"You don't even know if you're aware of what's happening unless you are in it":

the experiences of parent carers of disabled children as multi-service users

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April 2016

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Glossary & comments on the text

Wherever possible acronyms have been avoided. However, the following are widely used, and so have been adopted in the text:

ASD	Autism Spectrum Disorder
BCH	Birmingham Children's Hospital
CAMHS (LD)	Child and Adolescent Mental Health Service (Learning Difficulties)
CDC	Child Development Centre
DLA	Disability Living Allowance
ICA	Invalid Carers Allowance
OT	Occupational Therapist
PRH	Princess Royal Hospital
RJAH	Robert Jones & Agnes Hunt Hospital
RSH	Royal Shrewsbury Hospital
SALT	Speech and Language Therapist

In line with qualitative methodology we have remained as close to the original quotes from participants. This methodology does not include punctuation, as it is possible to alter the meaning by doing so. We have tried to quote directly from participants, using their words, but occasionally it was necessary to cut the text, in this case (…) is used.

(.) denotes a pause when the participant was speaking.

Any words added in for sense are in [square brackets].

In order to understand the emotions of the participants, such as laughter *(laughs)* and tears *(cries)* are also included in the transcription.

Abstract

Background:

Children with disabilities and additional needs often have access to multiple services, and their parent carers, as co-ordinators of their care, are multi-service users. Whilst current legislation aims to put parent carers and families at the centre of the interaction with service providers, previous research has suggested that the parent-professional partnership is not always achieved. Previous research from PACC suggests that parent carers are often subjected to inconsistent care provision, poor communication and have to fight for services.

Aim:

This project aims to explore the reality of the parent carer experience in relation to professionals and service providers, as multi-service users. It also aims to make recommendations to enhance partnership.

Method:

There were two stages of research. Stage 1 was a qualitative study, using thematic analysis; eight mothers of children with disabilities living within Shropshire Local Authority area took part in individual semi-structured interviews. Themes drawn from this data were used to develop a mixed methods questionnaire for Stage 2, which was distributed to PACC membership and parents of children at Severndale Specialist Academy, totalling 864 recipients.

Results:

Three themes emerged from Stage 1: *The child in context,* exploring inclusion and exclusion, and the acceptance and normalisation of disability; *Managing Outcomes,* exploring co-operation and conflict with service providers, and communication and empathy; and *The Impact on the Parent Carer*, exploring maternal identity and emotional impact.

Stage 2 took Managing Outcomes and the Impact on the Parent Carer further. It was discovered that, despite many positive comments about service providers, many parent carers felt professionals lacked empathy and did not understand their lives; additionally, many parent carers felt that they were not believed by professionals and at times felt patronised. Parent carers made suggestions relating to support, communication and meetings as areas for improvement. Times of transition in the child's life were highlighted as particularly stressful for child and parent carer.

Recommendations:

Professionals need to be informed of the complexities of parental care-giving. Parent carers and professionals need to work together to establish a common framework for partnership. The balance of power should be shifted from the caregiver (the professional) and the care receiver (service user) to a three-way partnership between parents, young person and professional, where all parties are equally valued. A good practice guidance for professionals outlines specific recommendations for developing positive relationships with parent carers.

Executive Summary

Background:

Most children with disabilities or additional needs are multiple service users, regardless of their condition and the severity of its impact; during their life they are likely to access a range of health, social care and education services. Even a child with less complex disability, such as speech and language delay, may access a number of services such as audiology, speech and language therapy, early years portage, and possibly occupational therapy. The parent carers of these children are the advocates for and co-ordinators of such services for their children.

Project Aim:

The aim of the research was to explore the reality of being a parent carer of a multi-service user within Shropshire Local Authority area. This aim falls within the Healthwatch Shropshire research project grant remit of "Exploring the Reality", and this research project has been supported by Healthwatch Shropshire grant funding.

In particular, it aimed to discover:

- The barriers parent carers face when dealing with multiple agency services
- If there is any specific impact of being multiple service users on the health and emotional wellbeing of the family
- The parental perceptions of how integrated the multiple agency services are.

The project also aimed to make recommendations in light of its discoveries.

It is estimated that there are between 2,500 and 3,000 families who have children with a disability or additional needs within Shropshire Local Authority area; this is based on figures of 3,826 children receiving additional support in schools, with 1,952 children with a Statement of Educational Needs or Education Health and Care Plan (as of 14th April 2015). 513 children access support from All In Short Breaks, and 141 children are supported by Specialist Short Breaks (such as overnight respite at Bradbury House or The Willows).

PACC is an independent local parent carer forum, which promotes the participation of parent carers in the planning and delivery of services for children and young people (0-25 years) with disabilities or additional needs in Shropshire Local Authority area. PACC is a pan-disability organisation, and at 1st April 2016, had 489 members, all parent carers and living in Shropshire Local Authority area.

Over the past few years PACC has collected a significant amount of feedback, through parent participation, about the experience of being a parent carer in Shropshire Local

Authority area. We have asked parent carers what makes them mad, sad or glad about being a Shropshire parent carer; we have explored what health and wellbeing means for families of disabled children and discussed what good information, advice and support looks like to our community. Throughout all these discussions there has been a consistent focus on how parent carers feel that there is a lack of understanding of their lives and the life of their family. Shropshire parent carers have told us that this lack of understanding leaves them feeling isolated and makes it difficult to see a positive future for their children.

It was therefore proposed by PACC to research the experiences of parent carers around the issues of being multi-service users, and to consider the issue of integration of services, which to date has not been in evidence for this group, with a view to suggesting how services may be improved.

The intent of the project is not to demonise professionals or to demoralise individuals who are trying to do the best they can in what are often difficult circumstances, but to raise awareness of the central role that parent carers play in the lives of their disabled children and the potential cost of that role to them as individuals.

Method:

There were two stages of research. Stage 1 was a qualitative study, using thematic analysis; eight mothers of children with disabilities living within Shropshire Local Authority area took part in individual semi-structured interviews. Themes drawn from this data were used to develop a mixed methods questionnaire for Stage 2, which was distributed to PACC membership and parents of children at Severndale Specialist Academy, 864 recipients in total, to discover if the findings of Stage 1 could be widened to the general population of parent carers within Shropshire Local Authority area.

Results:

Three themes emerged from Stage 1: *The Child in Context* explored inclusion and exclusion, and the acceptance and normalisation of disability, as well as considering the child within the context of the mother's care and beyond it; *Managing Outcomes* explored the parent carers' co-operation and conflict with service providers. Whilst examples of both good and poor practice were cited, communication and empathy was found at times to be lacking. *The Impact on the Parent Carer* explored maternal identity and emotional impact, and it was found that parents often viewed themselves as experts on their child, but that the "fight" to obtain services also had a direct and indirect impact on their self-image.

59 participants responded to the mixed methods questionnaire in Stage 2. Quantitative data showed that on average the children currently access 6.9 services each, the range being from 1 (low) to 24 (high), and have accessed on average approximately 10 services in the past, range 1 to 28. Children had a range of areas of disability, and those children who accessed the support of a social worker on average had more areas of disability than those

that did not. The most used services were the GP, Royal Shrewsbury Hospital, Paediatrician, Child Development Centre, Health Visitor and Speech and Language Therapist.

Two themes from Stage 1, *Managing Outcomes* and the *Impact on the Parent Carer* were explored further. It was discovered that, despite many positive comments about service providers, many parent carers felt professionals lacked empathy and did not understand their lives; additionally, many parent carers felt that they were not believed by professionals and at times felt patronised. Parent carers made suggestions relating to support, communication and meetings as areas for improvement. Times of transition in the child's life were highlighted as particularly stressful for child and parent carer.

Discussion:

In this study, many parents were happy with the services they received, and, whilst PACC acknowledges these positive experiences, it is necessary to concentrate on the negative comments in order to make recommendations for improvement. Many of the themes discussed in Stage 2 are not new findings; for example, PACC has previously reported that parents wish that services were more joined up, that there was better communication, that they did not have to repeat their story to several professionals and that meetings were scheduled to take parental responsibilities into account. However, the findings of the lack of understanding and empathy on behalf of professionals, and the emotional impact that has on the parent carer, are the central to many parental experiences.

One of the more distressing aspects of the accounts is the number of times parents feel that they are not believed by the professionals. They want professionals to "*witness*" their child's behaviour; they feel they have to "*convince*" professionals that they need help and that they are judged. Often they state they are not "*listened to*". So parents are not just set aside from other parents and subject to discrimination from the 'outside' (neuro-typical) world, but they also feel they are then subjected to judgement within the system that should be there to support them. This feeling of being judged inevitably impacts on their self-image and at times makes them feel belittled, and, at other times, combatant.

In particular, there are challenges around the transition of young people into the world of adult services, where there is rightly an increased focus on disabled individuals having their own voice; however, it is recognised in legislation that family carers do continue to have an important role. More work needs to be done on developing adult services' understanding of the role of family carers have in decision making, which is recognised and supported by the Mental Capacity Act, the Children and Families Act and the Care Act.

Transition is also a time when the co-ordination of services can become even more of a challenge, particularly in relation to health services. The role of the GP can at this point become central to the delivery of co-ordinated care and the maintenance of good health. Developing a positive relationship with GPs from an early age is important for families of children with disabilities so that good health can be maintained into adulthood. While in this research GPs were identified as a service that was most frequently used by the families participating, it is not clear in what capacity, and if that is related to the young person’s care or the care of the family carer.

Recommendations:

Parent- professional partnership

Parent carers and professionals should work closely together in order to understand the “big picture” of life as a parent carer. In this way, professionals will gain insight and parent carers may gain confidence in professionals. In order to achieve this, it is suggested that:

- Professionals attend workshops where they can learn first-hand about parental experiences, the potential emotional impact of caring for and supporting a disabled child, and how being a parent carer is different to the ‘normal’ parent role.
- Professionals receive training around help-giving styles, so that parent carers feel valued and understood and on an equal footing with professionals. Training would include using the Good Practice Guidelines on developing positive relationships with parent carers, outlined below.
- Parent carers are given the opportunity to understand the potential impact that having and supporting a disabled child may have on them as individuals, and to explore their own emotional responses. This support should include discussion on how they may positively manage their relationship with the system and the professionals they come into contact with; for example, through the use of person centred planning tools.

Co-ordination of Services and Communication

- Further work needs to be carried out on how services can be more co-ordinated, with a particular focus on reducing the burden of information sharing and provision that is currently carried by parent carers. This should be done in the context of the Special Educational Needs and Disability reforms, which promote a holistic and ‘tell it once’ approach to supporting young people with SEND, via the introduction of Education, Health and Care plans.
- Person centred planning tools are an effective way to share key information about individuals with disabilities or additional needs. Adult social care, and to a certain extent education and children’s social care services, in Shropshire Local Authority area are starting to use these tools as part of their day to day processes. It is recommended that all professionals providing care and support to children and young people with disabilities or additional needs and their families undergo training in person centred planning and the use of person centred planning tools.

Transition

- Professionals need to understand and acknowledge the reality that parent carers often continue in their caring role well into their child's adulthood. The continuation of this key role of parent carers as advocates for their children into adulthood should be recognised and valued by professionals, rather than treated with suspicion. Whilst those with disabilities and additional needs may need encouraging and supporting towards independence, professionals must recognise that the parental advocacy role is still crucial to those with greater needs.
- Families and professionals should be encouraged to have a good understanding of the Mental Capacity Act for those young people who are unable to make their own decisions.
- Work undertaken in the areas outlined above should improve parent-professional partnership, as well as communication and the co-ordination of services.

Role of the GP

- It is recommended that work is done to ensure that GPs actively support and engage with families of children with disabilities from the earliest point. There should be a focus on increasing GPs' awareness of the positive role that they can play in co-ordinating services and signposting families to support.
- There should also be a focus on ensuring that any young person with a Learning Disability is flagged on the GP data register, so that annual health checks are offered from the age of 14 and the GP is actively engaged in the transition process.
- Parent-led training for both GPs and practice staff, as outlined above, would facilitate a better understanding of the specific problems around being a parent carer of a child with disabilities or additional needs, and thus enable them to support both the child and the parent effectively.

Vision:

In this way, it is hoped that parent carers and professionals will work together to establish a common framework for partnership. The balance of power should be shifted from the caregiver (the professional) and the care receiver (service user) to a three-way partnership between parents, young person and professionals, where all parties are equally valued.

Improving Communication: A Good Practice Guidance for developing positive relationships with parent carers:

Always introduce yourself and explain your role in relation to the child.

1. Communication:

Implement a ‘tell it once approach’ wherever possible.

Use of e-mail and electronic sharing of information within and between services, such as consultants’ letters and changes to prescriptions to the GP or respite services, as well as with parent carers.

Joined up information between hospitals.

Text message service for appointments to be offered.

Forms to be user friendly, and not require too much repetition of the facts.

2. Language

Refer to parents by name. Do not use the word “mum”/”dad”.

Involve the child in discussions as and when appropriate; recognise the level of understanding and communication.

Consider the appropriate level of language and information for parents.

Recognise that the parent is the child’s advocate.

Avoid jargon (e.g. acronyms such as “FPOC”).

3. Signposting

Ensure parents are signposted to the appropriate level of information and support.

4. Meetings & Appointments

Preparation – read notes before meeting parents/child.

Circulate agendas beforehand if appropriate.

Timing – give adequate forewarning of meetings/appointments, checking that parents are available. Take both work and caring role arrangements into consideration, such as taking time off work or being back to meet the school bus.

Ensure parents have time to ask questions, and express views.

Introduction

Project Aim

Most children with disabilities or additional needs are multiple service users, regardless of their condition and the severity of its impact; during their life they are likely to access a range of health, social care and education services. Even a child with less complex disability, such as speech and language delay may access a number of services, such as audiology, speech and language therapy, early years portage, and possibly occupational therapy. The parent carers of these children are the advocates for and co-ordinators of such services for their children.

The aim of the research is to explore the reality of being a parent carer of a multi-service user within Shropshire Local Authority area. This aim falls within the Healthwatch Shropshire research project grant remit of "Exploring the Reality", and this research project has been supported by Healthwatch Shropshire grant funding.

In particular, it aims to discover:

- The barriers parent carers face when dealing with multiple agency services
- If there is any specific impact of being multiple service uses on the health and emotional wellbeing of the family
- The parental perceptions of how integrated the multiple agency services are.

The project also aims to make recommendations in light of its discoveries.

Shropshire Parent & Carers Council (PACC) Background

It is estimated that there are between 2,500 and 3,000 families who have children with a disability or additional needs within Shropshire Local Authority area; this is based on figures of 3,826 children receiving additional support in schools, with 1,952 children with a Statement of Educational Needs or Education Health and Care Plan (as of 14th April 2015). 513 children access support from All In Short Breaks, and 141 children are supported by Specialist Short Breaks (such as overnight respite at Bradbury House or The Willows).

PACC is an independent local parent carer forum, which promotes the participation of parent carers in the planning and delivery of services for children and young people (0-25 years) with disabilities or additional needs in Shropshire Local Authority area. PACC is a pan-disability organisation, and at 1st April 2016 had 489 members - all parent carers and living in Shropshire Local Authority area. Its trustees and officers are all parent carers themselves.

Being the parent carer of a child with a disability or additional need can be a life changing experience. It can involve a total change in expectations and the ability to do what others take for granted; it also brings new experiences, knowledge and understanding. Supporting a child or young person with a disability or additional needs can be challenging and inevitably impacts on family life, which can result in families becoming very isolated, unable to access information and lacking in opportunity. The bringing together of families into a supportive empowered community can lead to a fundamental change for the better in the quality of life for such families. PACC offers an opportunity for families of children with disabilities or additional needs to come together, to share information and to provide support to each other. It is also an opportunity to help create services that meet the needs of their families.

PACC's Aims and Objectives

- The creation of a Shropshire parent carer community that reduces isolation and strengthens the capacity of parents to support their family.
- The provision of information to inform and empower parents and carers about the issues that affect their families.
- The provision of opportunities for parents and carers to influence the decisions that affect their families and to contribute to developing services that meet the needs of their families.

How PACC works

PACC is an independent parent carer led organisation, and as such has a real understanding of the challenges faced by families of children and young people with disabilities or additional needs based on our own experience. Our work has shown that, while parent carers might be supporting children with a range of difficulties, many of the challenges faced by all parent carers are similar. Families have told us that they struggle to find useful information, often feel different from other families in their local communities and don't feel included in the decisions about the support their family receives. Life can be a constant challenge.

PACC works with families to improve services and to bring parent carers together to provide support to each other. We also work in partnership with local organisations that commission and deliver services for children and young people with disabilities or additional needs. We meet regularly with Shropshire Council and are developing links with the Shropshire Clinical Commissioning Group, both of which are key organisations in the planning and funding of education, health and social care services for families with disabilities or additional needs in Shropshire Local Authority area.

PACC supports and empowers Shropshire parents and carers of children with a disability or additional needs, to enable them to be actively involved in the design and delivery of the services that they use through the sharing of their experience and knowledge of their family's needs.

Parent Participation

Parent participation is when parents and carers are involved in service planning and decision making, so that services meet the needs of families with disabled children and resources are not wasted on services which parents and families do not take up. Effective parent participation happens when parents have conversations with and work alongside professionals, in order to design, develop and improve services. Working with parents and carers helps professionals to understand what needs to happen to develop services that meet families’ needs, and also helps parents and carers understand the complexity involved and the challenges faced by the professionals who have to bring about that change.

Working together and sharing knowledge enables parents and professionals to find solutions that work. There are three essential ingredients for successful parent participation: good information, honest consultation, effective participation. As parent participation develops, all three elements should be present and complement each other.

Professionals play a crucial role in the lives of families of children and young people with disabilities or additional needs, and how they deliver this role can be the difference between a family leading a positive and meaningful life and a family feeling cast adrift with no hope for improvement in the future.

Over the past few years PACC has collected a significant amount of feedback, through parent participation, about the experience of being a parent carer in Shropshire Local Authority area. We have asked parent carers what makes them mad, sad or glad about being a parent carer in Shropshire Local Authority area; we have explored what health and wellbeing means for families of disabled children and discussed what good information, advice and support looks like to our community. Throughout all these discussions there has been a consistent focus on how parent carers feel that there is a lack of understanding of their lives and the life of their family. Shropshire parent carers have told us that this lack of understanding leaves them feeling isolated and makes it difficult to see a positive future for their children.

Previous Research

There is a wealth of research around the experience of parenting a child with disabilities: for example: the effects on health of parenting a child with disabilities (1), child and family characteristics with relation to social care(2), gender differences within parenting (3), while more recent research looks at the more positive aspects of parenting a child with disabilities (4, 5).

However, it is still an obvious, but sometimes overlooked fact, that parent carers are central to the child's care. The Chief Medical Officer's annual report 2012 "Our children deserve better" (6) stresses that "committed collaborative efforts are required" and "we need everyone in the public services to 'think family and children and young people' at every interaction". The need for such a statement suggests that integration has not been happening.

Historically, the integration of services has been led through education, most recently with the introduction of EHC assessments, but research suggests that failures of parents to engage with the processes are labelled as "symptoms of individual parent/child deficits, rather than systemic ones" (7). Research focusses on the role of education describing "parent-professional partnership" as "an unchallenged mantra within policy relating to special educational needs"(8), however, parents experienced "professional dismissal of their own 'expert' opinions as unreliable on the grounds of their emotional involvement with the child" (8). However, the level of integration of services, referred to within the research, has been questioned by some parents: "knowing 17 different professionals isn't partnership" (9). More recently, the NHS, addressing partnership through National Voices (10), defined person-centred co-ordinated care as planning care "with people who work together to understand me and my carers, allow me control and bring together services to achieve the outcomes important to me".

Children & Families' Act and Care Act

Two new major pieces of legislation have recently been introduced, both of which highlight the importance of ensuring that professionals and parent carers work in partnership, alongside requiring that appropriate support is provided to deliver person centred outcomes.

The Children's & Families Act came into force in September 2014 and responds specifically to feedback from both parent carers and professionals, about the failure of the existing system to deliver good outcomes for children and young people with SEND. Parent carer participation is a key underpinning principle of the Act, and in Section 19 the importance of a collaborative approach is recognised by the legal duty placed on Local Authorities and others, to ensure that parent carer participation happens on both an individual and strategic level.

The Care Act 2014 creates a new legal framework for provision of services to those with care and support needs who are over the age of 18. It prioritises individual wellbeing, with a particular focus on person-centred practice and outcomes and putting people in control of their care and support. It also highlights the importance of preventing and reducing needs, and for the first time, it puts carers on a par with those for whom they care.

Previous PACC research

Whilst the foundations for the integration of services and parent participation have been laid, and researched in certain areas, within Shropshire Local Authority area there is still a call from parents for this integration and the problems around it to be addressed. In 2013, PACC carried out a survey of its members in response to Health Priorities as laid out in the Shropshire Health and Wellbeing strategy, with a view to feeding back to the Clinical Commissioning Group (11). In particular, PACC members requested a greater integration of services, including information sharing, to ensure a holistic approach to supporting young people with disabilities or additional needs and their families. Parent carers also reported frustration with continually having to repeat their story, and with the feeling that professionals are not fully informed about their situation. There were also experiences of poor co-ordination and communication between services that resulted in increased difficulties for the families and young person not being treated holistically with all aspects of their lives.

Project outline

It is therefore proposed by PACC to research the experiences of parent carers around the issues of being multi-service users, and to consider the issue of integration of services, which to date has not been in evidence for this group, with a view to suggesting how services may be improved.

The intent of the project is not to demonise professionals or to demoralise individuals who are trying to do the best they can in what are often difficult circumstances, but to raise awareness of the central role that parent carers play in the lives of their disabled children and the potential cost of that role to them as individuals.

The project was devised in two parts: a small scale qualitative study to allow individual experiences to emerge, and then a mixed methods questionnaire, to explore whether the themes found in the individual accounts could be generalised to a wider population. Suggestions for improvement were requested in the second stage.

Stage 1 – 8 individual interviews analysed using Thematic Analysis

Method

Design

An exploratory design, using the qualitative method of Thematic Analysis, as discussed by Braun and Clarke (2006), was used to examine the participants' experiences and opinions of being multi-service users. This method enabled the researcher to embrace Healthwatch Shropshire's research project grant theme of "Exploring the Reality".

Braun & Clarke state that "thematic analysis is a method for identifying, analysing, and reporting patterns (themes) within data". It is a flexible qualitative method of analysis, which has been widely used within health psychology research in different formats, and, in order for the reader to understand the aims of the research, it is important at the outset to define the approach adopted (12).

Braun & Clarke (2006) describe a theme as capturing "something important about the data in relation to the research question, and represents some level of *patterned* response or meaning within the data set". The researcher is actively involved in identifying these themes, and throughout the process keeps notes, and reflects upon the data. In writing up the results, there is a move from description to interpretation of the findings. Whilst the researcher may try to bracket her preconceptions and theories, there may be some position that influences the interpretation. For this reason, a reflexive diary was kept.

For the purposes of this report an 'essentialist' approach was adopted which "reports experiences, meaning and the reality of participants". Additionally, an 'inductive' approach, where underlying common themes were drawn from the data, was used. Themes are not fitted into a pre-existing coding frame in an attempt to answer specific questions, and may, therefore, "bear little relationship to the specific questions that were asked of the participants" (Braun & Clarke); they nonetheless elucidate the reality of the participants' experiences in relation to the overall research question. On a more refined level, the researcher largely adopted a 'semantic' approach, where the themes identified are "within the explicit or surface meaning of the data", as opposed to a 'latent' level which explores assumptions and conceptualisations revealed in other qualitative methods, such as discourse analysis.

Participants

Eight mothers of children with a variety of disabilities were recruited through advertising on the PACC website (one), at the PACC conference (five) and through personal contacts (three); all were given a recruitment sheet. The children varied in age from 5 to 20, although the majority were teenagers, which was determined by the people who volunteered, rather than selection on the researcher's behalf. (See Table 1). However, the recruitment criteria was set according to the Families and Children's Act, which classifies disabled children up to the age of 25.

Five of the mothers had partners, three were single. All were white and lived within Shropshire Local Authority area, within twenty miles of Shrewsbury. Two of the children were born outside Shropshire and their families had moved to Shropshire Local Authority area within the last five years. There were three girls and five boys. Three of the children had siblings (one girl, two boys) who also had some additional needs.

There was a variety of disabilities but to assure anonymity the names of identifying syndromes have been withheld; five of the children had named syndromes (although none of them shared a syndrome) and five children had Autism Spectrum Disorder; some of the children had co-occurring conditions, such as epilepsy, heart conditions, respiratory conditions; one child had special needs that had developed due to a medical condition after birth. Whilst all the children were in specialist educational settings, two of them did not have IQ defined learning difficulties.

Name	**Age**	**Child**	**Age**[1]	**Disability**	**Wheelchair user**
Christine	40	Elizabeth	5	Syndrome and medical condition	N
Helen	43	Simon	13	ASD	N
Jennifer	54	Leona	16	Syndrome, complex health needs & ASD	N
Molly	45	Scott	15	ASD	N
Naomi	46	Stuart	19	Syndrome, complex health needs and ASD	Y
Rachael	51	Sophie	20	Syndrome, complex health needs	Y
Rhiannon	39	Edward	7	Syndrome	Y
Shelley	54	Gareth	17	Medical condition & ASD	Y

Table 1. Stage 1 participant profiles

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[1] Age at time of interview

Data Collection

Each participant was interviewed in their own home. They were given a consent form to read, and offered the opportunity to ask questions at the start of the interview. They undertook an audio-taped, semi-structured interview, according to a schedule of open-ended questions (Appendix 1) which was developed to generate data. Participants were asked to describe their child and their diagnosis and the types of services they accessed. They were also asked to discuss the mechanisms by which they accessed the services, and reflect on their experiences. They were also asked to discuss both positive and negative experiences in their service use, and to reflect on their own wellbeing and health. This process gave them the opportunity to express their experiences in their own words. Interviews were between 32 minutes and 1 hour 46 minutes in duration. Participants were allowed to tell their stories and discuss their experiences, and the researcher followed some unexpected lines of enquiry, which illustrated their experiences. Afterwards, the researcher read a debriefing sheet to the participant and there was another opportunity for questions. At this stage, pseudonyms to protect the identities of participants and those of their children were also discussed.

Analysis

The recordings were repeatedly listened to before being transcribed verbatim. Attention was paid to the particular emphasis participants put on certain words and phrases, and these were annotated in the transcription process. Each transcript was read and re-read for accuracy, and corrected accordingly. In this way the researcher immersed herself in the data, and began to think about the content. Initial ideas and summaries were listed in the right hand margin of each transcript, and sections of the transcripts were highlighted and annotated.

Note making is also an important part of thematic analysis, where the researcher outlines ideas of themes, paying attention to the prevalence of certain codes. Notes were made both on the transcripts, in a notebook and recorded within the audit trail on computer. In this way, the researcher began to move through the individual accounts looking for recurrent themes, sometimes going back to check previously annotated accounts to cross check the data.

From these summaries, codes were identified and written in the left hand margin. Extracts of data from each transcript were put into files, according to codes, and a table compiled of codes (see Appendix 2). Finally themes were identified from the listed codes, and then these were reviewed and refined. Theme maps were drawn at each stage.

Braun & Clarke state “analysis is not a linear process where you simply move from one phase to the next. Instead it is more recursive process, where you move back and forth as needed, throughout the phases” (12). The themes were named and defined, and further defined within the writing up process.

