpinning motivators for the local authority decision making. However, the head teacher was in favour of the decision to re-structure the SEN provision across the county and designate this school an ABA lead. The evidence I gathered in the interviews with school and local authority stakeholders aimed to assess the underlying knowledge levels these providers had of ABA, its benefits and drawbacks and also what they perceived as the difficulties preventing the project from progressing. The latter will be explored in Chapter 4, but this next sub-theme will analyse the school's knowledge base of ABA and their perceptions of its benefits and drawbacks.

The school staff's knowledge of ABA

At the time of data collection none of the unit LSA staff, teachers and managers in the school had any formal training on ABA. They had taken part in one introductory session given by a Board Certified Behaviour Analyst (BCBA)® and were waiting to start a Registered Behaviour Technician (RBT®) course on-line. One of the LSA's in the KS2 class had previously worked as an RBT® before taking up her post at the school. All of the other staff interviewed were new to ABA and were enthusiastic to begin their training.

The staff were asked about their understanding and knowledge of ABA, along with their perceptions of what they thought the remainder of the school staff, local authority and the parents understood of ABA. S4 said that ABA was: '[…] *behaviour intervention programmes, [and] 1:1 teaching*'. S1 said, that she thought ABA changed behaviours by applying the correct techniques: '[…] *applying the correct techniques to get a behaviour from a child' S1.* However, some were aware of the role of collecting data and evidence on behaviours, and changes in behaviours. For example, S5's perception was that through the use of: '[…] *data to analyze behaviour and use support programmes to support learning behaviour*', improvements to behaviour would be seen.

This aspect of the application of ABA being evidence based through data collection was reported by S2 as: *'[…] behaviour analysis that is led from data gathered by observation and ways of handling behaviour positively*'. S3 and S7 reported that it was knowing the: '[…] *reasons behind our actions*'. From these quotes the staff I interviewed seemed to understand the application of ABA, and were very positive about it. It is: '*A programme we have to follow set by professionals designed for each pupil*', S3, and also: '*LRC staff would know, pupil centred programmes written by a [Board Certified Behaviour Analyst] BCBA and followed by staff trained to RBT leve*l', S7. Whilst they felt they had a good understanding of ABA, their opinions on other staff in the school was that: '[…] *the school as a whole, would not know what ABA meant*', S4. S1 and S2 felt that it was perceived as: '[…] *a programme to help schools and support with what to do when dealing with behaviour. Some of the staff know what it is, and know how to handle the behaviours',* S2. Furthermore, it was for: '[…] *helping children to behave, supporting them with the correct planned techniques*', S1. However, S5 said that whilst: '[…] *some of the (unit) staff members would know what*

it is and understand strategies and techniques to use', she felt that the implementation of ABA would not be understood on a wider scale across the school.

These participants did criticise the local authority's perceived knowledge levels of ABA, with responses such as: '*I don't think the Local Authority people are educated enough in what this is*' S1. S5 offered that the local authority misunderstood the level of knowledge and understanding of ABA that was required to implement it well: '*Local Authority, similar understanding to school, although they may not understand how to put it into practice*'. S2 and S4 said: '*I don't think they know enough or much about ABA. But they must know about it as the LRC was to be an ABA led unit'* and: '*They should know, as they have set up the unit for ABA therapy*' respectively. S3 was less gracious in her response: '*Not much, parents make a fuss, hire private companies then the authority tag along'*. This last quote implied that the local authority was being reactive in its planning and practice, and responding more to parent demands rather than evidence of needs.

When it came to asking about what they perceived the parents' knowledge and understanding of ABA to be, the staff suggested that the parents' view of ABA was similar to that of the local authority. It ranged in responses from parents perceiving that ABA is a panacea to cure all their children's difficulties, to simply an additional intervention that happens in the school day. S4, said: '*They think it will be the answer to all their problems*' and S3, '*1:1 activities done in class, OT assessments, [and] priority to their children*'. However, S5 saw it that: '[…] *sometimes it seems that they think it's a structured set of rules just to change negative behaviours rather than looking at all behaviours and positive behaviours'.* Moreover, S1 and S2 said: '[…] h*elping their child behave in the best way they can. I don't think many parents would either know what it is, and understand strategies and techniques to use it',* and further, that it was: '*Ways [that] behaviour is dealt with and how schools record. Helping their child with behaviour. I don't think many parents would know what it was, not many*' S2. I include these responses to highlight that the unit staff perceived their own level of knowledge and experience of ABA to be greater than that of the parents and local authority as shown by S6's quote which suggested that the unit staff team had a deeper understanding of ABA and its delivery than the other stakeholders: '*What's really good, is we don't have to do the spade work around having this ABA in'* S6.

School staff's view of the benefits of ABA

All the unit staff interviewed were open about their opinions of ABA, and shared mixed opinions with me on what they perceived were the benefits of ABA. As noted earlier, their experience of ABA was varied. One LSA had first-hand working knowledge of delivering ABA programmes, and had evidenced the benefits. Others offered that they had none, and there were a small number who had only seen ABA being delivered in one isolated case in the school, by an external provider. S7 viewed this practice as: *'[…] isolating, works with [the] LSA like a robot'*. S3 was honest when suggesting that she was: '*Not sure, as haven't seen the benefits yet. My opinion isn't high, as only witnessed a private company doing it*'. The responses were varied and appeared to be based on what they had learnt about ABA from their one session of training, for example: S2 said: '*Gives you a good amount of support and tells you roughly how to provide positive support for children. Positive behaviour is reinforced, and assists in learning and skills'*. There was the general perception by the unit staff that ABA produced positive results and positive behaviour outcomes. I assumed this was natural as they were commenting from a position where their knowledge and experience was theoretical, and they were not fully invested in delivering the programmes. Further probing questions to the staff on their understanding of why it was an intervention of choice, revealed that it appeared to be founded on their perception that it was parental pressure on the local authority to provide it. S3's earlier comment (p.109) attests that the parents led the local authority.

The school managers suggested that the benefits of ABA would be valuable for evidencing progress pupil progress, and that ABA was, as they saw it: '*Pupil centred, good for showing progress'* S7. It was not clear from analysing the interview data whether progress was perceived by school managers as improved behaviour, social skills, functional skills, academic or a combination of all of these factors. What I did gather from my data was the perception that the benefits of ABA would enable more children to be included in school; that the benefits would enable: '[…] *profoundly (autistic) children, who benefit from ABA, they are the non-verbal pupils, lower down the school',* to have access to the unit and be included; and for those that were: '[…] *successfully having ABA at home,* [it was] *successful in allowing them to function, in home life, being able to eat, cleaning teeth, etc*.' S6. In addition to this, S5 was aware of the potential of ABA as a tool for progressing

academic learning beyond that of functional skills and especially: *'[…] for behaviour, not just bad behaviour, but the behaviour of learning and managing themselves sort of behaviour?*' S5. The issue of how progression in academic skills using ABA could be evidenced was not seen in my data. The school had not had any experience or evidence of ABA supporting academic progress at the time of data collection, but there was an expectation that it would enable more unit children to access mainstream: '*We now have that success, we have children going in MS* ' S6; and *'The emphasis is, where possible to transition the KS2 children, those that can and are able will transition to MS. Initially they will go across with support*' S6. There was evidence that the unit managers were anticipating both the child's progress of transition to mainstream, and having to manage the parental expectations that came with that possibility. This was apparent when S6 spoke about one prospective child to the unit whose parents were insistent on his inclusion to mainstream classes, for example:

> But the plan here is that we would put him in the LRC in the main, and he would go out to mainstream when ready, and build that up progressively over time. Rather than put him in mainstream and end up having to take him because parents want him in MS 50% of the time (S6).

The perceived benefits S6 quoted were based on the functional skills that supported children to attend school. There was some scepticism over the ABA therapy that was delivered by the external provider that impacted on children's ability when in school, as S6 said that programmes were being 'repeated and repeated'. I took this to mean that progress was not being made. S6 also had: '[…] *grave concerns about private arrangements', S6.* Taken positively, this suggests that the school perceived they had the necessary levels of continuity, accountability and safeguarding required to provide services for vulnerable children and their families, whilst taking responsibility for their academic progress. In addition to this, the context underlying the interviews was one where the providers would have to, at some point in the child's education, take responsibility for the educational continuity and safeguarding of that child with SEN.

The School staff's view of the drawbacks of ABA

In general, the unit staff perceived the drawbacks of ABA in terms of the difficulties that would be experienced in implementing ABA in the mainstream setting, particularly, S1, S2, S3, S4 and S5. However, their responses may have been due a lack of experience with ABA; but as the teaching and support staff had had little to no training that was to be expected. S1 saw no difficulties initially: '*No[ne]. Difficult to sometimes implement in a class setting'*. S1 perceived ABA programs would be delivered to the whole class, which is understandable considering the paucity of training in ABA. Along the same vein, S2 and S4 also added that it would be: '[…] *hard to put some things into reality. Sometimes it's hard in class, lack of staff to implement ABA as class sizes are too big'*, followed by S4: '*Would be difficult to put it into practice with so many children'*.

Responses such as these confirm a lack of understanding of how the school intended to implement their ABA programmes. They also indicated that their perceptions were based on current ABA practice they saw in the school, and also what they understood of home-based ABA programmes. The only example of ABA being delivered in the school setting was where one pupil was taught in isolation from peers by a Registered Behaviour Therapist (RBT®). This gave a very narrow view of ABA and its application, as reflected in the following quotes. S3 commented that it is: '[…] *all 1:1 work, lose the chance to work and play with others, the child in my mind becomes or is seemingly spoilt'.* S7, on the other hand saw the drawbacks in terms of social exclusion: *'It is in isolation, social inclusion very limited […] doesn't mix with other children'* S7. This kind of perspective suggests a couple of opinions on how the unit staff saw the drawbacks of ABA. Firstly, that ABA is a useful tool for improving children's functional skills so they can access a school setting and *'mix with other children'.* The second consideration was that of implementing ABA in reality, and raises the question that if it works this well for inclusion and presumably academic improvement, what might the implications for the whole unit be. This data may therefore constitute drawbacks in the school's view. Therefore, the opposing paradigms of ABA being delivered in a mainstream academic setting versus ABA for functional skills in a home-setting might be creating a misrepresentation of the nature and value of ABA here. The implication is that the staff to pupil ratio for delivering ABA had not been thought through, as the numbers in the unit eligible for ABA were high. The impact of the increasing numbers of children in the unit

as a barrier to implementing ABA is addressed more fully in Chapter 4. However, what does constitute a drawback as far as S6 sees it, is that parents may view ABA as a cure for autism, and a route to full inclusion into mainstream education as suggested by the quote: '*You have to be wary about anything that has the word 'cure' to it*'. This was in response to advertising that parents had been viewing on-line that was promoted by private ABA provision.

While some parents had taken their requests for ABA for their children to legal tribunals and won, meant that the local authority had to provide ABA, and they had chosen to do that through a mainstream ABA led unit. However, tribunal outcomes had not, addressed the speed with which it would be delivered in the school. For example: '*Parents have been to court and now ABA is stipulated in his statement, if he comes here we HAVE to be delivering ABA programmes'*, S6. This delay in implementing ABA in the school was seen as a drawback by unit staff and parents alike. It seemed to be a drawback resulting from the authority and the school's planning and delivery of ABA, not a criticism of the practice of ABA, but more so the local authority's lead on the school's planning. Again, these issues will be covered in greater detail in the Chapter 4.

In summarizing this chapter on the stakeholder motivations for choosing ABA it emerged through the key themes that there was a lack of fundamental knowledge and understanding of ABA by the stakeholders interviewed. The parents were requesting ABA home-based programmes from the local authority, at a substantial cost for private ABA provision. In cases where funding was not granted or available to them, parents were resorting to taking the local authority to tribunal courts to have privately sourced ABA funded by the authority. The funding of externally sourced ABA was in part a motivator for the local authority to make ABA available through a specialist autism unit in a mainstream school. In parallel to the funding of externally provided therapy, the county was restructuring its SEN unit provision and rationalizing and specifying those units that were autism based. As a result of these changes, and in conjunction with a strong opinion and early plans initiated by a previous head teacher, the local authority responded to the parent demands for ABA by providing ABA through a mainstream setting. Initially the ABA provision was to be delivered by the external providers who would be commissioned to plan and

oversee ABA programmes. However, for a conflict of interest reason the authority chose to deliver and manage the provision themselves.

Parents with previous experience of ABA were requesting ABA therapy on the basis that they were seeing positive changes in their children's behaviour and functional skills. Others with no experience of ABA were following the recommendations of other parents; and for some it was coincidental that the unit would be providing ABA, as their prime concern was finding a suitable school placement. What was seen in my data was that all the parents interviewed reported that they experienced difficulties and challenges in accessing provision, whether ABA led or not.

The school itself was responding to the local authority mandate and at the same time managing non-ABA autism provision through a unit soon to be an ABA lead unit. In some ways the rationale of why the school wanted to deliver ABA was more to do with accommodating a previous planning strategy and addressing an inherited vision of ABA in a mainstream school. At the time of data collection, the school was waiting for training in ABA. There was no BCBA® in place to devise, manage and supervise staff delivering any ABA programmes. There was only one example of ABA being delivered in the school; where one child was receiving local authority funding for external provision that was delivered by an authority funded support teacher. This support teacher was also a qualified and experienced RBT®. The child was instructed separately to his peers at all times, and did not participate in any mainstream nor unit provision. His programmes were devised and managed by the external provider, and paid for by the local authority.

It was evident from my data that the unit staff was not as knowledgeable about ABA as first thought, and they showed many misunderstandings; including the distinction between ABA as a behaviour science and ABA as an application within EIBI. Parents expressed that they faced many difficulties and challenges in accessing provision for their children, not least securing ABA interventions. There also seemed to be little support for them to navigate through the education system. Some support for the difficulties they experienced was available through EY multi-disciplinary team providers. Nevertheless, they were researching ABA and other ASD provisions, and acting on that research themselves. They were challenging schools, the local authority and related professionals to source what they felt were the best options for their children. Despite being perceived by the school

and local authority as vulnerable, there was strength evidenced in this data, particularly in the way that they got results, and sourced ABA, or the funding to source it. However, despite strength and their independent research evidence, they were mostly influenced in their provision choices by other parents and the internet.

Furthermore, in addressing the question of where the demand for ABA came from; S6 and S7 perceive this to have come from the external provider themselves, and their influence on parents. '*I worry about that they [parents] are asked to pay an awful lot of money, for things that we can do here, very, very, quickly' S6. S*7's perception was also that parents were offered something by the external provider that was helping with their child's difficulties:

> […] and then parents would have to have some respite at home, so they were helping, and with things like toileting, dressing, washing. And they were having support for that which they were not having before (S7)

Parents were openly reporting that they were conducting their own research into autism therapies and accessing the local external provider. Other than P7, suggesting that ABA became a *'crutch',* and reinforcing the cost of ABA, which was corroborated by all three of the parents who had previously accessed ABA, there was no indication from them that their demand was being influenced by anything other than their own drive for ABA provision.

Chapter 4: Central tensions and barriers to implementing ABA in a mainstream school

Introduction

Once the decision to provide ABA in the mainstream school was made by the providers, there appeared to be a range of barriers to its implementation that had not been foreseen or planned. This chapter explores some of those tensions and challenges providers and parents perceived they experienced in organizing and delivering ABA-based interventions in a mainstream school unit. Successfully implementing ABA into a mainstream school unit or classroom is evidenced in other, recent studies (Grindle, 2012; Pitts et al, 2019). Researchers have reported success as improved gains in behaviours and functional skills and in the Lambert-Lee (2015) and Pitts et al's (2019) studies, improved academic gains in the key stages. Evidence of successful implementation of ABA is widely available, but at the heart of the tension perceived in my study is the delay in implementing ABA in the unit, and the delay came from an incongruence between the providers' intentions to deliver ABA and the barriers they perceived to implementation. The main barriers that were explored in my study were reported as difficulties in staffing the unit to deliver effective ABA–based interventions; funding and cost implications of setting up and staffing the unit; and also the tensions perceived among the stakeholders. These tensions existed between the parent group and the local authority; between the school and the local authority, and also between parents and the school. Further to these tensions, this chapter will also explore the perceived tensions between the stakeholder groups and the external providers.

The tension was explored in terms of its cause, which was perceived to stem from the providers' promise to deliver ABA, and the challenges they experienced in implementing it in the school. This resulted in the delay – the central tension, which arose from the intention to provide ABA and the barriers experienced to its delivery. The providers said that they lacked the understanding needed to deliver ABA in a mainstream school unit (S6, p.101).

The causes of the tension will be explored firstly, in terms of the provider's 'promise' to deliver ABA; the current situation in the unit at the time of data collection and also their plans for the future. Secondly, evidence from the stakeholders about the delay that created

tension between the intention to provide ABA and the barriers experienced to delivering it will be analysed. This will expand on the issues related to BCBA® recruitment and staff training; the cost implications of the project; and a perceived conflict of interest between stakeholders and the external ABA providers. The last section of this chapter will conclude and offer some evidence on the impacts of the tensions on the pupil group and the school unit staff.

In terms of the promise made to create a new ABA provision in the county the complexity of the undertaking was reported to be underestimated by both the school and local authority, which will be analysed further. The provision and the service offered by an existing unit was changed and developed into an ABA led autism unit within a mainstream school. In addition to changes to the unit's core function, the development took place in the new purposefully built school to accommodate the specialised ABA unit. In hindsight, and as S6 reported, some of those processes were undertaken without a full and thorough understanding of the issues and implications that the stakeholders would face. Before I focus on the central tensions that emerged from the data, I have included a section in this introduction that outlines the providers' interpretation of their expectations around implementing ABA in the unit.

