



Contents lists available at ScienceDirect

# Research in Developmental Disabilities

journal homepage: [www.elsevier.com/locate/redevdis](http://www.elsevier.com/locate/redevdis)

## Views of professionals about the educational needs of children with neurodevelopmental disorders

Jo Van Herwegen<sup>a,\*</sup>, Maria Ashworth<sup>a</sup>, Olympia Palikara<sup>b</sup><sup>a</sup> Department of Psychology and Human Development, UCL Institute of Education, United Kingdom<sup>b</sup> School of Education, University of Roehampton, United Kingdom

### ARTICLE INFO

No. of reviews completed is 2

#### Keywords:

Williams syndrome  
Down syndrome  
Autism Spectrum disorders  
Professionals  
SEND support  
Neurodevelopmental disorders

### ABSTRACT

**Background:** Professionals play a key role in supporting children with special educational needs in schools. However, the views of those working with neurodevelopmental disorders are less known.

**Aims:** This study examined the views of professionals (including teachers, teaching assistants, educational psychologists, speech and language therapists, physio and occupational therapists etc.) working with children with Williams Syndrome (WS), Down Syndrome (DS) or with Autism Spectrum Disorders (ASD) in terms of how informed professionals are about the disorder and their views about the type of support these children need to be receiving.

**Methods and procedures:** Professionals working with 77 children with ASD, 26 with DS and 38 with WS completed an online questionnaire.

**Outcomes and results:** Professionals in all three groups highlighted relevant areas of difficulty for these children, but they did not recognise some of the less phenotypical difficulties that children with a specific disorder may experience. In addition, there was a disconnect between the difficulties identified by the professionals and the type of specialist support that may be necessary.

**Conclusions and implications:** Although professionals have a lot of knowledge about the specific neurodevelopmental disorders, further evidence-based training would allow more effective support for children with neurodevelopmental disorders in the classroom but also equip professionals better and raise their confidence in meeting these children's needs.

### What this paper adds

This paper provides a current account of professionals' views concerning the needs and support required by children with neurodevelopmental disabilities, including Autism Spectrum Disorders (ASD), Down syndrome (DS) and Williams syndrome (WS), in order to best meet their needs in schools in the light of the most significant changes in England in the special educational needs legislation in the last decades. Whilst previous studies have mainly focused on the views of parents and teachers, the current study included the views from specialist professionals, such as educational psychologists and speech and language therapists. The results showed that, although professionals identified key difficulties for each of the disorders they worked with, they recognised the less phenotypical difficulties less frequently. In addition, there was a disconnect between the difficulties identified by the professionals and the type of specialist support that must be considered. The findings from this study, therefore, suggest that further evidence-based

\* Corresponding author at: Department of Psychology and Human Development, UCL Institute of Education, 25 Woburn Square, London, WC1H 0AA, United Kingdom.

E-mail address: [j.vanherwegen@ucl.ac.uk](mailto:j.vanherwegen@ucl.ac.uk) (J. Van Herwegen).

<https://doi.org/10.1016/j.ridd.2019.05.001>

Received 29 January 2019; Received in revised form 3 May 2019; Accepted 11 May 2019

Available online 24 June 2019

0891-4222/ © 2019 Elsevier Ltd. All rights reserved.

training for professionals about the disorder they work with would allow more effective support for children with neurodevelopmental disorders in the classroom but also equip professionals better and raise their confidence in meeting these children's needs.

## 1. Introduction

There are a number of professionals that contribute to meet the needs of children with special educational needs and disabilities (SEND) in schools in England, including classroom teachers, teaching assistants (TAs), Special Educational Needs Co-ordinators (SENCO), and specialist professionals such as speech and language therapists, occupational therapists, educational psychologists and many more. It is important to consider the views of professionals working with children with neurodevelopmental disorders and SEND. Not only do children spend a large majority of their time with education, health and care professionals, these professionals have an important influence on a child's learning (Thoonen, Slegers, Oort, Peetsma, & Geijsel, 2011), social and mental wellbeing (World Health Organization, 2003), and provide crucial services such as mental health support, occupational or physio-therapy, and speech and language therapy. Seeing the impact of the professionals on the life of a child with neurodevelopmental disorders, it is important to examine their views on how to best meet the educational needs of these children.

In England 2015, the new SEND Code of Practice (Department for Education & Department of Health, 2015) was introduced which includes a strong emphasis on a multi-agency approach, with professionals working together with parents and children in order to obtain a child-centred approach with regards to the type of support a child receives (Castro & Palikara, 2016). This change also means that statements of special educational needs (SEN) were replaced with Education Health and Care (EHC) plans. An EHC plan is a statutory document that describes in detail the short term and long-term outcomes for the child as well as the support that should be put in place in order for the child to achieve those goals and outcomes. The EHC plan is produced by a local authority, following an EHC needs assessment. An EHC assessment is usually conducted in collaboration with the child, their parents, school staff and a number of other professionals, including Educational psychologists, SENCOs and various other professionals. These professionals are often asked to provide input for a child's EHC plan assessment, including the difficulties and strengths a child with SEND might display and how outcomes may be achieved. As such these professionals require a good understanding of the child but also knowledge of the child's disorder and the SEND Code of Practice in general.

Recent research has examined the challenges that professionals experience with regards to the implementation of the SEND Code of Practice. This research has highlighted that many professionals feel increased performance anxiety, due to the fact that many professionals are expected to contribute to the child's EHC plan, without necessarily receiving the appropriate training about the SEND Code of Practice or the knowledge they need to formulate a child-centred support structure (Hellawell, 2018; Palikara, Castro, Gaona, & Eirinaki, 2019). In addition, research has shown that there is a decline in the number of children that are recorded to qualify for SEND support (Department for Education, 2018), which has been argued to be caused by the fact that professionals have been left feeling confused about the term SEN and are unclear about which children should receive support (Curran, Mortimore, & Riddell, 2017). This is also interlinked with economic practicalities, such as resource cuts, that influence professionals' decision making about the SEN support they can offer to pupils (Pearson, Mitchell, & Rapti, 2015). Therefore, the research so far seems to suggest that there might be a gap between the professionals' understanding of a disorder and the specialist support professionals view children need or are able to practically provide. However, it is not yet clear whether there is such a gap for all neurodevelopmental disorders. Research has also shown that there is a disconnect and sometimes friction between parents and professionals in relation to the relaying of knowledge and information between sides, and views on appropriate and effective provision (Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010; Stoner et al., 2005; Tissot, 2011). Clarifying professionals' views on these children's needs and the way these needs are met in schools could be beneficial to try and bridge the gap and improve communication between parents, schools and professionals.

The current research gathered the views of professionals working with children with three different neurodevelopmental disorders, namely children identified with an Autism Spectrum Disorder (ASD) and children with Down syndrome (DS) and Williams syndrome (WS). Whilst there is variability of individual differences in these neurodevelopmental disorders (Charman, 2014; Tsao & Kindelberger, 2009; Van Herwegen, Rundblad, Davelaar, & Annaz, 2011), the special educational, health, and care needs of these disorders overlap as well as show phenotypic differences (Rosner, Hodapp, Fidler, Sagun, & Dykens, 2004). Seeing the fact that children with DS and WS have similar cognitive delays, with overall IQs averaging around 50–70, and those with WS and ASD showing overlapping sensory and behavioural difficulties, comparing the professional views of how to support children with these overlapping and contrasting cognitive and behavioural profiles, as well differences in syndrome prevalence, will allow a better understanding of whether support is understood as syndrome specific or child specific.

