Parents perceptions of social inclusion for children with Williams Syndrome

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Abstract

This thesis explores parents' perceptions of social inclusion for children with Williams Syndrome; a rare intellectual disability with a distinct social cognitive profile. 5 interviews with parents give rich understanding to what parents' value for their child's education, and how this is achieved. Thematic analysis highlights key similarities and differences in experiences between parents of children attending mainstream schools and one special school. Severity of disability affects how parents perceive special education. Parents of children in mainstream experience considerable challenges to inclusion, and need a key figure to support both them and their child. Inclusion is more effective when the school and parents can successfully collaborate. Parents of children in mainstream schools focus on their child's social interactions, friendships and community values. These findings help illustrate parents' views on different schools, and indicate how to enable effective inclusion of children with Williams Syndrome.

Preface

I would like to thank the Williams Syndrome Foundation for their help and support, and the researchers for all their guidance. A special thanks to the families that participated in the study, without whom this study would not exist. Thanks also to the organisation Willík for sharing experiences of parents and children with Williams Syndrome in the Czech Republic.

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1   Introduction

1.1   Personal background

I became interested in researching into special educational needs when a module at University introduced me to the concept of Inclusion. Until this point I had not considered researching into an area linked so closely to me. One of my brothers was diagnosed with an intellectual disability called Williams Syndrome (WS) before I was born. My experiences growing up with a sibling with a disability have helped develop my perspective of special educational needs and/or disabilities (SEND). Through working in the topic of inclusion and SEND, my viewpoint shifted from that of a sibling to a genuine interest in SEND, WS, and perceptions of their families.

Over 20 years ago it was a simple decision for my brother to attend a special school, which he did from aged 4-19years old. The beginnings of inclusive policies and practice could be seen through his weekly trips to the local mainstream primary school, where he attended a Physical Education games lesson with children three years below his chronological age. Incidentally this was the same time as The Salamanca Statement (UNESCO, 1994) was agreed between countries to focus more on the inclusion of individuals with SEND into 'regular schools'.

Although my brother received education at a separate special school, I believe this was a successful form of education, enabling him to develop appropriate social skills, life skills and increased confidence. Our family experiences lead me to believe special education can be a suitable choice for many children with this type of disability. My parents' pro-special education decision has also heavily influenced me. However, research into the inclusion debate has begun to challenge this belief. To discuss this further, it is crucial to first define the term inclusion, and briefly explore the history of inclusive policies.

My brother's full scale IQ score was 59 when tested in 2013 using the Wechsler Abbreviated Scale of Intelligence (WASI) and he showed low adaptive behaviour and poor executive function. Scores were obtained when he attended a full-day assessment measuring his cognitive ability, social responsiveness, adaptive behaviour, anxiety, problem solving, executive functioning and special navigation abilities. His performance varied from an age-equivalent level of below 2years 5months to 9years 6months, whilst his chronological age at

that time was 23years 9months. Low adaptive skills reflect the motor and visuospatial construction difficulties that individuals with WS have, affecting daily living such as dressing, cleaning and cooking (Mervis and Klein-Tasman, 2000). In an examination of WS research, Martens et al (2008) highlighted that general intelligence for individuals with WS showed a mean IQ level between 50 and 60, with a range of 40-100 whilst Mervis and Klein-Tasman (2000) suggested IQ levels can mask large and important differences due to the unique combination of strengths and challenges in individuals with WS.

An intellectual disability, often referred to as a developmental disability in research in the UK, is defined by the American Association on Intellectual and Developmental Disabilities (AAIDD, https://aaidd.org/) as a disability that occurs when a child shows significantly low intellectual functioning and adaptive skills before the age of 18years. Adaptive behaviour includes practical daily living, conceptual and social skills, whereas intelligence can generally be measured by an IQ test. A typically developing person can score around 100 on an IQ test whilst those with moderate to severe intellectual disabilities may score around 20-50 (AAIDD, https://aaidd.org/intellectual-disability/definition#.V81gXjYkr4c).

1.2 Inclusion

History shows individuals with SEND have experienced negative responses from society. Since Ancient Greek and Roman mythology encouraged society to be God-like in beauty and perfection, people with disabilities have been viewed as helpless, a burden or joke (Reiser, 2006). The two dominant viewpoints in 20th Century England include needing assistance of a charity, or needing treatment from medical professionals; both perspectives encouraging society to view disability as helpless (Goodley and Runswick, 2011).

The human rights philosophy and social justice definition of inclusion suggests society can stop this type of discrimination through focussing on the education of all children without segregated schools (Avramidis and Norwich, 2002; Thomas and Loxley, 2007). However, previous discussions which confused inclusion with integration have meant that whilst several mainstream schools have improved the physical environment to enable children with certain types of SEND to access schools (Florian, 2010) the term inclusion has been used on occasions where children with SEND were not necessarily included as part of the whole

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school, but simply placed there (Avramidis and Norwich, 2002; Rodriguez and Garro-Gil, 2014).

1.2.1 Key Policies

A multitude of policies and legislation regarding the education of children with SEND can be traced back over the last 40 years when the 1978 Warnock report followed by the 1981 Education Act called for regular schools to make changes to be more accessible for children with different SEND (Hodkinson, 2010; Florian, 2010). The Salamanca Statement (UNESCO, 1994, p. viii) declared "every child has a fundamental right to education" and "those with special educational needs must have access to regular schools which should accommodate them within a child-centred pedagogy capable of meeting these needs". Therefore, all individuals with WS have the right to education in mainstream schools, where their needs should be met. Following this, the global 'Education for All' movement developed the notion of inclusivity, but it can be criticised for its focus on differences such as race or gender rather than disability. There is an absence of statistics on children with SEND, highlighted by Miles and Singal (2010) which suggests this group were still being excluded or underrepresented.

In 2005, Mary Warnock rejected the way inclusion appeared to be working since her 1978 Report, "if this means that all but those with the most severe disabilities will be in mainstream schools, (it) is not working" (2005:32). Warnock (2005) refined her idea of inclusion, which emphasised all children learning in the most suitable places for them. This created a dilemma of where a child would learn best, rather than educating all children in the same place. Ultimately, parents are responsible for choosing where their child learns best, but professionals and schools must help inform them to make this decision. What do parents of children with WS think about the different types of schools available?

Further policies such as The Equality Act 2010 attempted to combat issues of equality and human rights (Florian, 2010) by focussing on employment rights and a clearer definition of disability which seemed to emphasise inclusivity in society alongside the push in education. More recently, the introduction of the new SEND Code of Practice in 2014 emphasised schools' need for guidance in implementing inclusive education (DfE, 2015). It seems that inclusion can be a difficult term to define and use, as many policies have highlighted; it can change between places, people and contexts. Consequently, it is the practitioners' decision on which definition to use (Hodkinson, 2012; Miles and Singal, 2010) which suggests it is also

the parents' decision to define inclusion and what they desire from inclusive education. Unfortunately, the wide variances in definition indicate that in practice there can be many challenges to effective inclusion (Mackenzie, 2011).

1.2.2 Practice

Even though there was a move towards the placement of children with varying SEND into their local mainstream schools, there is evidence to suggest schools were abusing the term 'capable of meeting these needs' to reject some children from their provision (Barnes and Mercer, 2004). Although this may be due to children's' needs being better met in a different school, some research suggests it is linked to schools' league tables in which children with SEND were thought to negatively impact the school's overall score (Salisbury and Riddell, 2000; Broomhead, 2013). This was challenged by Farrell, Dyson, Polat, Hutcheson and Gallannaugh (2007) who contradict this statement.

Educating children with complex needs puts increasing pressure onto staff (Lacey, 2001). Children with WS can have various health, care and challenging behaviour problems, which require specific staff training and role adaptation (Lacey, 2001; Abbot et al, 2011). Carpenter, Egerton, Brooks, Cockbill, Fotheringham, and Rawson, (2011) encourage schools to meet the needs of children with profound and multiple learning disabilities (PMLD), as advances in medical care have seen an increase in their survival (Cooper, Melville, and Morrison, 2004). This has changed the population of special schools, which may affect how parents perceive these schools.

Researchers suggest inclusion of children with SEND may result in them being excluded from some classes or activities, with reduced access to a qualified teacher's input (Hodkinson, 2012; Radford, Bosanquet, Webster and Blatchford, 2015). However, it could be argued that working 1:1 outside the main class may enable delivery of appropriate therapies and intervention, during the provision of the same curriculum content as the child's peers (Radford et al, 2015; Tynan, 2016).

A further challenge highlighted by Sellgren (2016) is the funding and budget for equipping mainstream schools with the resources needed for inclusion. A recent news report suggested studies found 82% of mainstream schools in England did not have sufficient funding and

budget to provide for pupils with SEND (Sellgren, 2016). How aware of this are parents of children with WS, and would this influence their choice of school?

1.3 Williams Syndrome

Williams Syndrome occurs randomly with the microdeletion of approx. 25 genes on chromosome 7q11.23 (Hillier, Fulton, Fulton, Graves, Pepin, Wagner-McPherson, 2003). Prevalence is estimated to be around 1 in 20,000 worldwide (Scallan, Senior and Reilly, 2011). However, research in the Akershus County in Norway suggests the occurrence is as high as 1 in 7,500 (Strømme, Bjørnstad and Ramstad, 2002). According to WSF there are 1543 known individuals in the UK, of which 705 have has a positive blood test, contributing to an occurrence of 1 in 18,000 people (http://www.williams-syndrome.org.uk/).

Characteristics of Williams Syndrome can include congenital heart defects, hypercalcaemia and texture intolerance (Bellugi, Lichtenberger, Jones, Lai and St George, 2000; Martens, Wilson, and Reutens, 2008). Alongside global developmental delay, children will often experience difficulty with feeding, sleeping and anxiety (Scallan, Senior and Reilly, 2011).

The distinct cognitive and behavioural profile of WS differs from other disabilities, which makes it an interesting profile to research, and will be discussed further in the literature review (Mervis and Klein-Tasman, 2000; Bellugi et al, 2000; Martens et al, 2008). Furthermore, it is interesting to see how these differences may affect inclusive education. Research describes WS as having as wide variances in level of severity as there is in typically developing individuals (Martens et al, 2008). How may the individual differences that occur affect the inclusion of different individuals with WS?

1.4 Parents' Perspectives

Much is known about the daily challenges facing a child with disability and their caregivers, as well as the positive impact this can have on the whole family (Green, 2003; Scallan et al, 2011). Parents are a valuable resource that researchers can gain information from.

Whilst policies reflect the emphasis on inclusion and family voice, it is interesting to discover how this relates to practice (DfE, 2015). How are parents supported to make such vital

decisions for their children with SEND? What do parents know about inclusion, and how do they feel about it?

Some research suggests parents are not as involved in practice than they should be (Hess et al, 2006; Russell, 2003). This could rely on their knowledge of policies and disability rights. If this is the case, parents who are not as knowledgeable may have different experiences with their children at school.

1.5 Research Aims

Within my thesis I will present a rigorous analysis of previous literature that will link my research questions and highlight my rationale for this topic. My research question is to highlight parents' perceptions of social inclusion for children with Williams Syndrome.

Sub questions include:

- Why do parents choose a school?

- How do parents feel about different educational provisions?

- What do parents understand about the inclusion of their child at school?

- How does the distinct profile of Williams Syndrome affect inclusion in schools?

- How do parents and schools collaborate to ensure inclusion?

A significant part of this will be an investigation into how parents perceive social inclusion, interactions with peers and friendships of children with WS. Before analysing previous literature connected to the research topic, it is important to provide a thorough background to SEND and how disability is viewed by society. Furthermore, a detailed summary of the characteristics of WS offers a basis of research to inform readers of the context. Throughout the methodology there will be reflection upon my actions linked to theory, and a concrete explanation of methods used. I will then present my findings through a combination of data analysis and discussion. This will lead on to the conclusion of my findings, limitations and recommendations for further research.

2 Literature Review

2.1 Perspectives of disability

How disability is viewed by society has been debated for a long time. The Disability Movement of the 1970s used the Social Model at the forefront of their campaign. The movement consisted of a group of people with mainly physical disabilities who described disability as society's failure to include all people (Bury, 1996). Within its success, the social model helped shift the perspective away from solely medical model views of disability, which emphasised professional discourse and focussed on rehabilitation, treatments and cures (Reiser, 2006). Although the medical model view of disability places high value on professional knowledge, policies and research centred on the inclusion debate show a move towards the social model of disability, which values the knowledge of families and individuals themselves (Runswick-Cole, 2008; Hodkinson, 2010). One of the infamous sayings from the Disability Movement 'professionals on tap, not on top' helps to illustrate the shift in perspective away from professional-led treatment towards people with disabilities and their families approaching professionals to gain knowledge and understanding. Therefore, in the social model perspective, parents of children with WS will develop knowledge of their child by gaining information from professionals in certain areas such as health or education.

2.1.1 Criticisms of Models

The medical model brings vocabulary from the medical area into education, for example when professionals use terms such as condition, treatment, cure and specialist. Trussler and Robinson (2015) suggest that within education the focus is on 'fixing' the learner as opposed to analysing the teaching approach or system. Whilst this arguably stigmatizes the learner, leading to an over-reliance on the use of labels, it is also important to highlight the benefits of labelling different types of SEND. Identification of a disability can in turn lead to better understanding of and intervention for the individual and their family (Russell, 2003) through access to charities and organisations such as the Williams Syndrome Foundation(WSF) founded by parents for caregivers of children with WS. The social model however, does not focus on within-child factors, but instead looks at how the environment can be changed, for example the school curriculum, teaching style and attitudes to disability (Trussler and

Robinson, 2015). If relying solely on the social model, there would be no need for the WSF, but families and individuals with WS never meet. Therefore, it seems there is a place for both models in viewing disability. There has been a lively debate between researchers revealing many strengths and limitations to both models which has led to some rejecting the idea of two simple models, and instead focussing on the lives of people with different disabilities including the real impact of their disability (Shakespeare and Watson, 2002; Cameron, 2010; Edwards, Noreau, Boucher, Fougeyrollas, Grenier, McFadyen, Morales, and Vincent, 2014).

Runswick-Cole (2008) highlighted the medical and social models in her study when she suggested parents of children with SEND who attend special educational settings hold more of a medical model view, whilst parents of children with SEND attending mainstream schools hold a social model view. Furthermore, parents of children who changed from mainstream to special school cited educational system barriers as the main reasons, such as a lack of flexibility in including their child, or their child being taught mostly by a TA rather than a qualified teacher (Runswick-Cole, 2008). Additionally, Russell (2003) suggests conflicts between staff and parents occurred when staff viewed the child using a medical model rather than social model view. However, it seems inappropriate to label people with a simple social versus medical perspective. A perspective can change during a conversation, depending on the context or vocabulary used (Trussler and Robinson, 2015). It will be interesting to see if parents of children with WS share a view that could be labelled as social or medical model perspectives.

2.2 Parents' Voice

Linked to the wide use of the social model view of disability in the UK, there is an increasing focus on the importance of parents and family in the most recent SEND Code of Practice (CoP) statutory guidance (DfE, 2015). It is emphasised several times that parents should play an integral part in decisions affecting their children, and need access to the information, advice and support to help make these decisions. The SEND CoP suggests parents and families hold valuable information about the child with SEND which can help others to understand the child's needs (DfE, 2015). Russell (2003) emphasises this in her suggestion that there should be more collaboration between parents and professionals, so that parents can share responsibilities, discuss outcomes and express their needs. Resch, Mireles, Benz, Grenwelge, Peterson and Zhang (2010) extends this by suggesting parents and professionals

need each other to accomplish goals. He continues by suggesting "researchers, service providers and policy makers respect the singular perspective of parents by allowing them to be the experts on the realities of their daily lives" (Resch et al, 2010:147). It is therefore crucial to try and capture parents' own perceptions. In the case of individuals with WS, professionals may lack knowledge and experiences of the rare disability and associated challenges, forcing parents to become the expert. Therefore, it is vital to learn from parents and families who have lived with WS. Understanding and sharing their experiences can help other families as well as enabling services and supports to incorporate parents' needs (Resch et al, 2010).

2.3 Struggles

Previous research has focussed more on parents' wellbeing and the struggle that arises when they feel they must fight for their children's rights, as well as highlighting areas of support (Russell, 2003; Resch et al, 2010; Lewis, Davidson, Ellins, Niblett, Parsons, Robertson, and Sharpe, 2007). It seems that parents often feel a fundamental lack of support, information and advice while raising a child with SEND, which can lead to higher amounts of stress and anxiety (Russell, 2003).

