Parents of children with disabilities: Experience of the early years

School for Parents Research Report
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Preface

This report summarises the findings of an interview study conducted with 17 mothers of children attending School for Parents. School for Parents provides Conductive Education and other services to children who have a range of motor and developmental difficulties and their parents. Mothers in the study were asked about why they attended and what they and their children gained from their time in the School. In their responses mothers focused on aspects such as the family atmosphere within the School, the level of expertise and dedication of the staff, the welcome their child received and the support of other parents. In addition, there was great emphasis on how enjoyable the experience of attending School for Parents is for everyone.

Key findings are presented here primarily through the words of the mothers who took part in the study. The structure follows the themes that emerged from the data and consideration is given to the ways in which these accord with research about other early years providers as well as aspects which appear to be specific to School for Parents.
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Testimonials for School for Parents

through the fun that he has here and it is almost like it is just like a play group to him... but at the same time they are incorporating all of the other things that help him and they are helping him with his development and his movement and his speech and I just find everything really enjoyable and he really enjoys it as well (4)

we have been given a great start... so definitely we will come here still and when he starts school we would still want to come here for as long as we can (15)

and then people I have seen from the hospital and they say "wow how come Helen is doing so well!?" (10)

I would recommend it and I would recommend it to any of my friends that have babies in the future who have special needs and who need support I would recommend them as it is fabulous (5)

I would definitely recommend it and I have recommended it actually professionally in my job, I have recommended it to children (8)

they do a fantastic job, and to say that it is for free as well, and I know that it is a hard core two hours for him and he goes home completely tired... but it is completely worth it because to see everything that, like when he first started to him now the complete difference in him (7)

staff are just totally amazing, you know, so they, so once you get to the service and then you realise what they can do for your child, it is just taking that step really I think is the biggest thing, and knowing about the service, so, but yeah I was pretty impressed from day one to be honest (13)
Executive Summary

1. The stress of having a child with a disability is profound and wide reaching, affecting all aspects of the immediate and often extended family. The initial wait for the diagnosis can be an agonising time for families, particularly when they have concerns for their child that are not shared by medical professionals. The disabilities and developmental conditions of the children in this study generally have a life-long impact, but often in the early years it is the child’s health difficulties that cause the most stress to parents, directly due to concern for their survival, and indirectly through the endless appointments and procedures.

2. Some of the experiences described by parents in this study could be considered as trauma, leading to a need for a high level of support and care for the whole family.

3. The birth of a child who needs extra support and attention can lead to a decrease in income for the family when one or both parents give up work or reduce their hours to attend appointments and care for their child. The nature of the special needs of these children means this financial change can be long-lasting.

4. As the health of the babies increases parents turn their attention to development and realise that the extent to which their child will overcome their disabilities will principally fall to the family, and mostly the mother. Attending multiple appointments is exhausting, but so is the work that is required between seeing professionals, amongst much uncertainty relating to their own skills and the adequacy of the support they can provide.

5. Many parents reported good help from statutory services but generally felt that what they were offered in terms of time and frequency was grossly inadequate for their needs. They saw professionals as being constrained by time and resources. This particularly related to parents not being taught how to work with their child and not receiving any support for themselves.

6. Feelings of isolation and lack of support both from families and friends were commonly expressed by participants, they feel that people outside their situation find it difficult to understand their experiences or offer effective support. Having a child with a disability frequently breaks the natural support networks that parents previously had access to.

7. Parents typically contact School for Parents when they are looking for support with their child’s development, particularly in relation to physical and communication ability. Parents frequently feel disempowered in knowing how to help and support their children, who typically have very complex needs.

8. The ethos of School for Parents is warm, approachable and supportive with a focus on what can be done to help the children. It is a place of expertise, commitment and capability. Parents and children are able to attend every week, receive a great deal of time from staff and can learn at their own pace. They can ask questions and receive information whenever they need it. School for Parents is seen as open to collaboration with everyone and significant satisfaction was expressed by parents who had successfully invited those providing physiotherapy or education for their children to work with the conductors at School for Parents.

9. School for Parents is seen as providing support to children in terms of their skill development, confidence and independence. Children love attending.

10. Mothers reported how helpful it was for their children’s well-being that they met other children like themselves, particularly as the child’s awareness of their difference grows, and that this helped them develop positive self-esteem. It is reported that the increased confidence supports children when they go into different situations and leads to lasting resilience.

11. Enormous personal benefits were reported by mothers on behalf of themselves and their families. They feel supported emotionally through their
attendance at School for Parents and the relationships that they build there. They see School for Parents as a place where they feel welcomed, accepted, able to be themselves and express their fears and concerns. At School for Parents they find practical advice, and are gently supported to build their skills in supporting their children. Mothers talk about the lasting friendships they have made at School for Parents that enhance their lives, when previous relationships have been challenged by their changed circumstances.

12. When children reach school age parents find the transition particularly stressful, knowing that they must trust new people to educate and care for their child in the best way. They receive advice and emotional support from staff and parents at School for Parents and are able to keep their connection with the safety net of School for Parents by attending the Saturday gym club or communication sessions.

13. Having a child with a disability is a life-changing experience and many parents felt that their experiences have made them a different person. While acknowledging that they may have increased their anxiety levels many of them also express positive changes in terms of understanding and connection with others, compassion and empowerment. These changes are attributed to belonging to School for Parents.

14. Parents were asked how they discovered School for Parents and ideas about why other parents do not attend. One issue highlighted is that School for Parents is not widely publicised or recommended. Eleven of the seventeen mothers interviewed were told about School for Parents by a friend or someone who knew an attendee. This indicates the effectiveness of personal recommendations, particularly when parents are immersed in statutory services and rely on them for information. Many parents are angry and frustrated that professionals do not inform parents about the service.

15. School for Parents provides all aspects of a good service for parents, as identified in previous research including: information and advice; support to parents in developing self-advocacy skills and empowerment; gaining understanding of their child’s condition and how to help them; best ways to access and navigate services; meeting social and support needs of adults and children; and facilitating successful collaboration between services.
1.0  Background to the study

1.1  Issues for families of disabled children highlighted in previous research

The current UK model of service delivery and support to families with disabled children varies from place to place but mostly comprises a mix of visits to specialist centres, frequently in hospitals, and appointments with professionals such as physiotherapists, speech and language therapists and occupational therapists in people’s homes. From the birth of their child, or from the point of concern or diagnosis, parents are thrust into a world of multiple appointments. They need to learn to understand medical terms and how the health and care systems work. Since services generally do not offer a joined up provision parents need to learn who to ask about which aspect of their child and tell their story and concerns repeatedly. Children with disabilities spend more time in medical care than typical children, their parents need to learn how to negotiate the system (Bye & Aston, 2016) and frequently have to fight for the level of service which they desire for their son or daughter (Todd and Jones, 2003). When they do not have necessary knowledge or information this causes added frustration and fear (Bye & Aston, 2016). Todd and Jones (2003) found that parents mostly saw positive contact with professionals as atypical and felt that their role as a mother was undervalued. Mothers were fighting for their children but also for themselves to have the right to fight and not be seen as ‘pushy’ or ‘neurotic’. Findings of a meta-analysis of research about families of children with autistic spectrum disorders found services did not provide enough guidance, there were too many appointments and intervention took up too much time (Corcoran, Berry and Hill, 2015).

Previous research has investigated the needs of parents of children with disabilities and found that they appear to experience more stress than parents of typically developing children (Peer and Hillman, 2012). This is of particular concern as too much stress can impact on the parent’s ability to provide for the child. In addition, according to Peer and Hillman (2012), the more severe the child’s disability the greater the stress level. Other factors which determined the level of stress experienced by the parent included their personality e.g. whether they were judged to be an optimist or pessimist, and the level of social support they received. Knafl, Deatrick and Havill (2011) added the input of healthcare and education professionals and systems as contributing to the ease or difficulty of family management. They identified support from family and friends as beneficial but “others reported that those outside the family and society’s devaluation of the ill and disabled impeded families’ management efforts” (Knafl et al., 2011, p.8).

Having a child with disabilities in the family impacts on all members. Parents need to support non-disabled siblings who can experience less time and attention from their parents due to the increased care demands of the disabled child (Willingham-Storr, 2014). Fathers are frequently unable to attend appointments so can feel excluded and unable to adequately support their family (Willingham-Storr, 2014). They may also develop negative views of professionals, possibly because they do not have time to develop relationships with them (Hornby, 1992). Practicalities of everyday life are complex due to the amount of planning necessary for any activity and in turn this impacts on the isolation of all family members (Willingham-Storr, 2014).

1.2  Sources of help and support

Research has identified factors that support families, helping to reduce stress and increase coping and well-being. Reducing parental stress has been found to have a positive impact on their children (Weiss, Viecili and Bohr, 2015). Parents need to develop knowledge and self-advocacy skills (Etmanski, Collins and Cammack, 2011) which can be helped by the provision of quality information (Willingham-Storr, 2014). “Parents’ beliefs about the child’s capabilities are tied closely to their understanding of the condition and its associated demands and limitations” (Knafl et al., 2011, p.12). Parents
would benefit from being given help to access and navigate services (Etmanski et al., 2011).

Parents need to build peer support networks - parent emotional support and cohesiveness between parents and children positively influence children’s social skills (Haven, Manangan, Sparrow and Wilson, 2013). There is a need for collaboration between families and service providers and a family centred approach (Willingham-Storr, 2014).

Organizations are challenged to create practices that respect, empower and strengthen families by ensuring that initiatives incorporate the building of participant capacity as a central aim (Daly, Sharek, DeVries, Griffiths, Sheerin, McBennett and Higgins, 2015). Important factors in supportive services are the warmth of staff towards child and their interest in them, the level of experience of staff and the appearance of the building (Herbert, 2014).

1.3 Potential benefits of effective support and education
It is essential that services provide appropriate support to families as this can promote a positive mind-set around disability, build confidence and effectiveness in accessing services, bring beneficial changes in family dynamics and more effective community connections which combine to reduce the sense of isolation experienced by many families of children with disabilities (Daly et al., 2015). When parents are effectively supported their role can lead to fulfilment and empowerment (Willingham-Storr, 2014).

2.0 The interview study
2.1 Ethics
The study received full ethical approval from the University of Nottingham Ethics Committee. In addition, the School for Parents Board of Trustees approved the research. The School manager invited parents to participate and gave them information about why the research was taking place. Parents were told that they would be asked about their experiences of attending School for Parents and what it meant for them, and that this would help the School in applying for funding in the future. Once parents had expressed a willingness to be involved they were provided with a participant information sheet which outlined what they would be expected to do. They were reassured that their participation was entirely voluntary and that they could withdraw at any point with no consequence to themselves or their child. They were asked to meet with the researcher for around 30 minutes at School for Parents while their children were attending their usual session. Parents were asked for permission for interviews to be audio-taped and transcribed by a 3rd party. They were assured that all data would be kept securely and no one would be told what they had said. It was explained that their answers would form reports and publications, within which they may be quoted, but that no real names would be used. Some information may be changed in publications to protect their identity. Once parents had had the opportunity to read the Participant Information and ask questions they were asked to sign a consent form.

2.2 Participants
Although fathers were invited to participate only mothers volunteered. A total of 17 women were interviewed, 15 in person and 2 over the phone. The participants were a mix of 1st time and experienced mothers whose children have a range of different conditions and disabilities. Table 1 shows the demographics of the group. Fifteen of the mothers were living with their partner and many had support from extended family to varying degrees.
<table>
<thead>
<tr>
<th>Interview no.</th>
<th>Child</th>
<th>Child age</th>
<th>Age starting SFP</th>
<th>Siblings</th>
<th>Age of diagnosis</th>
<th>Disability</th>
<th>Finding out about SFP</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Colin</td>
<td>6 1/2</td>
<td>No info</td>
<td>Older brother, Twin who died at 1 day</td>
<td>birth</td>
<td>CP</td>
<td>Personal contact</td>
</tr>
<tr>
<td>2</td>
<td>Sam</td>
<td>9</td>
<td>14 mths</td>
<td>Sisters 5 &amp; 3</td>
<td>11 mths</td>
<td>CP</td>
<td>Family worker</td>
</tr>
<tr>
<td>3</td>
<td>Emily</td>
<td>4</td>
<td>2</td>
<td>Brothers 6, 5 mths</td>
<td>2 1/2</td>
<td>Retts syndrome</td>
<td>Family worker</td>
</tr>
<tr>
<td>4</td>
<td>Freddie Michael</td>
<td>3 y 3m</td>
<td>6 mths</td>
<td>brother 6, birth</td>
<td>DS</td>
<td>Myelin disorder</td>
<td>Parent at CDC</td>
</tr>
<tr>
<td>5</td>
<td>Polly</td>
<td>4</td>
<td>3</td>
<td>4 older</td>
<td>In utero</td>
<td>Spina bifida and hydrocephalus</td>
<td>Personal contact</td>
</tr>
<tr>
<td>6</td>
<td>Vicky</td>
<td>4</td>
<td>2</td>
<td>sister 6</td>
<td>Just before 2yrs</td>
<td>Muscular dystrophy</td>
<td>Internet</td>
</tr>
<tr>
<td>7</td>
<td>Martin</td>
<td>4</td>
<td>2</td>
<td>0</td>
<td>Pre-birth</td>
<td>DS</td>
<td>Portage worker</td>
</tr>
<tr>
<td>8</td>
<td>Philippa</td>
<td>4</td>
<td>9mths</td>
<td>0</td>
<td>Birth</td>
<td>DS</td>
<td>paediatrician</td>
</tr>
<tr>
<td>9</td>
<td>Kevin</td>
<td>3</td>
<td>1 yr</td>
<td>sister 10</td>
<td>Birth</td>
<td>Prem/ Complex needs</td>
<td>Personal contact</td>
</tr>
<tr>
<td>10</td>
<td>Helen</td>
<td>8</td>
<td>5 1/2</td>
<td>brothers 20 &amp; 14</td>
<td>From birth/officially 1 yr</td>
<td>CP</td>
<td>Personal contact</td>
</tr>
<tr>
<td>11</td>
<td>Shannon</td>
<td>6</td>
<td>18mths</td>
<td>Twin and younger sister</td>
<td>After 1 year</td>
<td>CP/prem</td>
<td>Personal contact</td>
</tr>
<tr>
<td>12</td>
<td>David</td>
<td>Boy 9 yrs</td>
<td>Official 2 1/2</td>
<td>sister 7</td>
<td></td>
<td></td>
<td>Personal contact</td>
</tr>
<tr>
<td>13</td>
<td>Mary</td>
<td>5</td>
<td>2</td>
<td>sister 7</td>
<td></td>
<td>oesophageal atresia/ developmental delay</td>
<td>Personal contact</td>
</tr>
<tr>
<td>14</td>
<td>Sarah</td>
<td>5</td>
<td>1</td>
<td>sister 11, brother 10, sister 7</td>
<td>6 months</td>
<td>Prem, hemiplegia</td>
<td>Contact on Facebook</td>
</tr>
<tr>
<td>15</td>
<td>George</td>
<td>2 ½</td>
<td>7mths</td>
<td>sister 4</td>
<td>birth</td>
<td>DS</td>
<td>Personal contact</td>
</tr>
<tr>
<td>16</td>
<td>James</td>
<td>5</td>
<td>22 mths</td>
<td>brother 7</td>
<td>problem highlighted 18 mths/official 41/2</td>
<td>hyper mobility/low muscle tone/Ehlers Danlos syndrome</td>
<td>Fundraising event</td>
</tr>
<tr>
<td>17</td>
<td>Rose</td>
<td>2</td>
<td>6 mths</td>
<td>brother 20 sister 18</td>
<td>birth</td>
<td>DS</td>
<td>Personal contact</td>
</tr>
</tbody>
</table>

Table 1. Demographics
2.3 Method
Semi-structured interviews were conducted; a set of questions were prepared in advance but asked in different orders with additional questions as appropriate. The emphasis within the interviews was placed on the comfort of the interviewee which meant that not everyone was asked all the same questions. Participants were asked to elaborate on their answers to provide depth of data, and allowed to talk for as long as they wanted. The range of length of interviews was between 32 and 78 minutes, with the average being around 50 minutes. Interviews started with an introduction to the researcher, a reminder of why the study was being conducted, clarification about the informed consent process and reassurance about confidentiality. Initial questions were designed to help the researcher to get to know the interviewee, have an understanding of their circumstances and start to build rapport and trust.

2.4 Interview questions
Mothers were asked to talk about their child and their family, how their child came to be diagnosed and what support they received from family and statutory services. Having provided background case history they were asked what brought them to School for Parents and what they and their child gained from attending. Lastly questions encouraged participants to consider whether their experiences had led to changes in their lives and whether they would like to see any changes in School for Parents.