Provider Interpretation of ABA and its implementation in the school

During the interviews all the stakeholders were asked about their perceptions of ABA, and how they thought ABA would be implemented in the unit. The local authority and the school said they felt they understood how to implement ABA in a mainstream school, but there was a contradiction in the data as S6 attested to by saying that: '*We may have got to this point quicker […]. Rather than stumbling across things and getting things to work*' S6. S7 concurred and perceived that the cause of the delay in implementing ABA had:

> […] been one hiccup after another, and if there had been a little bit of background research and how much training and support as a unit we would have needed, I don't think it was expected (S7)

From these quotes, I understood it that the school unit staff were overestimating their knowledge of how to organise its delivery within a mainstream unit curriculum. This is reflected by the local authority's willingness and support to deliver ABA in a mainstream unit, despite not being fully aware of the complexity of the process they were undertaking. It was not possible to ascertain from the interviews why this was the case; there was no reason given why the school and local authority had not researched and costed the undertaking more thoroughly, even after much probing. It appeared that they just simply had not. The providers, in particular the local authority was responding to the demands of the parents and the outcomes of tribunal hearings to fund ABA provision. As a cost effective measure, as I noted in Chapter 3 that providing ABA through a mainstream school was the most expedient way of doing this.

In exploring the unit staff and the local authority participants' thoughts on ABA provision further, they were trying to adopt a practice they perceived was based on evidence of what works. Their decision to provide ABA was based on ABA as part of EIBI being more effective when implemented earlier in the child's development, as S6 responded: '*So, the earlier you do the ABA the more effect you have*', S6, and also: *'Then the vision is, and always has been that we use ABA with the really young children coming first at the start', S6.* What the data from the providers also gave was an understanding that transition to mainstream school could be a possibility for some of the children in the unit. S6 commented on ABA in EY that: *'[…] if it's really focused on ABA, with the right children of the right age, then it will move them on quickly'* S6, and:

> […] really that's something that health can be a driver on, because by the time they get to us at 3 1/2yrs - 4 yrs old those children that would actually benefit from ABA are actually in a nursery somewhere (S6)

One of the unit's greatest benefits was perceived as inclusion by the providers; particularly transition from the unit into mainstream school. Because the unit was an integral part of the mainstream school it enabled children to access classes where their ability and behaviour permitted: *'[the school] is mainstream, and there are benefits here that this is a mainstream and there are greater opportunities for inclusion!'* S6.

When the local authority was asked about implementing ABA, the inclusion manager (LA1) openly offered that the process of finding a behaviour analyst was a '*difficult challenge'*. The local authority was taking advice from researchers in Bangor University on how to deliver ABA and advising the school: *'[…] on speaking to [a BCBA®] about [ABA in another school], they were having about 15 minutes of ABA in bursts, not 8 hours of it' LA1.* However, how ABA would be delivered on a day-to-day basis seemed clearer to the school managers than the remaining unit staff. '*[The] plan is that ABA programmes will be in the morning, RBTs will come in and their work will be set up in their stations and delivered by the LSA/RBT',* S7, in a designated 'therapy' room in the unit, set apart from the main classroom. How the school would decide which children received ABA, would come from statements and internal school individual education plans (IEPs), S6 said:

> We will go to ABA programmes for the children who are assessed of needing it, they will have their ABA, and then be part of the class, rather than the ABA is the 'golden elixir' that [the ABA] they get is part of the school day and curriculum, S6.

Yet, despite the providers' intentions, and perception of how to implement ABA, the barriers to implementing it in the unit remained varied. The next sections of this chapter analyse and discuss the themes and sub-themes relating to the barriers to implementation in more detail.

Exploring the central tensions necessitated taking the historical narrative the stakeholders were reporting into account. This was presented in the timeline in chapter 2, which outlined how the legacy planning from a previous head teacher, parental demands and tribunal actions were pressing issues to which the local authority was reacting. The decision to start up an ABA led unit in a mainstream school resolved some of these tensions but created others, as background research seemed to be deficient on implementing ABA (S6 and S7, p.101). However, other responses the providers gave showed me that some perspectives were evidence based, for example, LA1 said that: '*my ideal is that we have a heavier bias (for ABA) in the Foundation Phase […], when you broke it down, the vast majority of places were at Foundation Phase'*. This response suggests that evidence of the

earlier that behaviour interventions are started the better the outcomes (Lovaas, 1987; Eldevik et al., 2006; Howlin et al., 2009) is leading SEN planning, and that more focused evidence based decisions were being made with regard to EY planning for autism provision in this county

To re-cap on the data from Chapter 3, parents were seeking funding from the local authority, privately or charity funded sources to pay for local external providers to work with their children. This made the ABA accessible for them and therefore an option of choice. However, once the child entered the foundation phase in school, funding any subsequent ABA by the local authority was more difficult to access, without going to tribunals. Parents of children in EY settings were actively seeking solutions to their children's challenging behaviour and poor communication skills, and finding external providers of ABA to deliver it. In exploring the context of the tension, stakeholders were asked what they thought was driving the need and subsequent demand for ABA. S7 believed that it was the influence of external providers: '*the therapists here going into the homes and working with the children in a therapy room […] so those children were getting intensive therapy and making progress, parents were getting respite and behaviours were improving' S7*.

The funding of ABA became a source of tension between parents and the authority when the EY, three-year funding source became restricted once the child was of school age. This was evidenced by both S6 and P6 respectively, who said that:

> […] because they are not statutory school age the authority wouldn't do anything, until they are in that transitional phase, and once they are school age then it's up to the local authority (S6)

To re-iterate P6's quote in Chapter 3: '*Playgroup were saying his funding was running out, Education were saying there is no space for him to go anywhere, local authority couldn't say where he was going' P6;* epitomises the complex nature of the tensions all the stakeholders felt they were experiencing. However, supporting the evidence of the parents' rationale to source ABA and funding for it, S5 said that: '*because there are no schools in [the county] using ABA you can see why parents go to [external providers], because there isn't*

much available'. Nevertheless, the funding of external provision of ABA was a source of much tension for the local authority and the school. The central tensions as main themes and sub-themes in this chapter are organised according to the following tree-diagram and each will be explored more rigorously.

The Central Tension

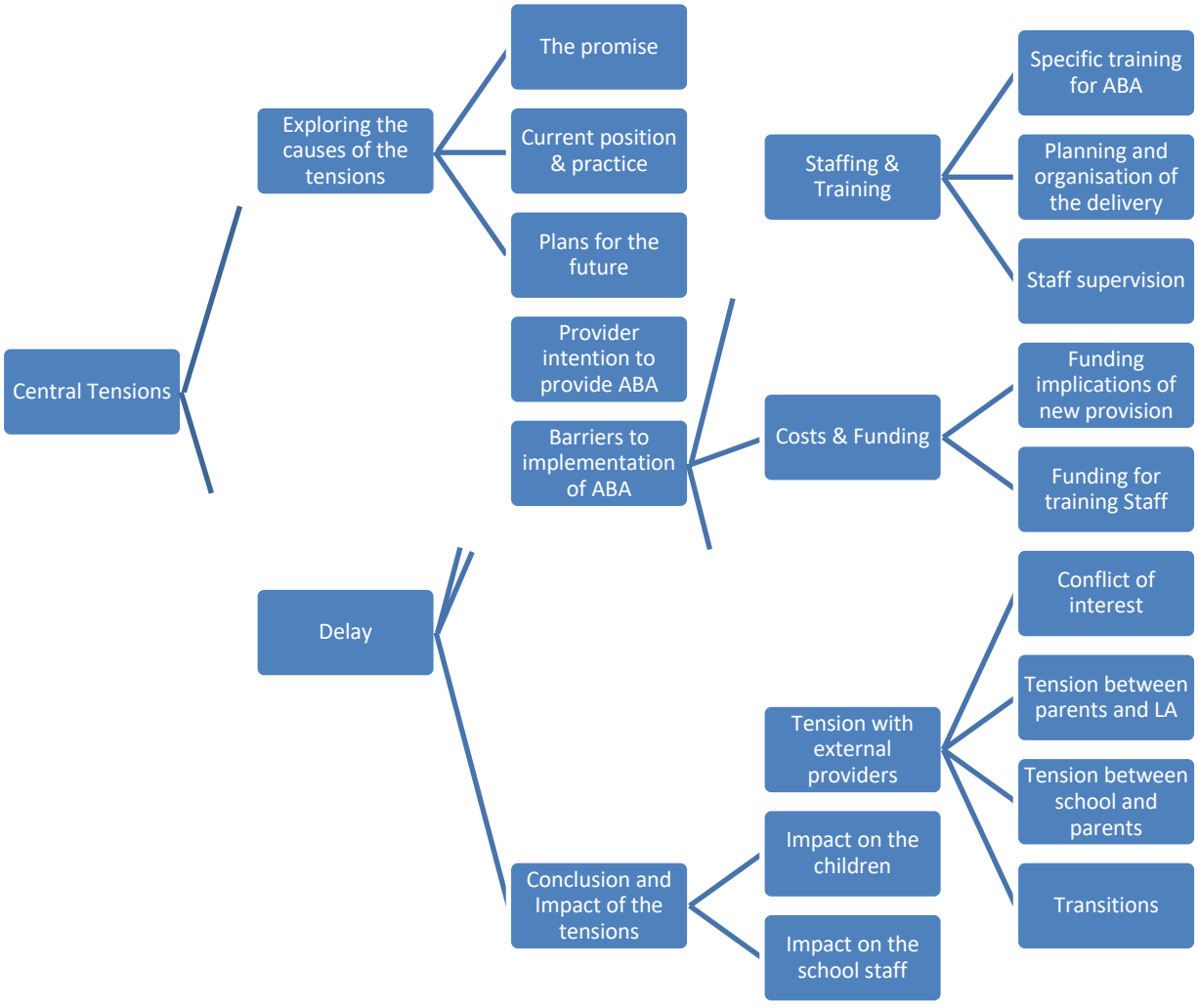

Fig 7: Themes and Sub-themes: Central Tensions

This first sub-theme explores the causes of the tension, which are believed to stem from the gap between the providers' intentions to set up the ABA led, the current practice and also their hopes for the future of ABA in that unit. The second sub-theme expands on the causes of the delay in delivery of the ABA provision, namely, the intention to provide ABA and the practicalities and barriers that were faced by the authority and school in implementing ABA. Three further sub-themes emerged from this: the staffing and training issues in the unit to manage and deliver ABA; the costs and funding implications of the provision and the perceived tension with the external private providers. The conclusion reviews the perceived impacts of these tensions on the stakeholder groups. The next sub-theme is in three sections, and the intention of placing it here is to offer some background and context in addition to that presented in the project's timeline in chapter 2, before analysing the causes of the tension and the barriers to implementing ABA in the unit more rigorously.

Exploring the causes of the tensions

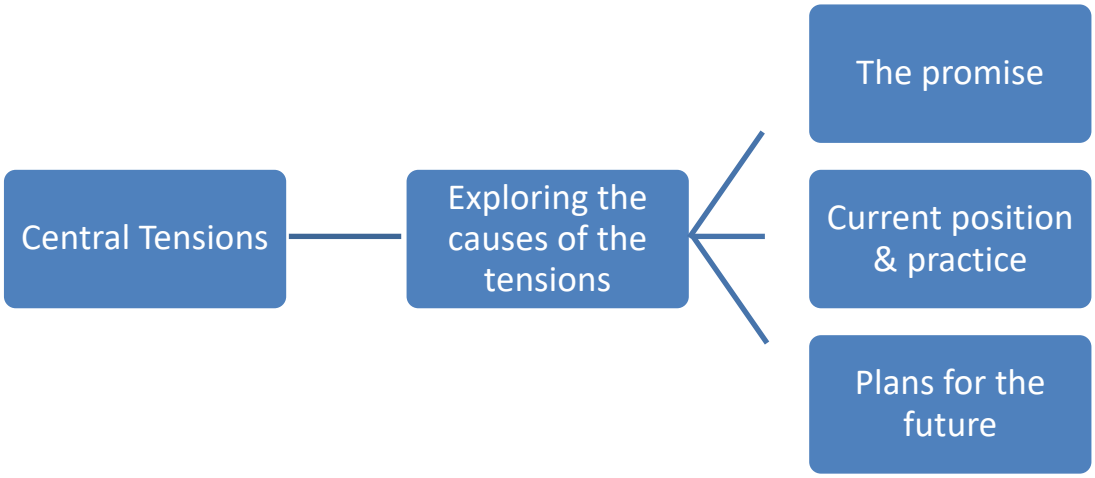

Fig 8: Themes and Sub-themes: Central Tensions - Exploring the causes

The promise

Originally, a promise was made by the local authority and subsequently the school to implement ABA in the unit. Historically this promise arose from a parent demand for ABA, at the same time as the local authority's expectation that a designated ABA unit consisting of two classrooms would be more cost effective than funding a number of home-based programmes through an external private provider. Based on future projections of need and the expectations of further requests for funding for ABA home-programmes, the decision to develop ABA as a provision in a mainstream school was taken. The local authority said it was unlikely to fund another ASD focused unit such as this in the county: '*The thing is there is no more money, so if we were going to have another unit we would have to divert money from somewhere else!' LA1.*

Parents sought ABA through the school unit, even though it was not available at the time of their children's enrolment, but because of the delay in implementing ABA in the unit, children who were difficult to place elsewhere were being accommodated here as a general autism facility. This created a tension that was felt by the school staff as it took the focus away from the unit's core as an ABA led unit.

The current position & practice in the unit

This section of the sub-theme expands on some of the difficulties the school and local authority were experiencing that contributed to that gap between the promise and the delivery of ABA. From the perspective of the school staff, the sources of the tension were numerous, all of which culminated in the delay implementing ABA. The delay was considered the main source of most of the tension. Foremost and crucial to the successful implementation of ABA was the requirement of a BCBA®. There was no BCBA® in place at the time of data collection, and staff were waiting for ABA RBT® training. The local authority and school were duly concerned but seemed unable to actively address the speed with which ABA was being implemented in the school.

A second important tension was the number of pupils in the unit. Pupil numbers increased from an initial cap of six pupils per Key stage classroom, to 24 across both Key

stages in four terms. The unit was supporting 24 children, 12 in LRC1 (KS1 Foundation Phase) and 12 in LRC2 (KS 2). There was a class teacher in place for each LRC, and four LSA's in each class: '*Staffing is based on the number of children in the unit. i.e. 24 children equals two teachers and 4 LSAs',* S7.

Whilst 24 children were attending the unit, eight were identified as requiring ABA. From the unit's current position, the plan was to stabilise the increase in pupil numbers by placing a cap on any further outside referrals; focus ABA provision in the foundation phase, and only once those pupils started to progress through to KS2 permit new starters into KS1:

> '[…] we are going to have three leavers in July (2019), and we need to press for **only** little ones coming in'. LA1;

This plan was perceived as a two to four year strategy. LA1 saw it: '*that KS2 LRC2, will have three leavers in 2019, and by 2020 six leavers. A two-year plan'.* In support of their decisions, the local authority wanted to have evidence to support the unit's overall progress outcomes, particularly where ABA is concerned. Even in the absence of ABA programmes in the school at the time of data collection, LA1 expected ABA to be successfully implemented: '[…] *we need to show that it is working, there will be an evidence base, not just the local authority saying it hasn't worked*' *LA1.*

A subsequent source of tension was securing a second unit teacher. There was a class teacher for each Key stage in the unit. Some disruption to the appointment of the Key stage 2 class teacher created tensions within the staff team and the parent group. A supply teacher was in post for two terms while a new appointment was made. Subsequently, after a short time, the newly appointed teacher took leave, and the supply teacher was reinstated.

The unit manager said of these disruptions in KS2 as: '*Been many changes in KS2 over the last year and due to change again – as class teacher now off*', S7. These changes were unsettling for both the pupils and the parent group as S4 and P1 attest:

> Parents generally not happy with a change to what they think was working and parents have been unsettled' S4 said: I was brought in (on supply) for two terms (Sept 2017 onwards) and I was kept on after the teacher change […] beginning of Easter Term and children were unsettled (S4)

> That's been hard, Mr. R is coming back in September and he's taken to Mr. R. I've had to say to the new teacher - "it's nothing personal, [he] just doesn't like you!". He doesn't trust her like he trusts the LSA […] and at first he wouldn't engage with her wouldn't do work for her (P1)

Further tensions were reported by school staff from what they perceived from the single example of ABA being delivered in the school. As there was no BCBA® in post, much of the staff experience and knowledge of ABA was garnered by observing ABA being delivered to one child in the school by an RBT®, in isolation from his peers. This ABA programme was devised by the external provider and funded by the local authority. The RBT® was an employee of the external provider but funded by the authority. As a result, the staff perspective of ABA and its application seemed limited, as indicated by S3 as:

> […] all 1:1 work, lose the chance to work and play with others, the child in my mind becomes or is seemingly spoilt […] socially exclusive and isolated (S3).