WS is a rare neurodevelopmental disorder, affecting approximately 1 in 20,000 live births, and is caused by the microdeletion of 26 genes on chromosome 7 (Martens, Wilson, & Reutens, 2008). People with WS have an uneven cognitive profile showing better spoken language, auditory memory and face processing abilities, but poor visuo-spatial and planning abilities (Martens et al., 2018). However, language abilities overall are delayed and develop atypically with better language production in contrast to language comprehension difficulties (Mervis & Becerra, 2007). In addition, people with WS can experience physical and mental health difficulties with poor gross and fine motor skills, complex health issues including severe heart conditions, sensory problems, and anxiety (Martens et al., 2008). Research has shown that parents of children with rare genetic disorders such as Angelman syndrome, Cornelia de Lange syndrome and Cri du Chat syndrome are concerned about not having access to professionals who are knowledgeable about their child's syndrome because they are less well known (Griffith, Hastings, Nash et al., 2011, Griffith, Hastings, Oliver et al., 2011). In addition, parents of children with WS rated professionals' lack of knowledge about their child's condition was significantly more stressful compared to parents of children with ASD and DS (Ashworth, Van Herwegen, & Palikara, under review). Drawing from this,

professionals may be less knowledgeable about WS compared to the more common disorders such as ASD and DS. Yet, the uneven cognitive profile, behavioural, and, sensory difficulties and health problems associated with WS make supporting these children in educational settings complex and requires professionals to have particular knowledge about the syndrome (Palikara, Ashworth, & Van Herwegen, 2018).

Down syndrome (DS) is a more common neurodevelopmental disorder occurring about 1 in 800 live births (Silverman, 2007). Despite individual differences, many individuals with DS have significant deficits with speech and language production, syntax, and language intelligibility, which benefit from professional support such as speech and language therapists (SLTs) (Roberts, Price, & Malkin, 2007). In addition, hearing loss is common in DS (Roizen, 2002), which provides an additional barrier for speech and language development, as well as speech intelligibly (Roberts et al., 2007). Many people with DS also have short-term memory impairments which can cause further problems with language learning and development, such as learning new words (Jarrold, Baddeley, & Hewes, 2000). These cumulative issues relating to the speech and language development for people with DS would require learning accommodations to be made at school, as well as interventions by education professionals and other practitioners. Many people with DS can also experience a range of physical disabilities in their motor development, including issues with low muscle tone, joint hypermobility, postural control, balance problems and sometimes obesity (Alexander et al., 2016; Block, 1991; Palisano et al., 2001), as well as congenital heart disease (Freeman et al., 2008). Due to these physical disabilities, many people with DS require interventions from occupational therapists (OTs) and physiotherapists to help with everyday functioning and participation in activities, such as writing in class and moving about within school (Champagne & Dugas, 2010; Daunhauer & Fidler, 2011; Mahy, Shields, Taylor, & Dodd, 2010). Although generally described as happy, many individuals with DS have increased mental health issues compared to a TD population (Chapman & Hesketh, 2000; Dykens, Shah, Sagun, Beck, & King, 2002) and experience issues such as attention deficit hyperactivity disorder, obsessive-compulsive disorder, and depression which require therapeutic and preventative interventions from professionals (Määttä, Tervo-Määttä, Taanila, Kaski, & Iivanainen, 2006). In addition, about 18% of young people with DS have been found to suffer from anxiety (Dykens et al., 2015).

Autism is a relatively common disorder with about 1 in 100 children affected (Baird et al., 2006). ASD is diagnosed through tools that assess the extent to which an individual displays ongoing difficulties with social communication and interaction, as well as restricted and repetitive patterns of behaviours or interests (American Psychiatric Association, 2013). Unlike WS and DS, people with ASD can have IQs ranging from below 50 to over 120 (Charman et al., 2011), and there is also large variability in the degree to which individuals experience the behavioural characteristics associated with the diagnosis of ASD (Rodriguez & Thompson, 2015). Nevertheless, many people with ASD do encounter significant problems with social communication and the use of language in communication that requires support from professionals, such as SLTs, particularly for the children with ASD who have very low or no verbal abilities (Geurts & Embrechts, 2008). There are similarities between ASD and WS in their difficulties with repetitive restrictive behaviours, and people with ASD often also have significant sensory issues (Myles et al., 2004). In order to address a child's particular sensory issues, occupational therapy is commonly used to aid well-being and optimal learning in the classroom (Case-Smith & Arbesman, 2008). Similar to people with WS, people with ASD can also have heightened anxiety that can benefit from mental health support by professionals (Rodgers, Riby, Janes, Connolly, & McConachie, 2012). Although there is individual variability, a high proportion of children with ASD display significant but subtle impairments in a variety of motor abilities, including producing speeded movements, planning and learning motor sequences, executing skills such as throwing, catching or balancing, and on more general tests of gross and fine motor skills (see Hilton et al., 2007, for an overview).

In sum, children with WS, DS, and ASD have complex overlapping as well as unique areas of education, health, and care needs (Rosner et al., 2004) and are likely to require the support from a number of professionals. Seeing the impact of professionals on the life and support (including the identification of that support) that children with neurodevelopmental disorders are receiving in schools, it is important to examine professional's views on provision for SEND for these children. A better understanding of how professionals view the needs and support for children with neurodevelopmental disorders can provide better insight into the current state of education provision and highlight areas in need of improvement.

There is a growing body of research that has gathered parental views on SEND provision (Lamb, 2009; Lindsay, Ricketts, Peacey, Dockrell, & Charman, 2016; Van Herwegen, Ashworth, & Palikara, 2018; Parsons, Lewis, & Ellins, 2009). However, there is limited research concerning the views of professionals on the needs and required provision for children and young people with neurodevelopmental disorders. One study that has examined the views of teachers ( $n = 204$ ) of children with four different rare neurodevelopmental disorders (Fragile X syndrome, Prader-Willi syndrome, WS and Velo-Cardio-Facial syndrome) found that teachers had limited knowledge of the syndromes and did not think needs differed greatly from other disabilities (Reilly, Senior, & Murtagh, 2015). Only 11% of teachers reported that they received any training about the child's syndrome, which would impact the educational planning in relation to the children's syndrome specific cognitive and behavioural profiles (Reilly et al., 2015). Eliciting the professional's views on educational provision in this study highlighted areas for improvement in training and also contrasts to parental views concerning educational provision.

In addition to the scarcity of the research, most studies that have examined professional views on SEND provision have mainly considered the views of teachers only (Able, Sreckovic, Schultz, Garwood, & Sherman, 2015; Emam & Farrell, 2009; Gilmore, Campbell, & Cuskelly, 2003). The lack of variety in the types of professionals from whom these views are obtained may provide a restricted understanding of professionals' outlook on SEND provision. Considering the scope of education, health, and care professionals that children and young people with neurodevelopmental disorders can come into contact with across their school career, it is important to gather the views of many types of professionals as possible to gain a reliable and accurate insight of the professional opinion of SEND provision.

The current study aimed to gather the views of professionals working with children with neurodevelopmental disorders.

Specifically, this research investigated 1) how informed professionals were about ASD, DS, and WS and where they gained this knowledge from, 2) professionals' views about the challenges they encounter when working with such children, as well as 3) their opinions about the SEND services and support the children receive. Together these questions would provide insight into what information and continued professional development professionals should receive in terms of developmental disorders and how to support children with WS, ASD, and DS in the classroom.

Due to the rarity of WS, it was hypothesised that professionals would have the least knowledge and be less confident in their knowledge about WS compared to DS and ASD. Similarly, professionals working with children with WS would have had less training about the disorder compared to those working with children with ASD and DS. In addition, although all three neurodevelopmental groups have complex needs, it was predicted that professionals' views about what support children with WS, DS, and ASD might be underestimated and that, despite their knowledge of the more common disorders, they may fail to recognise some of the less phenotypical difficulties associated with these, especially motor difficulties for children with ASD and mental health issues for those with DS.

## 2. Method

### 2.1. Participants

Professionals ( $n = 141$ ; 95% female) working with children with ASD ( $n = 77$ ), DS ( $n = 26$ ) and WS ( $n = 38$ ) voluntarily completed one online questionnaire related to one disorder group they worked with via the platform 'Qualtrics'. Although this number is rather small, in terms of geographical representation, the professionals lived throughout England and Wales. Participants were recruited by sharing an online link to the questionnaire through social media, as well as through previously established links with schools and professional groups by email, letter and phone, and by word of mouth through parental contacts. Professionals were teachers, SENCos, teaching assistants (TAs), and specialists including SLTs, educational psychologists, and OTs. As there was an equal distribution between the types of profession,  $\chi^2(6) = 11.93$ ,  $p = 0.064$  within each disorder group, respondents were treated as one group of profession for each of the three disorder groups.