2.5 Data analysis
The data were analysed thematically. Transcripts were read and codes given to all statements. These codes were then grouped into themes to present a cohesive picture of how mothers responded to the questions. Themes were then sub-divided. Table 3 shows all of the themes and sub-themes that were identified.
3.0 Findings

3.1 Key Themes
Table 3 shows the main themes that were identified in the data including 4 overarching themes (mother’s stress, experiences of statutory services, the impact of School for Parents and obstacles to attending) with their associated subthemes. Following this section sub-themes are discussed individually.

Table 3: Key themes

3.2 Causes of mothers’ stress
All of the mothers interviewed expressed stress arising from at least one aspect of having a child with disabilities. However, this stress sometimes did not stem directly from their feelings about the disability itself but rather about associated issues such as their child’s health, service provision and their feelings of isolation. The subthemes in
this section chart the journey the mother experiences from first knowing that there was something different or concerning about their child’s health or development, their efforts to find help and support and battle with isolation, the need to consider other family members and their concerns as their children start school.

3.2.1 Diagnosis and reactions to it

Eight parents had to wait considerable lengths of time (up to 4 years) before getting an ‘official’ diagnosis whereas 9 knew from birth or before that their child had a disability. In the latter category are children who have Down’s Syndrome or Spina Bifida. The parents in this study who knew about their child’s condition from birth experienced shock at the diagnosis in terms of the disability to varying extents.

*we had the screening for Downs syndrome and she was very low risk so it really was a complete shock when she was born* (8)

*obviously it was a shock and I am not saying that it was acceptance absolutely and immediately and it did take me probably a month or two to just, just get over the not having the child that I expected but all along it was still being really positive about having a baby, and just trying to find out what it actually meant really to have Downs Syndrome* (15)

For those who came quickly to terms with the disability they still felt the full impact of their child’s health problems.

*then all of a sudden we had the 20 week scan and were told it was Downs and then everything changes, but it wouldn’t have made a difference if we hadn’t had known and we were more prepared because we obviously looked into it and we knew what we was, what we was facing as it were and it still doesn’t help for when he has arrived and it is taking 45 minutes to feed him 90 mls of milk and he was diagnosed with heart failure at 8 weeks, it doesn’t, it doesn’t help you for that* (7)

*the Downs Syndrome was the last thing on the list that we were concerned about, it was right we need to get you fixed!* (15)

The parents who had to wait for a diagnosis had a variety of experiences. In several cases they went repeatedly to health professionals asking for their concerns about their child to be taken seriously and investigated. They were often met with reassurances that nothing was wrong or the response that they needed to wait until the child was older.

*the paediatrician we saw initially told us that he was a boy and he was probably a little bit lazy and that come back in six months’ time and we will have a look then* (16)

*but so we went back and, you know, we kept going back and saying look there is something else going on here and can you... investigate further and then they obviously had suspicions but what really annoyed me was that they didn’t talk to us and left us in such a position where we were just left literally just dangling and thinking what on earth is this* (6)

Some parents had intimations that professionals thought that something was wrong long before anything was expressly stated.

*she seemed really very adamant that you need to still be seen by a physio and which I was still a bit confused about why and no one else seems to be having physio* (2)
Mothers uniformly expressed the time of waiting for a diagnosis as extremely stressful.

\[\text{you take away the enjoyment of the little baby that you have got and you are waiting for diagnosis and you are waiting for something to happen (14)}\]

Once the diagnosis was received parents tended to experience shock, relief and anxiety about the immediate and long-term future.

\[\text{having had this, you know “this is what it is go and look it up on the internet”. We were still obviously thinking please god, maybe they have got it wrong, you know, and please let them be wrong! (6)}\]

\[\text{don’t get me wrong there was the moments and stuff and we were just sat and cried, you know, and you have to do a bit of grieving really because it was not what you were expecting (11)}\]

\[\text{it took me ages to kind of break down because really I didn’t really know what cerebral palsy was and how it was going to kind of affect him and you know whether it was going to be a long term thing (2)}\]

### 3.2.2 Children’s health problems

Thirteen of the participants in this study talked at length about the distress caused by their children’s health difficulties. These ranged from acute and life threatening to chronic and long-lasting. A child with spina bifida had a shunt inserted at 4 weeks, it blocked 4 times in her first 15 months, each time requiring urgent medical attention.

\[\text{Spina Bifida doesn’t bother me one bit and the spinal damage is just physical damage but the fluid on the brain can kill her so, the spinal damage can’t but the brain damage can, so that is my biggest fear that you know when things go wrong with her shunt that is the difference between life and death for her (5)}\]

Within the sample of 13 parents who talked about health problems there were an incredible range of crises and chronic illnesses they had to deal with. Many children were born prematurely which frequently leads to long periods of hospitalisation and bleeds in the brain which can cause lasting damage. Parents have to wait weeks, months or even years to find out the impact on their child. Many of the children have required major operations in their first years including hernia repairs, heart and hip surgery and a liver transplant.

\[\text{so he had a chest infection when he was eight weeks old and we went to the hospital and they said that it was in heart failure... you can watch the world fall apart around your ears and can watch him be resuscitated again and you can watch him being taken to theatre (9)}\]

\[\text{he was in there for a good 15 minutes before they got him back and before they revived him... we had lost him quite a few times... but that was the worst I would say time that we did nearly lose him (2)}\]

\[\text{we noticed then that her head was becoming slightly misshaped and it was very quick this was and we had her to the GP immediately (6)}\]

Long-term health issues included cancer, kidney problems, hearing and vision problems, lung complications and breathing difficulties.
so we just took him home and the first year was absolutely awful because he suffered from really bad colic and reflux (12)

we got him home and he just screamed and cried most of the day and night and it was just... when I look back I think just how horrendous it was (2)

As well as the stress caused by fearing for your child’s life or living with a sick son or daughter these health conditions potentially impact on the bond between an infant and their parent. Frequently children were incubated and some parents reported not being able to hold their child for many weeks. Babies were required to stay in the hospital for their first six months or longer.

he was in hospital for the first six months of his life and then when he came home he was on oxygen at home and for about another year and not all the time so initially it was 24 hours and then gradually he was weaned off during the day and went on still on at night but I think that we had the equipment at home and he was plugged in for about year so it was 18 months more or less (1)

Another major cause of stress and concern was difficulties with feeding children who were at risk of failing to thrive. Parents had to watch their children lose instead of gain weight, and were instructed that the operations their children needed could not be done until they reached a certain weight.

so when he did go in for his heart operation at six months he was below the weight they wanted him at because obviously the higher the weight the more chance of survival (7)

The focus on food and eating can take considerable time and attention and be a source of much anxiety.

he would gag all the time and be sick at most meals, I wouldn’t be able to clean his teeth before school because he had milk overnight and he would bring so much up and the calories were so important so we would send him to school with a tooth brush for when his milk and breakfast had gone down then they could clean his teeth (1)

Michael has been the most worrying one, because he doesn’t swallow correctly and it goes on to his lungs and so he is at risk of getting aspiration pneumonia all the time which he has had quite a few times (4)

they wouldn’t put speech and language in, despite the best efforts of his neonatologist at the time and didn’t qualify for that even though he would projectile vomit well over 14 to 15 months (9)

Naturally it is not only the immediate family who need to come to terms with and adjust to the diagnosis, which also has impact on wider family members.

we had to go home to this little girl and you know, her grandparents and people and, yeah, I am not quite sure how we actually held it together, I am not saying that we did hold it together but how we actually got through it I really don’t know, it was, it was the worst time ever, it really, really was (6)

Mothers had very varied situations in regards to the reaction of family members and the extent to which they were able to provide practical and emotional support. There were reports of rifts within families stemming from the birth of a child with disabilities and, in contrast, the forging of stronger relationships. The majority of mothers in this study described one or more members of the extended family offering some kind of regular
practical support, but other mothers described preferring to rely on friends or having to take the full burden.

my mum is supportive but she has her moments and I am not sure if she has come to terms with it as well as perhaps she would think that she has and I don’t know and I think sometimes she is, you know, she has been at schools for donkeys’ years and has recently retired and, you know, has worked with children with special needs and but I think that she has found it difficult with you know, her own grandchild being in this situation (6)

3.2.3 Concerns about development

Once children had reached stable health parents described turning their attention to development. Parents were generally very aware of whether their children were meeting physical milestones and described difficulties with sitting, rolling, hand control and walking and communication.

so at that age, you know, we were quite desperate in him taking those steps and will he or won’t he walk and nobody could answer that for us, you know, physios didn’t know (16)

all that time you are just very much desperate but Sam was so tiny and he really struggled, he could never sit on his own until four months ago (2)

Emily has never walked or crawled but she would just sort of spin around a bit and she used to have the ability to use her hands and she never really talked a huge amount and but she has a few words in her own sort of language and then we have seen I think in the last year we have seen her lose her hand function and she has, she can still roll over a bit and so even now sitting as she has got low muscle tone so sitting is quite hard work for her I think (3)

Parents had often been given warnings and poor prognosis in respect to physical and intellectual abilities.

they were saying take this child home but he has a very uncertain future (9)

Mary was going through so much, you know, we didn’t know whether she would have a genetic disorder and there was so much going on I suppose I didn’t really know why she wasn’t walking yet or why she wasn’t talking properly and because the medical professionals kept saying well, you know, she could just be delayed, because she has literally spent so much time in hospital, so she hasn’t built up those skills and it might be that it just comes (13)

However, when parents do not receive appropriate support it is very hard for them to know how to help their child.

he was frustrated and I was just so low that I let him get away with it really because I didn’t know, I didn’t know what else to do, you know, and every day on a daily basis I would say to him "are you going to stand up today David?“ And he would say “no thank you”. And I would say “oh. Alright then!” And that was it and because I just, I didn’t, I didn’t know how to help him. It was alright me saying, oh are we going to stand up today? Well he didn’t know how to stand up and I didn’t know how to help him and it was just a vicious circle and we weren’t getting anywhere (12)
3.2.4 Appointments and information

Eight of the participants reported that a very stressful aspect of caring for their child was the number of professionals they needed to be in contact with, the amount of appointments, and how difficult this alone was in terms of fitting in with the rest of their lives. Parents suddenly find themselves living in a different world which is difficult to understand and requires great amounts of time in hospital.

with all the hospital appointments and things like that and I have to juggle all of that and I think that is what I find hardest is the impact and how many appointments she has had to have. And when you are working and things like that and just trying to juggle everything and I think that is the massive thing really (17)

everyone is hitting you from every angle and you have then got speech and language, you have got OT and you have got physio and you have got your consultant and you have then got kind of Theraplay people who come from the hospital and people who I can’t even remember what their job title really was... but everybody seems to be knocking on your door (2)

When mothers were not attending appointments they felt they were expected to be doing exercises and therapy with their children.

you do feel that you are, that you have got so much to do, and I remember we had to do an hour, like half an hour sitting in the morning and half an hour in the evening, and we had to do tummy ties and really it was two hours which, when they are that age and you are bribing them with the whole play thing and try... it is hard (2)

so I took him back and she said "oh!" She said "I thought he would be doing more than he is doing!“ And I thought well, you know, nobody is seeing him and he is not being seen by anybody, we have only done what we can do at home and to be honest we didn’t really have a clue what we was doing, you know, we have got this boy bless him who just didn’t want to stand up (12)

Even though most of the mothers were living with a partner they reported that management of appointments and attendance fell to them.

I am the one who goes to all the appointments and the classes and stuff and my husband is like really supportive and will go to whatever but he works so he doesn’t have to sit and go through it when it is draining and tiring (11)

was a little bit tricky but I managed to tailor work so that I started work at half one and then worked late so I could get my hours in (3)

Mothers needed to learn new skills and develop an understanding of their child’s needs.

I remember back then it was very daunting, because I didn’t and I am not involved in any of that health, and so it is learning new skills (3)

if you are saying that we have got a child with cerebral palsy and he is at stage three and might not ever be able to walk and you’re offering one hour of physio every few weeks? And I am a mum, I am not a trained physio and I have just come into the world of cerebral palsy but I am supposed to be doing this every day and you are offering us an hour every two weeks?” So we were flabbergasted that how I am supposed to pick all this up and know what I am doing and I have got all these papers with it written out and it is hard because you are working
from different papers but really you need somebody there helping you and telling you what to do (2)

what we need to do and the appointments and, you know, the constant monitoring of, you know of all the little minutiae and Vicky is a very complex child in terms of her, you know, and people just think that her legs don’t work and well it is not even touch it, you know, it is the whole detail of her she is so complex (6)

What compounds the stress for many mothers are their own perceptions about what they want to be able to do for their child, having a sense of what would be ideal and yet falling short of this. They feel they do not have the skills, or the time, to give their child enough.

there is just so much help that is needed that I don’t know if I am strong enough to go through and do it (5)

I weren’t in control of his cerebral palsy because I didn’t know how to help him and that the worst feeling in the world (12)

he needs more that he is being given and I don’t know what I am doing growth and development wise. I could keep him stable medically but, you feel like you are lost and swimming as a parent when you have a profoundly disabled little child (9)

Many expressed that in the early days they put a lot of energy into trying to find services who would help them before making a realisation that ultimately they needed to do the work themselves.

he was about a year and I very much was passionate that the NHS wasn’t providing what he needed (9)

even though you have got these services you wait for and you get a worker, it is then down to you and they are not going to be doing physio every day with your child or working with her hands or working on communication it is, it is down to you really (3)

Another compounding factor is the non-availability of help and support that the mothers felt could make a significant difference to their child’s life and development.

and it has been hard and it just feels like a constant fight and when you have, and I hate the word, normal, but when you have a normal child you don’t have that fight on your hands that you have with a disabled child to get the right care and to get the right equipment and to get the right house (5)

it was awful, if, and I truly believe if I hadn’t had resourced and found and wouldn’t take no for an answer, I truly believe that Kevin would not be walking now, and I really don’t (9)

Yet another cause of stress is the financial aspect of having a child with disabilities. One mother described paying a large sum of money for what she thought would be an intensive course of physiotherapy only to find that she was only seen by physios for a short time each day and had to care for her child in a bedsit far from home. One parent moved home to be nearer to the hospital due to the cost of taking public transport long-distances to attend appointments. Several mothers had had to give up work as they could not make a full commitment to employers, or had to return to work and deal with trying to be both employee and carer.
my way of life has changed a lot since I have had Polly because I was working and I gave up my job to be her full time carer because she was in and out of hospital the first year of her life I couldn’t offer my boss commitment (5)

that put a lot of pressure on Tom because then he was the only bread winner and, you know, it is really hard when you have got a child with additional needs and then when it came to the time for me to go back to work they contacted me and at that point Mary was awaiting heart surgery. So I made the decision of how could I possibly go back to a demanding job and I just can’t do it, because I didn’t know what the future held for Mary at that point and I mean it was such a massive operation and so I just said to her I can’t come back, I did ask for more time but obviously I had already been off for two years at that point so, I had to resign from the job properly (13)

my husband… only does a four day week because we have found that we have got so many appointments and with three children it is hard to control all three, you know, but it will be easier when Owen is back at school. But he went down to a four day week to sort of help with the situation, and of course we have had quite a few hospital admissions with Michael (4)

These impacts can go beyond the nuclear family.

my Mum is a foster carer so she, you know, was she was the main person and I think actually at one point she had a break from foster care just so that she could be there to support me a bit more (13)

Around half of the participants in this study found the numbers of appointments and different professionals involved with their child a source of additional stress. However, others expressed being very upset about the lack of service in terms of frequency and duration of support, as is seen in Section 3.4.2.

3.2.5 Isolation and lack of support
Eleven mothers spoke about how isolated they had felt prior to attending School for Parents.

I am not the only one, there are more of us out there, do you know what I mean, but you just feel like you are the only one (12)

most of it I deal with on my own when she has gone to theatre it has been me and whichever nurse and we go down and when she comes back it is me who fetches her, the family support where they can but it is mostly all down to me (5)

Feelings of being alone and not having anyone who would be able to understand increases stress and unhappiness and reduces the ability to cope.