S7's perception of ABA was that: *'It is in isolation, social inclusion very limited […] doesn't mix with other children'.* Quotes such as these last two confirm that the staff at the time had a limited understanding of how ABA can be delivered in a mainstream setting. They saw the difficulties in terms of what would be experienced by implementing ABA in a classroom setting, as evidenced by S1: '*Difficult to sometimes implement in a class setting',* and *S2: 'hard to put some things into reality […] lack of staff to implement ABA as class sizes are too big'.*

Progress was perceived differently by some school staff to the parents and local authority. Parents commented that they were pleased that their children were now attending school where previously they had not; and were subsequently making progress in school. Progress for them was perceived as being happy at school, for example: *'[…] because he's here and he's happy and he wants to come to school' S1;* and: *'[…] its him being happy and settled is the more important thing' S6;* and also: *'If he can continue to be happy! and continue to make progress',* P2 (Father).

When the unit staff were asked about how the children's baseline in academic skills and ability were recorded and monitored for evidence of progress, S5 said: *' […] at the moment they use SOLAR and P-Scales, KS2 use P-Scales too, a few are on slightly higher but most are on P-Scales'.* SOLAR is a 'School On-Line Assessment and Recording' tool that provides summative and formative e-assessments (2016). The current practice was that an initial six week period of observation preceded an Individual Education Plan (IEP), at which point the child was recorded on SOLAR (S3). This period of pre-screening before the on-line entry was noted as: *'it's a bit all over the place […] I think it's fine'' S4,* implied that SOLAR was not wholly suitable, but it was the measurement tool they used even if it was not a behaviour monitoring and recording tool. S5 had experience of behaviour assessment and recording from a previous post, and added: *' […] because it's all curriculum at the moment they haven't got anything as set as [the Assessment of Basic Language and Learning Skills] ABLLS®, that identifies certain areas. There does need to be something like ABLLS®, to define the child's profile'*. S1 said of recording skills and behaviour: '*I don't know if she uses anything particular to work it out. I think maybe not*'. ABLLS® is an assessment tool, curriculum guide, and skills-tracking system used to help guide the instruction of language and critical learner skills for children with ASD or other developmental disabilities. Within the test parents or care/education givers identify skills (up to 544) across 25 different skills areas that include language, self-help, social interaction, and academic and motor skills that children generally acquire before entering nursery (Partington, 2006). The benefits of the ABLLS-R®, S5 continued, are that: 'you aren't just making assumptions about abilities and skills and behaviours, you have the data to say they can do this'. The unit was not set up to deliver ABA, so these quotes are understandable. Staff were not yet aware of the specific data requirements that ABA commands, which indicated a lack of working knowledge of ABA practices in a mainstream school.

The local authority thoughts were explored and reported that the current situation in the school was satisfactory for parents, at least temporarily, given the various tribunal rulings that had taken place recently. LA1 suggested that those parents that were only seeking a school placement were happy that their children were now attending school.

Those parents who expressly chose the school for ABA were satisfied that the school intended to provide it, and seemed relatively satisfied with the eclectic provision. The following quotes from a range of parents interviewed support the satisfaction that the local authority was reporting. For example, a parent whose child had been a school refuser for a number of years said:

> Because he's here and he's happy and he wants to come to school. There's been a few issues in the last few weeks, and I thought we were going back to him not wanting to come back to school, there's been some accusations of bullying and I know there's not been any bullying, but he's picked up on it and I thought I'm going to lose him and he's not going to want to come to school again, but because of school's support it's all been turned around (P1)

And another parent *'Focused on getting him to school at first, getting him to actually attend a school* (P4).

> Yes and no….it's good because he's actually attending school. No because of the way some things are done and I don't know what learning he's doing, but he's actually attending (P4)

> I was just looking for a school, nothing else just a school that he would fit in and be happy in (P5)

Parents were further satisfied that the school was meeting their children's needs, as attested to by the following quotes:

> Here he's just happier, academically his reading has come on, he's just generally a happier boy, he wants to come to school, he wants to engage (P1),

> Having a really good school, who understands what's going on in school and at home, it makes such a difference, it's amazing. We love it here (P1)

> And she does love coming to school […] School has been great for her it's been massive, she has her time away from us, and when she comes home she's really-chilled out (P7)

There was some dissatisfaction expressed at the time it was taking to implement ABA in the unit, as noted in Chapter 3 from P7, but generally the parents seemed satisfied.

This evidence of parental satisfaction was evidence for the local authority to assume that the unit was a resource that was functioning well, without ABA: '*[…] because it is doing so well', LA1.* But, they were aware of their accountability, and of the need to provide ABA in a robust and reliable way. According to LA1, the parent group was temporarily satisfied,

because their children were now placed in a school setting and were seemingly progressing, as indicated by the quote: *'We're holding them because the children are showing progress, but unless we honour what we've said we are going to do we will have six tribunals', LA1.* Yet, irrespective of tribunal outcomes, neither the local authority nor the school were actively addressing the speed with which ABA would be delivered in the school: '*Parents have been to court and now ABA is stipulated in his statement, if he comes here we HAVE to be delivering ABA programmes'*, S7. Indeed, the phrase: *'We're holding them',* implies tension because of the delay in providing ABA. The authority said it wanted to avoid any further tribunals, but also wanted ABA provision put in place robustly and accountably. LA1 said that: '[…] *if you could be doing something, it's got to be done properly, and that sometimes means that it's slower than you like it to be, so that it can be judged as valid and reliable'.*

Future plans

This section of the sub-theme looks at how the school and local authority staff perceive the future plans of having an ABA led provision despite implementation proving challenging for two reasons. Firstly, there appeared to be incongruence between the lack of knowledge and costed analysis of the practicalities of delivering ABA and the school and local authority's vision to support and sustain ABA in the unit; and secondly, unforeseen changes to the unit's pupil numbers imposed restrictions to the school's ability to plan for implementing ABA.

Primarily, there appeared to be difficulty in sourcing a BCBA®, which was accompanied by the local authority and school staff's awareness and confidence in how to best source a BCBA®. The BCBA® would also supervise the current staff to implement the programmes. The staff would be trained to RBT® level and would receive supervision and guidance regularly from the BCBA®. The local authority were progressing with the idea of 'commissioning one in'. In addressing this first the challenge, the lack of knowledge and understanding of what was required to deliver ABA in a mainstream unit LA1 said: '*But there is a tipping point; finding a* BCBA® *has been a challenge' LA1.*

When questioned further about the ABA provision, school and local authority stakeholders were not clear about what was required to implement ABA. The practical details were slow in working out. For example, S6 was aware that the main delay in implementing ABA was: '*I think practicalities, knowing what we want and how to access that!*', and:

> Every time it happens slower than parents want, but I think as long as they have seen children making progress through other means, they are (generally) happy that they know ABA is coming in (S7).

Some of this was attributed to not feeling fully informed at the outset of the project, as an earlier quote showed (p.2). But there was clarity in how the staff and future training would be managed.

> […] now the plan really is ABA, (by a Behaviour Analyst) and the training (Online RBT® training) and supervision in a block, and some over skype, and really speaking with this, it's getting those programmes set up, monitoring those programmes, and oversee the staff (S6)

There was a suggestion from unit managers that in the very long term they hoped that a BCBA® would be trained up from within the team. Up-skilling the current staff was perceived as a retention incentive; with the added bonus that it would further reduce the authority's reliance on bought in services, whilst supporting the need for continued professional development. S6 said that:

> When we've got a Behaviour Analyst (trained) again this is the vision, and we've got staff that are trained, we won't lose staff to be an LSA somewhere else […]or whatever, they will continue their professional development and be used as outreach' (S6)

From the plans to deliver ABA in this one unit, the school manager said they had a bigger vision where ABA would be delivered as an 'outreach' facility to deliver ABA to other schools. As noted earlier, LA1 was clear that there would be no further units in the county designated for autism. In Chapter 3 I noted that autism provision according to the parents'

perspective was already difficult to access. The aspiration that the unit become a central point for ABA in the county was understood to be a bold plan at this stage.

> […] once we are delivering it inside the school, that we look outside at how we can reach out with it. With really clever funding and a structure, and we are a hub for ABA in the area (S6)

However, the providers were perceiving it as a means to address a future need for parents to access external providers for ABA. How this might be funded was not discussed, other than suggestions that other counties may invest in the ABA available here:

> But then medium to long term there are opportunities for investment to bring that within the authority, and even throughout [the three counties] depending on demand there, but with [External Providers]there, there is obviously demand there (S6)

According to the school manager, the introducing of ABA was a specialized process. Quotes such as the following indicate that managers were aware of the specificity of ABA and also the knowledge needed to develop ABA interventions in the school:

> If you are doing ABA, you need to have that overview of the most qualified experts in this field, you don't want to be mucking about with it – you're just doing different strategies that you have identified in their IEPs (S6)

While this implies that the managers knew what was required to implement ABA, their focus was seemingly on parental satisfaction, not driving the implementation process. This was evidenced when S6 discussed what was perceived as a short term goal of parents being content. This was taken to mean that because ABA did not have to be sourced privately as it would be available in the school: '[…] *very, very, quickly (parents) were saying that we don't need this (ABA) at home, because they were getting this in school, parents were relaxed now.*'

In addressing the second of these challenges, where there was a swift increase in the unit's pupil numbers since its opening, there was awareness from the unit managers that capping the pupil numbers from outside referrals was imperative. A two-to-four year strategy was suggested by the inclusion manager; planning and projecting for the through-put of pupils within the unit and focussing ABA in the Foundation class (Key Stage 1). In the

earlier local authority quote the 'tipping point' referred to the swift increase in pupil numbers in the unit.

A key element of the increasing tension was cited as the increase in pupil numbers in the unit; the numbers had doubled since its opening. Originally there was an allocation of 12, six in each phase, which increased to 24; 12 pupils in each class within 18months of the unit opening. This unit was accepting the majority of the autism referrals across the county.

The rationale for there being more pupils in the EY phase was given that: *'[…] more at foundation phase but that's because we've had to put them in for interventions*', LA1; but in practice more were placed in KS2 which placed further pressure on staff and created tension. LA1 held the belief that it was this inclusion of a number of older KS2 children into LRC2 with a wide range of complex needs that had been one of the main reasons for the delay in developing the unit as an ABA lead provision: *'[…] so we have had older children entering that unit, so that has stalled it. [The LRC] has taken placements from children where the placements had broken down and weren't going to school at all'* LA1. The decision was taken to utilise the seemingly empty places in the system, but at the cost of delaying the ABA implementation plans of the unit. However, what school staff were saying surprised them was the limited notice they received from the local authority about a new placement: *'[…] sometimes I don't get told they are coming, or I might get told a few days before the local authority places them'* S7. It appears to suggest that communication between the local authority and multi-agencies was not wholly effective; or possibly, that together with poor communication the pressure placed on the local authority to place children was high. This quote also highlights the situation that the parents were in, with respect to the shortage of units and places. S7 also added that:

> I felt that parents often knew they had a place in the unit before I did. And that's still the case, more if the child / children are in crisis. If one is a non-attender, and the parents were choosing where they want to go (S7)

and :

> […] some of them [parents] are getting their own way, and children are placed without any chat with us or asking us. (Local Authority) admitted [them] against all recommendations and with reservations about placing that particular child in the unit, they were pressured into doing it anyway [by parents] (S7)

The reality of the placement allocation was said to create tension, as the school staff reported they experienced it was more complicated than the authority's strategy. The school was accommodating new pupils, often with complex needs at short notice; the local authority was under pressure from parents to place children, often with little to no *'choice'* (LA1) of placing them in the unit, and as reported in Chapter 3, parents were ardent in their pursuit of placements for their children. LA1 verified that the complexity of needs the unit was managing was indeed a challenge: '*So we've got almost like three tiers of specialist provision in that school', LA1.* In the difficult task of referral and placement setting, the local authority were saying that they were sometimes placed in a position of having to place children (sometimes not in the EY category) because an earlier placement had broken down, or a child was not in school at all, or there have been demands from parents / tribunals to resolve certain issues urgently. This kind of emergency placement had resulted in older children starting at the unit, often in the KS2 class:

> But [The Unit] has taken placements from children where the placements had broken down and weren't going to school at all, so we have had older children entering that unit, so that has stalled it (LA1)

Therefore, some of the tensions experienced by the unit teachers were due to the local authority's direction, not just a delayed start to ABA provision because of managing, and resource allocation for employing a BCBA® and RBT® training.

The local authority corroborated that this decision-making perceived by the school was creating tension, and suggested that it indicated the difficult situation that the parents were in, and also the shortage of units and places available: *'We get far more referrals than we have got places and we have work to do in making sure that all referrals are really appropriate.' LA1.* LA1 reported that they were often in situations of having to place children in 'emergency situations' as iterated by:

> Then of course you will always have those emergency referrals. It feels like its all-consuming, […] You can't plan for these. And then of course you get your out of county movers / referrals (LA1)

Underpinning this tension, S7 raised some concern over the needs of the children that were referred for unit places: '*It's a new unit and its flavour of the month at the moment so there's a lot of parents choosing to come here'.* S7 was perceived to be implying that autism may not have been each child's underlying need, and that school attendance might have been the motivating factor for the local authority and parents to place children in the unit. Differing children's needs placed unit staff under additional pressure:

> 'With the complex cases in KS2 Class, there wasn't a lot of choice to be honest, some of them may have accessed [External Provider] at some point, but in a way that wasn't the driver; the driver was that they weren't in any school', LA1.

With the desire to address the emergent tensions, and with the hindsight of the initial experience of placing children with complex needs in the unit, the authority and the school staff have said that they have redressed their placement planning strategy, with a: *'A two-year plan',* and that the local authority wanted to *'[…] target how [they] we refer'* LA1.

At the core of the school's thinking was a wider inclusion policy. There were intentions that those children able to transition to mainstream classes would do so for some of the school day or for specific subjects. The benefits of the school being a mainstream school created an opportunity for this to happen. To facilitate this, the mainstream school and the LRC unit curricula were being planned in parallel to create possibilities for better inclusion. Parents were seen by the local authority as wanting a place in the unit because they saw it as a route to mainstream education. LA1 pointed out that some parents' drive for a place in the unit: '*was on getting children into mainstream' LA1,* not ABA*.* Irrespective of the children's main difficulty being attending school, for behaviour or autism reasons, the increase in the number of pupils contributed to the tensions experienced

The next sub-theme deals with the central cause of tension perceived by the stakeholders, namely the delay in implementing ABA in the school.

The delay in implementing ABA

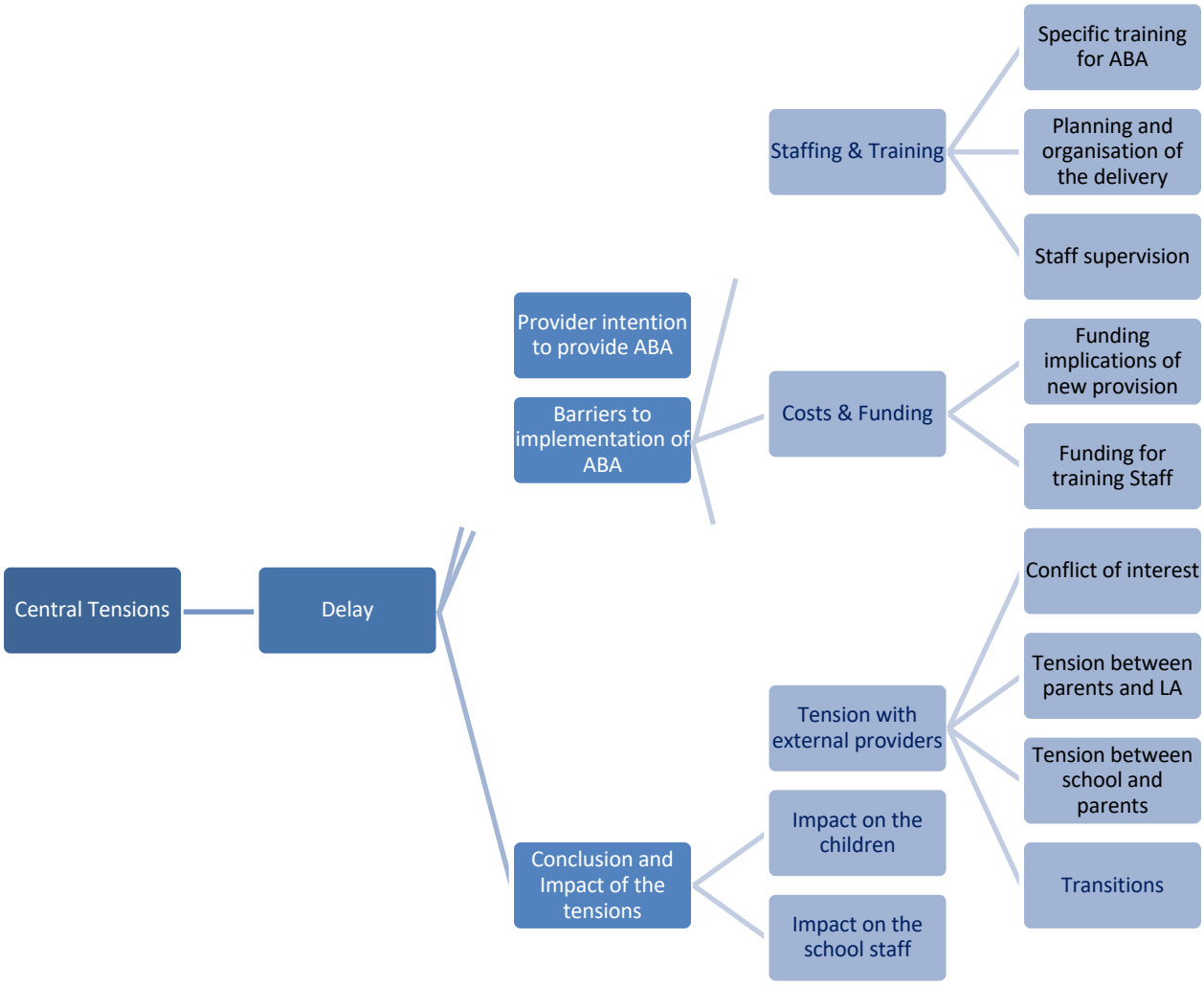

Fig 9: Themes and Sub-themes: Central Tensions- Delay in Implementing ABA

The delay in implementing ABA was perceived by all stakeholders to be the biggest source of tension in this project. This themed section is in two parts, and addresses the local authority's intentions to provide ABA, and then the barriers to implementing ABA in the school. The data will unravel these issues through the following themes: The intention to provide ABA, and also the barriers to its implementation through its organisation and delivery; the parents' and subsequently the local authority's perspective on its implementation. The first of those sub-themes will be analysed and expanded upon next.

