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All views my own? Portraying the voices of children with complex neurodevelopmental disorders in statutory documents

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ABSTRACT

Portraying the voices of children with complex genetic neurodevelopmental disorders about their health, care and education needs in their statutory documents is a challenging task. This study examined the ways by which the perspectives of children diagnosed with Down Syndrome (DS) and Williams Syndrome (WS) are portrayed in their statutory documents, namely the Education Health and Care plans, in England. Using the International Classification of Functioning Disability and Health for Children and Youth, we analysed the content of Section A of the Education Health and Care plans of 52 children and young people with WS and DS, between 5 and 26 years of age. A minority of statutory documents (7.7 %) explicitly reported the children's voices, and many failed to document how the children's voices were accessed. Only a few specific or evidence-based tools to access their voices were reported. Most statutory documents portrayed parental rather than children's voices concerning aspects of their health, care, and education. This study highlights the need to establish the use of evidence-based tools for ascertaining the voices of children with complex neurodevelopmental disorders and including them in decision making about their health, care and education needs.

Although there are individual differences in children with complex genetic neurodevelopmental disorders (Tsao & Kindelberger, 2009) there are also similarities regarding their health, cognitive, and behavioural needs. Children with Williams Syndrome (WS), a rare congenital disorder caused by the microdeletion of 28 genes on chromosome 7, affecting approximately one in 18,000 live births, experience complex difficulties. These include general cognitive delay, with average IQ scores around 56, health issues such as narrowing of the aorta, renal issues, as well as behavioural and sensory issues related to anxiety (Martens et al., 2008). Although their language abilities are better compared to their very poor non-verbal abilities, all children with WS show language delays and comprehension difficulties (Brock, 2007). Similarly, children with Down Syndrome (DS), a developmental genetic disorder with an estimated prevalence of 5 in 10,000, and caused by an extra copy, part-copy, or translocation of chromosome 21 (Steele & Stratford, 1995), also experience significant difficulties in many areas of development. In terms of cognitive abilities, average IQ score is around 55. The language skills of children with DS are delayed and they often experience motor difficulties. Health problems include cardiac, gastrointestinal, and respiratory conditions, as well as vision and hearing difficulties (Thomas et al., 2011).

Catering for the complex needs of these children is often a challenging task for the professionals working with them and for their families (Carrasco et al., 2005; Ashworth et al., 2019). Seeing the overall cognitive delay in children with WS and DS, as well as the

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difficulties that both groups of children experience in aspects of language and understanding, it may be particularly difficult for professionals to ascertain their voices and meaningfully include them in decision making about their education, health and care needs (Palikara & Castro, 2018; Roberts, 2017). Although capturing the voices of children with complex needs has been acknowledged as a basic human right (United Nations, 2006; Palikara et al., 2018), to our knowledge, no previous research has investigated how the views of these children are portrayed in their statutory documents and which methods professionals employ to ascertain them.

In England, the right of all children to actively participate in decision making concerning their lives has been recently re-emphasised by the new Special Educational Needs and Disabilities (SEND) Code of Practice (Department for Education, 2014), following the enactment of the Children and Family Act (Department for Education, 2014) (CFA) in 2014 (Department for Education and Department of Health, 2015). Other key changes introduced concerned the increased emphasis on multi-agency teamwork in meeting the children's needs and the replacement of the Statements of Special Educational Needs, with Education, Health and Care (EHC) plans.

The EHC plan is the single statutory document that should portray the child's voice, including their wishes and aspirations (Section A), as well as describe the child's needs and abilities in a multi-disciplinary and holistic way. The SEND Code of Practice stresses the importance of professionals capturing the voices of children to co-construct and plan intervention programmes and provision closely aligned to the child's own wishes and aspirations. This imperative for professionals concerns all children with SEND, including children with complex needs and for whom it may be more challenging to elicit their voices.