I think it was just a bit easier for us to lock ourselves away and just keep it in the family (11)

I think prior to coming to School for Parents the only contact I ever had with the outside world was going to appointments (12)

Some mothers had made efforts to contact parents in similar situations, usually without success.
I put the things on the FaceBook page, I have got a child with this condition, has anybody else got a child with similar difficulties, I would like to meet up and... nobody responded and who wanted to meet other mums who were going through the same journey (16)

you might go to the hospital but you would very rarely talk to anybody when you are there, you kind of go and you go in and that is it you don’t really meet anybody else outside (2)

Others had found leaving the house enormously difficult for practical reasons. Those who had attempted to join mainstream groups had encountered a different range of difficulties.

so none of the mother and baby groups just weren’t right for us, one we couldn’t go and two I found it incredibly difficult seeing people with babies that were doing all the things that they were meant to do, and yeah, I just didn’t want to engage with that (8)

Previous friendship groups often did not provide much solace, further deepening the sense of isolation.

your friends who have healthy babies, kind of, not didn’t want to see them, but it was hard to see them because you kind of, you were in a completely different world to where they were (2)

but you know all my friends work full time and yeah everyone just has busy lives and I don’t think that people really know what it is like to have a child with additional needs unless you are in that situation, you know, it is hard to describe really but it is, you know, it is just really demanding (13)

it is difficult and I think with Emily’s needs it makes it difficult to lean on friends (3)

In addition, mothers were typically doing most of the practical care of their child as well as considering the responses of their partner.

(my husband) worked away a lot and he wasn’t really there either and I think he was struggling with the... you know (2)

her dad doesn’t want to have anything to do with her (5)

The impact of lack of support and lack of close social networks could be introspection and helplessness.

I really did feel like everything was my fault and he can’t walk and that is my fault (12)

It is clear that even mothers who had supportive partners (as most of the participants did) and families who offer support when and where they can, end up feeling a sense of isolation when they do not know other people who are sharing these highly challenging circumstances. Ironically, the provision of appointments in people’s homes may contribute to this isolation, however, mothers also described how they found it difficult to meet people when attending hospital appointments or only meeting people who did not share their attitudes and concerns.
3.2.6 Impact on the family

For many families the health and development needs of the child dominate all aspects of life. This can be very disruptive to normal family life and to the relationship between the child and their parents. Trying to balance this and be mother and professional at all times increases stress.

"there were days that I felt, you know, why am I having to do this, I just want to be a mum and enjoy my child and I felt like I was a mum, I was a physio and I felt like I was everything rolled into one" (2)

Mothers indicate wanting to achieve some normalcy and to find space for their children to just be themselves.

"when we got them home I just wanted them to be my babies" (11)

Since children with disabilities and health difficulties take considerable amounts of time, attention and energy many parents who already had other children had increased stress in attempting to meet their needs too. There were frequent separations when mothers needed to stay in the hospital with their sick child, or visit every day, leading to considerable amounts of time away from siblings.

"his brother was two, just gone two when he was born so somebody needed to be constant for him and although I was getting to see him every day going home for short periods I wasn't at home for him" (1)

"I think that it was pretty difficult for her and I would definitely say it had an impact on her behaviour so, you know, because like as you can imagine, I just wasn't around much for six months but, and not only that, when I got Mary back home for the first time we were back and forth and I would say that the first year of her life she was in and out of hospital for most of that time" (13)

They describe how it was much more complicated to even leave the house.

"we were slightly stuck at times to be at home and Colin was on oxygen and I had to be careful where I was taking him and germs basically" (1)

On a more positive note some of these parents also observed a great closeness between siblings and the development of caring and concern for others in their non-disabled child.

3.2.7 Comparisons with other children

Inevitably parents with young children come into contact with other families, most of whom have typically developing children. This provides the opportunity to compare levels and rates of development, which can be painful and stressful in highlighting their child’s difficulties.

"in my day to day most people around me have got healthy and developing normal children and you feel like the odd one out" (3)

"you see everybody else progressing and you feel like you are not" (11)

"he was always the one who was sat on the nursery ladies knee and at the park and in the grounds of the nursery and you know he would always be lifted up to do things and all the others would be, you know, steaming around at that age" (16)
Parents frequently reporting adjusting their friendship groups to manage their feelings when mixing with non-disabled children.

*I actually found it easier to be with children with other special needs and their parents than be in the community of people without additional problems because for me I could see the differences with Philippa and their babies who were even six weeks old, so that wasn’t somewhere I wanted to be* (8)

Conversely many parents spoke about the perspective gained by meeting other parents of children with disabilities.

*I was meeting parents with children, with children who were having a tougher time and then thinking “God! What have I got to worry about, you know what have I got to complain about”* (1)

*when you come here you do not feel like the odd one out at all and everyone else is going through their own thing and I think that it can also remind you that even when you think that something as tough as Emily you might see someone else who are battling with getting no sleep at night or yeah, children who are not breathing through the night and parents are up all hours and I think it reminds you that actually it is not, it is not too bad* (3)

Feelings of difference for themselves and their children can be very upsetting for parents.

*she knows her friends at school, even though she is lucky because she has been there since nursery and they do protect her, and they are not like her are they? And she knows that* (10)

*but her standing frame is not due to go to school partly because we, we didn’t want to go right let’s just chuck in all the equipment and this child is so completely different* (6)

The converse situation is also true, where parents avoid meeting other children with the same condition as their child in order not to dwell too much on the future.

*that there is something that Emily may develop over time and like epilepsy, other breathing difficulties and I think that we have kind of, not wanting to go out and meet too many children for our own emotional sanity really because although it is helpful to get some support you will also see the other side of it* (3)

Parents obviously want their children to be able to enjoy the same experiences as their siblings and trying to make this happen, or having to accept that it is not possible is a painful process.

*we have never said that he can’t do anything and we have always helped to do everything but it is kind of when you go to the park and he has got two younger sisters and they want to go on everything... when it is me now on my own there is a lot I can’t take him on because he is not the little boy he was and he is heavy and you know, I can’t get him on it* (2)

3.2.8 School and separation

Seven of the people interviewed had children of school age or who were just due to start. For most parents having to send their child off to school at age 4 can be a time of anxiety and concern. The situation is generally much more complex for the parent of a
disabled child. It can be stressful finding a school that can provide the right care and support and who will also welcome the child.

at first I thought, it was going to be fine and then I had a sort of a period where I don’t know I felt like that they perhaps hoped that we would disappear, and didn’t stay in catchment (6)

Parents who have spent 4 or 5 years learning to understand their child and their physical, developmental and communicative needs have to learn to trust the people who will take over the care of their child on a daily basis. Having had a period of feeling supported by School for Parents and the network of parents there, the mothers were again grappling with difficult feelings. They expressed sadness at having to cut away from the security of attending School for Parents. They had concerns that their child would be seen as different, or not cared for sufficiently. Many of the children have complex medical needs and school staff require training to, for example, catheterise the child or do physiotherapy. Mothers worry that this will not be done properly.

she can stand and have quite an arched back that is not a good thing, it is promoting weakness in her spine and could promote scoliosis, and you know, just things like that and it is a worry, it is a worry and a big worry! (6)

A further complication is that for all of the child’s life mothers had spent the majority of their time caring for the child, even more so than with typical children. They therefore have to face the issue of how they will fill their time when the child is not there.

I think that because Martin is so dependent on us still don’t get me wrong he is getting easier but now all of a sudden that he is going to be gone for six to seven hours a day that is going to be, well what am I going to do, because, my house is going to be so clean it is going to be ridiculous (7)

Additionally, the emotional bond between mother and child can be more intense than is usual leaving the mother finding the separation very difficult to cope with.

she has been home a lot and so the odd days that she has done nursery recently was, like it felt like a complete loss without her because we have been together 24/7 so it is going to be weird and hopefully it will get easier (5)

Understandably many of the mothers are protective towards their child and aware of their vulnerabilities.

we are worried that Colin’s speech is so delayed and he is so quiet and you know preschool is busy and noisy and echoy (1)

it is the noise and he is very sensitive to noise and touch and sensory issues are sky high (7)

This is highlighted when the children themselves are aware of, and concerned about, differences to their peers. Mothers described their children asking questions about why they could not manage the same work as their peers, or struggling with specific skills such as writing. One child panicked about not being able to get herself changed for PE.

but she does get a bit anxious and the last year when she was in nursery she didn’t speak to the staff about anything and if she had a fall or if she banged her head she wouldn’t, and instead she would just get up and carry on, and she wouldn’t say anything, until she came home and she was running out of nursery and she would give me a big hug and she would say “Mummy I hurt myself today!” (14)
we still struggle with confidence levels and he does need a lot of encouragement and praise and he is a little bit of a worrier. I often feel that if he wasn’t so clever and had so much up here, I always say to him you have got too much up here and not enough down there, because I do think, that he is a thinker and I think that was stopping him “if I do that I might hurt myself or I might fall!” (12)

Even where parents were expressing positive views they still had a heightened awareness of issues that their child might find more difficult than in general.

but I don’t think next week it is going to be that bad, I think he is just going to take it really well, because initially with nursery once he got in with the other children and because there was 30 originally and then after December there was 40 and then after March they had some more and they ended up with 55 children in nursery and he tolerated that really and it went really well (7)

I am as nervous as any mum who is, you know their youngest child is off to school on Thursday for the first time but, yeah she is, she is looking forward to it. I just want her to make friends and enjoy being at school. I hope that she can keep up with the pace (6)

3.3 Trauma
Trauma is usually thought of as related to a specific incident, which is unexpected and catastrophic, outside most people’s experiences and would cause distress to anyone. This definition is not generally applied to the parents of children with disabilities but Hollins and Sinason (2000) suggest that having a child with severe disabilities should be viewed as a form of trauma. The importance of considering this as a possibility is related to the impact of trauma on the health and mental well-being of those who experience it. The impact of trauma can result in post-traumatic stress and symptoms can include revisiting the trauma, intense fear and helplessness.

3.3.1 Evidence of trauma
The relevance of this to all early year’s services for parents of children with disabilities is in terms of the level of support parents might need. Research indicates that people will have different perceptions of what is traumatic, and different reactions to it. It was evident to me that for many of mothers the trauma of early experiences was still very much with them, even many years later. This is not surprising when considering some of their stories. One mother was pregnant with twins and during her pregnancy had to make decisions about whether to terminate or potentially cope with two severely disabled children. Having chosen to continue with her pregnancy she then had to face the death of one of her babies when he was a day old. The remaining twin was also ill and at risk of dying for some time. Another mother of twins had to cope with one of her children having a massive bleed in her brain on the day after she was born and not being expected to live. Her parents were warned that she may have significant disabilities and they were asked whether they could cope with that and given the option of turning off the life-support machine. Remarkably the other twin of this family later contracted cancer and had to have a liver transplant. Many mothers relived a particular incident in their child’s life which was evidently traumatic.

I was sat there feeding him and then his stats were because obviously normally eight five to ninety and I just remember him going down to seventy, sixty, fifty and forty, thirty and then twenty and I was just screaming at the nurse, you know, look at him... and just everything just slows down... and the nurse was ok, we will put him in the cot and bag him, and obviously he just was not responding and there was nothing and so then I kept seeing the panic on her face and she called the doctor and remember the doctors running down the corridor and she
literally just ripped his baby grow open and just ran off to intensive care with him and (my husband) was at work and I think that was the most traumatic and even the woman who was next to me said I will never forget that (2) 

she was not expected to survive at that point and literally it was hour by hour and then she slowly started pulling through and, you know, but there were significant concerns over what her prognosis would be and obviously they don’t have a crystal ball and nobody does and, you know, at one point they suggested that if we thought that we couldn’t cope with, I don’t know how you decide what you can and can’t cope with, but then the option then would be that it would be viable that we could turn the machines off, you know, if she didn’t start to improve. Fortunately, my partner just said, well she is meant to be here and she will show us and that is what she has done and she has continued to do, so, from what her outlook was she is doing really, really well at the moment (1) 

Some families in the study are having to cope with their child having a limited life-expectancy and degenerative disease. It is never going to be easy for medical staff to give this sort of news to parents, but despite years of research about how to limit the trauma of this one mother described being given the news when alone (their partner was in the same hospital receiving cancer treatment) and another being given cursory information and being told to look up the diagnosis on the internet. A different approach from medical personnel is to try to prepare people for the worst. 

it is as if they always wanted to give you... the worst case (2)

Parents dealing with such profoundly difficult experiences have a range of responses. 

sort of life goes into a bit of a sort of slow motion and you know, you are not really thinking about anything and you can’t settle and your head doesn’t settle and so that was a very, very strange few weeks and actually the boys were born at 26 weeks and so really six weeks of very intense emotional time (1) 

it was such an awful time and I never thought that would ever happen to me, you know, wow, you have these babies in incubators it is awful it is like a bloody nightmare and then you finally get over that nightmare and then another one comes along and we have not had a minute and you are swept along on it whether you want to be or not, and you don’t get a minute, it is one thing after another and it is just hit us and hit us… you wouldn’t wish it on your worst enemy. It is just a feeling helplessness and not knowing what to do for the best (12) 

at one point Mary was really poorly and I had to go to the GP because I had come out and I kept on coming out in rashes on my body and the doctor said it was to do with stress and it has taken about two years for the rash to go away (13) 

Such negativity can stay with a parent for a long time, in the best situations leading to defiance, but possibly also to hopelessness.

I think the words were, you know, she might just be a body and she may not be responsive and she may not and it is quite likely that she will be blind, deaf and non-feeding and they basically described it as just like a shell and she could be a body shell but there would be nothing else. So you have to decide, and you need to decide at what level you can cope because we can’t tell you… we can’t tell you. (11)

Many of the families continue to live with the on-going threat of the loss of their child through illnesses connected to their disabilities, and repeated major operations.
3.3.2 Becoming a different person

Recent research has also investigated the potential for trauma, even when followed by PTSD, to lead to what has been termed ‘post-traumatic growth’. Some of the mothers in this study discussed how their experiences with their child has led to them making significant changes in their lives, and even feeling like a different person. From the interviews it became apparent that parents identified the experience of having a child with disabilities as something that provoked change in themselves.

I think that I just see things differently now and I have become quite a different person because of the kindness that we have been shown and I think that it shows you how, how to, how a small thing can make a huge difference basically (1)

definitely has altered where I am thinking about where we are going and, yeah, I don’t know what kind of parents me and John were before (15)

it is my third child I think that I am just appreciating it and everything and I think with my other two I just like, they grew up too quickly and you was constantly looking at the next thing but with Rose it is just enjoy every moment really and it is like I have been given a second chance to embrace that and because of the Downs syndrome as well it is talking her longer to do things so it is quite nice really! I am going to have her as a baby for a lot longer than I would have done really, so yeah she is really lovely (17)

Interestingly all but one parent saw the changes they had gone through as positive.

I am consumed with things a bit more, you know, you worry about him and you worry about his future and you worry about him going into school... he is not where his brother is at school and... your constantly worrying about, ok, well will he go to college? well what will you do at college? what will you do when he comes out of college? will he be with us for ever? what will happen when we go? All those sort of things go through your mind all the time (16)

I do get stressed when she comes out of school but I don’t know, I am just more, since I have been going out and meeting other parents with the same thing I have just been more laid back (14)

I’m used to struggling with doing everything on my own so with people helping is like something that is new to me and it is nice, I don’t know if somebody else has said this too you but sometimes taking help is a hard thing to do when you are used to being independent and strong, it, something like this makes you stronger in other ways but emotionally you are a lot weaker and you find the strength that you don’t know that you have got when you end up in these situations (5)

so my life has changed massively anyway just because of having a baby you know what I mean and I gave up my independence and my children were growing up, you know, so my life changed anyway, massively, but for the better massively for the better and a massive positive (17)

Some of the changes relate to parent’s view of the world and what they want from life.

I think that it changes your perception doesn’t it? (10)

so I wouldn’t have done that before I don’t think, but it is hard to describe really but I need to do a job that means something to me, because you know where I
am using the skills that I have acquired through, you know, Mary’s difficulties (13)

I would say that I appreciate things more, yeah. I appreciate the smaller things now and yeah, I think that I try and worry less about the insignificant things because you start to realise what is important and what is that you need to worry about and the rest of isn’t, no (3)

I just love the fact that now I am in a position where I feel as if I can help them people and that is what I love and, do you know what I mean, that is how far it has brought me, you know as a person (12)

that is another thing that I have found that I enjoy people’s company a lot more, I feel like, since I have had a child with special needs and I enjoy people in general more and I don’t try and judge people and I can’t stand people judging people when they don’t even know them (4)

Some parents in the study had had to give up work, or move to part-time hours, in order to be able to care for their child. Although some participants were happy to keep the work they had done before having their child others were planning new careers including a musician with plans to incorporate Makaton signing into her songs and offer sessions for children, a mother who has a place on a teaching assistant course and another who is working at School for Parents. As can be seen in section 3.5.6 parents grew in confidence and felt increasingly empowered. One mother described how she and some other parents had banded together to fight medical services for more input for their children. She reflected on regrets that she had in respect to her older children who did not get the support she now saw as important. Another recounted her motivation to lobby for changes in provision, contacting her MP and involving the media. Overall, where parents expressed going through changes, these were predominantly significant and positive.