Numerous articles have highlighted parents' perceptions of needing to fight for their child's rights in education (Hess et al, 2006; Runswick-Cole, 2008; Resch et al, 2010). Participants in Hess et al's (2006) study suggested this was due to the lack of communication and collaboration with school staff, which caused them to think staff did not care for their children. However, the method used in this study was a focus group; therefore, the discussion may have been influenced by more dominant participants as opposed to a conversation in a one to one interview setting. Likewise, Resch et al's (2010) focus groups also emphasised the importance of advocating for inclusion when parents shared stories of barriers to inclusion. Moreover, the sample in Runswick-Cole (2008)'s study was selected due to parents' appeals to a SENDist Tribunal on the grounds of disability discrimination, which already emphasises their stance on fighting for their children's rights. In a one-to-one interview setting, it will be clearer to understand participants' perceptions without being influenced by a group. On the other hand, Russell (2003) described parents who became dependent and passive. This difference may be a result of differing research questions and aims. For example, Russell

(2003) argues the importance of supporting parents to explore and review their expectations rather than investigating challenges experienced by parents of children with SEND.

Parents in focus groups by Resch et al (2010) emphasised school and community inclusion as a strong theme. The importance of this is highlighted in similar studies where parents wanted their children to be more than just physically present but socially included, welcomed and accepted into mainstream schools (Hess et al, 2006; Bajwa and Devecchi, 2014). Inclusion issues are further highlighted in a study by Broomhead (2013) which found some parents felt 'unwanted' in mainstream schools and that parents felt that schools did not focus on understanding and addressing the needs of their children (Broomhead, 2013). Although these studies highlight struggles to be socially included, research by Bennet and Gallagher (2013) promotes educating children with SEND alongside peers to develop and increase their social communication skills. Therefore, it seems parents highly value social inclusion but also feel hindered by many challenges.

2.4 Williams Syndrome Profile

Perhaps due to its rarity, research involving individuals with WS is incredibly useful. It can help explain the syndrome further, as well as exploring similar or contrasting disabilities. Many pieces of research have compared groups of individuals with WS with groups of individuals with Down Syndrome (DS) and Autism Spectrum Disorder (ASD) (Klein and Mervis, 1999; Jones et al, 2000; Bellugi, Lichtenberger, Jones, Lai, and St. George, 2001). The connection between WS and ASD has been particularly interesting to many researchers due to the overlaps and contrasts in behaviour and social difficulties (Karmiloff-Smith, Klima, Bellugi, Grant and Baron-Cohen, 1995; Klein-Tasman, Mervis, Lord and Phillips, 2007). Furthermore, research involving WS can also be useful in understanding people in general. For example, recent neurodevelopmental researchers from the University of California San Diego believe investigating cells from individuals with WS can help lead to a better understanding of the human social brain (Thanathom and Cleber, 2016).

Previous research on WS has highlighted a distinct cognitive and unusual personality profile compared to individuals with cognitively matched, IQ matched or chronologically aged matched peers and individuals with similar levels of intellectual disability (Mervis and Klein-Tasman, 2000). Research found that children with WS showed a marked delay in language

acquisition, but their strengths lie in vocabulary, syntax, semantics and word fluency (Mervis and Klein-Tasman, 2000; Jones et al, 2000; Brock, Jarrold, Farran, Laws, Riby, 2007; Martens et al, 2008). These characteristics help to draw their listeners into conversations. Brock et al (2007) outlined how research illustrating competent grammatical and phonological skills in WS individuals were frequently compared to a group of individuals with DS, a group which often experience linguistic weakness. Although Brock et al (2007) supported previous research in its findings of relatively good receptive vocabulary in individuals with WS, it most importantly highlighted the difficulties in comparing the strengths and weaknesses of individuals with WS with other intellectual disabilities (ID).

Interestingly, Jones et al (2000) found that unlike other groups, individuals with WS actively sought information from the interviewer during each question. After brief answers the questioner attempted to redirect the subject but many individuals with WS continued to ask questions. It seems that there is a clear attraction to social interaction from an early age, at the detriment of completing or focusing on cognitive tasks, which could be an avoidance technique (Jones et al, 2000). Jones et al (2000) further suggests that children with WS exploit their developing language abilities for social purposes. How do children with WS cope in the classroom when they are surrounded by opportunities to interact socially combined with potentially difficult cognitive tasks?

Further characteristics of note are individuals' high sociability, over friendliness and high empathy compared to cognitively matched individuals with disabilities (Mervis and Klein-Tasman, 2000). Considering this combined with their apparent strengths in expressive language, parents of children with WS may emphasise the importance of social communication and interactions with peers, as it was found for parents of children with mixed SEND (Martens et al, 2008). However, research also highlights children with WS have difficulties in making and keeping friends. Mervis and Klein-Tasman (2000) suggest that this is due to theory of mind, which comprises social-cognitive and social-perceptual components. They suggest individuals with WS may have trouble with the first, highlighting a significantly lower performance on false belief tasks. Only about 20% of the younger children, and about 40% of the older children with WS passed the false belief tasks. Furthermore, adolescents with WS had difficulty differentiating between lies and ironic jokes; classifying all non-literal statement as lies (Mervis and Klein-Tasman, 2000). Research shows significant failure for individuals with WS to understand elements of social communication and interactions, which

has the potential to affect their interactions with peers (Mervis and Klein-Tasman, 2000). Consequently, difficulties in relationships between children with WS and their peers could affect how their parents perceive school. According to Resch et al (2010) parents value community and being included, which suggests that they would desire more interactions with non-disabled peers to develop friendships rather than valuing other aspects of schooling such as academic progress. But how is this addressed in a special school where peers have varied severity of SEND? Runswick-Cole (2008) would suggest that these parents would hold a medical-model perspective, thus valuing other aspects of the school.

Interestingly, Weiner and Tardif (2004) found children with ID had a similar number of friends to children without ID. Although those with ID had friends with learning difficulties, were younger, and did not attend the same school. Furthermore, in the same study children with ID showed lower quality friendship, lower social acceptance, poorer social skills and higher levels of loneliness and problem behaviours compared to children without SEND. This suggests that difficulties in peer relationships for children with WS may not be syndrome-specific, but a general difficulty for children with ID (Mervis and Klein-Tasman, 2000). It will be interesting to explore parents' perceptions of their children's peer relationships, whether these difficulties are connected to WS, and whether it is a concern for parents.

Parents in questionnaires by Mervis and Klein-Tasman (2000) revealed children with WS experienced serious difficulties with attention, distraction, hyperactivity and concentration. This was worse compared to those with other disabilities. Similarly, it was found children with WS often failed tasks due to continued eye contact and engagement with adults, whereas control groups would often push blocks away or drop them on the floor showing frustration at the task (Jones et al, 2000). This helps demonstrate the extent to which such characteristics can affect the functioning of an individual with WS. For example, difficulty with distraction and concentration combined with high sociability used to avoid cognitive tasks could contribute to difficulty in a busy mainstream classroom.

2.5 Genetic research to qualitative research

As previously mentioned, individuals with WS form a rare opportunity to examine relationships between neuroscience, cognition and genotype (Martens et al, 2008). Furthermore, the gene which causes the characteristics of WS was only discovered by

geneticists in 1993 (Wang, Samos, Peoples, Perez-Jurado, Nusse, and Francke, 1997). This explains the cluster of research on WS which focusses on links between the genotype and phenotype, exploring the genetic profile of WS (Jones et al, 2000; Donnai and Karmiloff-Smith, 2000; Martens et al, 2008). This research is important as the behaviour phenotype within the WS profile has within-syndrome differences that occur between different genetic disorders (Fiddler, 2003). These syndrome-specific differences may affect the type of intervention or approach individuals need in education and other areas of life (Fiddler, 2003). On the other hand, the large amount of genetic research has resulted in an apparent absence of qualitative research which can help give insight into why people think or behave in certain ways. This helps encourage me to pursue research in perceptions and parents' understanding, to contribute a social research piece that could be useful to families and professionals involved in the day to day lives of children with WS.

Many of the studies highlighted earlier were conducted in USA, Australia and Canada, with some links to the UK, but Lough et al (2016)'s qualitative research featured 21 parents of children with WS in the UK. Through highlighting their atypical social behaviour and low intellectual ability, Lough et al (2016) emphasised an important issue of social vulnerability and lack of understanding appropriate social behaviour. However, a significant finding was the heterogeneity of WS, as not all individuals with WS were confident to engage or interact with others; some parents suggested their children were outgoing whilst others described their child as reserved. It was also found that variability could not be predicted by age of IQ, but that personality traits and the level of parental supervision could influence this behaviour. Many of the previous studies have also highlighted the importance of understanding individual differences within WS (Martens et al, 2008; Little, Riby, Janes, Fleck, Clark, and Rodgers, 2013). Lough et al (2016:9) suggests "this could be invaluable in helping to tailor support and avoid a one-size-fits-all approach to intervention." This research further emphasises the relevance of research that can help develop intervention and support for individuals with WS and their families.

2.6 Educational Placement

Existing research investigating parents' perceptions of different educational provision and experiences of inclusion use a sample of children with various disabilities (Wiener and Tardif, 2004; Parsons, Lewis, Davidson, Ellins and Robertson, 2009; Bennett and Gallagher, 2013;

Broomhead, 2013). Some studies use a sample of individuals with varying types of SEND (Wiener and Tardif, 2004) whereas other studies have specified their interest in ID (Bennett and Gallagher, 2013) but there is little research on this topic with children with WS (Tynan, 2012).

Research shows fewer differences between children placed in-class, in resources rooms or in self-contained special classes, suggesting social and emotional problems are not associated with the type of special education they receive (Wiener and Tardif, 2004). However, the sample of children in inclusive classes has milder learning disabilities, and there were no details as to the type of learning disability or challenges the children were experiencing (Wiener and Tardif, 2004).

A study in the North West of England interviewing 10 parents of children with SEND and challenging behaviour included visible disabilities such as DS and PMLD. Within this study, it was found schools held negative attitudes to those who may disrupt teaching and learning through inappropriate behaviour which was a direct result of their special need (Broomhead, 2013). This could highlight a lack of understanding of the disability, as well as teachers' attitudes towards inclusion. However, there is evidence to suggest children with SEND do not affect mainstream peers' academic achievement, and that differentiated instructions for various abilities can benefit all children, as well as developing awareness and tolerance to diversity (Lewis and Norwich, 2005; Bennett and Gallagher, 2013). Another benefit is encouraging peers to act as role models for appropriate behaviour for children with SEND (Wiener and Tardif, 2004; Bennett and Gallagher, 2013). Although Bennett and Gallagher (2013)'s study highlighting parents' perceptions of the positive effects of inclusion on their children and peers was only one High school in Canada. A strength of the study was the level of ID varied between individuals ranging from moderate to profound needs, and some were non-verbal, which provided a good mix of individuals with ID. But would parents of younger children with ID share similar opinions? Furthermore, despite the school's long history of inclusion, it is interesting that job coaches and parents held the most positive attitudes and beliefs about the inclusion of students with ID compared to teachers and TAs. Additionally, teachers and assistants were least optimistic about opportunities to socialise and form friendships, but students and parents were most positive (Bennett and Gallagher, 2013). This could highlight parents' perceptions of what they value most, as well as challenges in practice for school staff.

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Moreover, research on parents' perceptions of different educational placements highlights the absence of a place directly between mainstream and special educational schools (Bajwa-Patel and Devecchi, 2014; Runswick-Cole, 2008). In Hess et al (2006) study, when a parent could not find a school that matched their child's needs, options were limited. This is emphasized by one parent placing her child on medication to alter his behaviour at school, whilst another pulled her child from the school.

It has been questioned whether a postcode lottery exists, where different educational provisions and satisfaction depends on different parts of the country. Parsons et al (2009)'s national post survey of 562 parents across Great Britain challenges this. Overall, parents were satisfied that the school supported their child and they could choose the type of school. This is supported by other studies highlighting parents' general satisfaction with their school choice including both special and mainstream provision (Whitaker, 2007; Tynan, 2012). However, this is challenged by parents of kindergarten children who gave a "distinct tone of uncertainty about the future education placement for their child" but this may be due to the younger age of the children (Elkins, van Kraayenoord and Jobling, 2003: 127).

Amongst the most satisfied parents in the study by Parsons et al (2009) were those with children in special educational schools. Perhaps this may be due to the severity of their child's disabilities, as their children tended to have multiple learning disabilities, significantly greater than the children in mainstream, which may influence parents' perceptions. However, all respondents included parents of children with difficulties ranging from mental health, ASD, long term illness, language and communication and learning disability. Further details on the severity of the SEND may reveal differences in perceptions depending on the type of disability in relation to the type of school placement. Bajwa-Patel and Devecchi (2014) suggest parents' choice of the type of school is influenced mostly by access to specialist staff and facilities, although this was mentioned significantly more by parents of children attending special school. Other factors included the head teacher's approach to disability and how local the school was, which supports Resch et al (2010) emphasis of how important the local community is to parents.

2.7 Placement of children with WS

As previously discussed, the wide individual differences in WS means children show different severity of learning disabilities and cognitive functions (Mervis and Klein-Tasman, 2000; Martens et al, 2008). Therefore, it can be a difficult decision for parents of a child with WS to attend a mainstream or special school, which may be difficult for all parents.

Research shows a general balance of placement for children with WS in mainstream and special schools during primary education, age 4-11years, until the transition to secondary school where many children with WS will move to a special school due to the increasing difference in cognitive level to their peers (Udwin et al, 2007; Reilly et al, 2015). This is supported by current research on educational placement of individuals with WS in the UK by Riby and Hanley (in preparation) who found of 43 parents of children aged 5-11years, 60% were currently in mainstream whilst 40% were in special education. Of 19 parents of children aged 12-16years, 80% were in special education whilst 15% were in mainstream schools and the remaining 5% taught from home. Although this could be influenced by the level of severity of disability and amount of support available at the educational placement, it seems that there are significantly more children aged 12-16 years attending special school provision whilst slightly more children aged 5-11years attend mainstream school.

Tynan (2012; 2016) investigated inclusion for children with WS in the Republic of Ireland, by interviewing 7 children, their parents and teachers. Her study included 4 children in mainstream, 2 in special school and 1 in a special unit, which enabled her to compare the experiences of families in special and mainstream settings. Through exploring parents' perceptions of the child and chosen educational placement, Tynan (2012) found all parents were satisfied with the school placement, which also supports previous research on parents of children with SEND (Parsons et al, 2009) although she highlights Whitaker's (2007) argument that this is not necessarily a representation of whether the child's needs are being met, which could explain the differences in opinions between parents and staff in Bennett and Gallagher's (2013) study. Furthermore, Tynan (2012) lists parents' choice of school based on ability, health issues, whether siblings attended, facilities, reputation and openness. This suggests severity of disability plays a significant part in the decision, as well as being within the local community as parents seek advice from others through the reputation, openness and whether the rest of the family was attending. Tynan (2012) further highlights a sense of trying

the mainstream school to see how it went. This could highlight parents' anxiety and stress of raising a child with SEND (Russell, 2003), or the uncertainty they feel when making this decision (Elkins et al, 2003) as well as emphasising the dilemma parents face of which type of educational placement (Runswick-Cole, 2008; Bajwa-Patel and Devecchi, 2014).

Overall, it seems parents are generally happy with the type of educational placement their child attends, regardless of type of school, level of inclusion or severity of disability (Fidler, Lawson and Hodapp, 2003; Reilly et al, 2015). On the other hand, Reilly et al (2015) suggests the lack of training or input for teachers in mainstream schools could affect their teaching styles and attitudes towards children with ID. This study highlighted teachers' perceptions that all children with ID can be taught in a similar way (Reilly et al, 2015). However, significantly more parents of children with WS desired increased resources for handwriting/fine motor skills compared to other genetic syndromes who needed different specific resources. Therefore, although parents may be generally pleased with the type of school, there are often numerous areas of desired improvement such as a specific service, or the quality of the service (Fidler et al, 2003; Reilly et al, 2015).

When comparing parents of children with different syndromes with associated ID, it was found significantly more parents of children with WS mentioned wanting more musical aids and classroom assistance (Fidler et al, 2003; Reilly et al, 2015). This suggests parents of children with WS show understanding of syndrome-specific learning styles that differ to other disabilities. Tynan (2012; 2016) further supports this parental knowledge of learning styles including music and repetition. It will be interesting to explore how and if parents can share their knowledge of their child and WS with the school. In her study interviewing 28 parents of children with various SEND including ID, DS and ASD, Scorgie (2015) found role ambiguity as parents became information gatherers, advocates and teachers. Parents also confessed their loss of confidence in professionals who had less knowledge, creating an uncomfortable reversal of roles as the parent became the more knowledgeable one (Scorgie, 2015). This could be a situation for parents of children with WS, who may have more knowledge than the school.

