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### Article

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## **‘Supporting children with Down syndrome within mainstream education settings: Parental reflections’**

### **Abstract**

This study draws upon data gathered from five parents who have children with Down syndrome (DS), being educated in mainstream settings in England. The parental perspective of practices, both inclusive and otherwise, are explored through a qualitative lens. Findings suggest that early intervention, such as portage, is important. However, access to services varied across authorities. Additionally, some participants highlighted issues around the Education, Health Care Plan (EHCP) and subsequent Annual reviews. Overall, this study offers examples of inclusive practice in the areas of supporting language and communication needs, parental partnership and transition between educational phases for children with DS. However there are inconsistencies across providers and there is a need for more research into these areas in the future.

### *Key words:*

Down syndrome (DS), Education, Inclusion, Education Health Care Plan (EHCP), Language and Communication, Early Intervention, Partnership, Transition

### **Introduction**

This paper focuses on the support provided in mainstream education for individuals with one particular set of needs, namely those who are born with Down syndrome (DS). This genetic condition, is usually caused by an additional third copy of chromosome 21 (trisomy 21), (Laws and Hall 2014: Jackson et al 2014) and creates some degree of learning disability for about 750 children in the UK each year (DSA 2017). It is important to recognise that individuals with DS are not alike in their development (Alton 1998), both in relation to cognitive progress, as well as possible medical conditions such as; heart problems, hearing difficulties and issues in relation to the development of speech and language. (Mills and Black 2014: Davis, 2008: Hans et al 2010). Children with DS will have differing educational needs depending on the manifestation of their condition (Laws and Millward 2001) and therefore, support within mainstream education settings needs to be specific to the individual. This research provides an exploration of parental perspectives, effective practice and barriers, around the inclusion of children with DS in mainstream education, across all key stages (early years, primary and secondary school).

Historically, children with disabilities and additional needs in England did not attend mainstream school and were often placed within segregated settings. However, the recommendations of the 1978 Warnock Report (DES 1978) implemented within the 1981 Education Act, were defining moments in terms of inclusion. From 1981, children with special educational needs (SEN) could

be educated alongside their peers in mainstream education settings, with specialist provision provided for them (Lauchlan and Greig 2015).

Over subsequent decades, there has been an increase in children with DS educated within mainstream settings (Johnson 2006: De Graaf et al 2014). Bajwa-Patel and Devecchi (2014) suggest that this is a result of parental choice and preference. Furthermore, there is evidence that children with DS fare better in terms of academic achievement, language development and social interaction when they are in inclusive mainstream settings, (Buckley et al 2006, Turner et al 2008). However, inclusion is a complex area (Lightfoot and Bond 2013) and there are recognised barriers to the successful inclusion of pupils with DS, including negative attitudes from both peers and teaching staff (Fox et al 2004). Research (Boys 2003: Lyons et al 2016) identifies the lack of support from educational staff for children with DS as being the result of insufficient knowledge around the needs of individuals and limited professional development opportunities regarding inclusive practice (Mulholland and O'Connor 2016). Furthermore, Hodgkinson (2010) opines that there is a link between inclusion and academic accountability, suggesting that league tables and examination results can lead to a reluctance to include individuals with learning disabilities in mainstream settings.

In the context of supporting individual needs there are multiple levels that need to be examined to explore this complex area in-depth. The key policy change to education, health and care plans alongside transition, partnerships, intervention and support services are all highlighted in the literature as important factors in supporting children with DS and these are analysed within the literature review.

## Literature Review

### *Education Health Care Plans*

A key change implemented by the Children and Families Act (2014) was the replacement of the statement of Special Educational Needs (SEN) issued by local authorities (March 2014), with a single assessment known as the Education, Health and Care Plan (EHCP). Gough et al (2014:355) suggest that the EHCP may facilitate an improvement in interagency working, quicker care plans and safe transition across age phases within health care and education.