3.4 Parents’ experiences of statutory services

All of the parents in this study were in regular contact with health services, some with social and education providers too. They looked to statutory providers to tell them about School for Parents, particularly when the statutory provision offered to parents was usually less than what parents wanted and hoped for. To see the value of School for Parents’ provision it is important to look at the wider context of what services children with disabilities usually receive and consider why they generally fail to recommend School for Parents.

3.4.1 Parents’ encounters with medical services

Some of the mothers were keen to emphasise the good support that they received overall from the large number and wide range of medical professionals they encountered.

he does have dilation of the kidneys and he does have a large hole in the heart and he has Downs Syndrome and the paediatrician, they were very nice about it (15)

It is perhaps inevitable, given the complexity and seriousness of the medical conditions of many of the children involved in this study, that contact with medical professionals would not always be positive. Certainly, as seen in the sections above concerning diagnosis and trauma, parents were confronted with a variety of distressing information about their children, sometimes provided in less than ideal ways. Obviously many professionals have serious time constraints which may impact on their ability to provide a quality service. This would explain, to some extent at least, why when asked about their experiences many parents remember, dwell on and recount their upsetting and
frustrating experiences. However, this is not to say that these experiences are not real and potentially could have been avoided or improved. They are important to review here to further our understanding of typical provision and how it compares to the service provided by School for Parents, in order to find ways of offering complementary options for parents.

As seen above several parents had concerns about their child’s development for a while before any issues were identified by medical professionals. It was evidently very difficult for them when their concerns were not addressed. Once a diagnosis has been decided on by professionals the breaking of this news to parents is evidently a very challenging and skilled process. Despite doctors being trained in the least damaging ways to break bad news it appeared that for some of the mothers in this study problems still arose.

they knew that she had got the brain damage because they took us into the room to show us the scans but what they didn’t do was, and my partner had obviously gone up to the hospital for his appointment so they actually took me into a room on my own and didn’t wait for family or anything to come and they just put all these brain scans on this table and were telling me to the point that I just walked out because I had no one with me and there were no support worker or anything and they were just telling me that my daughter has got brain damage... but they did after that they did arrange a meeting and we did go and we did have a support workers and everything with us, but they just did it wrong the first time (14)

yeah you couldn’t make this one up, it was, it was horrific. My little girl as bright as a button sitting there, you know, chatting away because she is very able to do all of that and, this particular person must have known what she was going to tell us and basically had, she was rifling through her notes and she was hanging on the phone... because she wanted to check a test result which was actually fine anyway and all of this was going on and I am looking at her with my daughter and husband and the doctor and thinking hang on what is going on here and then literally red book came out and read to me what it was and what she had got and she then said to go and google it and that was the end of the consultation and we were left in the corridor at the QMC just our world had blown to pieces (6)

Following the diagnosis one of the first aspects that parents seek from professionals is information about their child including their medical condition, how that is likely to impact on development and life opportunities, and what parents and children can expect in the future. Professionals obviously have to be careful in what they say, the expectations they create or challenge and the level of hope they offer to parents. Sometimes it appears that this leads to confusion on the part of parents.

there was a consultant that spoke to us I should imagine and he said, you know he might just struggle with certain things with like dance or you know he might struggle with dancing or struggle with maths, or to grasp maths and everything and so they didn’t kind of know of know what to expect and cerebral palsy was never mentioned at that point (12)

his neonatologist when she discharged him fairly recently actually said for a long time, that he has out grown every expectation that she had, and he is walking, talking and thinking (9)

Parents looked to, and expected, support from the services they were in contact with but frequently found that there was little of this or that what was available did not support them emotionally. At a time of extreme need on the part of parents what they receive in terms of services, advice and support can feel very limited or lacking.
we had a very poor experience with the health visiting service and we only saw a health visitor once in the sort of first nine months when she was born, which if I could have been bothered to complain about I would, because you know Philippa was potentially quite a vulnerable child and I think that they just, the health visitor who was supposed to be coming in had gone off sick and they hadn’t actually replaced them and I would have found it helpful to have had a health visitor (8).

felt actually really quite isolated, and I felt as though I was battling the professionals which should have been helping him (9).

Parents lack emotional support I think. Personally, you know, you, for me I find sometimes that the doctors are very clinical and there is no, there is no people skills, you know and sometimes a little bit of people skills wouldn’t go amiss (5).

Parents report being upset by what they saw as overly negative responses and information.

we had somebody from City came to talk to us about George and what it meant to have a child with Downs Syndrome and I found that first contact, the paediatrician was very nice but it was a little bit, a little bit negative (15).

when like she got her diagnosis and it was, she might not do that, she might not do this (10).

think I was talking about everything that I wanted to do and I remember she said "you could do all of this, you could do everything for him but he probably still won’t walk by the time he is 14 (2).

they don’t really tell you what you need to know and they kind of drip feed things in... don’t patronise us and tell us what we need to know and tell us what you think and actually we are also thinking things too because no one knows our daughter like we do (6).

It seems that even when parents understand the reasons for medical staff caution or the provision of potential negative outcomes for their child, they do not want to have to receive this information or find it helpful. In parents’ accounts this negativity is frequently juxtaposed with the positivity and focus on what can be done that they identify as part of School for Parents.

3.4.2 Mothers’ experiences with physiotherapy

Although the parents in this study had children with a wide variety of needs one thing most of them had in common was the need for physiotherapy to address their motor control.

I had another physio Karen who was brilliant and I was really upset when they get to five or six and then you have to move on to community, and she always used to put us on the Friday afternoon and she would stay for two hours because she said because not every family puts in the hard work that you do (2).

Many parents were full of praise for the service that they received and it was particularly appreciated when links were made between the physios and School for Parents.

they don’t have an issue with it and they are very supportive and Kirsten has been working really well alongside our physio and supporting what they do (5).

with the physiotherapist the exercises they wanted Mary to do we were actually doing at School for Parents. So I used to feedback to them, that that was actually
what we were doing and you know, and they would say “brilliant that is really
good!” And it was really positive to be fair (13)

Some parents identified a rather more mixed reaction.

but she very much worked with Rutland House... saying you know when you are
at Rutland House ask them to do this and we kind of interlinked more whereas
the physio before and I always remember when I first came here and I told her I
was coming here “well then you are going to have to choose between!” (2)

I think that when I told them that we had joined School for Parents, they did say
“oh lovely we have heard of that”. But they have never mentioned School for
Parents to me. They have never said, you know, here is a leaflet and here is
someone who can support you between physio’s, they have never brought it up
(14)

I know that when we first started it was a very no, no subject with my physio and
then finally she come round to it but, you know, for whatever reason, I think that
they are better working with us now that they have ever been (12)

As with most statutory provision many parents experienced a fractured service.

he was an intelligent little boy who in his own way of muscle control was alert and
wanting to watch and wanting to interact and yet he couldn’t quite get there and
get his body to do what was next. Sitting, I didn’t know how to help him to
strengthen the bits that he needed to be able to sit and being seen once every six
to eight weeks or more by physio was not helping... but he needed more and I am
glad that we found here (9)

at that point we were having physio once a month for an hour and we have seen
an occupational therapist I think between once a month to every six to eight
weeks for an hour. Speech and language was even less than that, and we had a
good speech therapist but she has been off sick so I would say that we were
seeing her once every couple of months for an hour and so that was partly why
we wanted, and when we found out about here... how regular it was and the
package it just, it filled a hole really because when you seeing a particular physio
once for an hour every month it wasn’t enough to really teach you what to do and
a lot of the appointment as well was assessing what Emily was able to do and so I
think certainly coming here as well and what I was hoping was that we would get
more regular input because I think that you need to be doing it more often to
learn the skills that you need (3)

I mean as soon as they start listening to us parents and what not, I think that it
will be a lot easier for us to then, we can work together and we can come up with
a plan and because I mean when I went to see the physio they told me to do the
rolling and to do leg exercises with him which we did all of that, but it didn’t help
and that was the thing and there was no way I could go back to them either
because the physio I was given left and there was nobody to replace her, same as
speech and language, they have been, I don’t think I have seen the same speech
and language twice, when I have an appointment that is (7)

Parents were asked about their perceptions of statutory providers’ attitudes to School for
Parents.

The physio? She doesn’t sort of suck her teeth but she is uncomfortable and I
know she is uncomfortable and I respect her immensely... some of them have
said my hands are tied and it is a Trust issue (1)

the attitudes that I have had from other people the professionals, I think they
just think, it is all this repetitive, and I don’t know it is almost a quite old
fashioned view of it and I think that they have got it so wrong (6)
his physio declined to visit in the end! So I never did get her here, she wouldn’t come, she just wouldn’t come in the end (9)

Part of the reason for seeing the physiotherapy service as providing less than ideal support at times appears to be due to their working schedule.

I suppose I had nothing and I had no help there at all and the physio that we had at the time, as well, I mean it was literally she came in and they said “right you have to do this and this with them” and she would be there for 55 minutes, and she would always be looking at her watch and then say “right I have got to go!” (2)

sometimes the physio is there an hour and that is it, and you don’t see them again say for another month whereas here you see the same people every week and it is continuous care and it is really good (5)

even if it took half an hour for Sam to take his shoes off, you know he had to try and take his shoes off himself. Whereas when you are with a physio he has got just an hour and you know, everything is very rushed and we are going to do this, this, this and this so, it is very different in that respect and nothing is ever rushed here at all (2)

Despite the differences of approach between CE and physiotherapy there were often similarities in the kinds of exercises that both services would provide for the children.

nothing that is done here don’t absolutely complement and expand on the work that is being done by the little snippets that you can get through the NHS (6)

However, a number of differences in the nature of provision were highlighted by parents.

he absolutely loves music and singing and I think that, that is one of the things that helps bringing him along as well, with his development. Whereas there is not so much of that with the physio it is all very structured and all very serious (4)

the physio touch on it a little bit but School for Parents touch on things a lot more but then I feel like, that it is a lot more caring here whereas medically it is a job (5)

Some mothers appeared to express a lack of relationship with and trust in the statutory services.

like with the physio, you have got to do these actions and they are going to help with this and that but she doesn’t know that. Does she? (10)

I mean in terms of actual hands on physio mostly it is done by us at home... and actually going to see her main physiotherapist who is, I think that she is doing her best, but I do think a lot of it is down to managing equipment and maintaining rather than actually still working with it and I often feel that she doesn’t get her hands on her literally and to work on her and check her out, I have to sort of say “can you look at her feet, can you?” You know otherwise it can be taken up with, you know, playing lots of shopping games with the OT and a lot of things that we can do at home and I find it quite frustrating actually it, it can be so, so repetitive and I don’t, I feel that it is just more to tick their box’s than it is to actually look really at what Vicky’s potential is (6)

and I says “you know we are getting one session now every six weeks”. And I says ”he don’t like going and I don’t like going!” And I said “I come away all confused there must be something else out there, there must be somebody who can help us!” (12)
The lack of time available to statutory services and some changes of personnel probably contribute to the negativity expressed by some mothers. They describe a lack of understanding of the purposes and importance of exercise programmes.

*there was some physio in the neonatal unit as well but I don’t feel that that was particularly well explained to me and it wasn’t, it wasn’t consistent and it wasn’t regular (11)*

*we got given some sticks by the physio’s, and what are they called, quadrapods, everything has to have a stupid name and you know, nothing is simple, and she gave us the sticks and she said “right you need to get him doing that sort of action with him”. And that was as much as she told me, and I was like, what kind of action, I have never walked with sticks, you know, and it might be self-explanatory to her and I thought, how am I going to get him walking with these sticks, I don’t even know where to start (12)*

Mothers value the physiotherapy service and the expertise of the staff, but feel that the scale of service offered is inadequate for their children, many of whom have significant disabilities. The main difference highlighted between the statutory provision and School for Parents appears to be in terms of time, physiotherapists working for the NHS cannot afford to see these children frequently, for longer than an hour, or provide education for the parents to support children between monthly or six weekly appointments.

3.4.3 Mothers’ experiences with speech and language therapy

The majority of children in the study were developing speech and language well. However, others had difficulties eating and/or had very delayed or no communication and some were using alternative means of communicating such as sign language (Makaton) or eye-gaze technology. For these participants the provision of an effective service was of key importance.

*speech and language we battled for a long time to get them involved because he had a huge amount of swallow issues but they couldn’t decide on which criteria and which team he should go to, and so actually he spent a long time without that and then he was seen by them and they were extremely upset that he had been left so long without them! (9)*

*speech and language we have had briefly but then again that has been six months in between and they gave us targets and we worked for that and then carried on… as far as Martin goes he hasn’t seen one for about a year now (7)*

Parents experienced a difficulty in accessing the service and in one instance even resorted to obtaining private therapy. It seems that some of the children fall between different aspects of the service or are not seen as a priority.

*we needed him to develop his language and we needed to know that we were doing the right thing to support him with that and actually his feeding is poor but it is not dangerous therefore yes, there wasn’t anybody (1)*

*speech and language we went but because his language was still developing they said come back when his speech has developed more and so we can start working on the clarity and we have only just started going back (16)*

Makaton signing workshops were described as very helpful but parents wanted further support.

*the last speech therapist session I found pretty useless. It was just somebody asking how George is doing but not really coming up with any ways forward and mainly symbolic suggestions but, and I said, it is probably best if you go through some exercises now that I can take home with me but nothing was set up. So I*
did ask then if there would be any more workshops available because that was
definitely the most helpful thing for me and my family and George (15)

3.4.4 Mothers’ experiences of education provision

Thirteen of the mothers in the study were at the stage of their children starting school,
or had found nursery provision in addition to School for Parents. When children were
accepted at nursery or school this was often a great relief for parents.

she said “we will look after him”. And it was kind of a relief and she said "right!
You need to come to the play group!“ She says "I run it... I want to see you there
on Monday and no if and buts about it, if you don't come I will be fetching you!“
And it was the best thing I ever did and the people at the play group were lovely.
But again you feel the odd one out because their kids are running around and
David is just, you know, he was just crawling around (12)

For others a placement not going well was an upsetting experience.

I don’t know if we rushed the settling in but he just, he just freaked out and he
wasn’t happy and because I don’t think that I was totally happy with the setting
so I decided that it was too soon and I stopped sending him there and it was just
a bit busy and he needed a place that was calmer (15)

Finding the right education placement and securing services was evidently difficult.

when I walked into the first meeting it took my breath away because this was at
school the staff room was literally full of people and like a sea of people that, and
that wasn’t even everybody and the people from Great Ormond Street weren’t
there, but I just thought if you are telling me that this child doesn’t need an EHC
you must be joking because, you know, she sees so many people (6)

and that is what I can’t understand, if they have never had a child with Downs,
look into it, and look at what you can get and look at what he needs and I have
had to tell them absolutely everything. What can you do? They have got to learn
effectively and if he is the first one and then hopefully if they gets some more
then they will learn from it, and so that is the only, and I have to make light of it
because if I think about it I think, well it has been definitely interesting! (7)

The attitudes of education providers towards School for Parents were expressed as
predominantly positive.

thrilled to think that he has been having that level of input prior to starting school
(1)

his nursery have put up a poster and we have recruited another family (9)

Some mothers had been able to invite education staff to visit School for Parents and
forge a collaboration.

his visual impairment teacher has been to a session here and the TA has been to
a session here and in fact I am pretty sure that they came before Colin even
started school (1)

the early years’ specialist ... has been a few times with me and... a few times with
various children and parents and she thinks it is a brilliant place (4)

I would say that it has been a positive reaction and its really good that some of
the agencies have actually come to see her here because, especially for the
speech and language when they came the other week they sat mostly out of the
group but to get to see how Emily is using the Toby (eye-gaze activated
communication device) within the session so it was kind of, so it wasn’t just
about, right this is your Toby time and it was more like they were doing the
activity and the Toby was just at the side of it and it was seeing Emily access it, to say things about what we were doing and then carry on and it just showed them she can use it and she wasn’t on the spot so that was brilliant (3)

School for Parents reports for schools have also been found to be very helpful, even beyond the actual content.

Philippa has a really good transition document that Karen has written for her. Written in really simple and clear language about how and what Philippa’s needs are and what her strengths are and how she learns and with pictures and things and that is great, although we have also written something ourselves that document that Karen has produced is really excellent and really helpful for anybody who is going to be looking after (8)

you give them that report and they have to really take notice because they kind of think gosh you know, somebody has actually done this, and we owe it to this child to keep it up (1)

There were some less positive stories about the failure of schools to find time to visit School for Parents and support transition.