Although there is increasing acknowledgement of the importance of capturing the voices of all children, the development of appropriate methodologies and tools to enable portraying their views remains challenging for the professionals involved (Lewis et al., 2005). The communication difficulties that many children with more complex neurodevelopmental disorders experience, is one factor which complicates the development of relevant evidence-based methodologies (Lewis & Porter, 2006; Palikara et al., 2009). Some notable exceptions have recently derived mainly in relation to the voices of autistic children and concern the use of virtual reality learning technologies (Parsons & Cobb, 2013). Yet, these have so far had limited application beyond research grounds (Parsons et al., 2016).

This study aimed to examine how the voices of children diagnosed with complex genetic neurodevelopmental disorders (namely DS and WS) are being portrayed in their statutory documents, the EHC plans, and whether differences in reporting voice can be observed between the diagnostic groups. Despite their similar overall cognitive delays, the expressive language skills of children and young adults with WS is normally much more advanced than their non-verbal abilities, and this uneven cognitive profile is very different in children and young adults with DS, who often show better non-verbal abilities in contrast to their verbal comprehension and expression difficulties. Therefore, this study aimed to compare the two neurodevelopmental disorders in relation to how the voices of these children are portrayed in their EHC plans. It was predicted that if professionals consider mainly verbal abilities of the children, the voices of children with WS would be more likely to be captured than those of the children with DS. However, if it is the overall cognitive ability or mental age that guides whether or not their voice is portrayed, then we can predict that there is no difference in the way that their voice is captured. Additionally, this study aimed to provide a content analysis of how children's strengths and needs were depicted in section A of the EHC plans, depending on diagnostic group, type of provision, region, and age, generating important evidence regarding the quality of these statutory documents for these two groups of children.

1. Method

1.1. Participants

The EHC plans of 52 children with WS, and DS were gathered by formally asking participants who completed a survey about the SEND Code of Practice (Department for Education, 2014) if they would like to submit their child's EHC plan for further analysis. If participants did want to submit the EHC plan, they gave their informed consent before sending the EHC plan securely. The EHC plans of 19 children with DS (11 boys) and 33 with WS (19 boys) were analysed. The minimum age of the participants at the time of data analysis was 5 years old and the maximum was 26 years of age.

1.2. Ethical issues

The study was approved by the Ethics Research Committee of University of Kingston and adheres to the British Psychological Society guidelines. Written and informed consent to the research and to publication of the results was obtained from the children's parents. All EHC plans included in the analysis were anonymised. This data was kept in password-protected files on university computers (when in online format) and in locked cabinets in the team's research office.

1.3. Data analysis

The EHC plans in England include one section dedicated to the child's own view, namely section A. The content of section A of the 52 EHC plans included in this study was analysed following a systematic procedure of content analysis. Based on similar analysis conducted in previous studies (Castro et al., 2020), the content analysis performed was mainly deductive in nature (Elo & Kyngäs, 2008), with frequencies of categories computed following category identification. The analysis aimed to address the following items: 1) the number of EHC plans that use the first person in section A, as an indication of portrayal of the child's voice; 2) the number of EHC plans that explicitly reported the process by which the voice/perspective of the child was obtained; 3) the nature of the methods used

to access the child's voice; 4) the number of EHC plans with section A focusing on abilities, difficulties or on both; 5) the nature of the aspirations mentioned in section A; 6) the nature of the abilities mentioned in section A; 7) the nature of the difficulties mentioned in section A.

Descriptive statistics were used to illustrate the number of EHC plans that use the first and/or third person, as well as the frequency of abilities and disabilities. To analyse the nature of the ability and disability statements, the content of this section of the EHC plans was systematically linked to the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY; World Health Organization, 2007), following the recommended linking rules for matching health-related content with this classification system (Cieza et al., 2019). The ICF-CY was used as a coding framework because it is regarded as the gold-standard classification of disabilities and it has been extensively used in other related studies (Castro et al., 2014; Klang et al., 2016; Osborne et al., 2016). In the process of linking the content of Section A of the EHC plans to the ICF-CY, 10 % of the EHC plans were double coded by an independent and experienced ICF-CY coder, for calculation of inter-coder agreement (89 %) and establishment of final and consensual coding criteria.