Ethical Issues

Although the project was not subject to the approval of an ethics committee, the researcher is a member of the British Psychological Society, and as such is bound by their code of ethics. Participants were informed of what participation would entail, of their right to withdraw during and after the interview, and were given the opportunity to ask questions. Additionally, a timescale was agreed for withdrawing data, anonymity was assured and discussed with relation to pseudonyms and withholding identifying data. Written consent was obtained. Time was allocated to the participants’ questions both before the interview and during the debriefing process. The researcher also gave careful consideration to sensitivity and vulnerability during the interview process. Some participants became upset and they were given the opportunity to stop the interview; however, they stated they would like to continue. Where appropriate, the participant was pointed to sources of further information, such as support groups.

Results and Discussion

In line with the Healthwatch Shropshire’s research project grant theme for 2015, “Exploring the Reality”, the research question aims to explore the experiences of parents and carers of disabled children in their role as multiple service users. In particular it considered:

1. the barriers parent carers face when dealing with multiple agency services
2. if there is any specific impact of being multiple services users on the health and emotional wellbeing of the family.
3. the parental perceptions of how integrated the multiple agency services are.

Although, within the participant profiles, the particular diagnoses and syndromes have been generalised for anonymity, this research embraced the diversity of the disabilities of the children who are cared for by their parents. What constitutes a disability is topic of debate amongst sociologists and psychologists as a matter of social construction and beyond the scope of this report; however, within these results, any difficulty the child has in interacting with the world around them, which arises as the result of a diagnosed problem, is referred to as a disability.

Some of the young people normally would be classified as adults being over 18, and did access some adult services, as the recruitment criteria was set according to the Families and Children's Act, which classifies disabled children up to the age of 25. However, within these results the young people are referred to as children, because that is their relationship to the mothers who were interviewed, even if that means an adult child. Mostly the mothers discussed the children's services that they had accessed.

In order to understand the issues parent carers face as multi-service users, it is necessary to first understand what those services are and why parent carers engage with so many of them. Table 2 reveals the services that the mothers mentioned in their interviews[2].

Also included in the table are three siblings who all have autism spectrum disorders, (Child 2B & 5B) and in one case ASD and additional needs (Child 3B), who also accessed services. It is important to include those other children and their services when considering the parental role, as the child with the main disability cannot be isolated from the rest of the family that the parent has to care for.

Figures 1 & 2 show mind maps of services centred on a child with complex medical needs and one with autism spectrum disorder. In contrast, Figure 3 shows the services that a neuro-typical 21 year old sibling had accessed over his lifetime. (The mind maps of services accessed by all eight participants can be found in Appendix 3).

The graphics clearly demonstrate the complexity of the support systems most of these children have accessed, particularly those with high medical needs. Those with ASD within mainstream settings may not have accessed so many services, but the accounts reveal a number of exclusions from educational settings which in turn have prompted parents to request help from Child and Adolescent Mental Health experts and social care.

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[2] in some cases, after the interview was finished, they said there were other services they had not referred to

	CHILD 1	**CHILD 2**	**CHILD 2B**	**CHILD 3**	**CHILD 3B**	**CHILD 4**	**CHILD 5**	**CHILD 5B**	**CHILD 6**	**CHILD 7**	**CHILD 8**
Royal Shrewsbury Hospital	X					X	X		X		
Birmingham Children's Hospital	X					X			X		
Alder Hey Hospital	X					X					
Royal Stoke Hospital	X					X				X	
RJAH Orthopaedic, Oswestry	X					X					
Portage							X		X		
Child Development Centre	X			X					X		
Severndale Assessment Nursery	X					X	X		X		
Severndale	X					X	X			X	X
Mainstream Nursery		X		X					X		X
Mainstream School		XX		X							
Specialist Learning Support Unit		X		X							
Specialist/Residential School		XX		X							
Vision Impaired teacher							X				
GP	X	X				X	X		X	X	
Health Visitor									X		X
Paediatrician	X					X	X		X	X	
Specialist Nurse Consultant									X		
Community Nurse						X	X		X		
SALT	X					X	X		X		X
Social Care OT						X	X		X		
Health OT						X	X		X		
Physiotherapy						X	X		X		X
Audiology	X						X		X		
Ophthalmology	X		X			X					
	CHILD 1	**CHILD**	**CHILD**	**CHILD 3**	**CHILD**	**CHILD 4**	**CHILD 5**	**CHILD**	**CHILD 6**	**CHILD 7**	**CHILD 8**

		2	**2B**		**3B**			**5B**			
Wheelchair Services	X					X	X			X	X
Continence Services	X					X	X		X	X	X
Oxygen							X		X		
Neurology							X			X	
Respiratory consultant						X	X		X		
Cleft Palate Clinic						X	X				
CAMHS LD	X					X				X	
CAMHS		X	X	X	X			X			
Special Needs Dentist	X					X	X			X	X
Podiatrist	X				X	X	X				
Social Worker	X	X		X	X	X	X		X	X	X
Hope House	X						X				
Overnight respite	X	X				X				X	
All In Short breaks	X					X	X		X	X	X
Direct Payments	X	X			X	X				X	
Health-led nursing hours						X	X				
Privately funded childcare	X										X
Transport	X	X		X		X	X		X	X	X
Police		X									
Educational tribunal		X									
Ombudsman		X									
MP		X									
Support groups	XXX	X		X		XX	XX		XX	X	X

Table 2 – Services accessed by the participants’ children and their siblings

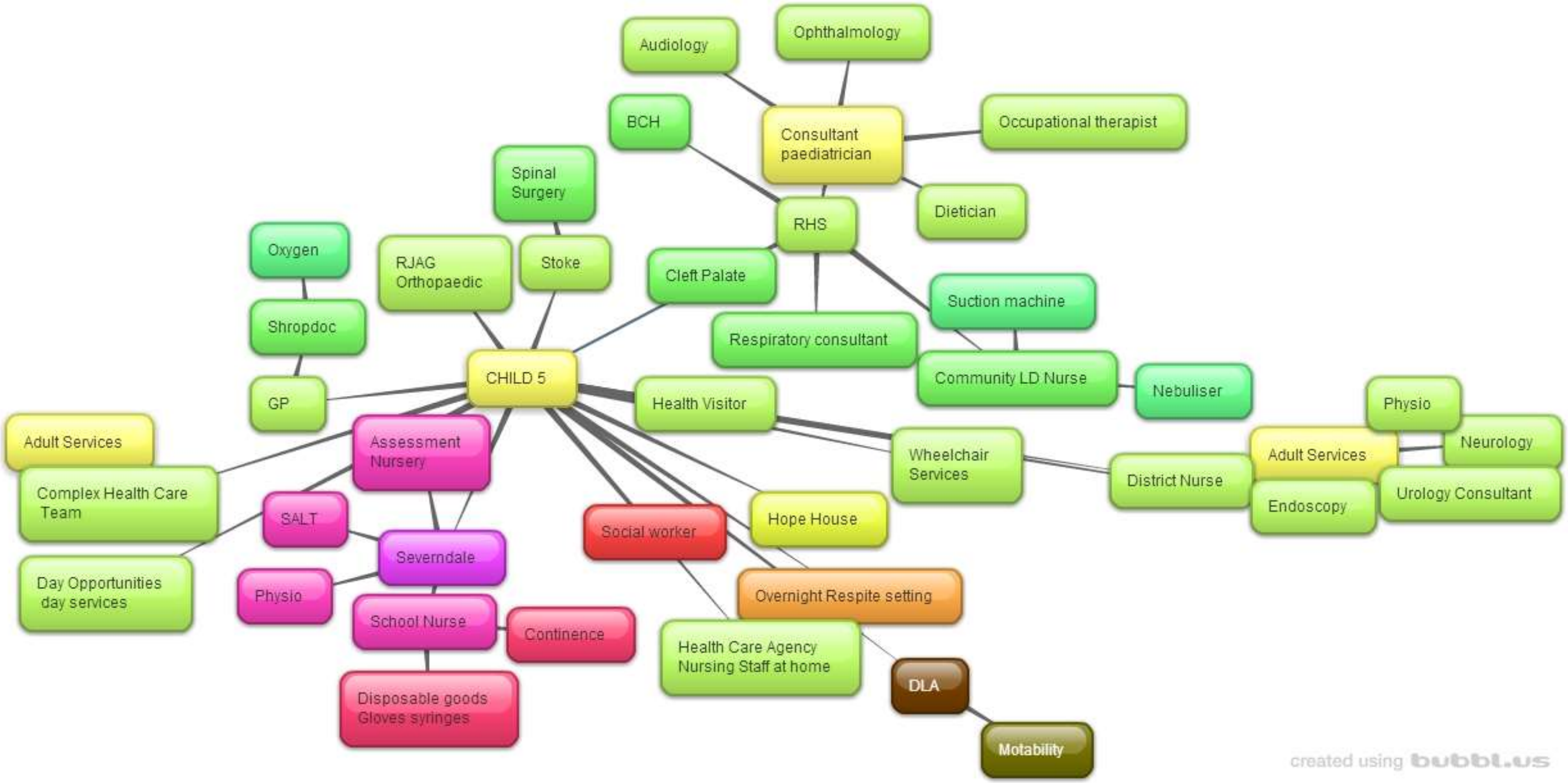

Figure 1 - Mind map of Child 5’s services – showing support systems around medical needs

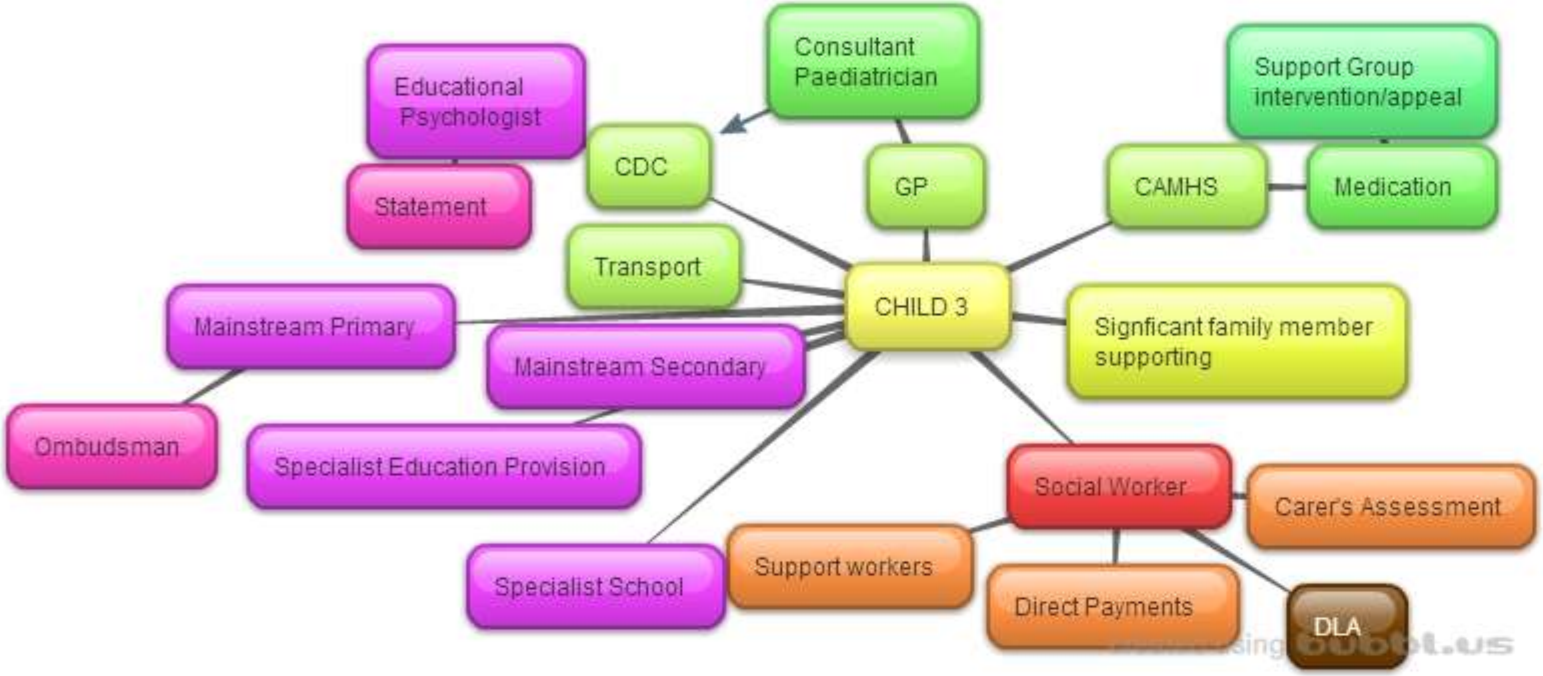

Figure 2 - Mind map of Child 3’s services showing support systems around ASD

Figure 3 – Mind map of the services accessed by a neurotypical sibling

As with any child, there is uncertainty as to how that child will develop, but the issues parent carers of children with special and additional needs have to face are of a different nature, whether that is life or death:

> *well actually our worry is that Down's syndrome just didn't even come into any of it so her disability was was irrelevant er because we didn't know if we were going to have a little girl who we were going to bring home or not*
> Christine, l.129,

or reaching developmental milestones that are taken for granted with typically developing children:

> *they never know (.) from a tiny baby how severe the disability's going to be you know it can be something small to something huge erm whether he'll walk whether he'll do this whether he won't do that you never ever know it just goes on the you see how he gets on along the the development scale of everything*
> Shelley, l.14.

Therefore, the support systems, whether that is health, education or social care, around a disabled child are demonstrated to be both complex and interlinked, and parents have to find their way through those systems as the child develops. Although Healthwatch Shropshire does not consider education within its remit, it is impossible to tease out education from the services these children access, as will become apparent throughout the analysis.

One mother commented about the system:

> *You don't even know if you're aware of what's happening unless you are in it.*
> Rhiannon, l.921

Three themes were identified throughout the analysis: *The Child in Context*, which explores subthemes of the child within and beyond the mother's care, inclusion and exclusion, and acceptance and normalisation of disability; *Managing Outcomes*, which explores themes of co-operation and conflict between parents and service providers, and communication and empathy; and finally, the *Impact on Parent Carer*, which considers subthemes of maternal identity and the emotional impact. See figure 4**.**

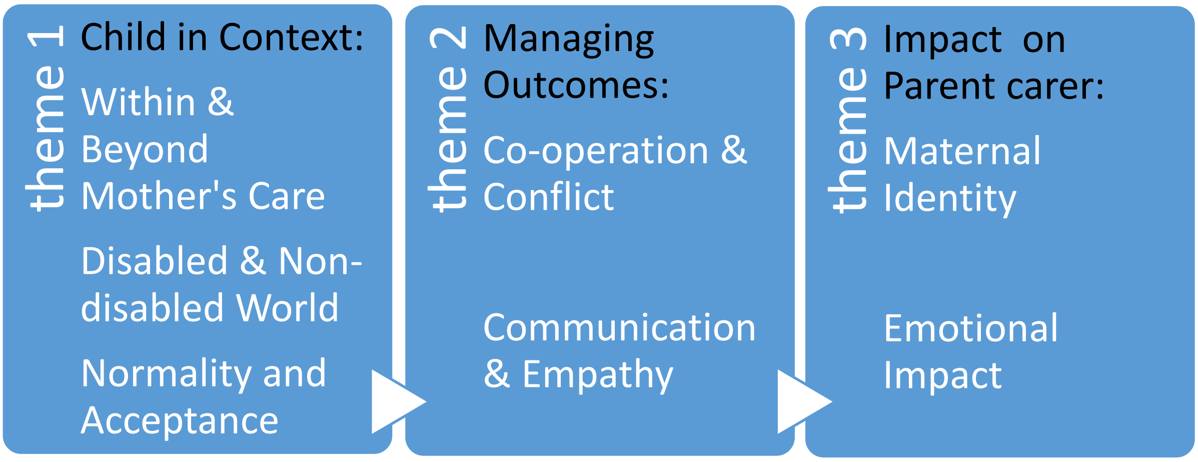

Figure 4 – Stage 1 Themes identified

Theme 1 – the Child in context

The Child in Context has three subthemes*: Within and beyond the mother's care*, which explores the mothers' accounts of their caring relationship with the child; *Between the disabled and non-disabled world*, which considers where the child fits in in relation to both the physical world and the social world around him; and *Acceptance and normalisation* which looks at both parental and service provider's views of the child's disability.

Within and Beyond Mother's Care:
The initial process of diagnosis has introduced these parents to the world of disability. Previous research has stated that diagnosis is important to parents for seven reasons: validation, information, procuring services in the school system, early intervention, support, curiosity and prenatal diagnosis (13), but even a diagnosis does not always offer these solutions, and the mothers are still understandably very protective.

The mothers in this study perceived the vulnerability and risk that their disabled children are exposed to. Any mother would typically feel protection and care for her unborn child, but for Christine this feeling went beyond the norm, when they discovered their child had life threatening physical complications before she was born:

> *C: as soon as she's born she's got to do it on her own that's when we're going to know*
> *I: mmh*
> *C: so it was part of me didn't want her to be born (.) I'm going now (cries)*
> *I: oh sorry*

> *C: didn't want her to be <u>born</u> because it was out of my control*
> *I: yes you*
> *C: and I didn't know then I was like "just stay where you are cos you're absolutely fine as you are - when you come out you've got to do all of that on your own"*
> Christine, l.103

Keeping the baby inside, kept her safe because the mother's body sustained her; once she was born the child's own disabled body had to keep her alive. It is this extra burden of care and protection that mothers of disabled children carry, whether it is an actual physical risk as in Stuart's case, which is witnessed by both mother and carers:

> *I had a fight to get a harness on him for his protection and everybody else who was with him's protection because he was throwing himself out of the wheelchair onto the road*
> Naomi, l.299

or an imagined risk beyond the mother's care:

> *the fact that he is non-verbal because that makes him incredibly vulnerable in terms of people taking advantage of him not knowing when something has happened to him (cries) God sorry*
> *I: oh sorry*
> *R: no no it's fine but you do just think you know if anyone did anything to him he couldn't tell me*
> *I: yeah*
> *R: so that's really hard*
> Rhiannon, l.563

The reality of having a child that is unable to speak, and therefore has limited communication, magnifies the maternal fear of the risk that any young child might fall victim to a predator.

For Helen, the knowledge that her son has limited social understanding increased the risk when he had run away from an emergency respite setting; it also strengthened her belief that his interaction with the real world might have had dire consequences.

> *he'd run away barefoot in a town he didn't know and was found by a kind elderly lady who sat with him while he sobbed on the pavement erm he could have been found by any predator Simon has no social understanding and if they'd have said "I've got puppies or sweets" he would have gone…and I would have been stood next to a grave it's just unbearable thinking about it*
> Helen, l.757

Consequently, engagement with the real world is fraught with dangers (both imagined and real). Published literature indicates that these aspects of vulnerability, negotiating risk and sometimes over protection by the parent become critical when the child approaches adulthood (14, 15, 16), so they are not problems which diminish with age, which they would with a child without disabilities.

Between the disabled and non-disabled world:

Parents are therefore faced with the differences between the disabled and the non-disabled world. Published literature describes how families with children with a disability "are disadvantaged in that they do not enter social interactions on an equal footing with others" (17), which is borne out in these accounts.

Wheelchairs are a universal symbol of disability and represent obvious physical barriers. However, for one mother having a child in a wheelchair presented additional problems as she also had a son with Asperger's; she explained

> *if we go out anywhere I've got to stop him running off while I've got his sister in a wheelchair and there's certain areas I can't go to in the wheelchair*
> Rachael, l.569

And as a result, she had had to ask social services for respite for her daughter, so she could take her son out [3]. So the wheelchair was a barrier, not just for her daughter, as it impacted on family life.

Additionally, the experience of stereotypical attitudes towards disability – the 'does he take sugar' approach – are not uncommon within this service user group. Naomi describes implications of the wheelchair for her son, Stuart:

> *it involves everything in his life being in his chair…just because … he's in a wheelchair and he can't speak I think a lot of people think he's that he has no intelligence at all*
> Naomi, l.264 .

Parents want their children to be included in the non-disabled world, especially as their children are growing up and developing; in some sense they are testing out the limits of the child's disability,

> *we didn't want Elizabeth just mixing with special needs kids…because well what stimulation is she going to get from them and is she going to be the most able bodied? the least? the most socially? you know aware? or the least*
> Christine, l.1260

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[3] Spending time with other children was outlined in the Regulations for Short Breaks for Carers (2011) as a criteria for accessing Short Breaks, but Sophie requested this support before those regulations were in place, and she faced considerable difficulties over the funding which was batted between social care and health.

and at times they have to come to terms with the differences, in order to make sense of the world that they as a family now inhabit:

> J: *and I had to sort of stomach the you know the sort of development rivalry between parents "my little child's doing this" and "my little child's" my child wasn't doing any of it do you know what I mean*
> *I: yeah*
> *J: she couldn't even sit up straight for goodness sake*
> *I: yeah*
> *J: but it didn't bother me because I just needed her to surrounded by mainstream children as well because otherwise you get this distorted world of every child is disabled you know*
> Jennifer, l.241.

However, with autism, it is not uncommon for the child withdraw from the normal world, both socially and from education:

> *M: and he had taster days at my school*
> I*: yeah?*
> *M: to see if he could manage in a mainstream placement but it was Scott's decision at that point he was in Year 9 and I think to stay at (special needs school)?...because he said he found it too stressful to try and fit in? with…with the the normal behaviour (laughs) if that makes sense*
> Molly, l.311,

and this self-exclusion sometimes impacts on the whole family, who may become socially isolated:

> *my son has er a disability that means that he doesn't cope with lots of social situations we have been a prisoner in our own home often because he just doesn't cope with going out*
> Helen, l. 250.

Therefore, parent carers are faced with typical barriers and stereotypical attitudes towards disability as well as self-exclusion, but also they have to confront exclusion from systems which they feel should support their child to be included in the normal world. Previous research has shown that it is not just non-professionals who need educating around what it is like to be the parent of a child with a disability; positively, Forlin &Hopewell (2006) found that trainee teachers were keen to work collaboratively with parents after hearing the story of one such parent, suggesting that work needs to be done at a grass roots level for a universal understanding (18).

Often the problems arise around understanding and providing the appropriate support for behavioural issues, which are part of the disability:

> *because he he food bolts he was at risk of choking all the time he needed someone with him all the time and erm the primary school that he went to made it very clear that he was the most challenging child that they had ever had and that was quite an imposition*
> Rhiannon, l. 350.

For Molly's son:

> *he was diagnosed at about the age of three with Asperger's' Syndrome from the Child Development Centre and I managed to him fully statemented when he entered nursery erm so that everything was in place for school erm but even so his primary placement even with a full statement erm broke down and he was excluded in Year 6 … there was a change of head and (.) she made it very apparent that erm (.) she really wasn't comfortable with child with special needs at the school*
> Molly, l.32.

The impact of this exclusion was far-reaching with the child suffering mental health issues and a withdrawal from school for nine-months, which in turn led to other agencies being involved. When education, in particular, has been working towards inclusion for many years now, these findings of exclusion are shocking.

It is apparent, therefore, that some settings recognise the issues but still consider themselves inappropriate places for disabled children, as they have limitations in dealing with the disability (whether those are staffing levels or attitudes). At times, they have to recourse to higher authorities, as happened with Helen's son who ended up in police custody, even though he was only 11, because his behaviour was so challenging at school.

Acceptance and Normalisation:

Having a disabled child, therefore, represents a deviation from the norm, either in terms of physical development or behaviour. The result for parents is identifying and dealing with the risks that that deviation presents, and looking beyond the risks to assess what would be good outcomes for themselves and their children. Within the accounts then there is a sense of adjustment to the disability, as well as consideration around what is normal. Published literature debates the meaning of normal and whether normal is meeting a specific standard or falling within an acceptable range: however, for these parents, normal is "a value-laden concept that represents different meanings for different people" (19) .

For a child with physical disabilities, this adjustment might be represented by the medical profession intervening for the child's best interests, for example a child having surgery to correct a faulty heart valve or knees or spine. Any surgery is followed by an assessment of its success and implications for the future. Sometimes these are complex: for example, for Rachael's daughter, Sophie, physical disabilities are interlinked. The curvature of her spine means that she will remain in a wheelchair, and therefore corrective treatment to her feet is unnecessary, as she won't stand on them even in a standing frame. Parents are involved with the professionals around making these decisions, but also have to come to terms with the implications of those decisions.

For children with behavioural issues, normality can be context specific:

> *generally at home he I mean if anyone else saw his behaviour it would obviously be vastly abnormal but for us it is normal and that's what he does and we all just work around it but the other two can be more demanding than him at home*
> *I: yeah*
> *R: when we go out it's different it's very hard work*
> Rhiannon, l.835

Parents can accept behaviour in the home because they are in control of that environment; outside the home a child's behaviour can present different challenges, for everyone. This problem is widely recognised despite successive political actions towards a more inclusive society; for example, research around leisure activities for disabled children reveals that there is still "inherent and embedded discriminations in favour of those children and young people who are perceived to be 'able'"(19).

Although parent carers do come to terms with their children's disabilities, there are instances when those disabilities are not always accepted: either by the child who has some understanding of the differences and stated he must be a "*horrible boy*" if this is what autism does to him, asking his mother to "*get rid of it*"; or possibly a rejection of disability by a different mother, who said "*if I could swap some of Luke's intelligence for some social acceptability and good behaviour and less aggression I'd do it in a second*" .

Despite the attempts at normalisation, life is different for families of children with a disability, especially for siblings as Shelley explained:

> *very often it'll be "hang on wait a minute wait hang on Gareth comes first Gareth comes first second third and fourth you have got to wait" and they get that you know they do get it they are very very good they've from little ones like my one son he was only four when Gareth was born and I think it does it does sort of change things it does sort of change things in the way you are in your in your life in your home you know it has to doesn't it really*
> Shelley, l.979

Normalisation is part of the process of coping with the disability, and research has shown that such normalisation, along with parental empowerment, leads to positive gain (20). Conversely, it was found that lower parental empowerment predicted parental distress. However, parent carers must then first acknowledge and adjust to their child's disability, as well as overcome the barriers of exclusion and prejudice, before they can engage effectively with systems and request support, whether that is in hoping children can access education, lead healthy lives, developing opportunities or, within, the wider family context, for parents to have a break from caring and do what other families do, by requesting respite.

Theme 2 – Managing Outcomes

Parents engaged with agencies because they were either referred through health or education, or because they actively sought help. This theme explores what happens when parents engage with the 'system'. Two subthemes were found: *co-operation and conflict* which explores what happens when agencies work together, with the parent, and what happens when they do not work together; *communication and empathy* explores some of the ways communication affects joint working and the parental role.

The interaction between parent and services is seen as a two way process, whether that is positive or negative:

> *people we've met along the journey professionals (.) we've certainly had an impact on them and they've had an impact on us*
> Christine, l.91

As Christine is the mother of a young child, it is heartening that she sees working with the professionals as a mutual two way process and does not see herself just as a recipient of services.

Co-operation & Conflict:

The interactions between parent carer and professional are, however, set against a backdrop of expectation and eligibility, which become apparent through the mothers' accounts, and it is these expectations that influence outcomes. The mothers in this study do not necessarily expect everything to be perfect, or just to be given services; at times their expectations are surprisingly low:

> *I am relatively forgiving of people … I don't really expect people to have that much expertise or experience so I you know I knew there would be limitations and they did what they could and I was quite happy with that*
> Rhiannon, l.322

However, there is a sense of safeguarding oneself from future disappointment, when she says:

> *I think there are some things you can plan for but if you get too rigid and have expectations I think you can end up disappointed or you know … you don't want to feel that you don't want to have regrets.*

Expectations, therefore, may be tempered by the uncertainty around the child's development. Although not all the mothers felt that, and in particular the mothers of children with autism (but not learning difficulties) expected their children to be included, and felt they had to fight for what their children deserved.