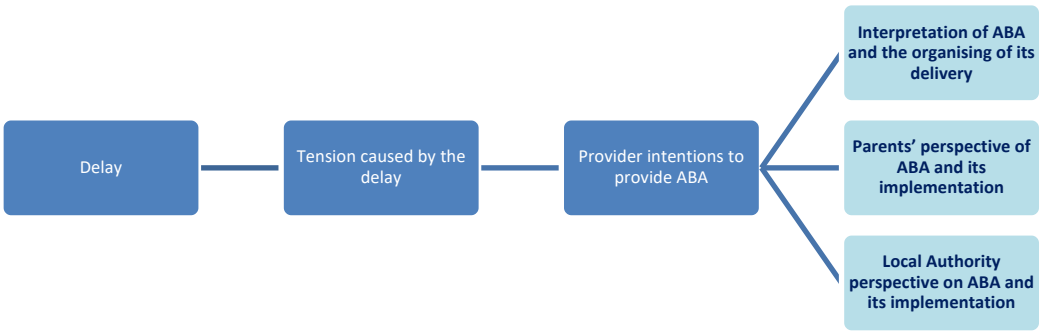

Fig 10: Themes and Sub-themes: Central Tensions – Local Authority intentions to provide ABA

Provider intentions to provide ABA

Both the school staff and the local authority perceived the implementation of ABA as complex, and it was partly due to the local authority processes of procurement and funding and training for staff, but also that senior managers and decision makers were unfamiliar with the requirements of procuring and delivering ABA and also the best way that it could be implemented into mainstream settings.

Interpretation of ABA and the organisation of its delivery

Evidence from S7, highlighted the crux of their understanding of the delay, and resultant tension. This quote from S7 is important because it exposed the root cause of the delay; in that it was a bigger venture than first considered:

> I personally, with hand on heart don't think the local authority meant for it to be so slow, and wanted it to be set up. I totally believe that it's bigger to set up than they first thought (S7)

The school managers S7 and S6, and LA1 were aware that the school was treading water amid the delay: *'When we have ABA, then you are making it far more specific, you know when you're doing it and why you're doing it? Whereas it's a bit pick and mix with us at the moment'* S6. The quote also reflects that the current practice was perceived as generic and using a range of eclectic interventions. Parental dissatisfaction at the delay in delivering ABA in the school was reported by the local authority and school staff as:

> There will be absolute uproar if this isn't a specialist unit for ABA. These parents have been kept waiting all this time, and they are fighting for it. The true ABA ones are fighting for it (S7)

As acknowledged in Chapter 3, some parents made a specific decision to seek ABA and a placement at this school, even though ABA was not in place at the time their children were enrolled. The unit staff said they would like to be able to meet both the demands of parents and the needs of the children. In particular S5 and S7 offered that: *'[…] it would be nice to have something that works out of school and in school'* S5, and further:

> I know a lot of the parents were excited to get a placement here because of the ABA, and some of the parents that I worked with are still waiting for it to be an ABA unit. So I think that is important for a lot of parents that it has got ABA (S5)

S7 went as far as saying that parents were *'promised'* the provision, and their children were not yet receiving the intervention after almost 18 months.

From a school manager's perspective the relationships with parents were hard-earned: *'We've built the trust; we've established it, now we really need to come through on our promises as far as ABA. This is about maintaining that trust, maintaining that (momentum)'.* The data gave the impression that progress was being made towards the implementation of ABA, and that the stakeholders continued to strive for its successful introduction: *'But for those parents coming here we HAVE to have that ABA moving forward, and really that it [is] happening' S6.*

Parents' perspective of ABA and its implementation

Parents who had campaigned to have ABA provision for their child wanted ABA in the most accessible form as possible. As noted in an earlier theme the local authority and school staff sometimes felt that parents saw ABA as a direct route to mainstream schooling, and that they had unrealistic expectations of their children's ability to access and achieve in mainstream school. Other parents as noted in Chapter 3 had no expectations at all, other than their children are happy and attending school. By the time the children were placed in the unit, some of those unrealistic expectations had been dismissed. LA1 remarked that during consultations with parents, they were often in states of confusion and distress and would demand certain targets be met: '*Sometimes parents think there is a "cure" [for] example where a parent wants the child in mainstream for 80% of the time'.* S6 added, that sometimes they felt that these expectations were as a result of external providers: '*I think there are a number of parents who were expecting it in the way that they were used to getting it from [External providers]' S6.* This evidence presented this as a tension here as the difference between home-based programmes and school-delivered ones are markedly different (Grindle et al., 2012). The school was not delivering ABA for the parents to make any comparison, and neither school nor local authority were advising parents clearly on how and when it would be delivered in the school, thus the absence of understanding ABA and its delivery created tension between the parents and the school.

Local authority perspective on ABA and its implementation

The next section of this sub-theme will explore the 'barriers to implementation', and more specifically the four areas that are at the core of the delay in implementing ABA in the unit. These were themed as: Staffing issues and difficulties; funding and cost implications; tensions perceived with external providers of ABA and finally the number of children and capacity in the unit itself.

The barriers experienced to implementing ABA

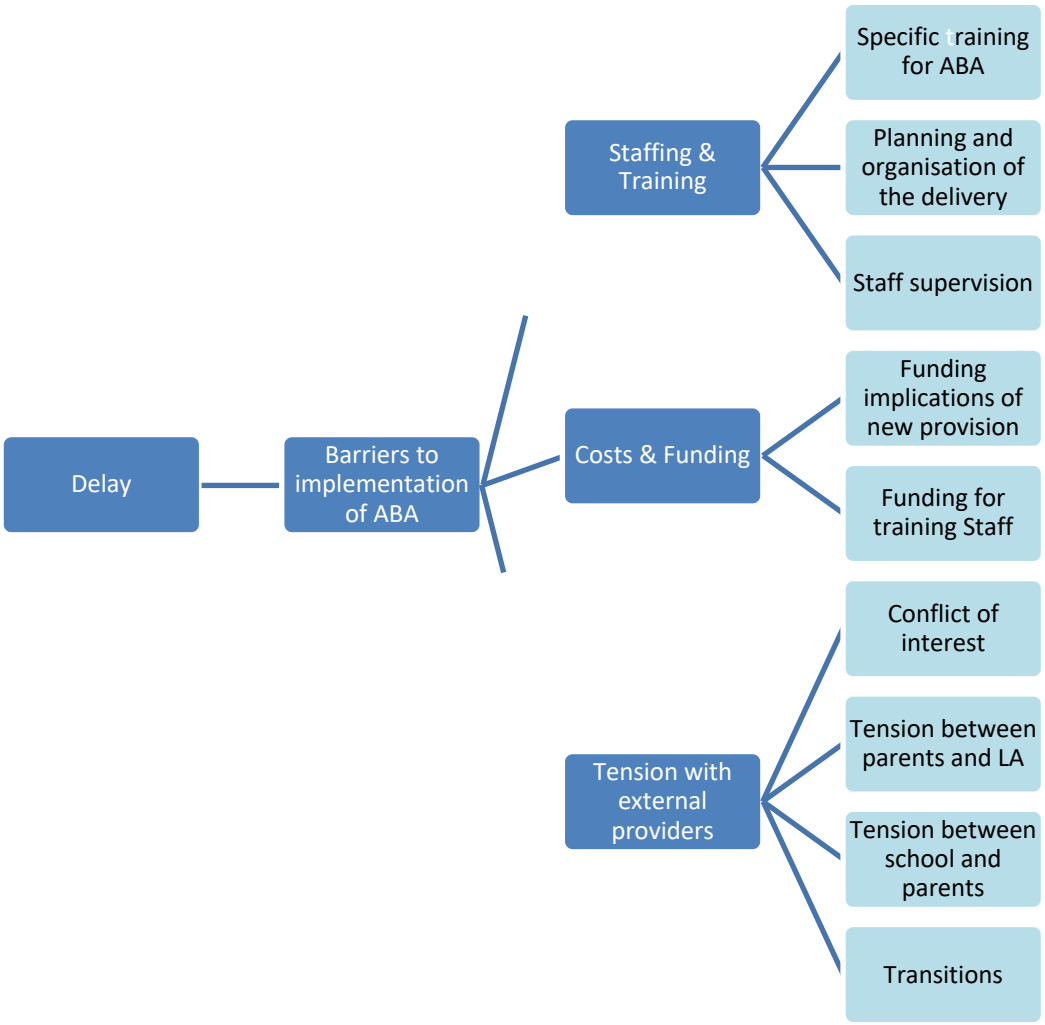

Fig 11: Themes and Sub-themes: Central Tensions – Delay: Barriers to Implementing ABA

This sub-theme explores how the school staff and local authority saw the barriers to implementing ABA. From the school staff these were noted as difficulties that would be experienced in directly implementing ABA to children in a class setting, particularly S2, S3, S4 and S5. Their responses showed a lack of experience with ABA and can be summarised by S4 as: '*Would be difficult to put it into practise with so many children'.* The local authority perceived the difficulties to be centralized around the absence of a BCBA®. The senior school and unit managers put this down to the local authority's inadequate research and planning in the project's early stages. Reiterating S7, who said it was: '*one hiccup after another […]'.* Some general misunderstandings over these difficulties may have been averted by earlier research and training into how to deliver ABA. Staff training and supervision was also cited as a barrier to implementation.

Staffing and Training

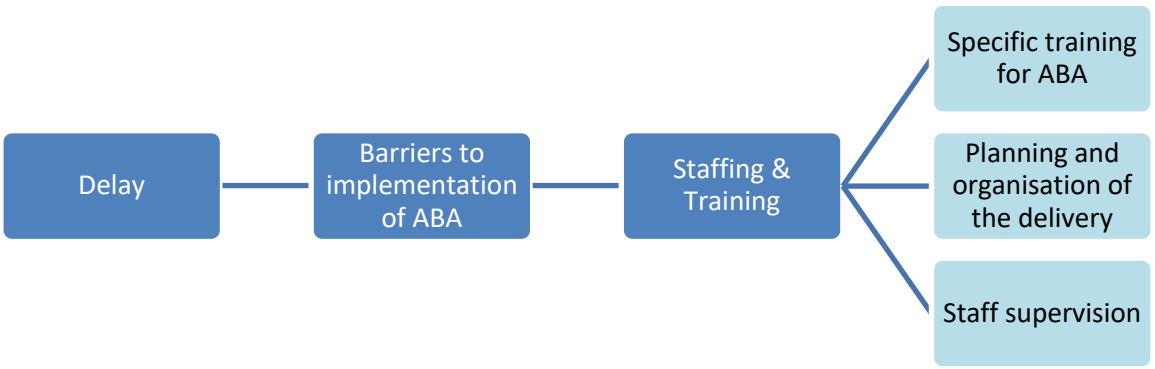

Fig 12: Themes and Sub-themes: Central Tensions – Delay: Barriers –Staffing & Training

For the local authority and the unit staff sourcing a BCBA® and staff training were the obvious causes of the delays experienced. It was unclear from the data whether the local authority was unsure of the practicalities of sourcing a BCBA®, or whether there were issues within the wider authority of financially supporting a post. However, it appeared from the data that a detailed understanding of what was needed to implement ABA was lacking by both the school and local authority. Both providers were aware that supervision is a key element to the delivery of ABA programmes. There was some expectation expressed by the unit staff that delivering ABA programmes would reduce the 'pick and mix' eclectic approach to interventions currently in place in the unit. In addition to these issues, a further unforeseen change in the unit's staffing structure created tension in the day-to-day practice of the unit.

The school staff interviewed were keen to be upskilled in order to deliver ABA programmes. S6, said that: '*upskilling our key staff, investing heavily in them so they've got that knowledge of ABA in order to apply it, that they are skilled practitioners'*, was a priority in the school's plan. This is a useful quote to show the enthusiasm and positive approach that the managers and staff had towards implementing ABA, despite the tensions they were experiencing.

Specific training for ABA

As noted earlier in the Future plans section of this chapter (p.128), training for staff was important. LA1 indicated that sourcing appropriate training for the School teaching and support staff to deliver ABA programmes, was proving difficult. Importantly, a BCBA® in particular, was difficult to locate in the area. The intention was that without the inclusion of the external providers in the project, the school would source their own BCBA®, and train up staff within the unit to (RBT) ® level. The BCBA® would not only devise the ABA programmes for the children, but oversee their delivery and supervise the school staff, as S6 quoted earlier. At the time of data collection, the authority had canvassed and agreed in principle to fund a BCBA® on a part-time contractual basis. This BCBA® would implement, manage and supervise staff delivering the ABA programmes, in accordance

with the Behaviour Analyst Certification Board (BACB®) requirements; but as LA1 said (p.118) that sourcing a *BCBA*® was difficult.

Planning the delivery of ABA

How ABA would be delivered on a day-by-day programme basis seemed clear to the school managers, not so, to the remaining unit staff: '*[The] plan is that ABA programmes will be in the morning, RBTs will come in and their work will be set up in their stations and delivered by the LSA/RBT®' S7*. This would take place in a designated 'therapy' room in the unit, set apart from the LRC unit classroom. Two points of interest can be drawn from this, firstly, how the school would go about deciding which children would receive ABA, and where the programmes would be delivered in the unit. S6 said that the information would come from the child's statement and internal IEP:

> We will go to ABA programmes for the children who are assessed of needing it, they will have their ABA, and then be part of the class, rather than the ABA is the 'golden elixir' that [ABA] … they get is part of the school day / curriculum (S6)

This response implied that it would be known which children would benefit from ABA, but not necessarily how that decision would be arrived at, i.e. through consultation with a BCBA® and/or through analysis of any baseline assessment data on the children, or both. There was a sense that much was expected of a BCBA® who was not yet in place. Not having clarity on these details supports the tensions the stakeholders experienced.

The second point is that on a practical level, the school was gearing up for delivering ABA. There was already space designated for ABA set aside from the classroom; and that as a part of the school's plan, additional training for staff was intentioned, as noted earlier the staff were keen to be upskilled to RBT® level, four of whom had been identified for the training. This shows that there was a planning intention; but the missing pieces in the planning were the actual BCBA®, and the data required to ascertain the children's baseline abilities.

Staff supervision

Supervision is a key element of delivering ABA programmes, as stated in the BACB® regulations for supervision of RBT's®, with at least two face to face supervisions per month, equivalent to 5% of the total time spent in programme delivery are necessary. Whilst those supervisions may be remotely managed; on-site observation is preferred, and at least one of those sessions must be individual (BCAB®, 2019). Supervision of staff is currently informal but was planned to change once ABA was being delivered. The unit team was small and close knit. Peer support was reportedly very important to those interviewed, especially S5, S6, S7 and S3:

> […] we are a close team and we are talking to each other. Peer support, and we are all very good at different things as well. N is very good at getting them all together for sport things, and I'm good at bringing them down, and think we all communicate really well (S5)

Re-iterating, S6 confirmed that the current situation was due to change, wherein staff supervision will take on a different structure, once a BCBA® was in place and ABA programmes were being delivered: '[…] *really speaking with this, it's getting those programmes set up, monitoring those programmes, and oversee the staff*'.

All those interviewed from the school were reportedly enthusiastic to be involved in the RBT® training. S4 said that the school was:

> […] open to trying new things, and certain staff have been trained in certain things / interventions (referring to an RBT in the LSA team), so it's making sure the staff are upskilled and got the requirements to complete the interventions (S4)

School managers were also keen to invest in staff, and do so within a strategy of retention and sustainability as part of a bold and broad vision for the school's future in ABA:

> One […] LSA has two degrees, they are qualified people, and we have to continue to invest in them. And they are such a mix, some are creative, some academic […] Invest in the staff. There is an element there that if you are training up and one goes, then it's sustainable (S6)

Investing in training was reported by S6 as: '*professionalising our professional development as a staff, to a level that they are not just LSA's who work through a visual timetable*'

and :

> When we've got a Behaviour Analyst […] again this is the vision, and we've got staff that are trained, we won't lose staff to be an LSA somewhere else, or Level 3 or whatever, they will continue their professional development [here] and be used as outreach (S6)

This perception from the senior manager (S6) shows that the '*pick and mix*' approach currently in operation was unsatisfactory: '*The really exciting thing, is that if we have that training on top of it is that the times that we get it right become far more', S6.*

Cost and funding issues

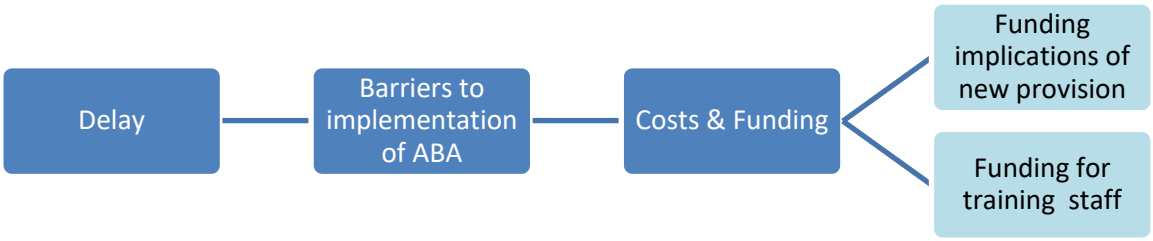

Fig 13: Themes and Sub-themes: Central Tensions – Delay: Barriers – Costs & Funding

The funding associated with the development of the new unit, and future funding to manage the numbers of children needing provision in the county was probed. This was in light of the current and rising costs of parental demands for ABA home-based programmes on the local authority to support. There appeared to be difficulties experienced in realizing the funding for a BCBA® and RBT® funding for training and supervising current staff. It was indicated that funds were ring-fenced for this. The school and local authority stakeholders

were disappointed more than frustrated by the current financial impasse, which was exacerbated by further budget cuts imposed soon after the unit opened.