2.8 Inclusive debate

Supporters of special schools emphasise specialist facilities, small class sizes and specialist staff that are often missing from mainstream schools (Simmons and Bayliss, 2007). Thomas and Loxley (2007) explain that accountants realised special schools were excellent services and money was agreed on number of places taken at special school, but this did not follow children who moved to mainstream school. But whilst Thomas and Loxley (2007) emphasise the difficulty in implementing policy into practice, Hodkinson (2010) suggests policy has overtaken practice. This highlights the UK educational system needs a radical shift to incorporate inclusive education whilst providing children with WS with the correct quality services and facilities (Florian, 2010).

A recent article from the Disability News Service suggests the UK is significantly behind on implementing inclusive education (Pring, 2016, http://www.disabilitynewsservice.com/uns-fantastic-inclusive-education-guidance-is-embarrassment-for-uk-government/). The Committee on the Rights of Persons with Disabilities (Office of the High Commissioner Human Rights, http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx) highlights the countries who signed the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) have an obligation to fulfil Article 24: Right to inclusive education, which means ending the current binary educational system in the UK. The UK's educational system features two systems of special and mainstream education whereas countries such as Italy made the transition to inclusive education by removing all special schools (Devecchi, Dettori, Doveston, Sedgwick, Jament, 2012).

With the current binary system in the UK, parents must be confident that the school they choose can understand and effectively educate their child. When Elkins et al (2003) surveyed 354 Australian parents, they found some parents believed that special schools would worsen or slow their child's social and emotional development. On the other hand, parents who favoured special schools suggested that their child's disability was too severe for the regular classroom. However, a study by Simmons and Bayliss (2007) investigated the inclusion of children with PMLD into a special school of children with severe learning disabilities (SLD), which found staff lacked training and understanding of PMLD. This suggests that the severity of a child's disability may affect their education in both mainstream and special schools, as

well as raising an important issue of how effective special schools are educating children with WS and various complex needs.

2.8.1 Wider Inclusion

Although inclusion is frequently connected to education, it is not limited to this context. Schools are a part of and within the community (Bryan, Austin, Hailes, Parsons, and Stow, 2006). By promoting inclusive education, children can develop the right attitudes and knowledge of disability. Reiser (2006) suggests this teaching ensures children will not learn misconceptions or inappropriate reactions to disability, which will create a more inclusive society. In contrast, Haines, Gross, Blue-Banning, Francis and Turnbull (2015) suggest inclusive schools will be in a good position to develop partnerships between schools, families and community members, which would create an inclusive community. This ensures society learns inclusive attitudes and knowledge of disabilities together with children in schools. Therefore, it is argued that the school is the foundation for developing inclusive perceptions into the community, or it is to be used within the community to ensure an inclusive society.

Bryan et al (2006:51) state:

"Multi-agency work brings a new set of care workers into the school and with it a need to liaise and to tackle problems in a shared way. It extends the school's work into preventative spheres beyond curriculum provision and the management of learning, though learning is a key goal and a strong protective factor. The school is being ascribed a community role and must be resourced to fulfil it. Situated within the community and a major service provider known to all, it is a key link for other services into the community."

According to Gross et al (2015) collaboration and communication is essential to fostering strong partnerships between schools, home and the wider community. However, Bryan et al (2006) found parents were more comfortable to approach key workers such as family liaison workers, rather than teaching staff. They propose this is due to the ease of talking less formally, which suggests communication must be carefully maintained for strong partnerships. Perhaps this is because other staff have more time to communicate with families. Positive attributes of staff were also highlighted as important to parents. Educators who were caring, supportive and respected children and their parents, through compassion, empathy, sensitivity and kindness (Scorgie, 2015; Haines et al, 2015). Parents feel respected

by staff when they are listened to, valued for their knowledge, and treated as equals in educational decision making (Starr, Foy, Cramer and Singh, 2006; Haines et al, 2015). This form of communication and collaboration has been highlighted as key aspects of working towards inclusion for parents, staff and children with SEND (Lacey, 2001; Elkins et al, 2003; Gross et al, 2015).

Bennett and Gallagher (2013:119) emphasise the vital need to ensuring inclusive communities for people with ID, in their study of high schoolers:

"Ensuring that individuals with ID are supported within diverse communities, where there is space for everyone through effective collaboration, planning and allocation of effective supports, is essential in ensuring that individuals with ID truly are part our community."

In contrast, special schools are often seen as a segregated system (Cooney et al, 2006; Simmons and Bayliss, 2007; Rodriguez and Garro-Gil, 2015), which may affect the inclusion of children with WS into the community. It is common for buses to transport children from home to special schools which can be a considerable amount of distance away (Cameron, 2010). This suggests a gap between the child and the local community. If a child spends most their day away from the local area, neighbours and leisure facilities, it could prevent their involvement and inclusion in the community. Without the partnership between the school and community, or the education of children with WS in mainstream schools, it is clear to see why some researchers believe special schools are a form of segregation and hinder the process of inclusion. Haines et al (2015) suggest that the lack of family-school-community partnerships could have a significant impact on inclusive education, and the process of moving towards mainstream schools.

2.8.2 Parent values

The previously highlighted research of parents' perception of school suggests that many parents of children with SEND emphasise a sense of belonging and acceptance (Hess et al, 2006; Bajwa and Devecchi, 2014). Haines et al (2015) extends this by emphasising belonging and acceptance in the whole community. Parents in Haines et al (2015) study stressed involvement in the community alongside knowing the school's commitment to meeting their child's needs as important (Haines et al, 2015). This was shown when staff were flexible in

addressing children's needs, used creative educational approaches and a willingness to learn about the child (Haines et al, 2015).

Parents in Scorgie's (2015) study suggested inclusion would be enhanced when staff focused on child's strengths, valued information sent by parents and assured parents that decisions made were best for the child rather than programme-centred. Moreover, parents appreciated when school staff were willing to learn about their child's disability, particularly if teachers are not able to determine the cause of challenging behaviours. Similarly, parents in Starr et al's (2006) study felt that an in-depth knowledge of the child's disability may lead teachers to develop their understanding of associated behaviour difficulties. On the other hand, parents also appreciated professionals who show that they see through labels and the diagnosis to the whole child (Scorgie, 2015). Therefore, it seems parents will seek a balance between wanting staff to know aspects of WS, but also see the whole child as they do.

Overall, it will be interesting to explore how parents of children with WS work with schools to ensure they are in the best educational placement, as well as highlighting parents' values and understanding of inclusion. Will parents of children with WS show similar perceptions to that of other disabilities? What challenges will children with WS experience in education?

3 Methodology

3.1 Research Design

A qualitative approach was the most appropriate to capture parents' perspectives. Although many researchers have debated over using exclusively quantitative or qualitative methods, a mixed model design has been argued to work effectively in research as it encompasses strengths from each side (Denzin, 2012). Initially, I wanted to use a similar approach to Green (2007) who surveyed a sample of 81 mothers of children with SEND and follow up interviews with 7. The mixed methods approach could arguably produce a more detailed, higher validity piece of research but I believe that a solely qualitative approach can provide thick descriptions desired in this type of study (Denzin, 2012). It was therefore decided due to feasibility, the most appropriate methodology that would answer my research questions was a qualitative design (Denzin, 2012). Furthermore, Resch et al (2010:140) suggest "a somewhat underutilized method of obtaining rich understanding of parents' experiences is through qualitative methodology."

Despite the risks involved in using only qualitative research, such as subjectivity, qualitative methods enable researchers to "obtain an extensive description of a single unit or bounded system, such as an individual, program, event, group, intervention, or community" (Mertens and McLaughlin, 2004, p.94). Although this emphasises my aim to understand what parents think and feel, Denzin (2012, p.82) suggests "objective reality can never be captured" but that we only ever see representations of reality. Due to this, I wished my sample to vary in demographic variables so I could obtain a range of different experiences from participants from different backgrounds.

3.2 Sample

I chose parents of children age 5-11 because children who were aged 4 years at the time of study would not have started education, and I wanted participants who had experienced at least a year of school so they had formed opinions and would be able to share experiences. Through speaking to parents at the WSF Convention (Minehead, 2016) I discovered that I could have been more flexible with my age range, as parents may have kept their child back a year at school. Although there was a volunteer parent of a 12-year-old child attending a

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mainstream primary school, I chose not to use this participant due to my tight restrictions. At the time, I was still eager to find parents of children who were attending special school, so that I could have a mix of parents of children who attended different types of schools. However, this was later disregarded as it was clear there were more children in this age range who were attending mainstream primary schools, and it was important to me to capture a relatively representative sample. Next time I would choose to interview this parent as it would have been interesting to compare their experiences of the whole primary school, and I believe this parent was looking at transitioning to a special educational secondary school.

Originally I would have liked to interview 6 parents, of which 3 would have children attending a mainstream setting and 3 with children attending special educational needs settings. However, in keeping with my volunteer recruitment, I dismissed this aim as it became evident that many primary aged children were attending mainstream school. Furthermore, due to the rareness of WS, I did not have access to a large sample where I could choose from volunteers that suited my aim. Therefore, my participants were parents of children age range 6-10years; mean age 7.8 years; 2 males, 3 females.

3.2.1 Demographics

Participants varied in demographic variables. 3 participants' children attended mainstream schools, 1 attended special school and 1 attended mainstream but was changing schools as well as organising a dual placement for September to bring in special education. There are approximately 97 children aged 5-11 years through members of the WSF. My sample covers about 5% of the population of children with WS aged 5-11years. 4 participants had a full-time job, 1 had a part time job and 1 was a stay-at-home parent. Most participants labelled their ethnic origin as White British, although 1 was White Other (Polish) and another participant White European.

Of the 5 sets of participants, three spouses were present in the interviews, but in two cases there was clearly a more dominant participant whose demographic details I obtained, whilst the third couple were equally as involved in answering the questions in the interview to the point of finishing each other's sentences. I received demographics from both husband and wife in this circumstance. Due to this, my participants' age range were 34-51years; mean age 41.7 years; 2 males, 4 females.

3.3 Validity

I was eager to have face-to-face interviews at participants' own homes if possible. This was so participants did not have to travel to meet me, which is often the case in WSF events because families and members are often spread widely over the UK. It was also for ethical considerations, to encourage them to be as comfortable as possible, so that they felt in control and confident to answer my questions in detail. It was useful to hold interviews at homes as opposed to busy environments such as cafés or public meeting places. Some interviews featured small distractions such as a musical toy or a busy family home, but this was easily minimised with software to allow me to transcribe the main speaker. Furthermore, by visiting participants at their homes, I could cover three different counties out of the six that are in the South West of England, allowing me to gain a more reliable collection of parents' perceptions from different places. I was somewhat restricted to this area as it was local to me and I had a limited timeframe. However, I could obtain a range of different demographics including size of school, location, participants' occupation and ethnic origin to increase validity. It was also important to be aware of the wellbeing of participants. Research has suggested many parents can feel increased stress and anxiety raising a child with a disability (Russell, 2003). I therefore encouraged participants to feel calm and in control, as well as enabling them to talk through their thoughts.

There has been similar research conducted by a parent of a child with disability, which could place them within the population (Russell, 2003; Green, 2007). As a sibling, this does not put me within my own sample population, but I cannot ignore the influences this may have on my study and participants. My experiences combined with the qualitative nature of the study may result in readers questioning whether this provides "potentially valuable insight or potential bias" (Green, 2007: 161).

Two participants were known to me previously through my family's experiences with WSF within the region. As my brother is considerably older than the desired sample, I believe my personal experiences with WSF and the local region did not interfere with interviews because the participants joined the Foundation after my involvement as a sibling. However, I needed to ensure participants were genuinely happy to be involved with this research, and not doing it as a favour. Although this could not be controlled, I believe they were interested in the research and willingly volunteered. During these two interviews, participants mentioned my

brother to highlight an example, or ask a question. Although I had to balance my role as sibling and researcher, participants may have felt more comfortable talking to me. On the other hand, it is important to highlight that this could have influenced how they answered the questions. Continuous reflection and note-taking ensured that I focussed on my role as researcher rather than a sibling.

3.4 Method

3.4.1 Interviews

Seidman (2006) describes interviewing as a form of story-telling. Interviews give researchers access to understanding the meaning behind actions. Other methods such as observations may focus on observing behaviours, whilst interviews enable researchers to put those behaviours into context, with more understanding as to why a behaviour or event may have occurred. Strengths of semi-structured interviews include flexibility of not limiting participants to pre-determined answers, but the uniformity of pre-thought questions. On the other hand, it can be time consuming in collection and analysis of data.

The interview guide was created through an extensive review of literature that focussed on parents of children with intellectual disabilities, different types of SEND, WS and educational provisions. Some research also featured questions for parents or teachers which proved useful for developing my own questions (Reilly et al, 2015).

I enjoyed the flexibility of semi-structured interviews, and developed my technique over the process of interviewing. My interview guide (Appendix A) began by asking how parents chose the type of school, and what type of support their child received. This was a relatively simple set of questions for parents to ease themselves into the interview. I also asked about their child's likes and interests, which can be a dominant characteristic of WS, and enabled parents to feel comfortable as they could confidently answer questions. I ended the interview with more difficult questions focussing on inclusion, how they defined it and their experiences with their child's school.

3.4.2 Completion of the Interviews

Interviews lasted between approximately 40-90minutes. The flexibility of semi-structured interviews enabled participants to lead the discussion e.g. one parent expressed their concerns about their child moving to secondary school, whilst another set of parents shared anecdotes about how WS affects their child. Although this was sometimes not related to my topic, it was more appropriate to encourage parents to share information. It enabled me to learn about their family, understand how parents felt, and what they considered important for their child. Another positive aspect of this style of interview was being able to use the information participants shared to develop further questioning. This may have given participants the feeling of being listened to and appreciated, whilst it helped me to broaden their answers and find out more. It also led on to shared experiences of different educational provisions which did not seem inclusive, as well as parents' knowledge, understanding and perspectives. Furthermore, it may have benefitted them to be able to talk about what they wanted, as previous studies suggest many parents may not feel they have their voices heard (Hess et al, 2006; Lewis et al, 2007; Resch et al, 2010).

A better questioning style developed throughout the interview process. It was difficult to ask a spontaneous question suitably. For example, asking a question which was not leading or closed, and include vocabulary that could influence the participants' answers. I began to ask different questions depending on the circumstance and participants' previous answers. For example, in the interview with parents of a child attending special school, some parts of the question guide became less important than for parents of children attending mainstream school. For instance, asking how the school helps the family, whether it was linked to other schools on the same campus, and how parents felt about the school rather than focussing on specific types of support for the child and how the school ensured inclusion.

On three occasions children were present in the room during interview. One child was non-verbal, whilst two other children were verbal and happy to talk with the rest of the family. I did not address questions to the children for ethical reasons. For example, this was not in my application for research, and I was aware of the complications when talking to a child with WS, including obsessional interests which steers the conversation, low cognitive level mixed with high speech ability, and eagerness to please the adult. If asked a question they may want to give me the answer I wanted rather than the true answer, which is typical of much younger children. On a few occasions parents would ask their child one of my questions, for example

who they like to spend time with at school. Although this was interesting, and often a child would reply with a name or few names, my study focussed on the perceptions of parents and so in transcription these interactions were minimally transcribed and bracketed.

3.4.3 Memos and notes

After each interview, I wrote down initial impressions, the overall feeling I perceived from the parents, and any outstanding details I deemed important. I also ensured to reflect on my own practice, and made a note of any improvements for my interviewing technique. This enabled me to consider how I was asking questions and how successful I believed the interview was, which helped me to build confidence in the next interviews. In this way, reliability was ensured through honest reflections. It was interesting to return to these memos after listening to the recordings and remembering each of the interviews. It was useful to compare my thoughts straight after the interview whilst coding the transcript and noting my own overall perceptions.

3.5 Transcripts

When typing the transcripts, I excluded fillers when participants were thinking or attempting to form the beginnings of sentences. The first three transcripts I created I included other fillers such as 'obviously' 'like' and 'you know' but realised these were unnecessary. The final two transcripts I completed without fillers and half sentences or miscellaneous words when the participants were talking before a sentence was fully formed.

I encouraged participants to lead the discussions when they were comfortable, which allowed me to gain more information and discover topics they were more concerned with. However, this meant that some of the interview was not relevant to my topic. I excluded these stories during the transcription stage, with a bracket describing the story and highlighting the section of the recording in yellow.