Through the accounts the phrase "*going above and beyond*" is used by some of the participants (Christine, Helen, and Rhiannon) to describe how individuals have gone out of their way to help, which has exceeded their expectations. In some ways, the examples of a pharmacist contacting the surgery, or the policeman calling back the next day to ensure the family is safe, suggests that expectations are not necessarily high of people in their professional roles, because they are impressed when those individuals have given a little extra support. It also suggests that the efforts of individuals are not just noted but also appreciated.

There are plenty of examples of good co-working throughout the accounts. Predominantly these were when the child had health needs, and in particular the Children's Community Nursing Team was praised, in the way that they had both supported the parents (Christine, Naomi and Rachael) and co-ordinated much of the care around the child. Christine said *"she was our focal centre person for everything*". Naomi mentioned the advocacy role the nurse took on, accompanying her to appointments to support and ask questions on her behalf.

But also other teams worked together to help both child and family:

> *Physio and portage came out and did some I think they may have done two joint visits because portage wanted to know what physio was working on so portage could integrate that into the games*
> Christine, l. 1189.

Sometimes this co-ordination was as the result of the mother taking control, as Rachael felt she had to:

> *R: it got to the point where they were all coming on different days and I was thinking "I'm never going to get out of the house" and I actually took the bull by the*

> *horns and said "right you can all come but you can come on Thursday and you have a one hour slot"*
>
> *I: oh wow*
>
> *R: I actually had (laughing) them passing in and out on the front door and <u>meeting</u> each other because a lot of these people had never actually met each other*
>
> Rachael, l.85

Rachael's account shows the somewhat ad hoc arrangement of meetings, and lack of co-ordination between services, which it fell back on her as the parent to organise.

Or as Jennifer organised dental care for her daughter:

> *we've had to push that yeah*
>
> *I: and when you say you push it do you have to keep ringing people or*
>
> *J: I contact our dentist who contacts the dentist there who then contacts the do you know what I mean*
>
> *I: yeah*
>
> *J: who contacts the plastic surgeon and but I keep saying "will the dentist be here?"*
>
> Jennifer, l.68.

Additionally, the co-ordination of services through Severndale received both praise and criticism. One mother commented that when they were new to the area:

> *we moved here and everything was so straight forward going into Severndale (.) the transition was so easy*
>
> *I: was it yeah?*
>
> *R: yeah I mean they they Shropshire agreed straightaway to honour the statement that he'd already got and didn't want to make any changes at all Severndale were happy to take him and literally I dropped him off first day with me this teacher and she went "okay see you later" and I went "hang on don't you want to know this this and this" they were completely used to dealing with it.*
>
> Rhiannon adds:
>
> *R: we kind of feel very cocooned at the moment because Severndale and the stuff that we get through school for us works really well*
>
> *I: yeah*
>
> *R: and the fact that Edward has a diagnosis and he needs a lot of help and people recognise that his safety is an issue we get the support and there's no*

> *questions asked which is actually which makes it much easier for us than me having to fight*
> Rhiannon, l.897.

Access to services, such as incontinence services, through the school nurse were seen as a positive by the participants who had accessed them. On the downside, access to Speech and Language and Occupational Therapy, were felt by some mothers to be controlled and limited.

For children with medical needs, a good relationship with the family's GP relationship was acknowledged, for example Christine recounted the advice she had been given by Birmingham Children's Hospital:

> *"the best people would be your GP get a good relationship with your GP and that will make your life a lot easier try and use a local chemist rather than your supermarket one get a relationship up with your pharmacist" erm and we did our GP has been apart from once he's been amazing*
> Christine, l. 437-441

However, beyond Severndale and moving into adult services, life is more challenging for parent carers of children with high medical care needs, especially when they lose access to the paediatrician:

> *R: Obviously there has been huge changes because we've gone over into Adult Services*
> *I: yeah*
> *R: erm so <u>everybody has changed</u> I mean some of the other services obviously we dropped along the way erm and picked up some bits and then dropped them erm but now we've obviously lost the paediatrician*
> *I: mmh*
> *R: who controlled all that <u>everything</u> from a health point of view erm and only referred out to specialists if there was a specific issue that they wanted more expert overview on erm so now well you move from a paediatrician they refer to all the individual consultants*
> Rachael, l. 216-226

See Table 3.

Rachael also feels that the transition for children's services to adult services could have been better co-ordinated:

> *R: I suppose there are so many new people to meet it would be nice to have meetings with the current provider and the new provider with us at the same time I mean we I don't know what sort of hand over there was from Community Children's*

> *Nurses to District Nurses but I certainly was never involved in it (…) it was months before the District Nurses actually came out and sat down and met with me*
> *I: mmh*
> *R: and Sophie*
> Rachael, l.859

Although, Rachael and Naomi were the only participants to mention these problems around transition, their experiences are more widely recognised. A Care Quality Commission (CQC) report looking into children's transition to adult health services (2014) stated that there was "a significant shortfall between policy and practice", and that "the system is fragmented, confusing, sometimes frightening and desperately difficult to navigate" (21). A Cheshire & Merseyside NHS pilot project found themes of a lack of understanding around transition, variable plans and experiences, poor communication, as well as variance in how people were involved in the process, leaving them feeling "fearful" and "battle weary". Additionally, families indicated that they had lost services throughout the transition process. (22).

Beyond co-operation and co-ordination, there is a recurrent theme of conflict throughout the dataset. When Molly says "*I just seem to have spent half my life battling for one thing and another"* she speaks of a common experience of parents of disabled children, acknowledged in published literature. (16, 23, 24)

Some of the issues raised by participants are around accessing services that a person without a disability would take for granted– for example the dentist. For children with autism and sensory issues the dentist presents real challenges, and the associations with the building can present real challenges. Both Naomi and Jennifer have accessed domiciliary dental care, but pressure on services mean that their children have not been seen as often as they feel they should.

Similarly, eligibility criteria set expectations for parents, and even if the child does not fit strict guidelines, parents may be confused and disappointed. For example, Shelley could not understand why her son did not fit the eligibility criteria to access respite at Hope House; she considered his epilepsy as "life limiting", due to its severity, as well as having the backing of specialists who advocated on her son's behalf. In this case, the parent must reconcile the child's condition with someone else's criteria, which has the potential to lead to internal conflict as well as conflict with service providers. For Shelley, however, this was a battle she did not want to fight and she let the matter drop.

Services accessed as an adult (co-ordinated by Mum)

1. **Health**

a. Consultants

- Respiratory, plus respiratory nurse
- Ophthalmic
- Urology
- Neurology – plus epilepsy nurse
- Orthopaedic
- Gastro, plus endoscopy unit (PEG) & Nutricia Homecare (feed & equipment)
- Also Audiology Department

b. Other Health

- GP & dispensary
- District Nursing Team
- Complex Health Care Team
- Dietician

2. **Services**

- Continence Service
- Wheelchair Service
- Home Oxygen Team
- Independent Living Centre (slings)
- Orthotics (boots)

3. **Care**

- Nursing Agency
- Independent College Day Opportunities (Monday – Friday)
  - Accesses SALT, Physio and OT through this service
- Out of county respite
- Charity run children's hospice (overnight respite and outreach to 2015)

4. **Equipment**

Ceiling track hoists (x2)	6 monthly service
Wheelchair lift	6 monthly service
Electric bath	
Suction machine	Annual service
Oxygen concentrator & cylinders	6 monthly service
Feed pump	2 yearly service
Nebuliser	Annual service
Airflow pressure mattress	
Hearing aids	
Motability car	

Table 3: Services accessed as an adult by a young person with complex and multiple healthcare needs

Expectations are not just around eligibility to access services, as Molly says about her son's exclusion from his primary school: "*they hadn't behaved ethically or morally or even legally*" (Molly l.62). Molly's own fight took her to an Ombudsman for disability discrimination, which she won, but her son was excluded anyway, hence her understanding that the school had not behaved legally. Whilst these are her expectations of what a Christian school should do, they can be generalised to other services.

The learning disabled children at the centre of these accounts are often portrayed as not having an influence in their care, because they are not necessarily aware of the role of the people they come into contact with. However, the intellectually able children, such as Molly's eldest son, who has Asperger's, could give his opinion, for example when he refused to go to CAMHS:

> *…main CAMHS not CAMHS LD erm but very quickly Luke refused to go because he didn't really see any benefit (sighs) erm and also he would be too disruptive but what I did I carried on with the appointments so that any advice or support I needed I would seek directly and then try and implement it myself*
> Molly, l.243

In such a case, the parent is left resolving issues in the face of the child's non-co-operation. The feeling that there is difference in attitude towards autism between CAMHS-LD and CAMHS is revealed in these accounts, particularly by Helen who felt that mainstream CAMHS did not acknowledge her son's autism. However, although those were the historic experiences of the participants, PACC recognises that there has been considerable work done around ASD within Shropshire Local Authority area within the past two years; the Shropshire Autism Needs Analysis was completed in July 2015, one of the recommendations being a focus on the availability of information and communication with families.

The mothers have to choose which battles to fight:

> *so I was trying to fight to keep Scott's direct payment and then he was excluded from school so I stopped the fight for the direct payment because keeping him in education was more important and I couldn't do both things*
> Molly, l.523

She was left having to choose between fighting for his right to education, or for support for herself, when she was entitled to both. The fact that parents put their child's needs before their own has been researched and documented, and it has been found that at times they have guilt, believing that they are being selfish if they request help to meet their own needs (25).

Parent carers not only expect their children to be treated appropriately, but also hope that they as parents will be supported by other services in challenging the limitations of their children's disabilities. For example, Shelley wants her son to be walked into school from the bus by transport assistants because that is what she does, but transport will not do this. She relates how she asked:

> *could you put him on a bus with someone who would walk him down the corridor "no we're happy to take him in a wheelchair" I said "no he doesn't go into school in a wheelchair" so I've said "hold it there" I said "what I'm going to do is I'm going to report you to social services because you are basically trying to deskill my son"* Shelley, l. 644

She feels that not only is she not being supported in trying to achieve positive outcomes for her son, but the service is in fact taking away something her son is able to do. This also effects other outcomes, as she cannot have a complete break when he is in overnight respite, because she is still going up to school on respite mornings to walk him into his classroom, as the services are unable to accommodate this request. Furthermore, this issue around walking him into school is only one step towards achieving more independence, as she wants her son to become familiar with transport taking him to school in the mornings (which she currently does), in preparation for his transition to his new college.

For young people with autism, this process of familiarisation is vital for positive outcomes; Molly had to invite her son's taxi driver in for a cup of tea, so that her son would see him as a friend before he would go to school with him.

In many instances, the mothers resorted to higher authority to resolve issues, whether that it is the social worker in the first place, ombudsman for educational exclusion, head of the council about the funding for respite care, or educational tribunal. These steps lead to more people being involved in their lives and additional stress, as they have to argue their cases and await decisions. Within the group the outcomes of such appeals were mixed, with some issues resolved quickly and others less successfully. These fights are very significant for the mothers because they represent the extremes that they have had to go to in order to secure good outcomes for their children. [4]

Sometimes, however, there seems to be no alternative but for the parent to resort to drastic measures, especially when the treatment a child has received evokes strong emotional responses:

Jennifer felt that school had failed in their duty of care, despite having behavioural specialists at hand to deal with her daughter's self-injurious issues; and it was this feeling that her daughter was being neglected in turn that prompted her to say to the school *"I can't manage this anymore " I said "you are driving me absolutely to the end" I said "I just feel like chucking us both in the river"*. She was then reported to social services as a safeguarding issue, when she felt it was the <u>school</u> who should have been subjected to scrutiny.

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[4] Individual cases are not quoted here because of the identifying nature of some of the appeals.

Jennifer's threat might be interpreted as a case of "extreme care" as defined by Dr Chrissie Rogers, a sociology lecturer at Aston University. In her book Critical Approaches to Care (24), Rogers writes

> *"when stories of a mother killing her disabled child hit the media, moral and ethical questions are asked. That might be about the care for the child, the mother's mental health, or the lack of care experiences by such families from external agencies and wider society"*

and in quoting examples she goes on to say "*these examples of extreme 'care' are important in attempting to understand the enormity of both practical care work and emotional work that some mothers experience in their mothering journey"* (p.134). In Jennifer's case the threat was made in a moment of exasperation, not as the result of mental illness, but nonetheless highlights both the practical and emotional pressure that she was under at that point in time. Parent carers feel that if they can look after their children in appropriate ways, despite tremendous stress, then the professionals should reach those standards too.

Communication and Empathy:

Good communication is essential to co-ordinated working between parent carer and professional. Poor communication, on the other hand, can exacerbate difficult situations for these mothers, and it is important to consider the range of methods of communication, in order to understand the problems encountered.

Firstly, it is about co-ordination between services. For those children who are admitted to hospital note sharing is important:

> *we did arrive at Birmingham once when they hadn't had any notes so (.) but generally it was okay*
> Jennifer, l.64;

> *each hospital doesn't seem to have they don't have notes from another hospital so each hospital will only have their own set of notes on him so I have to if they ask me a question about anything that's happened in another hospital then I have to explain it all to them*
> Naomi, l.97.

The mother's role becomes key. Maybe this would happen with any child, but the parents of disabled children are often dealing with behavioural issues, in unfamiliar surroundings, in a stressful situation at the best of times, and then, as Rachael explained, the professionals are turning to them for help, information and sometimes even advice. The lack of communication is not just between hospitals but also within services as Rachael also explains:

R: it's the co-ordination of it
I: that's the problem is it
R: that's huge and they don't really talk to each other a lot of them
I: so you're having to
R: which is why I am the person at the middle of that
I: yeah
R: because I am the only person who talks to all of them
I: yeah
R: yeah well Sophie is in the middle there as well with me but
I: yeah but you are saying it on her behalf
Rachael, l.1431

The mother's role of co-ordinator becomes central, and she acts on behalf of her child, who cannot communicate with the world, so she is not just dealing with co-ordinating care on behalf of the child, she is pivotal to the whole process.

Not only are parent carers pivotal in their child's care, but they are not always sure what that care packages should be:

R: the Community LD nurse does the Continuing Health Care assessments now erm (.) and we have those every twelve months
I: right is that to sort of check that the package is … well it's not really package is it?
R: you would think so there is a package but actually they just come and check that she is still eligible for funding and then they write to you and say "yes you are still eligible for funding"
I: like she's
R: but they don't actually list what that funding covers (laughs)
Rachael, l.675

A lack of clear communication about the package has left Rachael uninformed about exactly what her daughter is entitled to.

Furthermore, communication between parent carer and professional should be about knowing whom to talk to and being able to get hold of them: Rachael goes on:

I did think at one point that we did have a named person but I never seem to deal with them so I just you never get them on the phone either you just ring them up and leave a message on the answerphone cos they're not in during the day and eventually somebody rings back (.) and leaves you a message on your answer phone because you've gone out (laughs)
I: (laughs)
R: so you never actually speak to them (laughs) yeah erm so that's made life a bit more difficult
Rachael, l.503

Mothers can see that the local authority have built systems which facilitate communication in the past, but that cutbacks have affected outcomes.

> *I'd like to see them all actually communicate with each other better they erm we thought when children's services was moved right next door to Severndale it was because everybody was supposed to be able to work together and then you'd go for an appointment and you'd be right by school … and it ended up that they started moving the clinics out of there again and so that didn't happen which was going to be brilliant (.) consultants used to go into schools to see the children so that they were familiar people in familiar surroundings and that's stopped so I think that should happen again*
> Naomi, l.503.

Language:

Good communication is not just about having the right person in the right place with the right information. It is also about the language that is used, and that is not just about professionals using accessible language and explaining things clearly to parents, but about professionals understanding what parents are saying, and not making them feel inadequate or belittled.

> *CAMHS don't erm take your experience they just see you as "oh the parent" well actually I am my children's expert I live with them 24/7 and know what creates a problem erm I regularly be had erm language erm that I used to explain my children's meltdown belittled as well (.) if I say "meltdown" they say "oh oh that's what you call it" well no that's what it is it's a meltdown or erm red mist "oh oh that's what you're saying it is" "no that is what it is"*
> Helen, l.158

Although Helen's child can speak, he interacts with the world in a very physical manner when he is scared or angry, as his autism prevents him from expressing those emotions verbally. Therefore, Helen uses language that reflects the physical representation of emotions in order to explain what is happening with her son. The fact that professionals dismiss this language indicates to her that they do not understand the full extent of her child's fear or anger. Helen is not alone feeling this condescension. The finding that parents feel their concerns dismissed by professionals on the grounds of their emotional involvement with the child was discussed by Todd & Jones (2003), and has been identified as a stumbling block in the way of good co-working between parents and services (25).

The feeling of condescension or dumbing down is echoed by Jennifer:

> *I've had to really up my game I've had to say in meetings to say to people "excuse me it's my child that's got some learning difficulties not me so you don't need to talk to me in that I do understand what you're talking [about]"*
> Jennifer, l.792.

Additionally, parents often don't feel listened to, when service providers refuse to acknowledge the issues:

> *I think I think basically they should just listen more to the parents you know <u>listen</u> if parents are saying his wheelchair's not suitable any longer cos he's breaking the back of it instead of just waiting for it to be broken again and again and again they should listen really*
> Naomi, l.287.

For these mothers it is not just about being listened to, it is about monitoring a child's development, being believed and having some credibility when concerns are raised. As Molly explains:

> *Whoever has contact the most contact with the child in those early stages I think things should be monitored more closely and where a parent has concerns I think they should be listened to and paid attention because I don't think anyone knows a child better than their parent*
> Molly, l. 597-600.

These mothers recognise the need for co-working, and the term "listening", which really implies being understood and believed, reappears:

> *H: we need to start with them listening erm rather than them saying it's "them and us" they need to work with parents*
> *I: yeah*
> *H: erm listening to their points of view because they are the expert they may want I mean I had done a degree but there are many parents that haven't done a degree but they <u>do</u> know about their child they know what makes them tick*
> Helen, l.892.

This issue is not just between parents and services, but also between services:

> (professional's name removed) *went in who was fantastic with him and explained to staff why he behaved the way he did what they would have to do to ensure that he could gain the same education as everybody else and what support they would need to put into place and they would ignore her and she would come out shake her head and "I'm sorry Mrs C they're just not listening to me"*
> Helen l. 97

However, for parents it is not just being listened to and understood, but a hope that service providers will empathise with the child and the parent. Naomi reflects this wish, when discussing her dealings with Wheelchair Services:

> *… I had to ring them the other day about it the chair and she was just like "well nobody can come go up to see him today you know you'll have to bring him here" and I said "well I'm at work he's at school and it's broke on the way to school and nobody can bring it up" and she was just so "oh well you'll have to wait then" and I got quite upset about it thinking …that it's as if they're just not bothered about him you know about his his life's sitting in that wheelchair you know*
> Naomi, l.238.

The problem essentially is her child's problem, but the communication with the service provider does not suggest that they recognise that there is a child in a broken wheelchair behind the phone call, and just tells Naomi that she will "have to wait then".

Parents are advocates for their children, but for more able children the problems may arise when they have face-to-contact with service providers:

> *the last time Scott saw a psychiatrist at CAMHS the first thing she said to him at all was "do you hear noises?" (.) you know and Scott just said to her "I'm not crazy" and he walked out that's it it's just it's just bizarre they just seem to have no sort of erm skills in how to speak to children*
> Molly l. 443

With CAMHS, in particular, empathy has been recognised as a key issue that needs addressing, as Professor Peter Fonagy, from UCL discussed at the British Psychological Society Annual conference in 2013. For Molly, the lack of empathy she felt her sons were subjected to made her more protective, but did not deter her from engaging with services:

> *if at all possible I'd try and see people on my own erm also because I don't want to have to talk about the boys in front of them or to have them ask questions that they don't feel comfortable with*
> Molly, l. 463.

The mothers realise that although they may be in what they feel are unique situations, they, as parents, find support through empathy, usually from unofficial rather than professional sources:

> *I think that's what's really overwhelms me with having a child with disability working alongside PACC or the Shropshire Downs' Syndrome Support Group is the feelings are the same*
> *I: yeah*
> *C: but the experiences are so totally the disabilities are so totally different and I'm like "how do you know how I'm how do you know that I feel like that how do you know I feel like that?"*

> *I:* *yeah*
>
> *C:* *and that has just gone that has been my wow factor I suppose and there's some very good professionals who know that as well*
>
> Christine, l. 688.

Additionally, Helen mentions a speaker at a conference she attended, as someone who, for her, not only stood out above the professionals whom she feels have not shown empathy to her child and family, but who also made time to visit her family at home to give advice. Rhiannon talks about her childminder and health visitor, both of whom had previous personal experiences of disability and were consequently understanding.

So the empathy is not just about understanding the child's needs, but also what it is like to be a parent, and whilst Christine acknowledges that some professionals do understand, they are singled out as "very good", when perhaps that should be the norm. A particular incident when a professional had in Christine's eyes overshared information about her family led to an official complaint because:

> *she definitely hadn't hadn't put herself in a parent's shoes and that was in my complaint "how would I feel? And actually you'd feel pretty shite"*
>
> *I:* *yup*
>
> *C:* *and you know a lot of the other professional have have definitely had some or demonstrated some understanding*
>
> Christine, l.1365-1371.

Language of the accounts:-

Within some accounts, mothers mention particular incidents which reflect a feeling that the treatment they or their child receives is beyond a lack of empathy – almost as if the child isn't even recognised as a human being.

For Naomi, when she requested help from Wheelchair Services, she was told:
"Oh no we can't come out today it's Friday erm he'll have to stay in bed for the weekend until we can come out on Monday"… she felt "*It's like he's a dog or something*" (Naomi, l.220)

And the animal imagery is also seen in Jennifer's account. When her daughter returns home from school in "*a disgusting state her hair was all over the place and chewing her clothes",* she lodged a complaint.
"I said "my child has no dignity" I said "you treat her like an animal what's going on?"" (Jennifer, l.434)

For these parents, the interpretation that their children are sometimes seen as animals by service providers is their reality; in 2016 post-Winterbourne View Britain, this is a shocking finding. The language reflects not only how parents feel that their problems are not recognised by professionals, but also how undervalued and marginalised their children are by services and within society.

Theme 3 – Impact on Parent Carers

As discussed, parenting a child with disabilities requires some adjustment to the disabled context and alteration of expectations of not just the child but also the services provided. This third theme looks at two key aspects of the impact on the parent: *Maternal identity,* which discusses how using a variety of services impacts on the mother's own sense of being; secondly, the *Emotional impact* of multi-service use and how parents adopt coping strategies to deal with the situations they find themselves in.

<u>Maternal identity:</u>

First and foremost, the participants in this study see themselves as mothers who care for their children, as well as negotiating the system and, at times, fighting for what they believe their children are owed. However, what it means to be a mother of a disabled child essentially means coming to terms with the loss of the promise of a ‘normal’ child.

For the mother of an only child who is disabled this loss is acute:

> Mum: *I don’t know what a normal mother does (cries)*
> *I: oh sorry*
> *Mum: no it’s all right I can tell you*
> *I: shall I stop?*
> *Mum: no (.) I feel like I’ve missed out on being a mum*
> *I: mmh*
> *Mum: and I haven’t grieved for the child I never had*
> *I: yeah*
> *Mum: and I haven’t grieved for that feeling of motherhood and I should and I’ve been for counselling a couple of times but I just need to get on with it really.*

She has lost an opportunity for ordinary motherhood, but furthermore her involvement in caring for her child and all the services that entails, has meant that she hasn’t had time to mourn that loss. Her identity as a “normal” mother is therefore compromised, and she goes on to say:

> *what I mean because it is …such a thankless task and I think being a parent is you know you don’t expect anybody to turn round and say “oh you’re a fantastic mum” but when you’ve got a special child you actually do need people to say that.*

She not only feels that her experience is different to others, but the effort she puts in is unacknowledged, by people such as other family members.

For another participant, being a mother of a special needs child means never being able to switch off for her duty of care, and always being at the end of a telephone:

> *you can have help you know you can have somebody take him out for a couple of hours you can have somebody in the house but like with them (.) you know that everything’s fine you’ve got you still live with your phone … and even when he’s at school you still live with the knowledge you could be called off anything could happen* Shelley, l.1029.

The responsibility always lies with the parent; if services, which support the child, fail for whatever reason, the burden of care falls back on the parent, even if that puts both parent and child in situations of physical risk. For example, when Naomi’s son’s wheelchair broke, wheelchair services refused to go out on a Friday to fix it, and transport refused to take him home in a broken chair because it was a health and safety risk; however, she was expected to cope: to collect him from school and take him home on her own with a broken chair. The limitations of risk assessments illustrates the extent to which parents are expected to cope alone: as a single mum, Molly felt she was expected to look after three children singlehandedly, but social care risk assessments and insurance restrictions meant that her two sons had a one-to-one worker each, when they were being supported. Particularly amongst the single mothers in this study, there is a sense that being the parent carer of a disabled child is to be expected to cope when no-one else can.

Sometimes the mothers feel their parenting skills and, therefore, status as a mother is criticised by professionals, and even asking for help would be to compromise their identity as good parents; after a discussion with a social worker about family-based shared care, Rhiannon admitted:

> *R: there's a sort of barrier like "another family?" you know…and then you think "are we not a good enough family?"…*she continues *"maybe I should be able to cope with this on my own"*
> Rhiannon, l.690.

Whilst Rhiannon's doubt came from within, Molly felt that she had been criticized by CAMHS, who she says initially blamed her "*parenting skills*":

> *I did sort of ask them if that was the case that I also have a daughter who is 20 who's never had she's just graduated from uni erm and has no behavioural problems whatsoever apart from having had a very difficult upbringing with two brothers with different complex needs erm if it was my parenting then why she wasn't she illustrating the same behavioural difficulties*?
> Molly, l.417-422

The parenting role of the mother in relation to their disabled child has historically been under scrutiny for many years from professionals, whether that is Kanner and Bettelheim's attribution of autism being as a result of "refrigerator mothers" in the 1960s, or the scrutiny of social services in their child protection issues when doing assessments. The lack of recognition around the problems of dealing with a child with autism and challenging behaviour caused even stronger criticism of Helen's parenting skills when social services threatened to take her child into care. In published literature, parents are represented as "good" (nurturing, engaged in advocating for their child, whilst not overinvolved) and "bad" (emotional, possessive, over-involved) (15, 26) and parents recognise that they don't just have to look after their disabled child, but demonstrate it is done in an appropriate fashion whilst under the professional gaze. Parents of neuro-typical children do not have to endure such scrutiny once they have outgrown the services of their child's health visitor.

Within the accounts there are incidences of the mothers feeling isolated, not just from family and friends, but also within their marriages and family life as they take on the major burden of caring, particularly whilst the husbands work, or for the single mothers bring up the children on their own. (Although it is important to stress that there was one stay-at-home dad within the group who was the main carer, but who was not interviewed.) The emphasis on the majority of mothers being the major carer is borne out by the literature (9, 27). In our participant group, the mothers often felt they needed to be strong for their husbands and their other children, and consequently put on a brave face. Christine mentioned how she would chop onions in the kitchen to stop her children from seeing her cry. These accounts of family life are very personal and, given the context of the research with a small participant group within Shropshire Local Authority area, it was deemed inappropriate to quote the relevant passages for confidentiality reasons. However, it is important to acknowledge these issues as not only relevant but also having a significant impact on family life.

