Experiencing Educational Inclusion: Children with Williams Syndrome in Ireland

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ABSTRACT

This thesis explores the educational inclusion experiences of children with Williams syndrome (WS) in Irish primary schools from the perspectives of the children, their parents and teachers. Almost equal numbers of parents chose mainstream and special-education placements for their child with WS, although this choice was complex. Parents were very satisfied with their child's education regardless of setting. Parental and teacher perceptions of the WS educational profile differed little. Teachers presented a slightly broader profile, yet showed less awareness than parents of anxiety in the children. Findings indicate a capacity in the children to learn Irish and other languages successfully, despite their entitlement to exemptions from language learning in the Irish educational system. Some features associated with WS (such as sociability) enhance the inclusion of learners with WS, while certain maladaptive behaviours impede it. Evidence suggests that maladaptive behaviours may be caused by high anxiety and poor expression of emotion due to poor comprehension of negative emotions. In addition, these children display more internalizing and self-regulatory behaviours, when parent and teacher data is compared, than has previously been noted in the literature, which may actually negatively impact on the child's educational inclusion. Both parents and teachers support the children's learning but teachers' special education experiences and professional development influenced quality of supports and, hence, quality of educational inclusion. Some strategies used successfully by individual teachers to support learners with WS are those traditionally associated with autism, despite the sociability associated with WS. The children had clear images of themselves as learners and could identify personal learning strengths and challenges. Their liking for physical and social activities may be important aids to concentration, participation and, hence, inclusion.

Different interpretations of inclusion were evident from parents and teachers. A definition of inclusion was proposed to compare educational placements. Such a comparison showed that Irish mainstream placements should not necessarily be viewed as the most inclusive educational setting for learners with WS. Consequently, a framework, based on the individual education planning process, proposes a way to maximize the educational inclusion of children with WS, regardless of setting.

Key Words: Williams syndrome; inclusion; special education; inclusive learning; learner voice; individual education plan; Ireland; primary school.

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GLOSSARY OF TERMS AND ACRONYMS

ADHD	Attention-Deficit and Hyperactivity Disorder
ASD	Autistic Spectrum Disorder
CSO	Central Statistics Office
CT	Class teacher
DES	Department of Education and Science (until 2009)
	Department of Education and Skills (from 2010)
DS	Down Syndrome
EBD	Emotional and Behavioural Difficulties
EPSEN	Education for Persons with Special Educational Needs
FXS	Fragile-X Syndrome
GLD	General Learning Disability
ID	Intellectual Disability
IEP	Individual Education Plan
Lamh	A signing system for individuals with intellectual disabilities and communication needs in Ireland (similar to *Makaton*)
LS/RT	Learning-support/Resource Teacher
MS	Mainstream
NCCA	National Council for Curriculum and Assessment
NCSE	National Council for Special Education
NDA	National Disability Authority
NEPS	National Educational Psychological Service
OT	Occupational Therapist
PWS	Prader-Willi Syndrome
RT	Resource Teacher
SALT	Speech and Language Therapist
SC	Special Class
SE	Special Education

SEN	Special Educational Needs
SENO	Special Education Needs Organiser
SESS	Special Education Support Service
SNA	Special Needs Assistant
SS	Special School
TEACCH	Treatment and Education of Autistic and Communication-handicapped Children
WISC	Wechsler Intelligence Scale for Children
WS	Williams Syndrome
WSAI	Williams Syndrome Association of Ireland

CHAPTER 1   OVERVIEW AND RESEARCH RATIONALE

I think every child should get a chance, if they can, to have a child in their class with special needs (Sharon, mainstream class teacher)

Introduction to the Research

Williams syndrome (WS), sometimes referred to as Williams-Beuren syndrome, is a genetic condition characterised by unique patterns of abilities, challenges, behaviours and personality characteristics 'which set them apart from other learners' (Udwin et al., 2007:1). Most individuals with WS also have an intellectual disability (Dykens et al., 2005), thus, are categorised as having special educational needs (SEN). Enrolment of children with SEN in mainstream schools has increased significantly in Ireland since the 1990s. Hence, some children with WS attend special schools and some attend mainstream schools (Tynan, 2010a). This study explored stakeholders' experiences of the inclusion of children with WS in Irish primary schools (both mainstream and special), and sought to ascertain which placement provided the most inclusive learning experiences, from the perceptions of children with WS, their parents and teachers.

Special education provision has changed dramatically since the 1990s, both nationally and internationally. Separate education systems have been challenged, from a human-rights' perspective and a learner-outcomes perspective (Lipsky and Gartner, 1996; Thomas and Loxley, 2001), and trends towards inclusive education 'appear irreversible' (Shevlin et al., 2008:141). However, progress towards full inclusion is 'proving elusive' (Rose, 2005:12). In Ireland, this is partly due to insufficient conceptual and applied understanding of SEN, and inadequate teacher skills and education (Kenny et al., 2006:3-4). The educational experiences of a particular SEN group, like WS, provide a basis to examine such assertions and, by comparing the experiences from those in mainstream placements with those in special placements, can contribute to the understanding of inclusive education.

This chapter introduces the research by explaining WS, its profile and prevalence, and by outlining the complexity of defining and conceptualising inclusion. The rationale and research questions follow; the chapter concludes with details on researcher positionality and research design.

Williams Syndrome and its Associated Cognitive Profile

WS is described as 'one of the field's most intriguing genetic disorders' (Dykens, 2003:291), characterised by 'extraordinary loquacity, effervescence, fondness for telling stories, reaching out to others, fearlessness of strangers, and, above all, a love of music' (Sacks, 2007:318). WS was first identified by cardiologists Williams, Barrett-Boyes and Lowe, in 1961. The incidence of WS is significantly lower than the estimated prevalence of 1:7,500 (Strømme et al., 2002). In Ireland it stands at 1:20,000-25,000 (Green, 2011), based on the number of cases (n=3) genetically confirmed annually.

WS is caused by missing genetic material on chromosome seven in the area around the elastin gene (Ewart et al., 1993), with resultant cardiovascular, renal, connective tissue and endocrine complications. It is evident at birth, occurs across all ethnic groups and equally affects both genders. It produces 'a constellation of distinctive cognitive, neuroanatomical, and electrophysiological features' (Bellugi et al., 2001:1). The condition is particularly interesting due to the evidence of a genetic basis for temperamental characteristics and the dissociations between language and cognition, often attributed as the 'hallmarks of the syndrome' (Bellugi and St. George, 2001:i). Consequently, individuals with WS exhibit a distinctive cognitive profile 'with striking peaks and valleys of abilities across cognitive domains' (Semel and Rosner, 2003:5). Their learning strengths include language, memory, sociability and musicality. Learning challenges include distractibility, emotional hypersensitivity, over-activity, visuomotor/visuospatial skills, hyperacousis (heightened sensitivity to sound), repetitive behaviour fixations, peer relations and anxiety (Udwin et al., 2007). Individuals with WS have an average full-scale IQ of 50–60 (Martens et al., 2008) and a range of <30 to >100 (Howlin et al., 2010). Intelligence classifications for IQ bands vary between countries; the classifications used throughout this study are those used in Ireland, where a mild general learning disability (GLD) is defined as an IQ score of 50-69, moderate GLD is 35-49 and severe/profound is below 35. With a cognitive profile as described, most children with WS in Ireland are eligible to enrol in either mainstream or special schools in the Irish educational system.

Contextualizing Inclusion in the Irish Educational System

Conceptualising educational inclusion is both complex and controversial (Brantlinger, 1997), as interpretations of inclusion are contentious, diverse and conflicting (Clough, 2000:7). Definitions have centred on notions of integration, inclusion, inclusive schools, barriers to inclusion and inclusive learning. Integration, the forerunner of inclusion, primarily concerned an over-simplistic debate regarding location. To contextualise a

definition of inclusion for this research, it is necessary to present Ireland's educational continuum of inclusion from mainstream to special.

In Ireland children are legally required to attend school between the ages of six and sixteen, or until they have completed three years of post-primary school (Department of Education and Science (DES), 2004:5), although most children start school between the ages of four and five (DES, 2004). The primary-school system comprises eight levels: junior infants, senior infants, and first class through to sixth class. The principles of the *Primary School Curriculum*, which span both mainstream and special placements, include the provision of a broad and balanced curriculum which facilitates individual difference (Ireland, 1999a).

For pupils with SEN in mainstream schools, their needs are assessed on an individual basis, using the 'staged approach' as defined by Special Education Circular 02/05 (DES, 2005). Stage one stipulates the class teacher supports a pupil's needs through differentiated content or approaches. Where this is inadequate, the school progresses to stage two; the child is screened by the special education team (SET) and supported through a differentiated work programme. The time allocated to children at stage two is dictated by the general allocation model (GAM) (DES, 2003); the SET, in consultation with the principal, allocates time for individuals and groups of learners according to greatest need in a school. For pupils with more significant needs, stage three prompts an assessment by an educational psychologist, perhaps in conjunction with other specialists. A child may come to school with such an assessment and is automatically at stage three. Once a school submits these assessments to the special education needs organiser (SENO) resources are allocated to the child (provided they fulfil specific criteria) and may include resource hours (with a resource teacher) and/or a special needs assistant (SNA). Currently, there are 5,700 resource teachers in approximately 3,750 Irish primary schools (NCSE, 2013a) and over 6,200 SNAs (NCSE, 2013b). Children with mild GLD are ineligible for resource hours in mainstream schools, hence, are catered for under GAM. This has been found to poorly serve such learners (Stephens and O'Moore, 2009).

Similar to mainstream primary schools, special schools were established under the Rules for National Schools (Department of Education, 1965) following the Report of the Commission of Inquiry on Mental Handicap (Ireland, 1965). Segregated provision, in special schools or special classes in mainstream schools, was favoured at that time. There are currently 104 special schools in Ireland (NCSE, 2013c) which cater for specific categories of needs. Pupils must have a professional report confirming a SEN to validate enrolment (NCSE, 2013d). Special schools continue to be valued placements, particularly as the needs of pupils become more complex (Ware et al.,

2009). In the school year 2012-2013, 1.5% of Irish primary-school students attended special schools (DES, 2013). The curriculum in special schools is based on the *Primary School Curriculum* (Ireland, 1999a), despite these schools catering for students up to the age of eighteen. There is an expectation that pupils experience the same range of subjects as pupils in mainstream primary settings, except for Irish. In addition, most special schools introduce such subjects as woodwork and cookery for pupils of post-primary age, they may engage in certification (including State Examinations) and they emphasise life-skill development (Ware et al., 2009). There is a much reduced pupil-teacher ratio in special schools, dependent on the school's category of SEN. Challenges for special schools identified by Turnbull et al. (2011) in the US mirror those in the Irish context: large catchment areas, associated transport difficulties, and limited opportunities for face-to-face communication. These difficulties are generally not associated with special classes.

Special classes are hard to define in the Irish context (Ware et al., 2009) but exist within mainstream schools. There are currently 479 special classes in Ireland for specific designated categories of needs; 82% cater for pupils with autistic spectrum disorders (ASD) and 12% for pupils with mild GLD (NCSE, 2013e). Special classes have advantages of community-based education, reduced pupil-teacher ratios, flexible curriculum organisation and delivery, and can facilitate mainstream inclusion (Ware et al., 2009). However, there is an anomaly in State provision for pupils with mild GLD when one considers that in mainstream schools, with higher pupil-teacher ratios, pupils are only entitled to additional supports under GAM (Stephens and O'Moore, 2009).

Despite continuing trends towards inclusive education, special placements (special schools or special classes) continue to serve a percentage of pupils with SEN in Ireland, including those with WS. Prior to this research, the nature of the inclusive education provided in different settings for children with WS in Ireland was unknown. Inclusion is now frequently defined in terms of educational outcomes rather than placement (Rose, 2003), although conceptualising and defining inclusion remains problematic. Despite the national policy of many countries supporting the inclusion of pupils with SEN in mainstream schools, local practice may differ (Florian, 1998; NCSE, 2006). Inclusion is no longer seen as a human rights' issue for those learners who are 'different' (Florian, 1998); it is perceived to benefit all pupils as preparation for life (Shevlin et al., 2008).

Rationale

The research rationale arises from gaps in national and international research, firstly on the educational experiences of children with WS. There are very few studies on the

educational experiences of these learners, and enabling marginalized learners to share their experiences is crucial (Rose and Shevlin, 2010) to reinforce the value of individual experience (Mertens and McLaughlin, 2004). Secondly, there are few, if any, studies examining the educational inclusion of children with WS from parent or teacher perspectives. Thirdly, research clarifying the inclusion experiences of children with WS in Ireland is needed as part of the development of special education within Ireland's national policy and to highlight issues with existing frameworks.

While Ireland's educational policy favours the inclusion of pupils with SEN in mainstream schools 'there is little evidence of planning at a systemic level to facilitate this process' (Shevlin et al., 2002:1). In recent years, learners with moderate GLD have been found to benefit from mainstream placements with appropriate differentiation (O'Keeffe, 2011). Despite this, almost equal numbers of children with WS attend special placements and mainstream placements (Tynan, 2010a). This raises the question of why parents consider special placements where their child with WS has mild or moderate GLD, one of the issues explored in this research.

In the only research into parenting children with WS in Ireland, Scallan et al. (2011) identified educational provision as a daily challenge for parents; eighteen of 21 parents rated teachers as ill-informed, fifteen indicated poor differentiation and nine reported that due to their child's educational placement their child did not fully achieve his/her academic potential. By contrast, Tynan (2010a) found 21 of 31 parents to be satisfied with their child's placement despite poorly informed teachers. The difference between the two studies may, in part, be due to differences in sample size and approaches. Tynan distinguished between parents with a child currently in education and those in adult services. This showed higher parental satisfaction where the child was in education than parents whose child had completed their education. The anomaly of high levels of satisfaction with educational placement despite poor teacher knowledge of WS may relate to parental expectations and knowledge. As parents are the primary source of WS information for teachers (Fidler et al., 2002), it is necessary to establish parental knowledge of the WS educational profile to ascertain if they share accurate information with teachers. This may impact on their child's educational inclusion.

The successful inclusion of learners with SEN is dependent on various factors. The OECD (2005) isolates teachers as the most significant source of variation in in-school factors impacting on academic inclusion. The academic inclusion of children with WS is particularly challenging, as its rarity means practitioners have limited experience and knowledge (Oliver and Hagerman, 2007). Educators can wrongly perceive the WS educational profile due to its peaks and valleys, by either an over-estimation of ability, or an under-estimation of ability (Lenhoff et al., 1997; Elçioglu et al., 1998). This

research explores teachers' perceptions of the WS educational profile to ascertain how they influence interventions to support the educational inclusion of children with WS. Internationally, there is a need to explore and refine such interventions, particularly where inclusion is synonymous with inclusive learning. There is conflict about how this can be achieved, whether through moving from predictions that etiology-based approaches should work to researching effective interventions (Hodapp and Fidler, 1999:135) or moving from diagnostic-prescriptive teaching to inclusive pedagogy (Slee, 2001; Florian and Kershner, 2009). Increasing bodies of syndrome-specific methodologies are emerging from research (see Symons et al., 2001; Hatton, 2007) and various approaches have been proposed for children with WS, including a talent development approach (Tiesco, 2002; Reis et al., 2003). More research is needed to ascertain if it is realistic to expect services to respond to the needs of small groups of learners (Oliver and Hagerman, 2007), while acknowledging that inclusive approaches for one child can benefit many, if not all, learners (Rose and Shevlin, 2010).

Most developed countries have advanced inclusion policies in recent years (OECD, 2005), while still retaining segregated special settings (Watkins and Meijer, 2010). This manifestation of inclusion lends itself to juxtaposing the two systems to compare and contrast provision for specific learners, as in this research. This has not been done before for children with WS in any country. In Ireland, mainstream teachers support the concept of inclusion but acknowledge poor knowledge of specific disabilities and associated needs (NDA, 2006). The barriers to inclusion identified by Irish mainstream teachers include individual pupil characteristics, curriculum content, inadequate materials and deficient disability-specific information (Coffey, 2004). Such constraints are not associated with teachers in special settings due to the adaptation of the curriculum to meet individual needs (Day and Prunty, 2010). This research will highlight the strengths and challenges of educational inclusion in different educational contexts to form a basis for Ireland's first WS educational guidelines.

Research Questions

Gaps in the literature indicated the need for exploratory research on the educational inclusion experiences of children with WS, their parents and teachers. This research aims to identify comparative qualities of mainstream and special settings, while seeking to illuminate debates about competing concepts of inclusion. From this, possibilities of developing a new inclusion framework can be explored. The research questions, which follow, initiate that process (with subsidiaries to expand their interpretation).

1. **What are the experiences of parents concerning the educational inclusion of their child with WS?**
   a) How do parents perceive the educational profile of their child?
   b) What determined parents' choice of educational placement?
   c) How satisfied are parents with their child's educational placement?
   d) How do parents support their child's learning?

2) **What are the experiences of teachers concerning the educational inclusion of their pupil with WS?**
   a) How do teachers perceive the educational profile of the child with WS?
   b) How satisfied are teachers with the child's educational placement?
   c) How do teachers support the child's learning?

3) **What are the experiences of children with WS concerning their educational inclusion?**
   a) How does the child perceive his/her educational profile?
   b) How satisfied is the child with his/her placement?

Researcher Positionality

This research links with my personal and professional experiences, creating a unique positionality. Personally, having a brother with WS, now aged 31, I saw the challenges his education posed. Educated in a special school, he received an education tailored to his needs, despite not having a diagnosis of WS until age fourteen. His learning goals included reducing his hyper-social tendencies, developing fine-motor skills and promoting adaptive-living skills. The school used music and social opportunities as reinforcers. Such pedagogic adaptations appear to indicate that, in my brother's case, the teachers' awareness of his strengths and challenges did not require prior syndrome-specific knowledge. I wondered if this was always the case or if it was more common in special settings than mainstream settings. My brother also participated in two 'integration' projects with mainstream schools. The benefits of such experiences included his self-perception of 'normalization' and his social inclusion in the community. As there is no policy of dual enrolment in Irish schools, I wondered if other children with WS experienced such 'integration' projects, and what the outcomes of such experiences might be. In addition, as a member of the Williams Syndrome Association of Ireland (WSAI) I frequently hear parental anecdotes of generally positive educational experiences for their children with WS, coupled with some low expectations of provision and outcomes, regardless of setting. Some children with WS transfer from

mainstream to special settings during their primary education indicating some inadequacy with mainstream placements, although these inadequacies are unclear.

My professional experiences also impact on my positionality. As a teacher, I taught a child with WS for two lessons each week (as part of an 'integration' project) between 1998 and 2000. I experienced the challenges of including him in a mainstream context: dealing with high distractibility, short attention span and slower rate of learning. I am currently working as a schools' inspector with responsibility for special schools. This affords me the opportunity to observe best special-education practices regarding methodologies, resources and interventions. I implement these at the annual WSAI Music and Activity Camp where I teach music, drama and personal advocacy to people with WS. This has raised my awareness of the heterogeneous nature of the WS population.

These experiences impact on my positionality and I, consequently, consider myself an 'intersection' researcher: like a Venn diagram of two sets I am simultaneously both insider and outsider. As an insider, I am a member of the WSAI, having a brother with the condition. As an outsider, I am not a parent, which gives me greater objectivity and different viewpoints to parents. My professional background also sets me up as both insider and outsider. As an insider I worked as a primary-school teacher and taught a child with WS. As an outsider I am currently working as a schools' inspector which raises issue of power with teacher participants. This, and other issues, are explored further in Chapter Three.

Research Design

> The richness of an individual's life is very often not to be found in
> the surface of life but in how it is lived, in the person's experiences
> and reactions to the world (Greene and Hill, 2005:4).

WS studies have been dominated by medical models (Dykens et al., 2005) which highlight the common deficits of the group (Mertens, 2009). There have been few links with the ideologies of curricular approaches or school improvement strategies that Clough (2000) links to inclusive education. Most research around the inclusion debate in Ireland has accentuated adult stakeholders' perspectives (Balfe and Travers, 2011), although this is changing. While it is acknowledged that accessing the voice of learners with SEN is challenging (Carrig, 2011), pupils with SEN in Ireland are now regarded as valid, reliable participants in educational research (Motherway, 2011). Their engagement in research has proven effective and insightful (see Shevlin and Rose, 2003). Internationally, there are few studies which centred on the experiences of

individuals with WS; their participation in research continues to centre primarily around clinical trials and observations (see Dodd et al., 2010; Dai et al., 2012).

This study's underpinning philosophy merges interpretivism and transformativism, both of which focus on relationships, personal views and subjective reflection. Interpretivism is characterized by 'a concern for the individual' (Cohen et al., 2007:21) and acknowledges participants' context (Alvesson, 2002). This is significant considering the researcher's positionality. Transformativism rejects the deficit model of special needs (Seelman, 2000) and implies a strong participation of the minority group (Mertens, 2009). It furthers social models of research, discounting the homogeneity of special-needs group members (Mertens and McLaughlin, 2004:3).

The merger of interpretivism and transformativism points to an inductive methodology that seeks interaction with participants before devising theories, as with this exploratory research. To emphasise participants' experiences, a qualitative approach appropriately focuses on ordinary events in natural settings (Punch, 2009). A small sample is used, mirroring other research of low-incidence disabilities (Mertens, 2009) and the many early international WS studies, particularly those headed by Ursula Bellugi or Annette Karmiloff-Smith (see for example Bellugi et al. (1988a) with n=3 and Karmiloff-Smith et al. (1998) with n=8). The significance of those findings led to larger-scale studies (see Udwin and Yule, 1990; Mervis et al., 1999). This study focused on all the children with WS between the ages of four and twelve, registered with the WSAI, who were in primary education in the Republic of Ireland in the school year 2011-2012 and who agreed to partake in the study. Structured face-to-face interviews with the children and semi-structured face-to-face interviews with parents and educators form the main method of data collection.

Initially, baseline information on the Irish WS population was established during the piloting phase of the research through a scoping questionnaire (Tynan, 2010a) issued to all WSAI members. This identified the ages and educational placements of individuals with WS and indicated that most parents were satisfied with their child's education despite poor teacher knowledge of WS. The subsequent pilot interview with one parent (Tynan, 2010b) revealed satisfaction with the social inclusion of her child in a mainstream setting despite his failure to attain basic literacy skills. This raised questions around the quality of *academic inclusion* in mainstream settings. Further details on the research design, data collection and data analysis are supplied in Chapter Three.

Conclusion

This chapter outlined the rationale, aims and research questions of the study which focuses on the experiences of key stakeholders regarding the educational inclusion of children with WS in Irish primary schools. It presented WS as having a short research history, largely with a psycho-medical focus. The enigmatic educational profile of WS was described to highlight the possible difficulties with educational provision, and hence, inclusion, in any setting. This chapter also contextualised inclusion in Ireland by describing the Irish educational system and the placements available for children with SEN, from mainstream to special classes to special schools. The research questions which originated from gaps in national and international literature were presented after which the research rationale, researcher positionality and research design were established.

Chapter Two contains a review of the literature which includes a backdrop of the national and international conceptualisation of inclusive education, highlighting the complexity in defining educational inclusion. Chapter Three describes the philosophical underpinning of the study, the research methods and methodologies employed, and data-analysis procedures. Chapters Four, Five and Six report the findings from each stakeholder group. The findings are discussed within specific themes in Chapter Seven. Finally, Chapter Eight draws all of this together and presents a definition of inclusion on which educational settings can be compared and proposes a framework to maximise the educational inclusion of children with WS.

Introduction

This chapter presents the literature which informed the research and which helped formulate the research questions. It is set out in five main sections starting with the development of the concept and definition of inclusive education. Section two describes the WS cognitive profile and its associated 'peaks' and 'valleys'. Section three encompasses parental perspectives on education: parenting a child with SEN, choosing an educational placement, satisfaction with educational placements, parental knowledge and expectations, and parental support for learning. Section four pertains to teacher perspectives on education: teacher knowledge of SEN, attitudes to and expectations of pupils with SEN, and teacher supports for learning. Section five concerns learner perspectives on education: attitudes of pupils with SEN to school and their expectations of self. Due to the paucity of literature on WS for the topics addressed in sections three, four and five, the literature review incorporates findings from wider SEN research. The chapter concludes with the research questions which seek to redress the gaps in the literature.

Conceptualising and Defining Inclusive Education

> *Despite all the ideology, declarations, legislation, circulars, guide-lines and frameworks, inclusive education depends for its success on individual teachers, with individual children, in individual schools*
> (Day and Travers, 2012:1)

Understanding of the terms inclusion, inclusive education and inclusive schools vary (Clark et al., 2004). Inclusive education has developed from the concept of integration to inclusion to inclusive schools. It is now interpreted beyond SEN parameters and concerns diversity rather than assimilation (Ballard, 1995) for all pupils. Definitions of inclusion were traditionally rooted in a psycho-medical legacy, emphasizing deficits (Clough, 2000) and prioritising provision over quality education (Farrell and Ainscow, 2002). Ireland's inclusion policy occurred 'swiftly with little discussion' (Stephens and O'Moore, 2009:4). The first milestone in developing inclusive education in Ireland was the Special Education Review Committee (SERC) Report (Ireland, 1993) which drew heavily from Britain's Warnock Report (Committee of Enquiry into the Education of Handicapped Children and Youth People, 1978). The SERC Report (Ireland, 1993) signalled moves towards a human-rights' perspective of SEN, recommending the integration of children with SEN in mainstream schools, where possible. Children with

severe and profound needs were seen as educable: entitled to state education, rather than state care. This move from a medical model to a social model of disability was largely evident in the capital investment in special education or the 'social investment' as described by Oliver (1988). Internationally, terminology was changing at this time and 'integration', seen to imply assimilation, was replaced by the concept of inclusion. The pioneering Salamanca Statement (UNESCO, 1994), agreed by 92 governments (including Ireland) and 25 international organisations, reinforced the notion of inclusion and advanced the concept of inclusive schools. Its main shortcoming was the implication that mainstream schools alone promote an inclusive society. It influenced Irish and international educational policy-makers to include all learners, regardless of needs, in mainstream schools. As a result, inclusion is often interpreted as education in mainstream schools. Yell (1995) is critical of this interpretation and shows how, in citing a number of court cases in the US, this was never the intention of inclusive policy. In Britain, at the turn of the twenty-first century, the inclusion debate turned to identifying and remediating barriers to inclusion within mainstream schools through school development planning processes (see Booth and Ainscow, 2002), thereby linking inclusion to classroom practice and school improvement strategies (Clough, 2000). International literature consistently reports specific barriers to the inclusion of children with SEN in mainstream schools related to teachers, schools and systems. Teacher barriers include negative attitudes (Forlin, 2010a; Kaikkonen, 2010), lack of knowledge/experience (Forbes, 2007; Rose and Shevlin, 2010), inadequate professional development (Westwood, 2007; Forlin, 2010b), insufficient focus on learning (Hornby et al., 1997; Mowat, 2009), inappropriate methodologies and differentiation (Rix et al., 2009; Deng, 2010) and low expectations (Rose and Shevlin, 2010). School barriers encompass poor leadership (Forlin, 2010b; Watkins and Meijer, 2010), inadequate whole-school approaches (Howley and Kime, 2003; Westwood, 2007) and closed cultures (Koutrouba et al., 2006; Ainscow, 2007). Systemic barriers are reportedly class size (Evans and Lunt, 2002) and inadequate resources (Koutrouba et al., 2006; Deng, 2010). In addition, there is evidence of epistemological barriers due to poor shared understanding of inclusion (Ainscow, 2007; Hodkinson, 2010). This approach to defining inclusion was helpful for practitioners and policy-makers; when barriers were identified, strategies could be devised.

Subsequently, definitions of inclusion developed beyond barrier-identification to positive ethos and attitudes, underscored by problem-solving approaches. This influenced both individual and institutional practices (NCCA, 2005) leading to inclusive schools where individual differences were viewed as opportunities rather than problems (Farrell and Ainscow, 2002). Such schools believe students without SEN

benefit from the inclusion of students with SEN (Shevlin et al., 2008), a belief communicated in the opening quotation of this chapter. The EPSEN (Education for Persons with Special Educational Needs) Act (Ireland, 2004) presents a statutory framework for the education of pupils with SEN in inclusive environments, provided their needs can be met without adversely affecting their peers' education. The Act evades reference to inclusion and to inclusive schools. Its partial enactment highlights a lack of Government commitment to investing in supports for mainstream schools to become more inclusive educational placements. Despite significant developments in individual and institutional attitudes to inclusion in Ireland, a trend remains of pupils with GLD transferring from mainstream primary schools to special schools (Kerins and Day, 2012), either at the end of primary school or after a number of years in primary school. This may indicate that mainstream schools are not necessarily inclusive settings, depending on how inclusion is defined.

Definitions of inclusion in the past decade have developed to redress the imbalance between social and academic benefits for students, becoming more holistic in nature. Inclusion is now frequently defined by quality outcomes rather than concerning location or social development (Farrell and Ainscow, 2002). Inclusion requires teachers to ensure 'all children can learn and feel they belong' (Florian and Rouse, 2010:186). Similarly, Day and Travers (2012:2) define inclusion as facilitating learners 'to communicate, to participate, to learn, to achieve, to be as independent as possible and to receive an appropriate education'. Such definitions of educational inclusion apply equally to mainstream and special settings.

More recently, definitions echo transformative philosophies, with reference to learner experiences and learner voice (see Shevlin, 2010; Lawson, 2010), yet dilemmas remain. The title of a recent Irish publication 'Special and Inclusive Education: A research perspective' (Day and Travers, 2012) implies special education is not inclusive. However, this stands in contrast to the definition on which the book is written, quoted in the previous paragraph. Norwich (2000) refrains from using the term inclusive education, believing inclusion, equality and participation are implicit in the word education. To define inclusion is clearly problematic; interpretations require 'an understanding of the established cultures and traditions upon which societies have been founded' (Rose, 2010:3). Understanding of inclusion varies across and within schools (Clark et al., 2004). However, the assumption that inclusive education relates solely to mainstream placements is an unfortunate legacy of integration debates. Children with WS in Ireland are educated in a range of settings. It is, therefore, interesting to explore stakeholders' experiences of the educational inclusion of children with WS considering the asymmetrical learning profile associated with WS.

> Williams syndrome affords an extraordinarily rich and precise view of how a particular genetic endowment can shape the anatomy of a brain and how this, in turn, will shape particular cognitive strengths and weaknesses, personality traits, and perhaps even creativity (Sacks, 2007:331).

To date, research on the WS cognitive profile has been dominated by psycho-medical perspectives, with few practitioner-based studies detailing how aspects of this profile affect learners' educational inclusion. Mervis et al. (2000) defined the 'Williams Syndrome Cognitive Profile' in terms of 'peaks and valleys', due to distinguishing unevenness across subtests of intelligence tests. The 'peaks' include sociability, language (fluent, articulate speech and good vocabulary), memory (face recognition, number recall and auditory memory), and musicality. These are considered relative rather than absolute strengths (Jarrold et al., 1998; Grant et al., 2002), and may create 'an overestimation of the child's mental abilities' (Elçioglu et al., 1998:48). The 'valleys' encompass visuospatial, motor and adaptive functioning, anxiety, hypersensitivity, distractibility, inattention and over-activity. Individuals with WS typically have an intellectual disability with associated challenges or 'dual diagnosis', which may affect social and academic outcomes (Maes et al., 2003). Until recently educational interventions were focused on remediation of the 'valleys', but there is potential to view the WS cognitive profile 'through the lens of talents rather than weaknesses' (Tiesco, 2002:32). In line with this belief, the peaks of the WS cognitive profile are presented before the valleys in the following section.

Social Competence

Individuals with WS are extremely friendly and exude happiness (Levine and Wharton, 2000:364). Indeed, friendliness is a characteristic feature of WS identified by Williams et al. (1961), after whom the condition was named. Children with WS are significantly more approaching and significantly higher in intensity than chronological-age norms (Tomc et al., 1990). A smaller Dutch study, using a wider age-cohort of children with WS, found they were rated the same as typically-developing controls on measures of agreeableness, and higher than individuals with Prader-Willi syndrome (PWS) or fragile X syndrome (FXS) (van Lieshout et al., 1998). They are more likely than individuals with PWS or individuals with a GLD to initiate interactions with others, and to never go unnoticed in groups (Dykens and Rosner, 1999). They also display emotional and cognitive empathy (Smith, 2006), and are more likely to offer comfort or validation to others than IQ-matched children with PWS (Plesa-Skwerer and Tager-Flusberg, 2006).

Such strengths could be considered important in enhancing the educational inclusion of children with WS.

However, there are challenges associated with this sociability that concern personal safety and peer relations. Individuals with WS are significantly more likely to start conversations with strangers than typically-developing mental-age or chronological-age matches (Jones et al., 2001). One mother, in a biography of her child with WS, claimed 'Our daughter's over friendliness to strangers remained one of the biggest challenges we would face' (Strebe, 2008:54). This is common; Udwin (1990) found that 73% of British adults with WS remain overfriendly and lack restraint with strangers. However, an anomaly exists: children with WS are also more likely to experience difficulties in establishing and maintaining peer relationships than those with similar cognitive ability (Einfeld et al., 1997), which may negatively impact on their social inclusion. Studies have identified an atypical gaze in WS manifesting as a prolonged and exaggerated face gaze across tasks (Riby and Hancock, 2009), which has been found to reduce social interaction between children with WS and typically-developing peers in experimental settings (Mervis et al., 2003). In addition, their excessive empathy may actually hamper their intellectual development (Smith, 2006) as they focus on the emotional aspects of speakers rather than on the spoken content; thereby impacting on their language comprehension.

Language

Individuals with WS are noted for their adeptness and enjoyment of words (von Armin and Engel, 1964). Language has been identified as a relative strength in WS compared with general cognitive functioning and nonverbal abilities (Clahsen and Almazan, 1998; Bellugi et al., 2001), although some studies are contradictory.

Language acquisition in children with WS is usually delayed, yet once sentence formation begins their language 'spurts' (Mervis and Bertrand, 1997). By school-age they are generally fluent with a large vocabulary (Lukács, 2005:13), but may still fall below chronological-age expectations (Jarrold et al., 1998). Others assert that individuals with WS have linguistic abilities matching their general cognitive functioning, implying impaired language abilities (Grant et al., 2002; Karmiloff-Smith et al., 2003). They score surprisingly poorly on the vocabulary subtest of the Wechsler Intelligence Scale for Children (WISC), perhaps because they have to produce word definitions, which is a cognitive, not a linguistic skill, as argued by Bellugi et al. (1992). The WISC-IV (Wechsler, 2003) is commonly used by educational psychologists in Ireland, and may lead to an underestimation of the child's abilities. This may impact on the services, interventions or educational placements available for children with WS.

Individuals with WS also show abnormally high levels of linguistic affect (Dykens et al., 2005) by embellishing stories with exclamatory and lexical devises (Udwin and Yule, 1990). They frequently demonstrate unusual word choice and complex syntactic structures in spontaneous conversations (Bellugi et al., 1988a; Scheiber, 2000). However, grammatical comprehension is considered impaired (Volterra et al., 1996; Karmiloff-Smith et al., 1997), language comprehension is usually limited, and speech can be inappropriate and repetitive (Lukács, 2005). Other linguistic challenges concern spatial prepositions, temporal terms, terms of quantity, and cause-effect relations (Bellugi et al., 2001). In a British longitudinal study, it was found that language ability does not deteriorate or improve during early to middle adulthood (Howlin et al., 2010), thereby highlighting the importance of language development during school years.

Language is a broad and complex ability and studies continue to refine the WS linguistic profile. For this reason it is interesting to explore the experiences of Irish teachers and children with WS regarding Irish language learning in primary school as no studies describe second or foreign language learning abilities.

Memory

Like language, memory is multi-faceted, producing 'peaks and valleys' within the memory profile itself. It manifests as a comparatively stronger short-term phonological and verbal memory over visuospatial memory (Wang, 2006). Evidence identifies verbal memory as the strongest ability of WS, being more important in language acquisition than for typically-developing children (Mervis, 2006:199). Individuals with WS perform consistently strongly in short-term verbal memory and outscore those with DS (Klein and Mervis, 1999), particularly over time. They also score higher than expected on word span for their verbal IQ scores (Finegan et al., 1995). The phonological memory associated with WS has led to the hypothesis of links between phonological and tonal memory skills (Wang, 2006). Despite this, individuals with WS perform poorly at recalling phonemes that are presented separately, which causes difficulties when learning to read (Mervis, 2006).

Another short-term memory strength of WS is face recognition (Udwin and Yule, 1991). Children with WS can better remember names and faces of people than children with DS or chronologically-matched controls (Doyle et al., 2004). This probably connects to their hypersociability and unusual face-gaze tendencies (see Riby and Hancock, 2009). The relative strength of memory has benefits for language development (Patel, 2003), which is hypothesised to be linked to the musical intelligence associated with WS (Don et al., 1999).

> The first thing they noticed was Gloria's great attention span
> for music, even when she couldn't concentrate well on any-
> thing else (Sforza et al., 2006:100)

The little research on music in WS has been small scale, but it provides evidence that individuals with WS 'are demonstrably strong and unusual in their musical affinity and interest' (Ng et al., 2013:269). There is some evidence to suggest the sensitive period for learning music (usually until the age of six), remains open in WS (Lenhoff, 2009). Individuals with WS remember songs easily and have musical talent, but generally without savant qualities (Mervis and Morris, 2007). Their musicality matches, if not exceeds, their unusual language skills (Don et al., 1999) and appears to exceed their cognitive ability (Levitin and Bellugi, 1998), although most cannot read music (Lenhoff et al., 2001). A small sample of people with WS increased their understanding of mathematics, through a talent-development approach, using music (Reis et al., 2003), showing the benefits of utilising learner strengths and interests.