I was unsure whether I wanted to include my pilot interview in my research, because it was clear that although my confidence increased throughout the interviewing process, there were significant differences between my first interview and the others. Firstly, I realised the participant was giving me valuable information in a 'chat' whilst she was making a cup of tea before the interview had officially began, and I had not recorded it. Secondly, I used an

example of my brother to ask a question. This led me to using vocabulary which then influenced the participants' answer, thus I stopped using this as a technique. However, I felt much of the data was still relevant. Overall I decided the pilot interview could be used in my study, and I emailed the participant to ask for their permission again, ensuring they understood their right to withdraw, and then asked a few more questions to clarify their perceptions.

After all the transcripts were written, I also decided to ask another participant for some further information through email. Whilst I felt that my lack of confidence in the first interview meant I did not ask further questions that could have given richer detail and more information, looking at the transcript of the second interview I noticed there were more references to the previous school than the current school, and realised I needed to question the connection between schools, and focus the participants' perceptions on the current school. Subsequently these answers clarified the tone of the interview, and added more clarity to the participants' perceptions.

All participants were sent a copy of their own transcripts so they could confirm the accuracy of content. I felt this was important for two reasons. I had slightly changed words in Transcript_04 to make the sentence grammatically correct for example the word 'got' became 'have'. These words were highlighted in green so I could also re-check myself that I had not changed the meaning of the sentence. Furthermore, I wanted to ensure that participants felt confident in their answers, and were not feeling used or misused for research.

Two participants asked about reading my thesis upon completion. Although it is sometimes not recommended to share theses with participants as there may be comparisons or statements that they disagree with, I agreed. I hope I will have represented a group of parents' views and highlighted any positives and issues related to education, which could be useful for parents to read about.

3.6 Data analysis

For data analysis, I followed guidance from Braun and Clarke (2006:28) who argue thematic analysis is often overlooked but is a rigorous approach to obtaining "insightful analysis that answers particular research questions".

My interview question guide restricts the type of thematic analysis I can use because the type of questions I asked were connected to my previous reading and my own pre-conceptions. This meant that I potentially asked questions with an answer already in my mind. Whilst this could be interesting to see whether the parent agrees or disagrees with my own pre-conception, it also means that I have, on some level, thought about the potential answers. This could have given me an idea of what theme I could find. However, I did not write my literature review until after data was collected. This meant that during the data collection I was not working through previous literature which may have further influenced my questions towards answers compared to previous research. Instead, I worked on my literature review at different stages of the thesis.

Using my memos and notes, I read and listened to each transcript, highlighting phrases or words that were meaningful to participants, helped summarise their thoughts, or stood out to me in direct relation to research questions. Then I created a table with general categories where I could insert quotes from each of the five transcripts for comparison (Appendix C). I made mind maps to help me process and link the key ideas from the table and redrafted until my final thematic network map. Then I re-read each transcript again making notes of key impressions of parents' perceptions, to ensure validity. I colour coded the themes and highlighted notes in each colour. This enabled me to check I had captured what participants shared, and whether all participants showed similar perceptions under my themes. It also emphasised the differences between participants' experiences of school, for example, 03 and 04 highlighted more of two colours whilst the others highlighted more of two different colours. My themes related directly to the sub-questions of my topic. Although I wished to represent my participants' views and voices in research, this cannot truly occur due to my active part as a researcher, because I selected, edited and positioned their voices for my own argument, linked to my own research questions (Attride-Stirling, 2001; Braun and Clarke, 2006). It was therefore important to continually reflect on my decision to create themes that would be most important, answer my research question and represent all participants' views.

Using thematic analysis as a realist method, I could report experiences, meanings and realities for the participants. As a researcher, it was my decision to judge how key a theme was, which Braun and Clarke (2006) suggest does not necessarily depend on how many times a participant mentions it, but how important it was in relation to the research question. Whilst theoretical thematic analysis provides a detailed analysis of some aspect of the data, I

analysed at the semantic level, which meant I interpreted the findings, before attempting to theorise the significance of patterns, and then relate it to my literature review (Braun and Clarke, 2006).
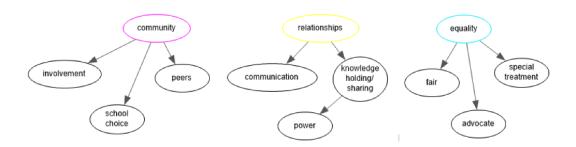
3.7 Ethics

I applied to the Norwegian Data Protection Official for Research for approval to conduct the research, which was accepted. I complied with their ethical guidelines, including confidentiality, safe storage of data and ensuring participants knew they had the right to withdraw from the study.

Furthermore, I met with the Professional Advisory Panel (PAP) to defend my research proposal. The PAP offers advice and support to the WSF, as well as selecting research to be conducted. The panel had granted me permission previously as he was aware of the limited time scale. I was therefore given permission by WSF to conduct research that would include members of the Foundation. It was clear during this meeting that they felt strongly about protecting their members. Research can sometimes be harmful to participants, and with a small group of potential participants, it was emphasised that large pieces of research should not be done at the same time, as the PAP did not wish people to feel over used or used in any way.

Although I had approval from the WSF, I ensured participants were aware that I was separate to the organisation in case they felt obliged to do this as a favour to the WSF. On the other hand, participants may have felt more inclined to trust me to represent their views accurately due to my connection with WSF. I was aware of ensuring participants were comfortable; that they understood my research aims and I hoped to benefit them in some way. One family asked for my own experiences as a sibling of a child with WS and I could help reassure them, whilst another family expressed their eagerness to be more involved with learning about different aspects of WS and research.

4   Data analysis and discussion

Three key themes represent my data set; community, relationships and equality. Several subthemes occur within each category, giving the reader an in-depth analysis of parents' perceptions.

4.1   Community

Parents look after the whole child, which is why in this study they did not focus on their child's academic progress or school work, but all activities involving their child. This is supported by previous research where parents emphasised school and community inclusion as strong themes and valued academic progress less (Hess et al, 2006 Resch et al, 2010).

4.1.1 Local

4 out of 5 parents stated location influenced their choice of school.

"Location was as important to us too, it was close to hand, and we could get him to walk to school." (02)

"It's 2 and a half miles away, so although initially we didn't move to the area with the aim of looking for a school we were already here, and then had the children and S was our closest one so it was our catchment area school" (03)

The participant who did not focus on location, chose a special school because it had a swimming pool. Simmons and Bayliss (2007) emphasise the lack of facilities in mainstream schools, which suggests that special schools have the desired specialist facilities. This

participant's child was transported to school via a bus, but parents were not concerned about the location as they prioritised facilities.

The remaining parents preferred local schools within walking distance, enabling parents to access the school easily. Furthermore, 4 out of 5 had attended a nursery that fed into the primary school which shows parents value developing strong local networks for their child. In one interview, parents praised the ease of transition between the closely linked infants and junior schools. Parents of children with different SEND also chose schools that were local (Bajwa-Patel and Devecchi, 2014). This supports research showing parents value location, encouraging their child to be accepted within the community (Bryan et al, 2006; Haines et al, 2015). Furthermore, school choice may be part of a wider decision to be within a certain community, as this is where parents chosen to live. The choice of school therefore is influenced by where parents want to be.

4 of 5 families had children who attended the same school as their child with WS, which was also highlighted by Tynan (2012). The exception was the child attending a special school who had no siblings. 01 emphasised the usefulness of having siblings who attend the same school, enabling her to keep updated on school information:

"Having older children there helps because you hear (laughs) stuff don't you about different things so, although that's going to change soon". (01)

The other parents put more emphasis on the community feel of the school. Perhaps this could illustrate the concept of parents' own perceptions stemming from attending school with their own siblings. Parents appeared to value family, community and keeping together.

4.1.2 Involvement

This subtheme can be divided into two areas; when the child is included in the class as much as possible, and when the child is part of everything. This was not necessarily a case of either or, but changed depending on context. However, parents could have been highlighting their child's full involvement when only linked to experiences they value most. Runswick-Cole's (2008) research showed parents of children in mainstream education hold a social model view of disability. The parent who referred to their child's full involvement in school was focussing

on social aspects such as trips and clubs, but also mentioned the suitability of adapted curriculum work in separate areas.

"When they're doing sort of things that they feel are at her level, she's very very much included in that. PE, she's obviously included in PE lesson. She has her lunch with all the other children, she has her breaks with all the other children, she's not kept inside separate from the other children. So the only times as far as I'm aware that she's ever segregated off is when she's doing her 1:1 work, when she's doing her OT stuff, or when she's doing her numeracy which she finds really really hard, she may go into a room and do that on her own with her 1:1." (01)

It is also worth highlighting 2 parents used more hesitant vocabulary:

"He's just one of the class, isn't he, as far as I can tell, from that point." (02)

This may be because parents genuinely cannot know how much time their child spends outside of the classroom, or because this aspect of their child's education is not integral in their perception of school. However, cautious vocabulary could reflect parents' anxiety associated with raising a child with SEND as suggested by Russell (2003), or the uncertainty felt when making important decisions (Elkins et al, 2003). Additionally, parents were aware of my research topic which may have affected the way they answered questions.

3 of 5 parents reported their child being fully included within the class. The parents of the child attending a special school described the class as learning and playing all together. This challenges the view that special schools are a form of segregation, as the parent emphasised his full involvement within the class (Cooney et al, 2006). This illustrates the difficulty in defining inclusion, and whether the child is part of everything the class does (Avramidis and Norwich, 2002; Hodkinson, 2012).

4.1.3 Trips

4 of 5 parents mentioned trips when discussing how schools ensured inclusion:

"It was just a case of she's coming, this is the day we're going and can you fill in the paperwork, which is brilliant because, I'm quite happy if they deal with it like that rather than

assume that possibly we don't want her to do everything, as far as I'm concerned, you know, just let her go in and do everything." (03)

02 highlighted adjustments the school made to enable them to send their child on a trip. This differed to how other parents highlighted school trips, who emphasised involvement with trips as a significant part of how their child is included. This further supports parents valuing community (Bryan et al, 2006; Haines et al, 2015). In contrast, 04 highlights the lack of trips that the school offers, which suggests all parents desire outings to different places within the community.

"But it is maximum twice a year. And it will be just to the park, nothing like cinema, theatre, nothing like that." (04)

This emphasises a key difference between special and mainstream education. It is useful to highlight parent's desire for their child to access the community. In this way, it could be argued that special education is segregating children from the community (Cooney et al, 2006; Simmons and Bayliss, 2007; Rodriguez and Garro-Gil, 2015). However, further comparisons are needed to investigate the experiences of children in mainstream and special schools.

4.1.4 Peers and Friendships

Interactions between their children and peers were highlighted in all interviews, suggesting parents view this as significant. All parents expressed some concern about their child's relationships with friends:

"You just think aww, you desperately want them to have a little friend" (01)

This reflects research emphasising the struggle children with WS have making and maintaining friends (Mervis and Klein-Tasman, 2000). However, there is little research to reflect the level of parental concern, due to research aims. Would parents of children with different SEND also have similar perceptions, or is this syndrome-specific?

Parents also highlighted the rareness of WS and their interest in enabling their child to spend time with peers with WS. Parents in 02 expressed desire to meet a child with WS the same

age, whilst 05 described the closer friendships their child developed with other children with WS, compared to her peers:

"And that's the really funny thing is the fact that even though they've only just met and they are very sociable beings aren't they, but they just got on so well together, better than her friends at school. They played really nicely, they were obviously all on the same level." (05)

It would also be interesting to investigate the differences between friendships of children with WS and without. Weiner and Tardif (2004) found children with SEND formed lower number and lower quality friendships with their peers. Would an investigation into friendships between children with WS reveal higher quality relationships than their typically developing peers?

Parents gave a variety of reasons for why their children prefer spending time with younger or older children. Perhaps parents felt compelled to explain why their child struggles with friendships with peers. 01 emphasised the lack of understanding and patience from same-aged peers, whilst 03 and 05 suggest their child plays games at the same level as younger children.

"But it's more her own age really that I don't think they really... they haven't got patience either. Whereas I think you need a bit of patience with E (laughs) because of the repetitiveness and stuff, and they haven't really developed that at that sort of age" (01)

A significant aspect of interactions parents mentioned was their child being mothered. 01 and 02 describe classmates looking after their child, including a volunteer buddy system.

"They want to look after them, because they do look really cute and they are really cute and they just come up and talk to you and they don't want to hurt you like some children might want to" (01)

In contrast, parents in 05 explained how their child would react negatively to being picked up by her peers:

"I suppose that's the reason they put her up on to that playground (infants) because they're the same mentality, same sort of mental age, so they play similar games, and he said the children on the bottom playground keep mothering her and picking her up. We've told him that they need to be told that she's got this (WS) and not to pick her up" (05)

This suggests both the parents and child in 05 rejected being mothered by her peers. In contrast, parents in 01 and 02 wanted their child to be looked after. In the same interviews, there were hints of their child being bullied. Is there a link between parents who have experienced negativity from peers and the desire for peers to be more mothering to their child?

It seems parents are eager to educate their child alongside their peers, with minimal age gap. When offered the opportunity to keep her child back a year, 03 did not wish for her to be separated from the same age peers. Similarly, 05 did not want their child to be separated from her peers when she was put on a different playground at playtimes, or when the head teacher suggested she spend more time learning with the younger age groups. Understandably, parents who wish their child to be educated alongside mainstream peers do not want them to be separated and put with younger children:

"We thought no we don't want to put her back in with children that are 4 years old, she'll start mimicking the way they behave and speak." (05)

This again shows that parents focus on who their child will be spending time with, which emphasises a community driven value (Resch et al, 2010). The parents of the child attending special school did not focus on his peers, which suggests parents of children in special education have a different focus.

4.1.5 Widening Peer Gap

3 of 5 parents highlighted the widening gap between their child and peers. Parents focussed on how they interacted and played with peers rather than the cognitive gap, reinforcing the focus on their child's social life.

"I would say it used to be more mutual but now as she's getting older it's getting less mutual because those girls like her and they'll come and talk to her but because the conversation's not reciprocal they get a bit bored I think and they just run off and play the games they want to play" (01)

01 and 05 suggest same-age peers do not have the understanding or patience needed to talk to their child. Parents in 02 showed awareness of the role that peers can play, suggesting their child can look up to and imitate his classmates. This emphasises parents' knowledge of the

role peers can play in helping children with WS to develop appropriate social communication skills (Wiener and Tardif, 2004; Bennet and Gallagher, 2013).

In contrast, 04 emphasised how their child prefers spending time with adults compared to children:

"Yeah, I think that he doesn't like children too much because he doesn't know what to expect from children, where as adults are more predictable and a child can do everything basically and he knows that." (04)

This supports previous literature which showed individuals with WS seek out interactions with adults rather than their peers (Karmiloff-Smith et al, 1995). However, not all parents highlighted this trait in interviews, which either suggests parents do not focus on this trait, or that it does not occur. This also highlights the heterogeneity of individuals with WS (Martens et al, 2008; Little et al, 2013; Lough et al, 2016).

The child who preferred spending time with adults had the most severe disabilities with WS. Is there a link between the severity of WS and having the skills or desire to interact with peers? Research suggests individuals seek the company of adults for conversations (Karmiloff-Smith et al, 1995). However, the child in this study had no speech, so it may not be related to WS but his other disabilities. Furthermore, parents stated that their child felt safer and more comfortable with adults.

4.1.6 Clubs

3 of 5 parents emphasised the unsuitability of after-school clubs. A key reason for this was tiredness, although 02 suggested there were no appropriate activities because their child could not participate in contact sports due to his heart condition. A further issue of supervision will be discussed later under a different theme.

Nearly all clubs that children attended were outside of school activities, reinforcing parents' perceptions on inclusion as part of the whole society (Bryan et al, 2006; Resch et al, 2010; Haines et al, 2015). However, this could be because parents had to find extra-curricular activities from elsewhere, as schools were not providing this.

"She does swimming and she does horse riding but she doesn't do any other kind of clubs… No, we do it, like at the weekend like at G (local swimming pool) she does that" (01)

Furthermore, parents in 02 highlight how clubs specifically for children with SEND were further away:

"Some of the special stuff is done in the county but it tends to be T or C which is you know, half an hour drive there and time consuming." (02)

This reinforces the concept of segregation for children with SEND, as clubs are outside of the local community.

4.1.7 School choice

3 of 5 children attended a village school, whereas another participant wanted a considerably smaller local school. 02 chose the closest school whilst 01 found a village school slightly further away. Parents placed large significance on the size of the school.