There were no differences between the three disorder groups for age of the participants;  $F(2,101) = .039$ ,  $p = .962$ ,  $\eta_p^2 = .001$ , nor for level of education or years within this profession (see Table 1 for further information about the participants). However, the professionals completing the survey for children with ASD were very experienced, with many having worked with over 100 children with ASD, compared to those completing the survey for WS where most professionals had only worked with one child with WS,  $\chi^2(10) = 84.09$ ,  $p < .001$ .

### 2.2. Materials and procedure

The questionnaire was developed by the researchers to suit the study aims and was part of a larger survey about raising the achievements and meeting the needs of children with neurodevelopmental disorders funded by the Williams Syndrome Foundation UK. This 30- to 40- minute survey consisted of a variety of answering formats including multiple choice and Likert scales and included questions around the themes of knowledge about the disorder. Participants were asked to think about each disorder in general and answer questions about the type of training and experience they had with this disorder, the number of children they had worked with, what training or information they had been provided and by whom, what they thought the educational, behavioural, and clinical strengths and difficulties for this disorder included (selected from a long list of difficulties and strengths put together from the literature), and what type of support children with this particular disorder may need. The questionnaire was piloted with a number of professionals prior to the main study and changes in the wording and the order of the questions were made as a result of professionals' suggestions of the pilot format of the questionnaire.

Data was analysed using Chi-Square analyses were used to examine differences between groups and standardized residuals were used to examine within group differences. Fisher's exact test was used when the count for a cell was less than 5.

## 3. Results

### 3.1. Professionals' knowledge about the neurodevelopmental disorders

Table 2 provides an overview of the answers per disorder group. When asked "How confident do you feel in relation to your knowledge about [the disorder]?", professionals working with individuals with WS reported that they were less confident in their knowledge about WS compared to those working with ASD and DS,  $\chi^2(4) = 34.49$ ,  $p < .001$ . There were no group differences in whether professionals were provided with any information about the neurodevelopmental disorder when they first started to work with the child,  $\chi^2(2) = 5.57$ ,  $p = .062$  ("Were you provided with any information about [the disorder] when you first started to work with children with [the disorder]?"). However, a significant number of professionals (40% in total) had not received any information about the disorder and all professionals in all groups sought their own information about the disorder they worked with,  $\chi^2(2) = 1.32$ ,  $p = 0.521$  ("Have you sought information yourself with regards to [disorder]?") (See Table 2). As many professionals had sought their own information, professionals in all groups felt that the information they had about the disorder was sufficient;  $\chi^2(2) = .436$ ,  $p = 0.804$  ("Was the information you have been given or sought yourself..."). However, there were some tentative group differences as to where professionals look for information about the disorder,  $\chi^2(10) = 18.31$ ,  $p = 0.050$ . Very few professionals

**Table 1**

Information about age, education level, profession, time in profession and the number of children worked with for professionals working with children with Williams Syndrome (WS), Down Syndrome (DS) and Autism Spectrum Disorders (ASD).

	ASD (n)	DS (n)	WS (n)	$\chi^2$
Mean Age in Years (Standard Deviation)	42.63 (12.57)	42.48 (12.19)	41.57 (9.69)	
What is your highest level of education?				$p = .138$
GCSE <sup>a</sup>	1 (1.3%)	0 (0%)	0 (0%)	
NVQ <sup>b</sup>	1 (1.3%)	4 (15.4%)	7 (18.4%)	
Undergraduate Degree	11 (14.3%)	5 (19.2%)	8 (21.1%)	
Post-graduate degree	37 (48%)	13 (50%)	19 (50%)	
Missing	27 (35.1%)	4 (15.4%)	4 (10.5%)	
What is your profession?				$p = .064$
Teacher	14 (18.2%)	5 (19.2%)	13 (34.2%)	
SENCo	20 (25.9%)	5 (19.2%)	5 (13.2%)	
Teaching Assistant	2 (2.6%)	4 (15.4%)	7 (18.4%)	
Specialist	14 (18.2%)	8 (30.8%)	9 (23.7%)	
Missing	27 (35.1%)	4 (15.4%)	4 (10.5%)	
How many years have you been in this role?				$p = .124$
1-5 years	16 (20.7%)	9 (34.6%)	16 (42.1%)	
6-10 years	13 (16.9%)	1 (3.9%)	3 (7.9%)	
11-15 years	9 (11.7%)	5 (19.2%)	3 (7.9%)	
More than 15 years	12 (15.6%)	7 (26.9%)	12 (31.6%)	
Missing	27 (35.1%)	4 (15.4%)	4 (10.5%)	
How many children with [the disorder] have you worked with during your professional career?				$p < .001$
1	1 (1.3%)	4 (15.4%)	25 (65.8%)	
Between 1-10	12 (15.6%)	9 (34.6%)	13 (34.2%)	
Between 11-99	32 (41.6%)	8 (30.8%)	0 (0%)	
More than 100	15 (19.5%)	2 (7.7%)	0 (0%)	
More than 200	7 (9%)	2 (7.7%)	0 (0%)	
Missing	10 (13%)	1 (3.9%)	0 (0%)	

<sup>a</sup> A qualification in a specific subject typically taken by school students aged 14–16, at a level, below A-level.

<sup>b</sup> National Vocational training/ work-based qualification.

working with children with WS used the Williams Syndrome Foundation UK as a source of information and instead used the internet (See Table 2). In all three groups a significant number of professionals, 34% for WS and 30% for ASD but only 16% for DS, relied on the parents to provide information about the disorder.

As there were no differences between the type of professional per disorder group, we pooled the data across the three developmental disorders to examine if there were any differences between the different types of professionals. However, there were no differences in their confidence or the type of information received between the different professional groups.

### 3.2. Professionals' views of difficulties and challenges for neurodevelopmental disorders

Professionals were asked to rate for each of the abilities listed below, whether they thought this was a challenge or difficulty for the disorder they completed the survey for. We have grouped these abilities into larger categories, reflecting the areas of need

**Table 2**  
Descriptive statistics for professionals' knowledge about ASD, DS and WS.

	ASD (n)	DS (n)	WS (n)	$\chi^2$
How confident do you feel in relation to your knowledge about [the disorder]?				$p < .001$
Not confident	1 (1.3%)	2 (7.7%)	10 (26.3%)	
Moderately confident	23 (29.9%)	9 (34.6%)	23 (60.5%)	
Very confident	45 (58.4%)	15 (57.7%)	5 (13.2%)	
Missing	8 (10.4%)	0 (0%)	0 (0%)	
Were you provided with any information about [the disorder]?				$p = .062$
No	21 (27.3%)	12 (46.2%)	20 (52.6%)	
Yes	48 (62.3%)	14 (53.8%)	18 (47.4%)	
Missing	8 (10.4%)	0 (0%)	0 (0%)	
Have you sought information yourself with regards to [the disorder]?				$p = .521$
No	2 (2.6%)	1 (3.9%)	0 (0%)	
Yes	67 (87%)	25 (96.1%)	38 (100%)	
Missing	8 (10.4%)	0 (0%)	0 (0%)	
Was the information you have been given or sought yourself:				$p = .804$
Insufficient	9 (11.7%)	3 (11.5%)	3 (7.9%)	
Sufficient	55 (71.4%)	22 (84.6%)	29 (76.3%)	
Missing	13 (16.9%)	1 (3.9%)	6 (15.8%)	
Where did you look for and found the most useful information about [the disorder]?				$p = .050$
Internet	20 (25.9%)	7 (26.9%)	19 (50%)	
Books	5 (6.5%)	3 (11.5%)	0 (0%)	
Educational Psychologist	6 (7.8%)	1 (3.9%)	0 (0%)	
Disorder Organisation	17 (22.1%)	8 (30.8%)	4 (10.5%)	
Parent	11 (14.3%)	4 (15.4%)	13 (34.2%)	
Other	4 (5.2%)	2 (7.7%)	2 (5.3%)	
Missing	14 (18.2%)	1 (3.9%)	0 (0%)	

identified in individual support plans, to extract the main themes (See Table 3 for an overview of the data and themes).