Another strength of the music profile of WS is hypertimbria (Dykens et al., 2000), where individuals can distinguish different makes of cars or vacuum cleaners from the sound produced. Many also display perfect pitch (Lenhoff et al., 2001), although this finding was based on only five individuals with WS. Another small-scale study involving eight individuals with WS in the US showed they could reproduce rhythmic patterns comparable to a typically-developing, but younger, comparison group. They were more likely than this group to produce completion patterns, even where they had gone wrong, showing a developed sense of rhythm (Levitin and Bellugi, 1998).

Musicality in WS also manifests as a greater range of emotional responses to music than typically-developing children (Don et al., 1999). New research on music in WS has shown higher elevation of hormones oxytocin and vasopressin in individuals with WS in response to music, compared to age-gender-race matched controls, which increases social drive and impairs cognisance of social cues (Dai et al., 2012). Similarly Ng et al. (2013) found evidence of a correlation between emotional expression through music for people with WS and their sensitivity to the emotions of others. Such findings strengthen previous assertions that music provides relief from stress, frustration and emotional tension for individuals with WS (Scheiber, 2000). This may have implications for educational interventions for children with WS, particularly where maladaptive behaviours are evident and emotionally based.

The reaction of individuals with WS to music holds great potential for educational interventions. They express greater liking of music than typically-developing peers (Don et al., 1999), are more likely to engage in musical activities than those with PWS,

and are significantly more likely than individuals with PWS or DS to play a musical instrument (Rosner et al., 2004), despite motor-skill difficulties.

Motor, Visuospatial and Adaptive Functioning

Individuals with WS generally have impaired motor co-ordination, poor gross- and fine-motor skills and difficulties with adaptive-living skills (Semel and Rosner, 2003). Their motor abilities are considerably lower than expected for their age or cognitive level (Dilts et al., 1990). This is partly due to their visuospatial functioning, a defining challenge of the WS phenotype (Bellugi and St. George, 2001). As a result, fewer individuals with WS engage in puzzles, or arts and crafts as a hobby compared to other SEN groups (Rosner et al., 2004). Writing and drawing are similarly challenging (Bellugi et al., 1988b; Wang et al., 1995). Their drawings usually comprise disjointed parts of the full picture, often making the object unrecognisable (Bellugi et al., 1994). Bertrand et al. (1997) found drawing development in WS to be delayed rather than impaired, as children with WS follow typical developmental sequences in learning to draw. Despite this, individuals with WS compare poorly to controls on tests for rote and long-term visuospatial memory tasks (Vicari et al., 1996). This may have an impact on the development of children's emergent writing skills which relies heavily on copying objects; it highlights the importance of developmental stages and readiness in the acquisition of such key skills. Fine-motor skills also impact on the acquisition of adaptive-living skills, such as tying shoe-laces or using knives, which most children with WS find difficult (Morris et al., 1988). In a large-scale study of adults with WS in the UK, Howlin and Udwin (2006) found that adaptive-living skills remain challenging; many adults continue to need support with washing, dressing, and food preparation. A later longitudinal study showed that adaptive-living skills continue to develop through adulthood (Howlin et al., 2010), although tasks involving motor skills can continue to cause some anxiety to individuals with WS (Atkinson and Braddick, 2012).

Anxiety and Hypersensitivity

Children with WS can be very dependent on adults for reassurance and support (Udwin et al., 2007), not least due to having considerably higher levels of overall emotional/behavioural difficulties than those with DS, FXS or typically-developing children (Einfeld et al., 1999). An Irish study revealed significant fading of most negative behaviours in individuals with WS over time, particularly over age 30 (Scallan et al., 2011). Other psychological issues appear to increase with age, including anxiety and depression (Howlin and Udwin, 2006). Individuals with WS have significantly more fears and a wider range of frequently occurring fears relative to peers (Dykens and Rosner, 1999; Leyfer et al., 2006). Specific phobias are more prevalent in WS than

generalised and anticipatory anxiety, with a large majority showing persistent and marked fears (Dykens, 2003). Social anxiety is particularly high in children with WS (Klein-Tasman and Mervis, 2003), although Dodd et al. (2009) claim it is not atypical. Despite being less likely than other SEN groups to be rated as self-conscious (Sarimski, 1997), individuals with WS are upset easily by criticism (Udwin et al., 2007) and worry about others' welfare (Mervis et al., 2003). Some also become anxious and deeply distressed by certain sounds or noises (Udwin and Yule, 1991; Leyfer et al., 2006). This sensitivity to sound (hyperacousis) is very prevalent: one British study found that 90% of children with WS displayed some hypersensitivity to noise, although only about 50% of adults remain anxious about certain sounds (Udwin et al., 1996).

The link between anxiety and other aspects of WS such as specific phobias is little understood by health-care professionals (Howlin and Udwin, 2006). Perhaps the level of anxiety experienced by individuals with WS accounts for some WS-associated behaviours (Semel and Rosner, 2003; Einfeld, 2005). Whether it contributes to maladaptive classroom behaviours is unknown.

Distractibility, Inattention and Over-activity

Some of the most overt maladaptive behaviours in WS are distractibility, inattention and over-activity (Udwin et al., 2007), which are frequently problematic (Pagon et al., 1987; Dilts et al., 1990). Children with WS are four times more likely to have attention-deficit and hyperactivity disorder (ADHD) than typically-developing children (Power et al., 1997). Indeed, some WS studies have been impeded by poor participant attention (Plesa-Skwerer and Tager-Flusberg, 2006). A parent survey found 67% of 48 children with WS scored above the 98th percentile on hyperactivity scales (Dilts et al., 1990), while a subsequent larger study revealed 65% of children with WS aged four to sixteen had ADHD (Leyfer et al., 2006). Claims that it persists over time (Einfeld et al., 2001) were later refuted by Mervis and Morris (2007). Parents of children with WS have also reported sleep disorders such as awakening, restless sleep and difficulty falling asleep (Arens et al., 1998). This may contribute to ADHD-related symptoms such as over-activity and distractibility (Mason and Arens, 2006) and to some of the cognitive deficits associated with WS (Annaz and Ashworth, 2012). Despite such distractibility, one study found children with WS to have highly focused attention for faces rather than for environment objects or verbal instructions, to the point that they 'significantly reduce their opportunities to learn about their world' (Mervis et al., 2003:263). Two small-scale studies successfully used medication to treat attention deficit in WS (Power et al., 1997; Bawden et al., 1997), yet research to identify educational interventions for such maladaptive behaviours is rare (Wang, 2006). It is an obvious hypothesis that if

effective interventions for distractibility can be devised for children with WS they could impact significantly on their educational inclusion.

Educating Children with WS: Parental Perspectives

Parenting children with SEN has both positive and negative effects. These children can make valuable contributions to family life and 'are sources of happiness and fulfilment' (Turnbull et al., 2011:17). However, the SEN diagnosis can lead to a spectrum of emotional reactions for parents (Hornby, 1995). The nature of the disability does not necessarily predict the family's response (Blacher and Hatton, 2001). Mothers of children with SEN have higher stress levels and incidences of stress-related illnesses than other mothers (Crnic et al., 1983; Orr et al., 1993). The diagnosis of a 'syndrome' elicits greater stress than that associated with cognitive disability or behaviour problems (Eisenhower et al., 2005). This backdrop of living with a child with SEN is important as parental attitudes and acceptance influence the educational decisions made by parents for their child with WS.

Parental Choice of Educational Placement

Parental choice of educational placement has been under-researched in Ireland (Winter and O'Raw, 2010). The Irish Constitution identifies parents as the primary educators of their children; the Education Act (Ireland, 1998a) and Education (Welfare) Act (Ireland, 2000) underscore parental rights, including that of school choice. Such decisions for parents, whether with a child with SEN or not, are influenced by school location, size, reputation, atmosphere, discipline, academic results, resources, approachability of staff and family traditions (Hughes et al., 1994; Bosetti, 2004; Bleach, 2010). Parents may choose different schools for their children depending on the child's birth order, age or gender (Gorard, 1997:189).

Parents of children with SEN have additional choices, as they must choose the type of school before they choose the actual school. Their views on inclusive education vary considerably (Farrell, 1997). The EPSEN Act (Ireland, 2004) reduces parental rights of choosing school placements to a general principle (Mac Giolla Phádraig, 2010), as cognisance must be taken of the child's best interests, the rights of his/her peers and the school's resources. Gaining access to a chosen school can be challenging for parents of children with SEN (Rose and Shevlin, 2010). Rose et al. (2010) report instances of Irish mainstream schools discouraging parents from enrolling children with SEN, rather than overtly refusing their enrolment. Another Irish study (Armstrong et al., 2010) found that almost 70% of parents found it easy to find a school placement for their child with SEN in Ireland, while 20% found it difficult, particularly if looking for

special-school placements. Some parents are concerned that their child's holistic needs will not be met in mainstream settings (Grove and Fisher, 1999) and hence, choose special settings. However, 66% of parents of children in Irish special schools found it difficult to secure a place for their child (Armstrong et al., 2010). This may indicate the principle of inclusion, or perhaps more accurately a policy towards mainstreaming, is diminishing parental rights to choice, particularly if special-school placements are not available.

Selecting appropriate educational placements for children with WS is challenging due to the unique WS cognitive profile, and ultimately there is no one placement ideally suited to these learners (Udwin et al., 2007). In deciding on an educational placement, Levine et al. (2013) advise parents to consider the child's needs and the school supports available. An American study by Fidler et al. (2002) found no significant difference in the placements chosen by parents of children with WS, PWS or Down syndrome (DS). Overall, around 60% of parents of each of the three syndrome-specific groups chose 'inclusive' (mainstream) or 'partially-inclusive' settings and 40% chose special settings. Considering the health and care needs associated with WS, it is unclear if a medical model formed the basis of parents' choice of special settings. This was not clarified in the study.

In the scoping questionnaire issued to parents of the WSAI, Tynan (2010a) found that of 19 children who had completed primary education eight (42%) attended special schools, five (26%) mainstream schools, one (5%) a special class, two (11%) private schools and three (16%) transferred from mainstream schools to special schools. The main reason cited for such transfers was lack of support for the child's learning in mainstream. However, changes in parental choice emerged over time. For those children who were in primary and post-primary education at the time of this research (n=11), three (27%) were attending special schools, five (46%) mainstream, one (9%) a special class, and two (18%) transferred from mainstream schools to special schools. With a strong push towards mainstream placements in Ireland, the question remains as to why parents of children with WS choose special settings over mainstream settings, whether there is a specific profile (such as medical or health issues) associated with those children, and whether parents are satisfied with their decision.

Parental Satisfaction with Educational Placement

Research indicates high levels of parental satisfaction with educational placement both nationally and internationally (Newman, 2005; Bleach 2010), with higher satisfaction among parents of children in primary schools than of those in post-primary schools (Newman, 2005; Armstrong et al., 2010). In Ireland, 87% of parents of children with

SEN agree that their child's educational placement is appropriate to his/her needs (Armstrong et al., 2010:49), due to supportive staff, effective differentiation, appropriate supports, quality home-school communication and learner progress. Dissatisfaction arose where parents identified ineffective teaching approaches, poor understanding of or interest in their child's needs, and inadequate resources. Such results show parents value inclusive learning and have expectations that their child will be supported in his/her learning.

International research on parental satisfaction with educational placements for children with WS is enigmatic. In America, Fidler et al. (2002) found no difference in satisfaction levels between parents of children with WS, PWS and DS, yet a British study of adult outcomes in WS indicated one third of parents to be retrospectively dissatisfied with their child's educational provision (Howlin and Udwin, 2006). Some parents felt their child would have fared better in special placements while those whose children were educated in special placements felt their child would have been better in mainstream. This indicates difficulties in accommodating the complex WS cognitive profile. Similarly, in Ireland, some parents were concerned that their child had not reached their academic potential in their chosen educational placement (Scallan et al., 2011). While that study did not indicate if these children were in mainstream or special settings, it highlights parental knowledge of the need for inclusive learning.

Parental Knowledge

> Parents are usually the 'experts' in relation to their own child…
> Parents have unique insights into the needs, likes, dislikes,
> motivations and moods of their children (Rose and Howley,
> 2007:100-101)

Parents want knowledge when their child is diagnosed with SEN (Stoner et al., 2005), particularly of a relevant and practical nature (Turnbull et al., 2011). Some parents feel knowledge about their child's genetic condition helps their child's outcomes (Zwink, 2011). Parents of children with genetic conditions, such as WS, play valuable roles in their child's education by advising teachers on their child's needs (Fidler et al., 2002). In some cases, the expertise of parents of children with SEN is not acknowledged adequately by professionals in decision-making (Rose and Shevlin, 2010).

Parents of children with social and/or emotional challenges are primarily concerned with the social/emotional aspect of their child's development (Baker et al., 2003); these challenges are part of the WS profile. Fidler et al. (2002) found parents in the US to be more aware of the visible maladaptive features of WS than the more subtle cognitive features. This knowledge of a child's syndrome-based educational profile facilitates accurate expectations of their child's performance (Ly and Hodapp, 2005:937).

Parental expectations have their basis in personal experience and beliefs (Koller, 2008); they are affected by interactions with individuals, organisations or cultures (Russell, 2003). Parents of children with SEN have different expectations of schools, dependent on their family circumstances (Carpenter, 2001). They expect educators to understand their child and to see their child as a person without a label (Lombana, 1983). Conversely, parents' expectations may be unrealistic if they fail to acknowledge their child's needs (Garvey and Niall, 1992) and expectations are rarely discussed with educators. In a comparative study of five jurisdictions' individual education plans (IEP) for children with SEN, Queensland (Australia) was the only state which included family expectations in the discussion (McCausland, 2005:46). Parents' expectations and knowledge may also influence the ways in which they support their child's learning.

Parental Support for Learning

Parental support is important for all children's learning, as parents influence their child's attitude to learning (Cullingford, 1985). Parental involvement in education positively impacts on child development (Fullan, 1991), educational achievement (Whitbread et al., 2007; Jeynes, 2011) and social competence (Webster-Stratton et al., 2001) but much depends on home-school relationships. Traditionally, such partnerships have frequently been reluctant (Jordan, 1994), conflict-laden (Davies and Davies, 1985) and resentful (Hornby, 2002). Parents desire respectful, information-sharing and collaborative relationships (Pollock Prezant and Marshak, 2006), but may be hesitant to question or challenge the school due to power imbalances in parent-teacher partnerships (Leiter and Wyngaarden Krauss, 2004). Parental involvement may be diminished due to social class, lack of time or energy, inadequate support systems, or poor school encouragement (Bleach, 2010). Parents may not understand educational jargon, procedures or teachers' limitations (Lytle and Bordin, 2001). Their involvement may cause teachers to feel professionally superior (Koegel and Koegel, 1995), pressurised (Nugent, 2002) or threatened (INTO, 1997).

For parents of children with SEN, home-school relations can be exacerbated by different cultural perceptions of disability (Lamorey, 2002). Yet positive relations are essential for the educational, social and emotional success of children with SEN (Winter and Schafer, 2005). Communication is, therefore, significant. A Dutch study on communication logs between teachers and parents of children with profound and multiple SEN indicated differences between 'the kind of things that teachers believe should be recorded and what parents regard as important' (Fonteine et al., 2008:482). Teachers and other professionals are encouraged to see parents of children with SEN as experts (de Geeter et al., 2002), although this advanced model of partnership is rare (Hornby, 2002).

Parents also support their child's learning by developing specific interventions, as they know their child best (Wyman, 2000). Parents of children with WS have successfully undertaken therapeutic roles in home settings (see O'Reilly and Lancioni, 2001). While some parents undertake such roles with ease, others find it stressful (Turnbull et al., 2011). Quite simply, family contexts differ. Wolfendale (2000) describes inclusion as taking the family context of the child into account and acknowledging the assistance and support the family provides. Considering the complex medical needs and intricate cognitive profile associated with WS, it is unclear how this assistance and support manifests. This has not been researched nationally or internationally. Similarly, it is unclear if parents share their knowledge and interventions with their child's teacher.

Educating Children with WS: Teacher Perspectives

Teacher Knowledge of SEN

A report of stakeholders' views of SEN provision in Irish primary schools found poor teacher understanding of SEN impeded quality education for children with SEN (Kenny et al., 2006). Irish teachers themselves identified poor information about particular disabilities and inadequate pre-service training as impediments to the academic participation of pupils with SEN (Coffey, 2004; Cooper and Jacobs, 2011). Internationally, researchers have also identified poor teacher knowledge and inadequate teacher education as barriers to the educational inclusion of pupils with SEN (Forbes, 2007; Westwood, 2007), as these pupils require carefully planned programmes and specific teaching approaches (Florian, 1998). Therefore, quality education for newly qualified teachers 'is the best investment that can be made' (Mittler, 2000:137). Even experienced teachers may have to develop new knowledge or skills to meet a child's needs (Rose and Howley, 2007) but by accommodating children with SEN, other pupils can benefit from curriculum or teaching adaptations (Ainscow, 1999). In Ireland, teacher education is now recognised as essential to developing knowledge of SEN (Winter and O'Raw, 2010; NCSE, 2013f).

Parents of children with WS, both in the UK and in Ireland, have found poor knowledge of WS among professionals to be a daily challenge (Howlin and Udwin, 2006; Scallan et al., 2011). They are less likely than parents of children with DS to have practitioners who share syndrome-related information with teachers (Fidler et al., 2002). Yet it is essential that the cognitive profile of children with SEN is considered to ensure effective teaching and learning (Rose and Howley, 2007). It would be imprudent to assume teachers would be trained specifically to accommodate learners with WS, and its benefits would be limited due to the 'great variability and diversity' of the WS

population (Reis et al., 2003:295). Nevertheless, knowledge of the WS learning profile may ease some of the frustrations and confusion of teachers (Tynan, 1999).

Etiology-based interventions are becoming more possible for children with different genetic syndromes (Hodapp and Fidler, 1999). For learners with WS, educational methodologies have traditionally reinforced a 'deficit model' (Lenhoff et al., 1997) yet more exciting methodologies, such as a talent development approach, are emerging whereby the peaks of the WS profile are used to remediate the valleys (Tiesco, 2002). Music has been used successfully to support the development of maths skills in learners with WS who display an interest and strength in music (Reis et al., 2003). In the Irish context, the use of music to develop social competence in a small sample of children with specific needs (anxiety-related disorders, learning disability and language deficit) also produced encouraging results (MacNamara, 2008). Refinement of this approach for children with WS would be an interesting venture. There is a need to actively ascertain the types of intervention in place for children with WS and evaluate the quality of such interventions (Hodapp and Fidler, 1999:135), although much depends on the attitudes and expectations of the child's teacher.

Teacher Attitudes to and Expectations of Pupils with SEN

Teacher attitudes can impact significantly on the educational outcomes of pupils with SEN (Wilkins and Nietfield, 2004) and are key to successfully including all pupils (Winter and O'Raw, 2010). However, the nature or severity of learners' needs can impact on teacher attitudes (Croll and Moses, 2000). Indeed, some Irish parents perceive a lack of empathy among teachers in dealing with their child with SEN (Armstrong et al., 2010). Teachers are reportedly more positive towards pupils with sensory/physical needs than those with emotional/behavioural difficulties (EBD), for whom they lack sympathy and tolerance (Lindsay, 2007). However, teacher attitudes can become more positive when resources and training are secured (Lindsay, 2007). Teacher education appears consistently in international and national literature as a means of overcoming negative attitudes (Humphrey, 2009; NCSE, 2013f). Where negative attitudes prevail, teachers frequently have low expectations of the learner and this combination can exclude children from enriching learning opportunities (Rose and Shevlin, 2010). Low expectations in some special schools are a 'severe limitation on the efficacy of the education received' (Shevlin et al., 2008:148). By contrast, high teacher expectations are associated with positive attitudes to school, high achievement and positive social behaviour in all pupils (Wang et al., 1993). High-expectation teachers spend more time giving feedback to pupils, using higher-order questions, implementing positive behaviour interventions and devising frameworks to support pupils' learning (Rubie-Davies, 2007).

Teachers' support for pupils' learning encompasses appropriate programmes of work and clear communication with parents. There is much discussion on the development of syndrome-specific pedagogies for different groups of learners (see Hodapp and Fidler, 1999; Reilly and Senior, 2007) but there is increasing support and evidence for effective inclusive pedagogies which can benefit all learners (Florian and Kershner, 2009). Teachers' support for the learning of pupils with SEN, including their approaches and interventions, is frequently documented as part of the child's IEP. The EPSEN Act (Ireland, 2004) accentuates the IEP process. The IEP is a 'tool that helps teachers to plan and teach pupils with SEN' (McCarthy, 2006:112); it is an essential aspect to the school's response to meeting the needs of pupils (Doherty, 2005). It should set out 'how teachers/educators prepare for, implement and review the various milestones on the journey and the signposts along the way' (NCSE, 2006:1) and must 'fit' the child and its family (Lordan, 2002). The quality of the process dictates the quality of outcomes for pupils (Nugent, 2002; NCSE, 2006), although this target-based approach to achieving outcomes will not of itself ensure effective teaching or learning (Proctor, 2003). There can be an over-emphasis on academic performance with failure to consider the social, emotional and behavioural needs of the child (Lordan, 2002), significant for children with WS. An Irish study found that 80% of teachers of pupils with mild GLD find the IEP process useful (McCarthy, 2006). In Ireland, debate continues about the responsibilities of schools to produce such IEPs as the balance tips between the non-enactment of this part of the EPSEN Act (Ireland, 2004) and the promotion of good practice. However, a recent study has shown schools have different interpretations of the IEP process but many demonstrate a 'reflective and experimental approach' to supporting pupils with SEN (Rose et al., 2012:115).

Educating Children with WS: Pupil Perspectives

Various Irish studies have demonstrated how pupils with SEN are capable of expressing self-perceptions (Flynn et al., 2011; O'Keeffe, 2011) and these studies show many pupils with SEN are happy at school (see Ware et al., 2011). Pupils with moderate GLD in Irish mainstream schools have 'positive, satisfying social and educational experiences' (O'Keeffe, 2011:55), although they may have a restricted curriculum. Some Irish learners describe a diagnosis stigmatisation with negative impact (Motherway, 2011). However, this contrasts with Renick and Harter (1989) who found the perceptions of individuals with learning disabilities did not differ significantly from their peers in the areas of social acceptance or self-esteem. In Britain, self-

perceptions of educational abilities were found to be higher for students in special schools than those with SEN in mainstream schools (Kelly and Norwich, 2004).

Socially, pupils with SEN feel most included when playing with their peers, engaging in extra-curricular activities, and participating in non-academic subjects such as Physical Education and Visual Arts (Balfe and Travers, 2011). However, high rates of bullying are reported for students with SEN, both nationally and internationally, more prevalent for students in special settings than mainstream (Norwich and Kelly, 2004; Motherway, 2011). Education in special settings can cause learners some unease if they are conscious of how their school is perceived in the wider community (Motherway, 2011). This highlights a self-awareness that has not always been recognised in pupils with SEN. Learners with SEN have also been found to be cognisant of the importance of their relationship with their teacher, which is generally reported to be very positive (Norwich and Kelly, 2004), although this appears to be less positive for pupils with EBD (Flynn et al., 2011). Reis et al. (2003), in developing a talent-development approach to learning mathematics with a group of sixteen adults with WS, found that these learners had had negative experiences of school and of learning. As adult learners, however, they were able to describe their preferred learning style, expression style and areas of interest, although most were also found to hold firm and sometimes inaccurate beliefs about their ability to learn certain skills (Reis et al., 2003:309). There is currently no other information on the attitudes of children with WS to school or perceptions of self as a learner either internationally or nationally.

Conclusion

Exploring the literature has revealed gaps in some key areas regarding the education of children with WS, areas also significant within the context of educational inclusion. This chapter highlighted the complexity in defining educational inclusion and provided a backdrop of national and international debate on the developments in its interpretation. It showed a clear move to define inclusion in terms of the quality of learning.

The most significant gaps in the literature concern parental knowledge about the WS cognitive profile, as unlike parents of other more common genetic conditions, such as DS, parents of children with WS are the main suppliers of information to school personnel. Inaccurate information may affect the child's individual programme, and hence, educational inclusion. Considering the complexity of the WS cognitive profile, with its distinctive peaks and valleys and associated maladaptive behaviours, it is unclear what determines parents' choice of educational placement and why, with a drive towards mainstreaming, parents choose special placements for their child with WS. Some Irish children with WS transfer from mainstream to special placements

during primary education (Tynan, 2010a) yet it is unknown what influences parental satisfaction with educational placement. The literature indicates parental knowledge and skill base should be recognised by professionals. However, it is unclear how parents support their child's learning and whether they have specific interventions to enhance their child's educational inclusion.

This chapter also examined a range of literature pertaining to teachers and their experience of pupils with SEN. It showed that inadequate teacher knowledge, low expectations and negative attitudes impede quality teaching and learning for pupils with SEN. The most significant gaps centre on teachers' perceptions of learners with WS and their supports for the child. There are very few published studies on educational interventions for learners with WS, although exciting approaches using learners' strengths have been found to be effective. There is currently no such information based on the Irish context.

Lastly, this chapter presented literature on learner attitudes and self-perception. It is now widely acknowledged that the learner perspective should be included in educational research, yet there are no national studies and few international studies, that explore the educational experiences of learners with WS. From the gaps in the literature the following research questions emerged:

1) **What are the experiences of parents concerning the educational inclusion of their child with WS?**
   a) How do parents perceive the educational profile of their child?
   b) What determined parents' choice of educational placement?
   c) How satisfied are parents with their child's educational placement?
   d) How do parents support their child's learning?

2) **What are the experiences of teachers concerning the educational inclusion of their pupil with WS?**
   a) How do teachers perceive the educational profile of the child with WS?
   b) How satisfied are teachers with the child's educational placement?
   c) How do teachers support the child's learning?

3) **What are the experiences of children with WS concerning their educational inclusion?**
   a) How does the child perceive his/her educational profile?
   b) How satisfied is the child with his/her placement?

CHAPTER 3   RESEARCH DESIGN

Introduction

This qualitative research is underpinned by two complimentary paradigms: interpretivism and transformativism. It uses a small-scale sample to explore stakeholders' experiences of the educational inclusion of children with WS in Irish primary schools. The sample was chosen from members of the Williams Syndrome Association of Ireland (WSAI) and comprises seven children with WS, their parents and teachers. Structured interviews were conducted with the children and semi-structured interviews were conducted with their parents and teachers.

This chapter presents the philosophical underpinnings of the research and their influences on the research approach, choice of methods, sampling and development of research instruments. The piloting and administration of interviews is detailed, followed by strategies for data analysis. Researcher positionality and ethical considerations are subsequently presented.

Philosophical Underpinnings

The epistemology and ontology of the chosen paradigms are significant in influencing all aspects of methodology. To this end, a merger between interpretivism and transformativism institute the philosophical underpinnings used in this research, fitting with changing attitudes to SEN.

Traditional philosophical assumptions regarding SEN are regarded as outdated (Wong, 2009; Kittay and Carlson, 2010). WS studies have traditionally been dominated by medical models (Dykens et al., 2005), not surprising considering the complex medical manifestations in WS. However, such models highlight common group deficits and override strengths, opportunities and individualism (Mertens, 2009). More recent philosophical approaches to SEN implicitly acknowledge the rights of those affected (Carlson, 2010). As the epistemology of special education (SE) developed from social stereotyping to identification of behavioural phenotypes (Goodey, 2006), it facilitated knowledge transfer from one genetic condition to another (Oliver and Hagerman, 2007). The researcher's positionality, as outlined in Chapter One, was very significant in rejecting a deficit-focused approach with the result that this study evolved through a transformative paradigm which is further tempered by interpretivism.

Prior to the development of an interpretive-transformative approach, the researcher developed a scoping questionnaire to garnish baseline data on the Irish WS population (Tynan, 2010a), using a predominantly positivist approach. This suited the search for generalizable knowledge (Wellington, 2000) and produced detached, objective knowledge. However, the findings lacked context and an interpretation of the thoughts and feelings behind the responses. The questionnaire failed to capitalise on the researcher's positionality. By contrast, interpretivism acknowledges that both researcher and researched bring different understanding to the situation, thus prioritising the construction and negotiation of meaningful activity in the research (Scott and Morrison, 2007). The subjective meanings of the researched have a context and add richness to the results as 'what we do cannot be understood as observable behaviours alone' (Pring, 2000:98).

In formulating the research design it was important that children with WS would be involved to ensure this study on inclusion was inclusive in its approach. Transformativism provided an appropriate foundation for their involvement. Largely reflecting the emancipatory paradigm, transformativism is commonly associated with minority-group research and implies member participation (Mertens, 2009). Its rejection of special-needs deficits (Seelman, 2000) was important due to the researcher's personal connection with WS. Transformativism replaces both moral and medical models to focus on environmental responses to special needs (Mertens and McLaughlin, 2004), clearly appropriate when exploring educational inclusion. It supports the advances in minority group research such as talent development approaches (Boykin, 2000), approaches which have been successfully tried with WS (see Reis et al., 2003). Transformativism further develops the social model of research, celebrating the heterogeneous nature of the group, a latent shortcoming of positivism. There are some commonalities between interpretivism and transformativism, but each also has specific features. For this reason it is necessary to present the epistemology and ontology of both.

Epistemologically, interpretivism appreciates that 'our approach to, perceptions of, and interpretations of what we experience are filtered by a web of assumptions, expectations and vocabularies that guide the entire project' (Alvesson, 2002:3). Transformativism compliments this interpretive stance by asserting that 'knowledge is not neutral but influenced by human interests' (Mertens and McLaughlin, 2004:3). Similar to emancipatory interest, it also acknowledges the power relationships that exist in social constructions of knowledge and facilitates the marginalised voice in producing knowledge (Habermas, 1972). The trusting relationship between researcher and researched is 'interactive and empowering' (Mertens, 2009:56). Throughout this

research the links between the researcher and many of the researched are strengthened, partly due to the involvement in the common community of the WSAI.

Ontologically, interpretivism insists that 'researchers are no more 'detached' from their objects of study than are their informants' (Miles and Huberman 1994:8), as they bring personal understandings and experiences to the research. Similarly, transformativism acknowledges the existence of different social constructs of reality, unlikely to be defined by marginalised individuals. To know what is real we must know who defines it (Mertens, 2009). Reality defined by minority group members promotes collective empowerment (Habermas, 1972), a central tenet in this research. A dialogical approach is critical for transformative researchers (Mertens, 2009) to give participants 'a chance to shape the themes or abstractions that emerge from the process' (Creswell, 2007:39). To this end the parents of the WSAI collectively constructed the research questions with the researcher at a meeting in November 2009 and later discussed the research outcomes at another meeting in November 2012. The teacher group was invited to collectively discuss the outcomes of the research as part of a WS teacher-support group which was established as a consequence of this research.

Research Approach

The interpretive-transformative approach lends itself to the choice of inductive, qualitative methods of inquiry involving a small sample, comprising members of the minority group. In Ireland, studies into other genetic syndromes (see Owens, 2001) concluded that inductive research approaches were needed to replace medical models. Inductive research allows the researched to tell their stories, with little emphasis on theory or frameworks (Holstein and Gubrium, 1995); thus, it was decided to explore the issue of educational inclusion for children with WS without the limitations of a particular inclusion framework, and information was taken 'from the ground up' (Creswell, 2007:19).

The small sample in this study lends itself to qualitative research which is concerned with how humans experience their worlds (Foddy, 1993); in this case, how children with WS, their parents and teachers experience educational inclusion. It rejects the production of scientific data with its emphasis on objectivity, measurability and causality, features of a medical model too commonly associated with WS research. Qualitative research seeks to reveal 'the authenticity of human experience' (Silverman, 2010:6). This approach facilitated the involvement of children with WS in the study, as surveys and experiments may not 'provide sufficient information or insight required to fully capture the nuanced complexity of children's experiences' (Darbyshire et al., 2005:467-8). Perhaps most significantly, qualitative research is used to empower

individuals, as they are given a voice, and the power relationship between the researcher and the researched is minimised (Creswell, 2007). Children with WS have rarely been given a voice in the literature.

The qualitative approach influenced the research questions, research design and data. The research questions changed and developed to reflect an increased understanding of the topic (Creswell, 2007). In exploring the inclusion experiences of children with WS, their parents and teachers, the questions were guided by a loose structure (Punch, 2009), allowing for greater theoretically-informed flexibility than quantitative research designs (Silverman, 2010). As the research process evolved, through exploring the literature, meeting with experienced researchers on WS, maintaining contact with WS families, talking to parents, teachers and children with other genetic conditions, and through the scoping survey, the research developed a clear conceptual framework. The data was subsequently examined inductively from specific to generalised perspectives, through different levels of abstractions (Creswell, 2007). The emergent data provided a source of well-grounded, rich descriptions and explanations in clearly defined contexts (Miles and Huberman, 1994). A qualitative approach also facilitated the collaborative exploration of an issue to 'hear silenced voices' (Creswell, 2007:40), and the enquiry into 'children's unique and individual encounters with their worlds' (Greene and Hogan, 2005:xi), thereby echoing the interpretive-transformative basis of the study. To emphasise the importance of individual contexts, and due to the limited number of children with WS available, a small-scale study had to be the chosen method.

Small-scale samples feature in many international WS studies which had ten participants or fewer (see Mervis and Bertrand, 1997; Volterra et al., 2003), and are also a common feature of transformative research (Mertens, 2009).

Population and Sample

The convenience sample included seven children, their parents and teachers, from a total of nine possible children with WS of primary-school age. The credibility of the overall study was enhanced through this triangulation of data from three sources (Creswell, 2007). Families were contacted through the WSAI as no other avenues existed for contacting families. It could be argued that the range of diversity is somewhat limited by using a parent-support group, as they are frequently well-educated, middle-class families (Fidler et al., 2003). This is, however, a common sampling method used internationally by researchers of genetic conditions (see van Lieshout et al., 1998; Ng et al., 2013). The WSAI holds a register of individuals with WS in Ireland. Its database had 55 families at the time of data collection, a small number

when one considers the incidence of WS and the population of Ireland. Internationally, the prevalence of WS is estimated to be 1:7,500 (Strømme et al., 2002). Based on the 2006 census (Central Statistics Office, 2011) one would expect between 168 and 210 members if all those with WS were identified and affiliated to the association. The incidence is somewhat different. There are on average three individuals diagnosed with WS each year, not all children (Green, 2011); therefore, it may be more realistic to expect between 16 and 24 children with WS in Irish primary schools in any given school year. Other options to increase the sample size were considered, including contacting all primary schools in the Republic of Ireland, but proved unethical, as it would require schools to breach the Data Protection Act (Ireland, 1998b).

Initial contact was made with families during an open forum at the annual general meeting of the WSAI in November 2009. Basic research questions were formulated that day in consultation with parents, a critical aspect of a transformative approach. An invitation was also published in the association's newsletter for families not in attendance at the meeting. Parents expressed the wish to create a profile of the WS population in Ireland to elicit the number of children with WS in school and to ascertain the different educational placements chosen by parents, feeling this information would support parents of young children with WS. A questionnaire was subsequently issued to all families. This scoping exercise (Tynan, 2010a) yielded a response rate of 55% of 55 families. The responses showed there were seven families with a child with WS in primary education. In the time taken to prepare the research study the population had shifted to nine possible children of which seven families agreed to partake in the research.

Inviting all available participants from the WSAI to be part of the research alleviated the issue of sample selection. There is an expected variation in WS populations (Reis et al., 2003), as with any population, which can skew the results when small samples are used. Some of the participating children had co-morbidity with other conditions (such as ADHD), and were from diverse geographical locations in the Republic of Ireland where the range of services and school provision differed. The uniqueness of this small sample could create difficulties in replicating similar studies (Mertens, 2009). When one examines the many research studies on WS, this is frequently the trajectory, but the findings from one specific small-sample study frequently lead to larger scale, longitudinal or refined research studies. The value of such studies is frequently underestimated. Some researchers argue that where the context is richly presented the reader should be able to determine the degree of transferability (Miles and Huberman, 1994; Mertens, 2009). Despite a small sample size, the sample represented 29%-44% of the total possible population of children with WS of primary school age at the time of

the research. This level of representation enhances the research credibility and dependability.

The teacher sample involved those teachers who were teaching the seven children with WS whose parents had agreed to participate in the research. In special schools the child's class teacher was invited to participate, in mainstream schools both the class teacher and the learning-support/resource teacher (LS/RT) were invited. In the one case of a special class, the special-class teacher and the teacher of the mainstream class into which the child was partially included were invited. In both the mainstream classes and the special class where two teachers worked with one child they were invited to be interviewed individually or together. In one case the class teacher asked if the SNA could also be part of the interview. Overall, teachers of six of the seven children agreed to being involved in the research.

The participants in the research are detailed in Table 3.1. The names of children have been changed to protect their identity.

Table 3.1: WS educational inclusion in Ireland: research participants (2012)

Child	School Type	Class Level	Home Interviews		School Interviews	
			Child	**Parents**	**School Personnel**	**Interview Type**
Annie	Mainstream	Junior infants: 1st year of school	No	Mother and father	Class teacher	Single
Brian	Mainstream	Senior infants: 2nd year of school	Yes	Mother	Class teacher Support teacher SNA	Group
Charlie	Special class	First class: 3rd year of school	Yes	Mother	Special-class teacher Mainstream teacher	Single
Dean	Mainstream	Second class: 4th year of school	Yes	Mother	Class teacher Support teacher	Single
Emma	Mainstream	Third class: 5th year of school	Yes	Mother and father	Class teacher Support teacher	Group
Fred	Special school	6th year of school	No	Mother	Teacher declined	
Gillian	Special school	8th year of school	Yes	Mother	Class teacher	Single

Data Collection

In line with a qualitative, small-scale study, the interview was the chosen research instrument for the three participant groups. A close connection to the participants, and the inclusion of children with WS, was necessary with the interpretive-transformative approach desired. The interview facilitates access to perceptions, meanings and

constructions of reality and suits an interpretive approach (Punch, 2009). It is also an adaptable research tool (Bell, 2009) which empowers the participants to articulate their views (Cohen et al., 2007) reflecting the transformative perspective. The interview was also deemed appropriate due to 'the richness and vividness of the material it turns up' (Gillham, 2000:10), which was lacking in the results from the questionnaire data (Tynan, 2010a). The interview was particularly suited to the child participants in line with the documented strengths of sociability and verbal competence. The piloting phase of the interviews greatly aided the development of structures to increase the participation of children with WS.