"So they have the funding, that side of it's good, but the fact that he can get lost in the crowd is more worrying, so ideally it would be a quote normal school unquote but smaller" (02)

"So I'd say it's pretty good, but it is a small school. Not sure what it would be like at the bigger school." (05)

The remaining participant emphasised the very small class size in the special school her child attends, which meant she felt her child did not need such close supervision as a 1:1 worker. This suggests that all parents value a small atmosphere and environment. Similarly, parents in Reilly et al (2015) study desired a smaller class size for their children with WS, which was a specific desire that differed from the parents of children with other types of ID.

3 of 5 parents emphasized how happy and or confident their child was, which helped clarify their decision in school choice.

"You see that your kid is happy to go there and has no issues and is not afraid to go there, and when we go for example for fun day with him to school, he is so excited, he wants to take us to his class" (04)

"She loves school though. It's your favourite place isn't it? We've already been asked if it's school tomorrow". (05)

The 1 parent who did not highlight their child's happiness is in the process of changing schools. 4 of 5 parents highlighted the type of atmosphere they sought or enjoyed at school. 2 parents compared their school to a family, with 04 describing the staff as parents' replacements and the parents in 05 describing the school as close-knit. This suggests parents view school as an extension of their home life, and wish their child to be in a caring environment. Moreover, 03 describes looking at a secondary school which did not have the right atmosphere:

"It just didn't feel the right atmosphere, the special needs area was on this dingy dark corridor, upstairs in this little room tucked away and I just thought, would I want to go and sit up there at lunch time and break times?" (03)

She emphasised the atmosphere of the room where her child would go for break times, which has been highlighted as key moments of the child's day in parents' opinions.

This supports research suggesting parents are generally satisfied with the school they have chosen, regardless of type of school, level of perceived inclusion and disability (Fidler et al, 2003; Parsons et al, 2009; Tynan, 2012). Although this suggests inclusive policies are working in practice, it does not show why parents did not choose other schools. In theory, all children with WS should be able to receive their education in any preferred school, so parents should not experience difficulty choosing their local school. However, parents who are satisfied with the school their child attends, have considered several different factors to help choose the school specifically suited for their child. In the case of parents in 01, they are not satisfied with the current school and so are changing to a different school. Moreover, the parent is not rejecting mainstream education, but is changing schools and selecting some parts of special education to contribute to her child's overall education. This contrasts with the parents in Runswick-Cole (2008) study who left mainstream for special education.

4.2 Relationships

A significant part of parents' perceptions explored relationships and the partnership between home and school. This involves how knowledge is shared and who it is shared between, as well as how communication is maintained.

4.2.1 Communication

One participant suggested communication was essential. Others seemed more relaxed but highlighted different how open and accessible they felt the school was.

"But I think the inclusion needs to have the communication thing, I think that's just the key, so the parent knows what's happening" 01

3 of 5 parents highlighted the importance of communicating with the school to maintain a good relationship. This supports research that communication is essential for this to ensure the inclusion of children with SEND (Lacey, 2001; Elkins et al, 2003; Gross et al, 2015). 01 suggested communications with the school is necessary for parents to be aware of what is happening with their child. On the other hand, 04 highlighted the benefits of an instant messaging system where parents receive messages and pictures of their child at school doing different activities. Both families perceive communication differently, whilst acknowledging its importance.

3 of 5 parents describe an open environment where parents can easily access the school and staff. The parents with children in mainstream schools value being able to physically visit the school and classroom, as well as speaking to their child's 1:1 daily:

"The 1:1 brings him out at the end of the day so if there's any problems she can tell me about it then. They're always pretty open, we can go in there any time we want to. Phone up if we've got a problem" (02)

On the other hand, parents in 04 emphasise the personal connection they see the staff have with their child. Moreover, they highlight the support the staff have given them. However, the parents of the child attending special school would not be able to visit the school daily to talk to staff, due to distance. Therefore, parents do not emphasise this as integral, but instead

highlight the messaging service which ensures regular contact, as well as 'Fun Days' where they can visit the school.

When communication is not working as effectively as it could, it can generate problems which causes further stress for parents. One set of parents explained their shock when the head teacher suddenly proposed that their child's needs could not be met at the current school, and perhaps they should consider a special school.

"It was dropped on us about F going to a special school. Nothing had ever been mentioned, and we had like a review meeting just to see how she was progressing… obviously she wasn't at the level of other children but she was progressing, at her own pace, and nobody had ever mentioned her going to a special school, and we were just completely blown away. We were just shocked by it." (05)

This emphasises the lack of openness and communication they experienced from their school. When the family-school-community partnership is not working, this can have a significant impact on the child's education, as well as the impact on parents (Haines et al, 2015). Parents can experience higher levels of stress raising a child with disability (Russell, 2003; Green, 2007). If the head teacher proposes that he cannot keep their child in mainstream school, it could be suggested that parents would feel unwanted, as highlighted by Broomhead (2013). This illustrates how integral communication is between home and school. Furthermore, this suggests why parents in 01 felt that it was vital to keep in communication with the school, to prevent the shock of finding out something new.

It was highlighted when the head teacher of the school was not approachable, or absent:

"This Executive Head, he was part time here and part time at this other school, but he was spending a lot of time at the other school. So you know, you take your eye off the ball what happens? Things do start to slip and not go in the right direction, and he admitted that… Because some weeks you wouldn't see him at all, he was never there." (05)

05 explained that the head teacher was an executive head teacher and so spent a lot of time at a different school. This could have contributed to the issues they experienced with their child at school, such as supervision, funding issues and meeting the child's needs. Similarly, 01 compared their current head teacher to the previous, stressing the benefits of his people skills and how interested he was in her child and the diagnosis of WS. This supports research

highlighting parents value schools that show interest in their child, and a willingness to learn about disability (Star et al, 2006; Scorgie, 2015). In other interviews the head teacher was not mentioned, which could be because there were no issues, or because parents did not see this as relevant.

4.2.2 Sharing of knowledge

3 of 5 parents found that when sharing information about their child with the school, it was gratefully received.

"We try to, in his statement, supply as much information as we can and they've always said that they've found it helpful, everything that's in there, especially the stranger danger thing" *(02)*

"When we bring some information or some new leaflets to them, to share with them, they are happy to take it and happy to learn more." (04)

This suggests parents understand the importance of giving information to the school, and when the school responds positively they acknowledge that parents hold valuable information about their child which is useful in an educational context (Gross et al, 2015; Haines et al, 2015). This supports Resch et al (2010) who suggests parents and professionals need each other for inclusion to work.

In contrast, when parents in 05 shared information with the school, this was rejected.

"And the thing is, we've handed them the teachers notes (guidelines)… I actually went in there and said have you seen the information we have brought in on this Williams Syndrome? 'Yes, I've read it'. So I went back down there the next day with a new one and I had actually highlighted all the issues she was raising about F like concentration, some behavioural. I actually highlighted it all, and gave one to the school, and one to the teacher." (05)

Similarly, parents in Scorgie's (2015) study felt devalued and lost confidence in the school when professionals disregarded their knowledge. 05 described occasions where the teacher received information on WS, but did not adjust her attitude or teaching style. Parents also acknowledged that this changed from teacher to teacher, as the Reception teacher was very good. However, they suggested one teacher reacted to the challenging behaviour rather than

understanding how WS affects their child. This was highlighted as preventing inclusion in other studies where parents felt knowledge of the disability would help teachers develop their understanding of associated challenging behaviours (Starr et al, 2006; Scorgie, 2015). This also supports research highlighting teachers' lack of knowledge of specific ID such as WS (Reilly et al, 2015).

Two parents show contrasting experiences with school:

"Because we know how the polish system for -education system for disabled children, and it's much worse. So probably we are a family who really appreciate the English educational system for disabled children. So we're not going to complain, we're not going to expect more from them. Because in our opinion, they just can't do more!" (04)

"What else could the school do? Just do what they should be doing." (05)

Whilst 04 expressed no issues with the partnership between home and school, it is also highlighted that they have perceptions of different educational systems from their own personal background. As well as different expectations, parents in both interviews show contrasting experiences of special and mainstream education. Furthermore, parents in 05 feel the school has not delivered on promises, effecting the inclusion of their child. The wide variances between the two experiences makes it difficult to distinguish the key reasoning for the successful and unsuccessful partnerships of home and school.

On the other hand, some parents gained knowledge from professionals at school. This happened to 2 parents in the early stages of education who were advised to send their child to a mainstream nursery. Most significantly, the parents in 04 emphasise the help and support received from special school, as well as highlighting the range of professionals that are involved in their child's life:

"Communication works very well with them; they are always there for us when we need them… They just can't do more! (laughs) They're very patient, they always have time. We see how they treat A." (04)

Their emphasis on professional knowledge was much greater than the other parents. This could be because their child had greater need for services including speech therapy, autism specialists, psychologists and paediatricians. Emphasis on professional knowledge is common

among parents of children attending special school, which shows a medical model view of disability (Runswick-Cole, 2008; Trussler and Robinson, 2015). Is this because parents are unable to learn the same in-depth knowledge of various therapies, and so must rely on professionals? The same parents also expressed their satisfaction that the school could organise medical appointments, enabling them to attend such appointments within the school.

Likewise, 2 other parents mentioned music therapy, without the same emphasis on professional knowledge. This could be syndrome specific due to the well-known affinity with music individuals with WS display (Martens et al, 2008). Therefore, this could be an example of the school failing to understand the child or disability, forcing parents to find an additional way to fulfil their child's needs. Similarly, research shows parents' knowledge of their child's learning styles and desire for increased musical resources and aids in the classroom (Fidler et al, 2003; Reilly et al, 2015; Tynan, 2016). Without knowledge of WS, how do schools ensure they are meeting the child's needs and ensuring access to the curriculum?

In contrast to the emphasis on professional knowledge, 03 describes staff having in-depth knowledge of her child rather than specific knowledge of WS. 02 and 04 also highlight staff knowledge of what the child wants or needs.

"Most of them just take him as he is, just try and cope with it, they're all used to dealing with autistic children and he doesn't behave in the same way as they do at all, so it is a learning experience for both sides" (02)

"I think they're really quite good about knowledge about her generally and moods and you know, how to deal with her and get the best out of her for work." (03)

The social model highlights knowing and seeing the child holistically rather than focussing on the label of their diagnosis (Runswick-Cole, 2008). 3 of 5 parents were satisfied with the school viewing their child in this way.

3 of 5 parents stated school staff actively sought knowledge about WS:

"Her 1:1 certainly does because I know that she has done a lot of research on it" (03)

01 and 03 reported their 1:1 did extra research, whilst 02 suggested some of the staff researched a small amount about the syndrome. Despite some of the parents' acceptance that staff did not focus on WS, others were happy when staff undertook research WS, which

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supports previous research (Star et al, 2006; Scorgie, 2015). However, it seems to be the 1:1 rather than the class teacher, but should this be part of the class teacher's role? According to Lewis and Norwich (2005) teachers do not need to focus on the child's disability to be able to understand how to teach them effectively, but Reilly et al (2015) highlighted the various preferred learning styles of children with WS.

When parents felt unable to seek information and support from the school, they had to find it elsewhere. 2 parents described actively seeking information from outside of school:

"But now, you've (J) been going to Parent Carers Course, and that's opened up no end of avenues that we didn't know about" (05)

"When I spoke to LH at the Foundation (WSF) about E at school how, what's happening with school with her behaviour, she said definitely try and get some music therapy" (01)

The parent in 01, who was experiencing some difficulty with their child at school, spoke to the WSF who gave advice to start music therapy. This emphasises the benefit of an organisation for families and carers, sharing valuable information and advice (Russell, 2003). Similarly, the parents in 05 highlighted the benefits of attending a recent WSF conference and a Parents Course in the local community where they gained confidence and knowledge to address issues within the school. This helped parents be empowered to advocate for their child which supports research where parents experienced a lack of information and advice whilst fighting for their children's rights in education (Russell, 2003; Lewis et al, 2007; Resch et al, 2010).

Parents who accessed support within the local community, received valuable help and information. However, this could have been supplied by mainstream schools. On the one hand, 01 emphasised a good relationship and communication with her 1:1, but described the class teacher's unawareness of what level her child was learning because the 1:1 did the academic work. This suggests the class teacher did not play as large a part in the child's life as her peers. Therefore, the child may not be receiving quality first teaching which can be a result of inclusion of children with SEND (Radford et al, 2015). However, the parent did not highlight this as a problem, although it could contribute to why there was difficulty in receiving the correct support and knowledge from the school. Furthermore, 05 struggled with role ambiguity when they had to become information gatherers and advocates. Staff may feel

threatened when parents become more knowledgeable, and in turn parents lose confidence in the staff with less knowledge (Gross et al, 2015; Scorgie, 2015).

Perhaps unsurprisingly, the parents in 04 who displayed the most reliance on professional knowledge, showed the least knowledge and understanding of inclusion. When given an example of inclusion, the parent suggested that inclusion was not possible for their child due to his cognitive ability.

"Obviously that never happened for A and probably is not going to happen because he is non-verbal and he doesn't understand what we are talking about to him. So he can't follow instructions. It's difficult with his understanding level." (04)

This is interesting because it highlights Mary Warnock's revised statements in 2005, suggesting there is still a place for special education if the mainstream school cannot meet the child's needs. In this case, I believe there is strong potential for their child's school to connect with the other schools on campus, creating more opportunities for inclusion. Therefore, special school does not have to equal segregation, and this school is missing more opportunities for inclusion.

4.2.3 Key Figure

All parents highlighted a member of staff who was particularly caring. It became evident that parents needed a key figure; for two parents the 1:1, one parent the SENCO and for one set of parents the family liaison officer. The parents of the child in special school were the exception, needing support from several professionals. Although there was no key figure, they emphasised a strong relationship between their child and his class teacher. On the other hand, participants in mainstream schools focussed on a key figure for both them and the child. Interestingly, parents experienced better communication with staff who was not the class teacher. Bryan et al (2006) suggests that this is due to their less formal approach, and their supportive role within the school.

"We've got an amazing liaison lady- family liaison officer, she's brilliant- and she tells us stuff she shouldn't tell us but we're glad she does." (05)

Parents mentioned their key figure several times, and the large role they play in facilitating their child's education. Two key figures were the 1:1 who worked with their child, and had

researched extra information on WS. This may have influenced how parents viewed them, as they also emphasised their caring natures.

"I think she's that sort of person anyway, obviously doing the fostering and stuff, she obviously is just that type of person; she cares" (01)

Two participants showed their anxiety at changing or losing their key figure:

"I was a bit concerned that if we started to bring in special ed, that it might mean the school would say to E's 1:1 that when E is not there we won't need you anymore, and she might look for another job" (01)

This suggests they play a significant role in mainstream schools. 3 of 5 parents emphasised having a key figure on their side, which suggests that parents perceive a struggle at school (Hess et al, 2006; Runswick-Cole, 2008; Resch et al, 2010). This was not an issue for the parent of the child attending special school. Why are key figures needed in mainstream schools but not special schools? Furthermore, schools may need to consider the impact of parents' reliance on one individual member of staff for parents to have a strong partnership with the school.

For 3 parents, the key figure needed to be available for a physical handover daily. Physical interactions enabled parents to exchange information and build a strong partnership:

"I said to her, I need you to take E from me, so now she takes her from me and we have a handover in the morning which is much better. And when E was in Reception last year she used to come out with all the children as well and I never got a hand over after school, but now, because we spoke to her, because we have this relationship which is really good, we spoke to her and said oh could you please bring E out and have a handover" (01)

Daily interactions ensure parents have a strong partnership with a staff member who closely works with their child. If this is the only source of information about their child during school time, it makes sense that parents value this staff member highly.

4.3 Equality

Children with WS require a different style of teaching to enable them to learn alongside their mainstream peers. This means they may be treated differently but it ensures all the needs of children in the class are met. An issue arises when defining inclusion using a social rights perspective which suggests children with WS should be treated the same as their peers. Schools must make adaptations to meet a child's needs, thus ensuring equity rather than equality.

4.3.1 Advocate

Parents showed awareness of disability rights and issues. 3 of 5 parents mentioned funding issues associated with mainstream school and getting the right support for their child:

"Her 1:1 gets pulled away which I think is kind of a funding issue and things like that which is obviously the constraints of a mainstream that you have and pressures on the mainstream school" (01)

This shows parents understand the funding issues highlighted by Sellgren (2016), suggesting their awareness of the constraints of a mainstream school compared to a special school. Although this does not cause parents to choose a special school, it may impact their confidence in the school to meet their child's needs.