As shown in Table 3, for emotional wellbeing, there were no differences for overall mental health with about half of the professionals selected this to be an issue within each group. Yet, more professionals working with ASD identified that anxiety was a particular difficulty, whilst most professionals did not rate this as a difficulty for children with DS and answers for those professionals working with WS were divided.

The majority of professionals in all three groups acknowledged that engagement was a difficulty for the disorder they worked with and there were no group differences (see Table 3).

For physical abilities, most professionals working with children with WS identified children with WS to have a range of motor and coordination difficulties, whereas only half of professionals identified children with DS to have difficulties in this area, and motor and coordination abilities were not considered an area of difficulty for children with ASD.

For language abilities, the majority of professionals in all three groups agreed that children with the disorder they work with have both language as well as comprehension difficulties and there were no differences between the three groups.

As can be seen in Table 3, more professionals working with individuals with ASD agreed that children with ASD have social difficulties and issues with empathy, compared to those with WS and those with DS. However, the views from professionals working with children with WS were divided.

For life-skills, although half of the professionals working with children with WS as well as ASD highlighted eating difficulties,

**Table 3**  
Issues and difficulties identified by the professionals for each of the three disorders groups.

		Group			$\chi^2$	Residuals
		ASD (n)	DS (n)	WS (n)		
<b>Emotional wellbeing</b>						
Anxiety	No	8 (10.4%)	14 (53.8%)	17 (44.7%)	$\chi^2 (2) = 28.538, p < .001$	ASD > WS > DS
	Yes	53 (68.8%)	5 (19.2%)	18 (47.4%)		
	Missing	16 (20.8%)	7 (26.9%)	3 (7.9%)		
<b>Mental health</b>						
Mental health	No	31 (40.2%)	11 (42.3%)	24 (63.2%)	$\chi^2 (2) = 2.868, p = .238$	ASD = WS = DS
	Yes	30 (38.9%)	8 (30.8%)	11 (28.9%)		
	Missing	16 (20.8%)	7 (26.9%)	3 (7.9%)		
<b>Engagement</b>						
<b>Attention difficulties</b>						
Attention difficulties	No	17 (22.1%)	5 (19.2%)	4 (10.5%)	$\chi^2 (2) = 3.614, p = .164$	ASD = WS = DS
	Yes	44 (57.1%)	14 (53.8%)	31 (81.6%)		
	Missing	16 (20.8%)	7 (26.9%)	3 (7.9%)		
<b>Physical abilities</b>						
<b>Balance</b>						
Balance	No	54 (70.2%)	16 (61.5%)	19 (50%)	$\chi^2 (2) = 15.505, p < .001$	WS > ASD = DS
	Yes	7 (9%)	3 (11.5%)	16 (42.1%)		
	Missing	16 (20.8%)	7 (26.9%)	3 (7.9%)		
<b>Coordination</b>						
Coordination	No	46 (59.7%)	9 (34.6%)	14 (36.8%)	$\chi^2 (2) = 13.132, p < .001$	WS > DS > ASD
	Yes	15 (19.5%)	10 (38.5%)	21 (55.3%)		
	Missing	16 (20.8%)	7 (26.9%)	3 (7.9%)		
<b>Fine motor</b>						
Fine motor	No	43 (55.8%)	6 (23.1%)	9 (23.7%)	$\chi^2 (2) = 21.075, p < .001$	WS > DS > ASD
	Yes	18 (23.4%)	13 (50%)	26 (68.4%)		
	Missing	16 (20.8%)	7 (26.9%)	3 (7.9%)		
<b>Gross motor</b>						
Gross motor	No	50 (64.9%)	12 (46.2%)	21 (55.3%)	$\chi^2 (2) = 6.265, p = .044$	WS = DS = ASD
	Yes	11 (14.3%)	7 (26.9%)	14 (36.8%)		
	Missing	16 (20.8%)	7 (26.9%)	3 (7.9%)		
<b>Language</b>						
<b>Language Comprehension</b>						
Language Comprehension	No	18 (23.4%)	8 (30.8%)	17 (44.7%)	$\chi^2 (2) = 3.668, p = .160$	
	Yes	43 (55.8%)	11 (42.3%)	18 (47.4%)		
	Missing	16 (20.8%)	7 (26.9%)	3 (7.9%)		
<b>Expressive Language</b>						
Expressive Language	No	21 (27.3%)	4 (15.4%)	16 (42.1%)	$\chi^2 (2) = 3.350, p = .187$	
	Yes	40 (51.9%)	15 (57.7%)	19 (50%)		
	Missing	16 (20.8%)	7 (26.9%)	3 (7.9%)		
<b>Social</b>						

(continued on next page)

Table 3 (continued)

		Group			$\chi^2$	Residuals
		ASD (n)	DS (n)	WS (n)		
Empathy	No	10 (13%)	16 (61.5%)	19 (50%)	$\chi^2 (2) = 32.826, p < .001$	ASD > WS > DS
	Yes	51 (66.2%)	3 (11.5%)	16 (42.1%)		
	Missing	16 (20.8%)	7 (26.9%)	3 (7.9%)		
Social Interaction	No	11 (14.3%)	11 (42.3%)	16 (42.1%)	$\chi^2 (2) = 14.056, p = .001$	ASD > WS > DS
	Yes	50 (64.9%)	8 (30.8%)	19 (50%)		
	Missing	16 (20.8%)	7 (26.9%)	3 (7.9%)		
Life-skills Eating	No	31 (40.2%)	15 (57.7%)	18 (47.4%)	$\chi^2 (2) = 5.008, p = .082$	
	Yes	30 (38.9%)	4 (15.4%)	17 (44.7%)		
	Missing	16 (20.8%)	7 (26.9%)	3 (7.9%)		
Personal hygiene	No	47 (61%)	16 (61.5%)	24 (63.2%)	$\chi^2 (2) = 1.773, p = .412$	
	Yes	14 (18.2%)	3 (11.5%)	11 28.9%		
	Missing	16 (20.8%)	7 (26.9%)	3 (7.9%)		
Self help	No	30 (38.9%)	11 (42.3%)	16 (42.1%)	$\chi^2 (2) = .739, p = .691$	
	Yes	31 (40.2%)	8 (30.8%)	19 (50%)		
	Missing	16 (20.8%)	7 (26.9%)	3 (7.9%)		
Academic Numeracy	No	52 (67.5%)	10 (38.5%)	20 (52.6%)	$\chi^2 (2) = 12.463, p = .002$	WS = DS > ASD
	Yes	9 (11.7%)	9 (34.6%)	15 (39.5%)		
	Missing	16 (20.8%)	7 (26.9%)	3 (7.9%)		
Reading	No	51 (66.2%)	22 (46.2%)	22 (57.9%)	$\chi^2 (2) = 6.331, p = .042$	WS = DS > ASD
	Yes	10 (13%)	7 (26.9%)	13 (34.2%)		
	Missing	16 (20.8%)	7 (26.9%)	3 (7.9%)		
Writing	No	49 (63.6%)	7 (26.9%)	14 (36.8%)	$\chi^2 (2) = 20.702, p < .001$	WS = DS > ASD
	Yes	12 (15.6%)	12 (46.2%)	21 (55.3%)		
	Missing	16 (20.8%)	7 (26.9%)	3 (7.9%)		
Information processing Sensory	No	14 (18.2%)	9 (34.6%)	17 (44.7%)	$\chi^2 (2) = 8.025, p = .018$	ASD > WS = DS
	Yes	47 (61%)	10 (38.5%)	18 (47.4%)		
	Missing	16 (20.8%)	7 (26.9%)	3 (7.9%)		
Hearing	No	57 (74%)	9 (34.6%)	32 (84.2%)	$\chi^2 (2) = 25.954, p < .001$	DS > WS = ASD
	Yes	4 (5.2%)	10 (38.5%)	3 (7.9%)		
	Missing	16 (20.8%)	7 (26.9%)	3 (7.9%)		

(continued on next page)

Table 3 (continued)

		Group			$\chi^2$	Residuals
		ASD (n)	DS (n)	WS (n)		
Vision	No	57 (74%)	11 (42.3%)	31 (81.6%)	$\chi^2 (2) = 15.544, p < .001$	DS > WS = ASD
	Yes	4 (5.2%)	8 (30.8%)	4 (10.5%)		
	Missing	16 (20.8%)	7 (26.9%)	3 (7.9%)		

there were no significant differences between the groups. Most of the professionals in all three groups did not consider the group they worked with to have personal hygiene difficulties. Yet, half of the professionals in each group considered self-help to be an issue within the group they worked with.