Historically, the statement of needs was designed to be a legally binding document that set out the provision required for individuals with SEN (Williams and Maloney 1998), and to ensure the provision of further funding from local education authorities to support the individual's needs (Gibson and Blandford 2005). However, literature acknowledges that there were many concerns around the statutory assessment procedures (Marsh 2014). It was found to be a complicated process (Boys 2003) that could take up to two years to complete (Williams and Maloney 1998). The resultant statements were also often vague in terms of support (Jones and Swain 2001). Ko (2015) suggests that parents found difficulties in obtaining the services that their

children needed, suggesting that there was limited liaison between the agencies involved in health, social care and education.

The introduction of the EHCP (only applicable in England) saw the age range of support increase to 25 years from 19 years within the areas of education, health and social needs (Mills and Black 2014; Hodkinson 2016). The intention of the EHCP is to be more personalised with parents and children having more input into the services and support that they feel would be beneficial (Ko 2015). The EHCP is not limited to children in schools as was the old statement but covers young people with DS within further education and training, allowing additional time for young people to complete their education (Down's Syndrome Association 2017) (DSA).

From September 2014, individuals with existing statements were expected to transfer to the EHCP within three years. Parents and children must be involved in discussion as to when the best time for transition from the statements to EHCP should occur over that three year period (Gough et al 2014). However, whilst Webster and Blatchford (2014) welcome these new reforms, they also acknowledge the challenges that may be faced by local authorities (LAs) in implementing such changes, particularly in transferring all children and young people from existing statements to the new EHCP within a three year framework. With the inception of the EHCP, it is envisaged that parents and children will have a more seamless and satisfactory experience of inclusive education. Therefore, this research, through the parental voice will establish the extent this has happened for the children involved in this study.

### *Partnership and Transition*

To support successful inclusion, literature emphasises the benefits of multi professional team working (Ko 2015; Hodkinson 2016). In addition, it highlights the importance of working in partnership with parents (Johnston 2009). As Lendrum et al (2015) acknowledge, the role of parents in the education of their child is crucial and an effective school and home partnership can have a positive impact on the educational outcomes of the child. The Children and Families Act (2014) (part 3), recognises the importance of involving children or young people and their families in decision making and the role of parental partnership with differing agencies (Devarakonda and Powley 2016). For children with DS and their parents, this is critical in order to support the individual developmental needs and to ensure the best for each child in their particular circumstances.

Byrnes (2012) recognises that successful transition between educational phases requires support for children and their families. The transition, particularly from primary to secondary school is viewed as being a difficult time for parents who have a child with DS (Lightfoot and Bond 2013) and Briggs (2005) suggests that it is at this point when many concerns are raised as to the successful inclusion of individuals with learning difficulties. However, Briggs (2005) further concedes that very close liaison between teachers, support agencies and parents, working in partnership, can ensure a positive and successful transition.

### *Early intervention and support services*

Early intervention is recognised as particularly important for successful educational outcomes for children with DS, (Paige-Smith and Rix 2006: Roberts et al 2007), for example research has shown that delays in cognitive, motor and language progress can significantly benefit from intervention at this point (Clibbens et al 2002). This early intervention can take many forms, including specialised programmes and related resources (Van Cleve and Cohen 2006) delivered by a range of agencies such as health care practitioners, Occupational therapists, Speech and Language therapists and Physiotherapists (Johnson 2006). Thus underlining the importance of multi-disciplinary team working.

An example of a well-received early intervention service that works in partnership with parents is Portage, a home visiting educational service, providing support for parents who have a child with additional needs within their own home environment (Byrnes 2012). Portage support is provided from an early age and may continue until the child transitions into an early years setting. Parents as well as other agencies can make a referral to this service (Russell 2007: Plimley et al 2007). The role of the Portage worker is to set targets aimed at developing specific skills within the differing areas of development for the child, importantly, they encourage parents to deliver activities designed to support their child's language, motor and cognitive development (Laws and Millward 2001: Rix 2003). Summers and Jenkins (2001) acknowledge that Portage work collaboratively with families and 'empowers' and 'enables' parents to support their children in the education process, a concept also discussed by Nunkoosing and Phillips (1999). Research over-whelming shows this to be a positive service, however, like many of these valuable services the implementation of Portage depends upon the funding available and may vary from one local authority to another (Paige-Smith and Rix 2006: Hodkinson 2010). Illustrating that alongside the individual differences of the children there is also the inequality of service provision across different areas, making the support much more difficult for some.