At times there is a struggle to maintain one's own identity, which can be affected by the interaction with services at times: Molly discusses how she felt isolated from her faith as a Christian as a result of her son's exclusion from a church school:

> *not only was my son excluded from school I felt excluded from church because I didn't feel I could go to church and see a priest that wasn't supporting my child with special needs or myself as a single parent struggling erm so since then I've not been back to church either so not only was Scott excluded from school I felt excluded from the support of my church*
> Molly, l.160-165.

Caring often impacts on the ability to work, which in turn impacts on identity. Jennifer stated she feels she needs people around her, "*work has kept me sane I need that for the social interaction",* but worries that working full-time may have affected her child's outcomes; she feels perhaps if she hadn't worked she could have brought her child "*on a lot more*", so there is an internal struggle between her own identity and that of being a mum. She says "*I need people around me to be me rather than to be Leona's mum*".

Other mothers work part-time, (e.g. Naomi and Shelley) or not at all (e.g. Rachael) because the co-ordination of services means they don't have time:

> *R: it is a full time job I don't I know I couldn't go out to work*
> *I: yeah*
> *R: because I couldn't physically juggle all these appointments erm that I have and these reviews and all the phone calls I have to make erm the equipment I have to order supplies and organising the servicing of all this stuff it's not physically possible*
> Rachael, l.969.

The inability to work brings a sense of insecurity around the future:

> *and a huge worry that crops up for the future is what happens when Sophie is no longer with us*
> *I: mmh*
> *RL is that actually this is my entire life now*

> *I:* *yeah*
> *R:* *and that could all disappear overnight…*
> *yes I suppose it's like a soldier being made redundant isn't it overnight and you weren't expecting it except that you've actually lost somebody at the same time*
> Rachael, l.1010-1034.

Her caring is a vocational job and losing that job would be devastating because it would not be just a redundancy but a bereavement as well, which would in turn affect her identity as a mother.

Furthermore, other participants have had to have extended periods off work to deal with the problems both their child and the services have presented; for example Molly took unpaid leave when her son was excluded from school for nine months. Looking to the future one participant, who works in a professional role, acknowledges that she may have to take career breaks to look after her child.

These findings echo those published (28) which outline that mothers of disabled children are limited in their work opportunities by limited appropriate childcare, and negative attitudes towards working mothers of disabled children. They also found mothers with "part time jobs did poorly paid work of low status, thereby encountering few opportunities to use their skills and abilities to the full", whilst mothers who attempted a full-time job experienced stress from the dual demands of home and work, and from "a fear that they were failing as mothers", as suggested by Jennifer's account.

Beyond caring for their child, the mothers have had to learn about their children's disability. Within the participant group, there were examples of very rare syndromes, which the medical profession generally are not necessarily well versed in. One family, having been informed of their child's syndrome following tests, were then referred to the internet as a source of further information by a consultant; the parents felt overwhelmed with the challenges that they read they might face. The mother felt they were given access to too much information at the outset.

Most mothers interviewed had attended conferences to gain information about their child's disability, and as a result considered themselves an expert in their child's condition. This is not an overstatement, but how they are also considered by the medical profession:

> *I started going to the conferences and erm what they were saying is she might have this she might have that so I came back and it was Dr X at the time and I said to her "right we want scans for this scans for that" cos she said to me "you've become an expert now in your child and your child's condition you'll know far about it than I do what do you need" I said "I want this I want eye tests I want this" so she went ahead and sorted it all out for us so*
> Jennifer, l.182-187.

Rachael similarly found that her GP would refer back to her:

> *there's some very very good doctors and they quite often ring me up and ask me things when they get letters from the hospital that they don't understand or test results and they are not sure of*
> Rachael, l.1322-1324.

Christine found she was more proficient at inserting her daughter's nasogastric tube than some of the nurses, who had never had to do it before. This sense of being an expert in turn does increase the parent's feeling of entitlement to opinions, but also exclusion at times when those opinions aren't listened to, as discussed in the Communication theme. The position of the parent as an expert may also bring about its own stresses as it may put pressure on parent, and in turn remove some of the responsibility from the professional. Additionally, sometimes mothers feel that they need to be qualified in some recognised way in order for professionals to accept their opinions. Helen mentions that she has a degree, which she believes gives her some credibility with service providers, but she also firmly believes that those parents without degrees should still be considered experts in their child's disability.

As experts, the parents are their children's advocates, throughout all the accounts, which sometimes leads to conflict and this can impact on parental identity. One mother described herself as a warrior:

> *you have to be a warrior parent unfortunately to get what you need but having been a warrior parent myself I now go and assist others because I support quite a few families in the county*, Helen, l.1002.

This concept was defined by Souza (2011) as "a reformulated archetype in the social construction of a good mother" who has to wage "battle against social and political forces to gain medical and educational interventions" for her child (29). Although there is reference to "fighting" for services throughout all the accounts, this example of a warrior is not felt by everyone. Other mothers say that they will fight to get what they feel their child deserves but they do not <u>want</u> to have to fight.

> *"I am really proactive and nosey and curious and stuff like that so I wasn't getting something that I thought I could get I'd go and knock down the door and ask"*
>
> Christine, l.1765

However, not only are they being advocates for their children and their families as demonstrated through Theme 1 and 2, they are also supporting others, to share their experiences, to provide support and also hopefully to prevent other people encountering the difficulties they have had. "*It was important for me to try and make sure that other people didn't sort of meet the same problems I'd met*" Molly, l. 359.

Rachael discussed the recognised maxim of "*the people who can shout loudest*" get the most, and voiced her concerns around those who did not engage with the system: "*I mean I* *do worry about a lot of people and think you know if that was me I wouldn't have got what I've got".* At the same time, she was keen to stress that her approach was what she considered a reasonable one "*there's making yourself known and putting your case forward and your argument in a structured and non-aggressive way*". Ultimately though, whether that is self-advocacy or on behalf of others, the mothers' accounts do concur that one does not have to be warrior mum to access services, but often but that process does often include a fight. Research suggests that "for many mothers, advocacy and activism are a major part of the experience of mothering a disabled child yet this remains a largely unrecognised role" (27).

Emotional Impact:

It is generally acknowledged that coming to terms with a disability is a grieving process which moves through stages, and at times it makes people angry:

> *that's the other thing it's made me really angry and you know I get really bitter and I don't suffer fools anymore if somebody complains that their child isn't folding their clothes up properly I feel like er saying*
> *I: (laughs)*
> *J: "get a grip" so erm yeah it has made me you know Miss Angry Rottweiler Steve calls me*
> Jennifer, l.784

However, the anger in these accounts extends beyond grief about the child's disability; at times anger is very strongly expressed with service providers, such as wheelchair services, transport and both social and educational services. (Healthcare services in general seem to evoke less anger, but individuals occasionally upset parents.) With the on-going fight and the anger also comes depression, as the stress of daily living as well as fighting took its toll:

> *"I got to the point where I couldn't fight for myself or my child any more I was exhausted and I needed someone to help us help do the fighting really"*
> *"you shouldn't have to fight for things that most people get given every day in life for free… it's exhausting and debilitating you know mental health and I've suffered from severe depression and anxiety over the years"*
>
> *Molly, l.390 & l.652*

Molly's accounts are extremely personal but are also indicative of universal experiences. Maternal stress and depression are well documented with published literature and especially amongst mothers of children with ASD. (1)

It is not only fighting but also a perceived lack of understanding and empathy which upsets these mothers. Naomi stated "*I was very I was angry and I get quite upset as well sometimes* " because she feels "*it's as if they're just not bothered about him*" l.288 and this in turn affects communication "*I was getting quite emotional on the phone with them*".

Naomi is not alone. Christine says *"I was so angry I really was for quite a while afterwards"* when information was overshared about her and her family (as mentioned in Theme 2). However, this works both ways, as one mother stated

> *I've got to a point I don't care who I offend or who I upset if it means my child is going to get the support that they so rightfully need I'll do it*

In the face of fighting for her child she has lost her empathy with the service providers.

At times, the treatment the parent carers received from professionals evokes strong emotional responses: such as Jennifer's threat to throw herself and her child in the river, as discussed above. But if parents continue to complain, their emotional responses can be misinterpreted and, in the case of both Helen and Jennifer, they have been referred to social services for safeguarding issues (neither of which were upheld). It suggests that instead of service providers dismissing parental complaints as emotional, they should consider why parents are so emotional in their responses to treatment.

In the face of their situations, parents adopt differing coping strategies. Rhiannon adopts both approach and avoidance coping strategies, by dealing with the practical day-to-day issues of her son's disability, she avoids dealing with the emotional impact:

> *I tend to be almost too the other way just keeping going and probably what the social worker said is true is that sometimes you kind of need to sit back and say well you know how are you actually feeling not what are you getting done today*
> Rhiannon, l.798-800.

Published research has shown that both denial and planning techniques have been used effectively by parents of children with disabilities to reduce stress (30). In Shelley's case, this extends to avoiding areas of potential disappointment or conflict

> *S: if something doesn't happen that I think should or if things aren't right I just think I'm not going to dwell on that it's negative*
> *I: yeah*
> *S: you know you only have to fill his life with positives and good moments and happy things you know that's how we look at it yeah*
> *I: yeah*
> *S: you don't want to be banging onto people that obviously you know aren't interested because it's a waste of time it's a waste of energy isn't it?*
> Shelley, l.338-346.

Although Shelley's reasoning might almost sound defeatist, explaining how it feels to have to discuss the problems with service providers who do not have any solutions, is described by Molly:

> *M:	it is exhausting for me it's almost like well here's all the problems erm they're all out there and then there's no answers as to how to deal those so you just have to kind of push them back inside again with no no way of dealing*
> *I:	no*
> *M:	with them and every time the process of getting them out and stuffing them back in it's just exhausting*
> Molly, l.690.

So although at times tackling problems and requesting help, which would be an approach coping mechanism, the stress of discussing issues that may remain unsolved produces further exhaustion and stress. Similarly, parents may feel they need to avoid certain situations, which may be sources of support, because they are not ready emotionally to engage, as Christine describes on her visits to an NHS run support group:

> *C:	(we) walked in there and you've got all of these well-meaning workers and mums and children and you're just like "er I don't want to be here"*
> *I:	yeah*
> *C:	"why do I need to be here? My baby's not doing <u>anything</u> how are you going to help my baby develop? when she's not doing anything(.) this is silly you're all talking you're like "ni-ni-ni my life's great" and you're like "<u>no no no</u> get us out get us out of there".*

In these instances, individual preferences need to be considered by service providers. For example, it may be important to remember that it is not just about mothers:

> *"I think Russell was more so not interested probably because he was a male and it was dominated by women"*
> Christine, l.756-77

Additionally service providers might consider parent carers as individuals: in this instance Christine admits that they are not "*main minglers*" anyway, and so wouldn't normally seek out social situations. Expectation of services may be that everyone should access the services they provide, but there has to be an understanding about if and when people are ready to do that.

Stage 1 Summary

The research question set out to identify:

1. The barriers parent carers face when dealing with multiple agency services
2. If there is any specific impact of being multiple service users on the health and emotional wellbeing of the family
3. The parental perceptions of how integrated the multiple agency services are.

It is fair to say that the mothers who took part in this stage of the project are all highly articulate women, but it is likely that their experiences highlight those of less confident individuals who would not come forward to be interviewed. Issues around communication are the main finding as to the barriers these parents face, in particular their opinions being heard and understood by professionals (Question 1).

The accounts of these mothers show that being a parent to a child with disabilities or additional needs is often an experience of navigating complex systems, encountering exclusion, conflict and a lack of empathy. Additionally, these experiences are often repeated across the services. It is clear from the accounts that there is a cumulative impact of repeatedly facing these challenges and barriers during interaction with multiple services, with the result that parent carers feel not listened to or not believed by a whole group of people, rather than just one person.

Consequently, their lives are impacted in both obvious and subtle ways and their identity as mothers is sometimes called into doubt, or altered as they take on the role of advocates. The effects are far-reaching influencing family relationships, work opportunities and even feelings of self-worth. The major impact therefore seems to be on the emotional wellbeing of the parents, rather than physical health. (Question 2)

There were good examples of joint-working mentioned, particularly in the areas of health and community nursing and co-ordination of services through Severndale. Lack of co-ordination, particularly at the point of transition from children's services to adult services was highlighted. So this part of the project would suggest that there is a mixed response to Question 3.

Given the small participant numbers, it was decided to take forward themes 2 & 3, *Managing Outcomes* & *the Impact on the Parent Carer*, to the next stage of the project, to explore how universal those experiences were, and to give a wider audience the opportunity to participate, and make suggestions for improvement.

Stage 2 – Mixed methods questionnaire

Introduction

The aim of the project was to explore the reality of the parent carer as a multi-service user. It was decided to carry forward Theme 2 (Managing Outcomes, including Co-operation & Conflict, and Communication & Empathy) and Theme 3 (the Impact on Parent Carer, including Parental Identity and Emotional Impact), in order to see if these findings could be generalised to the wider population.

Methodology

Design

Initially, it was decided to hold four or five focus groups, across Shropshire Local Authority area, with a variety of groups including parents of children with a range of additional needs and disabilities. However, despite widespread advertising of these focus groups through the PACC newsletter, website and direct contact with parent carers, it became apparent that there were not enough volunteers to generate adequate numbers, and represent a selection of disabilities. Consequently, a mixed methods questionnaire, loosely based on the original focus group schedule was devised by the author and two other PACC committee members.

The aim of the questionnaire (see Appendix 1) was to gather both quantitative data, around both the parent carer (participant) and their child (the service user), as well as qualitative data, which aimed to explore the parental experience. Questions such as ages of parent and child, occupation of parent, number of services accessed, were asked. Additionally, two questions with a five point Lickert scale (from strongly disagree to strongly agree) were asked to explore the issues around communication and parental opinions of their relationship with professionals. The quantitative data was put into Excel and basic descriptive statistics were obtained.

The qualitative section asked parents to contribute their views on when a service worked well for them, when a service did not work well, as well as the issue of empathy. There was also the opportunity to make suggestions for improving the parental-professional relationship. The qualitative data was analysed using thematic analysis (12), but in variance with Stage 1, specific questions were asked; the thematic analysis was therefore "theoretical" because the researcher was looking for specific answers, such as whether participants felt professionals were empathetic, as opposed to the "inductive" approach, used in Stage 1, where the themes were identified from the participants accounts, for example the topic of empathy emerged throughout the interviews but not in response to a specific question.

Participants

Participants were parent carers of children with a wide range of disabilities and additional needs. They were either a member of PACC, a parent carer of a child at Severndale Specialist Academy or both. The questionnaire was sent to 864 parent carers: 418 PACC members, and 446 parents of children and young people who attend Severndale Specialist Academy (which also includes the Futures and Mary Webb units). Care was taken not to send duplicate copies to those PACC members whose children attend Severndale (about 70 members). From this 60 responses were received; their profiles are discussed in the results section.

Data Collection

Paper copies were sent out with the January 2016 edition of Participate, the PACC quarterly newsletter, with a pre-paid envelope for return. The questionnaire was also advertised on the PACC website and by e-mail to PACC membership and was accessible electronically (although no parent took up this option). Participants were given one month within which to fill in and return the questionnaires. A consent form was attached to the questionnaire for participants to sign.

Analysis

The quantitative data was put in to Excel and basic statistical data was obtained. The qualitative data was typed up under the question headings, and analysed through thematic analysis (12). Initial notes were made in the right hand margin, and then re-examined for emerging themes. Notes were made during the process and themes compared across questions. Further analysis was undertaken during the writing up process. It was decided at this stage, that in keeping with the aims of Healthwatch Shropshire, it was important to include as many comments as possible (without too much repetition) for the individual voices to be heard. As with Stage 1, some comments about education settings were included, although they fall outside the Healthwatch Shropshire research project grant remit, as they impact on other areas of the service users' and participants lives, and in many cases are central to the child accessing other services.

Ethical considerations

A consent form was attached to the questionnaire outlining the participants' rights. In particular, they were informed of their right to anonymity, and it was explained that by signing they were consenting to the comments they contributed being reproduced within the report; each participant was assigned a number. They were also advised that comments about individuals within service provision would be anonymised. Additionally, participants were given a one week period to withdraw their contribution from the project, and the option to leave questions blank. Although no specific debrief form was attached, the questionnaire accompanied the PACC newsletter, which in itself is a source of support, and signposts other services, such as Face2Face befriending.

Results – Quantitative analysis

Participant profiles

60 questionnaires were returned. One was excluded due to cross-over with Stage 1 of the project. Out of 59 participants, 56 were mothers, 2 were fathers and 1 was a foster carer. The average age of the participants was 45 years old, with a range between 22 and 61, the median age was 41. Fig 5 shows the distribution of the participants' age in decades, with a concentration of participants in their forties. 61% were in paid employment, either at home or in a work place; 38% had part-time jobs as opposed to 23% who worked full-time. 24% described themselves as full-time carers and 13% stated they had "no work outside the home". There was some cross-over in categories as some participants described themselves as working part-time from home, working part time and caring, and 13% undertook some voluntary work, usually in conjunction with working part time. 2% of participants listed voluntary work as their only work.

Given that 57 out of 59 participants were women, these findings are in line with those published by Carers UK who state that "women aged 45 to 54 are more than twice as likely as other carers to have reduced working hours as a result of caring responsibilities". Carers are also more likely to have 'elementary occupations' because of the impact of caring (31). Carers UK research also showed that women were four times more likely than men to have given up work because of multiple caring responsibilities. Type of employment was not explored in this study, but would be an area for further research within PACC membership.

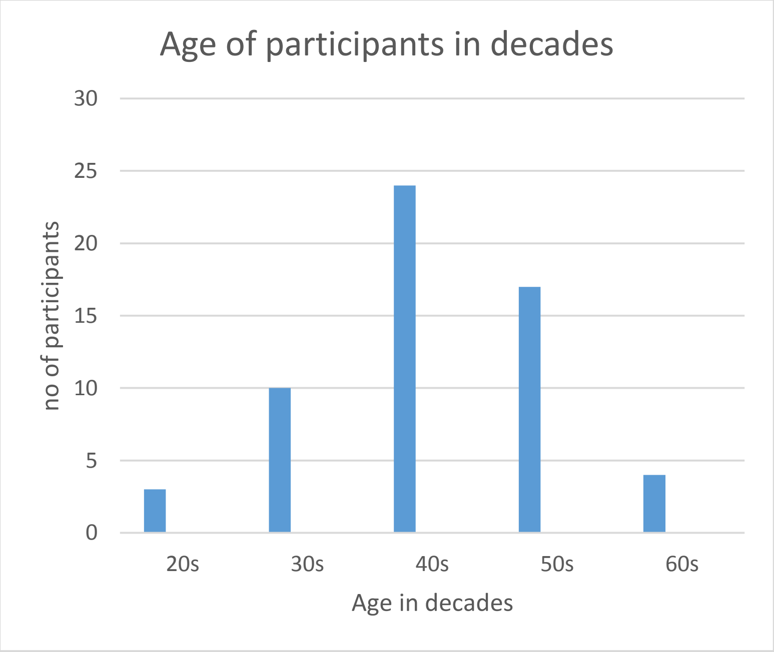

Fig. 5. Age of participants in decades

3 participants responded on behalf of two children, giving data on 62 children. The average age of the children was 11.45 years, with a range from 3 to 22; 29 children (47%) fell between 0 and 11 years old (primary), 26 children (42%) fell between 12-18 years (secondary/college) and 7 children (11%) fell between 19-25. These age bands were chosen to reflect transition stages, but it is recognised that with the variety of educational establishments accessed, the division between secondary and further education differs according to settings.[5] The categories are therefore used as a standard, and it is recognised that whilst one 19 year old may still be in full time education, another might have left education. Age at diagnosis was on average 4 years old, with a range of before birth to 14. 74% of children were diagnosed at 5 years old or under. Of the remaining 25%, who were diagnosed between 6 and 14, three quarters were listed as having ASD, which typically may not be diagnosed until later, especially in those children with Asperger's.

Categories of disabilities

Seven general categories of disability were carried forward from Stage 1: Autism Spectrum Disorder, learning difficulties, challenging behaviour, physical disabilities, medical conditions (such as epilepsy, asthma), mobility issues/wheelchair user and communication issues. The results are shown in Fig 6. The largest category was learning difficulties, followed by ASD and communication problems. This is not surprising since learning difficulties carries across a number of disabilities and is also a label which may cover a range of issues seen in different settings, from severe learning difficulties with developmental delay to dyslexia or dyscalculia. In this respect the population sampled reflected not only the general population, but also PACC membership.

On average each child was described as having approximately 2.7 areas of difficulties – for example ASD, communication and challenging behaviour may be coupled together; as were physical disabilities and mobility issues. Fig 7 shows the proportion of numbers areas of disabilities listed by participants. 72 % have three or less, whilst the remaining 28% have between 4 and 7 areas of disability.

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[5] Although a child is entitled to education until the July after their 19th birthday, those studying 'A's in mainstream would typically leave in the July after their 18th birthday.

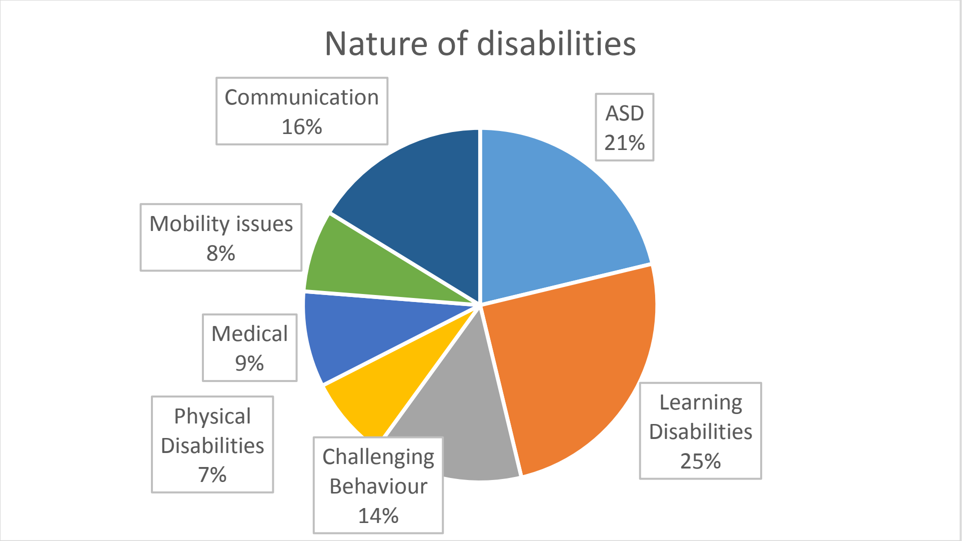

Fig 6 Chart showing the percentage of the nature of disabilities of the service users

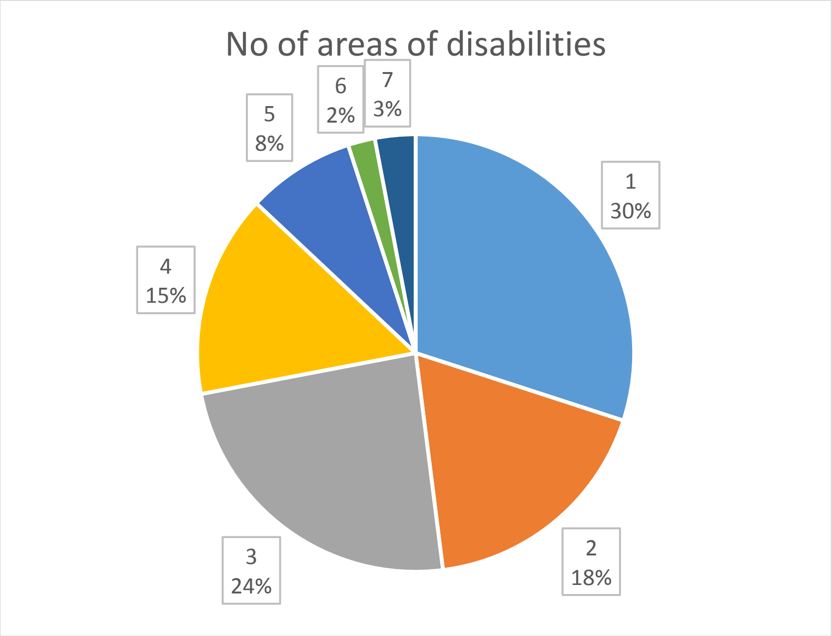

Fig 7. Chart showing the percentage of the number of areas of difficulties experienced by service users

Education

Figure 8 shows the type of education accessed by the participants' children. 66% were in specialist provision, whilst 20% were in mainstream, and 9% in both mainstream and specialist settings. 42% of the children currently attended Severndale Specialist Academy and Assessment Nursery, which may reflect the fact that the questionnaire was sent out to all parents attending Severndale, as well as PACC membership. This also reflects that Shropshire Local Authority is unusual in having only one special school, which takes children and young people with a wide range of disabilities from the whole of the county.

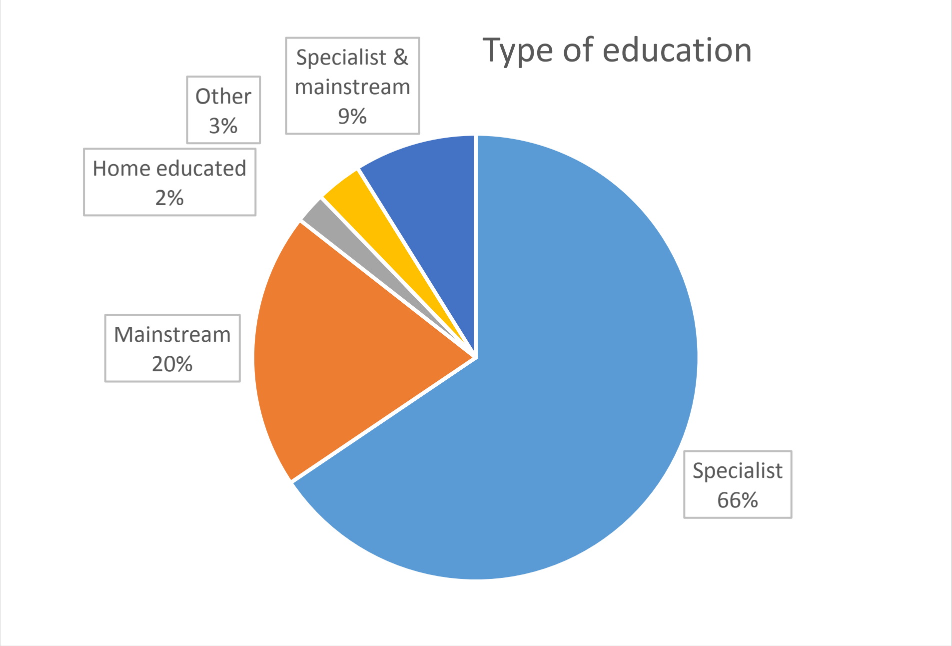

Fig 8 – Chart showing the type of educational setting accessed by service-users

Hospitals

Although 24% of children had medical, physical or mobility disabilities, 85% had accessed hospital care. 15% had not accessed hospital care and 33% were listed as accessing one hospital; 52% of the children had accessed two or more hospitals.

Royal Shrewsbury Hospital was the most used (86% of participants accessed it) followed by Robert Jones & Agnes Hunt Orthopaedic Hospital, Oswestry (39%), Birmingham Children's Hospital (35%), Alder Hey (25%) and Royal Stoke Hospital (5%). The questionnaire did not ask why they had accessed hospital, whether it was for screening purposes or for in-patient treatment, which would have illuminated whether these hospital visits were one-off visits, for regular treatment, or emergencies and in-patient stays (see Fig 9).