Pilot Interviews

Each of the child, parent and teacher interviews was piloted. The parent interview was piloted on two parents of children with WS who had finished primary education. The first interview was unstructured to ascertain which issues arose organically, although it centred on the research questions formulated from the parents. Following this, an interview schedule was drafted with prompt questions for each research question, which was then piloted using a semi-structured interview. The lessons learned from this exercise included informing the participant of the estimated length of the interview, ensuring the place for the interview is free from interruptions, as far as possible, and to have less verbal interjections from the interviewer.

The teacher interview was piloted on one teacher of a child with DS, another genetic condition. The interview schedule was devised to reflect questions in the parents' interview. There was a tight adherence to the interview schedule to experience a structured interview. The lesson learned from this interview was that when a participant talks at length with minimal interruptions they may raise issues or answer more interview questions in an organic manner. However, tight adherence to the interview schedule impeded the conversation style of the interview. This showed that the less structured the interview, the greater the interviewer skill required in communicating effectively, particularly regarding active listening and devising appropriate follow-up questions (Punch, 2009:151). Such interviewing requires researcher knowledge of the topic and interest in human interaction (Kvale and Brinkmann, 2009). This suited the unique positionality of the researcher, created largely from being a member of the interviewee's community. It was thereby decided to use a model between the semi-structured interview and the open-ended interview.

Significant differences exist between adult and child interviews for research purposes. Previous international research has shown the capacity of individuals with WS to participate in both interviews (Howlin et al., 2010) and questionnaires (Dodd et al.,

2009), yet to date, most research has focused on clinical observations, experiments, trials and assessments. Where qualitative approaches have been used they have usually been interviews with parents rather than with individuals with WS (see Einfeld et al., 1999; Fidler et al., 2003). Questionnaires, drawing or other 'writing' methods are less suitable research tools for children with WS due to associated fine-motor difficulties. The interview is appropriate for children with WS who generally converse loquaciously and respond enthusiastically to adult attention (Udwin et al., 2007). However, concerns arose from literature on child research, including children's verbal competence, capacity to express and understand abstract ideas, linguistic understandings, vulnerability to persuasion, inhibitions, acquiescence and desire to please (Perry, 2004; Hill, 2005), the latter of particular concern with children with WS.

The child interview was piloted twice on an adult with WS, one being an unstructured interview with open questions; the second, a structured interview designed as a sentence-completion task, based on one by Dykens et al. (2007), but developed to focus on schooling. As an adult, this participant was able to express his opinions about both models of interview. Based on the outcome of these interviews the structured interview format was deemed more appropriate as it was shorter, more focused and caused less participant anxiety. This structured interview lasted nine minutes, an appropriate time-frame for children with WS considering their concentration difficulties. Following the piloting phase, the interview schedules were adapted and finalised.

Interview Schedules

The interview guide, 'which structures the course of the interview' (Kvale and Brinkmann, 2009:130), was largely determined by the research questions elicited from the parents in the WSAI and was refined following the pilot interviews. Vocabulary was kept simple, while prejudicial language and leading questions were avoided as advised by Arksey and Knight (1999). As a result, overt questions on inclusion were circumvented as they appeared to make parents anxious and doubtful of their choice of educational placement, and they made teachers talk in politically correct terms, as emerged during the piloting phase. On the schedule for parents (Appendix C) and teachers (Appendix I) a common structure was followed where background information was elicited first to put the respondent at ease and, subsequently, different themes were explored using open-ended questions, backed up by a range of prompt questions.

The structured interview for the children was a sentence-completion task where each child was given the same language and instructions to complete the same sentence stems (Appendix K). The sentence-completion task was originally designed to get participants' perceptions of themselves and others in a casual manner (Holaday et al.,

2000). This approach has been used by different researchers of individuals with SEN (Zetlin and Turner, 1988; O'Keeffe, 2011); it provides enough structure to prompt a response from the participant while achieving spontaneity in answers (Dykens et al., 2007). Once the interview schedules were finalised, arrangements were made to conduct the interviews with each of the participant groups.

Research Interviews

Administration of Interviews to Parents

Each family was contacted by telephone to confirm their participation in the research. Interviews with both parent and children were negotiated at this point, along with the intention to interview the child's teacher. Parents selected a suitable day and time for the interview. Six of the seven interviews were conducted over the Easter school holidays 2012. One parent, expecting a baby during that timeframe, was interviewed six weeks later.

All parents suggested their home as the place of interview. On arrival there was a general conversation which merged into discussion about the research. This step was key to ensuring a common understanding of the research topic to promote a successful 'question-answer cycle' (Foddy, 1993:36). The interview was formally commenced at this point. In some cases the child with WS and/or other siblings were present in the room during some (but never all) of the interview. All parents agreed to the digital recording of the interview. In all cases the mother was interviewed and in two cases fathers joined in for part of the interview. As the interview approach was loosely structured, the sequence of questions followed interviewees' responses and unanticipated avenues were explored where relevant. The focus was on active listening; there were no time pressures. This approach had the advantage that questions emerged from the immediate context (Cohen et al., 2007). This interview type supported the philosophical underpinning of the research where the relationship between interviewee and interviewer was valued and power issues were minimised (Mertens, 2009). The conversation became so natural that in all cases the interviewees also asked questions throughout the interview which added to the naturalistic tone of the interview and led to a co-creation of reality. The interview presented some challenges, such as having to respond to unexpected interviewee behaviours (in one interview a mother began to cry and asked to stop the interview), having to deal with the consequences of one's own subjectivities, the phrasing and negotiating of questions (particularly around the use of the word inclusion) and dealing with sensitive issues (Roulston et al., 2003).

Interviews varied in length from 59 to 101 minutes. The interview was allowed to peter out to general conversation, at which point the recording was stopped. This prolonged and substantial engagement with the interviewees to ensure that critical issues were fully discussed promoted credibility (Guba and Lincoln, 1989). At the end of each interview the parents were given a brochure detailing the research for future reference (Appendix B). They were also requested to fill out a consent form (which had been discussed at the beginning of the interview) (Appendix D), a consent form for their child's interview (Appendix E), and a form requesting their child's school details (Appendix F).

Administration of Interviews to Teachers

Unlike the parent participants, teachers were initially contacted by letter at their school address (Appendix G) explaining why contact was sought and how their contact details were made available. A brochure, explaining the research aims and methods, was included (Appendix H), as was an indication of the intention to follow up with a telephone call. One teacher declined participation in the research when contacted. In two cases of mainstream-school teachers, the LS/RT and class teacher requested a joint interview, and in another case the class teacher and LS/RT asked if the SNA could be included in their interview. The advantages associated with group interviews included greater potential for discussion, the generation of a wider range of responses than individual responses and the bringing together of people with different viewpoints (Cohen et al., 2007). There were some initial concerns by the researcher that teachers may try to be politically correct when in a group or fail to reveal their true thoughts and experiences but this did not appear to be the case in the course of these interviews.

Eight interviews in total were conducted; the venue decided by the teachers. In six of the eight cases the interviews were conducted in the school, one in a hotel and one in the teacher's home. Seven of the interviews were outside of school hours and one within school hours. At the beginning of each interview the researcher explained the research and her research interest, and sought permission to digitally record the interview by getting teachers to fill in a consent form (Appendix J). Permission was not granted to record three of the eight interviews. In such instances extensive notes were maintained, using a type of shorthand and writing verbatim in inverted commas at times. These notes were transcribed immediately after the interview. The interviews lasted between 39 and 90 minutes.

Administration of Interviews to Children with WS

Despite using a structured schedule for the children (Appendix K), finger puppets and a microphone were introduced to the children to enhance interview engagement (Veale,

2005). In addition, a wide range of manipulatives was supplied to keep the child in the room for the duration of the interview and to meet possible sensory needs. The children were allowed to play with these as they conversed, which proved very effective. Two children did not complete the interview despite attempts at using different resources: one child directed the conversation to her own interests which did not include any aspect of the research, while the other child expressed no desire to engage in any interaction other than to sing nursery rhymes. Attempts to sing questions did not work.

In all cases the child's mother was present. The purpose of the interview was explained in simple language after a relationship was formed with the child. Verbal consent was sought from each of the children, along with written consent from their parents. Each of the sentences was read to the child and they were encouraged to respond. A short set of practice sentences was used to get the children used to the procedure and to reduce their anxiety. Their attention was maintained through affirmative gestural and/or verbal feedback and through the use of resources, as described. In one case the mother intervened several times during the practice questions, commenting on whether the answer was 'correct' for the child. This interfered with the child's participation and caused some degree of the child trying to produce correct responses.

A number of guidelines as proposed by Westcott and Littleton (2005) were useful to ensure appropriate techniques for interviewing children were implemented. This included refraining from repeating questions once the child had answered (so the child did not think their first answer was wrong) and from asking questions in a suggestive manner, not interrupting the child, accepting long pauses, and being watchful of one's own eye contact, posture and demeanour. In line with a transformative approach, the children were also conversed with before and after the interview to see if they wished to discuss other aspects of their life, schooling or area of interest not included in the interview. However, they were not consulted again regarding the interpretation of their responses, thereby falling back on an interpretive approach. It was feared the children may assume they made mistakes and this could have impacted on their self-perception or anxiety, which ethically would be unacceptable. However, a booklet on the collective responses was posted to each child participant. At the end of some interviews the child was asked to elaborate on some of the responses, in a conversational manner, to ensure their meaning had been understood. On one occasion clarification was sought from a parent to guarantee the child's language had been correctly interpreted.

Documentary Evidence

It was hoped that the findings from the interviews would be triangulated with documentary evidence, namely the individual education plan (IEP). The IEP is a

document named under the EPSEN Act (Ireland, 2004), and while not yet legally required, is deemed best practice. It contains both a profile of the learner and outlines the learning targets for an instructional period (NCSE, 2006), similar to the structure of education plans in other jurisdictions (McCausland, 2005). If one refers to the framework for classifying documents in educational research by Scott (1990), the IEP would be categorised under restricted access of a private official authorship. The IEP was to be accessed through parental consent. There was great variance in the use of the IEP. Of the seven children with WS in this study, only two parents had an IEP to share. One parent had thrown out the IEP, one did not know where she had put it, two did not think their child had an IEP and one child was not eligible to have one as he had not at that point qualified for resource hours. Consequently, this aspect of the research was abandoned.

Observational Profiles

In the absence of individual education plans, which emphasise the learner profile as 'the foundation from which the IEP is developed' (NCSE, 2006:12), it was decided to present the researcher's own observational profiles on the learners. This was to underscore the centrality of the learners and was of particular importance as two of the seven children chose not to participate in the interviews; therefore the profiles include them to some degree in this study. Similar to a naturalistic approach the researcher sought neither to 'manipulate nor stimulate the behaviour' (Punch, 2009:154) of the children who were observed. The observational profiles were based on the field notes maintained by the researcher during the interviews conducted in the child's home, with the child and/or his/her parents, as in all cases the child was in the room for part of each parent's interview. The researcher had taken note of a number of observations during the interviews related to individual children's personality, activities, behaviours, interactions (with the researcher and family members), expression, cognition, interests and reactions. Notes were also written on each child after the visit to document the overall impression of the child and provide contextual information which effectively accompanies the use of interviews (Cohen et al., 2007). Each child's profile was then analysed for commonalities with and differences between the other child participants. This is presented in Chapter Six.

Approach to Data Analysis

The data collected from the interviews were transcribed fully by the researcher with detailed field notes included to enhance the dependability of the research (Creswell, 2007). As the analysis of qualitative data is 'almost inevitably interpretive' (Cohen et al., 2007:368) the transcriptions were read through to select key words and themes. These

related primarily, though not solely, to the research questions. The researcher printed out each transcript and hand-wrote in the theme using a colour-code system. Each theme was highlighted in a different colour. The content of each theme from individual interviewees' transcripts was subsequently transferred into a table using Microsoft Word. Open codes were then assigned by isolating explicit and implicit conceptual categories (Punch, 2009:183) within this theme. This produced lengthy lists of codes which were later condensed to provide 'an abridgement of the meanings expressed by the interviewees into shorter formulations' (Kvale and Brinkmann, 2009:205). It involved replicating codes from the first coding or formulating new codes. The transcripts were put aside for a period of time to facilitate reading them 'cold' with a view to 'listening to the interview for a sense of the whole' (Punch, 2009:370). Coding was done firstly by the researcher and subsequently done 'blind' by a research peer, a primary-school principal, also involved in doctoral research. This led to discussion and then 'intercoder agreement checks' (Creswell, 2007:210) to further enhance the dependability of the results. The full range of initial themes that arose from the parent data in relation to their experiences of the educational inclusion of their child with WS were: choice (of educational placement), school profile, attitudes, child's educational profile, satisfaction with school, expectations, emotions, parent knowledge, supports, inclusion and impact. Table 3.2 shows the coding process for the parents' data related to the theme of 'choice' (of educational placement). It is presented as an example of the coding process.

Table 3.2: Coding process for parent data regarding choice of educational placement for child with WS

First Coding (name)	Code Assigned	Second Coding (name)	Code Assigned
Size	siz	School structure	ss
Structure	struc		
Single-stream	ss		
Location	loc		
Mainstream specific	m/s		
Special specific	sp		
Resources	res	Supports	sup
Pupils with SEN in school	SEN		
Friends	fr		
Support	sup		
Advice	ad		
Facilities	fac		
Principal attitude	pr_att	Leadership	l/s
Principal knowledge	pr_kn		
Reputation	rep		
Openness	open		
Pre-enrolment experience	enrol exp		
Child happy	happy	Child's needs	ch/needs
Health/care needs	h/c needs		
Educational needs	ed needs		
Ability	ab		
Assessment	ass		
Inclusion	inc	Parent attitudes	par_att
Visits	vis		
Fears	fears		
Siblings	sib		
Socialisation	soc		
Assessment	ass	Professional input	prof_i/p
Eligibility	elig		
Advice	adv		
Availability	avail		

This system was used for all eleven themes in the parent data. It was also used for the teacher data as shown in Table 3.3 where nine themes emerged: child's educational profile, teacher knowledge, strategies, attitude, expectations, impact of child, provision, inclusion and supports. The theme of 'supports' is used in Table 3.3 as an example of the coding process used for the teacher data.

Table 3.3: Coding process for teacher data regarding how teachers support learners with WS

First Coding (name)	Code Assigned	Second Coding (name)	Code Assigned
SEN-specific methodologies	SEN-meth	Academic support-SEN methodologies	Ac_SEN
individual programme	indiv	Academic support-differentiation	Ac_Diff
groups	group		
less work	less work		
focus on learner style	l/s		
slower pace	pace		
regular assessment	ass		
withdrawal from class	w/d	Academic support-non-inclusive teaching approaches	Ac_NITA
treat same as peers	treat same		
SNA as 'teacher'	SNA-T		
repetition	repeat	Academic support-general teaching approaches	Ac_GTA
short lessons	short		
use of manipulatives	manip		
encouragement	encour		
simple instructions	simp instruct		
clear rules	rules	Academic support-classroom structure	Ac_CS
strategic timetable	st t/t		
group work	group		
high expectations	high ex		
daily routines	d rout		
SNA	SNA	Academic support-resources	Ac_Res
visual aids	vis A		
specific resources	res-sp		
concrete materials	c mat		
ICT	ICT		
seek parental advice	par-ad	Academic support-open communication	Ac_Comm
share strategies with parents	par-strat		
liaise with professionals	prof-liaise		
behaviour strategies	B-strat	Emotional/behavioural support	Em/B
movement breaks	m/m		
positive language use	pos lang		
routine	rout		
model behaviours	model B		
professional advice	prof-advice		
accommodate learning style	l/s		
active learning	a/l		
reward pupil engagement	p/eng		
peer modelling	peer mod		
social interventions	soc inter	Social support	Soc
planned inclusion	pl/incl		
life skill focus	l/s focus		
safety needs	safety	Life skills support	L/S
care needs	care		
independence	indep		

The children's interviews were analysed and coded following the guidelines described by Dykens et al. (2007). However, Dykens et al. (2007) had a much larger sample and reported many of the findings in a quantitative manner which was not appropriate for this small sample. As with the parent and teacher data, themes emerged and were noted; although in this case only three themes were used: self-perception of educational profile, satisfaction with educational placement and emotions. Subsequently codes were assigned and, in some cases, were later adapted to allow for responses from different children to be grouped. A second coder (the same research peer) was also used to improve the dependability of the results. Considering the responses to each question were very short, the level of interpretation required was lower than in either the parent or teacher responses. Table 3.4 shows the approach used to code the responses relating to the pupils' sentence completion tasks regarding self-perceptions of educational profile.

Table 3.4: Coding process for children's data on self-perceptions of educational profile.

Sentence stem	Pupils' responses	First coding	Second coding
At school I am good at …	writing football dancing, maths or anything reading working	academic sport sport & academic academic academic	academic sport sport & academic academic academic
At school I need help to …	mind me and help me get outside write properly do maths read work	safety academic academic academic academic	safety academic academic academic academic
I am best when …	I'm better I am working I am the bestest boy, I just play I like playing I am doing my tests	health academic help others activity academic	health academic social activity social activity academic

This process showed how in some cases there was a need to assign more than one code to a response. The relationship with the participants was important in interpreting some of the responses as with 'I am best when … I am better'. This could have been coded as the child giving a literal response but the theme of health and well-being runs through this child's responses. This is discussed with the findings in Chapter Six.

Ethical Considerations

There are implicit ethical considerations in any research which are more significant where vulnerable groups are involved (Flewitt, 2005). There were commonalities in the ethical considerations for the three participating groups: parents, teachers and children, which will be dealt with first before the additional considerations for involving children

with WS are addressed. The overall aim was to ensure the sum of potential benefits to participants (in terms of the overall research outcomes and the knowledge gained) would outweigh the risk of harm to them (Kvale and Brinkmann, 2009:73).

Through all stages of the research process ethical implications were considered, particularly in the light of power relationships between researcher and researched. To reduce any semblance of 'power', which may be present simply by being in the role of a researcher/interviewer, I discussed my own situation regarding WS, relating information to my brother when interviewing the parents, and referring to experiences of teaching a child with WS when interviewing the teachers. I acknowledged the challenges experienced in both roles. Of most concern was the perception of my role as schools' inspector with the teacher sample and the semblance of power that may exist. As a result, it was decided to introduce myself as a doctoral research student who has a brother with WS and who had experience of teaching a child with WS. I did not present myself as a schools' inspector as it was not relevant to the interview. I was unaware if the teacher participants knew about this aspect of my positionality and it did not come up in conversation with the teachers. However, in one case I was the inspector for the school and the already established relationship supported an open and, what appeared to be, honest discussion. For the children, I made references to the shared experiences we had to date through the WSAI, prior to commencing the interview.

Ethical implications were informed by formalised, institutional procedures including the British Educational Research Association (BERA) (2004) guidelines. The research adhered to the University of Lincoln's ethics policy (University of Lincoln, 2004) which laid out moral and ethical principles to guide the research decisions. An ethical approval application (Appendix L) was submitted and approved. This highlighted the ethical issues and possible risks and harm associated with the research. Guidelines indicating good ethical practice were included on brochures given to adult participants (Appendix B and H). This outlined the scope and purpose of the research, their rights as participants, including the voluntary nature of their involvement and permission to withdraw from the study at any point (Silverman, 2010:153-4). Privacy and confidentiality were assured (Punch, 2009), the proposed length of the interview was indicated and the participants' had the right to choose when and where the interview should occur (Flewitt, 2005). Considering the nature of the research, which centres on the educational inclusion of children with WS, there were a number of issues regarding harm and risk. The sensitivity around feelings of guilt or inadequacy in parents and teachers was of concern and indicators, such as non-verbal cues where participants' eyes watered, where their faces showed strain or where they wrung their hands, were

monitored throughout the interviews. Where such signs emerged, further probing into the particular issue was abandoned. During one interview a mother cried and asked for the recording device to be switched off. After a short period in which we shared experiences of having a family member with WS, this mother suggested the interview be continued. At this point her permission was again sought regarding the recording of the interview.

The inclusion of children with WS in the research posed considerable ethical issues. Sensitivity is required when involving vulnerable populations (Creswell, 2007) not least due to their openness to persuasion, influence and, hence, harm (Hill, 2005). This has led to researcher concerns around vulnerability which has traditionally reduced the involvement of children with SEN (Clavering and McLaughlin, 2010). A transformative approach vehemently supports the inclusion of the marginalised. Reasonable ethical accommodations were made to ensure the children could participate. This included appreciating the rights of the participants to take part or to withdraw at any time (as happened with two children), having their dignity maintained (by not finding their answers incredulous or funny), being treated fairly and being protected from harm or discomfort (Hill, 2005). This was maintained at all times and supported by having each child's mother present through the interview. The interview was made relevant to the children and the language was adapted to suit the linguistic understanding of the child (Punch, 2009). This was done by using short sentences (to facilitate poor working memory), expression (which people with WS find particularly engaging), a limited vocabulary (to facilitate the child's intellectual capacity) but without necessarily avoiding 'big' words (which is attractive and engaging to people with WS). Every effort was made to reduce any anxiety which may present during an interview. The children were not pressurized into answering any question and where they had difficulty completing a sentence they were given time to process the information and given the option of moving on and coming back to it later if they wished. The use of resources such as finger puppets reduced the formality of the interview. This was used in some, but never for all, of the interview. It proved most effective where attention was waning. Similarly, a microphone was produced with which they could speak into which appealed to the dramatic nature of two of the children (again for parts of the interview). Finally, a bag of manipulatives containing a peg board, pencil and paper, felt shapes, playing cards and a geoboard were also made available to allow the children to engage in conversation while having their sensory needs met, to support their distractibility and to reduce any social anxiety that an interview situation may induce. They contributed significantly to the participation of the children. In addition, the research setting (the child's home)

helped to reduce the child's inhibitions which may otherwise limit the amount, value and validity of what they say (Hill, 2005).

Positionality

As stated in Chapter One, I consider myself an 'intersection' researcher, simultaneously being both insider and outsider. There is now a greater appreciation of 'insider' research in disability studies, promoted by those with a relationship with individuals with SEN (see Byrne, 2000; Kittay and Carlson, 2010). Insiders have the benefits of 'speaking from a place of proximity…thereby closing the gap between theory and practice' (Carlson, 2010:59). I have the benefit of such proximity having a brother with WS. I have seen the strengths and challenges both of the condition and of his educational placement. As an insider I am also a member of the WSAI since 1997. All families in this research were known to me, implying trust and understanding in our relationship. We have had many shared experiences which made it easy to discuss sensitive topics connected to the child's life. However, there were also challenges: the researcher must remain vigilant of over-engagement with participants as insider researchers are at risk of subjectivity and bias (Mertens, 2009). I also felt it inappropriate to ask the parents about their own education or socio-economic status, which are common contextual questions in qualitative research, thus, being an insider also had limitations.

My outsider position was defined by not being a parent. I have not had the responsibility of decision-making regarding education or other significant aspect of my brother's life. This position allowed me to be, perhaps, more objective of parental roles in their child's education as I have frequent discussions, and indeed arguments, with my parents regarding my brother's ongoing skill development. It has certainly made me very aware of my subjectivity. My position as an 'intersection' researcher presented a unique positionality. The parents appeared very happy to have an 'insider' to talk to and they asked many questions regarding my brother's educational experience, his lines of development and his outcomes. Interestingly, they did not ask for advice from an educationalist perspective showing they viewed me more as an insider than an outsider.

My profession creates a similar insider/outsider dichotomy. As an insider I am a primary-school teacher who has taught a child with WS and knows the WS learning profile, as well as the benefits of, and barriers to, educational inclusion. I am also very familiar with the Irish educational system and best practice in special education. However, I am no longer working as a primary-school teacher, but as a schools' inspector, which highlights an outsider position. The teacher participants caused a

degree of concern as I did not wish to emphasise my current 'outsider' position. This could have led to significant power issues in the interview which would have been detrimental to the responses of the participants and may have caused them anxiety and unease. It raised ethical questions which were discussed with a range of people. It was decided to focus on my experiences as a teacher but should any participant ask about my current job I would openly talk about my position as schools' inspector but this did not arise. My experiences as a teacher allowed me to give examples of personal classroom challenges, particularly around meeting needs of individual pupils. For the teacher participants I was careful not to ask questions which would appear to query their approaches, their treatment of the child or their understanding of the child's needs. For more sensitive issues I could probe using my own experience as a means of appropriately phrasing questions. Once again, the engagement felt comfortable and all teacher participants asked questions regarding the practices of other teachers of children with WS. The teachers in all cases treated me as an insider and like the parents asked a variety of questions relating to my brother's educational experiences, particularly regarding adult outcomes. The result is that each teacher expressed an interest in establishing a teacher-support group and wished to get copies of the research results to help inform their practice.

Conclusion

This chapter presented the methodological approaches used in the research. It began with an explanation of the interpretive-transformative philosophical underpinning of the study and its influence through all stages of the research design and implementation. Both approaches value the relationship between the researcher and the researched, and the perceptions and experiences that both bring to the research. Including the children with WS was a central tenet of the research, and was influenced by the researcher's positionality. As with many recent studies on SEN, a psycho-medical model was rejected in favour of an inductive approach. A small-scale study was undertaken, reflecting many other studies into WS, to ascertain the current situation in Ireland regarding the educational inclusion experiences of children with WS, their parents and teachers. While a convenience sample was used from those registered with the WSAI only seven families were available and willing to be part of the study. This is a highly representative sample (29%-44%) of the possible number of children with WS of primary-school age in Ireland. It was decided that the interview would be the most appropriate form of data collection; to this end a structured interview with the children was devised and a semi-structured interview with both the parents and teachers was prepared, piloted and finalised. The chapter outlined the approach to

data analysis and the challenges of using documentary evidence as part of the evidence base, which was abandoned. There were a number of ethical considerations connected to the sample and the researcher positionality which were discussed. With the approaches to the research explained, Chapters Four, Five and Six present the findings from the interviews with the parents of children with WS, the teachers and the children themselves. These chapters expound the answers to the research questions and give unique insights into the experiences of each of the stakeholder groups regarding the educational inclusion of children with WS in Ireland.

CHAPTER 4   EDUCATIONAL INCLUSION OF CHILDREN WITH WS: PARENTAL EXPERIENCES

Introduction

This small-scale, exploratory study sought to examine the experiences of parents, teachers and children with WS regarding the educational inclusion of children with WS in Ireland. This chapter portrays the findings from parents' semi-structured interviews. As stated in Chapter Three, parents of all seven children were interviewed. In two cases, both mother and father participated; for the remainder, mothers only were interviewed (see Table 3.1 for details). Discussion with parents centred around the following issues:

1. How do parents perceive the educational profile of their child?
2. What determined parents' choice of educational placement?
3. How satisfied are parents with their child's educational placement?
4. How do parents support their child's learning?

Perceptions of Educational Profile

The framework for presenting parents' perceptions of the WS educational profile combines the coherent structure used by Semel and Rosner (2003) to describe WS behavioural patterns with the educational focus of Udwin et al. (2007) in their guidelines for teachers, as seen in Figure 4.1 below.
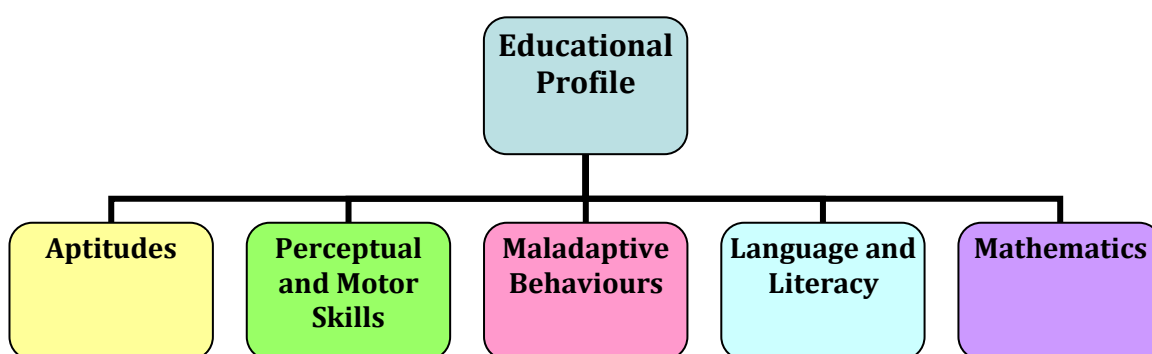
Figure 4.1: Educational profile of children with WS in Ireland: parental perceptions (adapted from Semel and Rosner (2003) and Udwin et al. (2007))

When discussing their child's educational profile, a number of themes emerged from parents. All parents described aspects of aptitudes, perceptual and motor skills, maladaptive behaviours and language/literacy. Six parents also discussed mathematics. Each theme and associated sub-themes from the educational profile is presented in detail below.

Aptitudes

As outlined in Figure 4.2, the main aptitudes identified by parents were sociability, curiosity/special interest, memory and musicality, reflecting those described by Semel and Rosner (2003).

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                        ┌─────────────────┐
                        │    Aptitudes    │
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         ┌───────────────┬──────┴──────┬───────────────┐
┌────────────────┐ ┌────────────────┐ ┌────────────────┐ ┌────────────────┐
│   Sociability  │ │ Curiosity/ Special │ │     Memory     │ │   Musicality   │
│                │ │    Interest    │ │                │ │                │
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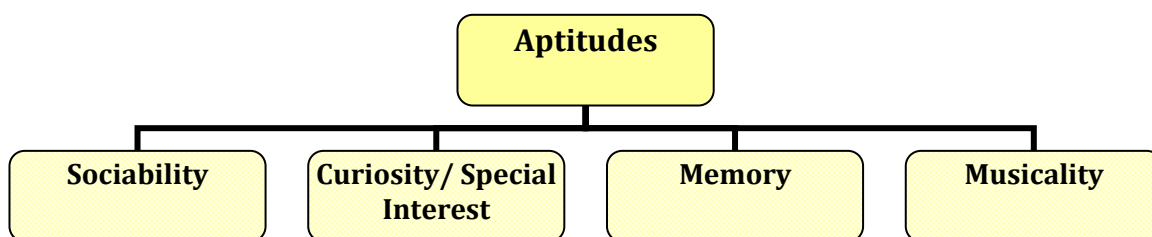
Figure 4.2: Educational profile of children with WS in Ireland: parental perceptions of aptitudes

Sociability was an area of evident parental pride. Some parents described skills beyond extroversion and friendliness, to an ability to read the emotional state of others and a genuine concern for others: '*When he started in the school, any of the kids that fell and hurt themselves, he'd go over and try to console them*' (Dean's mother). Plesa-Skwerer and Tager-Flusberg (2006) similarly described an empathic capacity in individuals with WS. Yet, this strong social impulse was also a concern identified by five parents: *If someone caught her eye (…) she'd nearly make her way over to talk to them. If she was looking at them and they looked at her she would strike up a conversation with them* (Emma's father). This over-friendliness, with no fear of strangers, appeared no more prevalent in younger than in older children, echoing findings by Jones et al. (2001) that adults with WS have much higher ratings of approachability to strangers than typically-developing peers, or mental-age matched cohorts.

Along with sociability, all parents also referred to the aptitude of curiosity or special interest for their child, which included music, farming, trucks, babies and animals. This showed the heterogeneity of the group, reinforcing the necessity of a transformative research approach. Three parents explained the value of special interests in devising learning strategies for their child, also suggested by Dykens et al. (2000).

Another aptitude identified by six parents was their child's auditory memory: the ability to remember words, phrases, rhythms, melodies and songs, in both English and other languages.

> *The big words! We do be laughing at the big words he comes out with 'cause we don't know where he heard them. He can put them together, he knows where to put the big word, course he can't even do the small words but he can do the big word [confused look]* (Charlie's mother)

This supports previous studies which indicate good phonological memory (Vicari et al., 1996) and verbal memory (Mervis, 2006). It is described in more detail under language. Parents related this auditory memory to their child's musicality.

Musicality, a defining characteristic of WS (Levitin and Bellugi, 2006; Sacks, 2007), was also described by six parents. Three parents identified instances where melodies or rhythms increased the child's engagement in, or comprehension of, tasks, similar to reports by Lenhoff (2006). Music also impacted on the child's mood: '*once he has something with music, that he has some kind of music going in the background he is 100% happy*' (Fred's mother). Furthermore, music was reported to enhance the development of the child's challenges, particularly with perceptual and motor skills, as previously noted by Reis et al. (2003).

Perceptual and Motor Skills

A number of sub-themes emerged regarding perceptual and motor skills (see Figure 4.3). These included visuomotor performance (incorporating gross-motor skills, fine-motor skills, and adaptive-living skills), auditory sensitivity and tactile sensitivity. However, where Semel and Rosner (2003) described visuospatial domains as part of visuomotor performance, this did not emerge strongly from the parent data and so is not presented. At the time of this research, all seven children were availing of occupational therapy due to challenges with perceptual/motor skills.
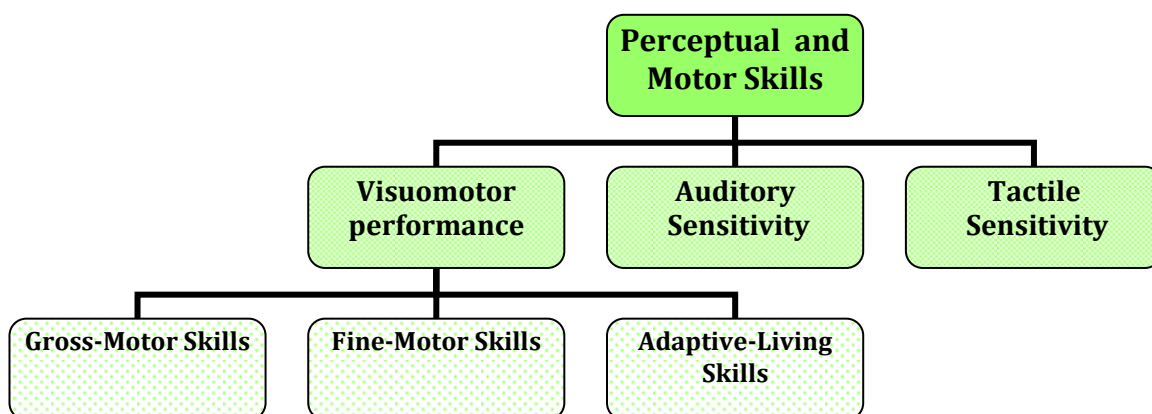
Figure 4.3: Educational profile of children with WS in Ireland: parental perceptions of perceptual and motor skills

Parental perceptions of visuomotor performance revealed strong gross-motor skills for five children, while fine-motor skills presented challenges for all seven children. Brian's mother described the delight when he learned to cycle at the same time as his peers: '*one day he just hopped up on the bike and took off with no stabilizers and he flies around on the bike. I never thought he ever would'.* This stands in contrast to all previous reports of gross-motor challenges in WS, including that by Udwin et al. (1987) in the UK, whose data was also gathered from parental interviews. However, the fine-motor challenges described by parents correlated with Bellugi et al. (1988b) and Dykens et al. (2000). All parents described their child's writing difficulties. It was an area that appeared to improve slowly, but remained an issue for even the oldest children. Despite these difficulties with fine-motor skills, Gillian's mother told of her

child's ability to play the violin; thus, highlighting scope to develop skills through interests. Similar to handwriting, all parents noted their child's challenges with adaptive-living skills, such as dressing and toileting which concerned them most when their child started school. They feared its impact on the child's acceptance, particularly in mainstream settings. Greer et al. (1997) described moderate adaptive delay in children with WS, linking it to challenges with visuo-spatial functioning. Parents did not allude to this link.

Despite evidence of musicality in WS, difficulties with auditory sensitivity were described by five parents. They highlighted their child's unusual sensitivity to sound (hyperacousis) and fears around sounds, although this decreased with age in three of the five cases. This is much lower than the 90.6% of people with WS in America reported by their parents to have auditory fears (Levitin et al., 2005). Furthermore, five of the children in the current study were reported by their parents to get upset by, or react to, certain words or tones of voice. According to Gillian's mother '*it ignites something*'. This is not apparent in international literature on auditory sensitivity but connects with studies on anxiety where 'arguments' cause anxiety for individuals with WS (Dykens et al., 2000; Scheiber, 2000). The findings from the children with WS in this study support this (see Chapter Six).

The children's tactile sensitivity was spontaneously mentioned by six parents, where it was identified as either a stressor (for four children), or as a strategy to reduce stress (for three children). One child had both tactile-seeking and tactile-defensive tendencies. The feel of certain textures or touches caused extreme tactile defensiveness for some children:

> *If I took off his socks and put him on the grass. Oh! Oh! He wouldn't like it. […] He won't even walk around the floor with his socks off, won't go around in his bare feet at all, <u>at</u> <u>all</u>. Refuses. Toes will curl up and every-thing* (Charlie's mother)

Considering the tactile sensitivity variation in these children, it should be explored for individual children with WS as it may contribute to maladaptive behaviours; Riby et al. (2013a) recently found sensory-processing abnormalities correlated to repetitive behaviours in children with WS.