Individuals with DS often experience difficulties in communicating, with possible delays within areas of speech and language. The severity of language difficulties varies for each individual and may require input from speech and language therapists (Laws and Hall 2013). Although Laws et al (2000) identify that regular access to speech and language therapists within mainstream settings may be limited. Additionally, some individuals may never develop speech, therefore alternative methods of communication such as signing are of significant importance (Jackson et al 2014). Signing can be introduced by Portage workers and parents are often involved in teaching their children to sign (Laws and Millward 2001). Sign language such as Signalong or Makaton which is a communication programme derived from British Sign Language, (Groen et al 2006) is often introduced at an early age to bridge the language gap, aiding language and comprehension and helping to develop speech and language (Alton 1998: Thomson 2003).

## Method

This study adopted a purposive sampling method allowing the researcher to interview people with relevant experiences (Robson 2002: Bryman 2004). A qualitative approach provided the opportunity to focus upon the experiences of parents whose children with DS were educated in mainstream settings. As Wellington (2000) acknowledges, qualitative research has many important features and the data collected from individuals is often descriptive and extensive.

This research followed BERA 2011 ethical guidelines. An initial approach was made to the Chairperson of the Down syndrome Association (DSA) in the North West of England requesting access to that particular organisation. Following discussion around the purpose and nature of the study, access was granted. All participants completed the relevant consent forms.

## *Participants*

Following the posting of the research outline on the DSA forum, five parents of children with DS, who were being educated within a mainstream setting within the North West of England, agreed to take part in the study. The children were aged between three and a half to 12 years old. Two were in nursery setting, two in primary schools and one in a secondary school (see Table 1 for participant information). Pseudonyms have been given to each child to project their anonymity.

Table 1. Information about the participants

Participant (all mothers)	Name and gender of child	Age of child	Education setting and Key stage
Participant A	Sarah, female	3 years 6 months	Mainstream nursery (Foundation stage)
Participant B	Tom, male	12 years	Mainstream secondary school (Key stage 3)
Participant C	Katy, female	4 years	Mainstream nursery (Foundation stage)
Participant D	Michael, male	5 years 6 months	Mainstream primary school (Key stage 1)
Participant E	John, male	10 years	Mainstream primary school (Key stage 2)

Four of the parents agreed to a face to face interview. These took place at the researcher's university, one parent (participant C) asked for a telephone interview due to travel difficulties. Bryman (2012) acknowledges the numerous benefits to this mode of data collection. Hence, the researcher considered that this method was an effective way of gathering qualitative data for this hard to reach parent.

### **Research Approach**

Semi-structured interviews were used to gather the perceptions and experiences from parents. This format allowed flexibility to add or omit questions during the interview and to clarify any ambiguous responses to the question asked (Bryman 2004) which supported the data gathering.

Interviews lasted between forty minutes and one hour thirty minutes. All interviews were audio recorded and transcribed verbatim and participants were each sent a copy of their interview to check for accuracy.

A thematic data analysis approach was used (Cohen et al.2007). Transcripts were read and re read with data selected, analysed and manually colour coded (Wellington 2000). Following coding, five themes emerged; inclusive practice and partnership, early intervention, supporting language and communication, transition and the EHCP.

### **Findings**

Whilst some of participants had similar experiences of mainstream settings, there were also experiences that were unique to the individual. Having said that, there was a strong sense from the data that parents overall were satisfied with the provision given by the schools that their children attended.