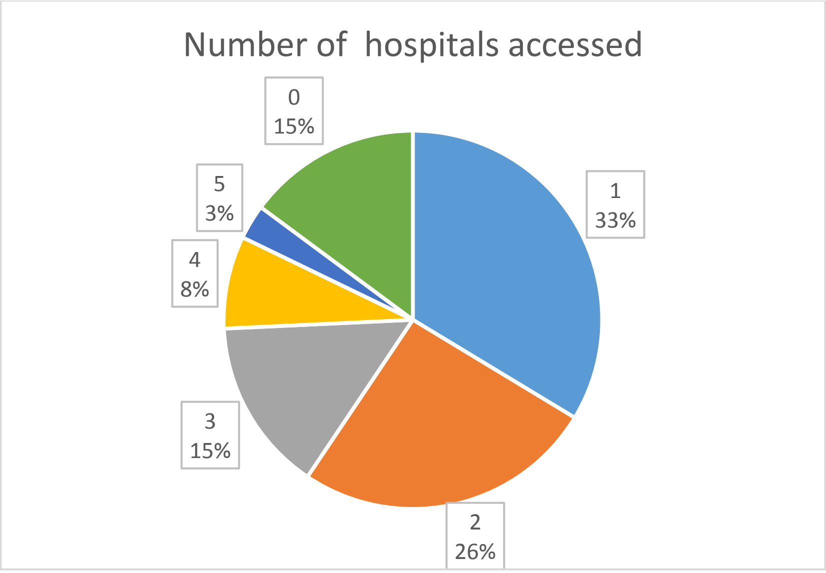

Fig 9 – showing the number of hospitals accessed by percentage of the service users.

Children with access to a social worker

27% of the participants (17 children) had accessed or continued to access a social worker, for their child. These children had on average 3.6 areas of disability (as opposed to 2.7 in the general population), and had on average accessed 2 hospitals, approximately a third accessing three or more hospitals (as opposed to approximately a quarter in the general population). Additionally, a large majority of these children attended or had attended Severndale Specialist Academy (82% - 14 out of 17 children), with only two children currently in mainstream accessing a social worker. Six children (35%) accessed specialist school or college, but five of those had also accessed Severndale (three) or mainstream (two) first. These figures would suggest that those children who access social work support have more complex disabilities, which is reflected by the fact that their parent carers have greater interaction with services. The average age was 16.8 years old, and only four were under the age of ten. What is not known is the age the children were when social workers became involved in their lives, and this might be an area for further research for PACC.

Services Accessed

The list of services was generated through those mentioned in Stage 1, but is not exhaustive (see Appendix 1 and Table 2). Some participants added other services (discussed below). The questionnaire asked participants to tick which services they had accessed in the past and which they accessed now. This question caused some inconsistency in answering when participants had accessed a service in the past and currently: some participants ticked both “currently access” and “accessed in the past”, where as some ticked either or[6]. However, the results in the bar charts (see Figs. 11(i) and 11(ii)) reflect which were the most used services, and it is clear that the GP is the most currently accessed service, whereas the Health Visitor is the most accessed in the past, which reflects the fact Health Visitors are only involved with pre-school children. The Child Development Centre (CDC) was also widely accessed in the past.

In order to standardise the result, the total number of users was calculated to eliminate the double reporting. See Figs. 10(i) and 10(ii).

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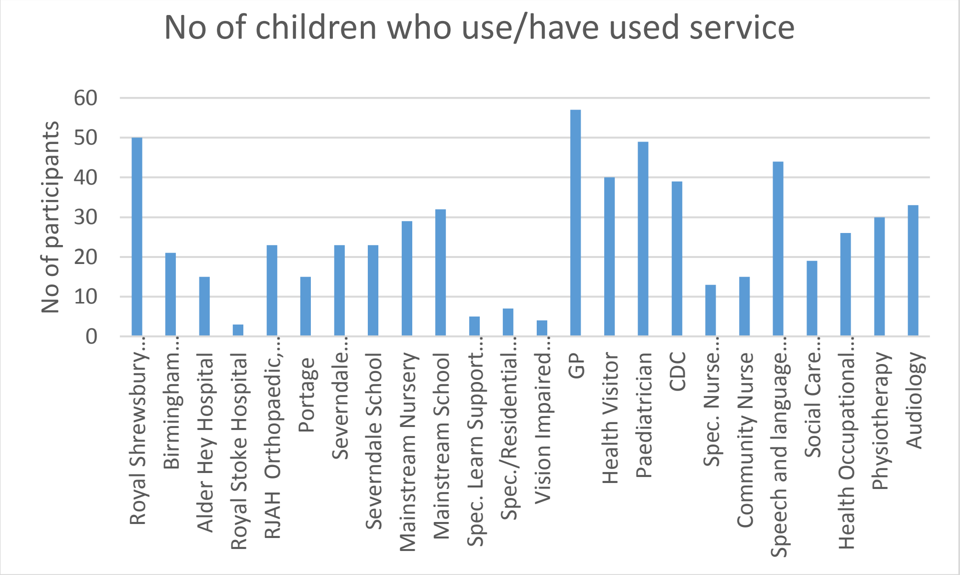
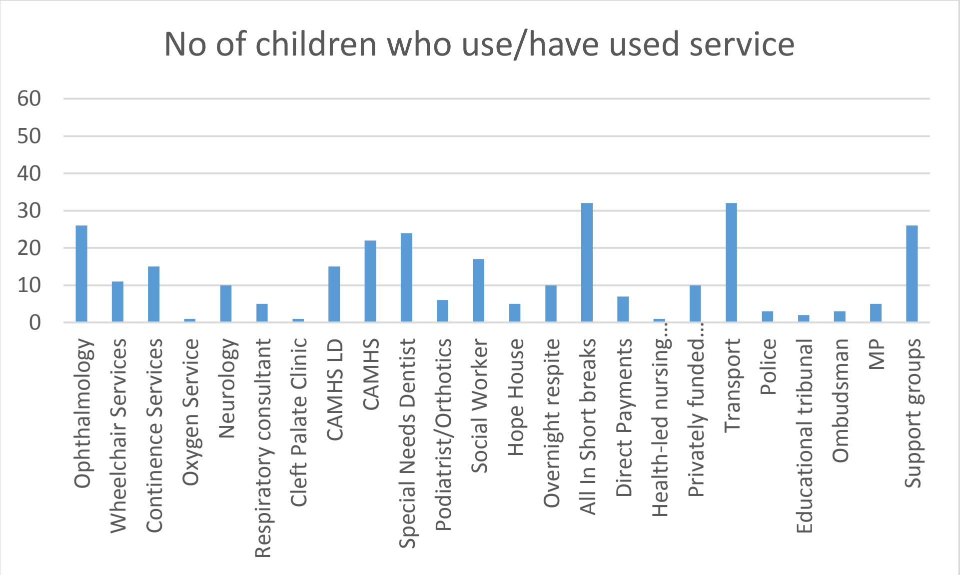
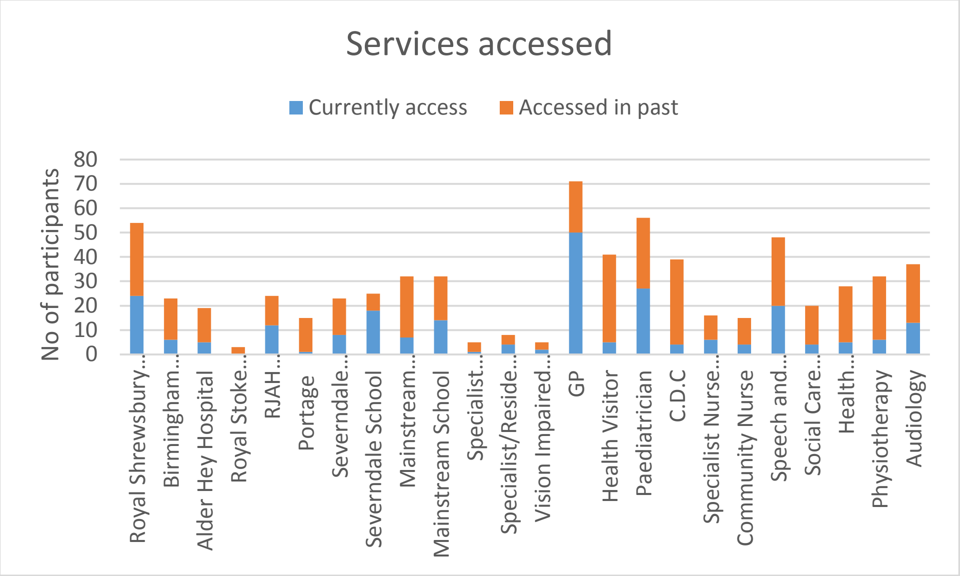
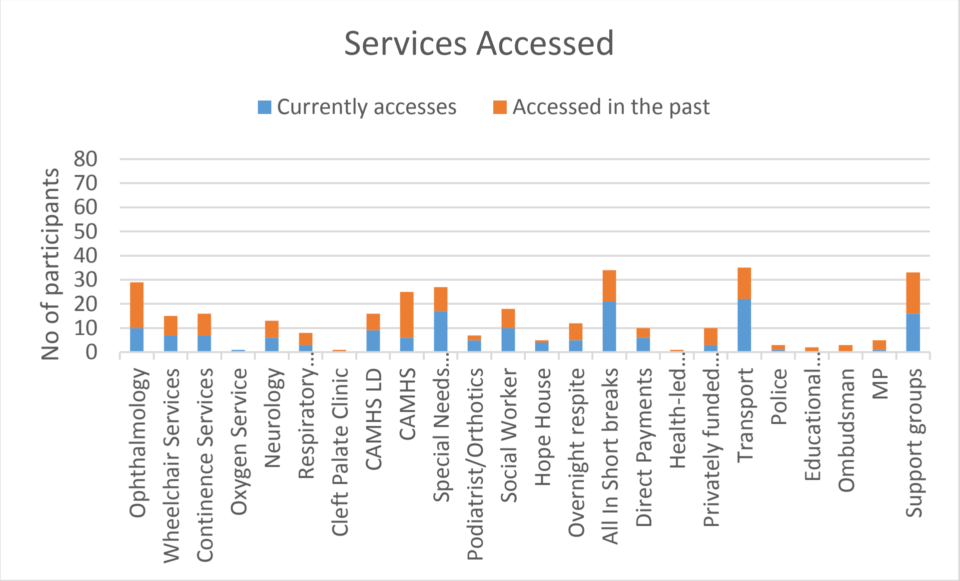
[6] (so the total for example for the GP is 70, as 13 people have ticked both past and present)





Figs 10(i) and (ii) Showing the total usage of services by children





Figs. 11(i) and (ii) showing the number of services accessed both currently and in the past

On average the children currently access 6.9 services each, the range being from 1 (low) to 24 (high), and has accessed on average approximately 10 services in the past, range 1 to 28.

Combined, the total number of services each child has accessed is on average 15, with a low of 5 and a high of 31. Typically those who access the highest number of services are described as having at least five types of disability, particularly those with high medical needs, whereas those using a lower number of services may have ASD and be in mainstream school. However, those with ASD in specialist schools may access as many as 15.

	Service	**Health/ Education/ Social Care**	**No of participants who use/have used service**
1	General Practitioner	H	57
2	Royal Shrewsbury Hospital	H	50
3	Paediatrician	H	49
4	Speech and Language Therapist	H/E	44
5	Health Visitor	H	40
6	Child Development Centre	H	39
7	Audiology	H	33
9	All In Short Breaks	SC	32
9	Transport	E	32
10	Physiotherapy	H	30
11	Mainstream Nursery	E	29
14	Ophthalmology	H	26
14	Health Occupational Therapy	H	26
14	Support Groups		26
15	Special Needs Dentist	H	24
18	RJAH Orthopaedic Hospital	H	23
18	Severndale Assessment Nursery	E	23
18	Severndale School	E	23
19	CAMHS	H	22
20	Birmingham Children's Hospital	H	21

Table 4 - the twenty most used services

14 services of the 20 most used services are health funded. The most used is the general practitioner, which is not surprising as everyone has access to their doctor, and their role as an entry point to other services is pivotal for children with additional and special needs. One parent commented:

> *The continuity of the GP is so much better than seeing lots of different doctors etc who know very little about your family, history etc. The deeper knowledge of the whole family picture that a GP has is invaluable and should be utilised, more to everyone's benefit. P25*

National data (38) seems to suggest that families of disabled children do not tend to have a strong relationship with their GP in terms of their child's care, so it might be possible that this result reflects parents accessing the GP as a service for themselves rather than their child, or alternatively for general ailments rather than anything specifically related to their disability. For many children with disabilities, particularly those with high health needs, the GP does not play a major role since the community paediatrician takes on that role of referring families to other services.

The first seven services on this table are also services that would be accessed as part of the screening process for disabilities. In particular, audiology and speech and language therapy are often the first port of call for those with ASD and communication difficulties, in order to rule out other difficulties such as hearing loss.

The fact that All In Short Breaks comes in after these screening/ health services and is the most accessed social care service, illustrates the importance of the breaks for both the parents and the children. Overnight respite, on the other hand, was only accessed by ten participants, with one participant expressing an interest: "I wish!" PACC's recent work on Accessing Social Care Support suggested that the lack of information about what social care support is available, and how to access it, is a major barrier for families.[7](32)

CAMHS is also a screening service as well as a support service, so it is not surprising that it was accessed by approximately a third of the participants (22 children); CAMHS-LD (learning difficulties) was accessed by 15 children, which combined would put these services within the top ten most used; given that 60% of the children were classified as having ASD, learning difficulties or challenging behaviour, this finding is not unexpected, and highlights the demand for such a service.

Additional services listed were: Behavioural Therapist, Genetics, Dietician, Sensory Inclusion Service, Educational Psychologist, and support services such as Autism West Midlands, Parent Partnership (IASS), Bridgnorth Buddies, Megan Baker House, Action For Children Outreach, Action for Children Youth Group, and volunteering in a mainstream school. Of these it is acknowledged that the dietician and educational psychologist should have been on the main list, as it is possible more participants had accessed their services. It is interesting to see that support services, such as IASS and Action for Children were deemed significant, and that the position of advisory and support services such as IASS and PACC were not clearly understood by all the participants. One parent commented that less should be spent on the "middlemen" and more spent on health services, which suggests that there needs to be more clarity and information around the independent standing of advisory and support services.

In summary, it is possible to see from this list that there is a wide range of services that impact on the lives of parent carers of children with special and additional needs. On

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[7] This is an ongoing area of work for PACC.

average children accessed 15 services. In total, the fewest number of services accessed by any child was 5 (7 year old) and the most was 31 (two children). Detailed statistical analysis of the number of services used in relation to age and number of areas of disability is beyond the scope of this project, and while it might follow that the older the child the more services they have used, there are some young children who have accessed a high number of services (for example an 8 year old who had accessed 31 services),[8] as the number of services used reflects the complexity of the children's disabilities. As explained in Stage 1, the parent carer is the main co-ordinator for the use of these services.

Relationships with Service Providers

The questionnaire addressed the findings of Theme 2 (Stage 1) considering conflict and co-operation, and communication and empathy, with two questions which required the participant to either strongly agree, agree, disagree, strongly disagree or express no opinion in relation to a variety of statements.[9]

The first question asked "generally, how do you feel about yourself in relation to professionals/service providers you deal with?" The categories were: involved and part of the decision making, you are the expert in your child's care, listened to, excluded, confused, in conflict, other please state". [10]

As is shown in Fig 12 below, the majority of parents feel:

- involved (63%)
- listened to (76%)
- do not feel excluded (59%).

49% parents did not feel in conflict, whilst 37% had no opinion on this question, leaving 14% of the total who felt in conflict; more accurately, this figures rises to 21% of those with an opinion who felt they were in conflict.

Individual examples of fighting for services, which bears out wider published literature, have been discussed in Stage 1, and were also mentioned by participants of Stage 2 in the Section of "services that did not work well for you or your child", which will be discussed below.

76% of participants believed that they were an expert in their child, which bears out the findings in Stage 1, with 47% strongly agreeing with the statement.

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[8] Larger participant numbers would be needed to carry out such statistical analysis.

[9] In order to standardise the numbers across the categories, any answers that were left blank were taken to be "no opinion".

[10] Opposites, such as rude/polite, involved/excluded, were included in the questionnaire to ensure participants fully engage with the questions rather than just ticking all one answer, such as "strongly agree"

The “no opinion” rose with the negative categories (excluded, in conflict, confused) which might suggest that participants have not considered the issues around conflict and confusion, or they do not want to be seen to be critical of services. 17 participants felt confused against 24 who did not (41% v 59% of the total with an opinion). Examples of conflicting advice from professionals were given in the comments section by some participants.

The figures were broken down into age groups (see Figures 12 i,ii,iii,iv) to see if there were any observable differences. Overall the trends are much the same between the age categories, although use of a more sophisticated statistics software package (such as SPSS) might have drawn out significant statistical differences. The group of parents of 19-25 was very small (7 participants) so it is hard to draw any meaningful conclusions from the data, but it is noticeable that these participants were less likely to answer “no opinion”. The most dominant answer is that parents believe they are the experts in relation to their child, which bears out the findings of Stage 1, and was also raised in the comments section.

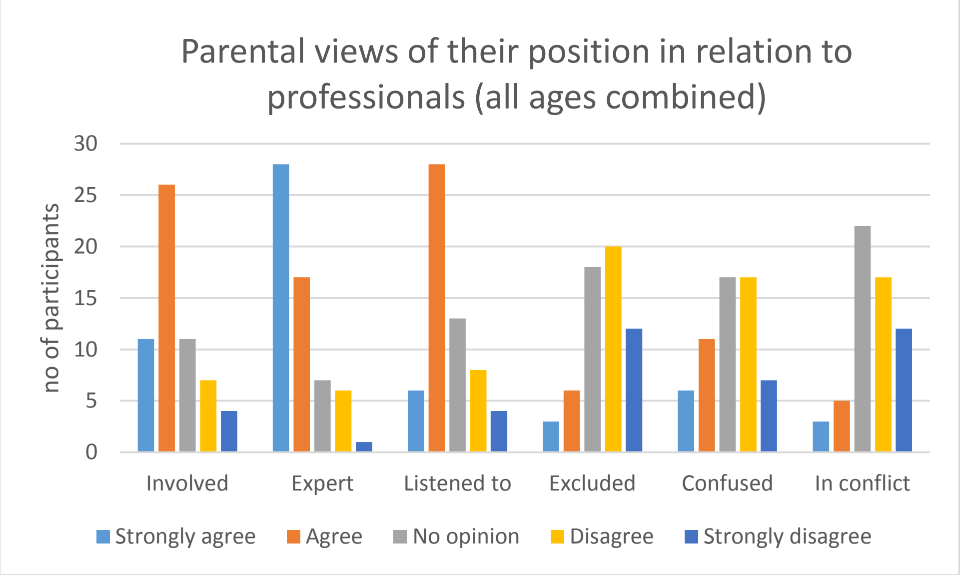

Fig. 12(i) Chart showing the breakdown in figures of parental views of their position in relation to professionals (all ages combined)

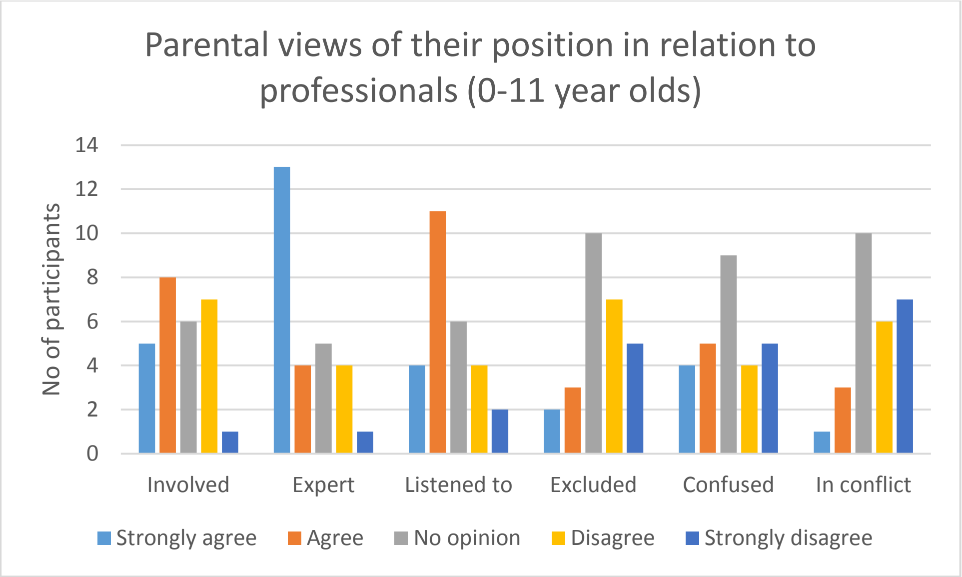

Fig. 12(ii) Chart showing the breakdown in figures of parental views of their position in relation to professionals (0-11 year olds)

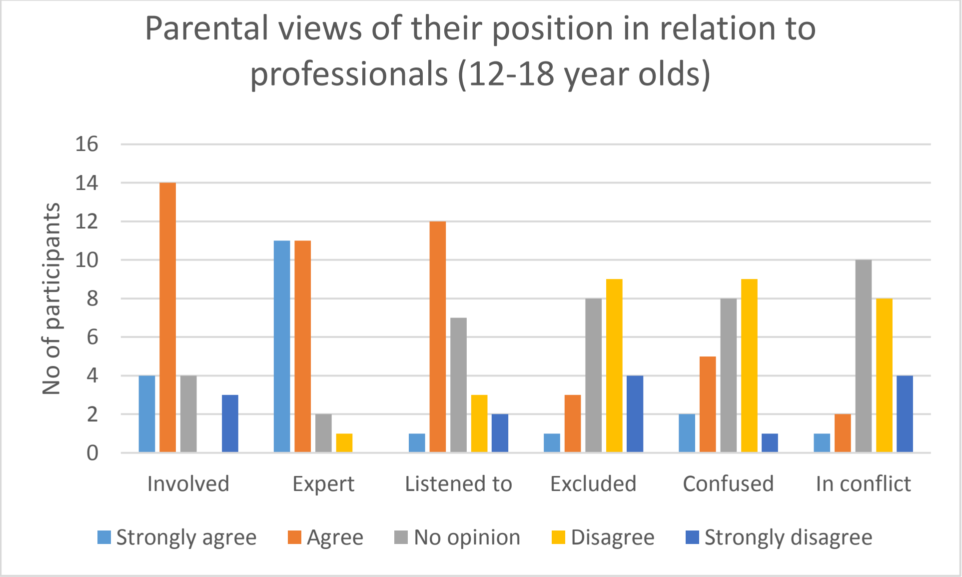

Fig. 12(iii) Chart showing the breakdown in figures of parental views of their position in relation to professionals (12-18 year olds)

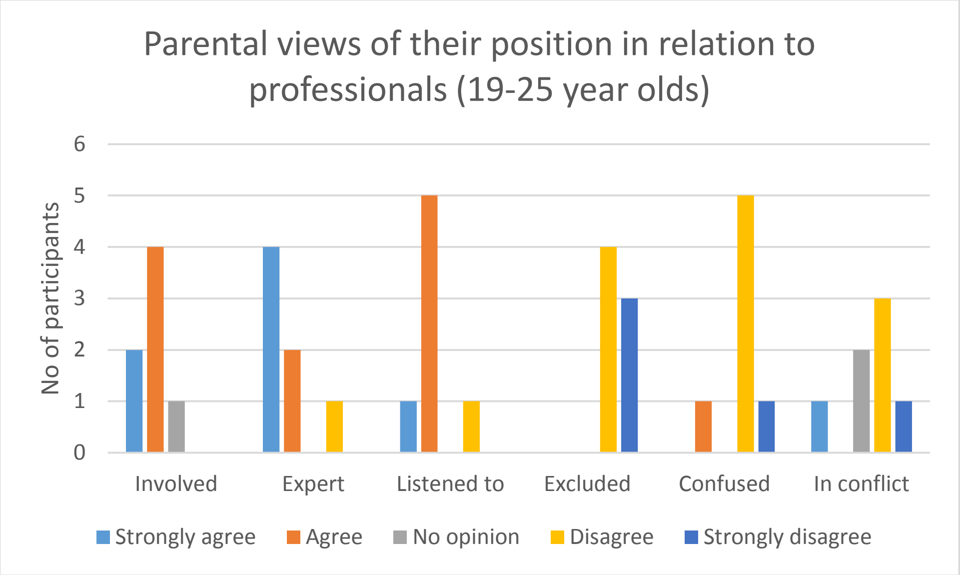

Fig. 12(iv) Chart showing the breakdown in figures of parental views of their position in relation to professionals (19-25 year olds)

Language

The second question asked "generally how do you find the language used?" with the categories: clear and easy to understand, confusing and alienating, polite, rude, supportive, threatening, practical and supportive but not empathetic; empathetic. The categories were drawn from comments from Stage 1, and the question aimed to explore whether these were universally held views. One parent in Stage 1 had commented that social services, in her experience, had been both "rude" and "threatening", whereas examples of the lack of empathy could be found across the participant group in Stage 1. It is clear (Fig 13i) that the majority of participants felt that the positive attributes (clear, polite and supportive) were apparent in the professionals' language;

- 63% agreed that language was clear,
- 73% agreed that professionals were polite, and
- 59% felt that the language used was supportive.

Conversely, 66% disagreed that professionals were rude, with only 4% agreeing, and 75% disagreed that professionals were threatening, whilst 7% agreed. Whilst these may be heartening results, it is important to acknowledge that there is still a minority who do not agree with the majority view that professional's language is positive. These opinions also emerged in the open questions, discussed below.

The two questions aimed to explore empathy were met with more ambivalence.

The question "generally how do you find the language used practical and supportive but not empathetic?" had a 40% "no opinion" response, which suggests that the question may have been badly worded. 32% agreed and 28% disagreed, suggesting a small minority who do not find service providers' language empathetic. When asked a simpler question, (if the language used was "empathetic") there was again a large (38%) group who had no opinion - participants who had an opinion were split, 42% agreeing and 58% disagreeing.

Again the data was split into the age groups – and it is here that the opinion about empathy becomes more apparent. In the 0-11 age group 7 participants agreed that service providers were empathetic versus 8 who thought they were not (12 no opinions), in the 12-18 age group 9 agreed versus 8 who disagreed (8 no opinions) but in the 19-25 age group 6 people disagreed that service providers were empathetic, no participants agreed and there was one "no opinion". (See Figures 13 ii,iii,iv). Additionally, two parents added "patronising" as a further category.