Although the number of professionals working with WS and DS was significantly higher, the majority of professionals did not consider the children they worked with to have difficulties with numeracy or reading. Yet, the majority of professionals did identify children with WS and DS to have writing difficulties, in contrast to those working with ASD.

Finally, there were a number of differences between the group when considering information processing difficulties: whilst most professionals agreed children with ASD show sensory processing difficulties, only half of those working with WS and DS reported such difficulties. Although most professionals agreed there are no hearing or vision difficulties in the children they worked with, there were slightly more professionals who identified children with DS to have hearing and vision difficulties.

In order to examine whether there were any differences between the different types of professionals (teachers, SENCOs and other professionals) with regards to their views about the strengths and difficulties of a disorder, only responses from those working with children with ASD were considered, as there were not enough responses for each type of professional in the WS and DS groups to provide a reliable analysis. However, there were no significant differences between the different types of professionals about the strengths and difficulties related to children with ASD.

### 3.3. Professionals' views about educational provision

Professional opinions were very divided about what type of school children with WS, DS, and ASD should attend but across the three groups most professionals reported that children with WS, DS, and ASD would experience difficulties when attending a mainstream school,  $\chi^2 (4) = 3.68, p = 0.451$ . However, the majority of professionals did not think that these children needed specialist support,  $\chi^2 (4) = 6.074, p = 0.194$  (see Table 4). Yet, most professionals agreed that those with DS and WS generally need an EHC plan but the opinion for children with ASD was split,  $\chi^2 (4) = 12.494, p = 0.014$ .

Interestingly, most professionals reported that the children they worked with required SLT support, (81%) as well as OT (77% in total) and there were no differences between the three groups for SLT;  $\chi^2 (4) = 6.014, p = 0.198$  or for OT;  $\chi^2 (4) = 6.34, p = 0.175$ . Yet, more professionals reported that children with DS and WS needed physiotherapy compared to ASD,  $\chi^2 (4) = 17.306, p = 0.002$ . Finally, the majority of professionals agreed that children with ASD would benefit from counselling in contrast to those with DS, but for WS their view is split,  $\chi^2 (4) = 17.28, p = 0.002$ .

## 4. Discussion

The current study evaluated for the first time the views from different professionals working with either ASD, DS, and WS about the information and knowledge they have about the neurodevelopmental disorder they work with, and their views about the type of support these children may need to be receiving. In line with the predictions, professionals working with WS had less experience and felt less confident in their knowledge about the disorder compared to those working with DS and ASD. This result is not surprising seeing the rarity of WS. However, overall 40% of professionals were not given any information when they first started working with the disorder and were reliant on finding their own information. This finding was consistent across all three groups and in all groups a considerable number of professionals relied on the parents to provide information about the disorder. This outcome, although better in terms of the number of informed professionals, is similar to a previous study which reported that teachers' knowledge of neurodevelopmental disorders is poor and that only 11% of teachers working with a rare neurodevelopmental disorder had received any training about the child's syndrome (Reilly et al., 2015). The current study therefore shows that a lack of information about the disorder might not just be a problem for professionals working with rare neurodevelopmental disorders but also for those working with more common disorders such as DS or ASD.

Professionals in all three groups listed a range of difficulties for each of the disorders and thus recognized the complex education, health, and care needs of children with WS, DS, and ASD. For example, the majority of professionals in all three groups identified language comprehension, expressive language abilities, and attention difficulties to be a challenge. In addition, the majority of professionals working with children with ASD recognized that those with ASD in general have anxiety, social difficulties, and sensory information processing difficulties. However, they did not recognise children with ASD may also have motor or coordination

**Table 4**  
Professionals' views of type of provision and support needed for each of the disorder groups.

	ASD (n)	DS (n)	WS (n)	$\chi^2$
Most children with [the disorder] will struggle to attend mainstream.				$p = .451$
Disagree	19 (24.7%)	9 (34.6%)	10 (26.3%)	
Neutral	5 (6.5%)	3 (11.5%)	7 (18.4%)	
Agree	39 (50.6%)	11 (42.3%)	20 (52.6%)	
Missing	14 (18.2%)	3 (11.5%)	1 (2.6%)	
Do children with [the disorder] need specialist support				$p = .194$
Disagree	37 (48%)	12 (46.2%)	16 (42.1%)	
Neutral	5 (6.5%)	5 (19.2%)	9 (23.7%)	
Agree	21 (27.3%)	7 (26.9%)	10 (26.3%)	
Missing	14 (18.2%)	2 (7.7%)	3 (7.9%)	
Do you think children with [the disorder] need an Education Health and Care plan?				$p = .014$
Disagree	21 (27.3%)	5 (19.2%)	3 (7.9%)	
Neutral	14 (18.2%)	3 (11.5%)	5 (13.2%)	
Agree	27 (35.1%)	15 (57.7%)	28 (73.6%)	
Missing	15 (19.5%)	3 (11.5%)	2 (5.3%)	
Do you think children with [the disorder] need Speech and Language Therapy?				$p = .198$
Disagree	4 (5.2%)	3 (11.5%)	1 (2.6%)	
Neutral	11 (14.3%)	1 (3.9%)	3 (7.9%)	
Agree	47 (61%)	20 (76.9%)	33 (86.8%)	
Missing	15 (19.5%)	2 (7.7%)	1 (2.6%)	
Do you think children with [the disorder] need Occupational Therapy?				$p = .175$
Disagree	1 (1.3%)	3 (11.5%)	2 (5.3%)	
Neutral	11 (14.3%)	5 (19.2%)	4 (10.5%)	
Agree	50 (64.9%)	15 (57.7%)	31 (81.6%)	
Missing	15 (19.5%)	3 (11.5%)	1 (2.6%)	
Do you think children with [the disorder] need Physiotherapy?				$p = .002$
Disagree	9 (11.7%)	2 (7.7%)	2 (5.3%)	
Neutral	36 (46.7%)	8 (30.8%)	10 (26.3%)	
Agree	16 (20.8%)	14 (53.8%)	24 (63.2%)	
Missing	16 (20.8%)	2 (7.7%)	2 (5.3%)	
Do you think children with [the disorder] need Counselling?				$p = .002$
Disagree	5 (6.5%)	7 (26.9%)	4 (10.5%)	
Neutral	17 (22.1%)	11 (42.3%)	14 (36.8%)	
Agree	40 (51.9%)	4 (15.4%)	13 (34.2%)	
Missing	15 (19.5%)	4 (15.4%)	7 (18.4%)	

difficulties. Yet, recent research has shown impairments in children with ASD across a range of motor skills and have even argued that motor difficulties may be a core feature of ASD (Fournier, Hass, Naik, Lodha, & Cauraugh, 2010; Hilton, Zhang, Whilte, Klohr, & Constantino, 2012). In contrast, the majority of professionals working with children with WS acknowledged motor and coordination to be a difficulty for children with WS. However, only half of the professionals viewed anxiety or sensory processing abilities to be a difficulty in children with WS, despite the fact that research has shown that both children with WS and ASD have anxiety (Rodgers et al., 2012) and sensory processing difficulties (John & Mervis, 2010), but the reasons why they experience these difficulties may differ (see Rodgers et al., 2012 for a discussion). The majority of professionals did not consider children with WS or DS to have reading difficulties or difficulties with mathematics, even though more professionals with WS and DS reported academic difficulties for children with WS and DS compared to those with ASD. Yet, research has shown that mathematical abilities are considerably delayed in both groups from infancy onwards (see Van Herwegen, Ranzato, Karmiloff-Smith, & Simms, under review) and, despite a lot of variability being reported for reading in both populations, for both groups reading abilities have found to be delayed compared to typically developing children of a similar age and may even rely on different mechanisms (Steele, Scerif, Cornish, & Karmiloff-Smith, 2013). Finally, professionals did identify vision and hearing difficulties to be areas of difficulty for children with DS. Children with WS can also have a number of issues with vision, such as strabismus, reduced stereopsis and acuity loss (Winter, Pankau, Amm, Gosch, & Wessel, 1996) but only a minority of professionals identified vision issues in the children with WS.