#### **Theme 1: Inclusive Practice/ Partnership**

The participants in this study discussed their experiences of practices within the mainstream education setting that their children attended. A positive attitude of staff towards their children was considered important by all of the participants. Participant C had spent considerable time looking at different schools for her daughter and had realised, that admission to schools was not guaranteed having met with negative responses from some of the head teachers, who felt that the setting would be unable to fully meet the child's needs. However, the school that her daughter now attended had experience of supporting children with DS and in participant C's opinion, were excellent in terms of support, with staff working closely with the parents. Participant B had only positive comments to make about her son's education from nursery through to secondary school. She acknowledged that *'None of the staff have ever underestimated Tom'*. When Tom was in primary school, participant B was invited by the school to deliver a talk on DS awareness which she felt was extremely useful not only for the children and staff but was also a good example of school /parent partnership.

When Participant A asked the nursery if her daughter would be able to attend the setting, staff were very helpful and stated, *'Of course we will do what we*

*can so that she can come here.*' Overall, her daughter's experience at the nursery has been positive and had provided opportunities for Sarah to achieve as much as she could within the nursery environment and the regular reviews with the head teacher were found to be particularly useful.

In terms of inclusive practice and parent partnership, participant E felt that her experience of both the nursery and the primary school was positive. Both settings communicated with her as the parent and the nursery was particularly good at asking what would be beneficial in supporting her son, recognising her own expertise as an educator of a child with DS. Similarly, participant D acknowledged that the nursery staff liaised very closely with her, initially providing a home book that outlined what had happened each day. However, this was replaced with discussion with Michael's one to one support each day about what he had been doing both academically and socially. Michael was unable to communicate about his daily experiences therefore, his one to one support would take photographs of various activities throughout the day and put them into a book as a way of record keeping. This good practice also continued the following school year. Both participants felt that there was an effective school/home partnership, with settings listening to their views and all working together in the best interests of the child.

## **Theme 2: Early Intervention**

All of the participants had experiences of working with differing outside agencies, but identified Portage services as an area of discussion in terms of early intervention.

### *Portage support and funding*

The Portage programme supports pre-school children who have special needs. All of the participants acknowledged the importance of the Portage service, however, not all of the participants were able to access this resource. Participant A spoke about her interest in the Portage programme but her local authority did not offer this service to parents.

*'Friends who live in a different local authority, literally a short distance from where I live, automatically got Portage when their child was born. It was something that I was really interested in but it wasn't available to us. It's the funding of different councils isn't it? It's a postcode lottery!' Participant A*

Participant A also explained that because of this 'postcode lottery', dependant to a large extent where you lived in terms of local authority, some parents were unable to afford the beneficial services that Portage included e.g. Makaton and suggested that the Portage service would be useful for all local authorities to deliver.

*'If we had lived in the next local authority, we could have done the Makaton course for free because that was part of the Portage service. We had to pay privately to do the course because we lived in a different area. We're just fortunate that we were in a position that we could do that, but some parents wouldn't be able to.'* Participant A



Participant C had a positive experience of Portage services, following some initial difficulties in accessing the service.

*'We had been promised that we would get the services but they were taking their time in coming to see us. However, they were great! We learnt baby signing through Portage and they recommended a fantastic nursery to use. They supported us so much!'* Participant C

### **Theme 3: Supporting language and communication needs**

Language is typically delayed for children who have Down syndrome and alternative forms of communication are used until language is acquired. Participants (n=4) discussed the use of Makaton within the settings that their child attended. Three of the participants stated that the educational settings, had sent members of staff to Makaton training prior to their child starting nursery and school. Makaton was also introduced to the other children within class and throughout the rest of the settings, a practice that was viewed by the participants as being very inclusive.

*'The staff were really supportive and wanted to learn Makaton. A teaching assistant and two other members of staff in reception went on a course so that they were fully Makaton trained when Tom started school.'* Participant B

However, participant E suggested that whilst the nursery setting were keen to use alternative communication (babysign) and key stage 1 used Makaton, as John moved to key stage 2, the signing decreased and usage was very dependent upon the individual teacher which participant E felt was perhaps down to the confidence of the individual teachers in delivering Makaton.