In the analysis of abilities and difficulties per ICF-CY domain, we have only included the codes that were found most frequently in this section of the EHC plans – five or more instances, either as an ability or as a difficulty. We recorded whether each ICF-CY category was present or not, to illustrate the nature of the content of the narrative.

We also examined, statistically, whether different distributions in geographical region, type of provision (mainstream or special), and diagnosis (DS or WS) would be related to different distributions regarding the use of the first person, or of the parent and/or professional only. These analyses were performed using the Chi-square test which tested differences in the distribution of categorical variables. Age was categorised into three groups: 5–9 years old ($n = 21$), 10–15 years old ($n = 11$) and 16–26 years old ($n = 15$); for five children, age was not released in the EHC plans. For region, the name of the local authority was used to classify the EHC plan into one of the following areas: East ($n = 10$), Southeast ($n = 15$), Southwest ($n = 6$), Midlands ($n = 6$), Northeast ($n = 7$) and Northwest ($n = 7$); one EHC plan did not include geographical location. The type of provision was recorded as: early years mainstream education ($n = 5$), early years special education ($n = 1$), primary school mainstream ($n = 19$), primary school special education ($n = 3$), secondary school mainstream education ($n = 4$), secondary school special education ($n = 8$), post-16 mainstream education ($n = 5$), post-16 special education ($n = 4$); three EHC plans did not contain information on the type of educational provision.

Lastly, Chi-square statistic was also used to examine the relationship between the nature of the content of section A (ICF-CY categories present in the narrative) and diagnostic group, type of provision, region, and age.

Table 1

Frequency of plans including the child's voice only, the child's and the parents' and/or the professionals' voice, and the parents' and/or professionals' voice only.

	Child's voice only n (using first person)	Child's and parents and/or professionals voice n (first and third person)	Parents' and/or professionals voice only n (third person only)
Diagnosis	2	15	15
WS ($n = 33$)			
DS ($n = 19$)	1	11	7
Type of provision			
Early Years Mainstream ($n = 5$)	0	2	3
Early Years Special ($n = 1$)	0	0	1
Primary Mainstream ($n = 20$)	2	12	6
Primary Special ($n = 3$)	0	1	2
Secondary Mainstream ($n = 4$)	1	1	2
Secondary Special ($n = 7$)	0	4	3
Post-16 Mainstream ($n = 5$)	0	3	2
Post-16 Special ($n = 4$)	0	2	2
Age of child			
5–9 ($n = 21$)	0	10	11
10–15 ($n = 11$)	1	4	5
16–26 ($n = 15$)	1	10	3
Region			
East ($n = 10$)	0	6	4
Southeast ($n = 15$)	0	10	5
Southwest ($n = 6$)	1	2	3
Midlands ($n = 6$)	1	2	3
North East ($n = 7$)	1	5	1
North West ($n = 7$)	0	2	5

2. Results

2.1. EHC plans that use the first person in section A

Table 1 shows the frequency of EHC plans describing the child's voice only, the child's and the parents and/or professionals voice simultaneously, and the EHC plans showing solely the parent and/or professional's voice. Four EHC plans (7.7 %) used exclusively the first person (3 for individuals with WS and 1 for an individual with DS), as if showcasing the child's own perspective. Twenty-two EHC plans (42.3 %) used the parent and/or professional perspective only (third person discourse) and 26 (50 %) EHC plans used both the first and the third person, denoting the perspectives of both the child and the parent and/or professional. No statistically significant differences (as measure by the Chi-square statistic) were found between type of provision ($\chi^2 = 10.59, p = .83$), age of the individuals ($\chi^2 = 4.03, p = .39$), region ($\chi^2 = 7.74, p = .65$), or diagnosis ($\chi^2 = .61, p = .74$).