These findings show that most professionals recognise the most prototypical difficulties in each neurodevelopmental disorder, such as children with ASD having problems with sensory, language and anxiety difficulties and those with DS showing hearing and vision issues, but also that they are less likely to acknowledge some of the less familiar difficulties (e.g., motor difficulties in ASD or vision issues in WS). There was often a divide within the views, with half of the professionals acknowledging a certain difficulty and the other half saying that this was not a difficulty, suggesting not only that there are individual differences but that some difficulties may be subtle.

These differences are not likely to be driven by the type of education received by the professionals as there were no differences between the different professional groups and all types of professionals received the same information about the disorder and felt equally confident in working with these disorder groups. However, similarly to previous studies, teachers working with rare neurodevelopmental disorders may have limited knowledge about the rare disorders they work with (Reilly et al., 2015). In addition, the prototypical knowledge of professionals might hinder a broad understanding of the child's needs and difficulties. The results from the current study suggest that there is room for further professional development with regards to the more subtle difficulties experienced by children with neurodevelopmental disorders in general and not just for rare ones and this training should be provided to all types of professionals. Furthermore, these findings indicate that, due to the overlap of difficulties and strengths between the three disorders, this training should focus on individual differences and emphasize a need for assessing the abilities of a specific child across a range of domains rather than assuming a certain profile for each disorder (see Gillberg, 2010 for discussion).

Although most professionals in all three groups recognized a wide range of difficulties that children with ASD, DS, and WS experience, when asked about the type of educational provision and support the children should receive, the majority of the professionals reported that children with neurodevelopmental disorders would not be able to cope in a mainstream setting and professionals agreed that generally children with WS and DS would benefit from an EHC plan.

These findings are interesting in that there has been a drive in the UK to ensure that students with SEN, including those with neurodevelopmental disorders such as ASD, experience inclusive education and are educated in mainstream schools. While most educators support a rights-based approach to inclusion in principle, the current findings reflect the tension that professionals experience with relation to the support available and barriers to provide such an inclusive environment, which includes the severity of the disorder (Avramidis & Norwich, 2002). Participants in the current study were asked to reflect on the difficulties of the disorder group they worked with and thus, this may have resulted in professionals reflecting more on the barriers in relation to inclusive education. In addition, participants were also asked to reflect on their knowledge about the disorder and this may have contributed to their views about children with neurodevelopmental disorders being educated within a mainstream school. Indeed, recent studies that focused on attitudes of stakeholders towards inclusive education have shown that both parents and teachers had concerns with regards to the level of knowledge and understanding of mainstream school staff and the need for more training in order to support children with neurodevelopmental disorders in the classroom (Kendall, 2018; Roberts & Simpson, 2016).

Whilst most professionals acknowledged that children in all three groups experience language and communication difficulties as well as attention difficulties, most professionals did not think that children with these neurodevelopmental disorder required any specialist support. The current survey study does not provide any insight into why professionals do not think specialist input would help children with neurodevelopmental disorders, despite the recognition of their complex needs. One option as to why professionals might not see that specialist support would help, is that professionals may consider that there is currently only limited support available due to resource cuts and therefore, that the limited amount of specialist support that the child would be receiving would make very little difference (Pearson et al., 2015). However, further research is required in order to examine this discrepancy further.

Considering the type of specialist support required, although participants identified no differences for mental health difficulties between the three groups, participants considered those with ASD to benefit from counselling, in contrast to those with WS and DS. This might be due to the fact that professionals may think that counselling therapies generally involve a lot of self-insight and language skills and that people with moderate learning difficulties may not be able to benefit from such a therapy (see Hatton, 2002 for a review). In addition, the fact that professionals did not always recognise the less prototypical difficulties for the disorder was also reflected in their views about the support these children need and professionals were less likely to agree that people with ASD need physiotherapy.

Although the current study is the first to include the views from a range of professionals working with a range of

neurodevelopmental disorders that have not yet previously been explored in depth, especially Williams syndrome, the sample size was very small and therefore did not allow us to directly compare the views from different professionals (e.g., teaching staff versus specialist professionals). Therefore, the findings from the current study should be replicated using larger sample sizes and be followed up by qualitative interviews in order to further examine the views of the professionals with regards to the type of support children with neurodevelopmental disorders should receive within the classroom.

Additionally, this sample may not be entirely representative of professionals' knowledge of the disorders. Due to social desirability effects, professionals may have overstated their confidence and knowledge of the disorder. Alternatively, professionals that were confident in their knowledge may have felt more inclined to volunteer to participate in the research, whereas professionals who were less familiar with the disorders, such as those in the early stages of their career, may have avoided taking part to maintain professional integrity. Furthermore, it should be noted that, due to the length of the questionnaire, not all professionals responded to all questions and that there were more answers missing for those working with ASD compared to professionals working with WS and DS. It is currently unclear as to why this is the case but it might be that professionals for children with WS and DS were more motivated to complete the questionnaires as they were recruited with help from the parents of the children at their school, whilst those working with children with ASD were recruited via parents as well as other social media support groups.

The current study only asked about the professionals' views about these disorder groups but included few questions about their daily practice and thus future studies may want to explore how the views, previous training and disorder knowledge of the professional might impact on their daily professional practice.

In sum, over all these findings seem to indicate that, although professionals have a great amount of knowledge about neurodevelopmental disorders, there still is a gap between the issues identified by professionals and the specialist support that these professionals may seem necessary to help the child. These findings suggest that providing professionals with a more in-depth training, including the lesser well-known difficulties of a developmental disorder and how these difficulties may affect children in the classroom. Additionally, providing professionals with evidence of what specialist support works in what circumstances and cases would support the closing of the gap between the difficulties experienced by children with neurodevelopmental disorders and the support provided for them. A better understanding of the disorders and providing the professionals with evidence based support would allow professionals to feel more confident when working with neurodevelopmental disorders, especially for the rare disorders.

## Acknowledgements

We would like to thank all the participants who took part in the research as well as the Williams syndrome Foundation, UK for funding this project.