Participant D's son attended a school that used British Sign Language (BSL) as a form of communication with children who were Deaf or hearing impaired. Initially, Michael was taught Makaton but as the whole school was immersed in BSL, a decision was made in partnership with the school, speech and language therapist and the parents to use single words of BSL which was delivered by his one to one support worker. Participant D did not have a working knowledge of BSL but was invited to attend BSL signing sessions that were delivered by the school at lunch time for welfare staff. The continuity of using BSL within the school and home environment was viewed as being beneficial to Michael and Participant D considered this to be an excellent example of collaborate partnership working.

#### *Speech and language support and funding*

Participants discussed their experiences of the speech and language therapy services with a number of issues being identified e.g. a long waiting list for access to the services, limited contact with the speech therapist and programmes of work being delivered by other people within the setting. Prior to her son starting nursery school, Participant E was involved with a speech and language therapist very early on but felt that this input was not particularly beneficial to the child. The only advice given to the parents was that they use signing which was something that they already did. Participant E stated:

*'I got the feeling that the therapist thought that having speech problems was part of having Down syndrome, which it isn't and that John was never going to be able to talk properly.'* Participant E

After admission to mainstream nursery, John was assigned to a school speech therapist and the experience for participant E was very different. Following John's assessment by the speech therapist, a number of useful recommendations were made and delivered. The speech therapist would leave a programme of work to be delivered by John's one to one support worker or the speech therapist assistant. However, participant E would have preferred the speech therapist to work with her son on a one to one basis more frequently than once every half term.

*'She doesn't come in as much as I'd like. I definitely get the feeling that she's under a lot of pressure and there are funding issues so she has to spread herself very thinly across a lot of schools.'* Participant E

Participant B stated that initially her son Tom had received speech and language therapy, however, from the age of six years, he was discharged from the service and the school continued with exercises that had been left for the teaching assistant to administer. She further acknowledged that the teaching assistant was excellent, undertaking her own research to find exercises that would support Tom's speech and language development. The issue of lack of funding to support the speech and language therapy service was discussed by participant D. Having been discharged from the hospital speech and language service, he was referred to community speech and language for support with feeding issues. Her son was put onto a waiting list and it was over six months before he was able to access support although participant D did acknowledge that it was not the individual therapists who were to blame, but the system.

*'I feel sorry for the speech and language services because I know how under funded they are but I had to ring every month to ask if there was space for him. I know it's hard for them as well, but it's just not ideal is it?'* Participant D

Although Participant A's child did receive some input in terms of speech and language therapy within the nursery setting, with goals set initially for her daughter to achieve, these goals were achieved within a month and it was several months before there was another review.

*'The speech therapist wasn't expecting Sarah to achieve those goals so soon because she has Down syndrome. Not all children with Down syndrome are the same! There is a huge spectrum. It was a preconceived idea of what she is capable of. Sarah is very capable and some things she is actually age appropriate for her development. So I said, if she is capable of hitting all her targets, you need to be aiming for the next level!'* Participant A

Participant C stated that there were a limited number of speech and language therapists employed by her local authority. However, parents or carers were encouraged to attend courses that gave them information and skills to work

with their children within this area whilst also having contact with the speech and language therapist if they needed advice and information. Participant C felt that this approach worked well for her and her daughter.

*'I've heard parents moan that the speech and language never come out to the home. Well, my thing is, you are the child's biggest advocate and teacher, you have to do it! The courses are useful and train you up to work with your child. Our speech and language person is fantastic! She is only a phone call away if we need her for advice.'* Participant C

#### **Theme 4: EHCP**

Three of the children had an EHCP (Tom, Katy and Michael). One child (John) was still on a statement of needs and one child had a draft EHCP (Sarah). Four of the participants had differing concerns about the EHCP.