Maladaptive Behaviours

Maladaptive behaviours are consistently associated with WS (see Tomc et al., 1990; Davies et al., 1998). All parents interviewed agreed that their child had high levels of both distractibility and anxiety, and six of the seven parents reported over-activity. Other less frequently reported maladaptive behaviours (not described below) included impulsivity, poor adaptability and low frustration levels, all of which form part of Semel

and Rosner's framework (2003). The presence of specific behaviours, as shown in Figure 4.4, is significant as it may indicate areas for which additional resources could be provided for children with WS within the current Irish mainstream educational system.
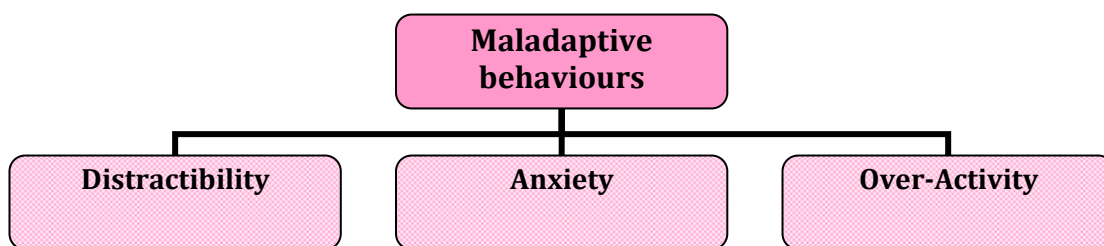
Figure 4.4: Educational profile of children with WS in Ireland: parental perceptions of maladaptive behaviours

Distractibility, identified by all parents, greatly concerned them due to its impact on their child's educational participation and progress: '*if we got ten or fifteen minutes out of him at a stretch we'd be doing well. Yeah. We might do it [homework] in two different bits, reading just before bed or something and do the writing earlier'* (Brian's mother). Indeed, it is one of the most prevalent maladaptive behaviours cited in the literature (see Dilts et al., 1990, Udwin and Yule, 1991). Yet, distractibility issues contrasted sharply with parental reports of absorption in certain activities for prolonged periods. Annie's father draws the contrast: '*she'd sit down on the floor now sometimes and do a jigsaw […] If you can get her at the right thing she could spend an hour or two'.* Udwin et al. (2007) negatively describe this trait as 'preoccupations and obsessions', while Semel and Rosner (2003) refer to it as a 'special interest', as in this research. Both groups of researchers, however, recommend using the child's interests to reduce distractibility. The findings of the current research indicate that distractibility in WS may relate to anxiety, although this is not widely discussed in the literature.

All parents identified specific fears or generalised anxiety in their child as another maladaptive behaviour. For six of the children, daily anxiety related to anticipation, separation, perceptual and motor challenges, or loud noises, which frequently impacted on behaviour as previously indicated by Einfeld (2005). Brian's mother described the connection: '*terribly anxious coming home sometimes, can't really separate very well from his friends. Like he'd cry all the way home or he'd, you know, he'd be howling or he'd run after someone's car'.* Two parents identified school assemblies as triggers for their child's anxiety (due to the risk of clapping), and this fear of loud noises prevented their participation in other school activities. Anxieties may be masked by the child's sociability as Brian's mother describes: '*they are so pleasant really to look at, and they look happy, and they're sociable people; you might think they're grand, whereas actually the child is trying to keep it all together'.* This profile contrasts sharply with reports by Howlin and Udwin (2006) that anxiety appears in late teens to early

adulthood, based on a parental survey in the UK, but mirrors findings by Dykens et al. (2000) that 96% of a sample of both adults and children with WS have anxiety-producing fears. Most recently, Riby et al. (2014) found, through parental surveys, that levels of anxiety in WS correlate to severity of social dysfunction, which the findings of the current study support.

Another maladaptive behaviour described by six parents was the over-activity of their child. Two children had a diagnosis of ADHD, but in four cases it was more subtle, such as needing little sleep. This description of over-activity is much lower than the 67% of children with WS reported by their parents to be at the 98th percentile or higher on a hyperactivity rating scale (Dilts et al., 1990). Udwin et al. (2007) recommend the use of self-talk as a strategy to improve over-activity, which has obvious links with the child's language skills.

Language and Literacy

While it is acknowledged that literacy incorporates language (DES, 2011), it is useful to discuss language separately from other literacy activities, as it is a much researched aspect of the WS profile. The language profile of individual children with WS from this study was varied. Data from parents revealed inconsistencies around good speech articulation and fluency (reported for three children), and wide vocabulary (reported for three children). This contrasts sharply with other researchers who highlighted excellent basic vocabulary (Dykens et al., 2000) and fluent speech by school-age (Lukács, 2005). The areas of consistency, from this research, were strong links between language and musicality, language and sociability, and language and behaviour (see Figure 4.5).
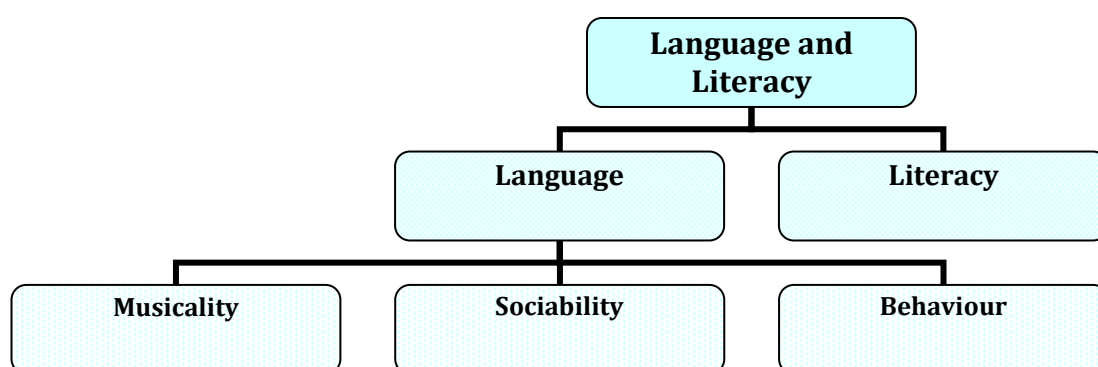
Figure 4.5: Educational profile of children with WS in Ireland: parental perceptions of language and literacy

The link between language and musicality emerged where two of the seven children with low levels of speech, frequently one-word utterances, could sing longer sentences. The 'musicality' of language also appeared to be motivating. The ability to remember words and phrase was reported by six parents, although three parents felt that despite this aptitude, comprehension was frequently masked, in line with findings by Lukács

(2005). Furthermore, four parents described their child's ability to remember words and phrases in both Irish and other languages, and the child's incidental use of these languages at home: '*from day one he was coming home from school speaking Irish phrases (…) like if somebody was out he'd say 'Rory wasn't in today b'fhéidir go bhfuil sé tinn' [perhaps he is sick]*' (Brian's mother). This indicates children with WS can benefit from second and additional foreign language learning. However, this aspect of language is only alluded to by Semel and Rosner (2003); there are no published studies on this aspect of the WS language profile.

The only aspect of language reported for all seven children related to language pragmatics, specifically language use in communicative contexts. This was connected to sociability. Six parents described their child's strong ability to initiate and engage in conversations, correlating strongly with the literature (Klein-Tasman and Mervis, 2003; Plesa-Skwerer and Tager-Flusberg, 2006).

Conversely, no strong profile of communication difficulties emerged, although four parents reported their child's difficulty expressing negative emotions (linking with the children's data) which triggered behavioural difficulties:

> *sometimes she finds that hard, to express that herself, you know,*
> *how she's feeling. You know, if somebody is rude to her, if some-*
> *body slaps her em …(…) she gets a bit upset, and shouts out and*
> *gets herself in trouble for shouting out* (Gillian's mother)

This link between behavioural problems and poor expression of negative emotions is not emphasised in the literature, although Semel and Rosner (2003) make brief reference to it. It may give new leads on behaviour management in children with WS.

Besides language, another aspect of literacy referred to by parents was reading, an area of much progress. All but the youngest child was reading to some degree. Six children responded favourably to phonological-awareness training, as part of emergent-reading programmes. However, five parents indicated their child learned to read using this approach combined with a whole-word approach. All previous research recommends a phonetics approach to reading over whole-word approaches (see Udwin et al., 2007; Mervis, 2009). Despite this apparent success with reading, some parents perceived comprehension difficulties. It frequently was not identified for several years, due to the focus on decoding words in junior classes, a common trend for children with learning difficulties (King, 2006). Emma's mother describes this:

> *Emma when she's reading appears to be a very good reader, but when*
> *it comes to asking her questions or actually understanding what she's*
> *reading then I would say she has difficulty with that. It's the comprehen-*
> *sion … any one listening to her will think My God she's really good but*
> *ask her then in five minutes to tell them what the story is about, she*
> *won't have that*

This difficulty has previously been presented by Howlin et al. (1998), Laing (2002), and Mervis (2009) in both adults and children with WS.

Mathematics

The last sub-theme of the WS cognitive profile which emerged was mathematics (maths), alluded to by all but the parents of the youngest child as a difficulty, with three claiming it to be their child's greatest academic challenge: '*She gets her own version of maths [for homework] the maths'll probably take the longest time depending on just what they're at. […] That would be her, we'll say her biggest area*' (Emma's mother). Number recognition appeared to come easily but the underlying concepts of number conservation and operations took longer. Udwin et al. (2007) indicated that poor perceptual, visual-spatial and motor problems affect the ability to manipulate numbers and structure mathematical operations. More recent research (O'Hearn and Luna, 2009) has shown a truncated developmental trajectory in maths in line with the neurological framework associated with WS.

Overall, the educational profile described by parents of children with WS shows strong consistency with that described by Semel and Rosner (2003) and Udwin et al. (2007). This shows parents hold accurate understandings of their child's needs, which has implications for the educational placement they choose for their child.

Choice of Educational Placement

The seven parents in this research chose different educational placements for their child with WS: four chose mainstream settings, two special schools (including one child who spent her first year in mainstream awaiting a special-school placement) and one a special class. This shows a move towards mainstream settings over special settings when compared to placements attended by older individuals with WS in the UK (see Udwin et al., 2007) and in Ireland (see Tynan, 2010a). This move reflects inclusive educational policy. Similarly, a US study found that 40% of parents of children with WS chose special settings for their child's (Fidler et al., 2002) but the authors did not indicate what influenced parents' decisions.

This study identified factors influencing parental choice of educational setting. They primarily concerned factors relating to school type (mainstream or special) and then to the actual school. School-type factors were the results of psychological assessments, parental attitudes to different educational settings, the child's needs and available placements. Parents' choice was subsequently determined by school structure, supports, and school leadership which encompassed the principal's attitude to SEN (see Figure 4.6).
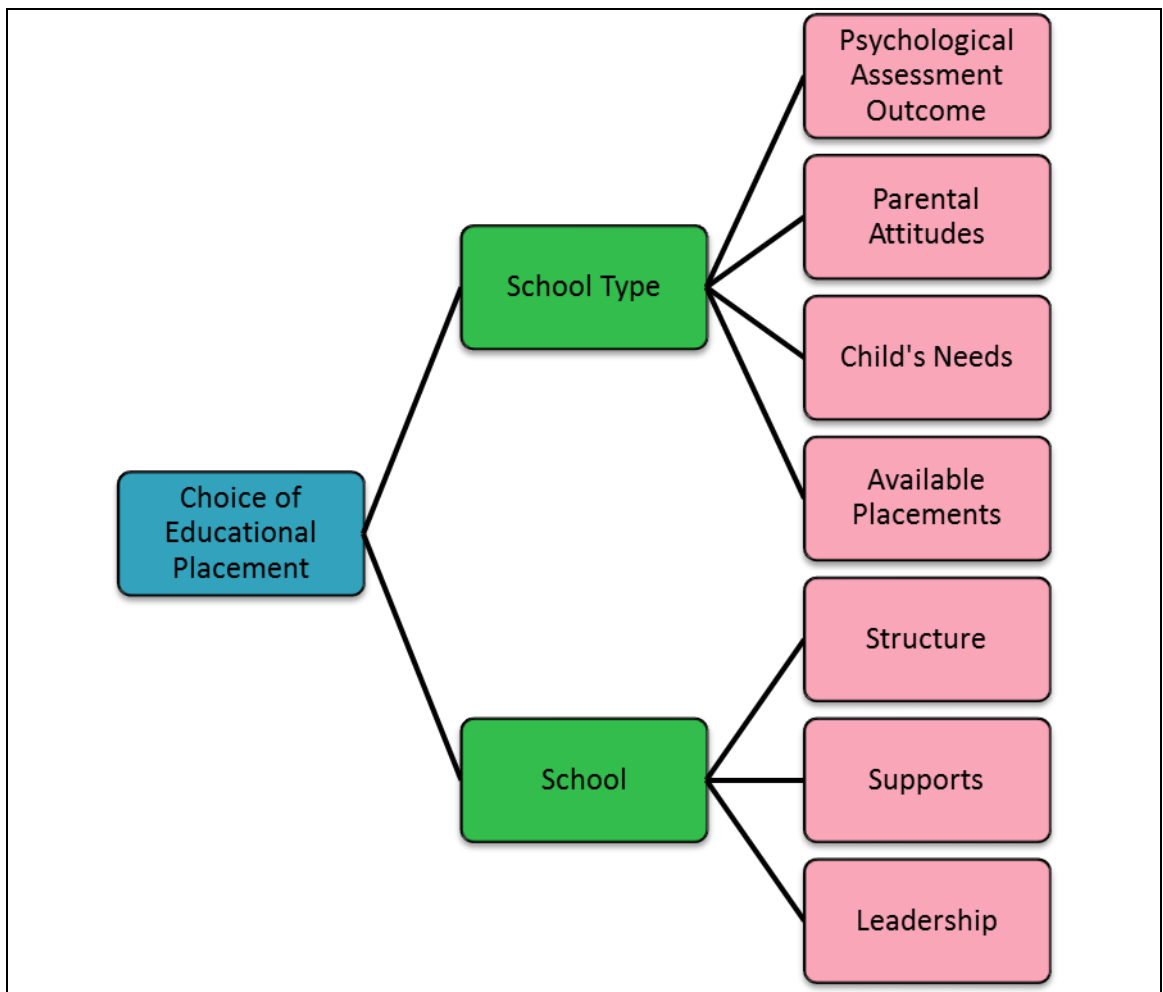
Figure 4.6: School placements of children with WS in Ireland: factors in parental choice (2012)

A psychological assessment, indicating the child's cognitive ability, initiated the decision-making process for five parents which was also the first step identified by Udwin et al. (2007). However, three parents reported psychological assessments were altered based on parents' preferred placement, adding to the stress of decision-making: *'…I thought that was a bit dodge [dodgey]…there was sort of two reports done, one for the mainstream and one for the special school'* (Gillian's mother)*. This raises issues regarding resource allocation in mainstream. As Annie's father indicated '*You have to be able to sound as bad as possible*' to maximise the child's resources. Where assessments were adapted to suit the intended placement, parents had to choose special or mainstream prior to selecting the actual school. Parental attitudes were, therefore, pivotal. Three of the four children in mainstream placements were 'eligible' for special settings, yet two of these parents neither considered nor visited any, contrary to advice. This suggests reluctance regarding special settings and preference for social inclusion. However, social inclusion was explicitly referred to by only two families (neither of whom visited a special setting when choosing a school for their child) but it was implied by the other two parents who chose a mainstream placement. It connected to parental attitudes to SEN, reflecting their inclusive view of education:

'*we just probably would have just preferred her to go there [mainstream] and see how she gets on and maybe not to isolate her … (…) at least be given the chance to mix among we'll say the local kids*' (Emma's mother). Annie's mother also valued peer inclusion, but furthermore, highlighted possibilities of moving from mainstream to special, but not vice versa: '*we thought she'd be better off going with her own pals you know that she's used to, and em, we just thought it's easier go back than go forward if she started off in a special school'.* This indicates a perceived inflexible inclusion continuum, being primarily one directional. Charlie's mother believed special classes provided the ideal solution, with specialised provisions and scope for mainstream inclusion:

> *He's in and out to the room, mainstream, now maybe five times a day.*
> *He goes down for his reading which is brilliant like. And I think he's*
> *learning more […] I think it's good that they have their own little private*
> *bit and I think that it's very good that they're in the mainstream as well*

Children's needs further influenced parental attitudes. Two of the three families that chose special settings based their decision on their child's care needs. Fred's mother explained how this limited their options:

> *I knew Fred wouldn't be able for mainstream school. I mean it was*
> *obvious, he couldn't talk, he wasn't toilet trained, he couldn't eat […]*
> *there was absolutely no way he could have gone into mainstream*
> *school, so it really wasn't a choice for us.*

Concurrent with trends towards mainstreaming, two parents were discouraged by professionals, such as psychologists, from choosing special settings. One of the two families who chose a special school could not secure a placement for their child without political intervention, so choice was also determined by the availability of special placements. However, this is less than the 66% of parents of children in Irish special schools who had difficulty accessing placements (Armstrong et al., 2010), although the sample sizes are not comparable. Overall three of the seven families in the current research had difficulty accessing a placement (mainstream or special), higher than the 20% cited by Armstrong et al. (2010).

Once parents knew their child's ability and available options, they chose placements based on school structure, supports and school leadership. Five of the seven families did not choose their local school, reflecting the decision's complexity: '*It was a very hard decision what to do with him…because I was saying am I doing right or am I doing wrong?'* (Charlie's mother). Five families visited at least one school beforehand to inform their choice, though not necessarily a special setting. Two parents felt smaller schools were better, while Annie's parents felt the associated multi-grade classes in small schools would be distracting: '*I suppose some people were saying it's better maybe em…a country school where she'd get more individual attention, (…) but I was*

just thinking in my own head no, because they're all different levels…she'd be just too distracted herself'. Two parents correlated larger schools to better supports: *'cause it was that bit bigger I reckoned they might have better facilities' (Brian's mother).*

Parents who chose special settings perceived inadequate mainstream supports or enhanced supports in special settings, as Gillian's mother explained: '*[the psychologist] said she'd be able for [mainstream] with support, but the supports aren't there. They tell you they are and they're not'.* Supports were also highlighted by parents of children with mild/borderline GLD, who do not qualify for automatic resource hours in mainstream (see Chapter One). Over time (sometimes several years) all four children in mainstream acquired resource hours, sometimes by parents seeking other diagnoses. This highlights the need for automatic resource entitlement based on the child's needs at enrolment. One parent linked available supports to the quality of school leadership. Indeed, the principal's attitude to SEN was a factor for three of the five parents that chose mainstream schools or a special class. Annie's mother was very animated in her description: '*He wasn't fazed like that she had it [WS] or anything…and no big major huge issue about having her'.* Two families experienced negative principal attitudes at enrolment. Dean's mother described this negativity: *'I'm not sure if this is the ideal school for him, but' [the principal] said 'I can't refuse him'. I climbed into a shell in that meeting … we came out of there feeling very low'.* Brian's mother described a similar experience:

> *I found it impossible to get the principal to arrange a meeting or even return my calls, this was over a period of a year or more. The secretary would always say it was a bad time, too early in term, too late in term, too busy etc. Eventually after being refused a place the first year…I doorstepped the principal … Her reception was reluctant and then frosty*

The fact that two of seven families were strongly discouraged from enrolling their child in mainstream schools highlights the irony of equating the term inclusive settings with mainstream placements. These findings are not isolated cases. They mirror assertions by Rose et al. (2010) that soft barriers to enrolment exist in Irish mainstream schools, despite inclusive educational policy.

There are no previous studies on the factors influencing parental choice of school for children with WS. It is clearly a difficult decision which was two-tiered: placement type followed by the actual school. The drive towards 'inclusive education', prominent in Irish educational policy, has resulted in a situation where demand for special placements appears to exceed supply, thereby reducing parental choice. At the time of the research, six of the seven children had remained in the school in which they first started; this indicates parents' satisfaction with their choice of educational placement.

Satisfaction with Educational Placement

All parents were satisfied with their child's educational placement. Despite differences in placement types, there were commonalities in the factors that influenced their satisfaction. Figure 4.7 shows the themes and sub-themes that emerged, centred around the child, the child's teacher and the school.
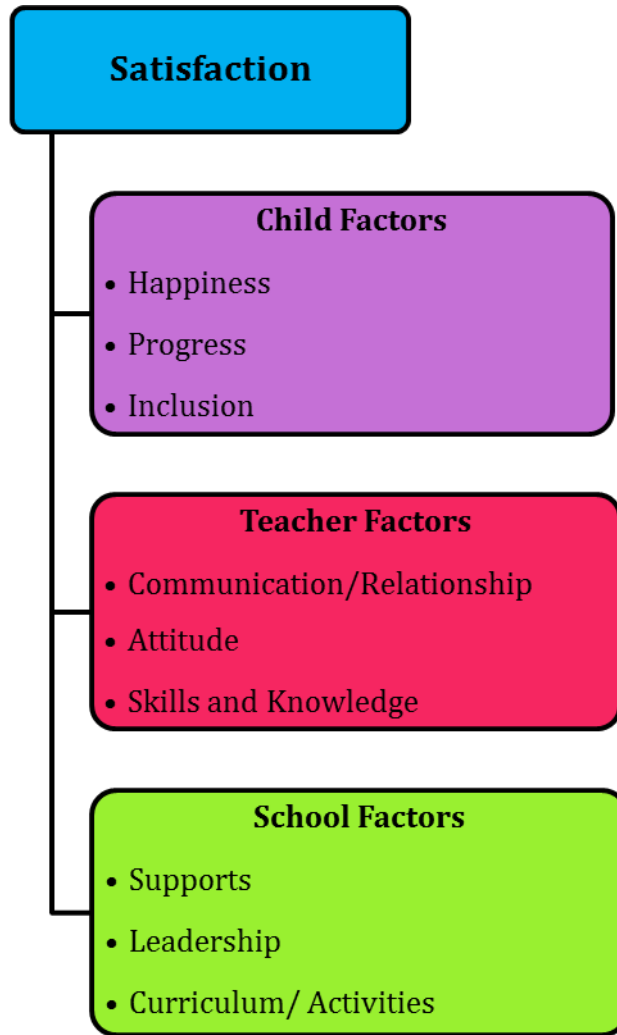
Figure 4.7: School placements of children with WS in Ireland: factors in parental satisfaction (2012)

Parental satisfaction was more influenced by child-related factors including their child's happiness, progress and inclusion (see Figure 4.8) than by teacher-related factors or school-related factors.
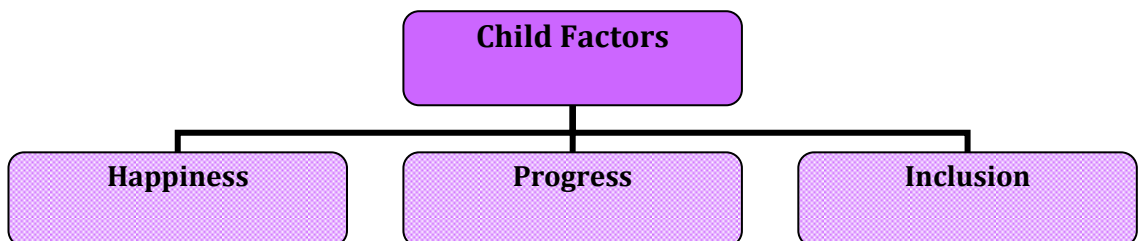
Figure 4.8: School placements of children with WS in Ireland: child factors influencing parental satisfaction

Parents were obviously very satisfied where their child was happy at school. This was referred to by six of the seven parents: *'She's happy in herself so that's probably the priority'* (Emma's mother). Six parents also expressed satisfaction where their child was making progress. This level of satisfaction is higher than the 78% of Irish parents of children with SEN who believed their child was making adequate progress in line with his/her ability (Armstrong et al., 2010). However, it contrasts sharply with Scallan et al. (2011) who found that nine of 21 parents in the WSAI felt their child had not reached his/her academic potential at school.

The child's inclusion also influenced parental satisfaction, but this was complex as different interpretations of inclusion were evident. For one parent, inclusion meant doing similar school work to class peers, regardless of its appropriateness to the child's needs. All five parents of children in mainstream settings or a special class expressed satisfaction with their child's social inclusion. Annie's mother emotionally described it: '*I was delighted because you know normally up to now it's just been birthday parties you know and the whole class would be going anyway but this little fella wants her over [for a play date]'.* Similarly, Charlie's mother, describing the special class, spoke positively about her child's increasing inclusion with mainstream peers for academic lessons. By contrast, Fred's mother regretted her son's lack of opportunity in a special school: '*in an ideal situation now I'd love to maybe have Fred in [his school] maybe four days a week and one day a week have him in mainstream'.* The literature produces equally contrasting findings. Shevlin et al. (2003) claim that children with SEN benefit from mainstream inclusion in Ireland, but Ring and Travers (2005), in their observations of a child with DS in an Irish mainstream school, found social inclusion to be difficult without targeted interventions. Yet other interpretations of inclusion were evident. Gillian's mother described the special school's approach to developing life-skills, thereby enhancing her daughter's long-term inclusion in society. By contrast, Emma's mother did not see teachers having a role in developing her child's inclusion, feeling her locational integration was adequate: '*she's never going to be we'll say real buddy buddy probably to the same extent as the other children, but she'll still have a little bit of a mix, or at least be given the chance to mix among we'll say the local kids'.* Similarly, this mother did not expect the teachers to adapt their programmes, activities or approaches for her child: '*there was never an individual education plan, it was always kind of em…you know, we'll go with the normal curriculum'.* This aspect of the findings supports observations by Whitaker (2007): parental satisfaction does not necessarily mean that the child's needs are adequately met.

While child-related factors were prominent in determining parental satisfaction, teacher-related factors were also significant. They included communication and relationships, teacher attitudes to SEN, and teachers' skill and knowledge, as seen in Figure 4.9.
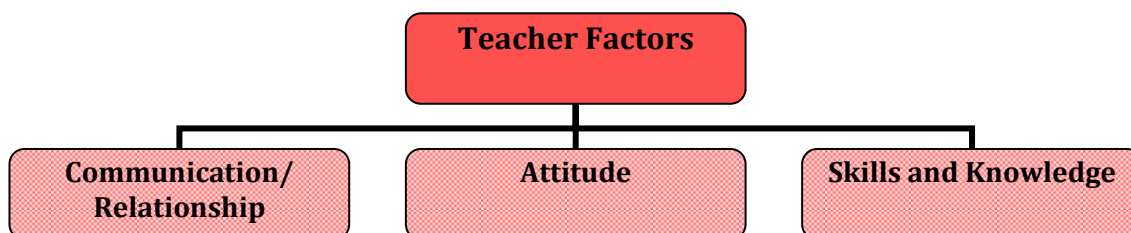
Figure 4.9: School placements of children with WS in Ireland: teacher factors influencing parental satisfaction (2012)

All parents referred to positive home-school relationships and open communication as impacting on their level of satisfaction.

> *Charlie's school is absolutely brilliant (laughs) brilliant, brilliant school. I couldn't praise it enough. It's brilliant […] I feel very valued […] I have a great relationship with the teacher […] I bring him in every morning and I go in and get him every evening and we talk about what he's done during the day* (Charlie's mother)

Four parents described the use of communication logs to share information between home and school but only one parent described quality communication through the IEP process. Two parents (both with children in special schools) explained that communication and positive home-school relations were teacher dependent and varied each year. Thus, satisfaction levels were subject to change. An Irish study identified home-school communication as significant in improving the experiences of parents of children with SEN (Armstrong et al., 2010:83) and communication logs are cited as models of good practice (see Elkins et al., 2003). However, poor whole-school approaches, evident where factors such as home-school communication are teacher dependent, are barriers to inclusion (Howley and Kime, 2003; Westwood, 2007).

Parental satisfaction was also influenced by teacher attitudes for five parents. They were cognisant that their child posed challenges to the teacher.

> *they're really very patient with him and they have had a very difficult year and a half with him before he was diagnosed and went on medication for the ADHD. He was biting kids, he was whacking kids the whole time and just shouting out in class…they come to me and they tell me what happened and they say 'look I know it was just compulsive and you know I just have to tell you this' (…) so you know they could, in another school, maybe react a lot more negatively* (Brian's mother).

The World Health Organisation has also emphasised the importance of teacher attitudes. Its *World Report on Disability* (WHO, 2011) states that teacher-education programmes should emphasise attitudes and values when developing the principles of inclusion.

Teachers' skill and knowledge, another teacher-factor associated with parental satisfaction, was identified by only three parents but this is important in the overall research findings. Some parents referred specifically to the teacher's SEN skills: '*Every time I collect her from school she has one of these in her hand, laminated about that size [demonstrates with fingers] 'home time' with a picture of the house. They're brilliant in there*' (Annie's mother). However, two parents did not expect teachers to have specific knowledge about WS and expressed surprise when teachers facilitated their child's academic or social inclusion. Parents of children in special settings had higher expectations of differentiated curricula and teacher skill/knowledge. The current satisfaction of Fred's mother, whose child attends a special school, was accentuated by dissatisfaction with a previous teacher's poor skill and knowledge:

> *he just hadn't a clue…he was a teacher for a mainstream school and he took the job because he couldn't get another job basically…the one he has now, she's there all her teaching career which is brilliant … she has the experience*

Both parents of children in special schools indicated that teachers frequently lacked adequate SEN skill, knowledge and experience, which negatively impacted on their child. This highlights an important aspect of special settings: teachers do not necessarily have additional qualifications in SEN. Indeed, between one quarter and one third of teachers in Irish special schools have a SEN qualification (Ware et al., 2009). Another Irish study on the satisfaction of parents of children with SEN similarly linked lower satisfaction to ineffective teaching approaches (Armstrong et al., 2010).

Alongside teacher factors, parental satisfaction was also influenced, to a lesser degree, by school factors. This included supports, curriculum/activities, and leadership (see Figure 4.10).
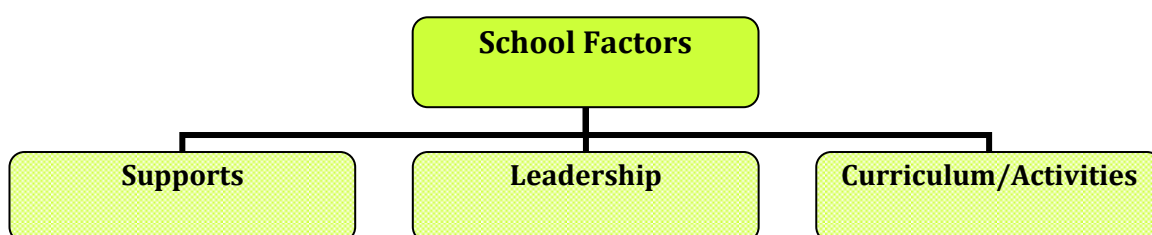
Figure 4.10: School placements of children with WS in Ireland: school factors influencing parental satisfaction (2012)

Supports came under several guises including resource hours, professional support, and SNAs. Where children with WS did not qualify for resource hours, schools supported them under GAM. Brian's mother was very satisfied with this support: '*they've given him more than half an hour a day of learning-support hours out of their general allocation (…) to do that they have to spread themselves fairly thin'.* Parents with children in special placements referred to the professional supports available

there, such as speech and language therapy (SALT), physiotherapy and occupational therapy (OT). These supports are generally not available as part of the supports in mainstream settings (Rix et al., 2009), but as Emma's mother indicated '*that was a choice that we made when we sent [Emma] to mainstream'*. Another significant resource was the SNA. All the pupils in mainstream placements had a SNA, usually full-time, but in one case shared. Pupils in special placements had access to a team of SNAs rather than being assigned one specific person. This created diverse attitudes to the SNA's role by both teachers and parents in mainstream. Three parents described situations where teachers abdicated responsibility of the child to the SNA, although two parents were not concerned by this. There appeared to be greater dependence on the SNA in mainstream schools than in special settings by parents, teachers and children. Similarly, Ware et al. (2011) found Irish mainstream teachers depended more on SNA support than on their own differentiated approaches to support curriculum access of children with SEN showing a lack of leadership within individual classrooms.

Four parents also connected the principal to their levels of satisfaction, where he/she was perceived as leading the school community, maintaining control and defining the school culture. One parent found poor leadership affected her level of satisfaction; the principal of her son's special school was not proactive in engaging pupils in certain initiatives or securing specific supports. The significance of leadership for SEN has previously been noted (Forlin, 2010b; Watkins and Meijer, 2010), and the NCSE (2013f) has called for ongoing SEN professional development for principals and deputy-principals in Ireland. Effective leadership is correlated with positive curriculum experiences for pupils (NCSE, 2011a) and affects the school culture, which in turn is linked to parental satisfaction with school placement in Ireland (Armstrong et al., 2010).

The final school-related factor impacting on parents' satisfaction was curriculum and school activities. Parents of children with WS in special settings were more likely to be satisfied due to the range of curricular experiences and activities provided than parents of children in mainstream. Activities such as dancing and swimming were viewed as being extra-curricular, despite these being mandatory in all schools. All parents of children in special settings were very satisfied with the focus on the child's holistic development, including life skills, social skills and behaviour. This was referred to by only one parent of a child in mainstream. Armstrong et al. (2010) also found parental satisfaction to be influenced by the curriculum offered to their child with SEN, although they found no differences in satisfaction for parents of children in mainstream schools and those in special placements.

It was clear from the findings that parents were very satisfied with the educational placement of their child with WS, regardless of setting. Their satisfaction was

determined by a range of child-, teacher- and school-related factors. There was some variance noted in these factors between school placements. The findings correlate with previous Irish studies on parental satisfaction (see Armstrong et al., 2010; Ware et al., 2011). Alongside high levels of satisfaction with their child's placement, parents also support their child's learning in different ways.

Supporting Learning

> *focus on their positive side because they all have a positive side,*
> *in some way or another* (Charlie's mother)

Every parent interviewed was active in supporting their child's learning. This support primarily concerned academic, physical, social and emotional/behavioural learning, as seen in Figure 4.11.
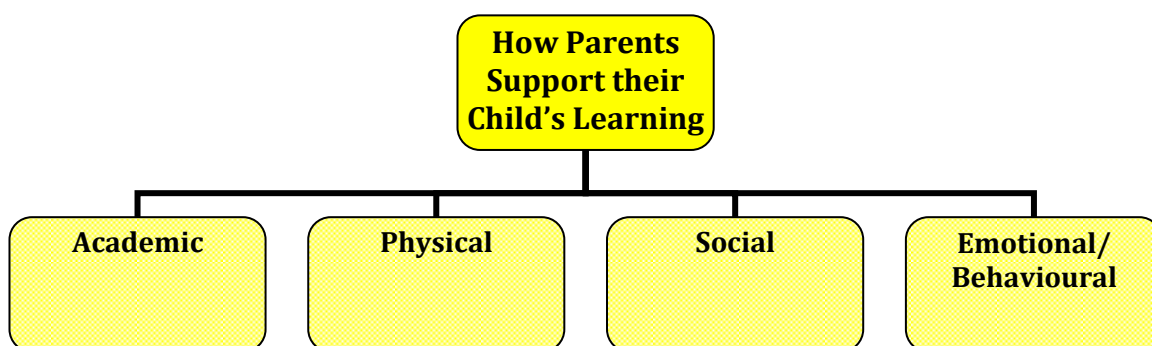
Figure 4.11: Supporting the learner with WS in Ireland: aspects supported by parents (2012)

Support for Academic Development

All seven parents supported their child's academic development by supporting the school's work: doing homework, the incidental or discrete teaching of cognitive skills, and sourcing additional supports. Homework was an activity prioritised by parents. Two parents, including Charlie's mother, indicated they did more than the assigned homework with their child. Similarly, Emma's mother works with her child through holiday periods to ensure retention of knowledge and skills. All seven parents described supporting their child's literacy (reading, writing, language and phonics) through the incidental reinforcement of skills: '*when we'd be waiting [for the school bus] we'd be looking out and we'd be saying 'I spy with my little eye something beginning with …' and we'd use phonics or colours*' (Dean's mother). These findings broaden a citing by Mervis (2009) that reading was the highest educational priority of parents of children with WS; this shows parents not only value reading, they are very active in supporting different aspects of literacy. Parents also sourced extra tuition or resources for their child including educational games, CDs, books and DES supports. Unlike other reports that children with SEN frequently got more homework than their peers (see Ware et al., 2011), this was not an issue for parents of children with WS. This in turn

facilitated parents' support of their child's learning outside of homework tasks, including the child's physical, social and emotional/behavioural development.

Support for Physical Development

All parents described supporting their child's physical development, through physiotherapy and OT appointments, through such activities as cycling, and through targeted interventions:

> *He has a John Deere go-cart … unfortunately it was quite expensive! But em it works (laughs), like he can now go, we've extended the foot-path out that side of the house so he can go around […] So to try to get him to think cos his spatial awareness is what brings him down the most* (Dean's mother)

Support was also provided through community sporting groups: swimming, rugby, football, camóige, athletics and bocce. Three children were involved in sports through Special Olympics (two of whom were in special settings). There is no reference in the literature as to how parents support the physical development of their child with SEN or with WS with which to compare these findings. It is interesting that these supports for the children's physical development also supported the child's social development in a community context.

Support for Social Development

Parents supported their child's social development through physical activities such as community sports or through organisations like Girl Guides. There were mixed reactions to play-dates and sleepovers. Six parents did not encourage them outside of birthday parties. Only Brian's mother actively sought play-dates for her son:

> *he gets invited to people's houses and I do say to parents you know he has slight issues so you know he might dash off you know, just keep the front door locked(…), yeah he leaps into the cars and goes off with them, visits and things like that, as happy as Larry!*

By contrast, Charlie's mother referred to party invitations and play-dates but did not prioritise them: '*I suppose mostly they're on a Sunday and that's probably my fault, cos I'm never here on a Sunday, I always go up home on a Sunday'.* Parents appeared to have conflicting attitudes regarding socialisation. Despite being pro- social inclusion, they were generally not proactive in encouraging peer relationships. There was a sense from six of the seven parents that the level of energy required in supporting their child's academic needs and engaging in community groups left little time or energy for other targeted interventions. They appeared to be satisfied with general social inclusion rather than developing individual friendships. This links to some degree with assertions from Turnbull et al. (2011) who claim families and professionals tend to focus on different aspects of the child's development apart from social development. There are

few studies which examine how parents support the social development of their child with SEN but there is an awareness of extra demands on parents' time where the child has significant needs (Tadema and Vlaskamp, 2010).

Support for Emotional/Behavioural Development

The emotional/behavioural challenges of some children with WS affected their opportunities for family socialisation to some degree, although this was usually linked to hyperacousis or anxiety. Four parents devised techniques to support their child's behaviours. Annie's parents used 'time-out', Fred's parents used a countdown technique and two mothers described musical interventions.