## References

- Able, H., Sreckovic, M. A., Schultz, T. R., Garwood, J. D., & Sherman, J. (2015). Views from the trenches: Teacher and student supports needed for full inclusion of students with ASD. *Teacher Education and Special Education, 38*(1), 44–57. <https://doi.org/10.1177/0888406414558096>.
- Alexander, M., Petri, H., Ding, Y., Wandel, C., Khwaja, O., & Foskett, N. (2016). Morbidity and medication in a large population of individuals with Down syndrome compared to the general population. *Developmental Medicine and Child Neurology, 58*(3), 246–254. <https://doi.org/10.1111/jir.12277>.
- American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders (DSM-5\*)*. American Psychiatric Pub.
- Ashworth, M., Van Herwegen, J., & Palikara, O. (2019). Comparing parental stress of children with neurodevelopmental disorders: The case of Williams Syndrome, Down Syndrome and Autism Spectrum disorders. <https://doi.org/10.1111/jar.12594> [Epub ahead of print].
- Avramidis, E., & Norwich, B. (2002). Teachers' attitudes towards integration/inclusion: A review of the literature. *European Journal of Special Needs Education, 17*(2), 129–147. <https://doi.org/10.1080/08856250210129056>.
- Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D., & Charman, T. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: The Special Needs and Autism Project (SNAP). *The Lancet, 368*(9531), 210–215. [https://doi.org/10.1016/S0140-6736\(06\)21011-1](https://doi.org/10.1016/S0140-6736(06)21011-1).
- Block, M. E. (1991). Motor development in children with Down syndrome: A review of the literature. *Adapted Physical Activity Quarterly, 8*(3), 179–209.
- Case-Smith, J., & Arbesman, M. (2008). Evidence-based review of interventions for autism used in or of relevance to occupational therapy. *American Journal of Occupational Therapy, 62*(4), 416.
- Castro, S., & Palikara, O. (2016). Mind the gap: The new special educational needs and disability legislation in England. *Frontiers in Education, 1*, 1–9. <https://doi.org/10.3389/educ.2016.00004>.
- Champagne, D., & Dugas, C. (2010). Improving gross motor function and postural control with hippotherapy in children with Down syndrome. *Physiotherapy Theory and Practice, 26*(8), 564–571. <https://doi.org/10.3109/09593981003623659>.
- Chapman, R. S., & Hesketh, L. J. (2000). Behavioral phenotype of individuals with Down syndrome. *Mental Retardation and Developmental Disabilities Research Reviews, 6*(2), 84–95.
- Charman, T. (2014). Variability in neurodevelopmental disorders: Evidence from Autism Spectrum disorders. *Neurodevelopmental Disorders, 137*–160. <https://doi.org/10.4324/9781315735313-17>.
- Charman, T., Pickles, A., Simonoff, E., Chandler, S., Loucas, T., & Baird, G. (2011). IQ in children with autism spectrum disorders: Data from the Special Needs and Autism Project (SNAP). *Psychological Medicine, 41*(3), 619–627. <https://doi.org/10.1017/S0033291710000991>.
- Curran, H., Mortimore, T., & Riddell, R. (2017). Special Educational Needs and Disabilities reforms 2014: SENCos' perspectives of the first six months. *British Journal of Special Education, 44*(1), 46–64.
- Daunhauer, L. A., & Fidler, D. J. (2011). The Down syndrome behavioral phenotype: Implications for practice and research in occupational therapy. *Occupational Therapy in Health Care, 25*(1), 7–25. <https://doi.org/10.3109/07380577.2010.535601>.
- Department for Education (2018). *Special educational needs in England: January 2018*. Available at: <https://www.gov.uk/government/collections/statistics-special-educational-needs-sen>.
- Department for Education and Department of Health (2015). *Special educational needs and disability code of practice: 0 to 25 years*. Available at: <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>.
- Dillenburger, K., Keenan, M., Doherty, A., Byrne, T., & Gallagher, S. (2010). Focus on practice: Living with children diagnosed with autistic spectrum disorder: Parental and professional views. *British Journal of Special Education, 37*(1), 13–23. <https://doi.org/10.1111/j.1467-8578.2010.00455.x>.
- Dykens, E. M., Shah, B., Davis, B., Baker, C., Fife, T., & Fitzpatrick, J. (2015). Psychiatric disorders in adolescents and young adults with Down syndrome and other intellectual disabilities. *Journal of Neurodevelopmental Disorders, 7*(1), 9. <https://doi.org/10.1186/s11689-015-9101-1>.