##### *Provision*

Participant B had experienced difficulties with the EHCP. Her son had a statement of needs from when he was in year 3 of primary school. At transfer to secondary school at age 11, the statement of needs was to be changed to the current EHCP with the assumption that what was provided within the statement of needs would automatically transfer to the EHCP. However, this was not the case.

*'It wasn't a like for like. What we wanted for Tom was the one to one full time support which he had all the way through school and we wanted him to be taught in a smaller classroom with similar children on his level really. This was already written in his statement. We were told that he couldn't have both for the EHCP. They said that they couldn't have too much money going no where! It wasn't about what was best for my child or what I wanted for him as a parent, it was all down to money.'* Participant B

##### *Completion of the EHCP*

The EHCP is meant to take six months to complete, but participant A had been waiting for nearly a full year for the final draft and expressed concerns that currently, it is only through the good will of the nursery that additional provision has been given in terms of one to one support by staff.

*'Until you've got the final draft, you can't act upon things. I think it's currently with the health professionals, waiting for their feedback. Maybe an unrealistic timeframe has been set and six months is not long enough for the plan to be completed, however, before Sarah starts school, the EHCP certainly needs to be in place.'* Participant A

Participant E discussed issues around her son John's statement of needs, acknowledging that there was confusion as to when John would transfer to the EHCP. The SENCo was unable to give a specific date, suggesting that the transfer may be after the next review but could not confirm this. Again, there was some anxiety that the EHCP would not be in place to support John when he transferred from primary school to secondary school provision.

### *Discussion with parents*

There was a concern that there was limited discussion between parents and other agencies as to the provision given to the individual child although participant E did acknowledge that the health care provision of the EHCP was not an important requirement for her son.

*'For my son, the addition of the health care part is not an issue for him particularly. However, after talking to other parents, there is not a great deal of discussion going on, especially on the transition from primary school to secondary school. You get this document and asked, is that alright? And you're like, 'yes' or 'no' and that's it.'* Participant E

### *Reviews*

An EHCP should be reviewed annually or at a key transition point from one education phase to another, to ensure that the special educational provision for the individual is appropriate and the plans updated to meet specific needs (Devarakonda and Powlay 2016). The annual review is also an opportunity for professionals who work with the individual to meet as a multi-agency team. However, participant D suggested that in her experience, the differing agencies did not all attend the review.

*'The whole team were invited to the EHCP meeting, the speech and language therapist came but the occupational therapist couldn't make it. The head psychologist was invited as well but couldn't come. A representative from all agencies should be there to discuss how things are going.'* Participant D

Participant D also felt that as her son had complex needs, it would be more appropriate and in her child's best interest for the review to be carried out every six months rather than annually.

*'Michael has got complex issues and is changing so quickly, I think they should be reviewing him six-monthly in order for the school to get help and support from outside agencies. But it's all time and money again, isn't it? They come in and they just get a little snapshot of what is happening.'* Participant D

### **Theme 5: Transition**

Participant A expressed concerns about the future transition from nursery setting to primary school for her daughter. She hoped that Sarah would not be excluded from activities and to be given the opportunity to learn to read and write like all the other children within her class. Participant A acknowledged that acquiring these skills may take longer than other children in the class but with the right environment and positive attitude from staff, these skills could be attained.

*'I am hoping that in the school setting that she attends, Sarah will be nurtured there, that she can learn everything that she can and that the school will not just say, 'well, she just can't do that.' I don't want her to be excluded from anything.'* Participant A

Of this sample, one of the participants (B) had direct experience of transition from primary to secondary education. They acknowledged that the transition had been well supported with additional visits to the secondary school allocated and Tom was able to meet his new teaching assistants regularly from May until the end of July prior to commencement of the new term in September. Both schools also liaised regularly with the parents about the transition process. At secondary school, Tom has a designated teaching assistant that liaises with participant B each day and a home/school book. Although in a mainstream class, he also has access to a resource base where he can go to read or for quiet time if needed. The resource base also offers after school clubs such as homework group or social and communication group three times a week which participant B felt was important in supporting her son and helping him to interact and make friends with others. Some of the teaching staff at parent's evening had conceded that they had never taught anybody who had DS before but it had been a really good experience for them. Participant B concluded that this positivity was reassuring. For participant E the future transition for her child was an area of concern. She wanted a mainstream setting because her understanding was that children with Down syndrome fared better in the future if they had attended mainstream secondary school.