> *if we were giving out to her we'd be tapping it out d'you know*
> *what I mean 'We will not do this, we will not do that' [tapping on*
> *table to the syllables]... anything with beats and rhythms work*
> *better. […] so anything that we wanted her to remember we used*
> *to just bang out or tap or sing* (Gillian's mother)

Two parents expressed reluctance to share strategies with their child's teacher, afraid of undermining the teacher or anxious that suggestions would be unwelcome. Once again there is little literature on how parents with children with SEN or with WS support their child's emotional/behavioural development, yet the findings here match those interventions recommended by Semel and Rosner (2003), showing parents use appropriate supports which link with the WS profile.

While all parents supported their child's academic, physical, social and emotional/ behavioural development, at times this was challenging as Emma's mother described: *'I've often sat here and cried like, d'you know what I mean? Thinking, do you what I mean? It's not, it's not easy …'.*

Conclusion

Parental perceptions of the WS educational profile showed consistency between parental responses and high correlation with previously described profiles (Mervis et al., 2000; Semel and Rosner, 2003; Udwin et al., 2007) around aptitudes, perceptual and motor performance, maladaptive behaviours, literacy (reading) and mathematics, although with less consistency concerning language. The main differences were parental reports of good gross-motor skills which contrasts with previous descriptions, and a lower prevalence of hyperactivity and hyperacousis than cited in previous studies (Dilts et al., 1990; Udwin et al., 1996; Levitin et al., 2005; Leyfer et al., 2006). Furthermore, most children in the current study were reported by their parents to react negatively to certain words or voice tones which parents linked to auditory sensitivity. This is not evident in the literature but rather is usually described as part of the anxiety

profile (Dykens et al., 2000; Scheiber, 2000). While anxiety is associated with WS (Howlin and Udwin, 2006; Riby et al., 2014), it emerged as a daily feature for most of the children, related to anticipation, separation, or perceptual/motor challenges, which frequently impacted on behaviour, as previously indicated by Einfeld (2005). In addition, this study suggests the distractibility of WS may relate to anxiety, which may be masked by the child's sociability. In the area of language, it emerged that children with WS have an aptitude for additional languages. To date, no other research has explored this language capacity. A link also emerged between behavioural problems and poor expression of negative emotions which may guide behaviour interventions for children with WS.

Choosing an educational placement was difficult for parents but broadly reflected a previous study on placements for children with WS (Fidler et al., 2002). Three of the seven families had difficulty accessing a placement (mainstream or special), higher than the 20% cited by Armstrong et al. (2010) for children with SEN in Ireland. Parents' choice of educational placement was two-tiered, where firstly the school type (special or mainstream) was selected and subsequently the school was chosen. Some parents perceived an inflexible inclusion continuum that was one directional, with possibilities of moving from mainstream to special but not vice versa.

All parents were satisfied with their child's educational placement, with higher satisfaction levels than previously published for parents of children with SEN (Armstrong et al., 2010) and for children with WS (Howlin and Udwin, 2006; Scallan et al., 2011). Satisfaction was more influenced by child-related factors than by teacher-related factors or school-related factors, similar to those cited by Armstrong et al. (2010). Some factor-variance was noted between settings; parents of children in special settings were less consistently satisfied. Interestingly, in describing their satisfaction with their child's placement, different parental interpretations of inclusion emerged.

All parents were very actively involved in supporting their child's learning, specifically, their academic, physical, social and emotional/behavioural development. There are no other studies with which to compare these findings. However, Turnbull et al. (2011) claimed families of children with SEN usually do not focus on the child's social development but the current research contradicts this to a point. Parental hold complex and conflicting attitudes to supporting their child's social development. They support their child's general social inclusion but most are not active in developing and maintaining individual peer relationships.

The next chapter examines teacher experiences of the educational inclusion of children with WS.

CHAPTER 5   EDUCATIONAL INCLUSION OF CHILDREN WITH WS: TEACHER EXPERIENCES

Introduction

This chapter presents the findings from the teacher data. Teachers of six of the seven children were interviewed. Where the child attended mainstream (MS), the class teacher (CT) and the learning-support/resource teacher (LS/RT) were invited to participate. In two of four such cases, both teachers were interviewed together, at their request. The special needs assistant (SNA) of one child joined the teachers in one of these cases (see Table 3.1). Where the child attended a special school (SS) the CT was invited to participate, and where the child attended a special class (SC) the class teacher of the SC and the teacher of the MS class in which the child was included were interviewed. Teachers' names have been changed to protect their identity. The three key areas explored, concerning teacher experiences of the educational inclusion of children with WS, were:

1. How do teachers perceive the educational profile of the child with WS?
2. How satisfied are teachers with the child's educational placement?
3. How do teachers support the child's learning?

Perceptions of Educational Profile

The report framework for teacher perceptions of the children's educational profile mirrors that used for parents' perceptions (see Chapter Four). The themes are identical (as seen in Figure 5.1) but the sub-themes vary, being broader in the teacher sample.
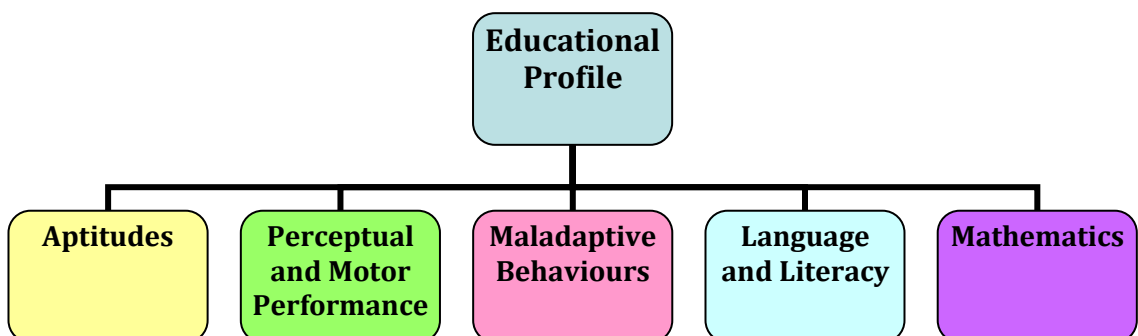
Figure 5.1: Educational profile of children with WS in Ireland: teacher perceptions (2012)

Aptitudes

The main aptitudes identified by teachers included sociability, memory, intelligence (IQ) and, to a lesser degree, musicality (see Figure 5.2).
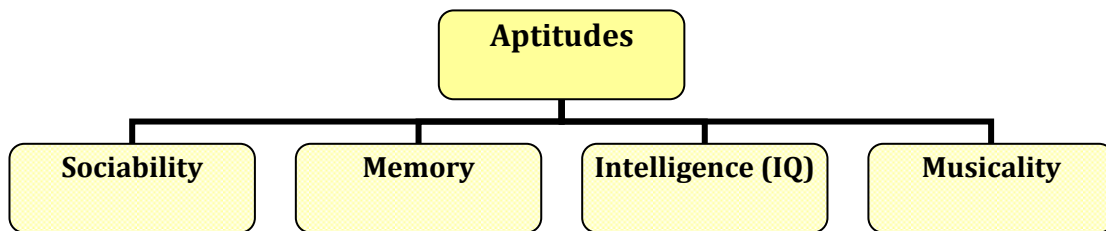
Figure 5.2: Educational profile of children with WS in Ireland: teacher perceptions of aptitudes (2012)

All ten teachers agreed that the child with WS was friendly and sociable, which aided the child's initial social inclusion and was a positive aspect to teaching him/her: '*he's wonderful at greeting people. He's got great social awareness. He's really a joy to have in the room*' (Jennifer, CT/MS). Nancy (CT/MS) described the child's impact, not just on class peers, but on the entire school: '*if he was walking up the corridor 'hi' (in child's voice) and he'd be chatting (…) even the big fellas, senior boys, going along the corridors, high five, everyone in the school knows Brian!*' These teachers' favourable rating of pupils with WS corresponds with findings by Levine and Castro (1994).

Another aptitude which all teachers identified was memory, particularly auditory memory. It manifested as verbal imitative skills (Udwin et al., 1987), encompassing the ability to retain words, melodies, rhymes, and other languages. The teachers were concerned that these memorising abilities masked poor comprehension: '*I don't know if he's learning a lot from me. I feel he's learning by rote, by listening to the others*' (Fiona, MT/SC). Semel and Rosner (2003) also noted this tendency to rote-learning, which they identified as a strength across all curricular areas except maths.

Much discussion arose from the teacher interviews about intelligence or IQ. The children's intellectual disability (ID) ranged from borderline to moderate, yet five teachers described the child's relative intelligence as an aptitude. This manifested as the ability to ask good questions, engage in higher-order thinking and work periodically at peer level. By contrast, some teachers felt the ID was masked by strong memory and/or strong expressive language, a danger also identified by Elçioglu et al. (1998). This difficulty with the IQ of WS is very frequently cited (see Udwin et al., 1987; Semel and Rosner, 2003) and is associated with the asymmetrical cognitive profile of WS (Mervis et al., 2000). Yet, the interpretation of assessment outcomes affects teacher expectations. Six teachers felt their initial expectation of the child, derived from psychological reports, test results and WS literature, was inaccurate:

> *I don't think they're [standardised test results] really accurate. I think he's actually a little bit better than that […] I think he was better than what I saw on the net. I think the net fills you with fear. I have to be honest with you. You read all that and you say 'Oh my God what am I going to do?!' (Josie, RT/MS)*

The teachers who used previous IEPs and consulted with the child's previous teacher felt they had accurate expectations of the child's ability. This highlights benefits of the IEP not previously noted in the literature; it is of significance because teachers are more likely to underestimate the abilities of children with SEN than to overestimate them (Wilson and Jade, 1999).

Tying in with both memory and intelligence was music, an aptitude identified for five of the six children. It was described as a love of rhythm and melody, good intonation and perfect pitch; it could mesmerise the child or could increase their participation. One resource teacher remarked on this aptitude: '*he's fabulous at music. He loves music. Now we have the digital piano in the classroom and so at the end of most days I would let him play it*' (Josie, RT/MS). Yet his class teacher failed to see this musical strength:

> *we do follow a music programme and there'd always be a little*
> *follow-up activity at the end where they'd have to tick which inst-*
> *rument or tick whether it's higher or lower, or you know that kind*
> *of idea. Em he wouldn't actually participate in that unless his SNA*
> *was actually guiding him...but I mean he'd be enjoying the experience*

This shows how teachers can fail to accommodate children's aptitudes but it also raises issues of inclusion. This teacher was satisfied that the child merely enjoyed the educational experience, indicating low expectations and an over-reliance on the SNA for curriculum inclusion, a concern also highlighted by Blatchford et al. (2009).

While each of the four aptitudes (sociability, intelligence, memory and musicality) was evident in at least four of the six children with WS, teachers were more likely to accommodate the child's IQ than harness the possibilities of other aptitudes. Only four of the ten teachers used memory, musicality or sociability to devise strategies for the learning challenges and maladaptive behaviours associated with WS. Three of these four teachers were teaching or had taught in special settings, and two of the four had SEN qualifications. However, no studies have been carried out on individual teachers' approaches to teaching children with WS with which these findings can be compared.

Perceptual and Motor Skills

As evidenced in Figure 5.3, teachers' perceptions of pupils' perceptual and motor skills were divided into three sub-themes which reflected the themes from the parent interviews: visuomotor performance (further subdivided into gross-motor, fine-motor, and adaptive-living skills), auditory sensitivity and tactile sensitivity.
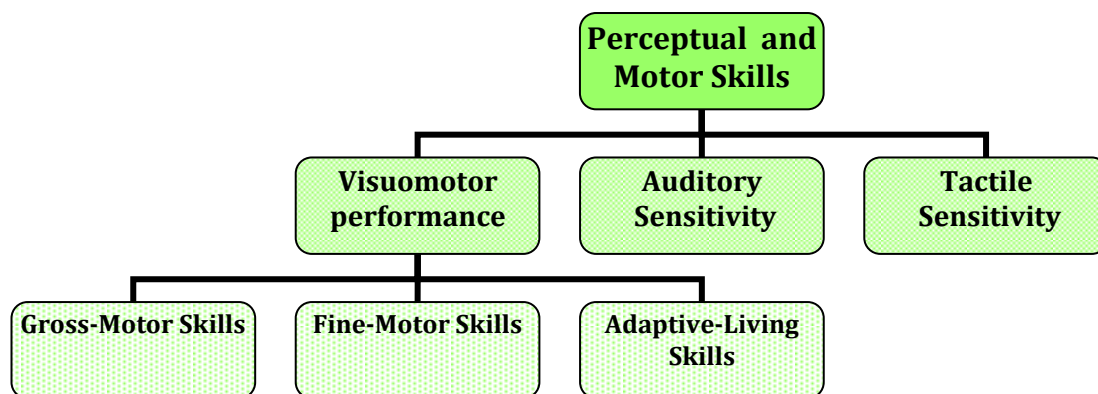
Figure 5.3: Educational profile of children with WS in Ireland: teacher perceptions of perceptual and motor skills (2012)

The sub-theme of visuomotor performance contained a number of elements. Six teachers referred to gross-motor difficulties which impeded the child's participation in Physical Education (PE). This contrasts with parental findings but aligns with previously defined profiles of WS (Udwin et al., 2007). All teachers discussed the child's difficulties with fine-motor skills, particularly handwriting, which developed very slowly as Jennifer (CT/MS) described: '*the handwriting is the biggest thing and like that, hasn't ever really been achieved in an independent way'*. Handwriting can be an obstacle to academic inclusion in mainstream classes across all curriculum areas. Similarly, adaptive-living skills, a difficulty identified for four of the six children, also presented as an obstacle to some children's inclusion, particularly where they needed help with toileting and feeding. Stefanini et al. (2008) linked difficulties with fine-motor and adaptive-living skills to an unusual grip found in a sample of 9-11 year olds with WS, a grip which promotes sureness but not precision. These visuomotor difficulties persist into adulthood (Howlin et al., 2010), yet studies have shown that targeted interventions for specific visuomotor challenges yield positive outcomes (see Stiles et al., 2000).

The remaining themes that emerged from teachers in describing the child's perceptual and motor skills were auditory and tactile sensitivity. While hyperacousis was an issue described by parents of five children, teachers of only two children referred to it. Noreen (RT/MS) described its effects on the child's concentration: '*today there was a very heavy shower and he just couldn't focus because of the rain'.* It also reduced the child's inclusion in school activities: '*if we were having assemblies … I was outside with him and he was crying and upset and he just didn't want to go back in'* (Nuala, SNA/MS). The literature also reports anxiety and distress with certain sounds (Leyfer et al., 2006), although at levels much higher than described here. This data also shows hyperacousis is more overt at home than at school, which has not been previously reported.

Tactile sensitivity was more commonly reported by teachers than auditory sensitivity where it was evident in five of the six children, with four teachers feeling it hampered the child's social inclusion. Three children were identified as tactile defensive with difficulties maintaining appropriate personal space. This strengthens warnings by Semel and Rosner (2003) that behaviours associated with tactile sensitivity may irritate the child's peers. In addition, tactile sensitivity was identified by two teachers as an antecedent to challenging behaviour.

Maladaptive Behaviours

As in the parent interviews, teachers described specific maladaptive behaviours in the children (see Figure 5.4). The most significant of these, evident in all children, were distractibility, emotionality and socialisation. Anxiety was identified in only three of the pupils, but is described due to the overall research findings in this area.
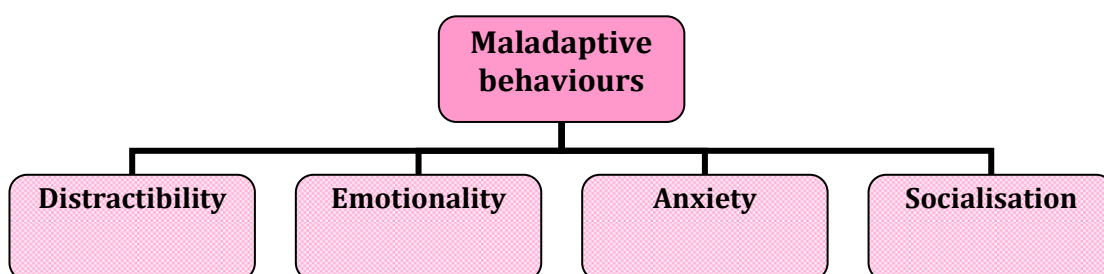
Figure 5.4: Educational profile of children with WS in Ireland: teacher perceptions of maladaptive behaviours (2012)

The level of distractibility was reported by teachers to vary from comparable to other pupils with ID to very severe: '*we're not being PC and I don't mean it against the child, but it was like having a puppy in the classroom (...) a puppy everybody loved, but it was... you just...it was just from one minute to the next you wouldn't know what he'd do'* Nancy (CT/MS). Such distractibility ameliorated to some degree with time and when working with the child on a one-to-one basis. In some cases, teachers found the child's distractibility impacted negatively on the class and also masked the child's ability, hindering social and academic inclusion. Three teachers found distractibility constituted a flight risk (where the child saw something/someone interesting and ran to it). Teachers in special settings used more techniques to address distractibility, and the flexibility of their curriculum appeared to help this. Three mainstream teachers were satisfied once the child did not disrupt the class and did not appear concerned about the child's participation or engagement. The literature consistently reports high distractibility in WS (Pagon et al., 1987; Mervis and Morris, 2007), although no studies have been published on teachers' perspectives. Similarly, the impact of high distractibility on engagement and hence, on educational inclusion has not been discussed, despite helpful interventions for distractibility being suggested by Levine et

al. (2013). Previous studies indicate a strong need to address distractibility as it persists in adulthood (Davies et al., 1998).

Emotionality was identified as another maladaptive behaviour for all six children. Teachers described emotional intensity, particularly when negative emotions were triggered: '*when she's crying it's like a waterfall!*' (Sandra, CT/MS). Triggers included the child not getting his/her own way, a teacher's disapproving tone or a reprimand to either the child or others. Conversely, Karen (CT/SS) found the child's excitability greatly enhanced the classroom atmosphere. These emotional descriptors are consistent with those of Plissart et al. (1994), although Dilts et al. (1990) link the emotionality in WS to anxiety.

The current research showed that anxiety was not frequently reported by teachers, despite the fact that the children were noted to pick up on their teacher's negative emotions and frequently tried to change their teacher's mood. No teacher linked this to anxiety; rather they described behaviours which appeared to have the function of keeping the teacher 'happy', which they found to be amusing or endearing. Anxiety is very commonly associated with adults with WS (Davies et al., 1997; Scallan et al., 2011), but it may be underlying and misinterpreted in younger children. An example of this may be the following description from Josie (RT/MS):

> *you might have been up that morning you might have gone out and forgot to comb my hair and he'll say 'your shoes are lovely' and you just say 'oh thank God he didn't see my hair!' And he really does, he just makes you feel woah this is alright!*

It is possible the child was reading the signs of dishevelled hair as being a danger (bad mood) which triggered his anxiety and caused him to react to prevent a situation arising, but it is interpreted by teachers as part of their sociability rather than a symptom of anxiety. This is certainly speculative but this may be significant considering the implications of anxiety in older individuals with WS, which include reduced success in employment (Davies et al., 1997). Therefore, this research hypothesises that sociability is masking anxiety in children with WS in educational settings.

Challenging aspects of sociability were identified by teachers of all six children and included difficulties establishing and maintaining peer relationships and personal safety. One teacher portrayed the child's peer relationships as '*a bit contrived*' (Frances, CT/SC), despite highly-developed individualised interventions. Three teachers described the child's preference to play apart from peers at break times. Perhaps of greater concern was that of stranger-danger, the lack of inhibition around strangers, which six of the ten teachers spontaneously identified: '*She's very outgoing you know if we're in the street and there's a man walking along the street she'll say Hi! or Hello!*' (Karen, CT/SS). This raises concerns about the child's vulnerability. Josie

(RT/MS) explained how despite teaching a child-abuse prevention programme she was not convinced the child had internalised the rules:

> *He doesn't actually see bad in anybody … that is something that wouldn't be in his level of awareness and of course the Stay Safe programme [child abuse prevention] tries to show that to a certain extent. But at the same time if he was actually put in a real life situation you wouldn't be confident at all*

The issues of sociability identified here correspond to previous studies regarding poor peer-relations (Dykens et al., 2000; Einfeld et al., 1997) and personal safety (Strebe, 2008; Riby et al., 2013b). It is recommended that strategies to support the safety of children with WS should centre on verbal mediation (Semel and Rosner, 2003) due to their relative strengths in verbal memory and language.

Language

All teachers made reference to language as part of the child's educational profile. This is multifaceted and manifested differently to the parents' perceived language profile, as seen in Figure 5.5 below.
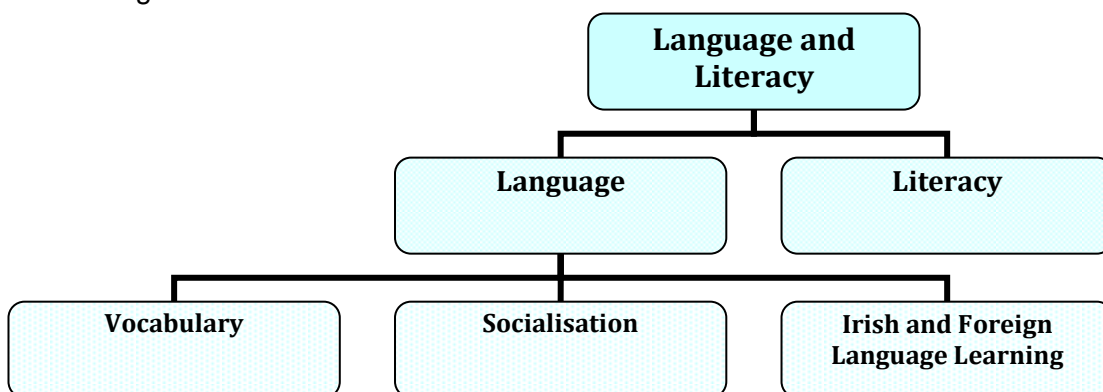
Figure 5.5: Educational profile of children with WS in Ireland: teacher perceptions of language and literacy (2012)

Teachers identified language as a relative strength for four children. They perceived a love of language and words and noted the child's wide vocabulary:

> *her language was unbelievable, she … I mean, my first experience (…) they went to computer buddies and they had to write down their favourite animals. And her first week she said 'my favourite dog is a King Charles cavalier puppy' and that was fine I thought 'wow! Jesus, she knows her stuff !'* Karen (CT/SS)

The child in the special class was included with his mainstream peers for oral language lessons. Fiona (MT/SC) indicated a superior vocabulary to his peers at times, an ability to ask effective questions and an engaging turn of phrase to the point that '*You wouldn't pick him out as different'*. Teachers of the two youngest children with WS described significant language development during the year. One child had started school with little language and her vocabulary had increased, thereby reducing aggressive behaviours. These language 'spurts' are usually seen in younger children in

WS (Mervis and Bertrand, 1997) as by school-age they are generally fluent with a large vocabulary (Lukács, 2005:13). There are no previous reports of a correlation between increased vocabulary and decreased challenging behaviours in school settings.

Another feature of language identified by teachers of five of the six children was the social use of language, frequently in relation to maintaining a positive relationship, as Karen (CT/SS) shared: '*she remembers a few bits like that, that'll…you know feel…make the person talking feel special'.* Udwin and Yule (1990) refer to an effusive hyperverbal conversational style in WS which Dykens et al. (2000) link to positive social interactions, also evident from the teachers' comments in this study.

Strong language skills were also apparent in the learning of Irish. Noting the aptitude for language, teachers generally involved the children in Irish lessons, despite all but one having an exemption (see Chapter One):

> *he's got a grasp even of Irish words…I mean…okay maybe the*
> *comprehension wouldn't always be there. His ability to absorb actual*
> *vocabulary and phrases is really…you know, is really very good (…)*
> *Because naturally I grappled with whether to do Irish or not (…) he*
> *actually enjoys the situation, he enjoys the whole experience of*
> *hearing words (Jennifer, CT/MS)*

In addition, Josie (RT/MS) described the German words her pupil had picked up from looking at the Volkswagon website (due to a special interest in trucks):

> *one week he came in and all his numbers were in German and I said*
> *to him 'do you have a German visitor at home?' 'No!' And I said 'God,*
> *this is very strange. I said 'where are you getting the numbers from?'*
> *Any of the maths we were doing and the answer'd be like 'Fier', 'Drei'*
> *and these were right. They were the right answers but in German!*

This capacity to learn second or foreign language learning, also identified by parents, has not been researched or developed. This is an unusual profile for most learners with GLD, highlighted by the exemptions from learning Irish granted to pupils with specific SEN in Ireland.

Teachers connected the child's phonological awareness, a perceived strength for four children, to the child's musicality. Consequently, teachers reported five of the children to be good readers. Comprehension difficulties emerged over time, mirroring a profile similar to other learners with SEN (King, 2006). Some of the children learned to read easily and followed the same programme and stages as their mainstream peers, while other teachers described challenges:

> *With the reading I wondered if he ever would be able to put the sounds*
> *together. Once he started reading we made up little books, we slowed*
> *down and did things so often, up to a hundred times, to ensure he was*
> *with me and then it all took off (Frances, CT/SC)*

Two teachers were concerned that poor reading comprehension affected the child's academic inclusion and performance in other subject areas, as Oonagh (CT/MS) explained: '*When she's doing history or geography she has no concept. Comprehension is a difficulty'.* By contrast, Karen (CT/SS) was confident of developing the child's comprehension by pitching the content appropriately:

> *every mainstream school might be talking about Titanic but we'll break it down into, it'd be smaller sections and less information but she'll still know about the Titanic. (…) I think it's just the fact that we can… take it back to suit them.*

This reading profile is similar to that presented by Udwin et al. (2007), although teachers described success using a phonological approach coupled with a whole-word approach, which is not recommended for learners with WS (Laing, 2002; Mervis, 2009). The language experience approach described by one teacher is also recommended by Levine et al. (2013) due to the motivation of the child's special interests.

Mathematics

The educational profile concludes with mathematics. Teachers of five children referred to this as a challenge. They appeared to lack expertise in, and confidence with, the teaching of mathematics; many were unsure how to assess and progress with the child, as Oonagh (CT/MS) shared: '*she has a problem with the concept of number though. You think she has it and then she'll say something which shows she has no concept of it'.* One teacher in a special school, despite having little teaching experience, was clear on the child's difficulties from observation and informal testing:

> *It's very hard for her to work independently. Now I'd say if I could give her a table book and told her 'learn off this' I'd have no problem and if she saw those sums on a page I'd say yes definitely she would be able to do it that way (…) But as for understanding that the two plus three is actually five and you count out two and then count on three, four, five, that she finds very challenging* (Karen, CT/SS)

This teacher brought the children shopping once a week to develop the concept of money in a real-life context. There appeared to be more scope in special settings than mainstream settings to develop mathematical life skills, consistent with findings from other studies (Ware et al., 2009). The mathematics profile presented here mirrors that of previously published studies (Levine et al., 2013).

Overall, teachers' perceptions of the educational profile of this sample of children with WS were similar to that of parents, with the same themes emerging but with some variations in the sub-themes. This was particularly true of maladaptive behaviours and language and literacy. Through this profile teachers identified areas which supported or impeded the child's inclusion in their specific educational placement.

Teachers, in general, identified more strengths than limitations regarding the child's placement. Figure 5.6 shows the strengths across placements, which included academic and social inclusion, progress with behaviours and life skills, and suitable structures and resources.
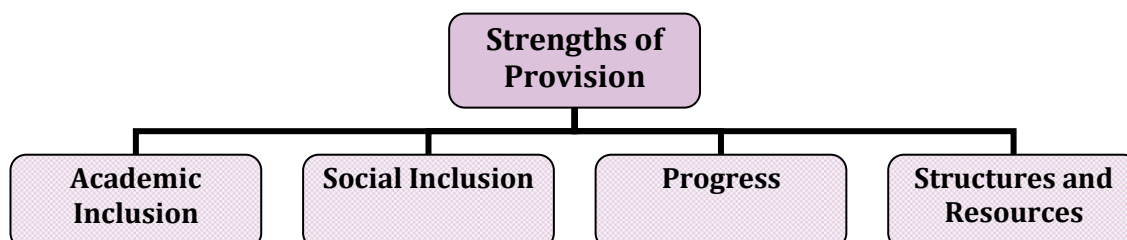
Figure 5.6: School placement of children with WS in Ireland: teacher perceptions of strengths of provision (2012)

The limitations (see Figure 5.7) concerned pupil engagement, inadequate structures and supports, difficulties with academic programmes and pace, and to a lesser degree, teachers' own experience. Some limitations related to mainstream placements only but there were fewer teachers from special settings interviewed so results should be interpreted with caution.
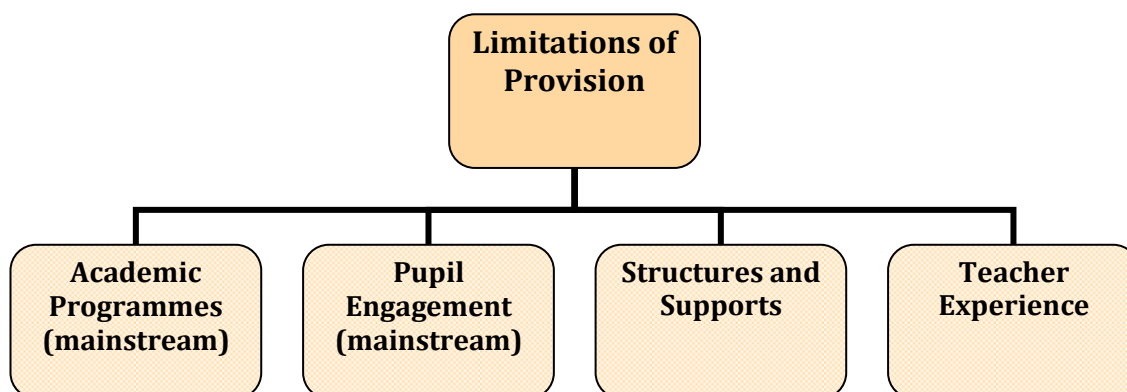
Figure 5.7: School placement of children with WS in Ireland: teacher perceptions of limitations of provision (2012)

The perceived strengths in some placements were perceived limitations in another, therefore, both will be described concurrently. Academic inclusion was one such area, dependent on teachers' interpretation of inclusion. All ten teachers described the child's inclusion in class work as a strength of provision, although this sometimes meant the child's locational inclusion. Six teachers in mainstream settings felt academic programmes were limited, five of them referred to issues with the pace of instruction and five reported poor pupil engagement at times: '*I suppose he might be…you know, in his own world but at the same time…no, he's not physically moving around*' (Jennifer, CT/MS). Ring and Travers (2005) also found mainstream teachers to be challenged in including a child with GLD in the same curriculum as his/her peers.

These challenges did not arise for the children in special settings. The literature also indicates that special schools have greater autonomy in the provision of tailored curricula (O'Keeffe, 2004), providing access to an appropriate curriculum (Ware et al., 2009) which increases academic inclusion. By contrast, some mainstream schools have been found to have an insufficient focus on learning (Mowat, 2009), inadequate differentiation (Rix et al., 2009) and low academic expectations (Rose and Shevlin, 2010) which was also apparent from this research.

Social inclusion was a cited strength of provision by all teachers, as the child was generally accepted by his/her peers. All mainstream teachers identified incidences of positive class impact, primarily regarding an atmosphere of care and sensitivity: '*I think they're all aware that he has his own needs (…) It does bring out a gentle side in them and just an awareness that not everybody's the same'* (Nancy, CT/MS). These findings reflect previous studies where mainstream inclusion is deemed to promote peer socialisation with positive peer impact (Shevlin et al. 2008). However, two mainstream teachers also noted the negative impact on the child's peers, due primarily to behaviours. Overall, mainstream class teachers tended to emphasise academic development over social development, replicating findings by Armstrong et al. (2010). Special schools were somewhat different. Karen (CT/SS) referred to the wide catchment area as a limitation of special schools, thus limiting social inclusion: '*the children here are so far away from each other (…) They come from all over…so they can't have friendships out of school'.* She also indicated less pupil understanding and tolerance of behavioural difficulties than typically-developing peers. The literature has deemed special schools to be able to provide opportunities for teaching specific social skills to children with SEN (Ware et al., 2009), which was apparent in the special class but not in the special school included in this research.

Another strength of provision identified by all teachers was the school's specific structures or resources. This included a dedicated SNA for the child, resource hours, pupil-teacher ratio, professional support and the availability of teacher time to support the child. Yet again, the strengths in one setting were limitations in another. One child was in a multi-grade mainstream class of ten pupils, an obvious strength of provision, while another teacher identified her pupil-teacher ratio of 1:28 as a limitation. Yet even with low pupil-teacher ratios in multi-grade classes two teachers still found they had little time for individual instruction for the child. By contrast, the teacher of a special class highlighted the benefits of the low pupil-teacher ratio which facilitated individual programmes. Most mainstream teachers identified the allocation of a SNA as a strength, while two teachers (both who had SEN qualifications) identified this as a barrier to the child's independence and social-skill development: '*We had to fight for*

resources and SNAs but there needs to be a limit at the same time. SNAs need a lot of training. If they are not familiar with the child and the systems they can do more harm than good' (Frances, CT/SC). In the same vein, the allocation of resource hours for pupils in mainstream placements was identified as a strength by mainstream teachers, although this was not without difficulties. The failure to have automatic entitlement to such hours was a limitation identified in one case, and the sharing of resource teachers in smaller schools was an identified challenge in another case, as the child did not have daily support. These findings around resources mirror other Irish and international studies. In Scotland, teachers also identified appropriate resources as necessary for successful inclusion (Clark et al., 2004) yet that study concluded with a warning that inclusion can be understood in terms of resource issues only. Similarly, teachers are deemed to over-rely on SNAs for curriculum inclusion (Blatchford et al., 2009) and sometimes for the child's social inclusion (Ware et al., 2009). Indeed, there have been calls in the Irish context for a review of the role of SNAs (Carrig, 2004) to maximise this resource.

Five of the ten teachers, across different placements, identified their progression of the child's independence and self-help skills as a strength of their provision, a strength associated primarily with special schools in the literature (see Ware et al., 2009).

Three of the ten teachers described a lack of experience as being a limitation of the child's provision. For one teacher it was a lack of teaching experience and not being sure of the parameters of cognitive development; for another it was not having special education knowledge or skills. This was a small percentage of teachers considering the literature indicates this to be one of the most commonly identified barriers to inclusion for children with SEN (Forbes, 2007; Rose and Shevlin, 2010).

Overall, there were more limitations identified by mainstream teachers than teachers in special settings. The strengths and limitations identified by each teacher were clearly context-based. However, teachers who had experience of SEN or who had a SEN qualification, while they did not identify these as strengths of provision, were clearly more cognisant of the need to support the different aspects of the child's learning, and hence, appeared to procure more effective academic and social inclusion.

Supporting Learning

The support that teachers provide to children with WS can greatly enhance their overall educational inclusion; this research showed that teacher support varied considerably. Findings indicate links between teachers' attitudes to SEN, SEN experience and qualifications, and the quality and range of supports provided. Figure 5.8 shows

teacher support centred around four themes: academic, social, emotional/behavioural and life skills/care needs. Teachers with less teaching experience and with no SEN qualification were more likely to expect the child to follow class structures and programmes and were less likely to provide differentiated services for the child. This has been identified by the NCSE (2013f) as a challenge for learners with SEN; hence, teacher education, incorporating strategies for differentiation, forms part of its recommended framework for the professional development of teachers.
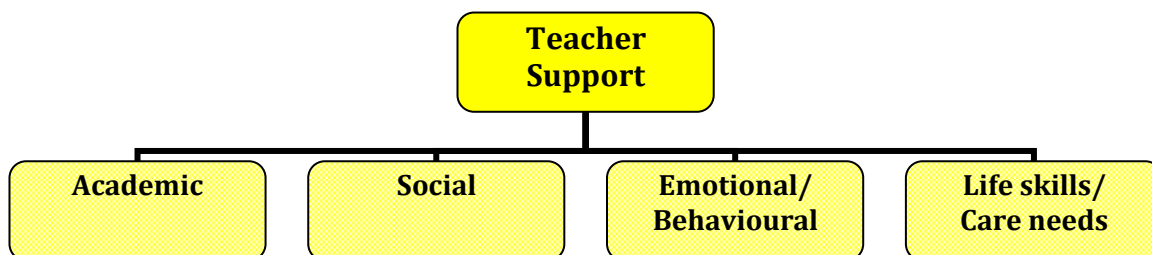
Figure 5.8: Supporting the learner with WS in Ireland: aspects supported by teachers (2012)

Support for Academic Development

Differentiation of content was provided for all pupils, although there was significant variation in its implementation. In one case it was an individual programme dictated by the child's current level of performance, in another case it was through ability groups for particular subjects, and in two cases it was assigning less work to the pupil. In some cases, the LS/RT appeared to provide the only structured differentiated learning, thereby absolving mainstream class teachers of responsibility, summed up by Jennifer (CT/MS): '*there's four classes so you see … I'm very much taken with the mainstream thing you know. But … as I say he's always had his resource hours'.* Some teachers indicated they supported the child, not by differentiating work, but by avoiding pressure: '*I just let her take part [in history and geography] and whatever she picks up on the subject is fine'* (Olivia, CT/MS)*.* This teacher had no SEN experience and only three years' teaching experience.