I did say to the SenCo about here and they have had a new SenCo and she said "oh I didn’t realise that these things were available!“ And I said “they are amazing, they are amazing!“ But they are so busy (10)

Another less positive finding was that sometimes statutory providers see School for Parents as providing something that could take the place of the provision they offer, for example suggesting that a child should only have a partial school placement because of attending speech and language sessions once a week at School for Parents.

she made me jump through hoops just to confirm that we haven’t got to have that and it is at the school’s discretion to let me have that morning off, and then become back in the afternoon (7)

we had portage and it has been, and we have a nice lady that comes but I think that because we are quite proactive with George and we take him to lots of music groups and are learning the Makaton with him and because we have input here, our portage worker wasn’t quite sure what she could add to it so, she and her manager wanted to sign him off. Which I am at the moment arguing because I don’t want him to be signed off because he is still needs help in lots of areas especially when he starts school and, you know, just putting things in place so that and that has been a support and information and we can call her if there are any queries with things like getting funding for nursery or queries about schools and about his assessments and they are there on hand but you have to phone up and nobody is just there for you week in and week out, and you have to but, you know, they are good when you contact them (15)

3.5 The impact of School for Parents

Having established the origins of the stress that mothers experience in relation to having a child with health conditions and disabilities, and the provision that they typically receive, the investigation turned to what brings parents to School for Parents and what they encounter when they attend. Parents are looking for help for their child but equally support for themselves in knowing how to maximise their child’s potential and for social support. The data reported in this section includes mothers’ perceptions of how they learn to support their child and how School for Parents impacts on them socially. Similarly, they consider how the children learn and ways in which they benefit from attending. There was considerable uniformity in perceptions of the welcome provided to them and their children and what they gain by coming to School for Parents.
3.5.1 Why parents attend School for Parents

Although there was some lack of clarity about what they could expect from School for Parents what motivates most parents to attend initially is the hope that their child will improve their physical and communication skills. Parents had a range of awareness of what the School was for and what they and their children would be doing. Some parents had found out about School for Parents before attending.

well it was called School for Parents, so and on the website it was to help parents to take things into the home and to help in everyday life and so I suppose that is what I thought I was going into and it was School for Parents and just to meet other families to share that with. So we were really looking forward to it and it was nice because we did have something to focus on and we knew that when he was six or seven months old then we could start tapping into this place (15)

I was really intrigued really in what this was, and they were saying it was, you know, they honed in on what they needed in development wise and just, so obviously I looked on the internet and looked at the web site and thought oh yeah this is, you know, and came and had a look around and said that we would like to come and we have been coming ever since really. Yeah, it is a fantastic service (17)

Mothers described what they were able to learn from initial visits and assessments.

when we were first shown around Karen told us what kind of things that they were doing and why they were doing it and just a gentle learning with songs and motor, you know, to try to improve motor skills so, no, I am not sure that there was more or should have done any more than they did early days, it was all quite clear (15)

from having spent the good hour and a half during the assessment they were telling me things that I am going “yeah, that does make sense!” And they were picking things up particularly about his hands and he had a certain posture with his hands that the physio were saying were just normal and it was fine, that actually they were linking to his previous brain bleed that he had. What they were seeing and being able to explain to me is what I was worrying about and then couldn’t put that into words. It was reassuring and I knew right from then that this would make a big difference (9)

Some mothers came looking for any kind of help whereas others had a specific area of development that they were concerned about.

I was coming here very much looking at the communication help that he might get more so than the physical and I think as time has gone on the help that he has had from the physical point of view has been the greatest as it goes (1)

I obviously knew that she obviously needed additional support in other areas in A. her mobility and B. with speech and with everything really. I mean Rose, she has been quite slow in developing and physically she only started sitting unsupported at 15 months so that was quite... and having that support here and just being able to give you things that you can practice at home and things like that and, you know, we wouldn’t be able to go to a normal play group... but you know it is all about being proactive for me and being able to support Rose the best that I can. So, to develop my knowledge really and so I can support her (17)

I did come here thinking would he ever walk and would he ever walk and will he ever walk and slowly that is gone and that needed to go, because it is not all about will he ever walk? Or will he ever do this? Or do that? It is about him being given the chance to just be a child and be happy, and that is the main thing. At the beginning they asked me what my main thing was and I wanted him to walk, I want him to walk unaided and I don’t want him to walk with aids (12)
we just wanted him to start hitting his milestones and start walking and, you know, whether it be aided with, you know, sticks or whatever else was on offer then we were prepared to make that commitment of coming here ever week (16)

I had no idea what I was looking for, I don’t know! Mainly support for Sarah because I thought that physio every six weeks was probably not going to be enough (14)

Parents were also clear that they were looking for a social environment for themselves and their child.

I was looking for just ways to bring his development along basically and to help him interact with other children with the same disabilities as him...but you know, just in general interaction with other children and me as well I suppose (4)

she could have half an hour in the hydrotherapy pool which is lovely and we both go and it was just really nice and we weren’t really doing that many fun things with her because we were spending a lot of time either feeding her or you know, going to the hospital, yeah, so it was enjoyable really (8)

Many parents identified School for Parents as being fundamental in bringing about positive changes and part of the motivation to take part in the study.

I would shout from the roof tops about School for Parents and there is nothing that I wouldn’t do for them because I feel that they have given us so much... and I can honestly say on behalf of all the parents that come to the gym club, you know, we would give back tenfold because it has changed all of our lives (10)

so from a mum who... who didn’t think she was up to it, you know what I mean, I have just changed so much... I am not the person that I was when I first started at School for Parents... I am a new person. I am never going to go back how I was before I had David because I do believe that I am a better person (12)

I suppose it is just talking to the other parents and because in your groups you have other adults with you and the children and I think just talking to the parents and then, I don’t know, I just started doing things on my own, and I had never really done it before and even my mum says, School for Parents, she says “they haven’t just helped Sarah” she says “they have helped you!” (14)

3.5.2 Ethos

School for Parents is described by the participants as a positive, welcoming place where they and their children feel safe, secure and celebrated. They feel that they are in the hands of experts who understand their children and guide child and parent carefully.

you couldn’t ask for such better people to work with your children and they are so kind and so encouraging and the encouragement that you get from the people that work here you know and the helpfulness (5)

I am so humbled to see a little boy that has out grown all expectations, medical expectations of him, and has been helped along his way by a team of people that believed in him from the word go, yeah, they made a big difference to Kevin (9)

the whole ethos of School for Parents is that we will draw out the maximum independence we can possibly get and the right attitude and we will go with that (6)

Mothers describe feeling a strong sense of belonging, the word ‘family’ to describe the community of School for Parents was used by 7 mothers.
everyone is so friendly, it is like a family, that I wouldn’t give it up for anything. (10)

I know that we have only been here a short time but we are going to miss it because it is like, everything that we seem to do is like being in a family and everyone cares and, you know, she is not treated as different she is treated as normal and I know that sounds bizarre but you don’t feel odd when you are here. If that makes sense? (5)

The sense of belonging to a group who understand your circumstances is a strong recurring theme and evidently of prime importance to the mothers in the study.

we would be missing out on a whole community if we didn’t have this place here really (15)

I sort of found what would you say, it has kind of been kind of a bit of a God! A bit of a church! You know? I have something that I am passionate about and spreading the word about, it has helped me so much and it has helped James so much through a difficult time of uncertainties (16)

the opportunity to make new friends with the other parents, and parents that actually understand what you are going through and aren’t judgemental when you missed a week or, you know, because we have all missed weeks and it is when you have been away and it is nice to have been missed and the vice versa for the same for them, you know, everyone cares (5)

Another aspect of the School for Parents ethos that is evidently highly valued is the way in which children are accepted and understood.

they will say “we know that you are tired just try a couple more like this!” And you are not having to explain and say, she is really tired because they can see it and they know that (10)

whereas here was safe and you are accepted and you don’t have to explain why your child is still in a nappy and, you know, why they are still struggling to eat solid food and… everybody has got their own challenges so it is very accepting place to be (8)

Children are described as being keen and happy to attend.

School for Parents is brilliant. I mean she is that comfortable with them but she loves it and even when we do a full week at school and we would get up on Saturday morning and I would think “oh gosh another day that I have got to get up!” And she wants to come, come what may and it is because… since we have joined it is the same children and… it is like a family and it is lovely to see everybody every week and we are all in the same boat aren’t we? (10)

we love coming here and Freddie absolutely loves it, oh he loves it. Yeah. Well I do I love to bring him here, so I hate it when we have got an appointment and we can’t make (4)

I think that it is also quite nice to see her progress and to be around the other parents and it is nice activity for us to do together as a family (8)
sometimes I think that it gives me something to look forward to and it is something to do, and I know that it is something that we enjoy doing and something to do together (5)

The ethos is described as one of positivity and a straight-forward focus on working on the child's progress.

what I loved about it when I first come... I was hanging on the every word they were saying and just, you know, and wanting to know will he ever walk ... but they never said anything and they never give you false hope and they never say "well he will do this and he will do that“ I love the way that they do it because we just get on with it and we never say never, you know, and we never talk about the cans and the can’ts and we just get on with it and we just see and it is, it is, it is just fantastic (12)

and being around these positive people, I am not the only one thinking, I think that my daughter is brilliant and she can do all these things, and no, they are pushing their children the same and they have got the same, the same thoughts (10)

Positivity is manifested by the whole staff approach of focusing on what can be done.

this isn’t a place of labels, we don’t talk about diagnosis (1)

disability compared to ability. Every child I have ever seen Erika or Kirsten work with has an ability, and you can transfer that thought straight across to many other therapy settings where there is a disability that needs making right, and there is a huge difference, because every child has many, many abilities and not disabilities. And it is supporting the child to then learn through their abilities and develop them the best they can rather than trying to fix every disability that is very much how it came across to me (9)

Parents find that not only staff are positive but other parents too, which is developed and supported through the warmth of welcome and focus on celebrating all achievements.

I think it is because we are all so comfortable and happy in the environment that is probably what brings out the support and the positivity (10)

when you see any child struggling with one thing and then they suddenly crack it, it is like, it is just brilliant, and... even if it’s a child who is at a more advanced stage than your child or you know something that your child has mastered and, you know and you can feel in your heart how important it is for that mum and that child because you work so hard to get the simple things and you really you could just burst because when they do it, it could be just your own child because it is just so overwhelming and like a group effort and everyone is just so proud of them and you can just feel that (11)

Mothers highlight their awareness of, and trust in, the staff expertise and commitment.

he trusts Erika and I trust Erika (1)

Right from the word go I trusted them (9)

they have got the knowledge, they are so confident in the way that they do the conductive education and they explain it to you and they explain it to the child (10)
The fact that School for Parents is such a social place where children and adults work together as a group seems to be a key aspect of the security and comfort mothers describe finding there.

3.5.3 Benefits for the child

Parents were generally keen to discuss how they felt their children had benefited from School for Parents. They describe progress on many aspects of physical and communication development as well as stamina, self-help and social skills. One mother described how her daughter with Rett’s syndrome has been able to develop her communication through a collaboration between School for Parents and the speech and language therapists. The child is able to access eye-gaze technology to communicate her needs and personality and practice the skill of using it throughout the day at School for Parents.

I feel like this place has brought him on more than anything else that we have done including physio, occupational therapy, you know, early intervention groups that we have done at CDC, just anything that we have done through the NHS I feel like School for Parents has brought him on much more than they have... even the signing and everything and we have been to signing groups and he picked it up much better here than anywhere I have been to (4)

she couldn’t walk and like her communication was... well she couldn’t talk and like from how she was when she started to how she was when she left she is walking and talking but the journey she has had to sort of take that took about two years to achieve (13)

we could have progressed a lot more in the weekly interaction that she has here rather than the monthly or six weekly or two monthly that we get from her own physio and I do feel that she probably progressed further if we had come earlier and I do think that in her confidence, her ability and emotions and everything I think, Polly would have been a lot further on if we had took the support earlier (5)

the main aspect I think that has helped him is the social, the social aspects and that has increased up until the mobility and the walking and in sessions we get absolutely everything, it is physio, it is language, eating, drinking, and even brushing their teeth and what not, we get absolutely everything and that is what they need, they need their life skills and I can do them like at home, but it doesn’t make a difference because when he is here he thinks, well I have got to behave myself now (7)

they are always the next step ahead of Philippa and so they do things that like wouldn’t have occurred to me to teach her at that age... so lots of practical things to do with eating... certainly the whole way that we communicate with her really offering choices and encouraging her to speak, and modelling the correct way of saying words and, also the expectation that she would come... and she will sit on the carpet and we will sing about her and her name and she will join in and she will sign and now she will match things and take it to board and sit at the table and I think that it has been really helpful in terms of preparing her for school. Whereas I feel that her nursery although they were excellent is nowhere near as structured as it is here (8)

he has done so well and he came in unable to sit, had no idea about weight bearing or balance, and within a year they had him up on his feet... he is a walking miracle, I was very, I was supported through the School for Parents as much to know how to help him but also to have faith in your own knowledge of what that child needs... development of his walking ability very much came from School for Parents and who supported some equipment that the physio’s said
would not actually help, yeah, they were a life line for him and now he is up, walking, running and talking I don’t think that he would be without them (9)

Somewhat surprisingly the focus of many comments was the improved confidence of their child – surprisingly in that it could be expected that physical benefits would be more highlighted given the focus of much of the time and work done with the children. However, confidence building is also one of the main aims of School for Parents, possibly since this is an achievable goal for every child, regardless of how they are limited by their physical abilities, and because it is fundamental for how the child faces all challenges. For a child to feel confident within the limitations of their disability is a great achievement and so important for future outcomes. Children with disabilities need the resilience to keep trying to learn, to feel a sense of optimism about the benefits of effort and practice and to avoid falling into helplessness.

I think that she has gained confidence from coming here... they have given her more self-awareness and it is helping boost her confidence ready for when she goes to school (5)

confidence and you know strength and the willingness to learn to do things... it has just given him the confidence to try and tackle stuff the best he can for himself and if he wants help he will ask for help (16)

confidence, you know, I mean when I look back to how she was when she started she was just a timid little thing and no confidence (13)

he does not shy away he will not think I am not going to get this right so I am not going to do it (1)

I don’t think that he would be as independent as what he is now and as confident (12)

I don’t know where we would be if we did not have School for Parents and I can’t imagine what we would have done and would she be where she is now? I don’t think so, because they really have given her a lot of confidence (11)

I think that School for Parents has massively helped with that in terms of confidence and you know, in like I say the way that she sees herself and she has got a very good self-image I would say and self-esteem (6)

Parents spoke about children carrying the confidence they had gained at School for Parents into school

because he knows that he can do that and because that is what he had done all the way through here, he is taking that to school and that is an enormous thing... it is a tiny thing... but it is enormous and one of the biggest things that I think and at school they just marvel at his “can do” (1)

Increased confidence that goes beyond School for Parents can lead to lasting resilience.

so as long as she is told the, you know, don’t give up because you can do it, she will keep going (14)

when you get to school and everybody can do it for a count of ten, and you can only do it to a count of 3, it doesn’t matter... and that attitude will sort him out and he will go far with that attitude and that attitude in a huge part has come from here because this is all about trying it 20,000 times (1)

I would say that there is nothing that David can’t do and nothing that he won’t have a go at. Sometimes we have to change things, you know adapt it to what he, you know, to David but we always say that there is nothing that you can’t do and you know, we have had him wall climbing at the climbing centre in
Nottingham and... he goes swimming and his swimming instructor has got him diving at the minute, you know, it is just fantastic (12)

Since most of the work undertaken in School for Parents is in groups parents and children meet others with similar abilities and needs. The familiarity with other children who struggle is also seen as helping children to not feel alone or different, assisting with their development of positive self-esteem.

because here is safe and here other children don’t always achieve (1)

she enjoys all of it to be fair and the social interaction with others and seeing that she is not alone and, you know, she is not the only person in a wheel chair and she is not the only person who can’t stand or walk or, you know that, that interaction with others and she is very friendly and bubbly and they all inspire each other in different ways (5)

she knew all the children and seeing and I think just seeing how the other children were doing and they were all similar but doing different things and one might be more advanced in this or the other and like just chattering and things and you see things perhaps what other children are doing and how the parents are doing it and you think, oh maybe that would work for Shannon or Shannon’s way of doing something might work for another child (11)

I remember when we moved from the one-to-one to the group, thinking “Oh no she is not going to benefit as much!”... actually I was so wrong to think that you know, that it wasn’t going to work because actually, you know, they just learn from each other don’t they and in such spadefulls it is just wonderful (6)

Just as mothers report the friendships they have made as being fundamentally important to them so too they appreciate their children finding friends and parents identified this as both a benefit to themselves and to their children.