2.2. Number of EHC plans that explicitly reported the process by which the voice/perspective of the child was obtained

Twenty-seven EHC plans (52 %) did not explicitly say how they obtained the child's voice. This was independent from the children's diagnosis ($\chi^2 = 2.73, p = .09$), age ($\chi^2 = 51.00, p = .43$), region ($\chi^2 = 4.54, p = .47$) and type of provision ($\chi^2 = 3.45, p = .18$). When considering only those EHC plans that showed the voice of the child only (first person discourse), or the voice of the child alongside the parents'/professionals' ($n = 29$), which in theory would be more likely to illustrate how the voice of the child was accessed, 12 (41.4 %) did not explicitly say how they accessed the child's voice.

2.3. The nature of the methods used to access the child's voice

When looking at those EHC plans that reported how professionals and/or parents communicate with the children themselves ($n = 25$), two categories of methods were identified: seven EHC plans where it was clear that the child/young person had expressed themselves orally, often with support and prompting from adults and peers; three EHC plans mentioned the use of pictures (e.g. 'Listen to me photos') in supporting children to express themselves, and the remaining EHC plans mentioned support from adults in this process without specifying the strategy.

2.4. Frequency of abilities, difficulties or both and aspirations

On average, the EHC plans mention more abilities ($M = 8.87$) than difficulties ($M = 10.79$) in section A. However, the great majority of the EHC plans included statements referring to both abilities and difficulties (90.4 %) [47].

The great majority of the EHC plans (47) included information about the child's/parents' aspirations for the child in section A (90.4 %); of these, 5 focused on the child's aspirations only, 20 focused on parents' aspirations only and 22 focused on both the child's and parents' aspirations for the child. Regarding the content of these aspirations, five categories were found – independence, the most frequent category (statements referring to the desire to become autonomous in performing essential daily routines activities), happiness/self-esteem (statements referring to the desire to become a self-confident and ultimately happy individual), contribution to society (statements referring to the desire to get paid employment in the future or to make some form of practical contribution to society), relationships (statements referring to the desire to have intimate relationships in the future) and others (various statements referring to short-term goals and aspirations, often referring to progression in the education system). Table 2 provides some examples of quotes for each category.

2.5. Frequency and nature of the abilities and difficulties mentioned in section A of the statutory documents

When analysing the content of section A in relation to the perceived abilities of the child/young person (see Table 3), the most

Table 2

Categories found in relation to the aspirations of children with DS and WS, and exemplary quotes.

Category	Frequency of statements (n)	Examples of quotes
Independence	38	'To be able to buy sweets on my own'. 'To be able to order in a café without mummy or daddy'
Happiness/Self-esteem	12	'We want X to be safe, secure and happy' 'To be happy, have high self-esteem'
Contribution to society	20	'x reports that she would like to find employment in the future. The areas she would like to work in might be: catering or gardening' 'He should be able to lead a fulfilled life by contributing to society through paid employment'
Relationships	7	'To have my own car, have children and a girlfriend' 'It would be nice if she could have a relationship and live semi independently'
Others	18	'X's mum would like X to remain at X preschool until July 2018. X will receive additional support of therapy within the school day 1:1, small group work outside of the main class and support at break times including monitoring of lunch' 'To take part in Ireland's Music and Activity Camp for adults and teenagers with Williams Syndrome'

Table 3

Differences between children with DS and children with WS regarding their functioning at the level of body functions.

ICF-CY codes	Abilities			χ^2	Difficulties			χ^2
	DS	WS	Total number of EHC plans		DS	WS	Total number of EHC plans	
b117 - intellectual functions	0	0	0	NA	9	16	25	NA
b122 - psychosocial functions	0	0	0	NA	3	4	7	NA
b126 - temperament functions	16	33	49	NA	4	3	7	NA
b134 - sleep functions	0	3	3	NA	2	5	7	NA
b140 - attention functions	0	0	0	NA	6	16	22	NA
b1400 - sustaining attention	1	10	11	$\chi^2 = 4.32, p \leq .05$	0	x	0	NA
b144 - memory functions	0	0	0	NA	6	2	8	NA
b152 - emotional functions	2	3	5	NA	12	21	33	NA
b156 - perceptual functions	0	0	0	NA	5	11	16	NA
b167 - language functions	1	0	1	NA	9	1	10	$\chi^2 = 15.72, p \leq .05$
b180 - experience of self and time functions	3	7	10	NA	0	0	0	NA
b210 - seeing functions	0	1	1	NA	7	6	13	NA
b230 - hearing functions	0	2	2	NA	11	18	29	NA
b320 - articulation functions	0	0	0	NA	4	2	6	NA
b410 - heart functions	0	0	0	NA	2	6	8	NA
b435 - Immunological systems functions	0	0	0	NA	3	2	5	NA
b455 - exercise tolerance functions	0	0	0	NA	1	4	5	NA
b710 - mobility joint functions	0	0	0	NA	1	5	6	NA
b760 - control of voluntary movement functions	0	0	0	NA	6	7	13	NA