Methodologies and approaches associated with general teaching were used by all teachers to support the child's learning. This included use of manipulatives, shorter lessons and relating new material to the child's experience: '*it would be just repeating all the time, just constantly, constantly' (*Nuala, SNA/MS), although such strategies had limited success: '*with repetition things work, she'll know it, you do it every day and she knows it. Then you leave it for a few days thinking she has it and you go back to it and she doesn't know it anymore and you wonder'* Olivia (RT/MS). Three of the ten teachers experienced success with specific 'special-education' approaches: lamh (signing system), TEACCH and social stories. The latter two are strongly associated with ASD, a link which is not explicitly presented in the literature. These three teachers

had special education experience and one of the three had a SEN qualification. Sandra (CT/MS) shared her success:

> *from having worked in special needs as well I had my own things I'd seen happening and things I thought might work (…) we did the you know 'first' 'then' (…) This was very good for her, very good for getting her to sit in her place because she'd, she wouldn't sit down in her place and she wouldn't do her work (…) And that was a big goal for us and now we've achieved that goal*

Three teachers regularly took the child's current performance and developmental level into account: '*We did a year and a half [of writing] on the whiteboard. I had tried reading and writing during that time but he wasn't ready. I kept going back through different stages to see where he was, I was going on readiness*' (Frances, CT/SC).

Teachers also supported the child's academic development by putting specific structures in place such as strategic timetables, routines and rules, and by sharing information and strategies with parents: '*getting Mam and Dad to actually ask him questions about what he's reading, you know, as opposed to saying that's fabulous reading, my God he's reading fourth class books!*' (Josie, RT/MS).

The supply and use of resources was also a means of supporting the child's academic inclusion. All mainstream teachers alluded to personnel resources, particularly the necessity of the SNA: '*If he didn't have a SNA he would be just lost completely and he would have had to be, because you've twenty-seven other boys, there wouldn't be a realistic way of coping in a class*' (Nancy, CT/MS). The question remains whether one-to-one SNA supports facilitates inclusion or exclusion, and will be presented again in the next section on social support for children with WS.

There are no published studies on how teachers support learners with WS but the findings show some correlation with reports on learners with SEN. Differentiation is a key strategy for supporting the academic inclusion of learners, yet here the evidence suggests this was done in a structured way by only a minority of teachers, those teachers having SEN experience or a SEN qualification. This replicates findings of another Irish study by Ware et al. (2011). Also, the practice of mainstream teachers not differentiating adequately because they saw this as the role of the LS/RT has been previously reported (Rix et al., 2013). Teachers with less teaching experience and with no SEN qualification are more likely to expect the child to follow class structures and programmes and less likely to provide differentiated services (NCSE, 2013).

Support for Social Development

Similar to supports for academic development, there was variance in the support for social development provided to pupils, and in the attitudes of teachers to providing such support. Specific interventions to promote the social inclusion of children with WS

were not always evident, yet in all cases they appeared to be needed, according to teachers' perceptions of the children's educational profile. Specific social interventions are recommended for children with WS (Dykens and Rosner, 1999) and were in place for three of the six children. Two of the three teachers implementing these strategies had SEN qualifications, while the third had SEN experience. Frances (CT/SC) described her approach: '*He hasn't much in common with the other peers. I got him a Chelsea football, after that he went down to the mainstream class and I put him sitting beside the boy who also likes Chelsea and a conversation started'.* Teachers of the two youngest pupils discussed the child's needs with the class, with some very encouraging results: '*what we said, and we've used it all year, that some people are younger and they need a little bit more help and they're fantastic with her. The class has grown with her'* (Sandra, CT/MS). In another school, the class teacher and the support teacher had very different attitudes to developing social inclusion. The class teacher was not concerned that the child played alone, despite target-setting by the support teacher to develop appropriate peer interaction. Josie (RT/MS) described the success of her intervention:

> *I was trying to get him social because you'd often notice sometimes in the playground he'll go to a swing by himself. He's quite happy … very happy in his own world, and so I was saying to [the principal], I asked [her] if we could bring the swingball out at break times so that he's mixing, that he* **has to** *mix*

In two cases the teachers did not see themselves having a role in developing sociability, including Olivia (CT/MS): '*she has problems with gross-motor skills and doesn't want to get involved [in break-time games]. She stands back and expects everything to come to her'.* Similarly, Karen (CT/SS) appeared to be aware of negative peer behaviours towards the child with WS but did not seem to be active in supporting the child's socialisation in this regard: '*some of the other girls in here are very good to her, they'll protect her and they say 'she can't help it' '.*

Once again there are no published studies on teacher supports for the social development of pupils with WS but there is much evidence to show that children with SEN need to be taught social skills where they are lacking, and that social interventions can work successfully (MacNamara, 2008), as indicated in this research. However, as also found in this study, social development is usually not a priority of professionals who work with children with SEN (Turnbull et al., 2011).

Support for Emotional/Behavioural Challenges

Teachers of all children with WS in the study perceived some emotional/behavioural challenges, the most common being distractibility, emotionality and socialisation. There appeared to be a link between pupils' emotionality and challenging behaviour. In most

cases, teachers devised interventions through trial and error. Teachers of one child sought help from a psychologist but no teacher sought help from the Special Education Support Service (SESS).

Each child had at least one teacher who indicated the need to support the child's distractibility. The findings here link closely with strategies for providing academic support. In most mainstream classes, refocusing the child was assigned to the SNA, and once the child was not displaying challenging behaviour, teachers were satisfied and did not devise specific strategies. Jennifer (CT/MS) expressed her satisfaction that the child would remain in his place, despite poor academic inclusion: '*even if his SNA isn't with him and you know even if he's not able actually to … take part in the activity fully, he would never get up and wander away'.* The most successful interventions for distractibility were implemented by teachers who had experience in special settings or who had a SEN qualification. The link between effective supports for pupils with EBD and teacher education has already been identified by Cooper and Jacobs (2011). These teachers in the current study were aware of working to the child's strengths and interests to help maintain a focus, having short lessons with a variety of active learning experiences and rewarding pupil engagement. The three teachers who devised strategies to support pupils' behaviour described more successful long-term academic inclusion, mirroring similar finding to Flynn et al. (2011) regarding pupils with EBD.

Disruptive behaviours were identified for four of the six children by their teachers: two in special settings and two in mainstream settings. Three of the four children were in the three youngest classes, reflecting previous studies which show challenging behaviours decrease with time (Mervis and Morris, 2007; Scallan et al., 2011). There were specific interventions in place for three of the four children. Each of the three teachers had experience of teaching in a special setting. The interventions in such cases were based on the WS profile, with a focus on positive language, musicality (singing instructions) and denying sociability (using time-out). Nancy (CT/MS) enforced the same class rules with her pupil who has co-morbidity with ADHD because '*[class peers] needed to know that the same rules applied'.* This could be interpreted as not supporting the child's emotional/behavioural needs. Such an attitude underscores the danger of equating inclusion with treating everyone the same. Teachers in special settings, and those with experience in special settings, described their own central role in dealing with behaviours. Sandra (CT/MS) described her approach:

> *Now I do have to remind a lot 'good sitting' and I just look over at her but I point to the others, 'good listening' or 'good looking' and 'good sitting' and at the beginning of the year for the first three months I was just constantly, I had these giant cues*

It had an unexpected spin-off effect for Sandra (CT/MS): '*it was like a teaching thing for me, a new method and I think I will use it again with junior infants'.* By contrast, two mainstream teachers described the SNA's role in managing behaviours (usually by withdrawing the child to minimise the impact on other pupils), highlighting a difference in attitudes to SNAs between teachers in special placements and those in mainstream. Rix et al. (2013) also found SNAs being assigned to support pupils' behavioural needs and warned of the role being 'blurred into the areas of psychological and educational intervention' (2013:79) for which SNAs are not trained. The role of the SNA was also intrinsically linked to providing support for the pupils' life skills and care needs.

Support for Life Skills/Care Needs

This research showed that teachers in special settings involved themselves in the explicit teaching of toileting/feeding skills, whereas in mainstream schools the SNA usually took responsibility for them. This was similar for other life skills such as dressing, although one resource teacher (with SEN qualifications) taught this to her pupil. Frances (CT/SC) explained the impact of developing pupils' independence and the role of the SNA in this process:

> *Promoting [his] independence, I need to keep pushing it. The first day he was told to go down to first class unaided he ran down the corridor shouting 'I'm on my own!' He was delighted with himself. SNAs need to do their job so well that they will lose their job as a result*

Where life skills were developed as part of the child's programme, the teachers valued parental involvement, as Josie (RT/MS) shared: '*I discussed all this with Mammy and Daddy (…) We've been working on it together and that has improved'.* One mainstream class teacher did not see herself having a role in developing life skills. This highlights a difference in attitude and curriculum between some mainstream and special settings in supporting pupils' life skills and care needs. Similarly, the research literature indicates higher supports for pupils' life skills in special settings than in mainstream settings (Armstrong et al., 2010).

These findings show that teachers in all settings provide a range of supports for children with WS which span academic, social, emotional/behavioural and life skills/care needs. More individualised supports were evident from teachers in special settings and/or teachers who had SEN experience or a SEN qualification. There were different interpretations of the role of the SNA in supporting the children with WS between teachers in mainstream settings and those in special settings. The findings also indicate that teachers would benefit from supports themselves, particularly in the area of professional development.

Conclusion

Teacher perceptions of the WS educational profile largely mirrored that described by Mervis et al. (2000) with identical themes to those of the parents but with broader sub-themes. There was consistency in teacher responses around aptitudes, perceptual and motor performance, maladaptive behaviours, literacy and language. Their perceptions of poor gross-motor skills contradicted those of parents but were consistent with published studies (Udwin et al., 1987; Dilts et al., 1990). Handwriting challenges were identified as an obstacle to the child's academic inclusion in mainstream settings, previously highlighted by Levine et al. (2013). Interestingly, hyperacousis and anxiety were reported less frequently by teachers than by parents. This prevalence difference between home and school has not appeared in the literature thus highlighting the value of triangulating data. There was more consistency among teachers than parents in describing the children's language profile, showing closer links to the profile described by Udwin and Yule (1990). For most children language enhanced their educational inclusion. Interestingly, the finding of a correlation between increased vocabulary and decreased behaviours is not widely discussed in the literature. Despite exemptions from Irish, most teachers encouraged the child's participation in these lessons due to this perceived strength.

Teachers identified a range of strengths and limitations of their provision, although these were context based. Strengths included academic and social inclusion, pupil progress and structures/resources. Factors pertaining to inclusion were influenced by teachers' interpretation of inclusion which varied between individuals. Perceived limitations, more prevalent in mainstream settings than special settings, encompassed academic programmes, pupil engagement, structures/support and teacher experience. Teacher perceptions of the strengths and limitations of their educational placement for children with WS have never before been researched.

Concurrent with studies in the Irish context (Ware et al., 2011; NCSE, 2013f) and internationally (Forbes, 2007; Rose and Shevlin, 2010), findings indicated that teacher attitudes, SEN experience and SEN qualifications influenced the supports provided to learners with WS. Like parents, teachers supported the child's academic, social, and emotional/behavioural needs, but unlike parents, teachers did not refer to supporting the child's physical needs. Academic supports were frequently over-reliant on general-teaching approaches, as expected (see Rix et al., 2013). Similarly, some mainstream teachers described an over-reliance on the SNA, which may reduce the child's inclusion as indicated by Webster and Blatchford (2013).

The next chapter examines the children's experiences of educational inclusion.

CHAPTER 6   EDUCATIONAL INCLUSION OF CHILDREN WITH WS: CHILD EXPERIENCES

Introduction

This chapter concludes the findings from the three stakeholder groups and presents the data from the children with WS. As highlighted in Table 3.1, five children participated in a structured interview (sentence-completion task). Three of the five children were in mainstream settings, two were in special settings (one in a special school and one in a special class). The children's responses to the sentence-completion tasks are presented to answer two key questions:

1. How does the child perceive his/her educational profile?
2. How satisfied is the child with his/her educational placement?

Perceptions of Educational Profile

This section is divided in two: the observed educational profile of the children by the researcher, followed by the children's responses to three sentence stems.

Observation Profiles

There were obvious similarities and differences in the researcher's observation profiles of the seven children. A striking similarity was the ability to engage fully in a conversation or remain focused on a task of choice, although two of the children engaged effectively in the interview **with** the support of interview aids. This contrasts sharply with reports of distractibility and poor concentration in WS (Pagon et al., 1987; Plesa-Skwerer and Tager-Flusberg, 2006). The two children who did not participate in the interview also showed a high degree of engagement in activities of their choice; one child with musical apps on his iPad and the other with play-dough. No other aspect of the cognitive profile was observed among all of the children. Four of the seven children were confident and expressive. Three of the seven children were observed as happy, engaging, friendly, curious, active/restless, and anxious. These observations show some commonalities in the WS profile but also highlight the heterogeneous nature of this group of children.

Self-perceptions of Educational Profile

Three sentence stems were presented to the children to supply basic information in relation to perceived areas of strength and challenge.

At school I am good at …

Four responses were academic: "*writing*" (Charlie), "*reading*" (Brian), "*work*" (Emma), "*dancing, maths or anything*" (Dean); and two related to activities "*football*" (Gillian) and "*dancing, maths or anything*" (Dean). Emma who said "*work*" curled up her nose while responding as if rejecting her answer. She appeared anxious and her mother corrected some of her responses during the sample questions of the interview. No child had difficulty thinking of something at which they were good. Dean's response had a double code assigned and indicates his confidence in a range of school activities.

At school I need help to …

Four of the five responses related to academic activities: "*write properly*" (Gillian), "*do maths*" (Dean), "*read*" (Brian) and "*work*" (Emma), while one referred to care/safety needs: "*mind me and help me get outside*" (Charlie). This shows that each child was aware of his/her needs.

I am best when …

Two of the responses were academic: "*I am working*" (Gillian) and "*I am doing my tests*" (Emma). This showed a link between school experience and self-perception. Two responses related to social activity: "*I am playing*" (Brian) and "*I am the bestest boy, I just play with Leanne*" [his baby sister] (Dean). Finally, Charlie's related to on-going health issues: "*I am better*".

It is striking that the children's perceived strengths were frequently academic in nature, in many cases reflecting their challenges. This may be the result of regular positive teacher feedback in these areas. This reinforces the view of Cooper and Jacobs (2011:59) that the teacher-student relationship is central to effective education, and teacher attitudes can influence pupil behaviour, as described here, by providing motivation.

There is no national or international research on the perceptions of children with WS to their educational profile. The findings from this research showed the children had positive and somewhat realistic perceptions of their cognitive profile. They displayed a confidence in their strengths and an awareness of their needs. This linked with their satisfaction with educational setting.

Satisfaction with Educational Placement

The children with WS were presented with additional sentence stems to examine aspects of school which they liked and disliked, their views on how they are perceived at school, and their emotional responses to aspects of school life, all of which could influence their satisfaction with school. This formed the most significant part of the pupil

interview to ensure the breadth of educational experience could be explored within a short timeframe. Some questions were very similar such as 'At school I like …' which gave scope to refer to any aspect of school, and 'At school I like to …' which limits responses to an activity. Such questions were not asked in sequence but are presented in sequence below.

The best thing about my school is …

Three of the children's responses related to activities: "*playing football*" (Charlie), "*play outside*" (Dean), and "*play basketball*" (Brian). Emma's response related to academic performance: "*that I work really hard*", and Gillian's to emotions: "*It's gas*" [fun]. Considering the issues children with WS reportedly have with motor skills (Dilts et al., 1990; Semel and Rosner, 2003) it was surprising that the best thing about school for the majority of these children related to gross-motor skills. Interestingly, this also links with the parent data, where parents indicated their child had strong gross-motor skills. This shows that motor skills, a frequently cited deficit of WS, can be developed through activities which are pleasing to the child. This finding may also indicate such activities aid the over-activity associated with WS (Udwin et al., 2007) or may satisfy sensory issues (Semel and Rosner, 2003). Children with WS may also have identified these physical activities as positive aspects of school life due to associated feelings of inclusion, which would correlate with Balfe and Travers (2011).

At school I like …

Four of the responses related to activities: two were sporting "*playing football*" (Charlie), "*playing basketball*" (Brian), two were curricular "*to do some art*" (Gillian), and "*doing art*" (Emma) (this response was later discarded), and one was social "*my friends*" (Dean). The theme of gross-motor activities and peer socialisation is again evident. Reference to art, which requires fine-motor skills, was also surprising considering the poor visuospatial memory associated with WS (Vicari et al., 1996).

At school I like to …

All responses concerned activities: two were social "*play with Amy*" (Charlie); "*play with my friends*" (Emma), two physical: "*play basketball*" (Brian); "*play on the swings*" (Dean) and one curricular "*draw and do PE*" [Physical Education] (Gillian). There was consistency in the responses, as results show the children, once again, preferring physical and social activities.

At school I don't like …

There was significant variance in responses to this sentence stem. Dean said "*I'm not quite too sure*". Charlie who has significant health issues said "*Paralinks*" [a

suppository], while Gillian identified "*sandwiches*". Emma said "*I don't like playing with the boys*", possibly revealing a compliance to her mother's viewpoint. Brian, who has ADHD, related his response to negative behaviours "*telling, being mean or bold*", showing an awareness of his behaviour.

At school I don't like to …

Dean and Brian did not respond to this. Charlie related it to a previous school incident: "*hurt my ankle*". Gillian's concerned an activity "*jump*" (gross-motor skills), while Emma's related to curricular activity: "*do art*" (fine-motor skills). She had previously referred to liking art. It was confirmed after the interview she does not like art.

At school I hate when I have to …

Two children referred to writing; "*write*" (Gillian) and "*do my Just Write*" [handwriting workbook] (Emma), Brian's referred to behaviours: "*be bold, be naughty*". Charlie, once again, indicated his dislike of suppositories: "*get the Paralinks*", and Dean answered "*I don't know what 'hate' is*" (imitating the researcher's exact pronunciation, tone and expression for the word *hate*). Fine-motor activities were clearly less popular than gross-motor skill activities. Brian again displayed awareness of his behaviours and their consequences. Charlie's mention of suppositories shows how health issues affect his educational experience. It was also unusual to have a child (Dean) in his fourth year of school claiming not to understand the word 'hate'.

Overall, preferred aspects of school life included physical and social activities. The least liked areas of school life showed fewer patterns although the children generally disliked areas they found difficult. Gillian, who does not like to write at school can play the violin, which shows the scope of developing fine-motor skills through preferred activities. This development of fine-motor skills through music has recently been proposed by Levine et al. (2013). Brian, who has ADHD, linked his behaviours with aspects of school which he disliked or hated, displaying an awareness of the impact of his behaviours, linking with the 'theory of mind' associated with WS (Plesa-Skwerer and Tager-Flusberg, 2006). This self-awareness was evident in all interviewed children, showing capacity to involve them in their individual education planning (IEP) process.

The answers to the following five sentence stems gave some indication of the attitudes of the children to aspects of school and thoughts of how they think they are perceived by teachers and peers.

My teacher is …

Overall, the children gave literal answers to this stem. Four of the five children named their teacher. Gillian replied "*nuts*". Her mother later indicated Gillian had a poor relationship with her teacher.

My teacher thinks I'm …

All answers were positive showing no difference between placements. This included "*good*" by four of the five children and "*good at eating*" by Charlie. The latter answer indicates positive reinforcement with an eating programme devised by Charlie's teacher and highlights the effect of teacher feedback. These findings support the claims of Norwich and Kelly (2004) that pupils with SEN report good relationship with their teachers.

My friends at school think I'm …

Answers included "*unbelievably mad*" [great fun] (Gillian), "*good*" (Dean), "*happy*" (Brian), "*friendly*" (Emma) and "*a brave boy and know my name*" (Charlie). Charlie fell at school nine months previously and broke his femur; this was his second reference to the incident. All responses were positive, revealing good levels of self-esteem, and a sense of belonging and acceptance among their peer group, regardless of setting, which contrasts with the sense of difference that Motherway (2011) reported for some pupils in special schools.

When I go to school in the morning I feel …

Four of the five children referred to positive emotions: "*happy*" (Charlie, Brian and Emma) and "*well*" (Dean). Gillian answered "*different*". This reveals positive experience of school, similar to findings by Ware et al. (2011) for other pupils with SEN.

This group of questions showed levels of satisfaction with school placement by children with WS by examining their perceptions of different aspects of school life. Overall, the responses were very positive for all children. There was little difference between those children with WS in mainstream settings and those in special settings, although they were slightly less positive for Gillian who was in a special school. She was the child who referred to her teacher as "*nuts*", said she felt "*different*" going to school in the morning and found homework "*lame*". This child had a poor relationship with her teacher but she was also the oldest to be interviewed so her age may be more significant than any other factor. This finding on satisfaction broadens the assertion of O'Keeffe (2011) that learners with SEN in mainstream have positive experiences of school.

The next group of sentence starters related to aspects of school life that elicit a specific emotion from the children.

At school I feel happy when …

Two responses related to activities. Gillian's was social: "*I have birthday parties*", Dean's related to everyday activities: "*I go outside*". Charlie's, once again, concerned health issues "*my pain in gone*". Two responses related to behaviours which elicited positive responses: Brian said "*I smile",* which was a consequence of being happy rather than a cause. He was subsequently asked what made him smile at school and he said "*being good*". Similarly, Emma said she feels happy when "*I am working*", again indicating effects of teacher feedback, and perhaps parental feedback.

At school I feel scared when …

Two responses were idiosyncratic. Charlie answered "*the monsters come in*". It was unclear if this related to a particular school event (such as a drama performance or story) or whether it was a general fear of monsters. Brian said "*I'll be like a clown*", which did not appear to fit with the stem, unless he meant he had a fear of clowns. Gillian and Emma stated that being shouted at by their teacher made them feel scared, and Dean said "*I don't know, I don't feel scared*". This opens a debate on the emotional understanding of children with WS and also highlights possible causes of anxiety, including the effect of teacher behaviour. Gillian and Emma's response correlates with Dykens and Rosner (2006) who found 85% of people with WS feared getting reprimanded, 79% feared making mistakes and 78% feared getting criticised.

At school I feel worried when …

Dean admitted "*I don't know*" and Charlie said "*I'm sad*". Charlie's response is difficult to interpret. It may show confusion of emotions, which was surprising considering Charlie's very good language and comprehension skills to that point in the interview. It may also indicate feeling worried if feeling sad. This links with the intensity of feeling expressed by people with WS, as described by Levine (1993) and Einfeld et al. (1997), and Charlie may be afraid of the intensity of sadness. Two responses concerned negative behaviours: "*someone's being mad, someone being in trouble*" (Gillian) and "*if the principal ground m*e" (Brian). Emma's response centred on poor academic performance "*something's wrong*" [incorrect]. These responses again show a possible link between anxiety and teacher behaviour, and again correlate with findings by Dykens and Rosner (2006). Responses also show a lack of understanding of basic emotions in some children with WS.

At school I feel angry when …

All the interviewees understood the emotion of anger. Three children referred to teacher or others' behaviours: "[teacher] *never lets me go to the hall*" (Charlie), "*my teacher would be bold to me*" (Brian) and "*somebody's mean*" (Emma). Gillian's related

to academic activity: "*I have to do homework*" and Dean said he was "*just happy*" at school. These responses again indicate the impact of others' behaviours and suggest the challenging behaviours associated with WS may be an unexpressed emotional response to the behaviours of others. These responses mirror the sources of anxiety identified by Dykens and Rosner (2006) in individuals with WS.

At school I feel embarrassed when …

Some responses may indicate poor understanding of embarrassment: "*I'll be tired*" (Brian) and "*I'm doing my work*" (Emma), unless this indicates feeling different to peers and being embarrassed as a result. Dean did not respond. Two children showed good understanding of the emotion. Charlie's related to peer perceptions: "*Amy thinks I'm a big bossy boiler*". Gillian's response related to peer behaviour "*Someone calls me names*".

There are no studies done to date with which this data can be compared regarding emotional responses to aspects of schooling in children with WS. The children's responses showed individual consistency with clear observable patterns running through the responses of each child. Brian had ADHD and made frequent reference to behaviours and activities. Charlie's health issues impacted clearly on his educational experience. Dean did not identify anything which he disliked at school and except for 'scared' did not communicate an understanding of negative emotions (worried, angry, embarrassed, hate). Emma was eager to please. Her mother frequently gave verbal feedback and reinforced answers regarding conformity and academic performance. Gillian showed that her negative emotions were strongly related to others' behaviour. Her mother reported some behavioural issues which, from Gillian's perspective, appear to be emotionally based and may be compounded by the poor relationship she has with her teacher.

Conclusion

Children with WS had positive experiences of school, regardless of placement. Similar to findings by Ware et al. (2011) regarding children with SEN, these children displayed a sense of belonging and felt they were liked by their teachers and peers. There was no indication that children in special settings experienced unease at how they or their schools were perceived by others, as found by Motherway (2011). Their favourite activities were physical and social, reflecting the over-activity and hypersociability associated with WS, yet contrasting with a profile which indicates poor motor skills and poor peer socialisation (Dilts et al., 1990; Udwin et al., 2007). These findings indicate physical activities and social outlets may be important aids to concentration,

participation and hence, inclusion. The children had fewer responses and fewer commonalities regarding areas of school life they disliked. There is no other research on the perceptions of children with WS of school with which to compare these findings.

The children also had clear images of themselves as learners and could identify both strengths and challenges. Interestingly, their perceived strengths were generally academic and appeared to relate to areas of regular positive teacher feedback. The centrality of the relationship with their teacher was underscored through responses to various sentence stems and links with the emotionality described for WS (Einfeld et al., 1997). Some children displayed poor understanding of negative emotions. There was some correlation in responses regarding what made them feel scared, worried or angry, frequently related to teacher or peer behaviour. The impact of others' behaviours may have a significant impact on their learning. Considering the emotionality of WS (Einfeld et al., 1997), this impact may be much greater than for other children without WS.

The findings of this study clearly indicate that children with WS can be part of research and are effective in articulating their perceptions and experiences. Sentence-completion tasks proved useful with children with WS.

CHAPTER 7: INCLUSION OF CHILDREN WITH WS:
REFLECTIONS ON CURRENT EVIDENCE

Introduction

This chapter merges the findings presented in the previous three chapters to discuss pertinent issues regarding the inclusion experiences of children with WS in Irish primary schools as perceived by the children themselves, their parents and teachers. The discussion, based on the research questions, centres around the following themes:

1. WS educational profile
2. Choice of educational placement
3. Satisfaction with educational placement
4. Supports for learners with WS

A number of barriers to inclusive learning emerged, some associated with the inclusion continuum and, therefore, placement-dependent. These are discussed in the light of other research on WS and from the wider field of SEN. To support the transformative underpinning of this research, some solutions which emerged from the findings are explored and recommendations made within relevant themes.

Perceptions of the WS Educational Profile

The knowledge of a learner's cognitive profile impacts on the effectiveness of teaching and learning (Reilly and Senior, 2007; Rose and Howley, 2007). There were high levels of correlation between parental and teachers' descriptions of the educational profile of children with WS around all themes with some variations in the sub-themes. The high correlation between parents and teachers was encouraging as parents are important sources of WS information for teachers (Fidler et al., 2002). The overall perceived profile mirrored profiles described by Mervis et al. (2000), Semel and Rosner (2003) and Levine et al. (2013). In addition, the majority of children with WS were able to share their experiences of school life which has added a new knowledge base to the WS educational profile: that of learner self-perceptions. The findings on the WS educational profile highlighted a number of issues relating to educational inclusion. These concern assessments, literacy, mathematics, child protection, music, emotionality and anxiety, behaviours and motor skills, which are discussed below.

Assessments

The findings on assessment indicate insufficient use of assessment data to procure inclusive learning for some children with WS. Mainstream class teachers generally used a narrow range of assessments to evaluate the child's capacity, and frequently

utilised norm-referenced or summative tests. As a result, most mainstream teachers were surprised by the child's intellectual capacity, a common phenomenon due to the peaks and valleys associated with WS (Lenhoff et al., 1997). Summative assessments may not suit children with WS due to the writing demands, the timeframe required to complete the test and associated anxiety of assessments, which may result in depressed scores. Interpreting these results in isolation 'may provide a misguided sense of development' (Annandale et al., 2004:105). DES inspection reports of special schools in Ireland show little evidence of assessment information being used to inform teaching and learning (Douglas et al., 2012). By contrast, it was teachers in special settings and LS/RTs in mainstream schools in this study who most commonly tailored assessment procedures to suit their learners. This included an assessment for learning approach, which is known to have a particularly positive effect on low achievers (Black and William, 1998).

As poor assessment hinders effective teaching (McPhillips et al., 2010), this may reduce the academic inclusion of children with WS. Therefore, to maximise these children's inclusion, as with all children, teachers should establish baseline data and build on the child's knowledge, skills and concepts (King, 2006). Effective ways of knowing the child's capacity, proposed by participants, were the use of multiple choice questions which reduced learner writing demands, consultation with previous teachers and using the IEP for baseline data. Douglas et al. (2012) advocate the need for measuring outcomes, progress and engagement in children with SEN. This study concurs and highlights the need for teacher education in the area of assessment to effectively measure these elements to enhance the academic inclusion of children with WS in all curricular areas, but particularly in the areas of literacy and mathematics.

Approaches to Literacy

Parents reported the success of phonological programmes using musical approaches, which reinforces the value of using learners' strengths (Tiesco, 2002). All teachers in this study used phonics coupled with a whole-word approach to teach reading. The phonetic approach recommended by Udwin et al. (2007) was found beneficial by teachers until blending was introduced. Consequently, whole-word approaches were used and found to work effectively, contradicting Laing (2002) and Mervis (2009). Difficulties with early-reading comprehension were reportedly masked by strong word-reading ability, and became evident in the middle standards of primary school, a common pattern for children with WS (Levine et al., 2013). Both parents and teachers indicated poor reading comprehension impeded the child's inclusion across the curriculum in mainstream settings. Yet two of the four children in mainstream settings

used the class reader despite these difficulties. This indicates poor differentiation and inadequate teacher understanding, which links with ineffective assessment procedures.

These findings reinforce broader international findings that insufficient focus on learning and inadequate differentiation are barriers to inclusion (Mowat, 2009; Deng, 2010). Only two teachers in this research talked about the child's reading readiness. Teachers with SEN qualifications or experience were most likely to develop the children's reading comprehension. Across the inclusion continuum, the most holistic approaches to reading were apparent in special settings and included the use of language experience approach. While these findings add to the literacy profile of learners with WS, there remains a need for research on the connections between literacy development in the mother tongue and in learning other languages.

Second and foreign language learning in WS is a phenomenon not generally discussed in the literature, although it is briefly alluded to by Semel and Rosner (2003). The finding from parents and teachers regarding some children with WS and their use of Irish was, therefore, unexpected. It showed an ability to learn Irish and use it spontaneously in different contexts. This transfer of skills is frequently a challenge for learners with SEN (King, 2006). Teachers indicated that the interactive methodologies used most frequently in teacher Irish to junior classes suit the learning style of children with WS. While many pupils with SEN in mainstream schools, and all pupils in special schools, are entitled to an exemption from Irish, Ware et al. (2011) claim such exemptions impede the inclusion of children with SEN in school and in society. This research concludes that an exemption from Irish is a systemic barrier to the educational inclusion of learners with WS and proposes these exemptions should not be assumed for learners with WS. Consistent and appropriate differentiation should be implemented at all stages of primary school for these learners. The teachers in the study concurred with this. Most were inclusive in their approach to the teaching of Irish in the junior classes, and many felt the child engaged and participated fully in Irish lessons, particularly where approaches included music.

Music

Along with music being associated with language learning, parents and teachers also described music as an aid to engagement, comprehension and mood for children with WS, as previously identified by Stambaugh (1996) and Lenhoff (1998). However, music was generally not used for such purposes in educational settings. Indeed, an academic rather than creative mediation of the music curriculum was described by some mainstream teachers. Consequently, no child in this study alluded to musical activities in their interviews, despite it being deemed a much loved activity of individuals with WS

(Semel and Rosner, 2003). Textbook-based music programmes may actually impede the inclusion of children with WS due to the children's associated distractibility, poor comprehension and poor writing skills. This research recommends the creative implementation of the music curriculum with regular opportunities for the child with WS to play musical instruments, to compose and to develop an appreciation and understanding of different musical genres, in line with the content objectives of the music curriculum (Ireland, 1999b). Some parents found musical interventions greatly supported their child's learning, yet only four of the ten teachers used **any** of the child's aptitudes to devise strategies for learning and behaviour. These teachers had either SEN qualifications or experience of teaching in special settings. In addition, Dykens and Rosner (2006) found music could reduce the anxiety, fears and maladaptive behaviours associated with WS. This needs to be researched in an educational context, considering findings in the current study link anxiety to maladaptive behaviours, to ascertain if musical interventions could positively impact on the anxiety, behaviours, and, hence, inclusion of children with WS. Furthermore, the successful approach of using music to enhance maths skills in young adults with WS (Reis et al., 2003) should be trialled on children with WS of school age.

Mathematics

Both parents and teachers identified maths as challenging for almost all the children with WS, showing high correlation to the literature (see Levine et al., 2013). They found discrepancies between the child's ability to count, order and sequence numbers and their concept of number, features associated with the WS profile (Camp et al., 2012). Teachers in all settings expressed uncertainty about mathematical-concept development. Only one child made reference to maths in the structured interviews where it was identified as an area with which he needed help. It was neither a liked nor disliked aspect of school and did not elicit an emotional response from any child, contrasting with Reis et al. (2003) who found maths to be a perceived area of weakness and anxiety for young adults with WS.

There was no agreement among teachers in the current study on effective strategies or resources for mathematics. This lack of knowledge, experience and expertise is commonly identified as a barrier to inclusion for children with SEN (Rose and Shevlin, 2010; Forbes, 2007). The recommended interventions by Udwin et al. (2007) such as using concrete materials were implemented by all teachers but did not ensure the child's success. Some parents described supporting their child's maths homework by using the child's interests or a musical approach. King (2006:88) recommends a programme of work based on the child's current mathematical understanding given the 'cumulative aspect to mathematics', although this is dependent on effective

assessment procedures. One school used computer programmes successfully to support the child's maths skills and increase his motivation. Technology facilitates curriculum access for learners with SEN and provides opportunities to produce work better matched to their ability than written work (King, 2006). There is scope for more research into mathematics to ascertain if such resources as *Numicon*, recommended for learners with DS, would benefit children with WS or if focusing on the strengths (particularly with music and sociability), as proposed by Tiesco (2002) and Reis et al. (2003), consistently yield successful outcomes.

Child Protection

The social strengths of children with WS make them impact positively on their peers and on the school in general, as evidenced from this research, and previous research (Mervis et al., 2000; Plesa-Skwerer and Tager-Flusberg, 2006). The children were deemed socially included in all settings by parents and teachers and they felt themselves to be perceived positively by peers and teachers. However, almost all teachers and parents referred to their concerns regarding 'stranger danger', yet not all teachers dealt with this. The fear of sexual abuse is commonly associated with parents of children with WS (Stinton and Howlin, 2012) not least because children with WS initiate contact with strangers (Dodd et al., 2010). The instinct to please others, a common feature of WS, increases their risk of abuse (Semel and Rosner, 2003). The most recent study on 'stranger danger' in WS concluded that there are substantial implications for the safety of individuals with WS, which emphasises the need for appropriate interventions (Riby et al., 2013b). It is imperative that teachers ensure the child with WS is more than physically included in child-protection modules. This research recommends the inclusion of targets concerning child protection in each child's IEP. Programmes should be presented in a way to suit the emotional understanding of the child to maximise their participation and engagement.

Emotionality and Behaviour

This study found children with WS able to articulate responses to sentence stems relating to emotional content quite successfully, although some showed poor understanding of negative emotions. This extends the knowledge that negative emotions are difficult for children with WS to express (Semel and Rosner, 2003) by showing it may be due to poor comprehension of the vocabulary of emotion. Considering the emotionality associated with WS and the indication of links between emotion and behaviour from this and other research (see Einfeld, 2005), the understanding of emotions is significant. It was apparent from teacher findings that maladaptive behaviours impacted on the child's academic and social inclusion.

Therefore, dealing with such behaviours is key to improving the child's educational inclusion (NEPS, 2010). This research also found fewer behavioural incidences over time in younger children as their vocabulary and language skills developed. This increases the scope to investigate if certain behaviours are reduced through emotion-related language development. Therefore, this research recommends the explicit teaching of emotional vocabulary, linking it to children's own experiences of emotion and, consequently, devising appropriate strategies for expressing such emotions.

Children with WS frequently linked their negative emotions to those of others, correlating with Dykens et al. (2000) who surmise that fears of arguments, teasing and punishment may relate to the empathic orientation of WS. Most teachers did not identify such effects, but the children with WS identified these as causing them to feel worried or afraid. This may be showing that children with WS internalise these emotions, which adds significantly to the literature on internalising behaviours in WS (see Dykens and Rosner, 2006). This is of consequence. Parents, much more than teachers, identified triggers to behavioural incidences as specific negative words and voice tones, which they related to sound sensitivity. More parents than teachers also reported hyperacousis; this difference is not apparent in any literature. It contrasts with reports of high reactivity and low self-regulation (see Semel and Rosner, 2003) and indicates there may be more self-regulation in children with WS than previously thought. This may actually increase distractibility, thereby negatively impacting on the child's academic and social inclusion. Teachers, by contrast with parents, described social strategies used by the child, which in the light of this research, suggest may serve to influence the teacher's mood. This poses a new hypothesis of whether sociability is masking high anxiety in WS in educational contexts.

Motor skills and Adaptive-Living Skills

In contrast to consistent reports of visuo-motor challenges in WS (see Dilts et al., 1990; Scheiber, 2000), parents reported good gross-motor skills and many of the children identified sports as preferred school activities. Yet mainstream teachers found gross-motor difficulties impeded the child's inclusion in certain activities, correlating with Semel and Rosner (2003). However, handwriting was an identified difficulty by both parents and teachers. It caused significant issues to the children, both in learning to write and, in mainstream schools, when participating in curriculum activities. Three children identified handwriting as an aspect of school they found difficult or hated. This fits with the documented fine-motor profile of WS (see Bertrand et al., 1997). Parents and teachers indicated conflicting advice from professionals regarding handwriting versus computer use. Udwin et al. (1987) and Levine et al. (2013) recommend use of computers to limit writing output and prevent fatigue. Teachers are also advised to

examine the developmental stages of writing and extend the child's activities accordingly, as writing skills follow a predictable sequence (Westwood, 2007). The findings indicated that the majority of mainstream teachers do not do this for children with WS, which again links to inadequate assessment procedures. Handwriting could also be developed through social or musical channels in line with a talent-development approach (Tiesco, 2002; Reis et al., 2003). Similarly, this approach could be used to enhance the development of self-help skills which were slow to develop in the children in this study, similar to most children with WS (Udwin, 1990). These skills will impact on individual children's inclusion in society in adult years.