The question of how the local authority was going to future proof the provision for autism was met with a response that there was a finite amount of funding available for the provision: '*We have a sum of money and no more coming in' LA1.* In response to being asked about future LRCs that would meet the increasing demand the county appears to have was: '*I can't see another one .We could change the focus of another LRC, but not [fund] another one!'*. This would inevitably leave the county short of general unit places in order to focus on autism specific LRCs, yet, if current local authority data are considered, there remains the problem that there would insufficient places to meet the demand in pupil numbers. When asked about the numbers of children across the county in a specific LRC, LA1 offered that there were 87 pupil places in Foundation phase and 59 in KS3 and KS4 (See Table 4). These were current for the academic year 2017/18, but there was indication that there were: '*more [pupil numbers] at Foundation Phase but that's because we've had to put them in for interventions' LA1.* There were no allocated general LRC places at KS2, according to the data.

Phase / Pupil Numbers	LRC	LRC Autism Specific
Foundation	87	18
KS2	N/A	18
KS3	59	24
KS4		

Table 4: Specific Autism Inclusion provision across the county by Phase (2017/2018)

There was clarity from LA1 that there may need to be some '*doubling-up of provision funding*', i.e. funding the unit and a small number of home-based programmes, which appeared to be the current situation. Whilst the provision for ABA in the mainstream school unit is in progress, it was noted earlier, that one child who remains in receipt of ABA from an external source is supported by local authority funding and taught in the school in isolation.

Funding implications as a source of tension for the new provision

LA1 had indicated in Chapter 3, that the cost of providing ABA in home-based programs by an external provider was on average £20,000 per year per child. According to unit managers the funding implications for the new unit were complex, and soon after it opened, budget cuts were imposed: *'Lost about £2,500 per pupil, because Autistic children used to get more if they were in a specialist unit' S7.* The impact of such budget restrictions on the unit in the early stages of set-up to deliver ABA is part of the reported delay and tension. Including the swift increase in pupil numbers, the unit was already experiencing tensions to deliver a special needs curriculum, before those of any ABA led provision.

This sum of funding did not include ring-fenced income directly from the local authority for a part-time BCBA®, as this was for the resourcing of the unit, its staffing and also for staff training. A rationale for the budget cuts was not given, nor evidenced. Senior managers were suggesting that ABA would be a means to manage the increased pupil numbers better. S6 offered: '*That's definitely part of the bigger ABA picture, as well as managing the 24 pupils in the LRC'.* S6 further offered that there were suggestions of using ABA, once it was established in the school as a form of income generation, when S6 indicated (p.130) that the unit could function as an ABA hub for the wider region beyond the county.

Funding for training staff

With regards to the cost of staff training, outside of that for ABA staff training was perceived as an investment by the school. There was no evidence from the data to suggest that the local authority was not supportive of this. Of additional training, S6 said that:

> […] what we need to realise is that there is a lot of money coming in here that we have responsibility [for], so don't feel guilty about sending people to one of these conferences, even if it's costing £200-300 (S6)

What I understood by this response was the importance placed on knowledge and acquisition of further training combined with spending wisely for best value outcomes for the long term for the unit. This evidence supported the bigger plan and vision, but not so

much the immediate need to deliver ABA; the source of the delay and the tension. The delays in implementing ABA appeared to be stuck at the procurement end in the local authority. *'Disappointed rather than frustrated'* was the phrase used by LA1 to describe the situation, the unit was currently in:

> […] and I think where [the school] has been disappointing. Not what we were planning…. is because it is doing so well, our aim is to go with it (ABA) intensively and get them out into mainstream (LA1)

The next section expands on the different dimensions of this tension between the different stakeholders

Perceived tensions with the external ABA provider

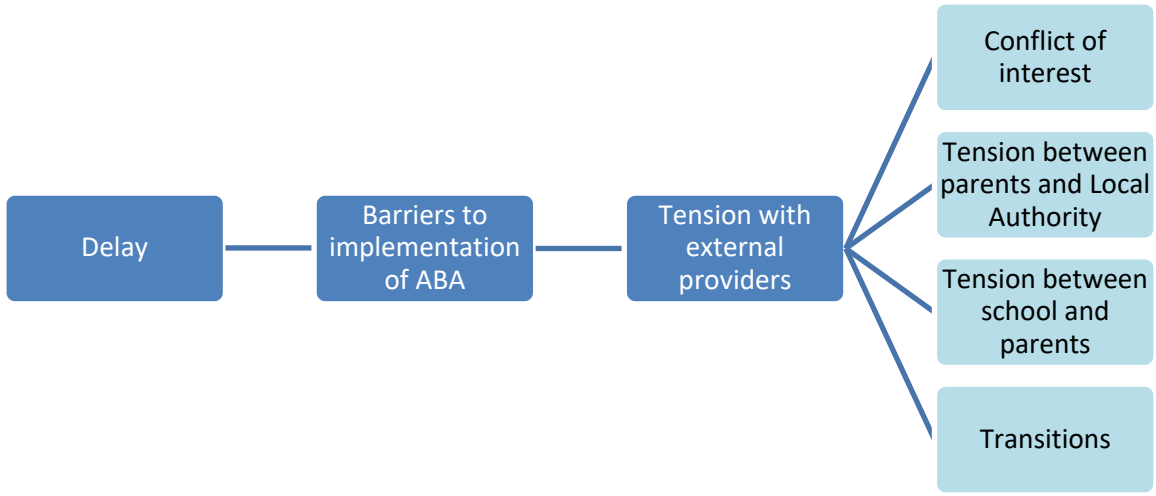

Fig 14: Themes and Sub-themes: Central Tensions – Delay: Barriers – Tensions between stakeholders

According to the school and the local authority staff cited in Chapter 3, the parents' perspective of ABA and the impact that it could have on their children, alongside the drive for its implementation was perceived to be fuelled by the external provider. The apparent influence seemed to come from parents' expectations of their children, especially where

inclusion to mainstream was concerned. Providers felt that at times parental expectations were unrealistic but indicated that they understood that parents may not fully understand how the school processes worked. The head teacher was concerned that parents were seeking a 'cure' for autism: *'You have to be wary about anything, that has the word 'cure' to it', S6*.

Because the school perceived that the external providers were suggesting a precedent for ABA in the form of home-based programmes, they were influencing the parents seeking ABA. From this perception I have assumed that parents expected the school to deliver ABA in a similar way. There were tensions perceived by the unit staff which were often expressed by the term '*difficult'*. This tension was said to present when staff were dealing with parents, managing local authority expectations or dealing with external providers when children were transitioning to school from home-based programmes. All of which was reported to involve considered handling and compromise by the unit managers and staff:

> Its been difficult being piggy in the middle (S7)

Conflict of interest with external providers

The expectations that parents had of their previous experiences of ABA from the external provider supported the tension felt by the school staff:

> Initially we really had pressure that this would be (by the local authority) an ABA provision here […]. Local Authority were telling parents that this was going to be an ABA provision. Parents were under the perception that they were going to get ABA, I think there are a number of parents who were expecting it in the way that they were used to getting it from [the External Provider] (S6)

S7 was more explicit on this:

> For parents, when they are seeing an impact on their children they are going to want more, and there was a lot of evidence produced from ABA, and when you have this and going to the Local Authority, you have a good fight then. So if the authority were not able to provide these programmes that the parents felt they should have. External providers] were also able to provide solicitors for the parents to fight for this (S7)

These were expressed as 'difficult' in school staff interviews as S7 attested:

> I've invited [the External Provider] in for all our meetings. Then now after five terms the parents have said they don't want them in now. At a time when the local authority are telling me they don't want them here, it's been difficult being piggy in the middle (S7)

Of the privately sourced provision S3 said that: '*Many parents within the LRC have paid for private ABA for their children',* and when asked about the external provider's ABA home-programmes, concern was expressed over how the parents were seeing home-based ABA. This was attested to by S7's earlier quote suggesting that legal support could be arranged by the external provider.

A further contributing factor to the tension between the two providers, was that when EY children entered the school system having had ABA at home, the available supporting data from the external provider was not seen as helpful by the unit staff for the transition from home and functional skills programmes, to school functional skills and academic learning programmes: *'I felt I was being bamboozled by charts and performance data [from External Provider', S6.* S7 said that whilst the external provider gave the school copies of some of their data that: *'[…] there was a lot of evidence produced from ABA',* yet data that the school could interpret in a meaningful way, and use, was not always available.

Whilst concerns over the quality assurance of external provider programmes are unfounded and speculative at best; as no BCBA® can implement behaviour programmes unsupervised or accountably according to the BACB® regulations. Quotes like these are useful to illustrate that a level of concern was expressed. On analysis and deeper consideration of the quotes above, I am suggesting that the school was unsure of how ABA works and how ABA data relating to evidencing progress would fit in with mainstream data systems.

Tension between parents and the local authority

As noted earlier, pressure that was placed on the local authority from the parents was perceived to be motivated by the external provider. These were as a result of the

delay in planning, managing and funding the implementation of ABA. However, further probing revealed that the local authority in concurrence with S7, questioned whether they would have made the same decision to support an ABA led unit had that compelling intention not been there: '*Now, whether that would be the same in another county that didn't have such a well know provider, I don't know, I think they [External provider] were only responding to demand' LA1.*

It is difficult to say whether the parent group, after researching autism therapies and interventions found ABA first, or whether they were drawn to ABA by finding the external provider's service to deliver it. When parents followed up on their findings, whether by internet searching or recommendation from another person or agency, and approached the local authority for financial support for Autism interventions they often asked specifically for ABA. According to LA1 this suggested a previous arrangement with the External providers: 'w*ith the younger ones, and the EY coming through we know if [External provider is] involved because they ask for ABA'.*

The evidence available from parent interviews suggested that they conducted their own research into effective autism interventions after following someone's recommendation, not necessarily a professional's advice. For those who had experienced ABA in home-programmes it was P5 and P7 who said they had been recommended ABA; and on researching the internet found the local External provider: *'When you see other kids coming on, you want to know what they're doing to get those results, another mum put me on to ABA',* P5; and P7: *'I was introduced to ABA from a friend whose son was Autistic and [External Provider] obviously the local company'*.

The local authority intended to involve the external provider in the setting-up, delivery and management of the ABA programmes in the unit. However, having them involved in the school ABA delivery at the same time as providing home-programmes for some of the same children in the unit quickly emerged as a conflict of interest for the local authority, as suggested by LA1:

> Then we had the dilemma, did we, almost, commission [External provider] to be really heavily involved; were we comfortable with that, and in reality we weren't because,

> it felt to us that it could be a conflict of interest. You had someone working with them [children] outside of school and overseeing provision inside school, and that didn't feel comfortable (LA1)

Inherent within this response was a certain justification to the delay to provide ABA in the unit. This left the school with their intentions, having begun construction on a new unit but no clear provider for the ABA that the parents were demanding. It was evident from earlier responses from LA1 that within the LA and Provider base there was a dearth of expertise and research on what ABA is and how it works, notwithstanding how it could be implemented in a mainstream setting. Other examples of ABA therapy in schools that were known to the local authority were of special school settings, not mainstream settings.

Tensions between the school and the parents

Some school staff expressed concern that ABA was being sourced privately, which created tension between the school and the parents. This was partly due to it taking longer than expected to implement ABA in the unit; but it also, related to the quality of that external provision (p.114).

Furthermore, whilst drawing attention to the parental vulnerability element of S6's earlier comment (p.114) it is plausible to assume that S6, S7 and LA1 would make these assumptions; as an element of influence was being exerted by the external providers, particularly when they supported parents by enabling legal representation at tribunals. S7 indicated as much: *'So if the authority were not able to provide these programmes that the parents felt they should have, [External Provider] were also able to provide solicitors for the parents to fight for this'*.

Transitions to school from home-based programmes

A further issue of note within this sub-theme is the tension underlying the intentions to have a seamless transition between ABA home-programmes and school programmes. As ABA was not set up in the school in time for the unit opening there was some discontinuity once the children started attending school. Generally though, transitions from non ABA interventions were considered to require some phased entry to school, as S6 indicated by:

> […] the most profound children may need a few hours of coming in, that's if they are coming in from home, but if they are coming in from another provision, then they come straight in. Children coming in from pre-school, we build it up, build it up and desensitize it (S6)

School staff said that enabling smooth transitions for the children coming in to the unit was not always possible despite: *'all sorts of fancy transition plans', S6.* Yet, in support of a holistic approach to the transition process for those with previous ABA programmes:

> […] we made sure that initially any child who is with [External Provider] were there (In school child planning meetings) […] we always have a transition meeting in, so I allow the one meeting to come in meet with our staff, so that we can gain all the different information that we have (need) and then as far as we're concerned, they're ours (S6)

The reference to the children belonging to the unit as opposed to the external provider in this latter quote is significant as it relates to the tensions the school was experiencing with the relationship they had with the external provider. There was an implication perceived that the external provider was questioning the school's authority: *'[…] to almost like be seen to be telling us what to do, and that was receptive to the parents', S6.*

The school was also reluctant for conflict of interest reasons to have school based ABA programmes delivered by the external providers, and cited the singular case of a child taught on school premises by an RBT® in isolation. S6 said:

> […] he's completely separate, doesn't even have an LRC place. So that. I have come under pressure from one parent that they wanted that to be in school, and my argument was, why don't you have, ABA at home?, and us on top? Because if you have any activities going on in school he's excluded (S6)

When prompted, S6 said that: '*I worry about that they [parents] are asked to pay an awful lot of money, for things that we can do here, very, very, quickly, with amazing and specialist staff*'.

A number of issues are implied in these two quotes, firstly that the school's management of ABA by external providers needed to be very clear. Secondly, that the inclusion in school life and all its social interactions was important for all children to access, and external provision of ABA in school time would erode a child's opportunities to engage with that and his peers. Thirdly, the school was defending its delivery of its current autism

provision. What I have inferred from this is that when privately sourced programmes were created for the EY children in school, those programmes would not be integrated into academic programmes, even when the Foundation Phase process teaches functional skills. The focus of the external programmes in school time would not include any academic work at their core. Whilst it was wholly recognised by the school that behaviour impedes learning, and addressing behaviour management is what enables children to engage more with school activities, staff in the school considered these as meaningful future strategies, as S5 attested: '*Bringing in more social and life skills […] into the curriculum more*, [as] *a lot of the things that stop them from learning are the behaviours'.* Children being excluded from 'school life' raised concerns, as exampled by the singular case of the child receiving ABA in school in isolation. At the parents' behest the child does not integrate with his mainstream peers, he was: '*totally excluded (secluded) works with [an] RBT from (External Provider) on his own', S7.* This was a point of tension between the school and parent group. S7 said: *'Then parents know that [External Providers] have been coming in with other children, one in particular […]. And I'm the face of that. I am the one the parents see every day'.*

Transition to mainstream school classes

The transitions within the school from the unit to mainstream classes were more positively perceived. These progress transitions seem to have gone smoothly. There were, however, some tensions experienced between parents and the school with regard to them, mainly that parents were expecting more mainstream inclusion. Whilst it is important to note that the unit's overall aim was not necessarily to access mainstream, but, where children were functioning at mainstream levels there were opportunities to progress to mainstream. As S4 said that:

> […] with some (pupils) there is the expectation of transition to mainstream with others they wouldn't expect to go into mainstream, but for instance 'T' we weren't meeting his needs in class, setting work that was appropriate, so he wasn't achieving what he could do and getting bored, and making it clear that the work wasn't appropriate, so he wanted to go with his peers to mainstream and work in that way', (S4)

Nevertheless, at the time of data collection the majority of the children in the unit were not functioning at mainstream levels, an indicated by S6: '*their development levels are still very*

much working on P levels at Foundation stage' S6.