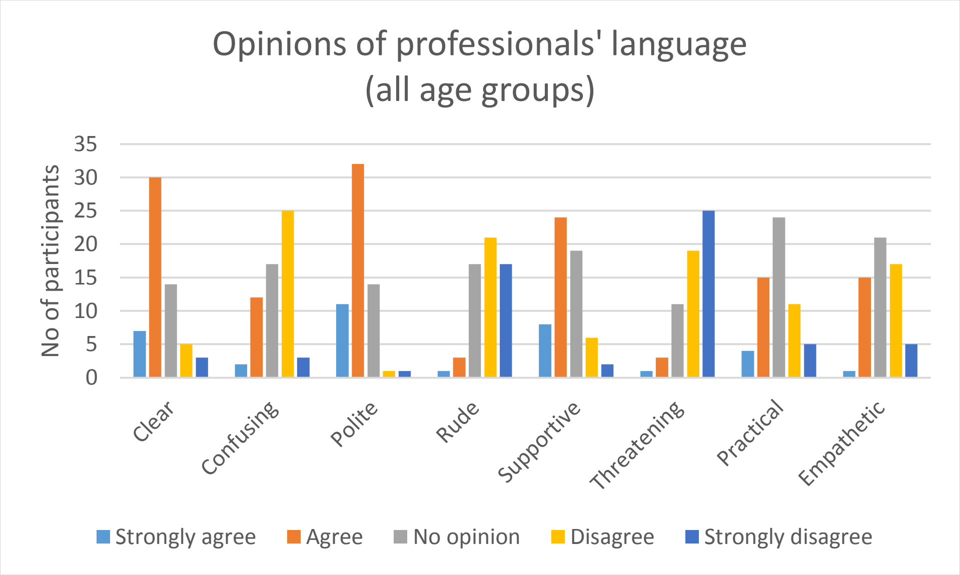

Fig. 13(i) Parental opinions of professionals' language (all age groups)

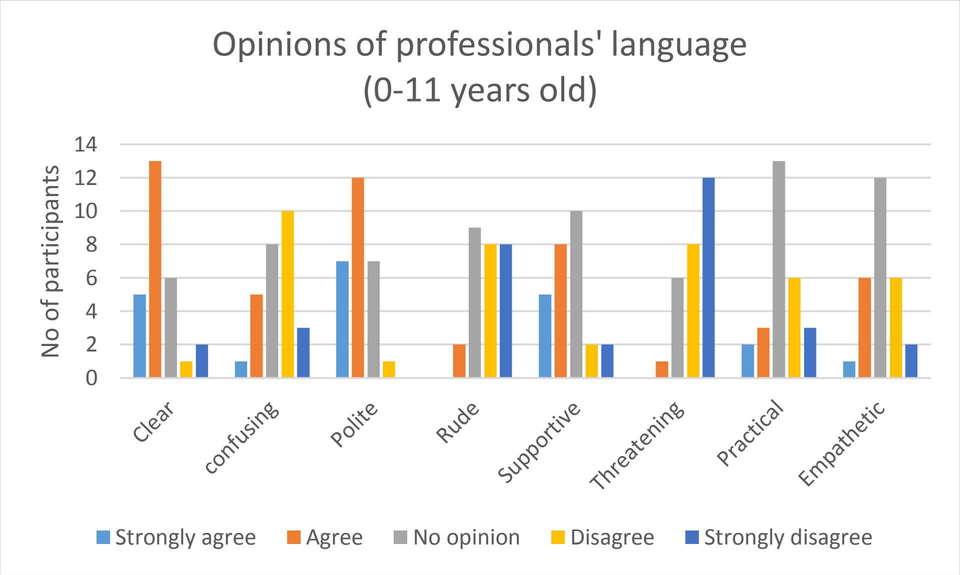

Fig.13(ii) Parental opinions of professionals' language (0-11 years old)

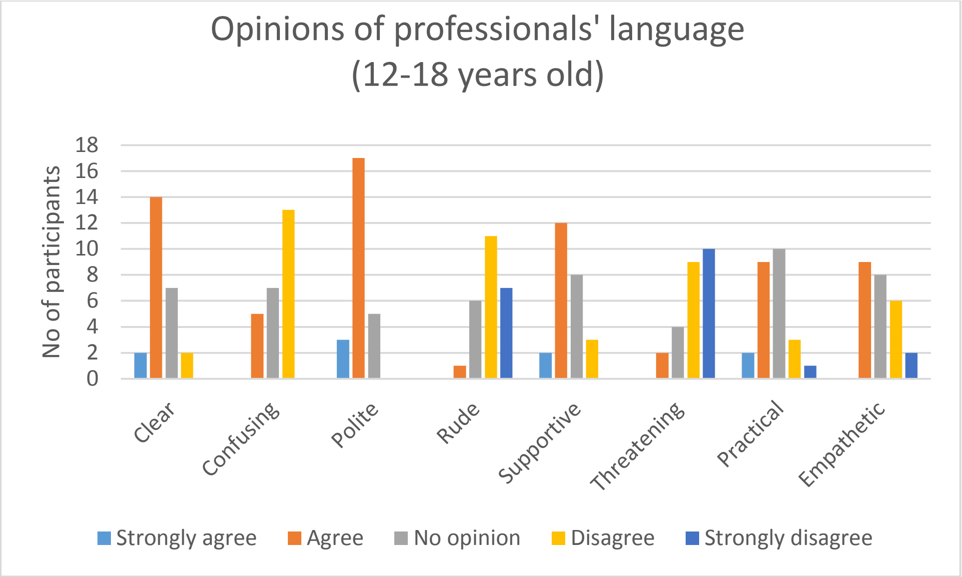

Fig. 13(iii) Parental opinions of professionals' language (12-18 years old)

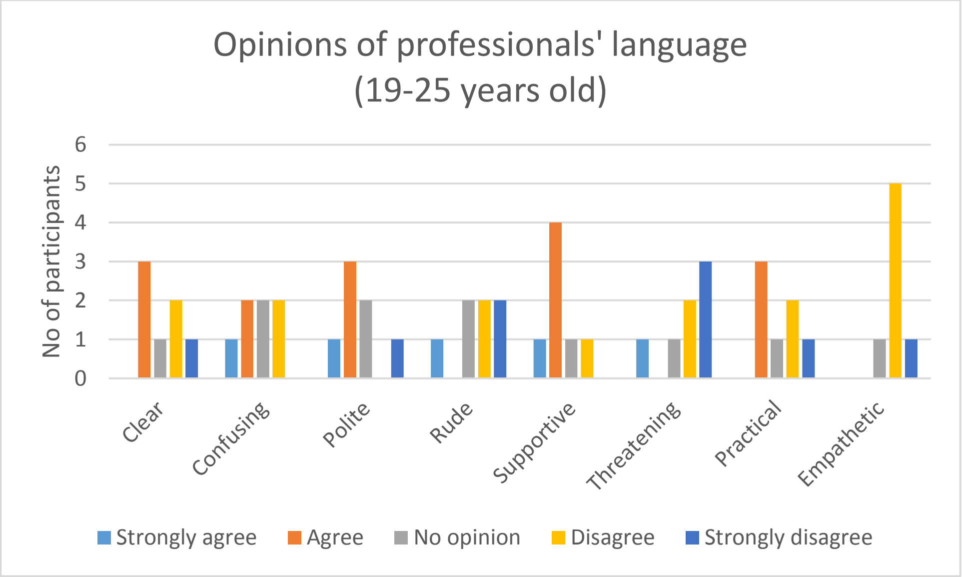

Fig. 13(iv) Parental opinions of professionals' language (19-25 years old)

These figures throw further light on the themes found in Stage 1. Participants generally believe they are the experts in their child. On the positive side, a majority of parents agree in general that they are involved and listened to, and that the language used by service providers is polite, clear and supportive. The finding of threatening and rude language was not supported within this participant group. However, there is still a percentage (24%) who do find language confusing, which in real terms means one in four people who meet with a professional are confused, and nearly 60% feel that professionals are not empathetic.

There are limitations with the data. Although the questionnaire was sent out to over 800 parent carers, only 60 responded. A larger sample would give a more accurate reflection of the population as a whole. It was then the participants' choice as to whether they responded. It was a ten page questionnaire, and it is possible that people who have busy lives may not have had the time or the energy to respond. The leaning towards positive responses may be explained by the fact that those people who are well supported, or in a good position, were more likely to respond because they had more available time. Therefore, the minority of negative responses should not be dismissed as unimportant, because they possibly represent many other parent carers who did not have the time or emotional resources to spare on filling in the questionnaire.

Additionally, the question asked “we are looking for your overall feeling about working with services in general and in general how that makes you feel” whilst acknowledging that “your relationship with some services/professionals might be different to your relationship with others”, so these are very general responses.

Finally, it is acknowledged that more sophisticated data analysis with an appropriate software package would tease out the significant differences between the groups.

It was therefore important to hear individual comments about services, and the participants own feelings, to be able to consider these findings in greater detail. The following is a thematic summary of the open ended questions, which aims to illuminate individual experiences and opinions.

Qualitative analysis

Emotional responses

The question was “Are you ever emotional in your dealings with professionals and service providers? How is that received? Are service providers and professionals empathetic?” 43 of 59 participants responded to this question, with a variety of attitudes reflected.

Grief on diagnosis, or sometimes misdiagnosis, anger (“*cross”, “annoyed*”) and frustration were all expressed, which resonate with the findings of Stage 1. One participant commented:

> “*evidently, as a mum to a child with special needs it is emotional, a constant rollercoaster”P56*.

Not all parents are happy to show their emotions, and at times there was an element of hidden emotion in the responses; one parent replied:

> *“No I have to make a real effort not to show my anger or frustration. But it pushes you to the limit at times”.P29*

Whereas another parent who feels well supported does not feel the need to demonstrate her emotions, although this attitude has changed with time.

> *“I am rarely emotional, I fully understand and accept what my child has. I am very educated about it and always expect most of the comments made. I appreciate the help and advice. When we were first told I was very emotional but all the professionals have been empathetic and supportive”* P27

Other participants found that showing emotions is necessary in order to be understood.

> *“I have found that in order to get things done I have had to resort to emotions to, on occasions, emphasise feelings. I have often come across the attitude of ‘those families who shout the loudest get what they need’ ”*P30.

(The participant doesn’t clarify if this attitude is amongst parents or service providers, or universally held.)

Occasionally, parents feel that humour is required, and is lacking in professionals

> “*some lack a sense of humour which is essential for parents like us – it’s all we have sometimes to cope with situations”*P25.

Showing Emotions:

- *Wherever possible I try to keep emotions out of it – very hard sometimes! P3*
- *Cannot comment. I only show my emotions in private. P5*
- *Not really, sometimes feel it but don’t show it. P9*
- *Yes I am emotional. Usually makes professionals listen more when they realise I am at the end of my tether and need assistance. P14*
- *I have found myself getting emotional in the past, this isn’t always me…as think it makes people uncomfortable. P20*
- *On initial diagnosis I was very emotional. P29*

Causes:

- *On occasion I have got annoyed if service providers are negative in their approaches i.e. stressing what can’t be done for your child instead of what can be done. P3*
- *I do get emotional if I feel no-one is listening to me. P7*
- *Sometimes it got too much. Some listened, some didn’t. I’ve given up now. P21*
- *I am emotional when told my child cannot get what he needs because there is no funding for it…but I wouldn’t be human if I didn’t respond would I? P12*
- *Mixed emotions. Professionals appear to be understanding but once of the phone, no follow up. P30*
- *Inevitably it is sometimes really emotional and usually professional/ service providers cope well. Some staff can come across as patronising. P51*
- *I have been emotional …I find people of authority do not listen properly or do not understand what I am saying. P58*

The cause of the emotional responses is also varied: the lack of support makes people emotional, and this is often interpreted as professionals not listening:

"*sometimes it got too much. Some listened, some didn't. I've given up now*" P21, but at times it goes beyond being listened to, as one parent commented

> *"it depends on the professional. Parents are looked down on and ignored by some professionals. Found that because my son doesn't fit with their interests they lacked understanding and patience. Sometimes they need to listen to the child and parents and be guided by them"* P22.

Some people see they are listened to but there is a perceived lack of follow up – *"mixed emotions, professionals appear to be understanding but once off the phone no follow up"* P30.

Additionally, the lack of an individual approach to a child's problems or even a lack of understanding of child's problems may cause emotional responses: "*nothing worse than feeling like you are part of a production line of patients*" P25

> *"sometimes I get emotional …due to the frustration of people not understanding why my son cannot speak in some situations but can speak at home*"P30
> *I am obviously emotionally invested in my son and have… felt like people have spoken as if he is a problem that needs solving, rather than an amazing individual with a unique perspective P20*

And there is a recognition that sometimes despite expressing their emotion, nothing can be achieved:

> "*I have expressed frustration when the system has failed to meet my son's needs. Practitioners have generally been sympathetic and apologetic but they can't do anything about the system either*" P33

The emotional responses are generally when parent carers feel there is a lack of support and understanding. On the other hand, there are a number of parents who are happy with the services, the support and the way that professionals have dealt with their emotions.

Positive responses:

- *Cross- acknowledged and accepted. Dealt with sensitively. P2*
- *I am very happy [in the way] all services are given to me in the help of my son's condition. P15*
- *Yes occasionally stress comes out. [It is received] with concern and attempts to get support asked for required. P31*
- *Everyone who I've had to deal with has been supportive. P32*
- *Usually they are supportive and concerned and try best to help with my primary issues. P41*

Empathy

The questionnaire raised the issue of empathy, and the majority of participants felt that professionals and service providers were not empathetic. This trend is reflected in the qualitative data obtained. In particular, it was felt that service providers could not understand if they had not lived with disability themselves, that people misunderstand the child, and that emotional parents were, at times, an embarrassment.

The issue for parent carers is when does sympathy end and empathy begin? As one parent said about their child's social worker, it is more than just sitting there drinking tea and saying you understand - these parent carers expect more than that; they want someone who will understand how difficult their life is, the problems they face with their child and want some follow-up or action. Parent carers want professionals to put themselves in their shoes, and by so doing understanding what they (parent carers) have to put up with, and consequently help them.

Empathy:

- *Can be a bit overwhelming at times when you have to face up to realities of child's developmental potential. If you feel let down or not listened to some professionals are more empathetic than others especially if system hasn't worked for you and your child at that time. P11*
- *I have burst into tears in meetings with professionals on a number of occasions. Professionals have always looked uncomfortable and ushered me out as soon as possible! No they are not empathetic! P50*
- *The worst part is when they say "I know what you're going through" but asked if they have a child with 'special needs' they don't, so they don't know what it's like. You can't get the information out of books you have to be there 24/7 for them. P13*
- *Some people don't listen. Some I've had have met my son and because he's disabled they speak to him like he's thick and doesn't understand. And he's the complete opposite. No they are not empathetic. If they were to have been empathetic and had put themselves in my shoes maybe I'd have got a lot more help when I needed it. P19*
- *Empathetic – yes but it makes no difference. P45*

Sometimes, the emotion spilled out into answers and this example illuminates what happens when parents feel their children's needs, and the limitations those needs place on the child, are not understood,

> *At the annual review for his EHCP, the woman from the council did not know he cannot deal with public transport and was surprised!! She kept insisting he could go on a bus to college. Well (a) he won't be going to college, but we hope he will*

> *continue with voluntary work and (b) he certainly is not ready for a bus! (c) she KEPT ON stressing him out, by talking non-stop about colleges and buses (d) I nearly ripped her head off! P29*

Generally, parent carers hope that, if they have been listened to and understood, and their child's has been seen as an individual, then they may get the appropriate support. For example:

> *SALT understood the needs, displayed empathy. Supported through home and school, gave action plans things to work on the help development. P6*

However, not every parent feels that empathy is a requirement of the professionals; one parent stated:

> *Yes, I have been emotional. All professionals and service providers have got it right in their response with me. Often don't need empathy from professionals, have friends and other support mechanisms for that, I feel from professionals I need them to be informed, on the ball, able to help and basically good at their job P58*

However, this parent is falling back on a network of friends and support groups, which are not always available to those who find that disability can be an extremely isolating experience.

Support

The responses to the questionnaire suggest that parents want professionals who understand what they are going through and be able to offer and procure some sort of support. The remaining questions in the questionnaire looked at times services worked well, when they did not work well, and asked for further comments. It also asked for suggestions as to how relationships between parents and professionals could be improved.

There were polarised views about services: in response to the question "Can you name a service that has not worked well?" one parent replied "*All has worked extremely well for my son"* P15, whereas another said "*Too many to list"* P17.

What is good support?

The examples of services that had worked well for participants were analysed and the following themes emerged as key in providing good support.

Being understood and believed, not judged:

Firstly, following on from empathy, it was important that parents felt that they were listened to, that their concerns were acknowledged and that they were not judged as poor or neurotic parents. It is also sad and of concern that parents at times feel that they are not believed when they tell professionals what is happening, and that they want professionals to "*witness*" what is happening, and not have to "*convince*" them.

Being believed:

- *Occupational therapist - Acknowledged there was a problem. Listened to my concerns, made me feel supported and outlined a plan of action. Made me feel valued as a parent who knows their child best. Gave me tools to help my daughter. P8*
- *CAMHS-LD - She was an independent, non-judgemental professional with the right tool set to map out plans and work with us to put in place tools and techniques to manage behaviour. Having someone able to spend time in the house and witness the difficulties we faced was just what was required. She was an amazing, patient and hugely talented individual and we felt supported for the first time in a long, long time. P14*
- *My 11 year old early intervention, being listened to from the start, not having to convince professionals I am making it up. P49*

Identifying issues & Information gathering:

Once they are heard, parents want to know what the cause of the problem is and how to deal with it, so that they have access to advice, and support. Signposting to other sources of support is important, as are the relationships which are built with professionals along the way. This is a process, such as a problem being identified by the health visitor, with referral to the Child Development Centre and then support put in place, for example at Severndale, and transport provided, and when parents can see the progression through a system such as this they feel well supported.

Identification of issues and signposting:

- *Paediatrician appointments/reports/reviews made it easy to flag up new issues, and get advice. [Name removed] was our daughter's paediatrician for many years and trusted our views as parents. She was very empathetic and we trusted her views. She made us as parents feel valued and we had a great relationship – it always felt like our daughter mattered and she was always interested in us as a family. She was also great at signposting to other services. P57*
- *My child going to secondary school, [name removed] Parent Partnership came with my child and me to look round the schools. She was asking questions that I didn't think of, usually the ones you remember when you get home. Having someone to support you makes all the difference.P11*
- *My health visitor was very helpful to me. The CDC was very helpful because of them, we know he has autism spectrum disorder. My son has a good progress at Severndale special nursery. The teacher and staff are awesome. They know what they are doing. The transportation is very helpful. I am pleased and happy with the service. P24*
- *As soon as our son was showing signs of delay our health visitor put us through for all the services. Everyone we encountered from audiology right the way through to paediatrics were supportive. Never made us feel we were imagining things, gave us advice, if they could not help they found someone who could. P37*

Child centred/ planning for future:

In line with current policy, parents want their children to be at the centre of care and to plan for the future. However, whilst support is child centred, participants feel it is important that the parents' or whole family's situation are also acknowledged. In this way, parents can be actively involved in professional support; for example the mother who was encouraged by portage to work with and develop her child's skills, thus building her own self-confidence.

Child centred planning:

- *The whole meeting went well because all the people round the table were on the same side – wanting the best outcome for our child. They were supportive, positive and proactive and that made us as parents very positive too. P3*
- *All the people that have worked with myself and my son have had our interests at heart. They worked to make sure my son's future is easier. It's been a joy and helpful. P33*
- *Portage – totally tailored to the child. I was taught how I could help alongside the portage activities. My portage worker was fab. I felt much more confident my daughter was doing well and that I knew I could help her develop. P23*
- *Audiology service at hospital is fantastic – consultants/nursing staff/audiologists treat me as one of their team discussing the best course of action, taking into account all aspect including impact on family and not just child P51*
- *Home adaptions – the planning of this was very thorough/quick/efficient and the professionals involved were very supportive of how we wanted our home and how we definitely didn't want it and the occupational therapist, supported the best way to adapt the house for our son's needs and to keep him safe without forcing anything we didn't want. P27*
- *Direct payments work well for our son as can organise hours/care to suit P10*

Reliability of service:

The reliability of a service is vital for parent carers, because it removes an area of potential stress. This could be a practical support, such as feeding pumps, as one mother quoted, or of a more emotional nature, such as being offered a break while supporting a sick child in hospital, and on the return home.

Reliability of service:

- *Referral and immediate emergency transfer from PHS to Alder Hey on discovery of [medical condition] P21*
- *My son's feeding pump and giving sets were until very recently provided by Nutricia Homeward. This service has never let me down. The pump and sets are of high quality, deliveries are on time, staff are very polite and helpful. One of my son's numerous services, this was always the best for efficiency. Sadly, it is now in the process of being changed to another supplier. P30*
- *Hope House outreach service – able to respond to need at short notice. Help when child in hospital …Continued supporting us after child discharged from hospital. P2*

On the other hand, unreliable services can cause real problems for parent carers:

> *When Action for Children ring up on the day and cannot do it, and it makes my son a handful* P36.

In this instance, short notice cancellation of support for a child, leads to disruptive behaviour on the child's behalf, and the parent is left feeling both let down by the service and challenged by his child. This is in effect worse than just being challenged by the child's behaviour.

Support for the parents:

Dealing with the challenges of everyday life with a disabled child can be "*isolating and frustrating*". Isolation is recognised as an aspect of caring; the need for support is apparent and that is not just support for the child, but also the parent. One parent comments about her daughter's physio "*she made time for me. Without her I'd have fell apart*".

It is apparent that these parent carers are often the mouth pieces for their children, and the co-ordinators of their care. They have to present the children's needs to professionals and ask for help, which inevitably means that the professional is in a situation of power, whilst the parent carer is the supplicant. Parent carers want support to be "*accessible*" and the people who help them to be "*responsive, understanding*" and "*well informed*". They also request "*honesty and realism" saying "don't promise thing which cannot be fulfilled"* P16.

Accessibility is key. Another parent commented

> *"I understand that professionals and service providers have to keep a "professional" distance from parent carers but feel it is important to distinguish between" accessible" rather than "too remote"* P3

However, parent carers look beyond the professionals for support, and may turn to other sources of support, for friendship and advice.

Support for parent

- *My most recent social worker has been fantastic. Accessible, responsive, understanding but not here to just drink tea and chat. Positive action taken, extremely well informed. P58*
- *It is invaluable to know there is someone there to listen who understands and can offer support. P46*
- *Physio - amazing supportive lady who made regular contact and helped me a lot. Even though she was there for my son, she also made time for me. Without her I'd have fell apart. P19*
- *CAMHS-LD Disability nurse helped me greatly when my child became at times violent and aggressive. I was very well supported and taking it through with disability nurse helped me and my child greatly, she helped me deal with issues i.e. tantrums, moods etc. in a positive manner. P32*
- *My best support and advice has come from a network of parent carers both of autistic spectrum children and neuro typical children. Dealing with what to some people would be non-issues on a daily basis can be isolating and frustrating. It is essential to have a good support network of friends. P20*
- *Other carers are brilliant support mechanism. Use FOSS & PACC, try and go to events. P58*

What is poor support?

The following examples of poor support were drawn from the question "please can you give an example of a time when a service or combination of services did not work well for our child and yourself?" Many of the examples quoted are the direct opposite of services that worked well.

<u>Post diagnosis – information and support:</u>

For many parents, diagnosis is the starting point for interaction with services, and a time when service providers and professionals have the opportunity to support parents and signpost them to other services and sources of information. It is also a time when parent carers may be extremely emotionally vulnerable.

Wrong diagnosis
Missing hospital records
No communication between hospitals
Mislaid hospital appointments
No-one listening P59

This stark summary highlights many of the things that can go wrong and frustrate parent carers. The examples below also highlight the lack of information and support on diagnosis, and the impact that had on them; in one case they felt they were perceived as "*overbearing neurotics*" and in another case the participant "*felt very alone*". Whilst the diagnosis itself had an emotional impact, that impact was compounded by the way they were treated by the professionals at the time.

Lack of signposting

- *There is no information for parents on services/organisations. Who can help while you are reeling from diagnosis? There is no signposting. Parents are expected to identify services then treated like overbearing, neurotics for trying to negotiate the most appropriate support for their children. P22*
- *At birth – the doctor who told us our daughter had Down syndrome was very abrupt /unhelpful and the nurses could not provide us with any info/ or someone to talk to. Felt very alone and will never forget that. P11*
- *Little understanding of how services function; difficult to get information. P44*

Not listening to the parents or understanding the child:

As demonstrated above, parents believe themselves to be the expert in their child, and know when something is wrong, and this expertise is acknowledged by some professionals, particularly those who have developed good relationships with the parent carers. Parent carers, however, do not necessarily believe they are the experts in their child's treatment, and consequently seek help when they believe something is wrong. Frustration arises when they feel they are not listened to. For example, this comment: "*Neurologist did not want to listen to anything we said as parents*" highlights the belief that the parent knows their child and knows when something is wrong, because they are close observers of the child's behaviour, but it also highlights the divide between the professional and the parent carers.

There were also examples of when the child was not listened to (P22), or was put in a difficult position because the parents were dismissed as not representing the child's views accurately (P44, P50), and the professionals try to impose their opinions on a situation rather than putting the child at the centre of the care.

> *A sick child's health dictates what they can do, and therefore what education needs to be provided. Usually, professionals (adults) dictate to children. They should be more willing to be led by the child or young person, to allow and facilitate arrangements that aren't normally allowed. Flexibility and a willingness to adapt is key.* P50

Lack of understanding

- *Neurologist did not want to listen to anything we said as parents. We were made to feel like we were paranoid parents and were wasting his time. Told us there was no way our daughter could have a brain tumour as she was happy and walked into the room. Dismissed all of the symptoms that we described daughter was having. Shortly after, our daughter had a 12 hour operation to remove a tumour!! P59*
- *Hospital consultant set unrealistic deadlines for son's recovery then announced it had gone on too long and despite evidence to the contrary said he was better and that was that. Our son broke down as not heard or understood. P22*
- *Our experience of consultant paediatricians have been bad. ME/CFS is an awkward illness. Many do not believe it exists. One told my sick 15 year old that he 'didn't have a GCSE to his name and once he was 16 his mum could throw him out on the street and what was he going to do about it?". It was a horrific experience. P50*

<u>Waiting times and crisis response:</u>

Waiting times reflect the accessibility of a service, and although there was some understanding (and frustration) from parent carers, it is the impact that these delays have on children with complex needs that needs to be recognised. P13's comment *"I know people have to talk to each other before they can give you an answer"* touches on the multi-agency nature of some of the issues faced by these service users. In another case, a parent resorted to privately funded speech and language therapy for their child, which they felt had made a difference to their child's development.

Waiting times

- *Long waiting times to access services from OT Physio Paediatrics CAMHS.*
- *Waiting for results because no-one has typed them out or "posted them". What century are we in? It delays other results/support for kids with complex needs. P12*
- *Took three years to get specialist speech services so thank goodness we could just about afford to do it privately otherwise we would be at age six and still not able to form sounds/words! P21*
- *Referral for CAMHS – diabolical service, couldn't get appointment even though GP referred as emergency. P37*
- *Sometimes you have to wait a while, that can seem like a life time when you are waiting but it isn't – it's just you want to know that's all, and I know people have to talk to each other before they can give you an answer. P13*

Additionally, experience has shown some parent carers that often treatment or intervention is given in response to a crisis, whereas early intervention would have supported both child and family and produced better outcomes. Parents want to be able to plan futures for their children, and look to professionals to support them in achieving this, but are frustrated by both waiting times and lack of early intervention.

Crisis response:

- *Waiting until a family is in crisis is often going to cost more than providing help at the first sign of trouble. In our case of post adoption it appears no-one would act until we got to the point of having our child taken back into care. P25*
- *CAMHS only took our child on when he became self-harm/talking about suicide. That is far too late. Once they'd tried a bunch of medicine that didn't work they dismissed him off their lists again. They only seem interested if they can administer drugs. If the drugs don't work you are on your own. P52*
- *Overall I am very let down by services and I do a lot myself. Personally, I have found that the lack of support is appalling. Surely all techniques, support and therapy should be in put in place earlier to support a better future!! P56*
- *I understand the budgets, but making everyone fight, cry, bang their feet and then eventually do something is not the way things should work. P17*

Inconsistent care/follow up:

The turnover of staff within certain services can lead to inconsistent care, differing opinions, and places an emotional strain on parent carers leaving them feeling undervalued. One parent carer commented the process left her feeling "*my daughter was not worthwhile*" while another understood a locum judged them to be "*rubbish*" parents. While professionals are just working their way through a clinic list, it is important that they understand the impact that the lack of inconsistent care can have on parent carers.