Note. NA = Not Applicable.

frequent aspects mentioned within the category of body functions and structures (from the ICF-CY coding system) were *temperament functions* (for WS and DS) and *sustaining attention* (for WS only), both part of the mental functions in the ICF-CY. Regarding their activities and the way they participate in daily routines, family relationships were perceived as the most important strength, followed

Table 4

Differences between children with DS and children with WS regarding their functioning at the level of activities and participation.

ICF-CY codes	Abilities			Difficulties		
	DS	WS	Total number of EHC plans (n)	DS	WS	Total number of EHC plans (n)
d115 - listening	1	8	9	0	0	0
d140 - learning to read	2	7	9	3	5	8
d145 - learning to write	2	4	6	0	0	0
d150 - learning to calculate	1	5	6	5	5	10
d230 - carrying out daily routine	3	3	6	3	3	6
d240 - handling stress and other psychological demands	0	0	0	2	6	8
d310 - communicating with - receiving - spoken messages	3	2	5	3	11	14
d315 - communicating with - receiving nonverbal messages	1	4	5	0	0	0
d330 - conversation	5	17	22	7	8	15
d335 - discussion	2	6	8	0	0	0
d360 - using communication devices and techniques	2	4	6	0	0	0
d410 - changing basic body position	2	2	4	0	0	0
d440 - fine hand use	0	0	0	7	13	20
d445 - hand and arm use	1	7	8	0	0	0
d450 - walking	4	2	6	3	5	8
d460 - moving around in different locations	1	6	7	0	0	0
d530 - toileting	0	0	0	6	7	13
d540 - dressing	2	3	5	4	4	8
d550 - eating	3	6	9	2	7	9
d560 - drinking	3	6	9	0	0	0
d599 - self-care, unspecified	0	0	0	11	9	20
d710 - basic interpersonal interactions	5	2	7	4	7	11
d720 - complex interpersonal interactions	4	8	12	0	0	0
d730 - relating with strangers	0	0	0	1	8	9
d750 - informal social relationships	0	0	0	4	11	15
d760 - family relationships	11	19	30	0	0	0
d779 - interpersonal interactions and relationships, unspecified	8	7	15	0	0	0
d825 - vocational training	12	13	25	0	0	0
d920 - recreation and leisure	4	7	11	0	0	0
d930 - religion and spirituality	16	30	46	0	0	0

by having a *conversation* which is part of the communication chapter of the ICF-CY (mostly for children with WS), and *complex interpersonal interactions* (see Table 4), which is part of the interpersonal interactions chapter of the ICF-CY.

When looking at what the children believe are the difficulties they have, we found that the most difficult dimension of functioning within the body functions category is *emotional functions* for both groups, followed by *hearing functions*, *intellectual functions* and *sleep functions*. *Memory* and *language functions* (within the mental functions of the ICF-CY) are predicted as difficulties significantly more often in EHC plans of children with DS than in the EHC plans of children with WS (see Table 3). The most frequent difficulties mentioned by the children in relation to activities they participate in relate to *fine hand use* and general *self-care*, followed by *informal social relationships*, *having conversations*, *communicating with – receiving – spoken messages* and *basic interpersonal interactions* (see Table 4). No significant differences were found between the distribution of these variables and region, type of provision, age, or diagnosis.