The impact of these tensions

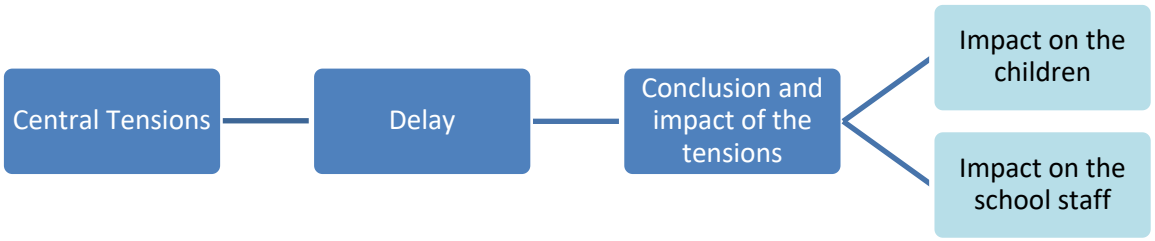

Fig 15: Themes and Sub-themes: Central Tensions – Delay: Conclusions

Drawing together the evidence from thematic divisions of the data, it is useful to conclude by considering the impact of the tensions on the newly placed children and staff in the unit. At the time of data collection, the unit was in a 'holding' situation, as a result of the delay in implementing ABA. The local authority perceived that they were providing well for the children, but they were aware that it was a short term resolution for all parties, so exploring the impact of these tensions on the children and school staff further is valuable.

How the tension because of the delay impacted on the pupils

Firstly, LA1 was positive and said that despite the delays in focusing the development of the unit as an ABA led provision, it was providing well for the children, albeit general autism SEN provision. According to S4, the size of the class had some considerable effect on the children:

> Not only that they have had new pupils as well, the class has almost doubled, when I came there were 7, and now there are 11 in there, over a half term and with different characters within those that have come as well (S4)

The tensions that unit staff were reporting were exacerbated by the difficulties experienced in maintaining adequate staff numbers and expertise. There were teacher continuity issues experienced by the children from the absence of the class teacher. One teaching position continues (at time of writing) to be covered by a supply teacher. '*One change might have worked at Christmas, but then there was another change at Easter, so they've had a change every term so far. It's a lot to take for them', S4.* Overall the staff felt that the class size and teacher instability affected the parent group, exacerbating some existing tensions they perceived were being experiencing: '*Parents generally not happy with a change to what they think was working and parents have been unsettled and since fallen out, this spiralled out of control', S4.*

Underlying these changes was the local authority decision to increase the unit's pupil numbers to 24. The intention was to focus ABA in Foundation Phase and move pupils up to KS2, during the unit's early stages, but KS2 became saturated with children exhibiting a range of complex needs, including autism. This scuppered the original plan of foundation phase children developing skills and progressing to KS2 as LA1 attested: '*Because by the time they get to KS2 we have equipped them to be able to cope with things',* LA1*.* The delays in developing ABA as a core provision in the unit have been identified in earlier sections. These amounted to complexities in sourcing a BCBA®, actualising funding for the BCBA®, and for training and supervising current staff. In addition to these, further unforeseen changes occurred in the staffing structure, and also the unforeseen budget cuts.

Overall, the reported impacts on the children have been perceived as positive, particularly in terms of attendance. Those who were not previously attending school, were now attending, and regularly. For some of the KS2 children and their families this was a monumental step. Functional skills and academic skills were seemingly improving (according to evidence suggested by unit teachers from SOLAR), and overall, parents were satisfied thus far. An Estyn inspection had taken place in May, 2017, and reviewed again in November 2018, where the outcome for the unit was favourable (Estyn, 2017). It is plausible

to argue that the local authority and school stakeholders were reflecting on 'improvement' as a feature of 'parental satisfaction' in this situation. However, there does need evidence to support any academic or functional skills improvement, and at the time of data collection the school were only gathering such evidence through SOLAR and P-Scales.

However subjective the data may suggest that the school's evidence of improvement is, S6 added a perception that was most interesting. More specifically, that inclusion and transitioning to mainstream was certainly in the school and local authority's thinking, for example:

> […] the emphasis is, where possible to transition the KS2 children (those that can/able) will transition to mainstream. Initially they will go across with support. And this is where our Donaldson timetable will need to synch, so when LRC are doing science mainstream will be also be doing science, and Year 5 & 6 might be doing science, e.g. there's no reason why [a child], with a 125+ reading / numeracy score couldn't be accessing the curriculum (S6)

This quote is quite relevant as it demonstrates a fundamental belief in pupil progress and inclusion to mainstream education. This was corroborated by LA1: '[…] *our aim is to go with it (ABA) intensively and get them out into mainstream'.* As noted in Chapter 1, the literature supports that the subjective assessments of professionals be taken more seriously, and as this quote suggests, the participants have a context from which to base their belief (Denne, Hastings & Hughes, 2017). Whilst the intentions for inclusion are worthy, and with further evidence gathered from ABA programmes when in place, there would be more specific data on children's behaviour and learning progress that could support that as progress. However, as S5 noted: '[…] *the only consistent structure that you have at the moment is the IEP'.*

How the tension because of the delay impacted on the school Staff

The impact of the delay in implementation on staff was also considered in this research. The paucity of ABA training has been discussed earlier, but the result of the increasing numbers of children joining the unit since its opening has made an impact. Workload and its complexity have increased, as S4 said: *'Not only that they have had new pupils as well, the class has almost doubled',* S4. Within this complex of increasing numbers, diverse needs and educational challenges, those teachers and support staff with limited

experience of behaviour issues, and or SEN teaching were finding it challenging to implement the national curriculum: *'Obviously if you haven't got the behaviour sorted there's no point to the education'* S4. But the main impact on staff was reported as being the growth of the unit and the issues around staffing it:

> I think being honest the LRC grew too quickly and wasn't staffed appropriately and they appointed somebody who wasn't able to start, and (because of) personal circumstances its changing again, it hasn't been able to bed in the academic planning (S4)

In summarising the key factors that have contributed to the delay in the implementation of ABA in the unit, it appears that they are centred around, the research and knowledge of how to set up a unit for ABA; the funding and cost allocations for such a unit; the training of current staff and importantly the acquisition of a BCBA®.

The underlying tensions came from parents pressuring the local authority for ABA and unit placements, the local authority responding and placing pupils in the unit until it reached capacity while planning for ABA was taking place. The school were under pressure to accommodate increasing numbers into what became a generalised autism unit, while trying to focus on specialising their staff in ABA. The evidence could not say conclusively whether it was just resource constraints that limited the scope of research that the local authority and school undertook to equip them with the necessary research and knowledge required to lead on an ABA unit. Since writing, the local authority have now sourced and released funding for a BCBA®. The school and local authority were presumably waiting for this to happen first, and from there, their level of knowledge of what was needed to run an ABA led unit became evident.

Chapter 5: General Discussion

Summary overview of the current research evidence

This thesis focused on the provision of ABA-based education for young children with Autism Spectrum Disorders (ASD) in a mainstream school unit in Wales. More specifically, the research explored some of the factors that influence the decisions that parents and providers make when they choose and commission ABA-based interventions

The question of how ABA-based interventions move from home programmes into mainstream classrooms in Wales is relevant to parents, teachers, commissioners of services and researchers. The contribution that research makes to this process is significant if the evidence of effective interventions is going to inform changes that are made in the classroom, in the planning of provision and changes to education policy for children with ASD in Wales. Moving ABA into mainstream classrooms is not without its challenges, as this dissertation's review of literature and evidence of tensions experienced by parents and providers shows. ASD children have made gains in studies using lower intensity programmes in classroom settings which is beneficial to the move into schools. Integrating ABA-based interventions with the national curriculum is complex requiring intricate individualised programmes aimed at developing specific skills for each child devised by a BCBA®, delivered by trained staff, monitored and amended regularly (BACB®, 2019; Eldevik et al., 2012; Grindle et al., 2012)

The evidence emerging over the last three decades of the effectiveness of ABA for some children with ASD is widely available (Howlin et al., 2009 and Reichow et al., 2012) as is the research documenting the application of ABA as EIBI (Lovaas, 1987, Eikeseth et al., 2002; Eldevik et al., 2012, Lai et al., 2014; Howard et al., 2005). The evidence further emphasises the more intensive the programme of 40 hours a week (Lovaas, 1987) and the earlier the intervention the better the outcome for these children (Lovaas, 1987; Howard, et al., 2005 and Remington, et al., 2007); yet EIBIs are still not recommended for the support and education of children with ASD in the Welsh education system, despite the potential

long term financial savings for parents and local authorities if the outcomes of EIBI for ASD children enables them to attend mainstream schools EIBIs would need to evidence that they generate larger benefits or cost savings to be more fully persuasive (Rodgers et al, 2020).

Combining the benefits of EIBIs with the potential benefits of inclusion for children with ASD in mainstream schools is constructive, forward thinking and cost effective, as the costs of supporting those with ASD in the UK is estimated at £34 billion per year (Rodgers et al., 2020). However, an intensive EIBI delivery model used in home-based settings does not lend itself easily to the school system as integrating a one-to-one intensive approach for 20–40 hours a week is not practical in a mainstream school day; but the available research of ABA-based interventions in schools that is emerging is promising (Eldevik et al., 2006; Kovshoff et al., 2011; Grindle et al., 2012; Peters-Scheffer, et al., 2010; Foran et al., 2015; Lambert-Lee et al., 2015 and Pitts et al., 2019). Eldevik, et al, (2006) was the first to report data on an application of ABA in a school system using much lower intensity EIBI programmes (12 hours across a school week for 38 weeks a year), resulting in significant outcome gains for young children in IQ, language and communication and adaptive behaviour measures. Kovshoff et al's., (2011) study with ASD children in a school setting extended on Remington et al's (2007) EIBI study with those children in their previous home-based EIBI setting. Again, with fewer intensive behavioural intervention hours across a school week and year (approximately 38 weeks) the children made gains in their IQ, language and communication and adaptive skills measures. Further studies of behavioural interventions in mainstream school settings by Grindle, et al, (2012) and Peters-Scheffer et al., (2013) delivering an average of 3.75 and 6.5 hours across a school week of behavioural intervention reported similar gains in the aforementioned measures. More recent studies in Welsh and English school studies by Foran, et al., (2015); Lambert-Lee, et al., (2015) and Pitts et al, 2019) where lower intensity behavioural programmes were delivered in ABA specific classrooms in a SEN schools (Foran et al., 2015; Lambert-Lee, et al., 2015; & Pitts, et al., 2019) reported positive gains made by ASD children in language and communication and adaptive skills. What was noteworthy in the last two studies cited is the children's age at the start of interventions. It was six to 18 years in Lambert-Lee et al., (2015) and four to 13 years in Pitts et al's., (2019) studies, both producing significant evidence of improvements in learning to learn skills. Improvements achieved in older children's outcomes is encouraging

evidence for ABA in schools, as progression is expected in mainstream schools from EY Foundation classes to Key stage 2 and 3. Children will progress from one education stage to the next whether their IQ and skills outcomes have improved or not; but a key factor of importance to parents and providers is the degree of inclusion in the education system and society that can be achieved as a result of their improvements. Demonstrating improved outcomes and subsequently improved inclusion for ASD children is positive news for parents and providers when we consider there is a finite number of ASD specific schools, SEN places in all authorities, and across the UK a deficit of over 7,500 ASD places (Griffith, et al., 2012). Schools would benefit from being more specific and effective in how they teach children with ASD in a 'system [that] has failed them' (McNerney et al., 2015; Lenehen et al., 2018).

Given that cost is cited as one of the main criteria of ASD child placement and intervention choice by authorities (Denne, 2017), it is self-evident that mainstream school is the most appropriate setting for some ASD children to receive their education and behaviour interventions. The resistance to promoting behavioural interventions by commissioners of ASD provision is complex (Denne, 2017 & Dillenburger 2012), and has a root in the cost implications of providing ABA, training staff to deliver interventions and devise and supervise that delivery. Resistance to ABA is also believed to be due to providers misunderstanding ABA on a fundamental level as a category mistake (Keenan et al., 2015; Dillenburger et al., 2010). McMahon & Cullinan (2016) speculated that a category mistake develops from professionals perceiving behavioural interventions through a constructivist perspective of child development (Piaget, 1976; Wadsworth, 1996), and as a result, making judgments based on one intervention being better than the other, not different; for example, eclectic interventions are better than behavioural interventions. There is evidence that suggest that EIBI is more effective than other eclectic interventions for some ASD children (Reichow et al., 2012), and there is promising evidence that successful low intensive behaviour interventions can be implemented in mainstream schools for ASD children (Eldevik et al., 2006; Kovshoff et al., 2011; Grindle et al., 2012; Peters-Scheffer, et al., 2010; and Foran et al., 2015). But providers of services are not deciding on provision from an evidenced based perspective, therefore misunderstanding ABA is perpetuated, and therefore the misunderstanding encourages policy makers to work against providing evidence-based ABA practices (Dillenburger et al., 2010 and 2014). Addressing the category

mistake at a provider level is a much needed activity, but in the meantime parents and their children with ASD are being denied interventions that could be effective (McPhillemy & Dillenburger 2018; Gillan & Keenan, 2017)

Overview of my research aims, findings and contributions

This research aimed to explore two things: firstly, the motivations behind parent and provider decisions to choose ABA as a school based intervention for children with ASD, and secondly to understand the barriers and tensions associated with setting up a unit to deliver ABA-based interventions in a mainstream school in Wales. Some of the issues that the school faced when setting up the ABA-based unit were reviewed and analysed using a qualitative research method. Central questions to the stakeholders related to the factors that influenced parental and provider decision making when choosing ABA as an intervention. The evidence base for the effectiveness of ABA in ASD treatment is well established (Eikeseth et al., 2002, Chasson, et al., 2007; Freeman, et al., 1991; Howard et al., 2005 and Zachor et al., 2010), and we know that parents make critical intervention choices for their children without much support or guidance from professionals (Romanczyk & Gillis, 2005; Miller et al., 2012; Tzanakaki et al., 2012; Grindle et al., 2009; Dillenburger et al., 2010; McPhillemy & Dillenburger, 2013; McNerney et al., 2015). We also know that parents often make intervention choices based on anecdotal and or belief-based evidence, but we do not yet have insight into the factors that truly motivate the following of that anecdotal and belief-based decisions. Indications are that the cost of home-based ABA interventions, additional pressures families experience as a result of ABA at home, and positive child outcomes are motivating factors for choosing ABA (Green, et al., 2006; Tzanakaki et al., 2012; Dillenburger et al., 2012 & Denne, 2017).

Accessing ASD provision in Wales is done through the health and local education authorities and SEND services (WAG, 2015), but providing ASD interventions involves a complex process of commissioning where providers across multi-agencies balance the child's needs against the health board's and local authorities' competing demands. The

competing demands of cost of interventions, the child's individual needs and parental demand for interventions have been identified as the providers' key motivators of decision making. And, these decisions are often weighted towards providers' perceptions of the value of ASD interventions, not on the evidence of their effectiveness (Rees et al., 2014; Wye et al., 2015; Denne, 2017). Inevitably, the competing priorities for local authorities has created confusion and tension for both providers and parents. In practice, professionals (SEN teachers) surveyed in Ireland have reported in a recent study that their self-perceived knowledge of ABA exceeded their actual knowledge, and that their knowledge of ABA was not related to their statutory training (Fennell & Dillenburger, 2018).

My current study was an opportunity to research the influential factors that motivated ASD intervention decision making, using a qualitative, semi-structured interview method to gather data on why the parents and providers chose ABA as an intervention. At the time of data collection, the unit was set up in the school, but ABA was not implemented, which gave me the opportunity to investigate the parents and providers' motivations for choosing ABA at a time when their confusion and the tension was quite high, and they were openly expressive.

Earlier studies by Denne (2017) in the UK's first internet survey of parents' beliefs about ABA to support children with ASD; and Green et al., (2006) both highlight the need for further research into the influential reasons behind parents' decision making when choosing behavioural interventions for their children. Wilson et al., (2018) found that parents cited a number of reasons for treatment choices which included the child's individual needs, the cost, the child's age; and their hope for improvement and recovery as well as concerns about side effects. Further research into the significance placed on the factors that influence parental decision making is necessary to get a better understanding of their underpinning motivations. In turn the research allows us to target educational approaches that promote evidence-based practice.

These studies' recommendations and the protocol used by Green (2007) have influenced the direction my research has taken, and the types of questions I asked participants in my study. These were based on a small number of questions that focused on how parents came to learn about ABA, their understanding of it and experience if any; as

well as their perceptions about its benefits and drawbacks. I also asked about the difficulties parents had in sourcing ABA and general school provision, and any expectations that they had for their children. Using a qualitative method, the study's two objectives were, firstly, to analyse and discuss stakeholders' perceptions about the decisions they make when choosing ABA interventions in the treatment of ASD, which was done to find out more about what influenced their decision making. Secondly, it was to analyse and discuss the process of implementing ABA-based interventions in a mainstream school ASD unit. This included the barriers perceived by the stakeholders and the resultant tensions experienced by the providers intending to deliver ABA.

Findings

A summary of the findings from Chapter 3: The motivations of parents and providers to choose ABA is presented first, then a summary of Chapter 4 findings: The central tensions and barriers to implementing ABA in the school unit. From these two sections the limitations of my study, reflections on the process undertaken and the outcomes I achieved are used to make recommendations for future research in this area.

Summary of findings

Motivations - Why parents and providers chose ABA

Parents

In the parent participant group three parents had direct experience of ABA from home-based EIBI programmes delivered by an external provider, some of which was self-funded. The fundamental question of what was driving their decisions to choose ABA was answered in two ways. Firstly, those parents with previous experience of ABA had seen positive changes in their children's behaviour and adaptive skills, and they wanted to continue the intervention. Secondly, they had previously conducted their own research into

ASD treatments, and subsequently followed the recommendations of others, not necessarily professionals and accessed a local external ABA provider (Tzanakaki et al., 2012; Grindle et al; 2009; Dillenburger et al., 2010).