*'I think he should be able to have the opportunity because he's part of the community and it's great that more and more kids with additional needs are accessing primary. It should be the same in secondary schools.'* Participant E

However, participant E felt that there were some reservations by staff including the special educational needs co-ordinator (SENCo), a designated individual responsible for ensuring that the needs of individuals with SEN are met, around her son attending the School they were looking at. There was also the concern by the participant that the previous parent partnership with the primary school setting would not continue at secondary level.

*'The school we have in mind have not been hugely welcoming. I hope it's just because maybe they don't know enough around the subject (Down syndrome). The SENCo is also a full time teacher as well and it's a big school so I think she's under an awful lot of pressure.'* Participant E

At the transition stage from primary to secondary school, participant D felt that her son, who has complex needs and attended a small primary school would not be able to cope within a large mainstream setting and expressed concern that there would not be the same support available for him. Therefore, even though the transfer to secondary school was a number of years in the future, the decision had been made by the parents that it would be more appropriate for Michael to transfer to a secondary special school. She acknowledged that if Michael could complete his primary education where he was that would be the best scenario as the staff were aware of his needs.

## **Discussion**

Overall, this small scale study is significant in that the parent's views about their child's education have been sought and issues that can impact upon the

inclusion process have been identified. Importantly, there are considerable positive practices that support the inclusion of individuals with DS within mainstream education settings.

When considering educational settings for her child, Participant C had experienced some negative responses from various Head teachers who felt that the educational setting was unable to meet her child's needs. Similarly, when considering the transfer of her child from primary to secondary setting, Participant E felt that there were reservations about the school being able to support her son which Boys (2003) suggests is often down to the teachers and other school staff feeling that they have no experience of supporting children with DS. This is a view discussed by Shevlin et al (2008) who states that lack of opportunities for professional development within this area may also be a contributing factor. However, research suggests that if staff are given information and support early on, this can make a difference to successful inclusion (Boys 2003). Vaughan and Henderson (2016) opine that having a greater understanding of DS and the challenges that can be faced by individuals with DS may help teachers to empathise and consequently respond in a more positive way.

A positive attitude towards inclusion was considered important by all of the participants, though for some of the settings, this was the first time that they had worked with a child with DS. Examples of good practice were shared by participants and included: Staff working in partnership with the parents (Johnston 2009), regular communication between parents and staff, never underestimating the capabilities of the child and recognising that the parents had expert knowledge in supporting children with DS. This recognition of the crucial role parents play in the education of their child is supported by Lendrum et al (2015).

Certainly, one participant felt that being invited to deliver a talk on DS awareness to staff and pupils was beneficial to all within the setting. This was an example of strong supportive action that mirrors policy expectations within the Children and Families Act (2014) around effective school and home partnerships.

Similar to the difficulties highlighted by Lightfoot and Bond (2013) around effective transition between primary to secondary school. One participant expressed concerns about the transition process, having encountered negative attitudes from staff members but was adamant that her son would attend a mainstream secondary school. However, other participants in this study have had a more positive experience which suggests that transition can be effective if schools have a positive attitude towards inclusion of children with DS and work in collaboration with the individual and parents (Briggs 2005) and provide relevant support (Byrnes 2012).

The importance of early intervention in supporting children with DS is well documented within literature (e.g. Roberts et al 2007). Findings from this study concur with research by Paige Smith and Rix (2006) who acknowledge that access to services such as Portage is dependent upon funding available

within individual authorities and can be viewed as a 'Post code lottery'. Similar to the findings of Johnson (2006) participants expressed the need for more speech and language therapists and conceded that again this was probably due to lack of funding. These findings concur with those of Hodkinson (2010) who discusses the conflicts for LA's in managing their funding and being able to provide for early intervention services.