03 highlighted knowledge of disability rights when a secondary school proposed they could not accept her child, which is illegal. In contrast, parents in 04 showed considerably less knowledge and awareness, which could be because they had no issues with the school. However, the same parents relied heavily on other professionals for knowledge. If a parent needs to fight for their child's rights, they have more reason to increase their knowledge.

3 of 5 parents emphasised the need or willingness to fight to advocate for their children:

"We're gonna get on top of it, and we're not gonna be a walk over… if she's not getting what she should be getting, we want to know why" (05)

Parents in 05 illustrated fighting for their child by using recently learnt knowledge to address issues. This supports previous research of focus groups where parents felt the need to fight. This suggests groups may not have been influenced by more dominant participants (Hess et

al, 2006; Resch et al, 2010). Furthermore, 01 suggested that if her child was not celebrated, she would have 'made a fuss' whilst 02 highlights their child's lack of achievement medals may be due to 'not making more of a fuss':

"E will get celebrated as well so she's obviously included in that, and I would make a fuss if she wasn't anyway (laughs) if she didn't I would be like 'why hasn't she been!' so yeah, so it is quite sweet. I don't know, I think I'm one of those sort of parents that's quite on the ball though, and I will say." (01)

Parents seem to feel it is their responsibility to ensure their child is treated fairly. Is it fair that parents of children with WS have more responsibility to ensure their child's inclusion? Furthermore, is it an issue for parents of children with different SEND?

4.3.2 Concern about special ed

4 out of 5 parents suggested children in special schools had more complex needs which meant it would be unsuitable for their own children:

"It wasn't even an option to go to SL (special school) there's just no way she'd you know, she would just go completely backwards, and she would just be well on from everybody else, in any of her age groups, both physically and you know, mentally I think, there." (03)

This is further supported by the remaining parent in my sample, whose child has a more severe diagnosis of WS combined with ASD and no verbal language. The parents who believe special schools are for children with more complex needs focus on their child's social interactions; who they will be spending time with at school. These findings support Elkins et al (2003) who showed parents believed special schools would worsen or slow their child's social and emotional development.

"Unfortunately she is not going to get all she needs from Specialist provision, as her peers would be far too severe, and she would have nobody to model, or play with as it stands." (01)

02 stated the school would not be able to meet their child's needs, whilst 05 suggested their child would react negatively to the children with more complex difficulties. This supports research emphasising the complexity of children's' disabilities attending special schools (Cooper et al, 2004). Therefore, many parents of children with WS feel mainstream schools

are the only option. 1 parent emphasized the lack of a place in-between mainstream and special schools:

"You don't know until you try it do you, and the biggest thing for me is there is no in between-y place in this area." (03)

This emphasises the need for special and mainstream schools to show they can effectively educate children with WS.

3 of 5 parents highlighted they would deliberate special school, but 'not yet'. On the other hand, 2 of the parents were starting the process of accessing some special education. 01 is starting a dual placement this September with a special school, whilst 05 mentioned starting music therapy at a special school.

"because E's behaviour has got increasingly difficult at home, which started to overspill into school. My thought, is that, she could be potentially struggling at school, with the academic workload, noise, and expectations, routines and rules etc., so I am hoping going to F (special school) during the week, will help her switch off slightly, and potentially have access to some therapies which might help, i.e Music therapy." (01)

This focus on therapies, which may be syndrome specific due to the characteristics of WS, suggests that parents view special schools as having the facilities absent in mainstream schools (Simmons and Bayliss, 2007). Therefore, schools may not be able to meet all the needs of a child with WS, without help from special education.

4.3.3 Same treatment

3 of 5 parents desired the same treatment for their child as others:

"So we haven't felt that he's ever been excluded from anything, he's been treated as normally as possible." (02)

Likewise, 03 emphasised how staff treated her child the same as her peers. Her child was not given an easier adaptation in sport, but treated the same as her peers. In contrast, 05 emphasised their approval that their child took part in races with younger year groups.

"They put her in the normal races and I guess I'm really friendly with the head- the teacher in her class who's a chap and he's head of all the PE and everything and he knows that I guess as parents we're both like 'get them in there, just chuck her on, don't let her have a head start, don't let her have- you know, I'm quite happy that she just goes in and she's treated and done the same as everybody else." (03)

This suggests parents have varied perceptions of same treatment and fairness. Moreover, 2 parents highlighted extra treatment through the school's organisation of additional swimming lessons:

"No I don't think they exclude her from anything. If anything they try and include her, with the extra swimming." (05)

05 explained their child struggled with water, but due to swimming lessons with her peers and the younger year group, she made massive improvements. However, are the extra swimming lessons special or equal treatment? In order to meet the child's needs and level of support, more swimming lessons were required. This causes ambiguity in parents' definition of inclusion.

Additionally, 01 highlighted unfairness when all the other parents received a letter except her, reflecting a desire for the same treatment:

"When you're a parent who's got a child with a disability, you want them treated exactly the same as everybody else, and I as a parent expected to be treated the same as well" (01)

4.3.4 Different treatment

3 parents suggested there was not suitable supervision at after school clubs. 02 and 03 emphasised the unfairness for teachers to have a child with SEND in the club.

"We always feel the clubs are just run by one teacher and many children so I think it's more us feeling uncomfortable, it's not fair on the teacher and a lot of things he wouldn't do anyway" (02)

This supports the previously mentioned ambiguity of parents' perception of fairness. Parents know that to include a child with WS in after-school clubs, extra supervision is needed.

However, parents in 05 experienced this differently. The head teacher implied that they should not send their child to holiday club due to the need for extra supervision:

"Well that was an issue because they invited F to attend and H to attend this club, and then during this meeting we had, the headmaster said if F comes we'll have to get an extra teacher in then… trying to get us not to send her" (05)

The parents decided to send their child, so the school had to bring in assistance. It is known that children with WS need extra supervision, but as 05 emphasised, it would be unfair for it to prevent them from certain opportunities.

3 of 5 parents mentioned a separate place or area for their child to work academically:

"But other than that I would say she's pretty much included in the class generally, and if she's doing her 1:1 academic stuff that she might not be able to sit in a small group and do, then she might have to go in a 1:1 situation out of the classroom." (01)

03 also refers to her child potentially disrupting or affecting other children's learning, suggesting that this would not be fair on everyone else.

However, it is arguably unfair for her child to receive her education outside of the classroom and miss being taught by a qualified teacher (Radford et al, 2015). On the other hand, this child's 1:1 was also a qualified ex-head teacher, so she could receive quality first teaching. Most support staff do not have as high qualifications, affecting the quality of education received (Radford et al, 2015). Likewise, parents in 05 were concerned about the level of teaching from the class teacher:

"And she's only had a TA, she's had no teacher input, and the Williams (Foundation) are saying she should have 50% (teacher input) we've told him this, and he's said I've seen her there doing something for about an hour or more and she just zones out. If he does what he says, then it'll be good but we'll wait and see" (05)

This is a crucial difference for children with WS or SEND compared to their mainstream peers, who usually do not have a 1:1 worker. However, only one parent highlighted this issue. This may be linked to parents' priorities of social and emotional development rather than academic progress.

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4.3.5 Parents feel need to do more

In two instances, parents illustrated a determination not to allow their child to be excluded. Parents in 02 described their child's full inclusion in swimming lessons, but with the help of the parent who joined the class.

"Well he went swimming when they went swimming, there was never a problem with that- 'no but I had to go too' (to help with changing)" (02)

This could reflect the low adaptive skills that individuals with WS have which affects their ability to dress (Mervis and Klein-Tasman, 2000). However, if the parent was unable to assist the child's dressing, would the school still have included him? Similarly, 05 suggested the school would not exclude their child from a residential trip, because the parent has already stated that she would attend the trip.

"They won't exclude her- no they won't because we've already said, I've already said that I would go with her." (05)

Although previous research has highlighted parents' willingness to fight, it does not explore how parents feel about inclusion. The 2 parents highlight concern their child could potentially be excluded, as well as their willingness to do more to ensure this does not happen. In contrast, 03 described a residential trip where her child had 1:1 assistance for the first three days, and for the remaining days had the support of the whole class teacher and her peers. This highlights significant differences in parents' experiences, which supports the theory explored by Parsons et al (2009) that this varies on location.

5   Evaluation and Conclusion

5.1 Conclusion

In answer to the research questions:

5.1.1 Why do parents choose a particular school?

Parents of children with WS prefer to choose a smaller school, close to their home. It seems that parents look to find a school that is within their chosen community, which is why many siblings attended the same school. They also consider the atmosphere and friendly feel of the school. The parents of the child with WS attending a special school outside the local community focussed on the facilities at the school, but were eager for their child to access the local community.

5.1.2 How do parents feel about different educational provisions?

Parents of children with WS attending mainstream schools rejected special education due to the changing population of children with increasingly severe disabilities. It seems parents of children with WS believe special schools are not appropriate for meeting their child's needs. However, the parents of the child attending special school were more satisfied all their child's needs were met.

Parents were aware their child would eventually attend special school, but felt that this was not yet appropriate. One parent highlighted the dilemma of finding the right school for children with WS. The parents of the child with WS who chose a special school did so because of his cognitive ability.

Parents wanted their children with WS to interact with similar-aged peers in a mainstream environment. The parent who did not focus on this had a child with WS who did not interact with children, but focussed on adults. Overall, the parents who focussed on potential friendships and social interactions for their child and peers feared this would not be found in a special school.

5.1.3 What do parents understand about the inclusion of their child at school?

Parents suggested their children with WS were included in most parts of mainstream school life. However, their emphasis of inclusion centred mainly on social aspects such as games, trips and relationships with peers. The parents of the child attending special school valued his full involvement in all class activities, but did not understand the term inclusion.

Ambiguity exists between parents' perceptions of equality and equity. Parents want their child to be treated the same as other children in mainstream schools. However, children with WS require adapted educational approaches. Parents are grateful when the school meets their child's needs. In policy, schools should be meeting all children's needs irrespective of disabilities. Why do parents feel grateful for something that should be happening? On the other hand, some parents felt they needed to take an active role to ensure their child's inclusion in mainstream school.

5.1.4 How does the distinct profile of Williams Syndrome affect inclusion in schools?

Although true for many children with different types of ID, parents expressed concern that their child with WS had difficulty making and maintaining friendships with their peers. Parents shared various reasons for friendship difficulties, as well as acknowledging that the developmental gap between their child and peers is widening.

Many children with WS transition to a special school after finishing primary education due to the increasing gap in cognitive ability with their peers. However, parents of children with WS show less concern over cognitive ability, except from the child in special school. If more children with WS continue through to Secondary school, how could this impact their social interactions with peers? Will their peers continue to be role models, mother them, or build friendships? On the one hand, this could help continue the community feel parents want, as children grow and transition together. On the other hand, the gap could continue to widen, leaving individuals with WS more isolated as their peers continue to outgrow them.

5.1.5 How do parents and schools collaborate to ensure inclusion?

Many children with WS need a 1:1 to enable them to access the curriculum alongside their mainstream peers. However, parents also need a key figure, usually a non-teaching staff member, to create a strong partnership with the school. In order to build and maintain this partnership, communication needs to be two ways. Parents need to exchange and receive information with schools. All parents had varying levels of communication and knowledge sharing with schools. The parents of the child attending special school felt disadvantaged at their lack of knowledge and relied heavily on help from various professionals. Parents of children in mainstream school who did not receive appropriate support had to find this elsewhere from the community. Parents value staff that research the disability, and have a good understanding of the child. Communication and collaboration is therefore essential for schools to enable parents to feel supported.

5.2 Limitations

Although the qualitative design enabled me to explore parents' perceptions, it should be highlighted that my personal background could not be separated from the study. However, I believe my continual reflection and awareness of this solved issues throughout. On the other hand, my inexperience as a researcher could have affected the study, specifically the methods. One limitation of my interviewing was my inconsistency in questioning, particularly in regards to asking the last question, which was to give an example of when their child was included or excluded. Next time I would spend more time adapting the interview guide, adding questions which could help participants direct their thinking, and exploring prompts to illicit more in-depth information and perceptions. Upon reflection, I should have focussed more on the type of vocabulary I used. For example, asking about hypersociability, which is a known characteristic of WS among researchers (Jones et al, 2000). Instead I should have asked about their child's behaviour and socialness, without using vocabulary that could lead participants to answer in a certain way, or influence their own thinking and opinions. Overall, there is appropriate data to suggest this study provides the rich detail necessary to answer the research questions.

5.3 Implications of the study

This study outlines the importance of understanding parents' perspectives of inclusive education. In asking parents what inclusion is, it is giving insight into parents' expectations and values. When parents' definitions of inclusion differ from the school's, this causes a dilemma where parents remain unsatisfied at the school's misunderstandings. Furthermore, if parents struggle to define what they want from inclusion and education, schools are unable to facilitate this. Parents of children with WS require more support from schools to ensure their child is receiving an appropriate inclusive education.

5.4 Recommendations for further study

Parents of children in mainstream education focussed more on the social aspects of school. How far is this syndrome-specific, due to the well-known sociability of individuals with WS? A comparison study with other intellectual disabilities could help highlight differences in parents' emphasis on social interactions.

Furthermore, an in-depth study of the experiences of children with WS in mainstream primary schools can help explore how parents and schools can collaborate to solve issues. A study that involves the perceptions of teaching staff can further enlighten us in ensuring inclusive education for children with WS.

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Appendix

Appendix A: Interview Guide

1.   How did you choose the type of school?

2.   What other types of schools did you consider, if any?

3.   What factors influenced your decision?

4.   What type of support does your child receive at school?

5.   What support would you like your child to receive?

6.   How knowledgeable are staff at school about WS?

7.   Who does your child like to talk to/spend time with at school?

8.   How sociable would you describe your child?

9.   How might their sociability affect their school life?

10.   How is your child actively involved in school?

11.   How does the school ensure your child is included?

12.   What do you understand by the term inclusion?

13.   Can you give an example of when your child was included/excluded?

Appendix B: Information Letter

Request for participation in research project

 "Parents perceptions of social inclusion for children with Williams Syndrome"

Background and Purpose

I am doing a Master's thesis on the perceptions of parents of children with Williams Syndrome. This project is through the University of Oslo. It has been approved by the Williams Syndrome Foundation UK, but is separate from the organization. I hope to highlight the value of talking to parents of children with disabilities, as they hold a lot of knowledge. I also hope to raise awareness of Williams Syndrome as it is a rare disability.

I am looking for parents of children aged 5-11years old with Williams Syndrome who attend different types of schools. I have selected regions Somerset, Devon and Cornwall as they are local to me in the South West of England, with a possibility of visiting Merseyside in the North West of England.

What does participation in the project imply?

I aim to do face-to-face interview in participants' homes using an audio-recorder. I will be asking questions about why you chose the school your son/daughter attends, the support they receive, and your understanding of inclusion. I am also interested in how the characteristics of Williams Syndrome may affect their inclusion in school.

What will happen to the information about you?

All personal data will be treated confidentially. All personal data and recordings will be stored in password protected hard drive and laptop. Personal details such as your name and gender will be stored separately from the other data. Personal details within the study will be replaced with a numerical code without any identifying information. Participants may be recognized in publication only through demographic variables such as gender and county. I will be working with my supervisor only.

The project is scheduled for completion by 9th December. From this point on all data will be anonymized so that you will not be identified in any way. They will then be destroyed following the University's guidelines on the disposal of confidential information.

Voluntary participation

It is voluntary to participate in the project, and you can at any time choose to withdraw your consent without stating any reason. If you decide to withdraw, all your personal data will be made anonymous.

If you would like to participate or if you have any questions concerning the project, please contact me, Katherine Gulliver +447969047069 gulliverke@aol.com

Details of Supervisor: Ivar Morken

Email: ivar.morken@isp.uio.no

Phone: +4722858123

The study has been notified to the Data Protection Official for Research, NSD - Norwegian Centre for Research Data.