Inconsistent care:

- *Feel it is like everything, it is the luck of the draw who you have a meeting with. We stated with a very supportive paediatrician but then saw a different one at the next appointment who reduced me to tears! P8*
- *Paediatrician. Would not give help even when I asked for it. Washed the problem aside and said would simply review in six months. Felt like she was trying to trip me up in questions. Did not make the follow up phone call she promised or write to school for CAMHS appointment. Took 4 months of chasing to finally do it. Made me feel my daughter was not worthwhile. P8*
- *Consistent use of 'locums' at CAMHS – one only talked to our child and concluded his conversation by telling us we were basically rubbish parents. P52*
- *Our children in particular like consistency and yet often we will see different people each time asking the same questions as previously done – giving the impression they have no prior knowledge of your child – not a reassuring situation for parent or child. P25*

The lack of co-ordinated services and delays can have a major impact in other areas of life, for children with special and additional needs. Below are a number of examples, where un-coordinated care has led to emotional problems within school, such as lack of understanding on behalf of the staff and bullying from other children, or physical problems, such as unnecessary weight gain due to lack of access to the dietician, which in turn affected other areas of the child's life and necessitated involvement from other services.

Lack of co-ordination:

- *Sensory Inclusion Service and mainstream school occasionally did not communicate well, but not any major problems. The school should have more empathy and compassion re psychological issues. P5*
- *Delayed psychological assessment and transition year at mainstream primary school due to staff turnover/ teaching & psych services. Because of this our child suffered bullying long than needed to, became anxious, withdrawn, alienated for over 12-18 months. P21*
- *My son was gaining too much weight and contacting the dietician was a difficult task. The dietician never actually saw my son at a clinic, but was changing his food intake. Eventually when we spoke, he needed to go on a diet! Explained that the impact of the delay had a huge impact on other areas for my son. His size affected his wheelchair, standing frame, moving and handling, specialist orthotic suit etc etc. All these items are expensive and require their own adjustments/replacements at clinics. A time consuming and expensive exercise. P30*
- *Orthotics service received through school – no joined up working with podiatry and difference of opinions between physio and orthotics. Inadequate level or service and monitoring and care of feet/ mobility etc overall given known risks associated with diagnosis. P31*
- *My child is now part of the case load with a nurse specialist. I believe she does not listen to me or know my child. When we have spoken and I receive letters (either 'copied in' letters of referral or typed letters of our meetings) the information is often incorrect. I have had to contact her again to correct her (which has resulted in my child not being referred to some services as he should have been). P47*
- *The services aren't always joined up – that is where my role is critical. Failure to read notes before we go into a room. Lack of notice of appointments. Multiple hospital visits totally un-coordinated. P51*

Parents feel, as Rachael did in Stage 1, that their role is "*critical*" in co-ordinating care. These problems will continue to arise if services, particularly health services, only see the child as a user of their particular service, and not as a multi-service user.

Social services

The majority of services quoted above were health related. There were a number of comments about education, however, it was felt necessary to single out the comments around Social Care, as social services were strongly criticised by some participants. In particular, parent carers felt that they were refused access to something that they should be entitled to. This may vary from being refused a request for an assessment, or, for example, fighting for some support for a child, who has access to Hope House (and therefore demonstrable needs). In both these cases, the needs of both the child and the parent carers were not recognised. Furthermore, at the handover from children's to adult services, parents don't perceive a change in the child's needs, or their own needs for support, but the services alter; as one parent commented "*my child is now 18 and I have been abandoned. No help and no support*".

Accessing services

- *When ringing social services and being told NO!! Can't help!! P34*
- *We contacted social services for a needs assessment but were refused. Following advice from PACC we made a formal complaint. Following his assessment we were awarded a small amount of support (direct payments) and discharged. We were refused emergency respite as they said it was not suitable for him. P26*
- *Where do I start?! Four years to get four hours a week of extra support for a complex young girl with many difficulties. P39*
- *Social Services have totally let us down. My child is now 18 and I have been abandoned!! No help and no support. P45*

Continuity of support

- *After nearly 13 years, have had about six social workers, [current worker] is the first good one, other than that they just chat, sympathise and then leave – I have better things to do with my time than help them tick the box! P58*
- *With so many different social workers in children's services, we were constantly giving the same information about our daughter to different social workers. Apart from one or two social workers where they seemed empathetic and knowledgeable about our daughter, it felt frustrating to be spending time repeating ourselves. P57*
- *My son attends part time specialist college for the past 3 years, the funding finishes this July, we now have a fight to find something else for him/ or to get more funding. P10*

Additionally, it is not just denial of access to assessments and support, but also inconsistency of support. Parent carers comment how they have to repeat stories and share information about their child to a number of social workers. But when it works, support is perceived as good, as one parent commented:

> *Changing to direct payments for overnight respite – social worker very supportive and available. Not so alone – someone to talk to if a problem arose/someone who understood. P31*

The importance of support from social services is highlighted by this one example -

> *Despite support from PACC, our local childcare provider effectively excluded our son. Appalling communication and, arguably, discriminatory practice, resulted in the loss*

> *of a salary. This treatment opened our eyes to the fact that if your child is disabled, it is not possible for both parents to work. P53 -*

because it highlights why parents need to turn to social services for support, when mainstream care providers cannot or will not support children with special and additional needs. The children with the most needs and, therefore, often the most demanding on the parents, have the least care options open to them within the mainstream domain. Caring for a disabled child can mean facing discrimination, reduced working opportunities and requesting help from others, rather than being self-sufficient.

As mentioned above, PACC is currently working with Shropshire Social Care, and progress is being made in making the service more responsive.

What do parent carers want?

The question "do you have any suggestions about ways to make the relationships between parent carers and professionals more effective and co-operative?" was answered by 40 out of 59 participants. Two main themes emerged: Communication and Meetings.

Communication:
A general message "*more understanding; more educating about disability" P36* echoes the findings of Stage 1 around discrimination and exclusive practices within the wider population. In particular, parents felt that there was a general discrimination against them, and that they are seen as simply parents and not professional people in their own right:

> *To avoid stereotyping i.e. to recognise that intelligent professional parents can have disabled children. To recognise that discriminatory practice exists. P53*

The issues raised around communication suggest that this problem could be addressed by giving parent carers clearer information about the processes, and actively engaging with them. Part of this process is about building a relationship with parents; participants suggested the everyday niceties, such as professionals introducing themselves, explaining what is happening, giving out contact details as well as showing the parents some respect, and understanding the wider family context. One parent said *"carers need to be treated as professionals and included in all meetings*" P38, suggesting a recognition of equal footing. Likewise, they would also like professionals *"to be accountable and accept criticism"*. P53

Parent – professional interaction

- *Always be professional - always explain the next step even if you are not directly involved in it. Always get back to parents/carers as quickly as possible. Always give contact numbers/ emails of the people you need to see/work with – now & in the future. P11*
- *I think it's important professional introduce themselves and what they are going to be doing. Occasionally, I haven't known who they are, what they 'test' involves and what the results show. P23*
- *It would be good if professionals could read up on the child before they enter the room so it doesn't appear as if they know nothing at all about the child. P41*
- *Spending time listening to what parents are saying.*
- *Professionals should request and ask, not tell. They should assume the parent is the expert, (someone who) lives with it day to day. P29*
- *Build a relationship with the child/young person and parent carers. This will build confidence. P57*
- *There is not just one child involved – [it] effects the whole family. Using language which is understandable in basic terms. Use examples to explain what you are trying to say. P59*

Spoken language:

Although the questions about language discussed above were generally positive in terms of language being clear, polite and supportive, parent carers feel at times that language can be jargon-ridden, which can make them feel excluded. Occasionally, it is interpreted as patronising; in particular mothers want to be recognised as people in their own right and not just referred to as "mum", especially in meetings. Additionally, although there needs to be a use of clear language, it is important for professionals not to dumb down, which echoes Jennifer's comments in Stage 1. The use of language is also seen as a way for the professional to recognise the individuality of the child.

Spoken language

- *If professionals could speak to you rather than at you and stop spouting clichés. I think most parents want a realistic and honest conversation about their child.*
- *You also want to feel they are speaking about your child and only your child. P20*
- *When talking to people remember we don't all use the same language e.g. SEN and we don't like asking people what does it mean all the time, especially when you are in a big meeting room, it makes you feel very small. P13*
- *Don't belittle me by calling me "Mum". I am also a professional person in my own right. P22*
- *Please stop referring to me as "mum" particularly in review meetings. It can be really patronising – the professionals all use first names or titles. Treat me as an equal party/partner in discussing my child. P51*
- *Less jargon is always useful, but that is not to say parents don't understand the information given, it's just sometimes medical /professional terms can be used in a way which excludes parents. P55*
- *Generally, we have had good experiences with professionals, however, I have always worked in social care so a lot of the language used is familiar to me anyway. I often wonder how it is for a parent who does not have that background. P55*

Written communication:

Written communication is seen as an area with room for improvement – one participant commented "*poor communication between professionals*", whilst another stated there was a lack of clear pathways.

Parents who are accessing a number of services, as demonstrated, are often inundated with paperwork and forms. The language on forms was criticised for being repetitive and aimed at the young person, which is not always appropriate for those with learning difficulties. Parents also feel that at times they need support filling in forms and signposting to sources of support for this would be desirable.

The feeling amongst many parents is that e-mail could be used more efficiently for information sharing with parents and between services, as well as between paediatricians and GPs around prescriptions, to avoid delays. Often a lack of information sharing can produce logistical problems for parents, such as getting the right prescription on time.

Written Communication

- *Language used for forms needs to be reviewed. A lot of importance is attached to questions being addressed to the child/young person – whether or not this is practical and I have to say that as my child is not capable of comprehending the questions on a form or completing them, I do find it annoying. Also I find questions often overlap leading to the same information being used for several questions. It is <u>very important</u> to keep paperwork to a <u>minimum</u> so parents don't feel snowed under. P3*
- *Paperwork can be difficult so [parent carers] do need help and you need to refer people to that help. P11*
- *Paperwork generally awful. Reports either too short or too rambly. P44*
- *Their departments should ensure they share knowledge in advance and pro-actively. P29*
- *Improve ICT – link hospital computers. Allow patients to be e-mailed appointments or texted them! P12*
- *I prefer to communicate by e-mail and in writing as it is easier to keep track of things and avoid misunderstandings. Sometimes I wish they would video record meetings. P20*
- *Again if more joined up working or some kind of shared electronic 'store' this might save duplication/ repetition. P31*
- *E-mail could be better used, all persons involved can be copied in. less time spent in individual meeting, less repetition of information. P30*
- *The hospitals and GPs sometimes don't have the same info and prescriptions are delayed …. e.g. I am told I can collect from GP and they say I can't and I end up back at the hospital or the other way round. P27*

<u>Meetings:</u>

Both the timing and place for meetings were suggested as key areas for professionals to accommodate parent carers. For parents working full-time being given full warning about dates and times are important for the relationships with their employers. A suggestion of meetings at evenings and weekends was made by one parent. Another parent carer emphasised that for them meetings needed to be arranged when their child was in school, and that appointments allowed a margin for them to get home in time to meet their child from school. The important message is that parents should not be excluded from meetings because they cannot make the agreed time. It is interesting that one parent suggests that this is a way the professionals can show empathy by providing choices.

Location was raised as an issue for those living in less central parts of Shropshire, one participant commented "*not being able to drive, you can't always get to places on time because bus services are not reliable*", whereas another commented "*luckily the people I do see usually see me at school, the Lantern, Shrewsbury or in my home so it's convenient*". P7

Meetings

- *To be empathetic and provide choices i.e. place, times of meetings. P53*

Timing

- *As a full-time working parent, it feels as if I'm very unusual. I have paid (by us) wrap around care to make this possible but the system isn't always helpful with lack of notice for meetings, timing of training etc. At least two weeks' notice should be a minimum unless it's an emergency. P51*
- *Don't rush appointments – parent carers often wait a long time to get the appointment and then don't have time to discuss all of the issues. Allow time for questions. P57*
- *I understand that it is difficult to organise a meeting to suit everybody when several people have to be included. Parent carers should <u>not</u> be excluded from meetings just because they can't make a particular time – it needs to be rearranged. P3*

Location

- *Local appointments can make a huge difference to time out of school and work issues – these appointments can make employer/employee relationships very stressful. P25*

<u>Preparation for meetings:</u>

"*Carers need to be treated as professionals and be included in all meetings*." Furthermore parents feel that they should have access to notes prior to meeting to check for accuracy and enable them to give their views. Repeatedly, parent carers request that professionals read notes before any meeting or consultation, in order to prevent them having to go over the same details again and waste valuable face time. Additionally, parents would like to know who is invited to meetings and if they have met the child in question.

Preparation

- *The most useful thing professionals could do is to read notes about the child head of the meeting and allow parents access to those notes as mistakes have been made and that then follows the child to each meeting. P16*
- *Share info prior to meetings. Don't just drop it on me and tell me what you have decided. Circulate agenda and ask for contribution. Forewarn if others are invited to meetings, who they are and have they actually met my son. P22*

Finally, one parent had advice for other parents, (as opposed to suggestions for service providers) which might be useful advice for professionals to bear in mind:

Advice from one parent to another
Not all carers/parents can take it all. It is difficult but the parent has to be on the ball with what medicines are being taken etc. One thing to help is ask other carers, google things, don't be afraid to question professionals – you always have a choice. Make notes before you go in and make sure you ask all the questions you have listed. If you don't understand ask again, and again, and again. P58

Transitions

In Stage 1, Rachael mentioned the changes that occurred in support once her daughter accessed adult services. This topic was not specifically developed in the questionnaire because of the age range of potential participants, however, throughout the analysis it was found that various transition points are a cause for concern for parents and children. These range from moving on from the process around diagnosis, moving from primary to secondary school, changing schools when a placement breaks down or the transition to adult services.

The shift in support post-diagnosis is highlighted by one parent, who felt that the paediatrician's appointments and reports *"made it easy to flag up new issues, and get advice…it felt like he was being monitored and we were supported"*. But following discharge, she says "*most services are now no longer available as routine*" and the problem for her is *"we no longer see anyone"*.

When school placements break down, life can be extremely challenging for both children and parents, as demonstrated by Molly and Helen's stories in Stage 1, with changes in educational settings having implications for both health and social care. Parents are often left to fight for a placement, as described by one participant, whose daughter was out of school for two years, before she was awarded a place at a specialist residential school. Another parent describes their experiences:

> *When mainstream school 'broke down' for my son there was quite a disjointed time when we felt no one really wanted to 'deal' with us! We had to be very 'pushy' to get to speak to different agencies – and to get some decisions made. P46*

Another parent discusses the impact a delayed transition from primary to secondary had on both parents and the child:

> *Delayed psychological assessment and transition year at mainstream primary school due to staff turnover/ teaching & psych services. Because of this our child suffered*

> *bullying long than needed to, became anxious, withdrawn, alienated for over 12-18 months. We went through a lot of anxiety trying to find the 'right' secondary option for our child. We did receive apologies but felt let down by the system. P11.*

A sense of abandonment and confusion is also felt by parents at the transition to adult services, but when handled appropriately, services can co-operate and make a success of the transition.

Transition to adult services

Criticism:

- *Transition to adult services – very poor communication from continuing healthcare initially. Nurse assessor impossible to get hold of – lost information emailed and given to her. Adult services need to look at disabled young people at least six months before they turn 18 and start planning. P2*
- *Transition from children to adult services is a very difficult and confusing time. More information is needed P10*
- *Social Services have totally let us down. My child is now 18 and I have been abandoned!! No help and no support. P45*

Praise

- *When my child was going through an important review hearing last year as part of a transition from children's to adults' services we were supported in a very positive group of people including teachers from the school that my child was currently attending, social worker, a representative from Shropshire Education Department and support worker for IASS. All these people helped my husband and myself through the process. The whole meeting went well because all the people round the table were on the same side – wanting the best outcome for our child. They were supportive, positive and proactive and that made us as parents very positive too. P3*
- *Transition to secondary – once agreed plan of action it worked really well. Professionals and teaching staff worked hard to make sure our child was settled. P11*

These examples illustrate that when services work together with parents, good outcomes can be achieved, but parents need to be kept informed of the processes and choices available. The question of choice is only lightly touched on in the accounts. Occasionally, as one parent comments "we have no choice", however, it is within the dynamic of the professional-parent relationship to explore the options and choices.

Luck?

Throughout the comments, as in Stage 1, there was the use of the word “*lucky*”. It reflects a recognition of the fact that although the parent carers have a disabled child, who they have to support, in some way they have access to something special which helps their situation.

Lucky

- *Felt able to rest and relax and felt extremely lucky to be eligible for this service because [I was] exhausted. P2*
- *I feel lucky to live in Shropshire because we seem to be very well supported. I would be reluctant to move to another county. P23*
- *We consider ourselves lucky and we work very hard to get the “right” support to meet our child’s needs but it feels like an uphill struggle some days. P11*

This support is not a right, but something that they have the good fortune to access; this discourse suggests that there is not an expectation that services will be provided: in some cases they have to be earnt.

Despite the criticisms of services one parent wrote - *THANK YOU – WE ARE VERY GRATEFUL FOR ALL THAT YOU DO TO HELP OUR CHILD & US* - and it is hoped that this account represents the positive views as well as the negatives.

Discussion

From the statistical data, it is clear that all the children are multi-service users, and that their parents are the co-ordinators of those services. Children with more complex needs (but not necessarily health needs) access more services, and this is particularly true of the group who have access to a social worker.[11] So it is assumed that all the participants involved had experience of being multi-service users. Research in developmental disabilities reported in 2009 that parents of children with disabilities have “more stressors and varied situations in their life than parents of children without disabilities” and that “parents of children with disabilities reported less stress and few depression symptoms when they had access to social support” (33). Effective support is therefore vital for wellbeing.

In this study many parents were happy with the services they received but, whilst PACC acknowledges these positive experiences, it is necessary to concentrate on the negative comments at this stage in order to make recommendations for improvement. Many of the themes discussed in Stage 2 are not new findings; for example, PACC has previously reported that parents wish that services were more joined up, that there was better communication, that they did not have to repeat their story to several professionals and that meetings were scheduled to take parental responsibilities into account. (11). However, the findings of the lack of understanding and empathy on behalf of professionals, and the emotional impact that has on the parent carer, are the central to many parental experiences.

Participants in Stage 1 discussed how their children are subjected to exclusion and occasionally discrimination, which is a finding borne out in the published literature (17). The mothers also normalise their children’s behaviours and limitations, which is part of the acceptance of having a disabled child, and become their advocates, which mirrors published findings. The parents are, therefore, very closely tied to their children and their experiences; in many cases, they are literally their child’s voice. At the same time, it has also been suggested that mothers are unwilling to voice their own needs at the risk of appearing “selfish” (24) and in case it undermined their efficacy as advocates.

In order to deal with the challenges that this altered life presents to them parents adopt coping strategies, which may be emotion-based (avoidance) techniques, such as not thinking about the future because there are too many uncertainties (Rhiannon) or problem-based techniques, such as fighting for services and taking control of those services when necessary (for example Rachael). Research also suggests that seeking out social support for emotional release, laughing and crying are all emotion based techniques; asking for help, doing things to help the children, and information seeking are problem-based solutions (34).

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[11] The questionnaire did not draw out the number of educational settings that those children with ASD have accessed, but it is clear from the accounts of Molly and Helen in Stage 1 that a number of educational settings, which failed, impacted on their child’s and their own wellbeing.

Examples of these are found throughout both the Stage 1 and Stage 2 datasets. Coping techniques have been found to be associated with improved parental empowerment and in turn well-being. Kelso et al (2004) also found that “*themes of commonly experienced stressful events related to the professional-parent relationship*”, adding that “*there is considerable scope for professionals to utilise the information provided by caregivers regarding what aspect of contact are stressful and thereafter modify practice so that coping is enhanced*” (34).

One of the more distressing aspects of the accounts is the number of times parents feel that they are not believed by the professionals. As mentioned above, they want professionals to “*witness*” their child’s behaviour; they feel they have to “*convince*” professionals that they need help and that they are judged. Often they state they are not “*listened to*”. So parents are not just set aside from other parents and subject to discrimination from the ‘outside’ (neuro-typical) world, but they also feel they are then subjected to judgement within they system that should be there to support them. This feeling of being judged inevitably impacts on their self-image and at times makes them feel belittled, and, at other times, combatant.

So whilst problem-solving coping techniques, such as seeking information and asking for help, are employed, and should aid parental empowerment and consequently wellbeing (20), these processes often make life more stressful for parents. The mantra of “who shouts loudest gets most” was only touched on by two of the 67 participants; in this study parent carers are actively asking for support and seeking help with what they feel are reasonable demands for their child, but, in light of services which they perceive are only given within crisis-response contexts, it is not surprising that they do become frustrated and demanding, and occasionally emotional.

Previous research has explored the emotional impact of having a child with disabilities or additional needs (1, 4), but more recently studies have looked at the specific nature of “caregiver burden” and the benefits of mothering a child with disabilities. In particular, it was found that parents are not necessarily grieving for the child they might have had, but rather they were worn out by the social and physical constraints their disabled child, and the systems around them, put on their lives. “We’re tired, not sad” one mother said (4). Whilst there are references to the emotions around the diagnosis of the child within the dataset, the majority of the emotional content is in relation to services and professionals, and the relationship between themselves and those professionals.

However, published research into parent-professional partnership within an educational context suggests that part of the reason that partnership working has failed is due to professionals dismissing parents as being emotionally involved with their children, and therefore not able to make rational decisions (8). Parents are also represented as being over-protective (15). Alternatively, parents might argue that, in the face of services who they feel do not listen to them or their children, they are their children’s advocates and their opinions should be heard.

Furthermore, the majority of these parents do not think professionals and service providers generally are empathetic. The lack of empathy manifests itself in a variety of ways, from the oversharing of information to not following up on promises made in appointments, and a belief that if professionals really understood what life was like they would ensure that the appropriate support was in place.

Parents also want to be able to plan proactively for their children's future, and in the face of diagnostic and problem solving practices in both health and social care, forward planning is a challenge. As one parent commented, services see what the child can't do rather than what they can and might be able to do with appropriate support. Research suggests that parents can be supported by professionals in seeing the positive benefits of caring and supporting a child in transition (35), but this equation needs to be turned around, and parents invited to actively work in an equal partnership with professionals for future planning, as the legislation of the Care Act suggests.

In order for this partnership to be successful, professionals need to be given an overview of the parental role within the child's care, rather than solely concentrating on their own particular expertise in relation to the child's problem. Research amongst trainee teachers, who listened to a mother's story, found that engagement on this level gave rise to increased awareness of empathy, understanding and personal growth (18). Additionally, research into help-giving practices suggests that both 'participatory' practices, which encourage joint-decision making between parents and professionals, as well as 'relational' practices, which address issues such as showing empathy and active listening, are "crucial" for the empowerment of both parents and professionals (5). In particular, help-giving practices may also improve the parental "perceptions about the extent to which they are viewed as competent" by those giving support.

Parents want to be on an equal footing with professionals: they see themselves as experts in their child's care, and are often infuriated by being patronised and called "Mum". Effective joint-working is crucial at those transition points of a child's life in order to support and plan for the future. Transition into adult services is a time that parent carers in general identify as being stressful and distressing. It is a period of change and when new relationships are forming. Whilst the child's views must be placed at the centre of any transition plan, professionals must accept that in many cases parents are the advocates for their children and that continues into adulthood, particularly for those children with the most complex disabilities, as demonstrated by Rachael's account.

There are particular challenges around this transfer as young people move into the world of adult services, where there is rightly an increased focus on disabled individuals having their own voice; however, it is recognised in legislation that family carers do continue to have an important role. More work needs to be done on developing adult services' understanding of the role of family carers in decision making, which is recognised and supported by the Mental Capacity Act, the Children and Families Act and the Care Act.

Transition is also a time when the co-ordination of services can become even more of a challenge, particularly in relation to health services. The role of the GP can at this point become central to the delivery of co-ordinated care and the maintenance of good health. There has been evidence published recently that individual with learning disabilities and /or ASD are likely to die younger and experience poorer health than the general population (36, 37)

Developing a positive relationship with GPs from an early age is important for families of children with disabilities so that good health can be maintained into adulthood. While in this research GPs were identified as a service that was most frequently used by the families participating, but it is not clear in what capacity, and if that is related to the young person's care or the care of the family carer. National research indicated that in most cases families do not go to their GP about issues relating to their child's disabilities or condition and that GPs' understanding of disability issues is poor; over 1 million people have a learning disability in the UK but only 200,000 are on the GP learning Disability Register. (38).

Strengths & Limitations

The strength of this project is that it actively engaged with 67 parents of children with disabilities and additional needs within Shropshire Local Authority area, and gave them the opportunity to express their experiences, comments and concerns. The qualitative aspect of both stages of the research ensured that those experiences were narrated and reflected upon. There was a wide range of disabilities and additional needs but the group was homogenous as all the parents had accessed a number of services.

The range of both positive and negative feedback reflects a range of experiences, but it should be considered that there might be more positive comments than in the general population because these parents have time and inclination to fill in the questionnaire. It is also acknowledged that a number of the experiences (in both Stage 1 and Stage 2) are historical, and it has been recognised that the system needed to change, and some issues have been addressed. However, they illustrate the impact this system failure has on parent carers.

The limitations of the design were in the questionnaire, where more definitive questions might have produced clearer data – such as the question around what services had been accessed in the past. Further research might put a time window, such as a year, on the question. Additionally, it is acknowledged that there was no question about the gender of the child. PACC intend to review the demographic section of the questionnaire and refine it for future research. Also, more sophisticated statistical software would have produced more powerful statistics.

However, it is felt that this piece of research, which is quite wide in its scope will serve as a pilot for other research within Shropshire's community of children with disabilities and additional needs.

Future research

Looking at children as multi-service users, it would be interesting to explore in detail the relationship between the number of disabilities and the number of services accessed, and how certain areas of difficulty, such as challenging behaviour or high medical needs impact on the number of services. Additionally, the length of involvement with specific services, such as social care, might be explored. The relationship between satisfaction with services and whether the child was in a mainstream or specialist school might be explored further.

This research was centred on parent carers. It would be interesting to explore the professionals' view of the parental role within a child-centred partnership, and to consider how they see the professional-parent interaction, with reference to empathy. In particular, the data around the role of the GP might be explored further, to discover how involved GPs are in the care of disabled children within Shropshire Local Authority area, and how that role changes at transition. It would also be advisable to explore what learning skills and support needs professionals think they require to develop successful co-working with parent carers.

More generally, the data around parents' employment suggests that more than half of parents work, although many of those are working part-time. An area for further research would be to explore the types of employment parent carers have within Shropshire Local Authority area, and whether their caring role has affected their careers and employment aspirations.

Researcher's statement

I must acknowledge that I am the parent carer of a young man with ASD and complex learning difficulties, and as such I fall into the category of a multi-service user within Shropshire Local Authority area. I hope that my experiences made me more empathetic to those people who I interviewed. Particularly, I tried to bracket my own experiences, and listen to their stories, but at times I shared my own reactions and experiences. I have endeavoured to remain objective in my analysis of the data.

I would like to thank all of the mothers and fathers who took part in this project, for their time and sharing their stories. Their contributions have been invaluable in producing this report.