One particular aspect of inclusive practice discussed by the participants within this study was the willingness for staff to learn alternative forms of communication such as Makaton and for BSL training to be provided for parents. This whole school approach concurs with the work of Briggs (2005) who also suggests that signing is not only beneficial to individuals with DS, but would also benefit a large number of pupils with additional needs including learning difficulties, hearing loss and attention disorders.

The final area this study explored was the EHCP. This is an under-researched topic and the parents gave their views about the effectiveness of the EHCP. A number of concerns were discussed particularly when pupils were transferring from the statement of needs to the EHCP. Participants assumed that provision within the statement of needs would automatically transfer to the new EHCP however, this was not the case. Contrary to the research by Ko (2015), who identified that parents should have more input into the type of provision given to their children, participants within this study acknowledged that there was limited discussion between themselves and the agencies involved, as to the individuals required support. Lack of funding was cited as the reason to withdraw some of the current provision. Devarakonda and Powlay (2016) suggest that the EHCP should be in place at key transition points to ensure that appropriate provision that supports the specific needs of the individual are met, however the parents in this study identified that the EHCP had not been finalised and in place when it should be, with the imminent transfer from one key stage to another causing anxiety and concern for those involved. Participants also discussed the time frame for the completed EHCP was taking longer than the recommended six months. It was also felt that for children with complex needs, the relevant support they required changed more frequently than for others who had an EHCP, therefore it was suggested that for those individuals, six monthly reviews would be more appropriate than the current yearly reviews. The issues raised about the EHCP suggest that this is an area of need requiring further research.

## **Conclusion**

This paper set out to explore parental perceptions of inclusive practice that should support children with DS in mainstream education settings. All children have the right to an inclusive education however, making this happen is not always straightforward. Parents are at the heart of their children lives and parental experiences and perceptions are vital if we are to understand and support children with DS. Findings of this study have identified some issues that may be potential barriers to the successful inclusion of children with DS within mainstream settings but importantly, this study has also identified a

number of excellent practices within early years, primary and secondary settings that support individuals with DS in reaching their educational potential.

Overall, the majority of the participants felt that there was a positive attitude by staff towards inclusion and importantly, a willingness to work in partnership with parents. This study has also identified that a working partnership is important for a successful transition from one education phase to another. To support language and communication for children with DS (and others who have speech and language difficulties) there was evidence of good practice in terms of staff learning alternative methods of communication such as Makaton, with one school inviting a parent to staff training in BSL. However, whilst there was willingness for some staff to learn Makaton within one setting, this was not consistent throughout the whole school and for this to be successful, there needs to be a whole school approach to using alternative methods of communication. Access to services such as Portage and Speech and language therapy varied across local authorities with participants identifying a need for more funding to support these services.

Some of the participants experienced a negative response to their child attending a specific school which could be due to lack of confidence and training for staff within the area of DS which concurs with the findings of Laws and Millward (2001) or lack of staff professional development within this particular area of disability. Lack of funding may be a contributing factor as to why this may not happen. However, previous research (Ellis and Todd 2014: Webster and Blatchford 2014) has also identified the need for sufficient training within initial teacher education establishments in the area of SEN. The EHCP was identified as an area of concern with lack of involvement between all agencies particularly during the annual review period. The process of completing the EHCP took longer than the recommended six months and consideration needs to be given to six monthly reviews for children with complex needs. Importantly, the EHCP needs to be in place prior to transition in order to ensure that the needs of the individual will be fully supported. Currently, there is limited research as to the effectiveness of the EHCP and this paper goes some way to starting to fill this gap as it is illustrative of parent's perspectives about the policy and the implications for their children's education.

There are limitations to this study including the sample size and lack of the father's perspective. It is also recognised that the education experiences of the participant's children will not be representative of all children with DS. However, this study adds to current literature, providing small scale, yet valuable parental insights into the generally successful inclusion of children with DS into mainstream educational settings found in this research.

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