There was a suggestion in the data from the school and local authority that the external private provider was influencing the parents to choose ABA and consequently driving up the demand for ABA. However, other than one parent reporting that ABA became a *'crutch'* (P7), I had no conclusive evidence to confirm the external providers were indeed influencing the parents in any way. All the parents with experience of ABA reinforced that the cost of ABA was a barrier to their accessing the provision through the external provider, but there was no indication that their demand for ABA was being influenced by anything other than their own drive for it (Chasson, 2007; Denne, 2017). It is probably reasonable to assume that the availability had increased demand for ABA.

Those parents with no experience of ABA were conducting their own internet based research on behavioural interventions and also following the recommendations of other parents, friends and non-professionals (Tzanakaki et al., 2012; Grindle et al; 2009; Dillenburger et al., 2010). For some within this group it was coincidental that the unit would be providing ABA, as their prime concern was finding a suitable and stable school placement for their ASD child. Nevertheless, what was evident in the parent data was that they all experienced challenges in accessing provision, whether it was ABA based or eclectic (Dillenburger et al., 2010). Parents were challenging schools, the local authority and related professionals to source what they felt were the best options for their children. There seemed to be little support for them during the challenges they perceived as difficulties (Green et al., 2006; Tzanakaki, et al., 2012; Dillenburger 2010; Khanas, 2014), although some was available through EY multi-disciplinary teams, and the school itself was emerging as a support network (McPhilemy & Dillenburger, 2013). Parents were perceived as 'vulnerable' to the providers in my study, yet despite a perceived vulnerability, parents sourced ABA or the funding to obtain it. Fundamentally, my data showed that parents were mostly influenced in their decision making by their own independent research evidence, other parents, and the internet (Green, 2006; Tzanakaki, et al., 2012 and McPhilemy & Dillenburger, 2013) this data corroborates Denne (2017).

The central roles that perceptions play in parental ASD provision decision making has shown to be valid in my research, and as parents are the key decision makers in their children's ASD provision their belief in what will work for their children has been the driving force behind implementing ABA in this (Dillenburger, 2012), and Denne's (2017) study into parental beliefs about ABA in a mainstream school. The latter study showed that previous experience of behavioural interventions, high parent education and high household income were associated with positive beliefs about ABA. I found previous experience of ABA a key motivator in parental decision making, but as I did not include any questions in the interviews on parent education and household income, I am unable to report on the outcome of those variables in my research. This is a shortcoming of this current study's methodology.

Providers

Local Authority rationale for providing ABA

The providers in this study were the school and the local authority, and in exploring their rationale for providing ABA, what was evident from the data was that neither teachers nor local authority providers were as knowledgeable about ABA as they perceived they were. This was to be expected, given the strategic decisions made that the school and staff structure had to accommodate to implement ABA (Fennell & Dillenburger, 2018). We know that misunderstanding ABA can have powerful effects on policy and decision making when providing ASD provision. In this current study, the misunderstandings (category mistake) appear to have been made in the early stages of the unit's development, despite attempts by the local authority to avoid doing so by seeking guidance on how to implement a best practice model of ABA in a mainstream school from researchers in Bangor University. Current evidence on the effectiveness of behavioural interventions in school settings is widely available (Eldevik et al., 2006; Kovshoff et al., 2011; Peters-Scheffer, et al., 2010; Lambert-Lee et al., 2015 and Pitts et al., 2019) and specific examples of ABA in Welsh schools is both recent, and demonstrates positive outcomes for children's improvement in IQ, language and communication and adaptive skills (Grindle et al., 2012; Foran et al., 2015).

What has emerged from my data is that whilst the local authority made attempts to avoid making a category mistake by seeking appropriate guidance and advice on implementing ABA into a mainstream school, it appeared that a misunderstanding had already been made (McMahon & Cullinan, 2016). With the focus on adhering to the SEND Code of Practice (2015) guidelines on commissioning evidenced based interventions for ASD, they perceived that they were attempting to avoid making a mistake that they had already made. The providers were responding to parental demands for ABA-based interventions, which was a way of meeting the SEND Code of Practice (2015) as they had sourced evidence based interventions, but they had not acted on the recommendations of the available research which identified an effective model of delivery in a mainstream school.

It is understandable that the local authority had not thoroughly researched the current behaviour intervention models of good practice in school settings, as the case studies of ABA-based interventions in a mainstream school are few. Griffiths et al's., (2012) census, recently updated by ABAAccess4ALL, (2020) identified that there are only three mainstream schools in Wales providing ABA-based interventions in the way that this school wanted to. In addition to the authority's limited research on models of best practice, the field of behaviour analysis has also fallen short of making it clear that ABA as an applied branch of the science of behaviour analysis is different to the procedures that are based on ABA (Smith et al., 2013; Denne, 2017). This shortfall has left the decision makers in my study confused and frustrated about how to deliver the provision, as the evidence on how-to deliver ABA-based interventions required a much deeper exploration than this authority and school had made at the outset.

Recent Welsh examples of ABA in an SEN school setting by Foran et al., (2015) and an ASD unit in a Welsh-medium mainstream school (Walker-Jones & Hoerger, 2015) formulate a model of low-intensity ABA intervention that have both a Welsh cultural and language context and show positive outcomes. Neither of these last two studies were in a mainstream school, so evidence of ABA interventions making a good fit with the national curriculum is sparse. One very recent example of the benefits of ABA supporting academic learning is Pitts et al., (2019), where researchers in a maintained special school evaluated the impact of behaviour interventions improving learning to learn skills that reduced the barriers to learning for older Key Stage 2 and 3 learners. This evidence is positive for the

school in my study, even though it is was not in a mainstream setting. The unit in my study developed very quickly into two classes, one for Foundation and the other Key Stage 2 aged children (6 to 11 years). Being able to access some academic work at national curriculum level in the unit is therefore hopeful for the children's future academic progress and inclusion. My evidence showed that whilst the school was a mainstream school the interventions were intended to be delivered in a specified ASD unit; and if improvements were made that enabled a transition to mainstream classes was within the learners' capabilities, a transition and progression to the main school could be readily facilitated.

As the local authority saw it, the demand was perceived to have come from the parents first, concurrently with their desire to avoid further tribunals (Tzanakaki, et al., 2012; Dillenburger et al., 2012). But their final decision to provide ABA was a pragmatic one, made by balancing up the costs of the provision if delivered in home-based programmes by external providers against the strength of parental requests (Denne, 2017). Having made a policy decision, implementing the model was more complex than first anticipated. Despite there being widely available evidence of the effectiveness of behaviour interventions in schools and models of their delivery in schools, my study highlighted that clear guidance on how to set up, manage and resource a mainstream school setting to deliver behaviour interventions was missing. My findings corroborate those by Denne (2017) and Matson & Konst (2014) suggesting a need for a specific guidance on the complex process providers and commissioners of ASD services undertake in local authorities and schools.

Rationale for the school to deliver ABA

For the school to implement ABA, it was not so much a choice, but a plan to deliver part of the local authority's change in SEN strategy, which was based on parental pressure and the cost of externally provided ABA. My data showed that the school's knowledge base of ABA and their perceptions of the benefits and drawbacks of ABA were challenges to the implementation of behaviour interventions in the unit. Little to no training of school staff (managers, teachers and LSAs) had taken place, except for one introductory session on ABA. At the time of data collection, the staff were waiting for online RBT® training to be available in the following academic year (2018-19).

Responses from the school staff indicated that they thought they had a better understanding of ABA than they did, as highlighted in the research literature (Fennel & Dillenburger, 2018). Some critical responses were noted of their perception of the local authority's knowledge of ABA. School staff perceived the local authority were reactive in their planning and commissioning of ABA provision but indicated that they recognised the overall positivity in the strategic decision to set up an ABA led unit. These perceptions are both understandable as the commissioning service was working without clear guidance on how-to set up a unit to deliver ABA-based interventions. The school staff were very positive about the unit becoming an ABA led provision and were enthusiastic about training as RBTs®. At the time of data collection, the school was also waiting for a BCBA® to be commissioned to devise, manage and supervise staff delivering any ABA programmes.

As teachers and support staff, their perceptions about the positive benefits of ABA were evident; especially for tracking the progress of SEN children in terms of behaviour but also for academic progress (Pitts et al., 2019). The results showed that some of the key stage 1 and 2 children who were operating within the national curriculum standards in the unit were capable of transitioning to mainstream and national curriculum levels. A few of the pupils had already done so and were now based in a main school classroom after a period of transition with LSA support. This was a positive and progressive move on the part of the school to develop flexibility for integration and inclusion into mainstream classes where children were able to do so.

Parents were reported as being satisfied with the provision in the unit, which concurs with Dillenburger et al's., (2012) study where parents of children receiving ABA-based interventions were generally more satisfied than their counterparts receiving TAU. Both the local authority and the school, in my example, were aware that they were operating a 'holding' scenario as ABA-based interventions were not being delivered. However, providers were aware that whatever levels of satisfaction the parents were expressing, it would be short-lived should ABA not be forthcoming. The school staff in this study expressed confidence that the provision they were delivering, albeit eclectic was meeting all the children's needs in the absence of ABA, and staff reported that they preferred this to the home-based ABA programmes that the external provider was

delivering. The rationale given by school staff was that children in a school setting had the possibility to focus on both adaptive skills and progress academically at the same time.

The school staff's view of the drawbacks of ABA was based on how they perceived behavioural interventions would be delivered on a daily basis in the classroom. Teachers and support staff expected the classroom set-up for delivery would be the same as that for home-based models, where intensive programmes are delivered up to 40 hours a week (Lovaas, 1987). However, this school had opted unknowingly for a model based on other studies such as Grindle (2012); Eldevick et al., (2012) and Foran et al., (2015) which used a low-intensity school based ABA model in a classroom setting, to produce positive outcomes in IQ, language and communication and adaptive skills. The model this school had chosen to follow would be delivered in a designated behaviour intervention classroom within the unit (Grindle et al., 20012; Foran et al, 2015). My data showed that the school had opted for this model based on their early consultations with researchers from Bangor University, combined with their decision not to commission the external provider. Despite this fact, there was no evidence to suggest that the providers had disseminated any information or evidence of what constitutes an effective school based ABA model to other teachers and LSA's in the school.

One key finding from data on parental motivations for choosing ABA was that the parents' success with legal tribunals against the local authority did not have any effect on the speed that ABA-based interventions were implemented in the school unit. While the pressure from parents was reported to be the motivating factor in provider decision making where ABA was concerned (Denne, 2017); parents' continued pressure did not seem to affect the interventions' timely implementation. From my data, the local authority's motivation to deliver ABA came from three different directions: the parents' demand for ABA, the cost of externally funded ABA and the legacy planning from a previous head teacher.

Summary of findings

Central tensions and barriers to implementing ABA in the school unit

The focus of Chapter 4 was to explore the causes and impacts of the central tensions the parents and providers were experiencing during the set-up of the ABA unit in the school. My findings suggested that the tension stakeholders experienced stemmed from the providers' promise to deliver ABA-based interventions, and the challenges that they experienced in implementing them. In light of the fact that, the providers, the local authority and school were developing an ABA led provision without guidance from any statutory authority, with no BCBA® expertise to draw from at the time of data collection, it is understandable that tensions existed. What was of interest to my study was how the providers reported their management of those tensions, and how they worked to resolve them. There is only a small sample of evidence of effective ABA-based interventions being delivered to date in mainstream schools in the UK, not least Wales. Unlike other ABA-based school settings (Grindle, et al., 2012; Eldevick, et al., 2012 & Lambert-Lee, et al., 2019) the school in this current study did not have an appointed BCBA®, nor a behaviour analysis advisor in the local authority to guide the planning and implementation of the model they had adopted. However, this setting was a very good example of a school at the very early stages of doing so. Not having a BCBA® in post appears to have prolonged the process of implementation at delivery in classroom stage but also in the planning stages. The result was a delay in delivering ABA-based programmes and high levels of tension between the stakeholder groups.

Central Tension:

Two main themes comprised the central tensions that were perceived in my study's evidence. Firstly, there was the delay in implementing ABA-based interventions, with the challenges and barriers to implementing ABA cited as the cause of the delay; and secondly, the increasing number of children in the unit. Whilst the latter was a challenge to providing SEN provision in general, and a barrier in itself, the increasing numbers were not a direct impact of the promise to provide ABA by the local authority. The issue of the increasing pupil numbers will only be touched upon in this discussion as the relevance of that issue was

the impact that it had on the teachers' and LSA's workload. An increase in staff workload and the accompanying tension drew focus away from the process of implementing ABA in the unit. Staff reported to be under resourced to manage the 24 children in the unit (Fennel & Dillenburger, 2018).

The central tension was created by a conflict between the promise to provide ABA, and the delay in implementing behavioural interventions in the unit. There was no BCBA® in place, and staff were not trained to deliver ABA-based interventions. The next section will explore the issue of the delay further, in terms of staffing and training required to deliver behaviour interventions in a school setting, the funding situation experienced and the perceived tension between the different stakeholder groups.

Delay

Firstly, the delay in implementing ABA in the school unit which was perceived as complex by the providers was partly due to the staffing and training situation.

Staffing & Training: At the time of data collection, there was no BCBA® in place in the school and the providers were unclear on how to source one. It was also unclear from the data whether the local authority was unsure of the practicalities of sourcing a BCBA®, or whether there were issues within the wider authority of financially supporting a BCBA® post. In other successful models where ABA is delivered in school settings the school had a BCBA® on the staff team as noted in the earlier research, which meant that accessing expertise and guidance was straightforward. In my study, the school's desire to avoid a conflict of interest by commissioning an external provider to deliver the ABA programmes added to the delay in delivering ABA in the unit, but in the longer term, the provider participants felt it was the more robust decision to make, as reports suggested the school was enthusiastic about developing expertise from within the staff team and building a knowledge base for best practice delivery (Matson & Konst, 2014; Fennel & Dillenburger, 2018). However, in the absence of appropriate guidance and consultation to navigate the best practice of implementing ABA as a school model, it added to the delay the school were experiencing.

Cost and funding issues*:* The costs and rising costs of parental demands on the local authority sparked the initial decision to provide ABA in-house, but the costs of the BCBA®, staff training for RBT® and follow on supervision was not sufficiently considered. It was not clear from the evidence why this was the case, as it was indicated that funds were ring-fenced for this. Possible reasons include the slow release of funds from the procurement side of the local authority, or a lack of pro-activity on the part of the senior managers in the school and local authority to push the initiative further, or both.

Perceived tensions between the providers*:* School staff perceived that the external providers were promoting unrealistic expectations through the parent group, on to the local authority and school. Parents were motivated to demand ABA and were bold in doing so. The school had raised concerns about the quality of the external ABA home-based programmes, particularly with respect to the children's academic and overall educational progress. The school was also in a difficult juxtaposition between the parents, external providers and the local authority on this issue, as they reported that the tensions were compromising their ability to provide good, if eclectic, ASD interventions. Some of this was perceived to be because of the delays in the planning, managing and implementation processes of the original promise to provide ABA in the school, but also to do with the local authority's policies on placing children in specialized units. Each party in the stakeholder group experienced some degree of tension with both the other parties. The data suggests that only the local authority as policy maker and overall decision maker of ASD provision was best placed to break the grid-lock. Not having the necessary guidance on how to set up a new ABA led provision was therefore at the core of this project's tensions and delays.

Aside from the absence of guidance, what is also of interest is that some of the tensions that arose between the stakeholders was about the differences between the model intended to be used by the school to deliver ABA-based programmes and the model the external provider used. The school saw it that their remit was a much wider one than that of the external provider's, in that they were focused on removing the barriers associated with functional skills to learning so that academic learning could take place (Pitts et al., 2019).

The providers, school and external providers were operating from very different models; one a low-intensity school delivery model in the region of 15 hours a week and the other a high intensity provision of up to 40 hours per week. The external providers were not consulted in this study, but from the evidence given by the parents, the majority of the home-based programmes that the external provider was delivering were cited as low-intensity.

The number of children accepted into the unit.

The second cause for the delay in implementing ABA in the school was cited as the increase in the number of children that were admitted into the unit. The original number was set at 12, six children in each stage of the EYF phase and KS 2. This rose quickly within the first 18 months of opening the unit to 24, with 12 children placed in each Key Stage classroom. The relevance that the increase in pupil numbers had on the implementation of ABA in the unit is used in this instance to highlight the absence of planning at local authority level for the set-up of an ABA-led provision. The absence of planning appears from the data to be because of a lack of available guidance for the commissioners of ABA-based ASD services to follow, but also inertia to seek it.

How the pupil referrals to the unit were made by the local authority was questioned by the school, and it was noted that the school were often excluded from the placement decision making. Cuts made to the schools' budget shortly after the unit opened also influenced the development of ABA in the unit. Budget cuts were made at a time when the increasing pupil numbers began to impact on the staff's resources and ability to manage the complex nature of the incoming children. However, at the time of data collection the local authority and the school staff had redressed their placement planning strategy, so that a focus could be resumed on the implementation of ABA not populating a general ASD unit. Having effective guidance at the outset of the provision planning could possibly have reduced, if not avoided the impact of reactive decisions made by the providers.

Finally, the impact of these tensions between the providers and parents resulted in the current 'holding' situation the school was experiencing. The local authority perceived

that they were providing well for the children in the unit, albeit an eclectic provision, but they were aware that it was a short term situation for them until a BCBA® was either in post or commissioned, and ABA-based interventions being delivered. Kovshoff et al., (2011) evidenced in their two year study that children receiving privately commissioned BCBA® devised and supervised behavioural interventions made significant and prolonged gains in IQ, communication and adaptive skills than those receiving interventions that were convened by university-based behaviour analysts and delivered by local authority staff. The privately commissioned interventions were perceived as more intensive and used consistent therapists to deliver the interventions, so the key notes are interpreted as intensity and consistency.