Individuality

Despite much consistency in the findings from parents, teachers and children with WS this study portrayed heterogeneity in the WS population. Each child displayed a unique personality and combination of likes, dislikes, interests and emotions. Anyone working with them must remember that they are individuals with WS rather than WS individuals. This distinction should be understood. It is quite clear from the findings that WS does not define the child. Indeed one of the children in this study did not fit the 'classic' WS profile to any degree. Levine et al. (2013) also warn of the deceptive nature of group-described traits when working with individuals with WS. The overt attention to individuality is drawn by the NCSE (2011b) but is sometimes missing in SEN literature for educators. Indeed Reis et al. (2003) found individual strengths, interests and learning styles impacted most on the learning outcomes of individuals with WS; thus, failure to accommodate them could be a barrier to their educational inclusion.

Choice of Educational Placement

Some parents of children with WS indicated difficulties in selecting and securing appropriate educational placements. While children should not be refused enrolment on the grounds of SEN (Ireland, 1998), two of four parents indicated that, while they were not overtly refused enrolment, they were strongly discouraged from enrolling their child in mainstream schools. This reflects similar findings by Shevlin et al. (2008) for children with SEN, but indicates higher levels than those reported four years earlier by Flatman-Watson (2004). This may be indicating an increase in such practices. Despite such exclusionary practices the children's teachers were welcoming of the child with WS and did not display negative attitudes as described by Chazan (1994) or Farrell (2000) for children with EBD. Indeed, all children reported positive teacher perceptions of them, regardless of placement. Some parents of children with WS sought only mainstream placements while others sought only special placements reinforcing assertions by Runswick-Cole (2008:176) that parents hold 'complex and conflicting

views about the policy and practice of inclusion'. The current study voices concerns that two parents were discouraged from enrolling their child in special settings by educational professionals and one parent found it difficult to secure a special placement. Similarly, Armstrong et al. (2010) described parents of children with SEN in Ireland finding it more difficult to access special placements than mainstream placements. It appears contradictory for professionals to discourage parents from choosing special settings until there is evidence that the services provided to children with SEN in mainstream are matched or better than those currently provided in special placements. There are currently no studies to compare provision. Interestingly, this is the second systemic barrier to inclusion identified in this study for learners with WS.

It is of concern that inclusion is not seen as a continuum, but as two disjointed continua, which are, in essence, one directional. Indeed, some parents indicated their choice for mainstream over special as it facilitated movement from mainstream to special but not vice versa. While this research points to very successful movement along the inclusion continuum through a special class, this is not borne out in the literature. Ware et al. (2009) report that half of special classes in Ireland do not promote inclusion to mainstream classes.

Many parents and teachers expressed concerns about the model of allocating resources to children with WS which also affected parents' choice of educational placement. Some parents described psychologists changing professional reports based on the setting chosen by parents. Some parents also had to get additional assessments to gain resource hours for their child in mainstream placements. Similarly, Armstrong et al. (2010) found that parents of children with SEN frequently seek private assessments to gain resources. The NCSE (2013f) has called for a revised model of resource allocation. The current research increases the evidence base that this is necessary. Indeed, resource allocation impacts on parental and teacher satisfaction with the child's placement.

Satisfaction with Educational Placement

Each stakeholder group was generally satisfied with the child's educational placement. All parents felt their child was appropriately placed, similar to other Irish parents of children with SEN (Armstrong et al., 2010), but contrasting sharply with Scallan et al. (2011), who claimed poor teacher knowledge and inadequate differentiation were stressors for parents of children with WS. However, Scallan's study included parents of children educated during the 1970s and 1980s when there was less awareness of inclusive education, and hence, less parental satisfaction. The current study identified the child's happiness as the most important indicator of satisfaction by parents. By

contrast, this was ranked fifth most important for parents of children with ASD in the UK (Whitaker, 2007), which may indicate differences between SEN groups. All parents described their child with WS to be happy at school, regardless of placement, higher than other studies on satisfaction of pupils with SEN in Ireland (O'Keeffe, 2011). Similarly, teacher participants frequently described the child with WS as happy and settled, and all but one child said they were happy going to school. The children also identified more positive than negative aspects of school, similar to other Irish learners with SEN (see Ware et al., 2011). None of the children in special settings showed any concern about how their placement was perceived by others, as found by Motherway (2011).

Academic Inclusion and Progress

All parents expressed satisfaction with their child's progress, higher than an earlier study involving parents of children with SEN in Ireland (Armstrong et al., 2010). This was despite the fact that for some children with WS in mainstream settings the curriculum got more restricted over time, an observation previously noted for other learners with SEN (O'Keeffe, 2011). Parents did not express concern at this. This strengthens previous assertions by Armstrong et al. (2010) that parents often have low expectations for children with SEN in Ireland. Some mainstream teachers also expressed concern at the widening educational gap between children with WS and their peers, which they linked to the child's needs. However, recent research found that children with SEN who were 'taught' academic content by teaching assistants (SNAs) rather than teachers had less appropriate and lower-quality pedagogical experiences than that of their peers (Webster and Blatchford, 2013), hence more explicit teaching by the class teacher may actually reduce the widening gap they described.

Some mainstream teachers also referred to the child's lack of engagement which teachers in special settings did not describe. This lack of engagement, frequently reported for pupils with SEN, is commonly blamed on pupil characteristics, curriculum content and lack of appropriate materials (Coffey, 2004). Some teachers placed too much responsibility on the child with WS to conform to peer standards, which indicates inclusion being interpreted as treating all pupils equally. It is also worth noting that poor engagement can be the result of high anxiety (Schoenfeld and Janney, 2008), evident in many children with WS (Udwin et al., 1987). Day and Prunty (2010) claimed adaptations of curriculum were down to school placement, being more learner-centred in special settings. However, the current study showed teachers with SEN qualifications or SEN experience felt they had a range of strategies and approaches to draw from, and they were less likely to delegate academic differentiation to the SNA.

All the children in this study were very aware of learning areas with which they needed support, similar to findings of other Irish researchers including Balfe and Travers (2011) and Flynn et al. (2011) who value and respect the learner insight. However, it appears that the learning strengths identified by the children were not necessarily the strengths identified by teachers or parents. They were usually learning challenges at which they worked, thereby showing the importance of regular positive feedback for the learners.

It can be concluded from the findings from parents, teachers and learners with WS that academic inclusion varied. It also shows discrepancies in their understandings of inclusion, inclusive education and inclusive schools (Clark et al., 2004) and indicates the need to explicitly define inclusion in any research concerned with this topic. This is discussed further in the next chapter.

Social Inclusion

There were some similarities across the inclusion continuum regarding the social inclusion of children with WS. Parents and teachers of children in mainstream described the child's social inclusion as having friends at school and being invited to the birthday parties of class peers, yet there were issues with the establishment and maintenance of genuine friendships. This concurs with previous studies on WS (Udwin et al., 1987; Levine, 1993) and with findings by White (2007) and Fennell (2008) regarding socialisation difficulties of children with SEN in Irish mainstream schools. Children with WS in special settings had school friends, but these were generally not maintained outside of school, due in part to the wide catchment area. Despite difficulties with maintaining peer relationships only one parent was proactive in developing school friendships; the reasons for this are elusive. According to Turnbull and Reuf (1997) parents of children with behavioural challenges express a lack of hope of their child making real friends. This did not appear true of the parents of children with WS. Kenny et al. (2005) claim that with mainstream inclusion, parents fear rejection, which was implied by some parents but never explicitly stated. Regardless, all parents engaged their children in out-of-school activities which provided them with additional social inclusion opportunities.

The most successful placement on the inclusion continuum for social inclusion was the special class, where, with phased inclusion, the teacher could develop and implement individual socialisation interventions for the child and for his mainstream peers. His challenges with feeding and toileting were managed away from his peers, within the special class which helped maintain his dignity. Such positive findings on social inclusion are not implicit with special classes in the Irish context (Ware et al., 2009) and should be interpreted as a model of good practice.

Teachers who developed social interventions for the children with WS had SEN qualifications or experience of teaching in special settings. Where such interventions were implemented they had a positive outcome, similar to outcomes described by Fennell (2008). Regardless of whether interventions were in place or not, the children with WS described perceptions of positive peer attitudes towards them and a sense of belonging, similar to other children with a range of SEN (see Norwich and Kelly, 2004). The children with WS identified activities they enjoyed which were frequently social in nature, but not 'socially intense' such as physical activities. This research indicates a need for social-skill development in the learning programme of children with WS as social inclusion will not happen automatically, despite their sociability. It is also imperative that SNA support for individual children does not reduce the child's opportunities for peer interaction, in formal lessons or during break-time socialisation.

Special Needs Assistants

The most noteworthy resource, noted by parents and teachers in mainstream settings, was the SNA. This topic was not broached with the pupils, which was a limitation of this study. There was a significant difference in the attitude and perceived role of the SNA between mainstream and special settings. Findings, similar to those of Ware et al. (2011), indicated SNAs in mainstream settings differentiated the taught curriculum, dealt with behaviours, supported adaptive-living skills and monitored the child with WS during break times. Where teachers abdicated responsibility to the SNA, parents did not seem to mind, indeed they viewed the SNA as a one-to-one teacher or personal assistant to the child. This raises the issue that SNAs may impede the educational inclusion of children with WS, a concern also voiced by Blatchford et al. (2009). A later study by Webster and Blatchford (2013) showed that statemented children in the UK with access to teaching assistants had less interaction with their teacher and peers as a result, which impacted on their social and academic inclusion. In the current study, teachers with experience of working in special settings or with SEN qualifications were more proactive in assigning support duties to the SNA and were also more likely to teach and manage adaptive-living skills and behaviours themselves.

Teacher Education and Experience

No teacher had experience of WS before, as one would expect (Oliver and Hagerman, 2007) and many mainstream class teachers felt they lacked adequate skills to cater for the child, similar to other teachers of children with SEN (Farrell et al., 2007; Forlin et al., 2008). SEN qualifications and experience in special settings were the most significant indicators of confident, competent practice, building on similar claims by Cooper and Jacobs (2011) and Rose et al. (2012) in the Irish context, and mirroring international findings (Grove and Fisher, 1999; Elkins et al., 2003). Teachers with SEN

qualifications or experience had a broader interpretation of inclusion evident by being more proactive in including the child with WS academically and socially, whether in special or mainstream, which further supports findings by Gregor and Campbell (2001) and Humphrey (2009). They were more likely to build on the child's strengths and learning style and to implement appropriate teaching strategies, with a wider repertoire to choose from, resulting in less teacher frustration and additional benefits for other learners. They were also the teachers who presented more holistic programmes rather than solely providing academic support, correlating with previous findings by Ware et al. (2009) and Winter and O'Raw (2010) in the Irish context.

This highlights the need for professional development to help teachers develop basic skills to enhance the educational inclusion of pupils. The OECD (2005), WHO (2011) and NCSE (2013f) have been vocal in highlighting the need to improve the quality of teachers and to ensure mainstream teachers have SEN training. In Ireland, the Teaching Council (2011) has mandated the incorporation of inclusive education into all initial teacher education programmes. However, such programmes for currently serving teachers are also needed (Rix et al., 2013) which was clear from this research, particularly as the findings show this has a positive impact on academic, social, emotional/behavioural and life-skill support for individual learners.

Supporting Learning

Both parents and teachers supported the child's academic, social, and emotional/ behavioural needs. Parents specifically mentioned supporting their child's physical development which teachers did not allude to and teachers described supporting pupils' life skills which parents generally did not mention. A number of effective strategies to support the learning of children with WS and promote their inclusion emerged from the data.

Overall, six of the seven parents interviewed felt teachers supported their child effectively and understood their child's needs, higher than the 70% of parents reported in a NCSE report (Armstrong et al., 2010). Individual teachers' attitudes and goodwill were more important to parents of children with WS than their skill or qualifications. However, teachers without SEN qualifications or experience tended to over-rely on general teaching approaches to support the child, with fewer strategies than teachers with SEN qualifications or experience. Parents of two of the three children in special settings found the quality of teachers varied from year to year, and reported a lack of SEN education and experience in some of these teachers which impacted on their child. This may also be symptomatic of poor whole-school practices in individual

special schools which can be a barrier to educational inclusion (NEPS, 2010; Cooper and Jacobs, 2011).

It is interesting that some strategies used successfully by individual teachers to support learners with WS are those traditionally associated with ASD. Visual schedules and other TEACCH materials were used by some teachers, social stories by others and lamh (signing) by one teacher. This raises the question as to the value of TEACCH work-stations for children with WS to support their independent work, free from distractions for specific time periods and to reduce anxiety, or if social approaches should always be promoted considering the social drive of WS. This finding has not been explicitly stated before in the literature and is, perhaps, of greater relevance in Ireland where access to certain special education courses is restricted to teachers of students with ASD, and where teachers of such students are prioritised over other teachers. Similarly in the research, one teacher found lamh signing effective in providing visual cues for the learner with WS. This raises the issue of whether the consistent use of lamh could enhance the comprehension and concentration of children with WS, despite their visuo-spatial challenges. These findings provide a basis on which future research on educational interventions could be based.

Individual Education Plans (IEPs)

It was initially planned that the IEP would be central to the research on the stakeholders' experiences of the educational inclusion of children with WS. The findings on the use of the IEP were disappointing. There was poor communication of the IEP between school and home and many parents were not aware of an IEP for their child, despite teachers having them prepared. Other parents who had an IEP did not find it useful. Yet one teacher felt that the most accurate information she got on the child with WS was from the IEP. As Douglas et al. (2012) have made calls for a system where the progress, participation and outcomes of pupils with SEN can be measured, the IEP could serve this purpose. The IEP holds high potential for enhancing the educational inclusion of children with WS, not least due to the opportunities for parents, teachers and learners to discuss the child's profile and programme of work. It could serve as a forum for parents and teachers to agree on the child's strengths and challenges, and to devise strategies (NCSE, 2006), with the possibility of involving the learner (McCausland, 2005; NCSE, 2006; NEPS, 2010). Only one parent described her child's involvement in the IEP process. Pupil involvement communicates a message that learners' views matter and this contributes to 'a sense of competence and positive self-esteem' (NEPS, 2010:22). Considering the use of IEPs was widespread, albeit with varying practices, an inclusive framework for the education of children with WS is

proposed based on the IEP process, to improve their inclusion, regardless of placement. This is presented in Chapter Eight.

Conclusion

This chapter merged the findings from each of the stakeholder groups. These findings contribute to the inclusion debate as differences in the interpretation of inclusion emerged: it was sometimes interpreted as treating the child the same as peers without needs or the child's physical presence for specific learning experiences rather than encompassing participation, engagement or outcomes, particularly in mainstream settings.

There was high correlation between teacher and parent perceptions of the WS educational profile and that of previous researchers (Mervis et al., 2000; Semel and Rosner, 2003) with some differences. Despite a clear profile emerging, individual differences were also noted, as emphasised by Reis et al. (2003). The sociability of the children reportedly enhanced their initial inclusion, yet the 'valleys' of their educational profile reduced their educational inclusion, particularly in mainstream settings.

The perceived learning challenges of the child were not always addressed in mainstream settings, oftentimes with an over-reliance on the SNA for differentiation. Inadequate assessment procedures significantly impacted on teaching approaches and programmes of work, and literacy difficulties reduced the child's participation and outcomes across the curriculum, an issue previously raised by King (2006). However, the learning of Irish and other languages was an identified strength for most children with WS regardless of setting, a capacity not previously discussed in the literature. This finding is of significance considering the automatic entitlement to an Irish exemption for these children in Irish schools. This highlights a systemic barrier to their academic, social and cultural inclusion, not been previously addressed for this group of learners.

Parental choice of educational placement was complicated by soft barriers to enrolment in some mainstream schools, as already indicated by Shevlin et al. (2008) and Rose et al. (2010), and by insufficient places available in special settings or professional discouragement from choosing a special setting, also previously reported in Ireland (Armstrong et al., 2010). This was another systemic barrier to inclusion. Findings indicate that parents see two inclusion continua: special education versus mainstream. The continua are interpreted by some parents and teachers to be one directional with movement from mainstream to special but rarely vice versa. This in not discussed in previous reports on parental choice of educational placements.

Satisfaction with placement was high; all parents felt their child with WS was appropriately placed, similar to parents of children with other SEN (Armstrong et al., 2010) and much higher than a previous WS study (Scallan et al., 2011). While most teachers were satisfied that the child was making progress, some mainstream teachers indicated some concerns about the child's academic inclusion, particularly the widening ability gap. Despite this, the parents of children with WS appeared more satisfied with their child's academic inclusion and progress than parents of other children with SEN (Armstrong et al., 2010). This was dependent on interpretations of inclusive learning. The quality of interventions, both academic and social, was dependent on teacher education and experience. Despite high levels of correlation between parent and teacher perceptions of learner profile, the IEP was not cited as an important forum for discussing this. Indeed, it did not emerge as a valued process by most parents or teachers.

This study proposes a number of avenues to be further explored which have the potential to enhance the educational inclusion of learners with WS. The first is developing an understanding of negative emotions in children with WS and teaching them a vocabulary to express themselves appropriately which should enhance their social inclusion. Secondly, specific interventions such as, lamh, social stories and TEACCH should be trialled in different educational settings to ascertain their effect on engagement, comprehension and anxiety. Many of these interventions were used in special settings or by teachers who had experience of teaching in special settings. This raises the question of which placement procures the most inclusive learning.

The following chapter answers each of the research questions and proposes a definition of inclusion on which the educational placements of children with WS can be compared. It also presents a framework to enhance the educational inclusion of children with WS based on this definition, regardless of placement.

CHAPTER 8: TOWARDS AN INCLUSIVE FRAMEWORK FOR CHILDREN WITH WS IN IRELAND

Introduction

While the topic of inclusion has been researched for decades, this is the first time it has been studied from the perspective of WS. Considering the enigmatic cognitive profile of WS (Mervis et al., 2000), the inclusion debate is furthered by examining the educational inclusion experiences of children with WS. This research has highlighted a number of issues for children with WS, their parents and teachers, which were described in the previous chapter. It is apparent from the literature (see Croll and Moses, 2000; Forlin, 2010a; O'Gorman and Drudy, 2010) and from the findings of this research that inclusion is sometimes assumed to be synonymous with mainstreaming. Different definitions of inclusion were discussed in Chapter Two (see Norwich, 2000; Farrell and Ainscow, 2002; Day and Travers, 2012) and various interpretations of inclusion emerged from both parents' and teachers' data in this research encompassing assimilation models, locational integration, social inclusion, and inclusive learning.

This chapter starts with a summary of the key findings in relation to the broad research questions regarding the experiences of educational inclusion of children with WS from the perspectives of parents, teachers and children. Subsequently, three main contributions to the inclusion debate are presented in this chapter. Some differences in experiences were evidently related to placement and connected to individuals' interpretation of educational inclusion. This dilemma of definition makes it difficult to compare provision in different settings for children with WS. Therefore, firstly, a definition of educational inclusion is proposed. On the basis of this definition the experiences of the educational inclusion of children with WS are compared: the experiences of those in mainstream and those in special settings, to ascertain which placement was the most inclusive. This adds to the current understanding of inclusion in the Irish context. Thirdly, a framework to enhance the educational inclusion of learners with WS is proposed, based on the barriers to inclusion and examples of good practice identified in this research.

Summary of Key Findings in Relation to Research Questions

1. What are the experiences of parents concerning the educational inclusion of their children with WS?

Overall, parents reported positive experiences of their child's educational inclusion, in all settings. Their perception of their child's educational profile correlated with the literature (Mervis et al., 2000; Semel and Rosner, 2003; Udwin et al., 2007) regarding aptitudes, perceptual and motor performance, maladaptive behaviours, literacy (reading) and mathematics. Deviations from the literature concerned gross-motor skills and language, with a lower prevalence of hyperactivity and hyperacousis than previously reported (Dilts et al., 1990; Leyfer et al., 2006) and a greater intensity of anxiety than previously described (Howlin and Udwin, 2006). As the primary source of WS information for teachers (Scallan et al., 2011), parents' accurate perceptions are important (Fidler et al., 2002). The most overt features of the seven children in the sample were the aptitudes of sociability, curiosity/special interests, auditory memory and musicality; perceptual and motor skills challenges (fine-motor skills, adaptive-living skills, tactile sensitivity), maladaptive behaviours (distractibility, anxiety and over-activity), language strengths (verbal memory and language pragmatics), reading ability (decoding and phonological awareness) and difficulties with mathematical concepts.

The child's sociability enhanced their educational inclusion. Behavioural issues, in particular, negatively impacted on it. This research suggests greater internalising behaviours in children with WS, in natural settings, than previously believed. Indeed, some researchers have attributed some challenging behaviours to frustration (Semel and Rosner, 2003). However, this study indicates that anxiety, poor understanding of negative emotions and an inability to express emotions may cause maladaptive behaviours in children with WS. This contrasts with the classic verbosity of WS (Mervis et al., 2000), where expressive language is an attributed strength of WS. Indeed, another significant finding in relation to language was parental descriptions of a language-learning capacity for Irish and other languages, an aspect of language not previously discussed in the literature. Despite this ability, all the children had exemptions from Irish, thereby reducing their academic, social and cultural inclusion in the middle to senior classes of primary school and in special settings. Difficulties with distractibility, reading comprehension and handwriting also impacted on academic inclusion, particularly for those pupils in mainstream whose curriculum frequently became more restricted over time as a result. It is important that all aspects of reading are taught, as longitudinal studies have shown that literacy scores do not improve over time once the person with WS leaves formal education (Howlin et al., 1998). Some differences between settings were noted in the development of literacy.

The factors determining parents' choice of educational setting for their child with WS differed from other Irish parents of children without SEN (see Bleach, 2010). School type was influenced by psychological assessment results, parents' attitudes, the child's needs, and placement availability; school choice was subsequently determined by school structure, supports, and school leadership. The findings suggest that the principle of mainstreaming, in the guise of inclusion, may reduce parental rights to choosing a school for their child; they experience soft barriers to enrolment in mainstream schools, consistent with previous findings by Rose et al. (2010) and Armstrong et al. (2010). Difficulties in securing placements in special settings were also experienced due to demand exceeding supply and discouragement from early-intervention professionals, also reported by Armstrong et al. (2010). Both these points indicate a strong systemic push to mainstream settings; showing that special placements are not always considered part of a single inclusion continuum nor valued as inclusive educational settings. This constitutes a systemic barrier to inclusion. Indeed most parents viewed the inclusion continuum as one directional, with possibilities of their child moving from mainstream to special but not vice-versa. Despite this, all parents were satisfied with their child's placement, dependent on factors relating to their child, their child's teacher and, to a lesser degree, the school. This concurs with previous reports on parental satisfaction by Bleach (2010) and Armstrong et al. (2010). Variations in parents' interpretation of inclusion emerged, in line with the literature (see Farrell, 1997); which impacted on their satisfaction.

There are few studies which have examined parental support for their child's learning but the NCSE (2011b:23) found parents to be 'interested in and willing to take part in their child's education'. All parents were very active in supporting their child's academic, physical, social and emotional/behavioural learning. Support for social development was contradictory as parents involved their child with WS in community groups, but generally were not proactive in establishing or maintaining individual peer relationships from school, thereby showing the complexity of attitudes to social inclusion. No other studies have been undertaken on how parents support the learning of their child with WS.

2. What are the experiences of teachers concerning the educational inclusion of their pupil with WS?

There was some difference in experiences between teachers in mainstream schools and those in special settings. Overall, the majority of teachers in mainstream settings felt the child with WS would be able to complete their primary education in mainstream, although some referred to increasing (academic and social) inclusion challenges. The only special-class teacher in the sample referred to her goal for the child with WS to

attend a mainstream post-primary school. This view of transition from special to mainstream is rare, both in this research and in the literature.

The educational profile presented by teachers was very similar, but broader, than that presented by parents. Despite reporting various aptitudes, a deficit approach to remediating the learning challenges was evident from most mainstream teachers, though this is commonly reported for children with WS (Lenhoff et al., 1997). Some perceived learner strengths enhanced the child's inclusion: the child's social use of language enhanced their social inclusion with peers and staff, strong vocabulary enhanced peer perceptions and academic inclusion, and ability in Irish increased their academic inclusion in the junior classes. While teachers identified the child's intelligence as a strength, they found formal assessment scores failed to reflect the child's abilities, further highlighting short-comings in the psycho-medical approach to the education of children with WS.

Some aspects of the child's learning profile similarly negatively impacted on his/her educational inclusion, including IQ which affected the child's curriculum (programme, participation and engagement), behaviour interventions and games in mainstream settings. Poor gross-motor skills also impeded participation in games, a deficit identified by teachers but not parents, which impacted on older children's social inclusion. In addition tactile-seeking behaviour, distractibility, challenging behaviour, poor peer relations, handwriting and reading comprehension had the potential to inhibit social and/or academic inclusion. Distractibility was particularly significant in hampering academic inclusion and was identified for all pupils (though varying levels were described). Teachers in special settings were more likely to promote pupil engagement and participation than mainstream teachers who tended to deal with distractibility only where other pupils were affected. Teachers of all children with WS described high emotionality similar to the emotional profile presented by Einfeld et al. (1997). They also described behaviours related to the child's sociability which impacted positively on the teacher (preventing teacher upset). No teacher suggested anxiety as an underlying cause of these behaviours. This research proposes sociability in children with WS is masking high levels of anxiety in educational settings. Being reprimanded by teachers was an identified trigger for worry, fear and anger in this study and a documented anxiety-trigger by Dykens (2003). Findings also support and develop a previous study (Einfeld, 2005) that asserted that anxiety may be the basis for many of the maladaptive behaviours associated with WS. Interventions focused on the comprehension of emotions and a vocabulary to accurately express emotions are proposed to support the emotional/behavioural profile which emerged.

Teachers identified more strengths than challenges in their provision for children with WS. These encompassed the child's academic inclusion and progress, social inclusion, and structures/resources. However, interpretation of inclusion varied, with some predominantly reflecting locational integration. Some teachers identified their own lack of skill and information as a limitation, consistent with the literature (Kenny et al., 2006; Forbes, 2007), yet no teacher contacted the SESS for support. This indicates poor awareness of support structures for teachers of pupils with SEN and, perhaps, inadequate whole-school approaches to continuing professional development for SEN. Teachers' support for the academic, social, emotional/behavioural and life-skills/care needs of the children was dependent on teachers' SEN experience and SEN qualifications. Teachers with SEN experience or qualifications were most likely to deal with learning challenges (which enhanced the child's social and academic inclusion), to capitalise on the child's interests and aptitudes, to devise interventions for emotional/behavioural needs and were less likely to devolve responsibility to the SNA. The use of specific approaches to accommodate the child with WS had a positive impact on the learning of his/her peers as expected from the literature (Ainscow, 1999; Rose and Howley, 2007). In Ireland, teacher education is now recognised as essential to developing teachers' knowledge of SEN (Winter and O'Raw, 2010; NCSE, 2013f). This study shows it is also essential for the effective inclusion of children with WS.

3. *What are the experiences of children with WS concerning their educational inclusion?*

All children with WS indicated positive experiences of school and displayed a sense of belonging and acceptance regardless of setting, similar to other children with SEN (Ware et al., 2011; O'Keeffe, 2011), and more positive than the experiences of children with EBD (Flynn et al., 2011). Children with WS in special settings did not indicate unease at how they or their school were perceived by others, as Motherway (2011) found of children with SEN in Ireland. The children also had clear images of themselves as learners and could identify both strengths and challenges in their learning, both most frequently of an academic nature. This highlights the benefits of praise and encouragement for learners with WS, which is also recommended for other learners with SEN (see Westwood, 2007). However, their emotional relationship with their teacher appears to be more significant than that of other learners.

The favoured activities of children with WS were most commonly social and physical in nature, the latter a surprising finding considering the evidence of motor-skill impairments (Semel and Rosner, 2003). Enjoyment of physical activities may be due to perceptions of increased social inclusion during these activities, as found by Balfe and Travers (2011) for learners with SEN in mainstream schools. It may also satisfy sensory needs or address the atypical activity patterns manifest in WS.

Some children displayed poor understanding of negative emotions, which may be the basis for maladaptive behaviours, a novel finding on the emotional profile of WS. There was some correlation in responses regarding what made them feel scared, worried or angry at school, frequently related to teacher or peer behaviour, similar to triggers identified by Dykens and Rosner (2006), although their findings were not related to schooling. The impact of others' behaviours may have a significant impact on their ability to engage and concentrate, thereby impacting on their learning. Considering the emotionality of WS (Einfeld et al., 1997), this impact may be much greater than for other children without WS.

The findings of this study clearly indicate that children with WS are valuable participants in educational research and are effective in articulating their perceptions and experiences, as has been found of other children with SEN (O'Keeffe, 2011; Motherway, 2011).

Contributing to the Inclusion Debate: Evidence from WS

While the sample used in this research is small, the findings show different experiences of educational inclusion by parents, teachers and children with WS, and indicate that special classes/schools remain valid and valuable placements on the inclusion continuum for children with WS. Some significant differences regarding the educational inclusion of the children were apparent between placements. This research proposes a definition of inclusion on which educational placements can be compared to see if current mainstream placements in Ireland should be viewed as the most inclusive setting for learners with WS and whether it is appropriate to assume mainstream education is synonymous with inclusive education. In line with Norwich (2008) this research suggests that it *should not* be necessary to talk about 'inclusive education' as apart from 'education'. However, the findings indicate that it remains necessary to define inclusive education as parents and teachers displayed different interpretations of this concept. Indeed, similar to assertions by Clark et al. (2004), this research found understanding of inclusion varied across and within schools.

Chapters One and Two highlighted the development of inclusion definitions and a number of definitions were presented to signify the conceptual changes. All have influenced the definition of educational inclusion which is presented:

> inclusion is the provision of a broad and balanced educational experience
> which supports academic, physical, social, emotional and behavioural needs
> to maximise educational participation and outcomes and to enable and
> empower students to lead as fulfilling and independent a life as is possible,
> with a sense of belonging.

Such a definition, which can be interpreted as a definition of inclusive education for any individual or group of learners, moves away from the idea of an inclusive school which has overtones of locational significance (see UNESCO, 1994). This definition contrasts sharply with the succinct interpretation by Norwich (2000), with a view to identifying key elements in educational inclusion. In this vein, it is clearly learner-centred and outcome based and reflects definitions by Rose (2003) and Day and Travers (2012). Using this definition to indicate what learners should derive from educational inclusion allows for comparisons to be made between special and mainstream placements for children with WS, although this could be done for any group of learners with SEN.

Table 8.1: Comparisons between the educational inclusion experiences of children with WS in mainstream and special settings (2012)

	Mainstream Setting	Special Setting (special school and special class in mainstream school)
Academic	Some differentiation, most often for literacy and maths, but dependent on individual teachers.	High levels of differentiation across the curriculum but dependent on individual teachers.
	High levels of SNA support deemed necessary, usually one-to-one, teacher dependence on SNA.	SNA not assigned to an individual child, no apparent teacher dependence on SNA.
	In some cases academic differentiation relegated to SNA.	Teacher-directed differentiation of academic tasks, SNAs manage or supervise a child when working.
	Some curriculum areas reduced over time, including Irish.	Curriculum areas not reduced, but Irish not offered as a curricular subject.
	Child's learning style taken into account by minority of teachers.	Child's learning style taken into account by all teachers, but variance in teachers noted from year to year.
Physical	Therapies (OT, SALT, physiotherapy) usually the responsibility of the parent to organise outside of school time.	Therapies (OT, SALT, physiotherapy) provided as part of the child's curriculum.
	Some of the above programmes may be delivered by SNA or RT.	Above programmes delivered by professionals, SNA or teacher.
	Poorer gross-motor skills reduce participation of some pupils in the Physical Education curriculum and in some games during recreations.	Peers with better or worse gross-motor skills, does not reduce participation as a result.
Social	Educated with siblings and local, non-SEN children in most cases, although child not always in local primary school.	Large catchment area; fewer opportunities to meet class peers outside of school (except for special class).
	Positive impact on the class in terms of developing social skills of peers.	Positive impact on the class in terms of modelling good social skills.
	Child sometimes treated as 'special' or 'different'.	Child not treated as 'special' or 'different' as all pupils have needs.
	Child usually has friends, but friendships not always 'genuine' but 'contrived' at times.	Child usually has friends.
Emotional	Some teachers concerned about the child being under pressure, not sure how much to push them.	Teachers did not express concern about the child being under pressure.
	Some teachers aware of triggers.	All teachers aware of triggers.
	Some teachers implemented supports for child's emotional needs.	All teachers implemented supports for child's emotional needs.
Behavioural	Some interventions managed by SNA.	Interventions managed by teachers.
	In one case the mainstream code of behaviour is applied to deal with the child's behaviour.	No reference to a school code of behaviour for dealing with individual children with WS, individual behavioural targets set instead.
	Peer modelling an advantage for appropriate behaviours.	Lack of modelling available, some peers with more challenging behaviours.
	Peer support with behavioural interventions (reported in one case).	Lack of peer support for some behavioural interventions (reported in one case). Challenging behaviours of one child can conflict with those of other children.
	One teacher discussed the child's behaviour with peers to promote their understanding and support.	All teachers discussed the child's behaviour with peers to promote understanding and support.

Participation	Half the teachers referred to a lack of engagement and participation.	Pupil engagement and participation not reported as an issue.
Outcomes	All pupils reportedly making progress. Most parents compared their child's outcomes to his/her class level. Most teachers indicated a widening gap between the child and his/her peers.	All pupils reportedly making progress. Most parents compared their child's outcomes to his/her mainstream peer level. No teacher referred to widening gap between child and his/her peers, in one case the (special class) teacher referred to the closing gap between the child and his mainstream class peers.
Life skills	In one case the school was developing discrete life skills (putting on coat). Life skills frequently managed by SNA (toileting, dressing), or in one case the RT.	In all cases the school was developing discrete life skills (eating, toileting, shopping, etc.) Life skills always managed by teacher, implementation supported by SNA.
Curriculum/ activities	The mainstream curriculum is provided with additional LS/RT support. It includes Irish, but pupils are entitled to an exemption. Mainstream curriculum implemented with some differentiation.	A more flexible curriculum with some specialist teachers for subjects such as Physical Education. Irish is not on the curriculum. Curriculum planned based on the needs of the class with differentiated programmes as necessary.
'Belonging'	All pupils had a sense of belonging in their school. All children described themselves as happy going to school.	All pupils had a sense of belonging in their school. One of the two children interviewed described himself as happy going to school.
Teacher skill and education	Teachers more likely to have SEN qualification if in LS/RT position. Those with SEN qualification or experience more 'skilful'. No teacher sought additional support through the SESS.	Not all teachers in special settings have a SEN qualification. Those with SEN qualification or experience more 'skilful'. Even inexperienced teachers in special settings benefited from whole-school approaches (to differentiation and behaviour management) and had built up a range of skills quickly as a result. One teacher sought support from SESS (for special class issues rather than WS).
Parental expectations	Low parental expectations: parents did not expect specialised interventions, more concerned with an open attitude and interest than skill.	High parent expectations for appropriate interventions.
Structures and resources	SNA support (usually one-to-one). Pupil-teacher ratio of mainstream class (from 1:10 in one rural school to 1:28). LS/RT hours supplied.	SNA support as required, not one-to-one. SNA deployment managed by principal. Reduced pupil-teacher ratio (1:15 for Mild GLD, 1: 8 for Moderate GLD … child in special class had 1:5). Flexible, within-school arrangements for support; this did not include resource hours.
Overall focus	Academic, mainstream, peer-level driven, focus on primary education years.	Holistic, individual, developmental, focus on future outcomes.

The comparison of inclusion experiences between mainstream and special settings for children with WS shows that differences exist. Table 8.1 also underscores the significance of individual teachers rather than mere placements. The comparison is not generalisable considering the very small sample used, particularly considering there were only two teachers in special settings involved in the research. It does, however, identify specific inclusive practices that can be developed, regardless of setting. To this end, a framework to enhance the educational inclusion of learners with WS in all settings is proposed, based on the definition of inclusion presented in this chapter and on the barriers to inclusion and the models of good practice identified in Table 8.1.

The proposed framework (see Figure 8.2) is based on the IEP process and can be integrated with that process. While this research indicated varying practices and perceptions of the IEP, findings also showed the IEP's role in providing valuable information on the child's educational profile. Indeed, IEPs are widely used in Irish schools but with significant variation in the content and review process (Rose et al., 2012). They can be a forum to discuss the child's abilities, skills, talent and needs (NCSE, 2006). This may help parents of children with WS to share their expertise and interventions with teachers, which they are reluctant to do.

The IEP is important for another reason; it is a plan for an **individual**. The data indicated clearly that children with WS, despite sharing certain traits and preferences, are a heterogeneous group. There is an increasing emphasis on the individual nature of learners, both in SEN literature (Westwood, 2007; Flynn et al., 2011; NCSE, 2011b), and in WS literature (Reis et al., 2003; Udwin et al., 2007; Levine et al., 2013). This emphasises the need for stakeholders to define the individual's profile and to make decisions which are not based on presumed deficits of the WS phenotype. Therefore, the gathering of baseline data is imperative, particularly considering standardised and norm-referenced tests fail to capture the true performance of learners with WS (see Chapters 5 and 7).

To reinforce a sense of belonging, which is one of the features of inclusive education proposed in this study, the child should be invited to participate in this process. A sentence-completion task can be useful to maximise the child's capacity to engage in a meaningful way in this process. Various models, including the widely used 'My thoughts about school checklist' (NEPS, 2010:97), are available, although this should be extended to include emotion-related sentence stems, which the findings indicate are an important aspect of the learner's profile. Those devised by the researcher and presented in Chapter 6 proved effective.