Consent for participation in the study

I have received information about the project and am willing to participate

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(Signed by participant, date)

Appendix C: Themes Table

	01	02	03	04	05
Lucky	Used x1 "I just think I'm quite lucky with my 1:1 though" Relationship	Used x1 "we were quite lucky in the fact that, at T (infants school), he would usually have no more than two workers in one year" Relationship	Used x10 "I just feel really lucky as well that H's 1:1 is also really nice and someone we get on with and well as a family" Relationship	Used x5 (different vocab) "we're not going to complain because we know how the polish system for -education	Used almost once but then sentence restarted "I think we're lucky that we got F into mainstream, well... she's fine in mainstream and we're not going to

			"we were quite lucky I guess, that we'd had a little school" Community	system for disabled children, and it's much worse." Equality "they provide for A everything he needs, and that's why I'm not going to moan" Equality	take her out of mainstream" Equality
Good communication with school / TA / staff	"it's so important as a parent with a child with additional needs that you have that communication with your, like the one-to-one and the school" Linked with key figure Relationship Communication book with TA, no links with class teacher. "But I think the inclusion needs to have the communication thing, I think that's just the key, so the parent knows what's happening" link to story Relationship "they don't necessarily know where E's at in terms of what she's doing work wise because her one-to-one kind of does it with her rather than.... (the class teachers)." No communication with teachers Relationship	Refers to handover – C "the 1:1 brings him out at the end of the day so if there's any problems she can tell me about it then. They're always pretty open, we can go in there any time we want to. Phone up if we've got a problem" Relationship "they all know him, yeah, I don't think there's a teacher there that doesn't know who he is" Have communication book but not used often. Community	Communication is good -Staff knows parents' wishes "chat to her (1:1) every morning, chat to her when I pick her up every night and if there are any issues then we're straight away able to chat about them so it's quite good" Relationship "know all her reports and things though are done by the class teacher as well, he's really really involved in.. and the SENCO at school is really good" Relationship Home school book/diary. Good. "as I said because we're seeing them on a day to day basis all the teachers anyway so I just think there's never that, you've never got that barrier" Relationship	Communication is good "every day messaging… We can send a picture from the weekend or they can send a picture to us from what A was doing at school" Relationship "And we can contact them every time we need something" Relationship "communication works very well with them, they are always there for us when we need them." Relationship "but speech and language therapist is lovely and she really helps him. And his teachers are great." Relationship	Linked with key figure – Liaison Officer "this Executive Head, he was part time here and part time at this other school, but he was spending a lot of time at the other school. So you know, you take your eye off the ball what happens? Things do start to slip and not go in the right direction, and he admitted that… Because some weeks you wouldn't see him at all, he was never there." Relationship "she's very much on our side. And she's watching F's back. She tells us stuff that's going on which we shouldn't be privy to, but I'm glad she does." (liaison) Relationship Recalls several meetings with Head teacher.

| Celebrated at school | "She also gets celebrated as well at school. They do, month by month they pick children to be celebrated for good stuff that they've done, and E will get celebrated as well"
Equality | "It's more like the rewards, he tends to miss out on the rewards systems that they have in place, either because he's not doing exactly the same as everyone else but I did feel that was a bit... (sighs)"
Equality

"Yeah I think they're certificates are goal based rather than effort based aren't they so you know what I mean (I don't know) T (infants school) often did a pupil of the week for effort (C 'yeah but, everyone got a turn of that whereas here I've noticed it tends to be the same kids coming out with the certificates and they're the ones that've suddenly got the little medals and stuff, and you think well hang on a minute, you know. But yeah, that's probably me not making more of a fuss I don't know)"
Equality | Not mentioned | | "On a Friday they have family assembly and if you get a certificate (from home) you can send it in and be called in for it. Like she got a swimming certificate and you can take it in and they'll reward you with it in front of the school. She loves that. They have like, if you've done some good work at school then you get a teacher certificate and you get those on a Friday in family assemble."
Community/Equality |
| If child is happy, school is working | | | "would know if she's not happy"

"and she was really happy right from the start"

"she's happy at the moment where she is and I think unless they're unhappy there's no point in changing it" | "I think being a special parent for special kids, when you see that your kid is happy to go there and has no issues and is not afraid to go there, and when we go for example for fun day with him to school, he is so excited, he | |

				wants to take us to his class" "And it's important for us that we see he feels very safe, because as i told you, he is not afraid of changing location or routines, but some places he doesn't like… he is very anxious then, and it's very difficult to calm him down" "So, in here (home) he is confident, you can see that he feels safe, he knows where everything is, and the same when he is at school, and for me that is enough." "seeing a smile on his face and him being so confident over there (school) it's amazing, and it's enough."	
Refers to funding issue	Mentioned "her 1:1 gets pulled away which I think is kind of a funding issue and things like that which is obviously the constraints of a mainstream that you have and pressures on the mainstream school"		Mentioned (After WSF Convention, Birmingham, 2013) "we then got her statemented which everyone was like, you know, it's important to get her statemented in case all the funding cuts."		Issue "we thought no we don't want to put her back in with children that are 4 years old, she'll start mimicking the way they behave and speak. And we had a meeting with our liaison lady and she was devastated because he didn't have her best interests at heart and it was just a money saving exercise." "obviously money is a problem now, and that's why we

					don't want money to be a problem so we've gone for this full time statement.” “But it transpired that she's not been getting the 5 hours at lunch time, they've been using that money to fund her afternoon sessions”
Relationship with peers	Peer gap “I would say it used to be more mutual but now as she's getting older it's getting less mutual because those girls like her and they'll come and talk to her but because the conversation's not reciprocal they get a bit bored I think and they just run off and play the games they want to play” Community If close to peer, staff highlights “and there might be the odd day where something's written in where she was playing on a bit of apparatus with another child, that was written in on Friday I think that she was doing that” “And this is obviously the problem she has with her peers because she doesn't really make conversation.” Community “People warm to her naturally, and parents warm to her	“But J get's on with most of his classmates. A couple of girls look after him like F (girl's name).” “Yeah they do look after him. But, he doesn't have a particular friend”. Community “He does struggle to interact with children his own age...” “they've all grown up with him, and they're used to him” Community “Due to the close links between school, and the fact that a great deal of Joel's peers moved with him, we found the transition very smooth.” Community	Peer gap “I mean her peers in her year, you can just see it just peeling away, you know where the peers are off and doing different things, where as she naturally lends herself down towards the younger children and just wanting to run around” Community “she used to always be really really focussed on the adults.”	Adults “He prefers spending time with adults rather than children. But i think that's because he feels more secure- but really he is not aware of danger or he doesn't feel the fear.” If close to peer, staff highlights “even on our last meeting with his teachers they were happy because he had joined some, not game, but a child was playing in a house and he joined that child so they really appreciated that moment, because he is not joining with other children to play.” Community	Peer gap “We read that there's a peer gap and he seems to think that the peer gap is starting now, to widen. Her friends are doing different things and she's still doing her thing.” Community Importance of being with peers “she said in her meeting that F should be referred to an OT and nothing's happened. So i spoke to her and she said 'oh has that not been done?' no that's not been done, 'so how's F getting on? what's happening to F in September?' and I told her, and she was 'no, no way... she should be kept with her peers'” Community

	because of her sociability so it's nice because she gets involved in things like at the moment she still gets invited to parties" Equality "But it's more her own age really that I don't think they really... they haven't got patience either. Whereas I think you need a bit of patience with E (laughs) because of the repetitiveness and stuff, and they haven't really developed that at that sort of age" Community				
Concern with friendships	Parent concern "you just think aww, you desperately want them to have a little friend" Community	Parent concern. Doesn't have any WS peers "obviously it is something we worry about but, difficult isn't it. We've never met another Williams Syndrome child of his age, so we don't even know if they would play together anyway, you know" Community	Mentions concern with Secondary "And her peers are really, I mean they're all really good and really lovely but you can just tell they're already in their little- you can see the start of how it is in Secondary, where you get into like little groups" Community	No major concern although mentions lack of relationships with peers	Got on better with friends with WS than her peers "even though they've only just met and they are very sociable beings aren't they, but they just got on so well together, better than her friends at school. They played really nicely, they were obviously all on the same level." Community
Spends time with older/younger children	Older and younger "she very much gravitates towards the older children at school and I don't know if that's due to the fact that she's got older brothers, and it is boys that she gravitates towards" Community "they want to look after them,	Older (Buddy system) "There's a small team of volunteer children that look after younger children…And yeah, he's been exceptionally helpful." Community	Younger (family friend) "I guess no one stops her from playing with all the younger ones because, break times are at the same time so they're all, pretty much allowed to play with whoever they want to play" Community	None "Yeah, I think that he doesn't like children too much because he doesn't know what to expect from children, where as adults are more predictable and a child can do everything basically and he knows that." Community?	R – tries to talk to ch J – more drawn to adults "if it's an older child or an adult, they'll think ah she's cute and they'll start talking to her, but if it's somebody her own age then they don't seem to understand." Relationship?

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Looking ahead	Assessing year on year "for Reception year, most definitely" just finished Year 1 Anxious about losing TA Changing school Bringing in special ed		Looking at Secondary schools (age 10)		Thinking about Secondary school (sibling in his last year of school) "We are worried about Secondary, what to do with her for her Secondary education that is a real worry." "Yeah I think as she gets older we're noticing it perhaps more and when she goes to Secondary it will be quite difficult I think." (gap with peers)
Decision of school	One of the chosen pre-schools fed into this school "she was doing well socially which is a good strong characteristic of a Williams person/child and we just felt it would suit her really well and we felt that she could manage being in Reception" "but we didn't foresee any issues or anything with her going to mainstream school full time in reception" Equality "Unfortunately we experienced	Chosen pre-school fed into school Location important – local school Community "he thrives on copying other children so peer pressure comes into it" Early clear diagnosis, simple to get solid statement for the right support "we got a recommendation from his, portage worker to use a local nursery, and that fed into the local primary school" Relationship	Location – already there, local school Community "You don't know until you try it do you, and the biggest thing for me is there is no in between-y place in this area."	Facilities – out of two special schools, one had swimming pool "he was delayed in development from early age, and so he went already to special nursery. And after nursery we went straight away to special school, we just had a choice between two special schools in C (town). And we chose B because they had a swimming pool and A loves swimming, and that's it to be perfectly honest" "That's how our	Chosen pre-school fed into school Community Diagnosed after starting school – no change "We were told there was no reason why she couldn't be in mainstream at the time." Equality "it's only as she's gone on through the school that the educational issues have become more apparent."

	some problems at ESC, and have made an incredibly difficult decision to move E. (I'm feeling very stressed and worried about the whole thing!)” “So I'm not feeling particular good with E's current Mainstream school, and feel anxious about the next” “because E's behaviour has got increasing difficult at home, which started to overspill into school. My thought, is that, she could be potentially struggling at school, with the academic workload, noise, and expectations, routines and rules etc, so I am hoping going to F during the week, will help her switch off slightly, and potentially have access to some therapies which might help, I.e Music therapy.” Equality			paediatrician explained to us, because obviously we are not professionals, so we take what they say (laughs) We are not going to argue. If professionals and assessments, at school, at home, and in some special clinic, psychologists and paediatrician and another lady who is specialist in Autism, social communication schemes” Relationship Ch's SEN too severe to attend mainstream; re verbal “Obviously that never happened for A and probably is not going to happen because he is non-verbal and he doesn't understand what we are talking about to him. So he can't follow instructions. It's difficult with his understanding level.” Equality	
Reject special education	“Unfortunately she is not going to get all she needs from Specialist provision, as her peers would be far too severe, and she would	“certainly in his current age to go there, they'd be struggling to help him be independent, and keep up with everything else.” Equality	“Certainly we feel we've made totally the right decision with Primary. I wouldn't have wanted- and everyone else we've spoken to are like 'I can't imagine her		“because obviously they have children with quite complex medical needs and stuff, she would just freak out” Equality

	have nobody to model, or play with as it stands." Equality		having gone anywhere else' and also she sees herself as being a part of everybody else." Equality "it wasn't even an option to go to SL there's just no way she'd you know, she would just go completely backwards, and she would just be well on from everybody else, in any of her age groups, both physically and you know, mentally I think, there." Equality		
Small school benefit	Not mentioned (later this became a question to Pp) and does not seem to be an issue Email "We are in the process of moving Evie mainstream Schools, ESC, where she currently goes, is a village school, Evie is about to go into year 2. In her new class, there would be 30 children. At her new School, AS in M, obviously, it is another Village School, there will be 28 children in her class." Community	Local, large school 500 children "So they have the funding, that side of it's good, but the fact that he can get lost in the crowd is more worrying, so ideally it would be a quote normal school unquote but smaller" Community "I'm sure if you asked any parent they would say exactly the same thing no matter what they situation... that they would just like the school to be more compact. And therefore, all the children really identifiable, and they have that sort of community feel to it." Community "But certainly I found in my experience, that he's reaching the point now that	Local, tiny school 55 children "and it's rural, it's the middle of nowhere, and there's only 9 children in H's year" Community "we were quite lucky I guess, that we'd had a little school" Community	Bus Tiny class 8 children No real mention of size or concern "He doesn't have 1:1. His class has about 8 children, and it's one main teacher and three teacher assistants. But they learn, study, play all together." Community "even on the bus, on the transport to school and you can see, although actually on his bus everybody sits separated. They all look not bothered about each other (laughs)."	Local 120 children "So I'd say it's pretty good, but it is a small school. Not sure what it would be like at the bigger school." Community

		child can be a bit cruel, and so it would be nicer to have a smaller environment for him." Community			
Siblings – comfort knowing school	Know school well "having two older children… it worked really well for her to go there as well" Community	Know school well?	Sibling attended but not emphasised	None	Sibling attended but not emphasised
School holds little knowledge/1:1 does research	"Although the 1:1 is really good because even yesterday there was a Williams course in T (nearby city/town) and she heard about it because she's a foster carer" Relationship "school generally no. I get the feeling they're not, really, that, kind of bothered about really finding out about it. We've had a change of head (teacher) who really isn't that approachable, and she doesn't really want to know, where as our previous head he was more of a people person and he was a bit more interested and i spoke to him about it" Relationship	"Some of them take the time to learn a little bit" Staff get to know child rather than WS "most of them just take him as he is, just try and cope with it, they're all used to dealing with autistic children and he doesn't behave in the same way as they do at all, so it is a learning experience for both sides" Relationship	"Her 1:1 certainly does because I know that she has done a lot of research on it" Relationship "So, I'm quite happy generally with their knowledge of her, and things, but like I said, in terms of detail not that, as much, apart from her 1:1 who I know when she first started looked up loads of stuff about it" Relationship		"It has varied on teacher" "her Reception teacher was amazing… that's where they wanted to put her again" Relationship "We've told him that they need to be told that she's got this (WS) and not to pick her up" Relationship Late diagnosis "And they still didn't know she was Williams Syndrome then, and the speech therapist did some work with her and then decided something wasn't quite right, she didn't know what. Referred her to the paediatrician and she walked in the room and he told us within minutes, of what he thought it was, just by looking at her really, and he hadn't seen another child for 6 years" Relationship
Parents share knowledge of WS with school		Parents supply useful information in statement "We try to, in his statement, supply as much information as we can and		Parents share information/lea flets "when we bring some information or some new leaflets to them, to share with them, they	Parents share information/leaflets but Staff ignored leaflet/showed little understanding "And the thing is, we've handed them

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Staff see the individual rather than diagnosis vs staff see the behaviour rather than the syndrome	Poss? Food.		"they probably just treat her as an individual and deal with the problems that we get with her, maybe, rather than go, because you know if you look up stuff sometimes you just, well as a parent, you frighten yourself looking up stuff" Relationship "I think they're really quite good about knowledge about her generally and moods and you know, how to deal with her and get the best out of her for work." Relationship		"They don't get it. It's not like she's being naughty. They don't get it. It's like they don't realise with the concentration and the way that she is, is part of her condition." Relationship "they're giving it as negatives but it's not negatives, it's just the way that she is. And you should adapt in your learning (teaching) for that." Relationship Class 2 teacher - "But of course, F does not sit still, does not do her work and of course she couldn't manage that. She couldn't cope with that (teacher). She (F) didn't fit in that box. Whereas H did, and F didn't, and that was evident." Equality?
Acknowledge the extra supervision needed at clubs (fair?) (Also tired or not relevant for ch)	No mention of school clubs. Community clubs e.g. Rainbows but "when she went she was so hyper, she finished at 7, got her home, she was so hyper that I literally couldn't get her to go to bed." "When I spoke to LH at the	Would need more support to attend club – not fair on teachers "The reluctance between, most after school clubs are run on a voluntary basis by the teachers. He requires rather more perhaps attention than can be given easily at a one-to-one club" Equality	Would need more support to attend club – not fair on teachers "I kind of feel as a school, because they haven't got a 1:1 in the after school club it's not really fair for them to be expected to do it." Equality Also too tired	Holiday club, but not going.	Holiday club "Well that was an issue because they invited F to attend and H (sibling) to attend this club, and then during this meeting we had, the headmaster said if F comes we'll have to get an extra teacher in then (reluctantly)… trying to get us not to send her" Community/Relationship