well he has made friends and he regularly sees children who wear splints like him so he doesn’t have, you know, a self-consciousness about certain things that he might otherwise have (1)

she is with children who are like her and she has built loads of relationships up and they encourage each other and when they are doing their activities and they have got empathy for each other in the respect of there if there is a little boy there who will sometimes cry and she will say “come on, you know, you can do it!” (10)

3.5.4 How children learn at School for Parents

Parents were able to identify how their children were supported to learn and develop at School for Parents. This obviously varied according to the age and stage of the child but common themes were identified such as repetition and routine, the building of relationships with staff and other children, and by building skills through small steps.

it was everything really and it was I think being consistent so being in the same small group every week, you know, for Mary seeing the same faces and feeling comfortable with the staff and, you know, the other children and doing very small group activities and the one to one. It’s how to make the child feel comfortable, you know, and they seem to know how to bring the best out of each child. And it is, you know, what they do and they sort of look at where your child is up to and then they set targets together, you know, between myself and the member of staff. So you know, they are working with me to get, to you know to get the outcomes and then they would set little targets for Mary and find different ways to achieve things (13)
Some children inevitably show resistance at first, particularly if they have already experienced difficulties in achieving skills.

he never used to tolerate other children and when we first started sessions here, he did nothing but scream the whole way through the two hours (7)

we did have a lot of hard sessions with her because she would just put her head on the floor and just not want to do anything but I think that we went to one session and Erika stood at the other side, well about five or six steps away from Sarah, and she was really trying her hardest to try and get her to walk and the first time that she actually did it, it was five steps to Erika, but I just think that having an extra adult for encouragement with the children it just makes the world of difference. I don’t think that Sarah would be as advanced as she is now if she had not gone to School for Parents (14)

I remember going in each week thinking is she going to join in this week? Is she going to join in any of the songs or the activities but I think that for children because it is such a small group setting and that the staff are so skilled she, oh, it has just helped her no end and to get the one to one help with the activities and like in the morning there would be the group work and then the afternoon would be, you know you would get one to one help with letters or numbers and things like that and she really needed that and she wouldn’t have got it in any other setting and so, and I mean, I can’t praise them enough really (13)

Another emphasis from the interviews was play and the children having fun so that they do not see that they are doing exercises or attempting anything difficult.

so you go from him standing up and to then he is walking along and she is encouraging him “oh bring the cars to the garage!” How is she getting him to do that, that is magic, I couldn’t get him to stand up let alone, he is walking, you know this was amazing and it was such a big thing (12)

it is based around care to a degree but it’s, in a way it is like through play and we are playing together rather than, and I do try and incorporate a lot of Polly’s physio into play now and into nappy changing times and things like that rather than actually doing the full on, it is something to look forward to and its fun and Polly enjoys it and I enjoy it as well and I enjoy bringing her even though like you have to drag all the equipment with you, it doesn’t feel like a hassle and I don’t know, it is just been something fun to do and with really nice people (5)

Parents identified that the repetition of games, songs and activities was helpful at all ages.

George was so little and not doing very much at six months so when we came it was, I didn’t really know what was to be gained in those early days. Because we didn’t really know what George was able to comprehend and, you know, we knew that he was in a different place and different people around him but we were singing songs and doing actions and they, the babies were looking at themselves in mirrors, and I think that all of the parents at first were thinking “what is this doing?!“ But then it soon became, and week by week over the months they, because of the brilliant repetition of the most important things they learn lots of different, lots of different things and actions and words and songs through what we were taught (15)

here it was initially it was we were coming here twice a week so it was like a routine and it was like a little project... and you could see what you were doing that was making a difference slowly... say from just liking and recognising a song to actually selecting it herself was like a little journey that she went on and, you
know, it takes time but something small like that and you can just see the process (11)

it is just perseverance with it to be fair, and it is working slowly, very, very slowly but we are getting somewhere and so I am happy with that (7)

Staff at School for Parents provided and modelled ideas for working on skills and through this were able to build parents’ confidence so that they would provide the same opportunities at home.

they give good help with eating and early on they really persuaded, encouraged us to help, and let our child feed themselves which I might not have started so early or to let George eat so much, you know, by himself because I was worried that he didn’t have teeth and so he might choke but just to give us, you know, the encouragement and give it a go (15)

Many children were described as having developed strong bonds with the staff who regularly worked with them that motivated them to try their hardest.

he has got that rapport with her and that he thinks so much of her, you know, and he wants her to be proud of him I suppose as well I guess, as well as me and his dad and everybody else (2)

Together with the development of confidence identified in section 3.5.3’ these skills support children in feeling positive about themselves and becoming increasingly independent.

3.5.5 Benefits for the mother and family

All of the mothers were clear about the kind of support that they and their families had received, aside from the benefits for their child. The benefits that they describe are broad and far reaching, extending into the change of self-hood discussed in section 3.3.2. Benefits stem from a number of aspects of School for Parents such as the warm and understanding ethos, the family atmosphere, the emphasis on developing parents’ skills and the facilitating of supportive relationships between parents and between children.

I think that is because the mum is so well supported that they have been able to continue. Massively! Absolutely! I think that I would have crumbled (16)

but what an absolute fantastic support really, it is just so nice to be with other mums and dads in the same position really, with the same challenges that you have to go through, you know, because there is a connection there and, you know, it is more so than just going to a mother and toddler group really because they understand the challenges that you are up against (17)

the sense that I get is that the families that come here they all want the same thing and we will do whatever it takes, do you know what I mean, to, to get the best for them, for our children do you know what I mean? (12)

Different kinds of support were identified including the provision of help, information and ideas for dealing with systems which come from staff and other parents. Mothers describe the provision of a holistic approach.

we have portage and we had physio and I think that School for Parents kind of combine everything together and it was just everything in one place, you know, we were singing and we were counting and we were, but at the same time we were exercising and stretching and it was, it was just brilliant because everything was just, it is the whole package just in one process (11)
it gave me and my husband a real direction of how to help George learn because we, we didn’t quite know how to go about it for the best, and just do the normal parent things that because they, they introduce lots of singing really early on and the sign language really early on and because George seemed to respond so well to that I think I hooked into that way and then started to try and learn Makaton myself and take him to lots of music groups (15)

Crucially, parents develop and embed the ability to support children to develop at home through learning how to incorporate Conductive Education principles into everyday life.

they do phonics and things here as well music... so I will very often do that at home now and we very often sing a lot of the songs that we do when we are here, and we do a bit of counting as well which we do here, so I don’t think that if we had not come here we would be doing those particular things and I wouldn’t be doing them at home (4)

I have learnt more about how to care for Polly in a way because I have learnt about skin care myself and posture and sitting... and I have learnt about new ideas on exercises to do with Polly (5)

lots of sort of tips about sort of making the most of Philippa’s abilities and ways that she learns best and I think that as a result of coming for all these years we do a lot of the things ourselves as part of our routine and without thinking about it because it has just become sort of integrated into what we do, so things like offering choices and, you know, encouraging her to expand on her speech and encouraging her to do things to improve her mobility and that is all just become second nature from coming here. And with both of us coming we both obviously know what we are supposed to be doing (8)

absolutely I have found it to be a whole new world really and it is a whole new learning curve you know, yeah and you take it for granted that a child just sits up, and you know, and I learnt, oh she isn’t just going to, she was 15 months before she sat and she had to learn, yeah, I am learning all the time (17)

Mothers described the sort of emotional support they received including being able to express fears and concerns.

I come here and they make the mistake of asking me if I am alright today, and I say “well actually I am not!” and it all comes out, but instantly that I have shared it, you know, and they haven’t got any definite answers for me sometimes and they can’t say, right, well that is the answer to that problem and, you know but just sharing it and just knowing that people are there for you it makes a hell of a lot of difference (12)

whereas when I came here, you had an instructor with you, you worked with them and you are still there doing everything, but you have got a professional with you and, you know, someone who you can talk to and support you and tell you what is going on and what is good and you know, and you can slowly see them improving (2)

they understand what you are going through and when you say, oh this is happening or that has happened, and there is more understanding and if you haven’t been able to make if for whatever reason then you know they will ring you up... and see how you are (5)

Mothers highlight the value of the social networks that they form through coming to School for Parents. Some of these connections are made in regular sessions, others through special events. These social networks are described as particularly valuable as they afford the possibility of meeting other parents who will have clear understanding of their situation.
I thought it was an amazing environment and then once she progressed from the one to one sessions into a class then that was really good because then I got to meet the other parents and it is just that feeling of, you know, those parents know what you are going through because you are all in the same boat sort of thing (11)

being around other positive parents in the same situation we sort of said "well they can do that and we are going to make sure that we can do that and or we are going to put everything into them so to make sure that they can do the best they can". And it is being around people who, that are going through the same thing because my other friends who have other children with no disabilities they don’t have the same things to worry about do they? (10)

I have never really been confident in going up to adults and just making up a conversation where at School for Parents they involve you and you have got to go and make that effort, they automatically just, I don’t know, you just automatically fit in with them all (14)

you just understand each other a bit more I think. Rather than my friends that I have got in the outside world so to speak, they don’t understand Downs Syndrome so much so they don’t always fully know how to interact with Freddie whereas the friends that I have made here have got no inhibitions about trying to chat with him or you know or when they speak to you about him, whereas some people in the outside world aren’t, are a bit apprehensive (4)

One less positive aspect is that the social opportunities cannot always be the priority.

sometimes there would be like half an hour where the mums would just sit and have a coffee and the children would be playing with the support workers and that was magical time, you know, and we would all be trying to sort of swap best swimming lessons or whatever we might be, and it was too little of that time when we could just speak to each other (1)

Many friendships formed through School for Parents were described as bringing lasting support and enjoyment.

now we have now become best friends and we do everything together, and the children are such good friends (2)

I do still struggle with children who are the same age as Philippa whereas this gives us you know access to friends who are at the same sort of developmental stage (8)

I call them my special friends because that truly is how you feel and they are going through it as well and they can empathise with you, and that is what we do and I am so lucky to be able have this group of friends because otherwise I probably wouldn’t be coping the same (10)

Participants were clear that they were comfortable asking for advice about a whole range of matters from both staff and other parents.

the staff here they do seem really open to listen and they have usually got and do give good advice and you talk to the other parents as well because the other parents have definitely been there... yeah there is always somebody that generally knows who to ask and or what to do (15)

just the support and just, you know you look forward to you know, catching up with other parents and having a bit of advice, and you know just, it is like a security net, just, or like a security blanket, it just makes you feel safe and you
know that you can ask, you know advice on equipment or do you think that this right, and it is almost like a second opinion (11)

you get to know the other parents you talk to them about problems that you have and they often have some solutions and things and also Karen who leads our group is a source of support and you can talk about how we are going to potty train her and the best ways to do it and to learn things to do when they are going to school (8)

Parents also spoke of valuing the support that their child receives from other parents in the group.

she will do something and because all the parents are there every week and one of the parents will say “well actually Helen I saw you do that, and last week you were good but this week you were that bit better!” And the children’s faces they just beam and it is just lovely and to have that support as well (10)

during the year of volunteering I couldn’t stop crying because every time one of the kids did something new I would stand there and cry so there was me crying and the mum crying and I just couldn’t help it because it was so amazing and I knew, I knew how it felt because I know how it felt for me, so I knew how it felt for her (12)

Much satisfaction was expressed by mothers regarding skills that they had developed through their attendance.

I have learnt so much since she has come here (10)

I knew what I was looking for and didn’t realise how much more, we were going to get and because I hadn’t got a clue how to begin to give him the skills to strengthen to develop. How would you start that as a lay person? (9)

The building of skills together with feeling a sense of social connection and knowing that support and advice are always available have very positive outcomes for mothers in terms of their confidence and attitude.

yeah, confidence, and so in terms of personally what I have personally gained it was (1)

I wasn’t a very outgoing person and I had kind of in the last year I have not really gone anywhere with Sarah because, it just wasn’t me and I just never really went out and mixed with other people and I just did what I normally did and then when we started going there I have got more confident in myself and I just, we have benefitted as a family by going there (14)

and that is how I feel now, nobody and I think that it is a bit big headed, but nobody can do it like we do it, so you know what I mean, but I didn’t feel like that all them years ago, because I would have let anybody do it because anybody could have done it better than what I was doing it that is how I felt, you know, I was useless and that is how I felt (12)

I think I would have done that anyway but I suppose they have made you have more confidence in doing that than I may have done before (3)

Even beyond confidence some parents expressed feeling empowered, within themselves and through School for Parents support

when you are here and when you observe them you see what they are capable of in a different way because at preschool you leave them don’t you and you are not observing them at that sort of microscopic level and gosh they can do that, and
maybe as a parent empowers you to then think, well actually we can do better than this (1)

I would never probably have done that, I would have gone with what we had. But obviously being here and then you see that somebody else has got something that you haven’t and you wouldn’t have known and you start pushing, you know, in that respect then I wouldn’t hesitate to ring and say, you know, “well I think that Sam needs this and why wouldn’t he have that?” (2)

Seeing their own child and other children progressing helps parents to be optimistic for their child’s future. They are supported to feel positive about themselves and their children and what might be possible.

we have been in sessions where we have seen a child’s first steps, and that is magical and, you know, that is going to get you out of bed, you know, even if it is not your child frankly because it is just amazing (1)

George was very tiny and not being able to do much straight away but there was another child who was older that was doing more and so I felt that... I could see that another child was, you know, thriving and it was really good to meet the other parents and talk to them about where their children are now so it wasn’t just that it was somewhere to go and there was more to it than that (15)

it gave me that hope, extra hope, you know coming in here each week and we have seen other kids start to do things and even though James wasn’t taking the steps yet you could see that progression in the other children and you would follow their Facebook and see other success stories and, you know, you got together with other parents at social events that we had and, you know, you could see that everybody was just singing their praises and, you know, to me that was just amazing! (16)

it is nice to come back here and hear Erika will say “remember where he was, remember what he could do and look at where he is now!” and I think that it was nice from a professional rather than your family sometimes because you are hearing it from somebody who knows and you know she knows more than anybody (2)

3.5.6 How mothers learn at School for Parents

Many mothers explained that they felt they needed to develop their skills in supporting their child and this was sometimes a motivation for attending School for Parents. They describe being given exercises to do by physiotherapists but finding it challenging to remember how to do them or feel confident that they were doing them correctly. In contrast they were able to develop skills by attending School for Parents through the length of the sessions, the regularity of attendance, repetition of exercises and gradual building up of tasks. Parents identify that children learn through repetition (section 3.5.4) and similarly they learn themselves by being able to watch and copy the same or similar activities over time which become gradually embedded into everyday tasks and incorporated into their home life.

over time because you are watching and when you are learning the basics, and it is a couple of hours every week and you are watching them doing it and they will probably show you or Erika is good at teaching me to do transitions of movements and you don’t just pick Emily up, she will show you how to get her up from the changing bed and how to do things and I think over time you just start doing it because you are doing it regularly and you are seeing it and it becomes more natural to do it (3)

started understanding it a bit better and then just watching what they were doing and the techniques they use and the words they used and we just get home and we start doing it at home. And then I say to my husband, “don’t do it like that!
We don’t do it like that! We do like this! And when we are doing it we say this. Right! Don’t ask why! Just do it. That is all I need to do!” And so, yeah and we started doing it at home and things started changing very slowly and just calming down a bit and as he got better I got better and I felt more confident with him then, finally, I can do this (12)

I am just watching and picking up on, on what they are doing and I can see that that is helping him so I try that at home myself and see if I can, if I can do the same thing basically. They don’t say, do this and do that, although they have in the past said, try and concentrate a little bit more on, on standing or whatever, but they don’t really there is nothing pushy about it here, you need to do certain things or basically I just watch what Karen does and try and incorporate it at home really and it seems to work (4)

there is not a second wasted, like everything is an opportunity to do or learn or practice something and every transfer and it just makes you think of things at home that you can be doing that makes you stop and look at your child and you know and putting it in the high chair and you know you help them to do it themselves and it just changes your mind set (11)

Although much emphasis was placed on the gentleness and subtlety in the way parents are taught sometimes a more direct instruction was appreciated.

I would go straight back to their skills which are phenomenal. It is less of a medical model but it is very socially inclusive and not only of the child but the family I think makes the difference. Because you need to teach the family for the child to survive. I can think of an example where I saw some work in progress that was very interesting here where I am sure that the work was being done more with the parents than with the child, and when the parent grasped it the child succeeded and that I think is a, is a huge thing for a team to be able to achieve and achieve very well (9)

Parents describe being rather confused or unaware of their learning at first but a gradual realisation dawning over time.