The framework of educational inclusion for learners with WS is designed to encourage reflection and action on the definition of educational inclusion which emerged from the findings. It is a four-step process as seen in Figure 8.1.
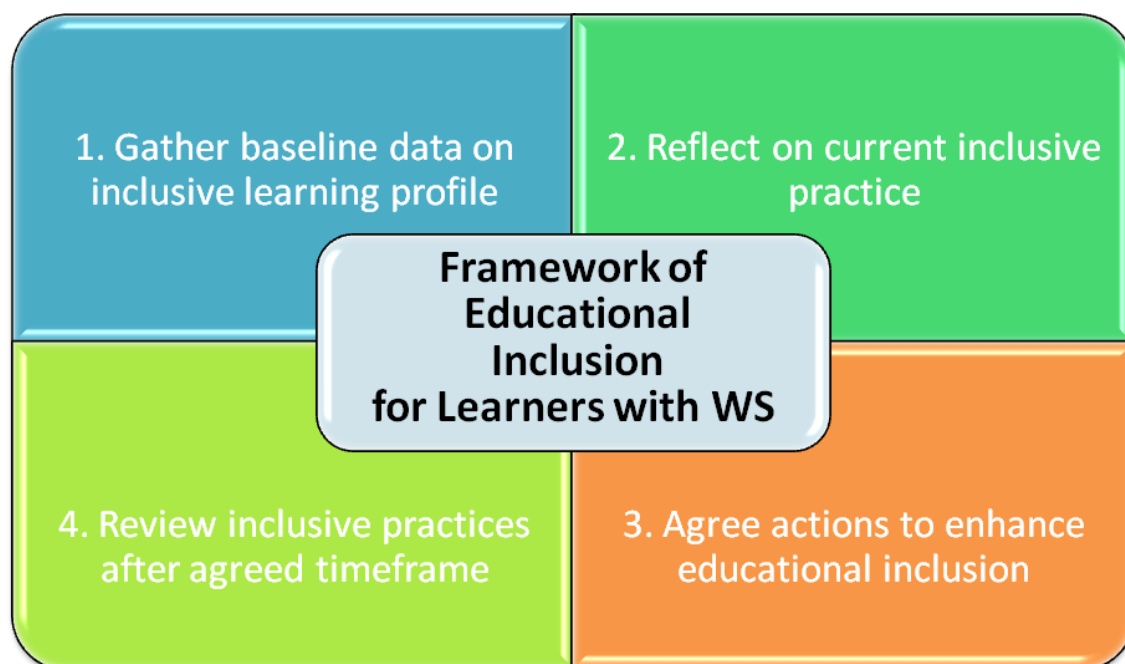
Figure 8.1: The framework of educational inclusion for learners with WS

Each stage of the framework is focused on the learner with WS and should incorporate as many stakeholders as possible who support the learner including parents, class teacher, support/other teacher (if applicable), SNA, principal, other professonals from the multi-disciplinary team and the learner him/herself. Each stage is now explained.

Stage 1: Stakeholders should be invited to provide baseline data (evidence) on the learner's current level of performance in the eight areas which define educational inclusion for learners with WS: academic, physical, social, emotional, behavioural, participation and engagement, life skills and self-esteem/belonging. This should be done with a focus on the learner's interests to have strategies to motivate, the learner's strengths on which to capitalise and the learner's challenges with which to understand the learner's experiences. This approach to structuring baseline data is presented as 'the inclusive learning profile for learners with WS' (see Figure 8.2). It forms an intrinsic aspect of the framework of educational inclusion. Baseline data, on the different aspects of the inclusive learning profile, should be gathered from a range of sources including observation, running records, checklists, interviews, recordings, questionnaires and work samples for each of the eight areas, by different stakeholders, with a view to providing an accurate profile of the learner in different social settings. Previous IEPs may also provide valuable baseline data. One person should assume responsibility for co-ordinating this process.

Figure 8.2: The inclusive learning profile for learners with WS

Stage 2: Stakeholders should reflect on their own current practice, individually, to ascertain the success of current interventions and practices in line with the baseline data gathered from the inclusive learning profile (Figure 8.2 above). The practices identified as central to the successful educational inclusion of learners with WS should be used as a basis for this reflection and are contained in the WS inclusive education reflection and actions template (see Figure 8.3). The reflection should continue at a joint meeting of stakeholders, which could happen at the IEP meeting. This allows for greater sharing of experiences on the successes or challenges regarding current practices. The baseline data will determine what aspects of the reflection and actions template are important for the individual learner in question. The WS inclusive education reflection and actions template can be viewed on the following two pages.

Professional

- Review interventions in the light of educational information
- Communicate with the school regarding assessments and interventions
- Be available to school personnel to answer queries

Principal

- Ensure inclusive ethos and culture underpins all school activities
- Review school health and safety: entry/exit to school by pupils and visitors, car parking for parent of child with WS
- Attend to school's soundscape: evaluate use of alarms and bells and use of clapping in school assemblies
- Research and source available resources to support the learner
- Review whole-school policies and procedures which may impact on the learner
- Ensure appropriate and effective use of SNA to maximise learner's inclusion and independence
- Arrange professional development for staff/individual teachers
- Seek opportunities to link with other schools (special if in mainstream school, mainstream if in special school)
- Ensure IEP is prepared, agreed, shared, implemented and reviewed
- Organise break-time socialisation strategies
- Build a positive relationship with the learner

Parents

- Communicate regularly with school
- Share effective interventions, resources and programmes
- Implement agreed interventions
- Do homework with your child, reinforce learning incidentally in different contexts
- Engage your child in community sports and social groups
- Support the development of your child's relationships with individual peers
- Develop your child's life skills in the home context
- Reinforce the school's child protection programme in different social contexts
- Reinforce the vocabulary of emotions in context and model the appropriate expression of emotions
- Note antecedents to challenging behaviour and share with the school

Teacher

- Arrange supportive classroom layout to reduce sensory issues, maximise participation and minimise distractions
- Implement a predictable, strategic timetable which includes movement breaks
- Plan and prepare for lessons with attention to differentiation to maximise the inclusion of the learner; use his/her interests where possible
- Implement the agreed targets in the IEP
- Implement positive classroom management approaches
- Use active teaching methodologies to suit learner's learning style
- Check regularly for learner comprehension in lessons
- Ensure learner's engagement and participation in lessons
- Give regular positive and realistic praise
- Have high, realistic expectations of the learner
- Devise inclusive assessment approaches
- Develop alternatives to written tasks for learner
- Know the learner and develop a strong positive relationship with him/her
- Engage in whole-class teaching of socially appropriate behaviour
- Develop the vocabulary associated with emotions and model the appropriate expression of different emotions in context
- Note antecedents of challenging behaviour and devise strategies accordingly
- Cultivate a culture of understanding, tolerance and inclusion in the classroom among peers
- Ensure regular review of child protection programmes and share with parents
- Establish clear role for the SNA, ensure learner does not become dependent
- Teach specific life skills in school context; share strategies with parents
- Seek support from the principal, colleagues, the learner's parents, the SESS and other professionals as necessary
- Engage in appropriate professional development as needed; consider availing of training on lamh, TEACCH and social stories

SNA

- Maximise learner's independence
- Agree interventions and strategies with teacher
- Share observations
- Encourage peer interactions during learning activities and during break times

Learner

- Discuss views on learning
- Agree learning targets and approaches
- Try hard
- Engage in self-assessment
- Celebrate successes

Figure 8.3: The WS inclusive education reflection and action checklist

Stage 3: Each stakeholder should contribute their opinions as to the learner's current priority and agree the targets to best support the child's educational inclusion (these may also be the targets of the learner's IEP). Subsequently, stakeholders should determine which actions from the reflection and actions template they will develop within a set timeframe to enhance the educational inclusion of the learner with WS.

Stage 4: Stakeholders should agree a date for review of their individual actions and of the agreed targets. Interim reviews may be held between the parents and teacher(s) considering the input required from both of these stakeholders. The learner should be enabled to contribute to all meetings.

This framework of educational inclusion for learners with WS should provide support for stakeholders to enhance their provision. To maximise its success, it is necessary for all stakeholder to engage with the process and to see the process as ongoing.

The Transformative Effects of this Research

The transformative aspect of this research cannot be ignored. The transformations to date are that parents are now contacting the researcher to seek information on specific educational issues. This has included questions about specific reading interventions, appropriate reading tests for children with WS, how to mediate homework in Social, Environmental and Scientific Education, strategies for involving their child in the curriculum without the stress of writing, and how to move a child from initial letter sounds to blending sounds. A teacher-support group for teachers of children with WS is currently being established. The date of the first meeting is planned for 17 May, 2014. Preliminary discussions were undertaken with facilitators from the SESS in May and June 2013 regarding the findings about links with WS learning and ASD-specific approaches. They have expressed interest in reading the full findings of this research and may agree to prioritise teachers of children with WS for professional development for ASD-specific courses (such as TEACCH and ABA which currently require teachers to have a child with ASD in their class). This research will also form the basis for Ireland's first set of educational guidelines for parents and teachers of children with WS, some of the information which is currently being uploaded to the WSAI website (www.williamssyndrome.ie). This effort to transform and positively impact on the educational inclusion of children with WS was at the heart of the research intention.

Conclusion

This research on the experiences of children with WS, their parents and teachers regarding their educational inclusion establishes a new knowledge base on the

educational provision for children with WS in Ireland, their perceived educational profile in the Irish context and the supports provided for their learning by parents and teachers. It adds to the international knowledge base on the voice of learners with WS, which has never been researched before for children of primary-school age, and provides a valuable comparison between teacher and parent perceptions of the WS educational profile which highlights some interesting discrepancies not previously identified. In addition, it extends the current knowledge of factors influencing choice of educational placement for learners with SEN in Ireland, previously researched by Armstrong et al. (2010) by alluding to one specific group of learners with a complex educational profile.

The findings also contribute to the inclusion debate. Interpretations of inclusion varied among parents and teachers in this study and reflected the many historical concepts which have defined inclusion, from locational integration to assimilation, from an identification of barriers to features of inclusive schools and inclusive learning. Consequently, some significant differences regarding the educational inclusion of the children were apparent between placements. To compare these experiences a definition of inclusion was proposed on which educational placements could be compared. The researcher posited that educational inclusion is the provision of a broad and balanced educational experience which supports academic, physical, social, emotional and behavioural needs to maximise educational participation and outcomes and to enable and empower students to lead as fulfilling and independent a life as is possible, with a sense of belonging. Using such a definition showed that special placements were overall more inclusive settings, thereby proposing that mainstream placements should not be seen as synonymous with 'inclusive settings', and that special settings have a very valuable role on the inclusion continuum. Results should be interpreted with caution due to the very small sample size, but it does provide indicators that special settings continue to provide a worthwhile, inclusive educational placement for children with WS. This is significant in the Irish context in a climate where educational policy is reducing the number of special placements available and professionals recommend mainstream placements over special purely on the grounds of inclusive policy. However, teacher education and experience of teaching children with SEN were also very important factors in effective inclusive strategies for learners with WS. Therefore, a national programme of professional development on SEN for all teachers would greatly enhance the quality of inclusive learning in mainstream schools, particularly considering the very valuable contribution individual teachers make.

The transformative nature of the study underscores the need to take the research findings and use them as the basis for much development in the Irish context to refine

and develop educational inclusion for all children with WS. As a first step, the findings of the research were used to devise a framework to promote the educational inclusion of learners with WS, regardless of placement. This process is based on the IEP process, a process which is widely used for learners with SEN in Ireland although with differences in implementation (Rose et al., 2012). This framework encompasses four stages which entails gathering stakeholders' evidence of the learner's current level of performance in the eight areas which define educational inclusion for learners with WS: academic, physical, social, emotional, behavioural, participation and engagement, life skills and self-esteem/belonging, while also focusing on the learner's interests, strengths and challenges. A reflection for each stakeholder group was devised based on the practices identified as central to the successful educational inclusion of learners with WS which emerged from this research.

The overall findings of this study indicate very positive experiences of the educational inclusion of children with WS by parents, teachers and children in all settings. Despite differences between settings, individual teachers contribute significantly to a child's successful inclusion. This is particularly true where teachers have SEN qualifications or experience. With the evident good will of both parents and teachers, there is great scope to continue to develop and enrich the educational inclusion experiences of learners with WS.

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APPENDICES

Appendix A: Letter of Invitation to Parents

<div align="right">

10 Victoria Place,

Castlebar,

Co. Mayo.

01 April, 2012

</div>

Dear   ,

I am currently doing research into the education of children with Williams syndrome in Ireland, the experiences of the WS learner, their parents and teachers. As you probably know, I have a brother myself with WS (aged 29). I would be very interested in having you participate in my research.

Participation in the research would involve an interview with you or your partner about your experiences of your child's education, a very short interview with your child about his/her attitudes to school and an interview with your child's teacher about the experiences of teaching a child with WS. This is with a view to identifying further supports needed to help children with WS in schools. I've enclosed a brochure which will give you the finer details of what it entails.

I very much hope that the outcomes of the research will be of benefit to families who have a child with WS in primary education.

I would really appreciate if you would seriously consider being part of this research as there are so few pupils with WS that I am aware of who are currently of primary-school age. You can phone me to discuss the matter further, or you may wish to text me if you decide this research does not suit you at this time. My phone number is 087-9802691. I would appreciate a reply by Thursday, 12th April.

With every good wish,

What about confidentiality?

All information collected as part of this research will be kept confidential. Each person interviewed will be given a different name when the research is written up. The information from parents will not be shared with teachers and vice-versa. Your child's name will also be changed to protect his/her identify. The interviews will only be heard by the researcher. This will be discussed further with you if you agree to be interviewed.

What happens if I change my mind?

Nothing! When you meet with Fionnuala she will explain the process to you before she starts. You can discuss any concerns you have or ask any questions.

You have the right to refrain from answering any questions asked, you may end the interview at any time and you may request to see transcripts of the interview before they are used as part of the research.

You may decide not to engage in one, some or all of the three activities mentioned, and you do not have to explain your reasons.

Why is this research important?

*No research has been done on the educational experiences of children with WS in Ireland.

*It is not certain what pupils with WS enjoy about school and what they find stressful.

*It is unclear why parents choose one educational setting over another, what their experiences have been to date of their child's education and the types of support they give to their child.

*It is also unknown what teachers know about this rare genetic syndrome, what their strategies for supporting learners with WS are and what their needs are as educators of children with a rare condition.

*The Williams Syndrome Association of Ireland, when contacted by parents or teachers, provides documents from the WS support groups in Britain. There are no support documents based on the Irish context.

It is hoped that this research will lead to a set of guidelines for parents and teachers to help them better support the education of children with WS.

The Education of Children with Williams Syndrome in Ireland

What is this research about?

This research aims to explore the experiences of children with Williams syndrome (WS), their parents and teachers, regarding their education.

Who is the researcher?

* The researcher is Fionnuala Tynan who works in education and has a brother with WS.

* This research is being undertaken as part of a doctorate in education.

* Fionnuala has taught at the WS Music and Activity Camp in Lisnaskea, Co. Fermanagh for the past seven years.

* Fionnuala can be contacted on 087-9802691.

Who is involved?

This research will involve children, of primary-school age, who present with Williams syndrome, their parents and teachers.

These children may be in mainstream national schools, special schools or special classes.

What is the time-frame?

It is hoped that the interviews can commence this month, March. It is envisaged that they will be conducted at weekends and during the Easter holidays. You can decide when suits you best, you can choose the day and the time.

Preliminary results of the research will be presented at the WSAI AGM in November 2012.

What does it involve?

To get detailed information on the education of children with WS in Ireland, there are a number of activities proposed. You will decide what aspects of the research you are happy to be part of: an interview with you, an interview with your child and/or the discussion of documents in your child's education file.

What happens at the interview?

1. Interview with you: this will take approximately 90 minutes. You can decide when it will take place and where it will take place. The researcher is happy to travel to your home to carry out the interview. It can be conducted over two sessions if you prefer. The interview will be like a conversation. You are encouraged to be as open and as honest as you are comfortable with. Confidentiality is guaranteed.

2. Interview with your child: your child with Williams syndrome will be <u>invited</u> to a short interview, of approximately 15 minutes. It is believed that the research should involve the learner as they have their own perspective on their schooling. You can decide if this is appropriate for your child, in consultation with your child. You are invited to be present for this interview. The researcher will use puppets, pictures and other objects to encourage your child's participation. The researcher has a particular interest in the attitudes and opinions of the learner with WS.

You can decide at any time to withdraw your child from this interview. You may wish to have your child interviewed on the same day as you. Any other arrangement can be facilitated.

What documents will be discussed?

Your child most probably has a number of 'educational records'. The reason this is included in the research is because it is a way of examining how other professionals view the WS educational profile and to see if the WS way of learning is recognised. It is also a chance to examine the content of Individual Education Plans (IEP) to see if help and support is needed by schools to draw up an effective IEP for the learner with WS. This in turn should lead to better provision for our children with WS. Therefore, 'paperwork' may include psychological reports, IEPs, school reports, school communication logs/homework notebooks. Some of these will be discussed as part of the interview. You may be happy to show all, some or none of those mentioned. Your decision on such matters will be respected.

Will this benefit me and my child?

It is hoped that your child will benefit in the long term, as links are made with schools and an accurate picture is built up of the current state of educational provision. Based on the findings good educational practice can be shared and specific, tailored guidelines can be offered to schools and to parents on how best to support the learner with WS in the Irish context.

Prompts for Researcher:

- Express thanks

- Duration of interview (90 mins approx.), time availability of interviewee

- Outline of research

- Assurances regarding confidentiality and anonymity

- Completion of consent forms

- Permission to record

Background information

Family
- Can you tell me a little bit about your family, where x comes in the family, relationship with siblings etc.

Child with WS

- Describe x (personality, interests, strengths, challenges)

Child's school

- Type of school (pupil numbers, teacher numbers)

- Distance from home

- How many pupils in his class?

- Supports available (resource teaching, SNA, therapies, etc.)

Research Question: What determined the parents' choice of educational setting?

- Is this the local mainstream school? Do your other children go to this school?

- What options did you examine before he started school?

- What support/advice did you get regarding this decision?

- Did a psychological assessment give direction? What is your child's level of functioning? Was this explained to you?

Research Question: How satisfied are parents with their child's educational placement?

- **What is your child's experience of school?**
    - Is your child happy in this school?

    - Has he friends at school? Does he go on play dates/to birthday parties?

    - Have there been any negative social issues?

    - Did any incidences happen which reassured you that you had made the right decision or made you feel you made the wrong decision? Tell me about them (inclusion/acceptance).

    - Do you feel your child is fully included in all aspects of school life?

    - Does your child get homework? Is it appropriately pitched/differentiated?

- **Do you think his needs are appropriately met?**
    - Do you feel the school is adequately resourced to support your child's learning?

    - Is he making progress? What subjects do you think are taught most/least effectively?

    - What supports have been put in place for your child's learning and social development? (e.g. differentiation, resource teaching, buddy system, behaviour plan)

    - Do you think teachers have adequate knowledge of WS? Are they adequately skilled to teach your child effectively?

    - Does your child have an IEP? Is it useful?

- **As a parent what is your experience of this school?**
    - Enrolment process?

    - Attitudes of others (principal, teacher, parents, peers)?

    - Do you feel valued as a parent in the school? Do you think your child is valued (included)?

    - Describe the most positive experiences for you, as a parent, with this school?

    - Describe the greatest challenges for you as a parent, having a child with WS in mainstream education? (academic issues, social, behavioural, attitudes, emotions)

    - Are you adequately informed about your child's education? What forms of communication are used?

    - What are the strengths/challenges of this placement?

Research Question C: How do parents perceive the educational profile and learning style of their child?

- **Tell me about your child's learning profile.**
  - Cognitive ability? Reading, maths, spellings?

  - Language: expression and understanding?

  - Social skills?

  - Memory (visual/auditory)?

  - Gross/fine motor skills and self-help skills?

  - Is he musical? Artistic? Dramatic? Athletic?

- **Tell me about your child's behaviours?**
  - Happy, friendly, seeks to please, co-operative?

  - Even-tempered, irritable, fearful/anxious?

  - Distractible, poor concentration, active, obsessive, attention-seeking?

- **How do you deal with (name specific behaviour)?**
  - Have you discussed behaviours/strategies with your child's teacher?

  - Have you been called into the school because of any of them?

- **How does your child learn best?**
  - Special techniques/approaches you've used or developed yourself?

  - Have you ever prompted your child's teacher to try different approaches

Research Question: How do parents support their child's learning?

- How do you help your child?
  - academics,
  - behaviour,
  - social,
  - emotional,
  - self-help/adaptive living skills.

Closure

- Any questions or comments?

- Thank you

Parent Consent Form

Please read the following statements and tick yes or no as appropriate:

1. The research to be carried out by Fionnuala Tynan has been explained to me

    Yes □   No □

2. I agree to be interviewed for the purpose of this research

    Yes □   No □

3. I agree to have this interview digitally recorded

    Yes □   No □

4. I agree to have the information from the interview used for the purpose of educational research

    Yes □   No □

5. I would like to receive a copy of the interview transcript

    Yes □   No □

6. If the researcher requires clarification on any issues that may arise from this interview I agree to being contacted.

    Yes □   No □

Signed: _____

Date: _____

Child Consent Form

Please read the following statements and tick yes or no as appropriate:

1. I consent to Fionnuala Tynan interviewing my child for the purpose of her research

    Yes □   No □

2. I agree to have this interview digitally recorded

    Yes □   No □

3. I agree to have the information from the interview used for the purpose of educational research

    Yes □   No □

4. I would like to receive a copy of my child's interview transcript

    Yes □   No □

5. I consent to my child's photograph being used in future educational presentations about Williams syndrome by Fionnuala Tynan

    Yes □   No □

Signed: _____

Date: _____

<u>My Child's School Information</u>

Name and Address of School:

_____

_____

_____

_____

Name of Principal:

_____

Name of Class Teacher:

_____

Name of Support Teacher (if child attends mainstream)

_____

10 Victoria Place,

Castlebar,

Co. Mayo.

14 May, 2012

Dear   ,

I am conducting research into the education of children with Williams syndrome and I got your contact details from ..., mother of ..., who I believe you are teaching this school year.

I would be very grateful if you would consider being interviewed as part of this research. I have located a mere seven pupils with Williams syndrome of primary-school age in the country so your experiences would be of great interest to me. The topics to be discussed would include ...'s educational profile, your strategies for supporting ... across the curriculum, the impact of teaching a child with Williams syndrome and supports you find beneficial. I have included a brochure with more details on the overall research project.

I will phone you at school to discuss your interest in the coming days. Alternatively you may wish to text me a time/day that suits you best for this phone call on 087-9802691.

Kind regards,

_____

Fionnuala Tynan

Why is this research important?

*To date no research has been carried out on the educational experiences of children with WS in Ireland.

*It is not certain what pupils with WS enjoy about school and what they find stressful.

*It is unclear why parents choose one educational setting over another, what their experiences have been to date of their child's education and the types of support they give to their child.

*It is also unknown what teachers know about this rare genetic syndrome, what their strategies for supporting learners with WS are and what their needs are as educators of children with a rare condition.

*The Williams Syndrome Association of Ireland, when contacted by parents or teachers, provides documents from the WS support groups in Britain. There are no support documents based on the Irish context.

It is hoped that this research will lead to a set of guidelines for parents and teachers to help them better support the education of children with WS in the Irish context.

What about confidentiality?

All information collected as part of this research will be kept confidential. Each person interviewed will be given a different name when the research is written up. The information from parents will not be shared with teachers and vice-versa. The child's name will also be changed to protect his/her identify. The interviews will only be heard by the researcher. This will be discussed further with you if you agree to be interviewed.

What happens if I change my mind?

Nothing! When you meet with Fionnuala she will explain the process to you before she starts. You can discuss any concerns you have or ask any questions.
You have the right to refrain from answering any questions asked, you may end the interview at any time and you may request to see transcripts of the interview before they are used as part of the research.
If you decide not to partake your decision will not be questioned.

The Education of Children with Williams Syndrome in Ireland

What is this research about?

This research is to explore the experiences of children with Williams syndrome (WS), their parents and teachers, regarding their education.

Who is the researcher?

* The researcher is Fionnuala Tynan who works in education.
* This research is being undertaken as part of a doctorate in education.
* Fionnuala has a brother with WS.
* Fionnuala has taught at the WS Music and Activity Camp in Lisnaskea, Co. Fermanagh for the past seven years.
* Fionnuala can be contacted on 086-2063773

Who is involved?

This research will involve children of primary-school age who present with Williams syndrome, their parents and teachers.

These children may be in mainstream national schools, special schools or special classes.

What is the time-frame?

It is hoped that the interviews can commence in April. It is envisaged that they will be conducted after school hours. However, if you wish to conduct the interview during school time and have cleared such a decision with your board of management, the researcher will be happy to meet at the time you suggest. Alternatively, you may prefer to be interviewed during a weekend. You can decide when suits you best, and every effort will be made to accommodate your requests.

Preliminary results of the research will be presented to parents at the WSAI AGM in November 2012. Depending on feedback from teachers, a forum for sharing the results of this research will be announced to which you will be invited.

What does it involve?

To get detailed information on the education of children with WS in Ireland you will be interviewed once. The interview will be semi-structured.

What happens at the interview?

*it will take approximately 90 minutes.

*you can decide when it will take place and where it will take place. The researcher is happy to travel to your home, school or other location to carry out the interview.

*the interview will be like a conversation. You are encouraged to be as open and as honest as you are comfortable with. Confidentiality is guaranteed.

 *you can decide at any time to withdraw from this interview.

* any concerns you have regarding the interview can be discussed in advance.

Will this research benefit me?

It is hoped that this research will establish links between the researcher and teachers of children with WS. Some teachers have already expressed a wish to set up a support-group, an annual meeting, an informal get-together or e-mail contact with other teachers.

If you have specific questions or issues arising from teaching a child with WS the researcher will be very happy to provide any support or advice she can.

Based on the findings good educational practice can be shared.

Specific, tailored guidelines may be offered to schools and to parents on how best to support the learner with WS in the Irish context in the coming years based on the outcomes of this research.

It is the long-term aim of this research to produce guidelines for teachers on the education of children with WS. You may not benefit directly from these guidelines if you only teach the child for one academic year. However, you will be providing very valuable support to future teachers who may struggle with trying to work out effective interventions for a child with WS.

Prompts for Researcher:

- Express thanks

- Duration of interview (90 mins approx.), time availability of interviewee

- Outline of research

- Assurances regarding confidentiality and anonymity

- Completion of consent forms

- Permission to record

Background information

Career

- Can you tell me a little bit about your career to date.

Experience of SEN

- Have you taught pupils with other SEN, genetic conditions? Have you experience of teaching in special settings? Professional development?

Reaction to having a child with WS

- What did you know about WS? Where did you get information/support?
- Experiences early in the year?

The child with WS

- Tell me about … (personality, strengths, interests, challenges).

Research Question: How do teachers perceive the educational profile and learning style of the child with WS?

- **Tell me about the child's learning profile.**
    - Cognitive ability? Reading, maths, spellings?
    - Language: expression and understanding?
    - Social skills?
    - Memory (visual/auditory)?
    - Gross/fine motor skills and self-help skills?
    - Is he musical? Artistic? Dramatic? Athletic?
    - Learning style?

- **Tell me about the child's behaviours?**
    - Happy, friendly, seeks to please, co-operative?
    - Even-tempered, irritable, fearful/anxious?
    - Distractible, poor concentration, active, obsessive, attention-seeking?

- **How do you deal with (name specific behaviour)?**
    - Have you discussed behaviours/strategies with the child's parents?

- **How does the child learn best?**
    - Special techniques/approaches you've used or developed yourself?

Research Question: Strengths and Limitations of placement

- **What is it like to teach a child with WS?**
    - Impact on you, peers, others in school?
    - How is his/her learning different to that of class peers?
    - What do you feel you teach the child best/less well?
    - What are the strengths/limitations of your provision?
    - Has your teaching changed in any way?
    - What are the attitudes of other teachers/principal/parents/peers to this child?
    - What supports would have been useful to you at the beginning of/during this school year?

- **What are your views on this placement for the child?**
    - Adequate supports?
    - Meeting child's needs?
    - Expertise of staff/education of staff?
    - Is the child fully included in all aspects of school life?
    - Where do you see the child in the future (primary education, post-primary, life)?

Research Question: How do teachers support the child's learning?

- **Academics/Curriculum:**
  - Is there a particular way to teach this child? Use of strengths?
  - How do you support his/her reading/writing/maths/spellings/other areas?
  - What types of differentiation strategies are needed?
  - What is your approach to homework?

- **Participation:**
  - Do you have to make adaptations to your teaching to promote participation?

- **Social development**

- **Self-help skills**

- **Behaviours**

- **Communication**
  - Tell me about the communication you have with his/her parents.
  - Does the child have an IEP? Tell me about how this works.

Closure

- Any questions or comments?
- Thank you

<u>Teacher Consent Form</u>

Please read the following statements and tick yes or no as appropriate:

1. The research to be carried out by Fionnuala Tynan has been explained to me

    Yes □   No □

2. I agree to be interviewed for the purpose of this research

    Yes □   No □

3. I agree to have this interview digitally recorded

    Yes □   No □

4. I agree to have the information from the interview used for the purpose of educational research

    Yes □   No □

5. I would like to receive a copy of the interview transcript

    Yes □   No □

6. If the researcher requires clarification on any issues that may arise from this interview I agree to being contacted.

    Yes □   No □

Signed: _____

Date: _____

<u>Interview Schedule for Pupils</u>

I met you before at … Do you remember? I wanted to come back to have a chat with you. I'm trying to find out what school is like for boys and girls like you. Would you like to have a chat about that? Thank you, that would be a big help to me.

Now, I've got some interesting things in my bag here, would you like to see (show microphone, finger puppets and manipulatives). Would you like to use any of these while we chat?

Time to settle and talk about the interview aids.

I'm going to read out the beginning of some sentences, and you have to to finish the sentence for me. Okay? So there's no right and there's no wrong answer, you can just tell me whatever you think. Are you ready?

(use aids if necessary to maintain attention)

1. I would like to
2. I wish that I
3. I am
4. People think that I am
5. I worry about

Discuss the above in terms of the participation and approach by child. Praise, reassure, re-focus as necessary.

For the next part I want to ask you about school. Is that okay? So we'll do the same thing, I'll start the sentence and you finish it off. The first one is …

1. The best thing about my school is
2. At school I like to
3. My teacher is
4. My teacher thinks I'm
5. At school I don't like
6. At school I need help to
7. At school I don't like to
8. My friends at school think I'm
9. At school I like
10. At school I am good at
11. At school I hate when I have to
12. Homework is
13. When I go to school in the morning I feel
14. At school I feel scared when
15. At school I feel happy when
16. At school I feel worried when
17. At school I feel angry when
18. At school I feel embarrassed when

Closure:

- Praise

- Thanks

- Chat

EA2

Ethical Approval Form:

Human   Research Projects

Please word-process this form, handwritten applications will not be accepted

UNIVERSITY OF
LINCOLN

This form must be completed for each piece of research activity whether conducted by academic staff, research staff, graduate students or undergraduates. The completed form must be approved by the designated authority within the Faculty.

Please complete all sections. If a section is not applicable, write N/A.

1 Name of Applicant	Fionnuala Tynan
	Department: Faculty: **CERD** **MHT**
2 Position in the University	Post-graduate **doctoral** student
3 Role in relation to this research	Principal researcher
4 Brief statement of **main Research Question**	The research is to collect the views of parents, teachers and pupils about their expectations and experiences of the education of school-age children with Williams syndrome (WS), a genetic disorder resulting in a spectrum of intellectual disabilities. The research questions are: 1. What determines parents' choice of educational provision and to what degree are they satisfied with their choice? 2. What do parents see as the strengths of their child's educational placement and what do they see as opportunities for development? 3. What do parents know about the WS educational profile? 4. What do teachers know about the WS phenotype and

educational profile?

5. What are the strengths and challenges faced by teachers in teaching a child with WS? Are there any opportunities for teachers to teach WS children more effectively?

6. To what extent is the WS phenotype taken into account when designing an individual education plan for WS children at primary level? Do differences exist between the individual education plans for WS children in mainstream education and those in special education settings? If so, what are these differences and why do such differences exist?

7. How do parents and teachers support the learning of children with WS?

8. What do pupils with WS enjoy about school? What aspects of school life do they find difficult?

5 Brief Description of Project	The research is part of an EdD programme for which a doctoral thesis will be written. The research design is a multiple case-study of six pupils with WS in primary school. Each case study will comprise a semi-structured interview with a parent, class teacher and support teacher (where the child is in mainstream education) of each WS child, a chaperoned interview with each child accompanied by a parent/guardian and an examination of each child's education plan, psychological reports, and homework journal.
	Approximate Start Date: September 2011 / Approximate End Date: July 2012
6 Name of Principal Investigator or Supervisor	Fionnuala Tynan
	Email address: fionnuala_tynan@eircom.net / Telephone: 00 353 87 9802691
7 Names of other researchers or student investigators involved	
8 Location(s) at which project is to be carried out	In homes and schools of each of the children with WS (in various locations around the Republic of Ireland).

9 Statement of the ethical issues involved and how they are to be addressed –including a risk assessment of the project based on the vulnerability of participants, the extent to which it is likely to be harmful and whether there will be significant discomfort. **(This will normally cover such issues as whether the risks/adverse effects** **associated with the project have** **been dealt with and whether the benefits of research outweigh the** **risks)**	The project will be conducted according to UL Guidelines for Conducting Research with Humans, and also according to the Revised Ethical Guidelines published by the British Educational Research Association (2004).Arising from such guidelines a number of issues are identified and pertinent to this project: *Respect for persons* This research involves interviewing parents and teachers of children with WS as well as children between the ages of 4 and 13, all of whom have a genetic disorder, Williams Syndrome, which results in a spectrum of intellectual disability. To ensure their dignity all participants will give consent to participate in the research. With respect to the diminished autonomy of participating children with WS, the parents/guardians of the child will be asked to give consent on their behalf. The child will also be given the opportunity to give consent. Due to their vulnerability at least one parent or guardian will remain in the presence of the child being interviewed. Due to the age and intellectual capacity of the children, the interviews will take the form of short, informal conversations. *Beneficence*: The possible harms include making parents and teachers feel inadequate or guilty regarding a child's level of functioning, their specific needs and their educational placement. This will be done by careful and sensitive wording of questions and being watchful for the non-verbal cues of the interviewees. To minimise these harms, questions will be carefully worded and interviews will be brought to a positive close. *Informed consent*: When selecting the sample for this research, potential participants will be informed about the scope of the research, the intended use of the data and their rights to anonymity, confidentiality, refusal to answer questions and to withdraw at

any stage from the research without explanation. All teacher interviewees, parent interviewees and parents of the WS children interviewees will have the right to see transcripts of the interviews. They will have the right to alter these transcripts.

Potential participants will only become part of the project if they provide written consent for themselves (and for the children) to be interviewed. In addition, their written consent will be required for the researcher to have access to selected documents.

The documents to be examined include the child's education plan, psychological assessment report and homework journal. These are all owned by the parents of the child. Written consent will be sought for each document. A copy will be made and the child's personal details will be removed with a code name supplied for research identification purposes. The parent has the right to supply all or none of the documents without affecting their participation in the research.

Privacy

All participants will be anonymised. Pupil details such as name and address will be removed from documents. Confidentiality will be maintained throughout.

Security

The questionnaires, interview transcripts and documents will be kept in a locked filing cabinet until such time as they will be shredded.

Risk assessment

Working within the above guidelines it is not considered that there are any risks that may be considered exceptional. Due regard will be given to the possibility of sensitive disclosures from the adults involved in the research, and any such instances will be managed in a way that prevents harm or damage to others. In the case of the interviewing of children with special educational needs, the informal style of the interview and the parental presence will help to protect the child's sense of dignity and security.

It should be noted that the Williams Syndrome Association of Ireland (WSAI) does not have a code of ethics for researchers but I have sought, and obtained the Association's permission to approach its members. In giving this permission, the issue was first discussed by their national committee who agreed to put the matter to the WSAI's Annual General Meeting in November 2009. Approval was given by all members present following a discussion and presentation from myself about the research, its implications and requirements. I made clear that no child, parent or teacher would be included in the research without written consent, that they would be able to withdraw at any point, would be given transcripts of interviews and could make adjustments to these transcripts. It was also made explicit that participation or non-participation would not affect their WSAI membership in any way. The WSAI committee would not be informed of those families who accepted or declined participation. Details of the research were also published in the WSAI's newsletter for those families who were not at the AGM.

I will be providing updates on the research to the WSAIs national committee at their regular meetings and to all the members through the WSAI newsletter.

Ethical Approval From Other Bodies

10 Does this research require the approval of an external body?	**Yes** X☐ **No** ☐
	If "Yes", please state which body:- **Williams Syndrome Association of Ireland**

11 Has ethical approval already been obtained from that body?	Yes X☐ -Please append documentary evidence to this form.
	No ☐
	If "No", please state why not:-
	Please note that any such approvals must be obtained and documented before the project begins.

WSAI

WILLIAMS SYNDROME ASSOCIATION OF IRELAND

Patron: The Right Hon. Desmond Guinness   Registered Charity Number – CHY 9654

13 Kilgarve Park, Ballinasloe, Co. Galway, Ireland.

Tel: 090 9643247   email: wsai@eircom.net

Ms Fionnuala Tynan

Victoria Place

Castlebar

Co Mayo

Dear Fionnuala,

I wish to confirm that your request at the Annual General Meeting of the Williams Syndrome Association of Ireland in November to carry out research on our members has the approval of the committee. You have the updated mailing list of our members and you may contact them by letter or face-to-face at our WS events.

Best wishes,

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Carmel Daly (secretary)