At the time of writing up this dissertation, the school have confirmed that they do now have a part-time BCBA® in place, commissioned by but not appointed through the local authority; four support staff are trained as RBTs®, and appropriate ABA supervision is taking place in accordance with the BACB® Professional and Ethical Compliance Code for Behaviour Analysts (BACB®, 2014).

Limitations of the study, conclusion and recommendations for future research

This thesis has explored the availability of ABA-based education and learning provision for children with ASD; and to some extent evaluated how ABA can be introduced into a new unit in a mainstream school. The core interest was the motivation behind the decisions that parents and providers make when choosing, and providing the ASD interventions that they do.

It became clear over the course of this dissertation that there were no easily accessible guidelines available for any of the stakeholders on how to implement ABA in a mainstream school, nor how to access ABA in a mainstream school. Despite seeking guidance at the start of the project the local authority faced a number of barriers in their search for a BCBA®, releasing funding for staff training and in disseminating information on

practice to the school and related multi-agency teams involved in commissioning services. The school worked to the local authority directive in preparing to deliver ABA interventions at classroom level, but were delayed because of no BCBA® and lack of training; and parents were sourcing their information on ABA for themselves. There is guidance available for the training and supervision of behaviour analysts and RBTs®, and there is internal guidance at local authority level on how they commission their services, but there was no bridge for the gap perceived in the stakeholders' knowledge of ABA and their ability to translate that into practice to deliver ABA-based programmes in a mainstream school (Denne, 2017). Without a BCBA® to advise the local authority and school on the practice of ABA, and any statutory framework to follow on implementing school based ABA models, the providers remained frustrated and the delays in service provision were inevitable. There is a need for further research into the development of a guidance framework or protocol on how best ABA practice can be implemented in mainstream school settings. The development of which should include the commissioners of the ASD provision and the multi-disciplinary teams that signpost parents through the system (Guldberg 2010; Khanas, 2014; Matson & Konst, 2014). The contribution that an implementation guidance framework would make to the future success of school ABA-delivery models may support the widening availability and subsequent access of ABA to schools who do not have any established ABA practice (Freeman et al., 1991). To support the implementation of behavioural interventions in mainstream schools a recommendation is that commissioners of services, school practitioners and other multi-agency professionals who are part of the ASD support mechanism are involved in the development of an ABA implementation framework. These data could go some way to addressing the deficit of knowledge of ABA perceived by professionals (Fennel & Dillenburger, 2018); and the issue of category mistakes could be removed if the stakeholders were involved from the outset.

Conclusions

The thesis started with questions about the availability of ABA based education and learning provision for young children with ASD in a Welsh local authority, and the motivations behind parents' and providers' decision making processes. What I found from my data was that implementing ABA-based interventions in a mainstream school created an array of tensions which came from a deficit in a number of core, and critical understandings about ABA and how to implement it. The first of those critical understandings is that a concept shift is required for all those stakeholders involved in the process of implementing ABA in mainstream schools to understand what ABA is. As an applied branch of the science of behaviour it can be many things as each ASD child's needs differ and change over their time in education services (Fisher, Piazza & Roane, 2011). A concept shift necessitates a deeper inquiry from commissioners of ASD provision to get it right, and direct resources and staff effectively. Secondly, what motivates parents to choose ABA requires deeper analysis of both the implicit and reported reasons for decision making (Wilson et al., 2018). Thirdly, having robust evidence of the effectiveness of ABA-based interventions in making transitions from home-based to mainstream school settings and measuring the effectiveness of improvements to academic learning is necessary for the success of best practice models. Fourthly, there is a point at which the stakeholders need guidance that is based on the evidence of effectiveness, and of how to implement best ABA practice in a mainstream school (Freeman et al., 1991; Denne, 2017).

The overall and most important implication from this research, then, lies in developing an approach that takes a continued and diligent account of the four critical understandings above; but more so, enables a more widespread implementation of ABA-based interventions in mainstream schools. The current cost of ASD provision was cited at £3.4 billion per year seven years ago and is unlikely to reduce (Rodgers, 2020; Buescher et al., 2014). There are at least two undiagnosed children for every three diagnosed (Baron-Cohen, 2012), suggesting that the numbers of ASD children needing effective evidence-

based education will not be reducing soon. Cost of ABA-based provision is the first criteria considered by commissioners and providers of services when choosing provision for ASD children (Denne, 2017). Therefore, continuing to address the first three critical understandings separately, through further research will benefit the existing data that professionals can draw from that enables them to make more evidence-based decisions.

How this research can be used to bridge the gap between researcher and stakeholder

As noted above, I explored the tensions that parents and providers experience in implementing ABA in a new ASD unit in a school setting and my findings highlighted an understanding of the difficulties these stakeholders found in relating policy to evidence-based practice. Therefore, developing a guidance document on 'how-to' implement ABA-based evidence-based practice in school settings is perhaps an expedient starting point. Commissioners of ASD services were basing their decision making on what they perceived was evidence-based practice without a clear understanding of that practice, or what was truly needed to implement it in the school. This is despite the SEND Code of Practice (SEND, 2015) specifying that the services and interventions provided should be drawn from evidenced-based. My research outcomes, through the development of a guide on 'how-to' implement ABA-based interventions in mainstream classrooms, could make some in-roads into bridging the gap between researchers and the invested stakeholders (Matson & Konst 2014).

Evidence-based practice is a set of principles and practices to be adopted and developed for implementing in the classroom by teachers but also by researchers. It is a way of approaching the implementation of ABA-based interventions practically, and applying 'what works' back to policy in the knowledge that good evaluative procedures will encourage changes to the core-critical understandings required to support the wider adoption of ABA in mainstream schools (Hargreaves, 1996; Reynolds, 1998; Hillage, et al, 1998; Tooley, 1998; Atkinson, 2002)

Traditionally, not all teachers are researchers and vice versa; and the vivid discourse amongst ABA experts serves to confound the misunderstanding and confusion that practitioners experience when engaging with evidence-based research papers (Foster, 2014; Keenan, 2015; Jordan, 2001). Affording practitioner-teachers the time, effective initial training, continuing professional development and a bridging guide to implement effective evidence-based practice will inevitable support the adoption of ABA-based interventions in Welsh mainstream schools (McLellan, 2016; Guldberg, 2009).

All stakeholders with a vested interest in the field of behaviour analysis and ASD provision would benefit from better collaboration and an understanding of the differences that could divide the practice. This is a process that will require dedicated resourcing and potentially some enabling policy changes; and lastly, better multi-agency collaboration (Guldberg, 2009; Khanas, 2014; McMahon & Cullinan, 2016).

Personal reflection

This Ed.D thesis has undergone a number of shifts and twists from its original intention. It began over twenty years ago as a PhD into the learning theory of addiction, exploring the use of behaviour modification theory and techniques related to what triggers certain addictive behaviours in people. My career has changed, and after re-training as a special education needs teacher predominantly with young people with ASD, the desire to make a real difference for children and young adults was rekindled.

During a master's course in Bangor University there was a possibility of changing my pathway to the Ed.D and as a result this thesis emerged. Throughout my career as a teacher and special education needs teacher I have never doubted that behavioural interventions work, and the notion that it could be widely available and accessible to children in SEN schools and mainstream schools is inclusion at its best. Enabling ASD children to develop skills that support their transition between home and school settings, right up to higher education offers children and young people with ASD that inclusion. My experience as a teacher, Steiner Waldorf teacher and SEN teacher has shown me that inclusion creates opportunities, and it opens up possibilities to succeed, achieve and gain access to employment, purpose and meaningful lives.

My interest in why parents in particular make the decisions they do has been a core question of this thesis. What motivates them to take on the authorities, campaign and challenge for access to a provision that is not widely available has been intriguing. I wanted to know more about the strength of belief behind their motivations to access ABA. This study only allowed me to go part of the way into that process. Had there been more time, a BCBA® in post in the school then data to support the effectiveness of ABA in this setting might have been available, and also allow me a deeper analysis of the driving factors of stakeholder decision making in the commissioning process. But what has tumbled out of this thesis, is that the providers and the parents want the same thing – effective interventions for children with ASD, and this is promising for ABA. All agents were pro-active up to the point where they ran out of resources and accessible knowledge on how to proceed with implementing behavioural interventions. This is where the researchers and practitioners in

the field of ABA can bridge the gap so that the commissioners of ASD services can give ASD children the best flying-start they deserve.

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APPENDICES

Appendix A: Ethics Consent

COLEG BUSNES, Y GYFRAITH, ADDYSG A GWYDDORAU CYMDEITHAS COLLEGE OF BUSINESS, LAW, EDUCATION AND SOCIAL SCIENCES

PRIFYSGOL
BANGOR
UNIVERSITY

05/02/17

Annwyl/ Dear Helena O'Boyle,

Yng/ Re: Staff Perceptions of the British Early Special School Teaching (BESST) Model.

Diolch am eich cais diweddar i Bwyllgor Ymchwil Moeseg CBLESS.

Mae'r pwyllgor wedi ystyried eich cais, ac fe wyf yn awr mewn sefyllfa i roi caniatâd, ar ran y Pwyllgor Ymchwil Moeseg CBLESS, i chi gychwyn eich prosiect ymchwil.

Dymunaf yn dda i chi gyda'ch ymchwil.

Thank you for your recent application to the CBLESS Research Ethics Committee. The
Committee has considered your application: Staff perceptions of the British Early Special School Teaching (BESST) model and I can confirm on behalf of the CBLESS Research Ethics Committee, approval for the commencement of your research project.

I wish you well with your research.

Yn gywir iawn/

Yours sincerely,

Dr. Marguerite Hoerger
Chair, CBLESS Research Ethics Committee Cadair, Pwyllgor Ymchwil Moeseg CBLESS

PRIFYSGOL BANGOR, CANOLFAN WEINYDDOL BANGOR, GWYNEDD, LL57 2DG

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Registered charity number: 1141565

Appendix B: Information Sheet

School of Education/ Ysgol Addysg
Prifysgol Bangor University: Education Doctorate (Ed.D) Degree Course

Why parents and providers choose Applied Behaviour Analysis (ABA) for Autism Spectrum Disorder: Motivations and barriers to implementing ABA in a mainstream school

Thank you for taking the time to read this. You are invited to take part in a study that is carried out by Lindsey Roberts from the Education Department in Bangor University. Before you decide to take part or not, it is important for you to understand why the research is being carried out and what it will involve.

The following information is for you to read and carefully consider before deciding whether you would like to take part or not. Please ask Lindsey Roberts if you need anything explained in more detail or if you would like further information to help you to decide.

The research project is evaluating the provision for children with Autism and aiming to assess how interventions including ABA-based programmes improve inclusion for children with Autism. It will also look at how parents / schools and LA decide which programmes to provide.

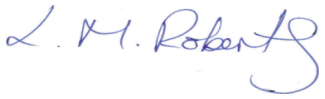
You have been chosen to take part in this study because you may be able to help us with understanding more about how to inform and guide service providers on the specific needs of parents to educate children with Autism.

If you chose to take part in the study you will be asked to sign a consent form to say that you agree to take part in the research, and that your child may be assessed before and after interventions; and that you agree to take part in an interview with Lindsey Roberts. This interview will not last more than an hour and will be at a convenient time for you. You will be free to withdraw yourself or your child from the research at any point without giving a reason. If you withdraw from this study it will not affect the educational provision your child receives at school.

All the information Lindsey collects about you will be strictly confidential, stored securely and will have any identifiable information deleted. The results will be used as a basis for a doctoral thesis as well as journal publications and conference presentations.

For any further information please contact Lindsey Roberts at edp38e@Bangor.ac.uk or 01570424737.

Thank you very much for taking part in this research



Lindsey Roberts (April 2018)

Appendix C: Consent Form

School of Education / Ysgol Addysg
Prifysgol Bangor University

Education Doctorate (Ed.D) Degree Course

Why parents and providers choose Applied Behaviour Analysis (ABA) for Autism Spectrum Disorder: Motivations and barriers to implementing ABA in a mainstream school

Consent Form

I confirm that I have read and understand the information sheet about this study and have had the opportunity to ask questions. I am therefore willing to assist *Lindsey Roberts* in her research work and for any interview work to be recorded and transcribed.

I understand that all documentation relating to this interview and / or my child's assessment in the study will be stored safely and will be destroyed at the end of the study.

I also understand that all her written work will be carried out with professional confidentiality, and I understand that my anonymity will be preserved on all research documentation, and that I can withdraw my consent at any time.

Print name: ……..

Signature: …… Date: ……

Researcher Name: Lindsey Roberts

Signature: ……..… Date: ……

Appendix D: Debrief Information

School of Education / Ysgol Addysg
Prifysgol Bangor University

Education Doctorate (Ed.D) Degree Course

Why parents and providers choose Applied Behaviour Analysis (ABA) for Autism Spectrum Disorder: Motivations and barriers to implementing ABA in a mainstream school

Debrief Note:

Thank you for taking part in the assessment of your child and a research interview for the above project.

This research project is evaluating the provision for children with Autism in Wales and aiming to assess how interventions and / or ABA-based programmes improve inclusion for children with Autism. It will also look at how parents / schools and LA decide which programmes to provide.

The intention of this study is to find out whether Autism interventions and / or ABA-based programmes are effective in improving school inclusion. It also aims to investigate some of the reasons why people choose the interventions for their children that they do, and why the schools and LAs provide them.

This was achieved by testing children's abilities in certain skills and functions before and after an intervention; then conducting a number of interviews with parents, school staff and key stakeholders in the LA, and asking them about their perceptions of the interventions and / or ABA-based programmes to find out why they decided to use or endorse them.

Please contact me: Lindsey Roberts, at the following e-mail address edp38e@bangor.ac.uk if you have any questions regarding this study.

THANK YOU AGAIN FOR YOUR CO-OPERATION

L. M. Roberts

Lindsey Roberts

Appendix E: Interview Schedule - Parents

Themes & Outline: Parent Questionnaire

1. **About your child**
    a. **General details**: Age, Gender, Family make-up, LA
    b. **Diagnosis**:
        i. ASD diagnosis?
        ii. When
        iii. How long was the process?

    c. **Current educational / intervention provision** :
        i. What choices did you have over school / education ,
        ii. Why did you make these choices?
        iii. What do you think will support your child and why?
            1. ABA?
            2. Other interventions?
        iv. What provision or therapies are you receiving?
            1. What challenges are you experiencing?
        v. Where are these interventions / therapies delivered?
        vi. How are these delivered?
        vii. Why did you choose this setting?

    d. **How did you learn about ABA**?

2. **Your Expectations:**
    a. **Expectations prior to interventions & ABA based programmes**
    b. **At home: Life skills**
    (e.g. social skills, communication, concentration, gross & fine motor skills, challenging behaviour, independence, quality of
    c. **At school : Academic Skills**
    d. **How have you met or tried to meet those expectations?**
    e. **Why did you make the decisions that you made?**

3. **What are the issues arising for you from implementing interventions and / or ABA based programmes?**
    a. Availability
    b. Cost
    c. Time considerations
    d. Changes in your child's behaviour
    e. Impact on you as a parent and family

4. **The future: Post Intensive Intervention or ABA-based programmes**
    a. **Expectations post interventions & ABA-based programmes**

b. **At home : Life skills**
c. **At school : Academic Skills**
d. **With the knowledge and experience you have gained what would you do differently?**

Appendix F: Interview Schedule – Providers: School Staff

Themes & Outline: School Staff Questionnaire:

1. **What is your role and responsibilities?**

2. **Which interventions does your organisation provide**
    a. Why are these delivered?
    b. How are these delivered?

3. **Why the choice and eventual decision to provide ABA?**
    a. Main influencers – parents / LA/ outside agencies?
    b. Previous knowledge / practice?
    c. What do you perceive as the benefits and drawbacks of providing ABA based programmes?

4. **Explore the participant's expectations of the interventions**
    a. What do you hope to achieve?
    b. What are the drivers for the staff member / school / pupils and parents?

5. **What measures do you use and why?**
    a. Pupil baseline for skills
    b. Pupil baseline for academic

6. **Where would you say the emphasis lies – skills or education?**
    a. Skills – explore perceptions and views on self-help / self-stimulating/ toileting / personal care
    b. Other skills measured?
    c. Education – explore perceptions and views on engagement / inclusion / academic & academic progression

7. **Data :**
    a. How do you collect, track, evaluate, and use the data?

Appendix G: Interview Schedule – Providers: Local Authority

Themes & Outline: Key Stakeholder Questionnaire:

1. **What is your current role and professional responsibilities?**

2. **Which interventions does your organisation provide and favour?**
    a. How did you arrive at your decisions to fund / implement or endorse the interventions and programmes that you do?
    b. What and how was evidence used in making those decisions?

3. **Why the choice and eventual decision to provide interventions and ABA-based programmes?**
    a. What would you say are the main influencers of the demand, and why?
        i. Parents / Schools / outside agencies?
        ii. Evidence of any previous knowledge / practice?
    b. What would you say are your views on the policy/policies?

    c. What do you perceive as the benefits and drawbacks of providing ABA based programmes in particular?

4. **Explore the participant's expectations of the interventions**
    a. For their organisation
    b. For Schools
    c. For Parents