I think for the first few weeks it was a bit kind of like we were doing the sessions but not really knowing what is going on and you just kind of follow the drill of right ok well we will do the singing and we are going to try and stand from sitting, or you don’t ever realise what they are trying to do and then a few weeks later it is, it sort of clicks and you are ah, now I realise why we are doing that now, and that is why they are putting a mirror in front of them doing this to get them to move towards it or, or getting them to, I don’t know whatever else we would do in session and it kind of clicks with the parent, like, ah, ok, I understand this now! (16)

They appreciate the subtle, gradual building up of their understanding and skills in supporting their child.

looking back now with, with Kevin I was guided very subtly and very gently on a couple of occasions towards different areas that would help and benefit him. Perhaps not where my focus was at that time but it needed to be (9)

I can see now that they taught us things like standing and things but at first you do think, what, what, what does that do, and then you know we do the mouth exercises and the, it is all to do with the muscle tone and building that up, but you do think, what? (17)
you learn here and it is undetectable and you don’t realise that you have learned it really, how to speak to your child as well, you know, the staff model so amazingly and they are so consistent as well (1)

In addition, parents learn through observing the way that staff do things and explain them to the children, parents can see that children develop autonomy and independence as adopt similar methods at home.

“... to help slow you down or we are going to do some counting and the reason that we are slowing you down is because A, B and C“. So then it puts it in Helen’s head and then I am understanding it as well and maybe the first few weeks she doesn’t get it but as time has gone on and you look on the charts the scores have improved or if she has had a bad week we know why her scores have gone down and because she will say “I didn’t do that very well this week it was really hard.” And they know and that gives me more satisfaction (10)

if Erika says something about your child she means it and she is not, there is not any throw away praise, that is perhaps the wrong word praise, as there is massive praise and encouragement and that is what it is all about, but the comments and the specific things that are noted they mean something, but at the end of all the sessions we talk about what the child has done well that day and now in gym club they are at the age where they can decide what they have done well and it is really important that they can say to the group, this is what I have done well, and it has taken Colin a long time to get to that point where he can confidently and happily well a. remember with a little bit of prompting from mum or dad and b. just sort of say it proudly and, but then if Erika thinks he has done well and it is not what he said she will add it and you will know, yeah, of course you did, you were brilliant... and that is what makes you confident and that is what makes you go home and talk to your child in the most effective way or be a certain way (1)

3.5.7 How parents see their children
The mothers interviewed all expressed very positive views of their children, no matter how significant their difficulties were. It is not possible to know whether this positivity was there from birth or had developed once their children had been stable medically and making progress.

she is very lively and very determined and she will try everything and which puts her in good stead because up until she started nursery she was only just walking with a frame and wasn’t walking and like now she is doing everything and she is very driven (10)

he has always had a bit of a fire in tummy and you could see it right through, right through from the hospital, he had a bit of fire in him and I just knew he was capable of more than what he was doing (12)

he is a bit of a thespian and he likes music and acting I suppose, and his facial expressions are pretty good... that is also a way of communicating to me for lots of different things and he is yeah, he is very cheeky and loves to have a laugh (15)

he thinks that he is one of the boys and when my son gets his friends around a lot after school and that and they are all playing and Freddie wants to join in with them and he just wants to do everything that they are doing. He really tries bless him (4)
the rest of the time she is so eager to do everything and she is going to be quite, a hopefully, be quite an independent little girl (5)

Inevitably, the children could not always be happy and positive. Mothers described the frustration that some children experienced at times, particularly when they encounter things they cannot do.

her speech and language is just fantastic and she has got very good comprehension again she doesn’t like writing though. Writing things down is just too difficult and she doesn’t do drawings very well she is always making marks but there is no structure to her mark making at the minute (5)

he is a lovely little angel and he is so cute and so charming but as soon as you get him to do something that he don’t want to do or he feels uncomfortable doing then he will scream at you (12)

3.6 Obstacles to attending
Apart from the many reasons that parents attend School for Parents and feel that they are benefitting some participants also expressed difficulties in relation to attendance. It is obviously important for School for Parents to understand the reasons why parents fail to attend or stop attending after only a short time. Asked whether the participants knew why other parents did not come some provided conjecture, based on their own experiences, and others had had conversations with non-attenders.

3.6.1 Practical issues
At a practical level it can be difficult to make arrangements to come, particularly when families have more than one child, and need to travel long distances.

I have to admit that initially I used to find it very difficult to come. It would be the whole day and for some reason it would feel... I would feel really pushed on a Wednesday (1)

I suppose it is quite a commitment in terms of time isn’t it, a lot of the parents travel quite a long way to come here and we are lucky that we don’t (8)

sometimes it is even the commitment of travelling as well because it is a good 30 minutes in the car to here from where we live (5)

One parent highlighted the cost of sessions as a reason that she had not attended sooner.

my only regret is that we couldn’t come sooner. If I had known, because we couldn’t financially afford it, maybe I should have looked into a fund and that has changed now so we would have come sooner now, and I wish there was more children that could get the opportunity to do what we do (10)

Attending can also be tiring for both the mother and child.

he used to be exhausted after a Wednesday, well we both were quite frankly, but you know, because they are heavy sessions and even lunch times wasn’t a down time (1)

it is hard work, it really is and, do you know, don’t get me wrong I used to go home and I used to be, you know, really excited about what we had done but I was knackered, and I used to think this is doing him the world of good but in the same respect I am knackered (12)

Mothers sometimes have to persist through children not liking sessions and crying.
it was perseverance by us actually and we had to keep coming and putting him into it and most parents and this is what Karen said "most parents wouldn’t have done that" they would have said "right well he doesn’t like it and they would take him away or out of the room" or just not turn up, but we had to, we just had to get him out of that stage and it worked, it is just perseverance with absolutely everything (7)

she is very stubborn and if she doesn’t like something it is very hard to get her to do anything... and a couple would be brilliant and one would be crying and then the next week it would be someone else and so it wasn’t ever a problem, because we understood how it felt to be that, that it was your week, you know and it is hard and it is stressful and sometimes I had to take her home when, and when she was being so disruptive and, you know, it just became too much and I would take her out and that was it, you know, other times Erika and whoever was in the room would say "I will take her, you go!" And the others mums would say, we will just swap and if we all swapped kids we might get a bit further because they behaved so much better for the other parents, and you know, she would fine with somebody else but to do it for me, she would protest (10)

there was many a times I used to take him out of the session because he was just so disruptive and there was only the two of them and he was just, everything was about him and he turned it all about him... and yeah he just disrupted the whole session (12)

Some parents explained that when they first heard about School for Parents they did not feel ready to attend, either because their child was struggling with health issues, or they had a great many appointments, or because they needed time to come to terms with the diagnosis.

because I think for the first year of being there she was probably ill a lot and she had lots of gaps so she might go one week but then they probably didn’t see her for a good few weeks... I mean it was only one day a week and it took, it was probably at least year and a half before she was physically well enough to do a full day and that is probably why it took longer to get Mary joining in. But once she was physically well enough to do a whole day I think that has been when she started to thrive really and she is really coming into her own (13)

wish I had come here and was told about them probably a year and a half ago but at the time wasn’t in a stable place to make a commitment and to be able to come somewhere every week and there was a lot of medical stuff going on (5)

Although a number of parents expressed how delighted they were that they have been able to bring and involve siblings of their disabled child to sessions for others trying to meet the needs of all children makes attending School for Parents difficult.

at the time Billy was younger as well and more needy and so it was taking on board it is not just Polly’s needs but his needs as well... I didn’t have any other help other than me so obviously to be in two places at once with two children was also difficult (5)

3.6.2 Finding out about School for Parents

Obviously, for some people, they did not attend at first because they did not know about it. Eleven mothers were referred to School for Parents by personal contact, one found out about School for Parents at a fundraising event, one was referred by her paediatrician, two through family services, one through the Portage service and another through an internet search.

I may have found School for Parents through my own research down the line but I don’t know whether that time without somebody’s endorsement because we were so, we were so hospitalised and we were very much, you know, quite
correct and doing what the hospital says and what the hospital told us to do, I don’t know if then perhaps we might have veered off the path, or not had the confidence to do that, so you are always looking to someone’s endorsement and so if I not had my friend to introduce this I may not have found it and even if we had found it a lot later so would we be at the point that we are now? Maybe not (11)

Eight mothers talked about their ongoing frustration that they were not told about School for Parents and had to discover it for themselves or through a friend, and their belief that parents were still not being told.

I wish that that the physio’s and I guess the physio teams and support services would recognise the work and you know, I really think they should be promoting other services like this and you know it is and they are not and surly everything should be mutually beneficial for the good of the child and nothing ventured and nothing gained and it is not going to harm and, you know, it is not a crazy, crazy ideas, it works! Our children have proved that it works and I think that there is enough now of us now coming from the CDC and then coming to School for Parents they must start seeing, you know and I can’t see that the benefits can just come with physio alone and I just wish that other services would recognise the work that School for Parents does and the benefit and promoting it to other families (11)

it is a shame that I hadn’t heard of it other than by word of mouth because they deserve a lot more credit for what they do (5)

why had nobody spoken to me about this at the hospital? (1)

I think that the biggest thing for me though was finding out about it and I think that is such a shame and that is what bothers me, that these people, there are mums out there feeling how I felt and, do you know what I mean, and we are here, we are here to help you (12)

so we had gone through the health visitors and we had gone through the paediatrician and we had gone through genetics and we had gone through neurology and even though James wasn’t walking back then, nobody had mentioned that we could access this service here. We were going through physio as well (16)

it was actually our portage lady, she had another child that came here and he has left now but she, but what annoyed us though she, we had her for about year or so before she even sort of mentioned School for Parents and we needed the help and she was coming every two weeks for an hour and just sitting and playing with him and seeing how he was developing and what not, and when he could have been here for that extra 8 or 9 months, yeah, but, eventually she told us about this place and we came for an assessment (7)

Another obstacle was the negative view of Conductive Education that they or their contacts held.

and my father remembered and Kevin’s social workers’ manager remembered that (TV programme) and said "Is it really right to put a child through?" And I am looking at a child who used to come every week and Kevin absolutely adores it and the minute that there was tears they are clever and quick enough to distract the child and move on, and then they make it into a game, and but yes that film is still remembered (9)

One parent thought, when viewing School for Parent’s promotional literature, that the service may not be suitable for her child. It is possible that other parents hold off
contacting School for Parents as they are unsure about whether it will be the right place for their child.

but the literature that I read it was heavily, to me it was just a service for children with Downs syndrome... so I wasn’t sure whether it was the right service for Mary, because Mary hasn’t got Downs syndrome but she is delayed developmentally, so I was a bit unsure you know (13)

I found out about here through a charity fun day at a local pub who were raising funds for here... and the lady who runs it “oh, I have told them about James and they want to hear from you!” And I said “but he isn’t a boy who has got cerebral palsy, and he hasn’t got Down’s Syndrome”. And she said “well it doesn’t matter he is not walking, they will want to help you”. So she gave me a leaflet and I went home and typed in School for Parents. Watched the video. Cried! Played it again and watched the video and cried and looked at all the pictures and made the call and came in for an assessment and the rest is history, yeah (16)

All participants were in regular contact with NHS professionals and were keen to follow their advice. This accounted for some people attending when it was recommended by a statutory worker but conversely when it was not recommended this led to a negative impression.

people can suddenly get quite stuck in doing what the hospital are telling you to do and whatever and you get quite hospitalised and you just rely, you rely on their advice and you take their advice (11)

I have told so many people about this place and how they work and what it is all about including OT’s, physio’s and, you know, and various other people and it is really sole destroying because actually this kind of attitude of “well go and try if you want to!“ and I think that means that actually that people will miss out on the benefits of an organisation like this of what they have got to offer because I think that you have got to kind of have some, I don’t know you have got to dig deep for, to go out and find other things on your own (6)

It was therefore important to have the endorsement from a professional or a friend in order to take the first steps to attending.

it was a parent that... told me about it, and I think that if I had looked it up more and took it on board more, if it had been in my face a bit more then I might have stepped forward sooner, but I don’t know because I was just fed up with appointments at that time as well, you know, sometimes there is just so much going on and there are so many different clinics because you have not just got one issue, there is about five and there is neurology, urology and orthopaedics and then physio and the then the OT’s as well and then the paediatricians and we were under a dietician at the time and the speech and language so, so to take on something else I just physically couldn’t do it, although this would have probably been better to not have some of the other appointments and do this instead (5)

3.6.3 Attitudes to parenting and disability

Once parents know about School for Parents there are a range of aspects that are likely to determine whether they will attend. Firstly, everyone will have a view of their role as a parent which will encompass the extent to which they feel it is necessary for them to be instrumental in their child’s development and the degree to which they feel able to take control.

I think because, well it is School for Parents isn’t it, so we have always felt that we needed to be there to see what happened and so we can then do that at home (8)
I think that you are either the sort of person who will go above and beyond the call of duty to get the help the child needs and that I find is the people who come to School for Parents. But then you have the other people in the world who are a bit like, yeah whatever, you know, so the further I got talking to this couple I was, I got a sense of and I knew straight away, you are wasting your time, you know “does he wear a splint?” “He should do but he doesn’t like wearing them, and so we have left them at home” you know. And that kind of feeling and you know “well my son goes to School for Parents, you know it is this fantastic place and they have helped him with this and the other, check out their website!” “Yeah”. And do you know what, and I knew and I just knew they wouldn’t and I kind of thought well, you know, you can only put it out there and if people and I don’t know why, I don’t know why (12)

I think you have to go out and find it, you know, it is not and luckily I am that sort of person, and I think for some parents that aren’t like that then I would imagine it could be, you know, really difficult (13)

It is possible that School for Parents attracts parents with a particular outlook on life or on their role as a parent. This may manifest in an ability to be positive in the face of adversity and to adapt to stress.

if somebody tells me I can’t do something I am pretty much the kind of person that thinks “yes I can!” And certainly the same applies with both my daughters “yes they can!!” And I think that the people that I have met here are you know, everyone has had the same kind of attitude that they just are about, it is not even like just making the best of it, it is about “this is who we are and this is what we are going to do!” And it’s like a quiet confidence almost (5)

nobody has got a crystal ball and know body does know what the future holds and nobody does know, you know, if things are going to work or not but for me you have got, for me I want the best for my children and I want to strive to help them and I don’t want to look back and think I wish I had done that, you know, there are things that I probably haven’t done, as best as I could and I have been tired and I, you know, I know that we haven’t been doing physio every day... but you know on the whole we have been trying to move forward with an attitude of, you know, let’s do it and see where it gets us (11)

sometimes as people helpfully tell me, you know you do know what this means don’t you? And you do understand the severity of this condition? “Yes I do, but, that doesn’t mean that we will ever give up on trying with her!” And my thing all along has been, ok, we keep her in the best shape we can possibly keep her in and we you know, we stretch her in every way and give her motivation and things to strive for and then let’s see where we are (6)

if you just sort of let him sit and fester that is not going to get him anywhere and it is not going to get me anywhere and what sort of life is he going to have if he doesn’t, if he is not taught and he needs to be taught effectively, so, yeah, this place has been an absolute Godsend (7)

I think that also your perspective does get different as the years go by doesn’t it and as it changes you do, to start with your focus is, this is a problem that we need to fix, you know, rather than Philippa is Philippa and we will do what we can but, and actually being able to sit back and, and to say it is not my fault she is this way and she doesn’t sit at this age and that is not because I didn’t do all the physio exercises and there is that need to kind of move back from it as well (8)

you think about the future for them and how they are going to cope in the outside world but because I am quite relaxed I and sort of just take each day at a time and I don’t and I try not to worry about the future and I try to enjoy each day as
it comes because if you worry too much about the future then you would drive yourself mad wouldn’t you (17)

A mother who describes herself as being anxious, particularly about her children, was still able to put a positive spin on her situation.

that it is all relative and yeah we have had more issues than most but I have my son and my friends have just lost theirs and Shannon is now in a main stream school and she has gone to school this September in big girl pants which we have managed over the summer, which is huge because I never thought I would see the day, and you know she is walking independently and you know she might not be top of the class but she is here, and she is fighting and she is learning and she is developing and they both are, in their own right, so I try as much as it is hard I have to be grateful because I know that there is a lot of people that would, that would prefer to have what I have got, do you know what I mean, I would love kids to be happy and healthy and not have to have a care in the world and unfortunately we do, and it is just relative you just deal with what you have and I try and think of it in that respect, that there is always somebody worst off (11)

One mother described her friend, who despite urging to attend School for Parents had chosen not to.

she takes (child) to play group and she stays with her and everything, and she is happy just doing that, whereas for me I just feel I need to be in more of an environment that is more focused than that and then you can, I don’t know, it is everyone to their own isn’t it (17)

Taking the first steps to going beyond basic care to becoming their child’s teacher requires parents to accept that their child is in need of extra help and has a disability.

she wasn’t walking or talking at the relevant stages and a friend of mine recommended School for Parents and initially I was at that sort of stage where I thought “oh no we don’t need to go there and she will be fine” (13)

One mother described how attending School for Parents for the first time highlighted her child’s difficulties.