- Dykens, E. M., Shah, B., Sagun, J., Beck, T., & King, B. H. (2002). Maladaptive behavior in children and adolescents with Down's syndrome. *Journal of Intellectual Disability Research*, 46(6), 484–492. <https://doi.org/10.1046/j.1365-2788.2002.00431.x>.
- Emam, M. M., & Farrell, P. (2009). Tensions experienced by teachers and their views of support for pupils with autism spectrum disorders in mainstream schools. *European Journal of Special Needs Education*, 24(4), 407–422. <https://doi.org/10.1080/08856250903223070>.
- Fournier, K. A., Hass, C. J., Naik, S. K., Lodha, N., & Cauraugh, J. H. (2010). Motor coordination in autism spectrum disorders: A synthesis and meta-analysis. *Journal of Autism and Developmental Disorders*, 40(10), 1227–1240. <https://doi.org/10.1007/s10803-010-0981-3>.
- Freeman, S. B., Bean, L. H., Allen, E. G., Tinker, S. W., Locke, A. E., Druschel, C., ... Dooley, K. J. (2008). Ethnicity, sex, and the incidence of congenital heart defects: A report from the National Down Syndrome Project. *Genetics in Medicine*, 10(3), 173.
- Geurts, H. M., & Embrechts, M. (2008). Language profiles in ASD, SLI, and ADHD. *Journal of Autism and Developmental Disorders*, 38(10), 1931. <https://doi.org/10.1007/s10803-008-0587-1>.
- Gillberg, C. (2010). The ESSENCE in child psychiatry: Early symptomatic syndromes eliciting neurodevelopmental clinical examinations. *Research in Developmental Disabilities*, 31(6), 1543–1551.
- Gilmore, L., Campbell, J., & Cuskelly, M. (2003). Developmental expectations, personality stereotypes, and attitudes towards inclusive education: Community and teacher views of Down syndrome. *International Journal of Disability, Development and Education*, 50(1), 65–76. <https://doi.org/10.1080/1034912032000053340>.
- Griffith, G. M., Hastings, R. P., Nash, S., Petalas, M., Oliver, C., Howlin, P., ... Tunnicliffe, P. (2011). "You have to sit and explain it all, and explain yourself." Mothers' experiences of support services for their offspring with a rare genetic intellectual disability syndrome. *Journal of Genetic Counseling*, 20(2), 165–177. <https://doi.org/10.1007/s10897-010-9339-4>.
- Griffith, G. M., Hastings, R. P., Oliver, C., Howlin, P., Moss, J., Petty, J., & Tunnicliffe, P. (2011). Psychological well-being in parents of children with Angelman, Cornelia de Lange and Cri du Chat syndromes. *Journal of Intellectual Disability Research*, 55(4), 397–410. <https://doi.org/10.1111/j.1365-2788.2011.01386.x>.
- Hatton, C. (2002). Psychosocial interventions for adults with intellectual disabilities and mental health problems: A review. *Journal of Mental Health*, 11(4), 357–374. <https://doi.org/10.1080/09638230020023732>.
- Hellawell, B. (2018). 'There is still a long way to go to be solidly marvellous': Professional identities, performativity and responsibilisation arising from the send code of practice 2015. *British Journal of Educational Studies*, 66(2), 165–181. <https://doi.org/10.1080/00071005.2017.1363374>.
- Hilton, C. L., Zhang, Y., Whilte, M. R., Klohr, C. L., & Constantino, J. (2012). Motor impairment in sibling pairs concordant and discordant for autism spectrum disorders. *Autism*, 16(4), 430–441. <https://doi.org/10.1177/1362361311423018>.
- Hilton, C., Wente, L., LaVesser, P., Ito, M., Reed, C., & Herzberg, G. (2007). Relationship between motor skill impairment and severity in children with Asperger syndrome. *Research in Autism Spectrum Disorders*, 1(4), 339–349. <https://doi.org/10.1016/j.rasd.2006.12.003>.
- Jarrold, C., Baddeley, A. D., & Hewes, A. K. (2000). Verbal short-term memory deficits in Down syndrome: A consequence of problems in rehearsal? *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 41(2), 233–244. <https://doi.org/10.1037/0278-7393.26.6.1626>.
- John, A. E., & Mervis, C. B. (2010). Sensory modulation impairments in children with Williams syndrome. *American Journal of Medical Genetics*, 154(2), 266–276. <https://doi.org/10.1002/ajmg.c.30260>.
- Kendall, L. (2018). Supporting all children to reach their potential: Practitioner perspectives on creating an inclusive school environment. *Education*, 3–13, 1–14. <https://doi.org/10.1080/03004279.2018.1520278>.
- Lamb, B. (2009). *Lamb inquiry: Special educational needs and parental confidence*. available at: Nottingham: DCSF Publ. <https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DCSF-01143-2009>.
- Lindsay, G., Ricketts, J., Peacey, L. V., Dockrell, J. E., & Charman, T. (2016). Meeting the educational and social needs of children with language impairment or autism spectrum disorder: The parents' perspectives. *International Journal of Language & Communication Disorders*, 51(5), 495–507. <https://doi.org/10.1111/1460-6984.12226>.
- Määttä, T., Tervo-Määttä, T., Taanila, A., Kaski, M., & Iivanainen, M. (2006). Mental health, behavior and intellectual abilities of people with Down syndrome. *Down Syndrome Research and Practice*, 11(1), 37–43. <https://doi.org/10.3104/reports.313>.
- Mahy, J., Shields, N., Taylor, N. F., & Dodd, K. J. (2010). Identifying facilitators and barriers to physical activity for adults with Down syndrome. *Journal of Intellectual Disability Research*, 54(9), 795–805. <https://doi.org/10.1111/j.1365-2788.2010.01308.x>.
- Martens, M. A., Wilson, S. J., & Reutens, D. C. (2008). Research Review: Williams syndrome: A critical review of the cognitive, behavioral, and neuroanatomical phenotype. *Journal of Child Psychology and Psychiatry*, 49(6), 576–608. <https://doi.org/10.1111/j.1469-7610.2008.01887.x>.
- Mervis, C. B., & Becerra, A. M. (2007). Language and communicative development in Williams syndrome. *Mental Retardation and Developmental Disabilities Research Reviews*, 13(1), 3–15. <https://doi.org/10.1002/mrdd.20140>.
- Myles, B. S., Dunn, W., Rinner, L., Hagiwara, T., Reese, M., Huggins, A., & Becker, S. (2004). Sensory issues in children with Asperger syndrome and autism. *Education and Training in Developmental Disabilities*, 283–290.
- Palikara, O., Ashworth, M., & Van Herwegen, J. (2018). Addressing the educational needs of children with Williams syndrome: a rather neglected area of research? *Journal of Autism and Developmental Disorders*, 48(9), 3256–3259.
- Palikara, O., Castro, S., Gaona, C., & Eirinaki, V. (2019). Professionals' views on the new policy for special educational needs in England: Ideology versus implementation. *European Journal of Special Needs Education*, 34(1), 83–97.
- Palisano, R. J., Walter, S. D., Russell, D. J., Rosenbaum, P. L., Gémus, M., Galuppi, B. E., & Cunningham, L. (2001). Gross motor function of children with down syndrome: Creation of motor growth curves. *Archives of Physical Medicine and Rehabilitation*, 82(4), 494–500.
- Parsons, S., Lewis, A., & Ellins, J. (2009). The views and experiences of parents of children with autistic spectrum disorder about educational provision: Comparisons with parents of children with other disabilities from an online survey. *European Journal of Special Needs Education*, 24(1), 37–58. <https://doi.org/10.1080/08856250802596790>.
- Pearson, S., Mitchell, R., & Rapti, M. (2015). 'I will be "fighting" even more for pupils with SEN': SENCO s' role predictions in the changing English policy context. *Journal of Research in Special Educational Needs*, 15(1), 48–56. <https://doi.org/10.1111/1471-3802.12062>.
- Reilly, C., Senior, J., & Murtagh, L. (2015). A comparative study of educational provision for children with neurogenetic syndromes: Parent and teacher survey. *Journal of Intellectual Disability Research*, 59(12), 1094–1107. <https://doi.org/10.1111/jir.12210>.
- Roberts, J., & Simpson, K. (2016). A review of research into stakeholder perspectives on inclusion of students with autism in mainstream schools. *International Journal of Inclusive Education*, 20(10), 1084–1096. <https://doi.org/10.1080/13603116.2016.1145267>.
- Roberts, J. E., Price, J., & Malkin, C. (2007). Language and communication development in Down syndrome. *Mental Retardation and Developmental Disabilities Research Reviews*, 13(1), 26–35.
- Rodgers, J., Riby, D. M., Janes, E., Connolly, B., & McConachie, H. (2012). Anxiety and repetitive behaviours in autism spectrum disorders and Williams syndrome: A cross-syndrome comparison. *Journal of Autism and Developmental Disorders*, 42(2), 175–180. <https://doi.org/10.1007/s10803-011-1225-x>.
- Rodriguez, N. M., & Thompson, R. H. (2015). Behavioral variability and autism spectrum disorder. *Journal of Applied Behavior Analysis*, 48(1), 167–187. <https://doi.org/10.1002/jaba.164>.
- Roizen, N. J. (2002). Medical care and monitoring for the adolescent with Down syndrome. *Adolescent Medicine Clinics*, 13(2), 345.
- Rosner, B. A., Hodapp, R. M., Fidler, D. J., Sagun, J. N., & Dykens, E. M. (2004). Social competence in persons with Prader-Willi, Williams and down syndromes. *Journal of Applied Research in Intellectual Disabilities*, 17, 209–217. <https://doi.org/10.1111/j.1468-3148.2004.00200.x>.
- Silverman, W. (2007). Down syndrome: Cognitive phenotype. *Developmental Disabilities Research Reviews*, 13(3), 228–236. <https://doi.org/10.1002/mrdd.20156>.
- Steele, A., Scerif, G., Cornish, K., & Karmiloff-Smith, A. (2013). Learning to read in Williams syndrome and Down syndrome: Syndrome-specific precursors and developmental trajectories. *Journal of Child Psychology and Psychiatry*, 54(7), 754–762. <https://doi.org/10.1111/jcpp.12070>.
- Stoner, J. B., Bock, S. J., Thompson, J. R., Angell, M. E., Heyl, B. S., & Crowley, E. P. (2005). Welcome to our world: Parent perceptions of interactions between parents of young children with ASD and education professionals. *Focus on Autism and Other Developmental Disabilities*, 20(1), 39–51. <https://doi.org/10.1177/10883576050200010401>.
- Thoonen, E. E., Slegers, P. J., Oort, F. J., Peetsma, T. T., & Geijsel, F. P. (2011). How to improve teaching practices: The role of teacher motivation, organizational

- factors, and leadership practices. *Educational Administration Quarterly*, 47(3), 496–536. <https://doi.org/10.1177/0013161X11400185>.
- Tissot, C. (2011). Working together? Parent and local authority views on the process of obtaining appropriate educational provision for children with autism spectrum disorders. *Educational Research*, 53(1), 1–15. <https://doi.org/10.1080/00131881.2011.552228>.
- Tsao, R., & Kindelberger, C. (2009). Variability of cognitive development in children with Down syndrome: Relevance of good reasons for using the cluster procedure. *Research in Developmental Disabilities*, 30(3), 426–432. <https://doi.org/10.1016/j.ridd.2008.10.009>.
- Van Herwegen, J., Ashworth, M., & Palikara, O. (2018). Parental views on special educational needs provision: Cross-syndrome comparisons in Williams Syndrome, Down Syndrome, and Autism Spectrum Disorders. *Research in Developmental Disabilities*, 80, 102–111. <https://doi.org/10.1016/j.ridd.2018.06.014>.
- Van Herwegen, J., Ranzato, E., Karmiloff-Smith, A., & Simms, V. (2019). *Foundations of mathematical development in Williams syndrome and Down syndrome* (under review).
- Van Herwegen, J., Rundblad, G., Davelaar, E. J., & Annaz, D. (2011). Variability and standardized test profiles in typically developing children and children with Williams Syndrome. *The British Journal of Developmental Psychology*, 29(4), 883–894. <https://doi.org/10.1111/j.2044-835X.2010.02015.x>.
- Winter, M., Pankau, R., Amm, M., Gosch, A., & Wessel, A. (1996). The spectrum of ocular features in the Williams-Beuren syndrome. *Clinical Genetics*, 49, 28–31.
- World Health Organization (2003). In S. Skevington, I. Birdthistle, & J. Jones (Eds.). *Creating an environment for emotional and social well-being: An important responsibility of a health promoting and child-friendly school* (pp. 10). Geneva, Switzerland: WHO Information Series on School Health.