3. Discussion

This study is the first to examine how the voices of children with complex genetic neurodevelopmental disorders, namely WS and DS, are portrayed in their statutory documents in England. The results of the study demonstrated that only 7.7 % of the EHC plans explicitly reported the views of the child, assumed by the use of the first person. Most statutory documents (42.3.1 %) of both children with WS and DS portrayed only the parental/professional rather than children's voices concerning aspects of their education, health and care. More importantly, when considering the EHC plans that included a narrative using the first person, as if the child or young person was expressing him/herself, 41.4 % did not make any mention as to how their voice was obtained. Although parental perspectives can often enhance the health, care, and education decision making for children with complex neurodevelopmental disorders (Adams & Levy, 2017; Van Herwegen et al., 2018) and should be included in statutory documents, these results demonstrate that the voices of children themselves might not have been adequately portrayed.

The use of the first person in statutory narratives cannot be seen as guarantee that the child himself has expressed those views. The frequent absence of detail on how children expressed themselves when the first person is used certainly raises questions of an ethical nature regarding the design of these statutory documents and the level of genuine child/young person representation – does an adult have the right to assume what the child/young person would have said/thought? If not, shouldn't the adult be explicit on how the voice of the child was accessed to enable to use of the first-person discourse? We argue that this lack of clarity concerning how the children's voices were accessed and the underrepresentation of children's voices is alarming. This finding calls for further research on how the voices of other groups of children with complex needs are elicited and portrayed in related statutory documents.

Our findings also revealed the majority of EHC plans (52 %) did not state the methods used to ascertain the voices of the children, and only a few specific or evidence-based tools to support access to the children's perspective were reported. This finding concerned the EHC plans of both children with DS and WS, regardless of the type of provision attended, their age, or the region where they lived. Moreover, when their voice was elicited, this was only done using oral measures and thus favoured children with relatively strong verbal abilities. This raises serious questions about the methods employed by professionals in eliciting the views of children with complex neurodevelopmental disorders. Previous research has pointed out that ascertaining the voices of children with complex neurodevelopmental disabilities is not a simple task in terms of the skillset required by the professional involved, time constraints, and availability of appropriate tools (Iacono, 2006). However, with the adoption of appropriate methodology and relevant training, the 'real' voices can be reliably ascertained and portrayed (Palikara et al., 2009). Some interesting pointers towards this direction have been proposed recently, such as the use of behaviour state ethogram when working with children with profound and multiple learning difficulties (Simmons & Watson, 2015).

One curious finding of this study was the observation that the most frequently mentioned ability reported for children with WS was 'Conversation' whilst, 'language' disabilities were statistically more frequently reported for children with DS. Given this fact, one would expect children/young people with WS should be able to articulate themselves and therefore should have been consulted in relation to their own needs, in comparison to children with DS, in our sample. However, we have found that the use of the first person was independent of diagnosis. The use of the first person was also independent of age. This suggests that the ways in which the voice of the children are represented in their statutory documents seems to be arbitrary, matching similar research for children with SEND (Palikara & Castro, 2018). Together, this might be illustrating a lack of evidence-based practices in statutory screening procedures, as well as a missed opportunity to document the children's communication profiles, which would be useful for intervention purposes.

This study provides new evidence that the representation of children's voices in their statutory documents is lacking rigour, by not following evidence-based practices regarding methods of accessing the children's own perspectives. The results of the study suggest that statutory documents are developed based on arbitrary procedures, therefore, highlighting the imperative need for the development of appropriate and evidence-based methodologies and tools that can be employed by professionals to reliably and ethically elicit and include the 'real' voices of children with complex neurodevelopmental disorders in important decision-making about their health, education, care and life.

CRedit authorship contribution statement

Dr Olympia Palikara was co-investigator of the project and conceptualised and written the paper. Dr Susana Castro-Kemp did all the analyses and contributed to the writing of the paper. Ms Maria Ashworth contributed to conducting the study, coding the data and revisiting the intellectual content of the paper. Dr Jo Van Herwegen was principal investigator of the project and contributed to the writing of the paper. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Conflict of Interest

The other authors have no conflicts of interest to disclose.

Data Availability

The authors do not have permission to share data.

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