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	Foundation (WSF) about E at school how, what's happening with school with her behaviour, she said definitely try and get some music therapy" from special ed. Equality "But she does swimming and she does horse riding but she doesn't do any other kind of clubs. (I: is swimming through school) No, we do it, like at the weekend like at G she does that, but she can be a pickle though" Community	C "we always feel the clubs are just run by one teacher and many children so I think it's more us feeling uncomfortable, it's not fair on the teacher and a lot of things he wouldn't do anyway" Equality "pretty tired by the end of the day"			"when there's a group of children I get a bit worried that they've (Adult/supervisor) only got one pair of eyes and if they're on their own, they've got all these children to watch and if F wanted to take herself off somewhere, she'll take herself off somewhere"
Involvement		Trips "we were allowed to pick him up at bed time and take him away so that he could be part of the whole experience." (camping trip where children have to stay overnight) Community Plays – ch struggles with audience noise, parents decide not to participate Relationship/Equality	Trips "It was just a case of she's coming, this is the day we're going and can you fill in the paperwork, which is brilliant because, I'm quite happy if they deal with it like that rather than assume that possibly we don't want her to do everything, as far as I'm concerned, you know, just let her go in and do everything." Community "You know, she's not given a role to sit in the background and do nothing, they're very much like no, that's fine, put her in and let her do it, so she's in all the school plays, she's in all the - any production-y things they do at school. And you know, is expected to do all	Family fun days at school Community	"And any trips, she goes on school trips and stuff like that." Community "She got up in front of the class and described what this soldier was wearing, so she does get involved in class stuff"

			the sport and those kind of things." Community		
Exclusion – from school or from child	"and all of the parents received a letter from the teacher that had taken over in the interim, talking about their child's progress. Well I never got one, so I was cross…I know it's really really minor, but to me it was quite big. Every other parent received a letter and I didn't" "it's just, I expect to be treated fairly." Equality "sometimes I think she's kind of left in a group and kind of viewed upon in the group, which I think's fine, as long as she has almost someone on her shoulder, but there are times throughout the day where she's taken away, and she has the one-to-one kind of time, which is good." Relationship "which i wish she was included a bit more is assemblies, she's kind of not, but then I've been told it's when she does do her therapy sessions like her OT sessions" Equality "But other than that i would say she's pretty much included in the class generally, and if	Not much C on certificates "Well he's one of the few that's only had the one, and that's after *I* said something. So I think he can get overlooked that way and that annoys me a bit" Equality "Well he went swimming when they went swimming, there was never a problem with that- C 'no but I had to go too' (to help with changing)" Equality	None Her concentration due to chatting… "quite hard to concentrate on, which is, you know her school work, which is why quite often she's got a separate space and separate areas that they go to when she's got to do something that's actually quite serious" Equality Easily distracted so "she goes to a separate place when, you know if they're doing something that's quite serious like curriculum based that is gonna be something that she won't be able to deal with or you know, theres no point in her learning" Equality "but I think that's down also, as I say to the main teacher in her class- or, he's acting head at the moment. You know, he's very much like 'yep, she's in there, she's part of the class, she's doing' and they have her in the class for as much time as they can unless its real, you know, curriculum stuff where she needs to go separately and then they kind of know from her, whether to put her out" Community/Relatio nship "I'd rather that they did work	None – or all "No idea, well, our school is in a campus, of schools. So there's probably I would say, four schools there. And there's a sports school, and mainstream primary and I think mainstream secondary there. But I don't know if there's a connection or not." Community	"they won't exclude her- no they won't because we've already said, I've already said that I would go with her." Equality (pp feels they need to go to stop her being excluded. Should this need to happen?)

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	she's doing her 1:1 academic stuff that she might not be able to sit in a small group and do, then she might have to go in a 1:1 situation out of the classroom." Equality		appropriate for her, and they did that outside of the classroom" Equality "but I wouldn't want her to disrupt or effect anyone else's sort of, schooling or, because I kind of think well that's not fair on everybody else" Equality		
Inclusion/perce ived inclusion	"when they're doing sort of things that they feel are at her level, she's very very much included in that. PE, she's obviously included in PE lesson. She has her lunch with all the other children, she has her breaks with all the other children, she's not kept inside separate from the other children. So the only times as far as I'm aware that she's ever segregated off is when she's doing her 1:1 work, when she's doing her OT stuff, or when she's doing her numeracy which she finds really really hard, she may go into a room and do that on her own with her 1:1." Community/Equ ality "when you're a parent who's got a child with a disability, you want them treated exactly the same as	"he has, a few special lessons when they're doing some things he might go off and learn cookery or something. Yeah, he's included in class with his assistant, even down to Maths and English he's often present with his worker, he doesn't go off *too* many times" Equality	"they put her in the normal races and I guess I'm really friendly with the head- the teacher in her class who's a chap and he's head of all the PE and everything and he knows that I guess as parents we're both like 'get them in there, just chuck her on, don't let her have a head start, don't let her have- you know, I'm quite happy that she just goes in and she's treated and done the same as everybody else." Community/E "she's kind of just seen as in there and part of, and she is just part of the whole school and they just take it that she'll do everything else that they're all doing" Community/E	Activities outside of school, in the community "But it is maximum twice a year. And it will be just to the park, nothing like cinema, theatre, nothing like that." E Head teacher at school when showing parents around "she said that in the future in B they try to find out what is the best skill of your child, and let's say if they discover that he is amazing at playing guitar or in music subject, then they will send for that lesson, a child to mainstream school." C "she used to be in mainstream but she just really couldn't cope with the amount of information they supplied. That's why everybody	"They don't stop her doing things do they (talking with sibling) I know she wishes she was excluded from assembly. No I don't think they exclude her from anything. If anything they try and include her, with the extra swimming." C

	everybody else, and i as a parent expected to be treated the same as well" Equality			decided she would be better off in special (education) but they told her as well that if they picked a subject her daughter is very good in, she will be going to mainstream for that subject" E "But they must have some connection if they are able to do it, to send a child to mainstream for some, just one subject." C	
Inclusive feel		"He's just one of the class, isn't he, as far as I can tell, from that point." C "So we haven't felt that he's ever been excluded from anything, he's been treated as normally as possible." E	"It's like a sort of big sort of family really" C "she's pretty much included in everything, she's certainly like a big part of the class." E		
Definition of inclusion – confident to define (mainstream) vs not sure (special)	"she goes to a mainstream school and she is just included in as much as what happens there as possible" E "to get included and to feel like she's part of something and not to be isolated... and just encouraged to be a part" C "so that to me isn't inclusion, at all, they're just at a mainstream school and that's it, and it shouldn't be that way. They	"well it's to be as much a part of, his classroom educational experience as any other child in that classroom." C	"I would feel that, if the school or anybody is doing a main thing that that child would also then be involved in doing whatever that activity might be, so at no point would there be any exception that that child wouldn't be able to join in, I guess?" C	"What is inclusion, I don't know it." Although this could highlight an example of how segregated schooling can exclude children with SEND from society, it might also be an example of unknown vocabulary for the participant, who is using English as a second language.	"Well, inclusion I would say, being included in the class, what the class are doing, in all the activities, that's how I would understand it." C "So that disabled children have the same opportunities as what a normal child would, that's my understanding of it" "Yeah, integrated" adds Pp. E

	should be treated as a pupil like all the other pupils are treated, that's to me, that's the idea of it anyway." E				
Hand over	Key "I said to her, I need you to take E from me, so now she takes her from me and we have a handover in the morning which is much better. And when E was in Reception last year she used to come out with all the children as well and I never got a hand over after school, but now, because we spoke to her, because we have this relationship which is really good, we spoke to her and said oh could you please bring E out and have a handover" R/C	Key "Mostly C (parent) but sometimes me would get him into his classroom, get his bag unpacked and everything, hand him over then to his 1:1 worker" R/C	Mentioned "so you know I speak to her 1:1 every morning, you know, chat to her every morning, chat to her when I pick her up every night and if there are any issues then we're straight away able to chat about them so it's quite good." R/C Talking about chosen secondary school "and they have a special drop in drop off area in the mornings so you can go straight in and she gets dropped off with her 1:1" R/C	Bus – not emphasised. "even on the bus, on the transport to school and you can see, although actually on his bus everybody sits separated. They all look not bothered about each other (laughs)." C	Picked up from school, mentioned in passing through another story. Perhaps absence linked to lack of relationship with 1:1?
Key figure	One-to-one x11 1:1 x15 "I feel she can tell me things and I can tell her things" R Anxious of losing key figure "I was a bit concerned that if we started to bring in special ed, that it might mean the school would say to E's 1:1 that when E is not there we won't need you anymore, and she might look for another job" R "The hope is, that E's one to one will move	Not as much of a key figure but still mentioned a few times, SENCO – new one in Sept, cautious language SENCO "really stuck up for that aspect of school so she was very good, but, we'll wait and see what the new one's like" R Email – "For the last year the junior school provided very good support. However, the very excellent SENCO left her position a few	No true key figure, mentions TA (ex-headteacher) and the class teacher/acting head	No true key figure, mentions child listening to one particular adult Emphasises good relationships between A and staff "you see A listens to a lot" R	Advisory Teacher x3/liaison x9 "We've got an amazing liaison lady- family liaison officer, she's brilliant- and she tells us stuff she shouldn't tell us but we're glad she does." R "she's very much on our side. And she's watching F's back. She tells us stuff that's going on which we shouldn't be privy to, but I'm glad she does." (liaison) R "and our liaison lady is gonna keep an eye on it and

	with her (trying not get my hopes up too much!) S, E's current one to one, has previously worked at AS, and the Head is the same so knows her! I have written a plea to the Head Mistress in the hope they can stay together! S left AS on good terms and when the head showed us around, she told us she would've kept S at the School if she could of!" R	weeks before the last term ended and we noticed a drop off in the level and quality of support." R Key figure – previous infants school T x 8 "We have to say T was exceptionally good at trying to include him in everything and this year at his Junior school he took part in the sports day pretty much on his tod, in a lot of things." C/R			we're gonna meet regularly..." R
Caring Figure	"I think she's that sort of person anyway, obviously doing the fostering and stuff, she obviously is just that type of person; she cares" R		"And I just feel really lucky as well that H's 1:1 is also really nice and someone we get on with and well as a family you know, she meets up in the holidays with us even" R	"the meetings with teachers that they will cuddle him if he comes for a cuddle. So there isn't that distance between teacher and student in his school. They treat them like their own children, more. He likes singing, he likes people singing to him, and so they will sing to him." R	
Negative/scare stories	Story – taught in corridors "I heard a story from a parent… he was at a mainstream school originally and he was just being taught in the corridors and I just thought that's just not what I would ever want for E." E	None?	Looking at mainstream secondary schools "it just didn't feel the right atmosphere, the special needs area was on this dingy dark corridor, upstairs in this little room tucked away and I just thought, would I want to go and sit up there at lunch time and break times?" C	Story – teachers would not meet care needs "we know an autistic Mum, she had a son who was 8 or 9 and still in nappies but kind of learning knowledge wise, he was okay in mainstream. But because of the nappies they didn't	Own story: meeting with head teacher, might not be able to meet her needs "it was dropped on us about F going to a special school. Nothing had ever been mentioned, and we had like a review meeting just to see how she was progressing… The head master was like, because F is growing up, they didn't feel they

			"which is a really high sort of achieving school…she said 'there's no way for H's needs that we would be able to adapt any lessons or any type of schooling' and, which is totally illegal, because they can't actually say that" E	want him in mainstream, because they are not teachers of those kind of needs when he is 7 or 8. So they don't want to change nappies. And they had a massive issue there because she didn't want to put him in mainstream school because his intelligent level will go down because they don't have the expectations of mainstream school so she didn't want him to change school" E	could facilitate her, that's his words." E "obviously she wasn't at the level of other children but she was progressing, at her own pace, and nobody had ever mentioned her going to a special school, and we were just completely blown away. We were just shocked by it." E/R
Going so far	"We just assess it year on year, so rather than assume that she would always be there full time, we just thought we'd just let her go and see how she went."	"I don't think we were ever overly concerned to begin with that he wouldn't be able to go to a normal school to begin with, at least" C	Relating to Secondary school, see how it goes "really extreme special needs, so there's a lot of children there all in wheelchairs and on oxygen which is brilliant for children that need that, but for H, you know it's all sort of gated exits and entrances in every area and, I don't think for H, you know, she's kind of so far managed with Mainstream so we're kind of hoping, though I don't know whether" E	No sign of wanting different provision in the future.	Shocked at meeting when mainstream was sprung upon them. "we find that it's no detriment to the special schools, but we don't think she's there at that point... not yet, not yet" E
Confidence in school	Careful vocab "other than that I'm pretty sure she's in the classroom with her peers." C Email: "Unfortunately we experienced some problems	Careful vocab "we've just lost our SENCO, so, we don't know what's going to... (fades away)" R "She was a very powerful personality but we shall see if	Slightly tentative but more confident vocab "I mean I'm not there to see how much she is out, but from what they've said I don't- and from what the other children say I think	Very confident "So I think B school is really good because we feel they're okay and A does very well, they treat A amazing, and everyone is so friendly over	Careful vocab "So we're gonna keep an eye on that and go from there really." E Nothings' happened/that never happened/they never did it x3

	at ESC, and have made an incredibly difficult decision to move Evie. (I'm feeling very stressed and worried about the whole thing!)" C	someone might come in which is more formal perhaps." R "Yeah, he's included in class with his assistant, even down to Maths and English he's often present with his worker, he doesn't go off *too* many times." C	generally she's pretty much in the classroom all the time, or the majority of the time" C	there, and they organise all the fun days" C "So they are a huge support" R "they just can't do more! (laughs) They're very patient, they always have time. We see how they treat A." R "No we are both really glad that we chose B because they have the personal connection with children. We are really happy with the support they give to A and give to us. It's great that we can always ask them for help if we need something." R	"What else could the school do? Just do what they should be doing." E "And she's only had a TA, she's had no teacher input, and the Williams (Foundation) are saying she should have 50% (teacher input) we've told him this, and he's said I've seen her there doing something for about an hour or more and she just zones out. If he does what he says, then it'll be good but we'll wait and see" R/E
Supervision / support	TA supposed to be with at break times "she is supposed to be supervised on a 1:1 basis all day every day at school" "This is probably one thing I could say actually that I would like them to do, with E, work with her during lunch, to take her to children and try and get a game going and engage" R One TA	Break times… Talking about lunch times "and even then someone was keeping an eye on him. So we were happy" R "Basically we've pushed for as much cover as possible" R One TA then gradually Two TAs	Very small school, no 1:1 needed at break times. C "We're really happy with what she's getting at the moment because I don't think you could really ask for any more than she's getting at the moment" One TA but gradually over years TA's swap over so child doesn't become too attached "they're trying to wean her to different people so she's not reliant on one person, they've always tried to you know, spread it out so that the 1:1 also does	No TA but very small class Emphasis on professional knowledge, mentions psychologist, speech therapist, physio, paediatrician, specialists, incontinent-s nurse R	Asking for more supervision in statement Unsuitable TA. Lots of mistakes. "So she's off sick again and last September she had a lot of sick time again and we said we don't want F being with her all the time, because it's not good. So they were going to split her up, but they never did it, and it's happened again." R "So what the TA is saying she can do, she can't actually do… we had all our trust and faith in this TA..." R "they've been putting her on the

			occasionally other children" R TA – ex-head teacher, teacher from another class		playground with the infants' because there's more dinner ladies up there… but she doesn't want to go up there and they're still putting her up there. And all her friends have been down on the bottom playground." C/R
Needing to do something/chan ge something - Advocate	"E will get celebrated as well so she's obviously included in that, and I would make a fuss if she wasn't anyway (laughs) if she didn't I would be like 'why hasn't she been!' so yeah, so it is quite sweet. I don't know, I think I'm one of those sort of parents that's quite on the ball though, and I will say." E "whereas other parents might just send their child to a school and just let them get on with it, think they're there so their fine, they're included. Whereas I like to make sure, and having older children there helps because you hear (laughs) stuff don't you about different things so, although that's going to change soon". (sibling moving to secondary) C	Celebration – Pp did 'make a fuss' "and they're the ones that've suddenly got the little medals and stuff, and you think well hang on a minute, you know. But yeah, that's probably me not making more of a fuss I don't know)" E "Well he went swimming when they went swimming, there was never a problem with that- C 'no but I had to go too' (to help with changing)" E	No need	No need	"we're gonna get on top of it, and we're not gonna be a walk over. And even the lady (liaison officer) who has told him that R and J (parents) are not going to be walked over" R/E "if she's not getting what she should be getting, we want to know why" E "But now, you've (J) been going to Parent Carers Course, and that's opened up no end of avenues that we didn't know about" R(self-knowledge)