I think I remember feeling, for me it hit me then that she is not doing the things that she should be doing because the things that they wanted her to do she couldn’t do and I remember feeling quite upset about it... because I suppose it was the first time I’d been part of that and because prior to that she was going to, she went to nursery and obviously it is different because conductive education is quite different but you are part of it as well as a parent and you know with the tasks that they what the child has to do (13)

Four other parents had had previous professional experience related to people with disabilities which they felt had helped them to a certain extent.

special needs has always interested me to a degree anyway and I worked with a boy who had like stumps for fingers on one hand and he liked working with me because I was the only one who treated him normal (5)

I had supported adults with Downs Syndrome so yeah probably that made me more aware... even saying that though it is very different having a child of your own even though you have got awareness and it is very different and whole new different thing (17)

so I think that our knowledge was probably detrimental really because we were worried about her heart and all these possible things that could happen and actually the majority of them didn’t happen so (8)
it can be quite difficult having a little bit of insight and also having the personality that is not going to sit there quietly and say “I don’t agree with you!” Because when you are passionate about a child that you love, I couldn’t sit, and just let him not get the chances that he deserves, and look where he is now, he is doing really, really well (9)

For some families their child’s disability will bring stigma and painful emotions, which may be possible to avoid while their child is still young. Even where acceptance occurs they may not want to join, or to be seen to belong to, a specialist service.

fear I think and for some people fear of the unknown and of not knowing... and I have come across as well, when we attended the hospital, culture sometimes is an issue and they feel that it is, disability is stigmatised you know, it brings shame on the family (10)

I have met another parent who has got a son with cerebral palsy and it is very mild but still struggling and she did not want her son, I think that she was at the stage where I was at, where you think, I don’t want them to be, I just want them to fit into a, and I say normal loosely, into a normal setting and she decided not to send her son to School for Parents but you do, you sort of have to accept that as a parent that while my daughter has got this condition and this is an organisation that sort of specialises in helping children that have delayed developmental and things like that, and so you have to accept that as a parent otherwise you don’t take that step (13)

so if it is not supported by your physio maybe you don’t seek it out yourself, and perhaps some people just don’t want to admit and maybe, and I would have come earlier, if I had known I would have tried to come earlier, but I don’t think at that time I was... until somebody had actually told me, yes you have cerebral palsy even though I knew and until it was written I don’t think that I was ready to accept that either, and maybe some people just can’t and don’t want to and I guess some people just think, it will be ok and or maybe some people think that what is the point? I don’t know. What is the difference? What difference is it going to make? And perhaps they don’t or haven’t yet started to see the small, the small changes and then once you start seeing that you want more, and you want more, and more (11)

I think that if you have a more passive way of coping and maybe if you don’t want to engage with the sort of community of parents of children with special needs then this isn’t the place for you (8)

Denial of difficulty may manifest as thinking intervention is not necessary and they just need to wait for their child to develop skills. Linked to the negative view of non-statutory services in general, and CE in particular, some parents may think that there is no point in attending as it is unlikely to make a difference. Even if people decide to try, if they don’t see progress initially they may lose their motivation to attend.

perhaps as well when they come perhaps they think, you know, because it is not immediate, you know what I mean, the results aren’t immediate perhaps, you know, some people aren’t willing to do, you know what I mean, to pursue it are they? (12)

I think that when I first got the phone call and they are just going to offer Thursday morning session I was a bit disappointed, thinking oh... because you just want as much help as possible (3)

there is a lady with twins that lives near us, who are now three probably and one has a weakness down one side and she came for an hour’s trial and I see them every so often and increasingly I see the little girl is becoming more clawed and I think “why? why didn’t you, why didn’t you go?” and I said to them “you didn’t
come and you didn’t join us?” And she said “we decided just to wait and see what happens” (9)

Another obstacle is the anxiety expressed about when their child becomes upset, screams and disrupts the sessions.

I do remember that when she was much younger doing and learning to roll over and, you know, having to put your arm up in a certain way and do it and she didn’t really like it but, maybe I am a bit sort of, like well, you know, we need to do it for short periods of time even if you don’t like it because it will help with your development... I sort of took the attitude that a lot of children don’t like the things the first time that they do it, but actually you do need to keep doing it, so it is not as if it is somebody that she doesn’t know making her do it and the fact that you are sat there the whole time and I think it makes it easier than say leaving her in a day nursery where you are not there (8)

some weeks I did seem to have Sam crying all of the time and you think, why am I bothering, but I wasn’t on my own and there was a lot of children and when they are that very tiny age, he didn’t cry at the exercises that we were doing because he loved that (2)

I think that there is certain children that it doesn’t work so well for and I think that there are children who are more, Philippa is not really a very boisterous child so you can kind of put her in one place and she will do what is front of her and what with her walking being delayed in a way that made her sit and concentrate but I think that there are other children perhaps whose motor skills are more advanced and have come to Rutland House and fitted less well in the group because they have sort of been in cupboards and where ever else and I think that maybe parents dealing with that sort of challenge would find that Rutland house would not be so good for their child. Maybe there have been children that left that I think possibly do for that kind of reason (8)

Overall the mind-set of parents attending School for Parents is key in the mutual support and reassurance they offer each other.

but everybody here were here for the same reasons that as I was, because there was, you know, we just wanted to help them (2)

we are still a family and our daughter is very much here, and you know, that, that needs us and rather than actually grumbling, that needs us to find the positive and I, I obviously found, you know, School for Parents and I am glad that I did, and I really am and I have to say, you know that they have, they are realistic but they are positive and the people that you meet here, you know parents as well, they are like minded. Because it would be very easy to, and I can see how, how it happens if you, if you went along with the sort of the I guess the NHS route or the social care route and this institutionalised way of actually existing. It is absolutely destructive and it is awful... I could never put up with this one size fits all approach I really couldn’t bare it so we have done all sorts (6)

3.6.4 Social relationships

In the same way that parents are motivated to attend in order to develop links and friendships with other people in the same situation, when this does not happen immediately or easily they may be less motivated to keep attending.

I mean as soon as we got here the first session I was very nervous because I came on my own and obviously I couldn’t bring my friend (12)

when we first came we were in a very small group and there was only one other child at that point and I think that I was disappointed initially and thinking “oh,
and I thought that we would be in a bigger group and we would meet more people initially” (3)

Some parents felt that they would have wanted more time and opportunity to talk to other parents.

my sort of friendships were slightly later developing if you like because you would see people quickly but you would be busy with tubes or whatever (1)

In the same way that seeing other people’s children making progress was inspirational the lack of progress in one’s own child, and their reaction to some of the sessions could cause negative reactions.

because you can see the progress that the children are making and not so much Colin initially to be honest and maybe that was partly why it took me a while to warm up into it (1)

sometimes it is day in day out and you think, and you can sometimes think, why aren’t you making no progress and then you actually have to kind of pull yourself, pull yourself back and look where he was and look how far he has really come (2)

Recommendations

Parents in the study were asked for their recommendations of things that they would like to see School for Parents offer or change.

I think trying to create a bit more time for the mums or the dads or whoever is bringing in the children to have a bit of time and I know that it is not easy because there is a lot to fit in to the sessions and I have already said that the sessions were a long day for me and it took me away from things that I needed to fit in, but, maybe there is something around that, and maybe, maybe even having a separate, even an evening, an evening group where the mums are encouraged or facilitated and it would need to be, it would need to be easy and it wouldn’t need to be, oh leave it for the mums to sort it out because I think, those type of things are always good if it’s organised for you especially when you have a child with special needs because you don’t prioritise yourself (1)

can we have a photo copy of the targets to have on the fridge at home (1)

they seem to have quite good equipment and facilities, but it would always be nice to get more funding for them to get more (4)

it would be nice to have a lock up all to themselves and loads of up to date equipment for them to meet everybody’s needs, and it should be available to everyone (5)

It is clear from the data included here that School for Parents offers a comprehensive and much appreciated service that benefits children and parents. Despite the success there are some aspects that arise from the data regarding School for Parents that could be introduced or further developed.

1. Operate a buddying system for new parents run by existing parents. This could include information, explanations of how Conductive Education will work, the way that children learn and reminders to persist through child resistance and lack of progress.
2. More time and opportunities for parents to meet and get to know each other alongside sessions.
3. A range of publicity materials that emphasise who can be helped at School for Parents.
4. Set up a group suitable for more active children enabling them to learn to calm
and fit in with other groups.

5. Enlist supportive professionals working within the statutory services to work as ambassadors for their colleagues.

6. Continue to build on the collaborations already made with professionals from health, education and social services.

It is clear from the data that most health, education and social service professionals want to do everything that they can to support the parents in this study. It is recognised that these same professionals are facing difficult time and financial constraints. However, it is also evident that there are ways that statutory services could further support parents with children experiencing chronic health conditions and disabilities, particularly when these are long term. The mental health of mothers, of children and the wider families are put at risk when a child is born with serious needs which has potential long term consequences. The success of School for Parents in providing effective educational and emotional support could provide a model for service development. As seen in this report mothers who receive education and training in how to support their child feel positive and empowered. They are able to integrate facilitation skills into their homes and child’s everyday life which could and should have positive long term benefits for the child and parents. It is possible that this enhanced resourcefulness and confidence will reduce the need for care and support from statutory services in the future. Children who receive good levels of provision from services and their parents develop confidence and resilience that stand them in good stead for starting school. In the light of this further recommendations are made:

7. There is a need for services to offer parents coordinated provision and the flexibility to proceed at a family’s own pace.

8. There are some excellent examples of the benefit of joint and collaborative working in this report. This should be seen as a requirement on all service providers rather than being up to the attitudes of individual workers.

9. Service providers need to recognise the impact of a child’s serious health conditions or disabilities as traumatic for parents and build in care for parents as well as for their children.

10. Service providers need to recognise the benefits of mothers and babies meeting socially as well as for appointments.

11. Therapists who have constrained amounts of time need to prioritise developing the skills of the parents in supporting their children. They need to recognise the considerable difficulties the majority of parents face when given a set of exercises to do on a daily basis without the on-going support and education of a professional.

12. Information about non-statutory services should be provided to all parents allowing them to make decisions about the sorts of provision that they would find beneficial for their circumstances, situation and attitude, including School for Parents.

To further these recommendations two complementary systemic changes are suggested:

1. When a child is identified as having a special need an advocate or key worker is assigned to the family to provide continuity of care until the child reaches 25 (in accordance with EHC plans). The role of the advocate would be to provide information and advice to the parents, find services relevant to her needs and those of her child and siblings as well as the wider family. They would coordinate appointments and help families to navigate the system. They would befriend the parents, offer emotional support and would be trained to recognise signs of trauma and to refer to counselling where necessary.

2. Parents in this and previous studies (See and Gorard, 2013) appear to benefit from having a centre to attend where a range of support and provision can be provided under one roof. A centre for families of children with SEND could provide physio, occupational and speech and language therapy, conductive education and
other support such as that for children with visual or hearing difficulties.

Conclusion

This study involves a group of parents who have exceptional children and an overwhelmingly positive attitude to life and to the future. The difficulties participants encounter on a day to day basis are of a practical and logistical nature, emotionally demanding and stressful. Their challenges, following years of anxiety about their children and inconsistent support from services, could have led to helplessness or hopelessness. However, all of those interviewed identify as strong, capable and empowered.

Perhaps remarkable, despite very individual personal circumstances, is the degree of shared experience the mothers in this study describe. They tell of a journey from the initial struggles to understand and to come to terms with their changed circumstances, often while simultaneously attempting to cope with life-threatening health conditions and huge numbers of appointments and investigations. Their lives are no longer under their own control or direction and they describe feeling fearful, frustrated and uncertain. For a while the future they had planned comes crashing down and they have to spend their time coping from day to day. The next phase they enter is typically an awakening of realisation that their child will not develop in the way they hope without considerable time and energy from the family and particularly the mother. This puts all family members under considerable strain and leads to significant feelings of isolation for the mothers who give up work, outside interests and friendships. At this point, for most of the interviewees, they looked for help with their child and a new community where they would find understanding and support. By coming to School for Parents they gain knowledge, skills, friendships and empowerment. All of the children were going to, or destined to go to, mainstream schools, which is unlikely to have been the predicted outcome at the time of their birth. Satisfyingly they all say that attending School for Parents has made a huge and positive difference to their lives, and, it can be surmised, to how they feel about their children and the future. This is what motivated the mothers to be interviewed for this study, as well as their concern for those parents who do not receive the same level of support.

It is possible that School for Parents only attracts people who have these positive attributes in the first place. Certainly many parents had stories about friends or contacts who had chosen not to come. However, most of the parents also talked about being motivated by knowing that they wanted to help their child, that they were frustrated that not enough was being done, that they lacked confidence and knowledge in helping their child and that they were facing lack of social support or even isolation. From this starting point parents made time in their over-crowded schedules for yet another appointment which took up much of their time. This alone suggests that School for Parents was offering something much needed and of significance to the child and parent. In addition, parents provide detail and depth of information about the ways in which they have benefited from attending, indicating positive changes for themselves and their child that they attribute to School for Parents.

School for Parents sets out to provide a service to help parents to help their children. The data included in this report outline how children have developed their skills in walking, communicating, socialising, independence and confidence. Where relevant children have received help with literacy, hand-writing and self-care. Parents have joined in sessions on a routine basis over months or years to embed the facilitation of learning skills that becomes part of their everyday life. Children go to school with a positive attitude and when they encounter new skills that they find difficult they, with the help of their parents, know how to tackle them. School for Parents provides reports and practical support to children at school to help to smooth their path. This may account for why none of the children were attending specialist provision, all were included in mainstream schools and nurseries.
There is a clear relationship between the positivity of parents and the well-being of their children. Parents who are highly anxious about their child are more likely to feel helpless, to accept the status quo, to not seek help or support which can even lead to depression or the ill effects of long-term stress. If children are to have strong self-esteem and well-being it is obviously key that their parents are well and have robust mental health. The more positive parents are, the better the outcomes and quality of life of the child.

It is clear that the social and emotional support that parents in this study described receiving through belonging to the ‘family’ of School for Parents significantly increased their well-being. They describe feeling empowered to help their children physically and emotionally. They had learned subtle but powerful ways to be the best possible parent to a child with significant needs and were spreading that ability to family members and friends. Children felt empowered to leave the safety and security of School for Parents and tackle the challenges of school with the knowledge that, with support and practice, they can achieve.

At the beginning of this report the literature related to the most effective provision for parents of children with disabilities identified a number of key factors. School for Parents can be seen to deliver on each of these factors. Parents need knowledge and information to build self-advocacy skills (Etmanski, Collins and Cammack, 2011; Willingham-Storr, 2014). The mothers in this study gave numerous examples of receiving useful advice and information from staff at the School and from parents they met there. It appears that even in the internet age people value hearing other people’s opinions and experiences first hand. In addition, parents recognised the very high level of skill and competence of the staff and knew that specific advice could be provided about the needs of their child.

Research identified the parents’ need to understand their child’s condition (Knafl et al., 2011). Some of the participants described learning this from statutory providers, but they had also learned to understand their children’s difficulties and how to overcome them from attending the School. Etmanski et al. (2011) referred to helping parents to access and navigate services. School for Parents provide reports for schools and nurseries, visit other institutions to talk about the child, and welcome all interested to the School to see what they are doing with individual children. This openness to sharing practice is of significant benefit to the child and parents and meets the need identified by Willingham-Storr (2014) for collaboration between service providers and families and a family-centred approach. At School for Parents all members of the immediate and extended family are welcomed and encouraged to attend.

The social and support needs of parents are also highlighted by research (Haven et al., 2013). School for Parents brings families together, some couples attend together and describe how it is an enjoyable activity to share with each other and their child’s siblings. There is much stress in the data on the benefits that families gain from meeting other parents like themselves, in terms of their situation but also their outlook. The feeling of connectedness to others, of enjoying sharing the highs and lows, brings strength and empowerment to parents and therefore to their children too.

The call for practices that strengthen and empower families (Daly et al., 2015) is central to the work of School for Parents. With a relatively modest income and staff School for Parents provides a model for other organisations in how to foster appreciation, positivity, the ability to celebrate small successes, to collaborate and to build positivity. The parents who attend feel enormous affection and loyalty to the organisation and its staff and leave School for Parents better equipped to support their child in the future. One of the exceptional aspects of the School is the warmth of welcome and building of a sense of community. This very effectively reduces the isolation of parents and children.
References