Recommendations

Parent- professional partnership

Parent carers and professionals should work closely together in order to understand the “big picture” of life as a parent carer. In this way, professionals will gain insight and parent carers may gain confidence in professionals. In order to achieve this, it is suggested that:

- Professionals attend workshops where they can learn first-hand about parental experiences, the potential emotional impact of caring for and supporting a disabled child and how being a parent carer is different to the ‘normal’ parent role.
- Professionals receive training around help-giving styles, so that parent carers feel valued and understood and on an equal footing with professionals. Training would include using the Good Practice Guidelines on developing positive relationships with parent carers, outlined below.
- Parent Carers are given the opportunity to understand the potential impact that having and supporting a disabled child may have on them as individuals, and to explore their own emotional responses. This support should include discussion on how they may positively manage their relationship with the system and the professionals they come into contact with; for example, through the use of person centred planning tools. (39)

Co-ordination of Services and Communication

- Further work needs to be carried out on how services could be more co-ordinated, with a particular focus on reducing the burden of information sharing and provision that is currently carried by parent carers. This should be done in the context of the Special Educational Needs and Disability reforms, which promote a holistic and ‘tell it once’ approach to supporting young people with SEND, via the introduction of Education, Health and Care plans.
- Person centred planning tools are an effective way to share key information about individuals with disabilities or additional needs. Adult social care, and to a certain extent education and children’s social care services in Shropshire Local Authority area, are starting to use these tools as part of their day to day processes. It is recommended that all professionals providing care and support in to children and young people with disabilities or additional needs and their families undergo training in person centred planning and the use of person centred planning tools.

Transition

- Professionals need to understand and acknowledge the reality that parent carers often continue in their caring role well into their child's adulthood. The continuation of this key role of parent carers as advocates for their children into adulthood should be recognised and valued by professionals, rather than treated with suspicion. Whilst those with disabilities and additional needs may need encouraging and supporting towards independence, professionals must recognise that the parental advocacy role is still crucial to those with greater needs.
- Families should be encouraged to have a good understanding of the Mental Capacity Act for those young people who are unable to make their own decisions..
- Work undertaken in the areas outlined above should improve parent-professional partnership, as well as communication and the co-ordination of services.

Role of the GP

- It is recommended that work is done to ensure that GPs actively support and engage with families of children with disabilities from an earliest point. There should be a focus in increasing GPs' awareness of the positive role that they can play in co-ordinating services and signposting families to support.
- There should also be a focus on ensuring that any young person with a Learning Disability is flagged on the GP data register, so that annual health checks are offered from the age of 14 and the GP is actively engaged in the transition process.
- Parent-led training for both GPs and practice staff, as outlined above, would facilitate a better understanding of the specific problems around being a parent carer of a child with disabilities or additional needs, and thus enable them to support both the child and the parent effectively.

Vision

In this way, it is hoped that parent carers and professionals will work together to establish a common framework for partnership. The balance of power should be shifted from the care-giver (the professional) and the care-receiver (service user) to a three-way partnership between parents, young person and professional, where all parties are equally valued.

Improving Communication: A Good Practice Guidance for developing positive relationships with parent carers:

Always introduce yourself and explain your role in relation to the child.

1. Communication:

Implement a 'tell it once approach' wherever possible.

Use of e-mail and electronic sharing of information within and between services, such as consultants' letters and changes to prescriptions to the GP or respite services, as well as with parent carers.

Joined up information between hospitals.

Text message service for appointments to be offered.

Forms to be user friendly, and not require too much repetition of the facts.

2. Language

Refer to parents by name. Do not use the word "mum"/"dad".

Involve the child in discussions as and when appropriate; recognise the level of understanding and communication.

Consider the appropriate level of language and information for parents.

Recognise that the parent is the child's advocate.

Avoid jargon (e.g. acronyms such as "FPOC").

3. Signposting

Ensure parents are signposted to the appropriate level of information and support.

4. Meetings & Appointments

Preparation – read notes before meeting parents/child.

Circulate agendas beforehand if appropriate.

Timing – give adequate forewarning of meetings/appointments, checking that parents are available. Take both work and caring role arrangements into consideration, such as taking time off work or being back to meet the school bus.

Ensure parents have time to ask questions, and express views.

Acknowledgments

This research project has been supported by Healthwatch Shropshire Research Grant funding. PACC are very grateful for the support and encouragement of Healthwatch Shropshire in this project.

Shropshire Parent & Carers Council would like to thank all the individuals who participated in this research project for their time, and for sharing their experiences and stories, which were often very personal, and sometimes emotional, journeys.

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Appendices

Appendix 1

Stage 1 - Interview schedule for semi-structured interviews

Stage 2 – Questionnaire

Appendix 2

Stage 1 – Table of codes

Appendix 3

Stage 1 - Mind maps of services accessed by participants' children

Appendix 1

Stage 1 - Parent Carers as Multi Service Users - Interview Schedule

DIAGNOSIS

Can you tell me a bit about your child?

What is their diagnosis? How old are they?

Prompts: what age were they diagnosed; who was involved in that process; who were the key people?

How did you feel about it at the time?

SERVICES

What are the main services you access? (show the maps of Child A and Child B's services as a prompt)

How did you find out about those services? How easy did you find them to access?

What problems did you encounter? Did you find the services shared information about your child or about other services with you?

IMPACT (of using services not the child's disability)

What impact did using those services have on your child, you? Your family?

Can you tell me briefly about your own health and the health of your family?

WINDING DOWN

Do you think your child is aware of the services they access? How do they react? What do you think they think? (question to be adjusted dependent on child's cognitive level)

Do you have any suggestions/changes you'd like to see with regards to your child's services?

Finally - to end on a positive: can you think of one positive/benefit of a service for you child and you as a parent carer.

Stage 2 Questionnaire

PACC Shropshire, PO Box 4774, Shrewsbury. SY1

The experiences of parent carers of children with disabilities as multi-service users: a Questionnaire

Please can you tell us what it is like to be a parent carer?

We are asking PACC members to fill in this questionnaire, as part of PACC's current project (funded by Healthwatch Shropshire). We aim to explore the reality of being a parent carer of a child with a disability or additional need who is using a range of different services.

From PACC's experience of talking to parent carers it is clear that many families of children and young people with disabilities or additional needs are often in contact with numerous services related to their child's disability or additional need, at any one time. Parent carers often talk about the impact of maintaining a relationship with several services and professionals and this project is exploring that further.

We have now completed the first stage of the project and found three themes:

1. the *child in context*, looking at exclusion and inclusion;
2. *managing outcomes*, exploring communication, and conflict and co-operation between parents and service providers;
3. the *impact on the parent carer*, which explores parental identity and emotional impact.

The next stage of the project will take themes two and three and explore them further, to tell us what it is like to be a parent carer. We are therefore hoping you can spare a bit of time to fill in this questionnaire.

It is divided into three sections to tell us about your child, yourself and then your relationship and communication with service providers.

If you are able to help us, please first read the brief statement about consent and anonymity below, and if you are happy to continue then sign and date it. You should then return this to us with your completed questionnaire.

If you have any questions or concerns please do contact Katharine Slade on 01743-761279 or katslade27@btinternet.com

Thank you very much for your cooperation.

Consent and anonymity

All the information that we use in the PACC Healthwatch Shropshire report will be anonymous. We will give a number to each completed questionnaire and we will not refer to your name or the name of your child. When we include any comments about service providers these will also be anonymous.

If you fill in the form, and return it to us, you have a one-week period within which you may withdraw your comments from the project if you change your mind. You may leave blank any questions you do not wish to answer.

If you agree to take part in this survey then please complete the form below and return it to us.

…….

Consent and anonymity form

I have read and understood the above conditions, and am happy for my comments to be reproduced anonymously within the Healthwatch Shropshire report.

Name ……………………………………………

Signed ……………………………………………………………………………………………

Date …………………………………………………………….

SECTION 1: Your child

Please tell us a little bit about your child:

1. What are the main areas of your child's disability? *Please tick ……..*

Autistic Spectrum Disorder	
Learning Disabilities	
Challenging Behaviour	
Physical Disabilities	
Medical conditions (such as epilepsy)	
Mobility issues/Wheelchair user	
Communication issues	

If you would like to tell us their diagnosis please write it here:

………

2. How old is your child

………………………………..

3. What age was your child diagnosed?

………………………………….

4. What type of nursery/ school/college does your child attend:

Specialist	
Mainstream	
Home educated	
Currently excluded	
Other, please state:	

5. Please look at the list below and tick all the services which your child is currently using or has access to, and those you have accessed in the past.

	Currently have access to	**Accessed in past**
Royal Shrewsbury Hospital		
Birmingham Children's Hospital		
Alder Hey Hospital		
Royal Stoke Hospital		
RJAH Orthopaedic, Oswestry		
Portage		
Severndale Assessment Nursery		
Severndale School		
Mainstream Nursery		
Mainstream School		
Specialist Learning Support Unit		
Specialist/Residential School		
Vision Impaired teacher		
GP		
Health Visitor		
Paediatrician		
Child Development Centre (CDC)		
Specialist Nurse Consultant		
Community Nurse		
Speech and language therapy (SALT)		
Social Care Occupational Therapy		
Health Occupational Therapy		
Physiotherapy		
Audiology		
Ophthalmology		
Wheelchair Services		
Continence Services		
Oxygen Service		

Neurology		
Respiratory consultant		
Cleft Palate Clinic		
CAMHS LD		
CAMHS		
Special Needs Dentist		
Podiatrist		
Social Worker		
Hope House		
Overnight respite		
All In Short breaks		
Direct Payments		
Health-led nursing hours		
Privately funded childcare		
Transport		
Police		
Educational tribunal		
Ombudsman		
MP		
Support groups		
Any others, please list:		

SECTION 2: Yourself

6. Are you …. ? *(please tick one)*

A mother	
A father	
Family carer (eg grandparent)	
Other type of carer (eg foster parent)	

7. What is your age?

………………………………..

8. Do you work? *(please tick all that apply)*

Full time (paid)	
Part time (paid)	
Voluntary work	
Work from home (paid)	
Full time carer	
No work outside the home	

SECTION 3: Relationships with Service Providers

9. Generally, how do you feel about yourself in relation to professionals/service providers you deal with? (We recognise that your relationship with some services / professionals might be different to your relationship with other. We are looking for your overall feeling about working with services in general and in general how that makes you feel). There is space later on to add any comments about specific services.

On a scale of 1-5 with (1 being Strongly agree, 2 agree, 3 no opinion, 4 disagree and 5 being Strongly disagree) ** please circle as appropriate* :

	Strongly agree	Agree	No opinion	Disagree	Strongly disagree
Involved and part of the decision making	1	2	3	4	5
You are the expert in your child's care	1	2	3	4	5
Listened to	1	2	3	4	5
Excluded	1	2	3	4	5
Confused	1	2	3	4	5
In conflict	1	2	3	4	5

Other, please state…………………………………………………………………………………………………

………

10. Generally, how do you find the language used?

	Strongly agree	Agree	No opinion	Disagree	Strongly disagree
Clear and easy to understand	1	2	3	4	5
Confusing and alienating	1	2	3	4	5
Polite	1	2	3	4	5
Rude	1	2	3	4	5
Supportive	1	2	3	4	5
Threatening	1	2	3	4	5
Practical & supportive but not empathetic	1	2	3	4	5
Empathetic	1	2	3	4	5

11. Are you ever emotional in their dealings with professionals and service providers? How is that received? Are service providers and professionals empathetic?

Please comment:

12. Please can you give an example of a time when a service has worked well for your child and yourself? You might want to include the following information:

Why did it work well? Were you well supported?
Who supported you? How did that make you feel?

13. Please can you give an example of a time when a service or combination of services did not work well for your child and yourself?

AND FINALLY….

14. Do you have any suggestions about ways to make the relationships between parent carers and professionals more effective and co-operative? Consider the

language used, places and times of meeting, paperwork relating to meetings.

Please add any other comments if you would like to……

Thank you for your participation!

Please return this questionnaire to PACC using the pre-paid envelope included. If you would rather complete electronically please request an copy to be emailed to you by contacting PACC at enquiries@paccshropshire.org.uk

Appendix 2 – Stage 1 Table of Codes

Codes/Participants	**Christine**	**Helen**	**Jennifer**	**Molly**	**Naomi**	**Shelley**	**Rachael**	**Rhiannon**
Child in context: a)Disabled/non disabled world	l.1263, l.1373	l.259, l.763, **l.827**	l.248	l.41	**l.128, l.335**	l.18,	l.17, l.569	l.360
b) within/beyond Mother's care	**l.103-115**	l.649, l.772, l.781, l.806	l.688,	l.329,l.336, **l.188**	l.180	l.104, l.164	l.36, l.1010, l.1248	l.573
c) within family setting;	l.678	l.22, l.258, l.386	l.354	l.420, **l.439**		l.26, **l.983**		l.271
d) within educational and social setting	l.1257, l.1261	l.188, l.607	l.248	l.54,l.287	l.313	l.359	l.902	l.360
Communication a) Parent/ Service	l.92, l.56, l.621	l.98, l.153-161, l.432, l.806	l.73, **l.792**	l.145, l.429	l.88, l.118, **l.149, l.287**	**l.861**	l.252, l.503, **l.1294**	l.471, l.921
b) Inter-service	l.435, **l.576**	l.80, l.147, l.810	l.64, l.994	l.917	l.97, l.168, **l.503**	l.262	l.103. **l.412,**	l.763
c) Service/Child	l.1337	**l.698**	l.467	l.141, l.194, l.443	l.331, l.435	l.359	l.1439	l.650
d) Parent/Child	l.1145	l.134, l.432, l.671	l.922	l.470	l.250,l.256, **l.376**	l.154	l.1439	l.504
Adjustment/ normalisation	**l.129**	**l.866-70**	l.96	l.292, l.320, l.865	l.304, l.342	l.988, l.264	l.308, l.189, l.330	l.655
Advocacy	l.798	l.57, l.64, l.169	l.147?, l.629	l.349, l.359-374, l.1001	l.136	l.326	l.70, l.340; l.636	l.61, l.284, l.239
Support	l.185, l.798	l.113, l.169, l.394, l.457,	l.191, l.298, l.336; l.391,	l.243, l.378	l.13-30	l.170	l.698, l.916	l.289, l.305

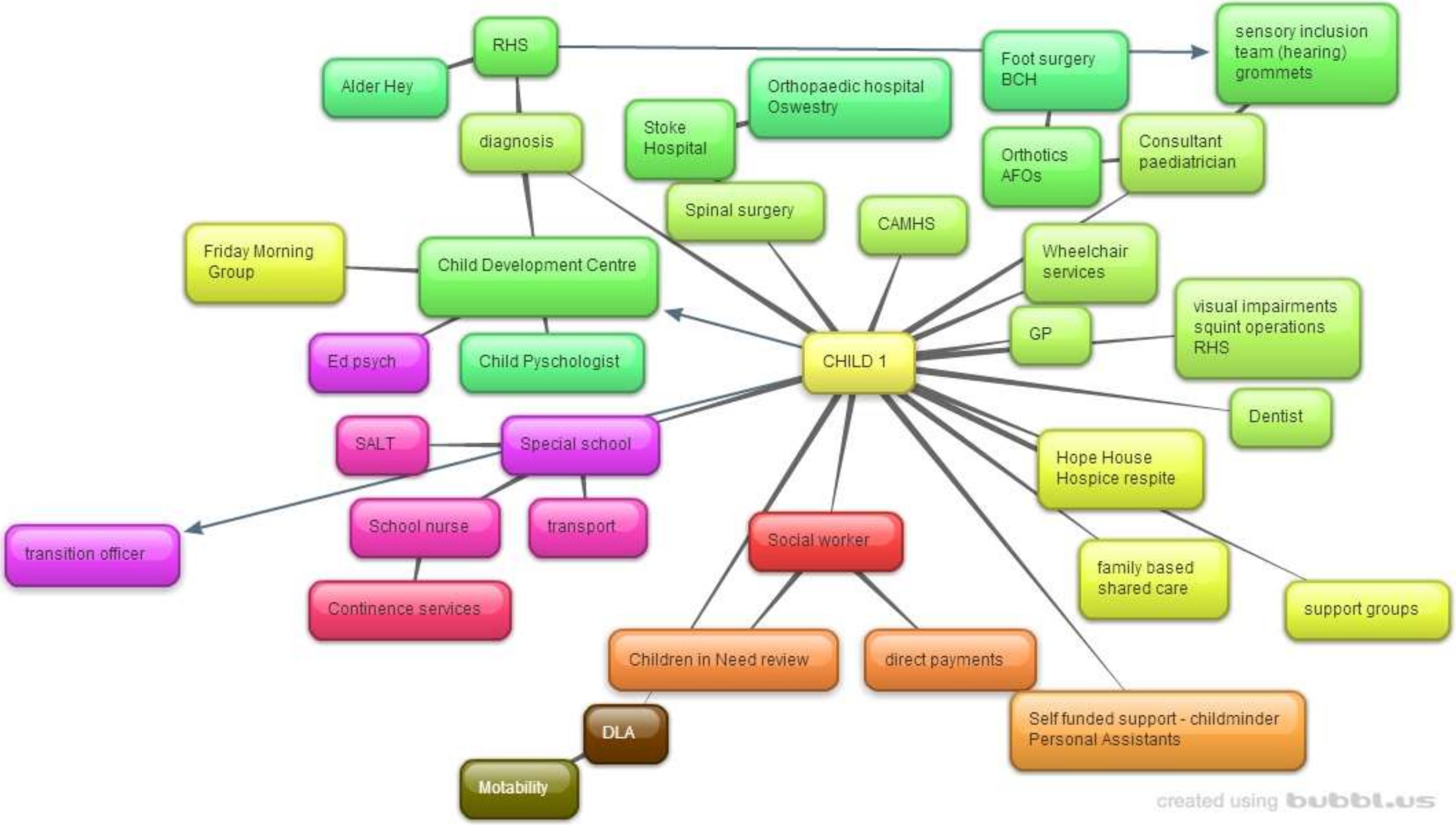
		l.560	l.598					
Resorting to higher authority	l.254, l.1309	l.104, l.130, l.196, l.729	l.445, l.616, l.977	l.59,385	l.136	l.647, l.659	l.587	l.300
Codes/Participants	**Christine**	**Helen**	**Jennifer**	**Molly**	**Naomi**	**Shelley**	**Rachael**	**Rhiannon**
Empathy	(l.258), l.615, **l.685, (l.820)**, l.1397	l.269, l.284	l.505-511	l.814-5	(l.180), l.245	l.495		l.58, l.285
Emotional responses	l.253, l.341, l.611, l.1098, **l.1226**	l.88, l.163, l.705	l.188, l.426, l.434, **l.721**, l.784	l.75, l.152, l.205, l.218	l.238, l.269-273, l.323	l.714	l.120, **l.442**	l.113
Isolation	l.1431	l.878	l.217, l.724	l.73,l.81,**l.161**		l.567	l.542?	l.154, l.592
Exclusion	**(l.768)**	l.24, l.316		l.33-170 l.161	l.133, l.450	l.647		l.313
Parental identity	l.398, l.618, l,1062, l.1111	l.340, l.349. l.708	**l.185, l.201,** l.755	l.160-5, l.218, l.338	l.86	l.791,792	l.611, l**.948**, l.971, l.1032, l.1322	l.133
Control	l.204, l.	l.237	l.439	l.712	l.366	l.342,	l.88,	l.395
Expectations	l.451, l.603, l.657	l.78, l.151, l.405, l.995	l.367; l.420, **l.437, l.471, l.495**	**l.62**, l.265	l.145, l.562	**l.286,** l.722	l.1225, l.1251	l.181, l.446
Regret	(l.1269)		l.452	**l.294**		l.556		l.118
Eligibility/restrictions	l.733	l.527	l.527	(l.178), l.236	l.184, l.340, l.352-355	l.262, l.277, l.837	l.680	l.386
Co-operation	l.1735	**l.892**	l.192	(l.538)	(l.240)	l.623	l.906	l.471

Challenge/Conflict	l.27, (l.1736)	l.173, l.125, l.339, l.439	l.192, **l.326**	l.113, l.495, l.524	l.299	l.861	l.582, **l.726**	l.289 (l.602)
Problem solving	l.1190	l.898	l.109	l.448, l.488	**(l.176), l.405**	l.142	l.550	l.612
Luck/Fortune	l.64		l.846	l.817		l.545	l.596	l.426
Codes/Participants	**Christine**	**Helen**	**Jennifer**	**Molly**	**Naomi**	**Shelley**	**Rachael**	**Rhiannon**
Blame	l.343, l.1016	l.107, l.253, l.339, **l.439**	l.448,	l.417, l.908	l.129	l.38	l.32	l.322
Risk	l.12, l.27-30	l.637	l.173	l.171	l.169, l.305	l.665	l.612	l.303, l.356. l.568
(Lack of) Trust	l.72	(l.16)	(.l.434)	(l.161)	(l.149), l.427	l.359	(l.1247)	l.372
Transition/ continuity?	l.478	l.74, l.393	l.482	l.108	l.54, l.464	l.131	l.217	l.366
Future	(l.215)	l.994	l.28, l.526-565	l.326		l.396, l.631	l. 617, l.1010	l.607, l.958

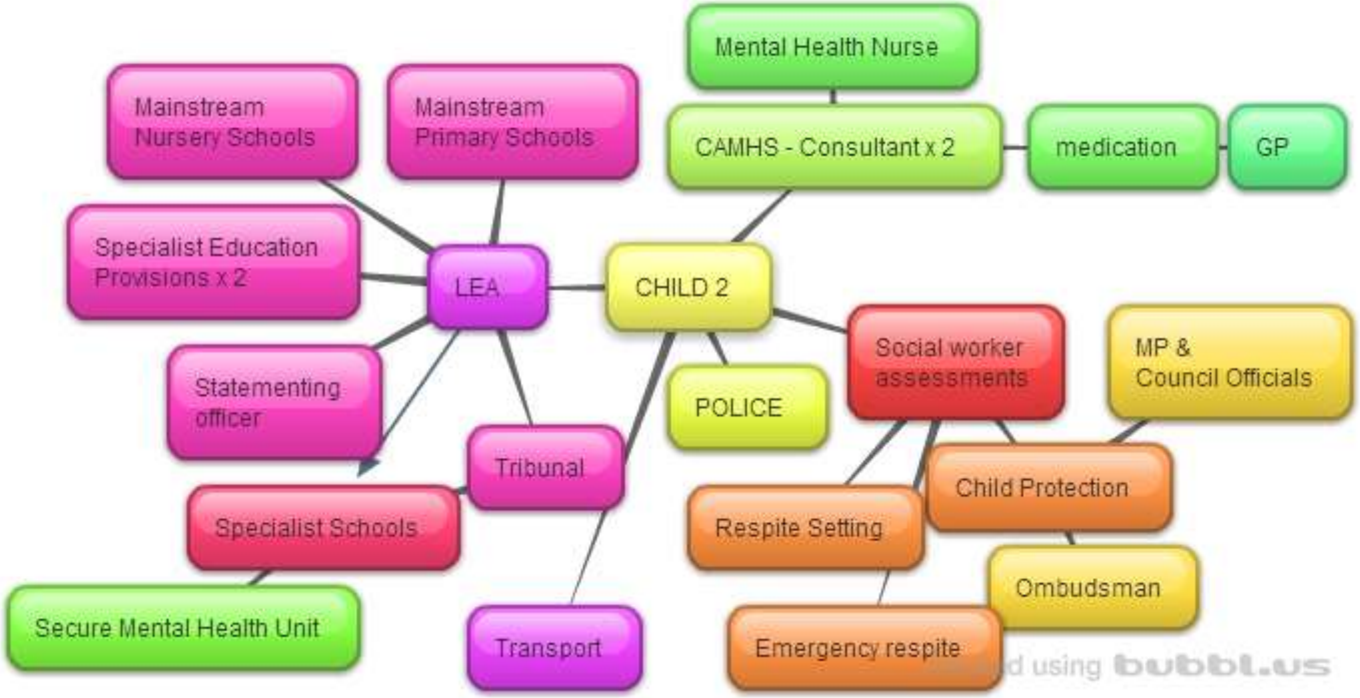
Table of identified codes, showing line references in transcripts

KEY
l. = line
Bold= key quotes,
(…)= the opposite e.g. (l.215) under Future = refusal to look to the future

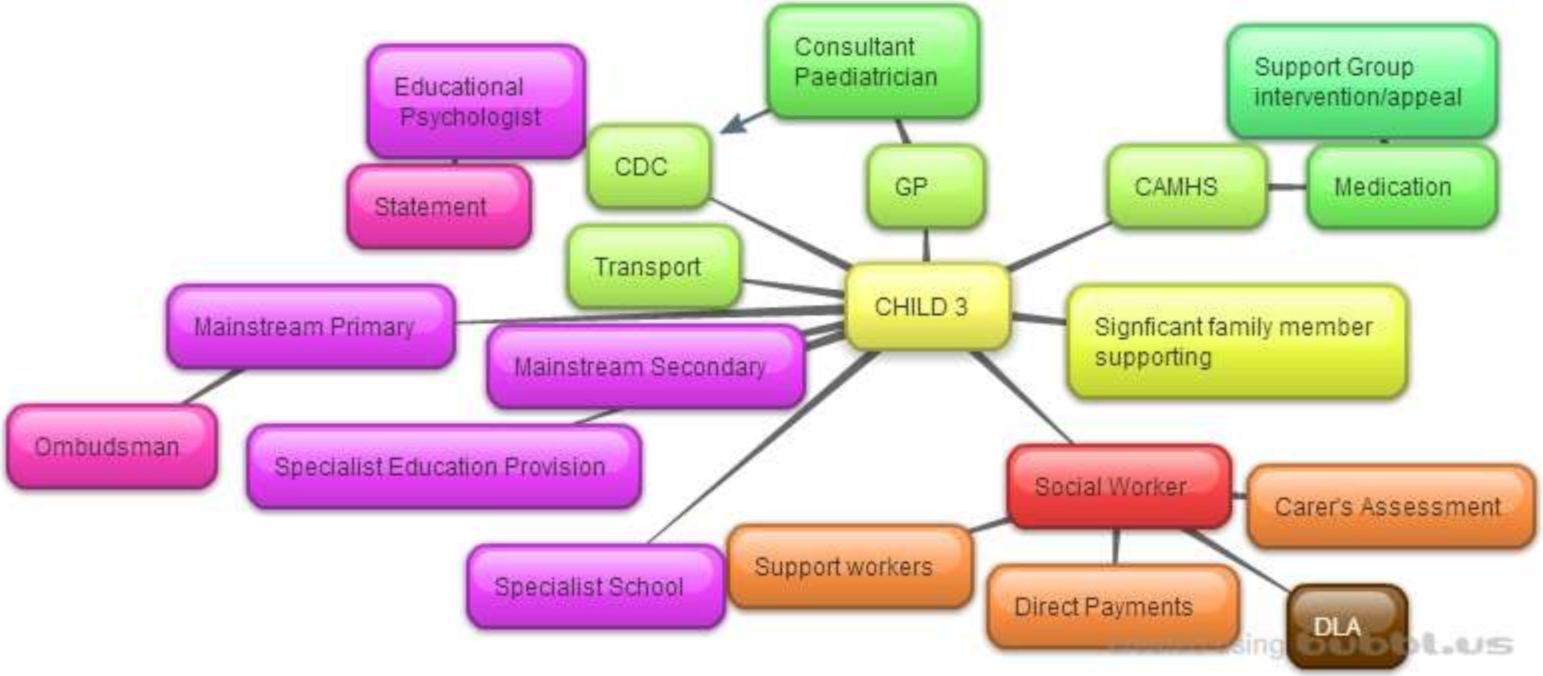
Appendix 3 - Mind maps of Services accessed by children



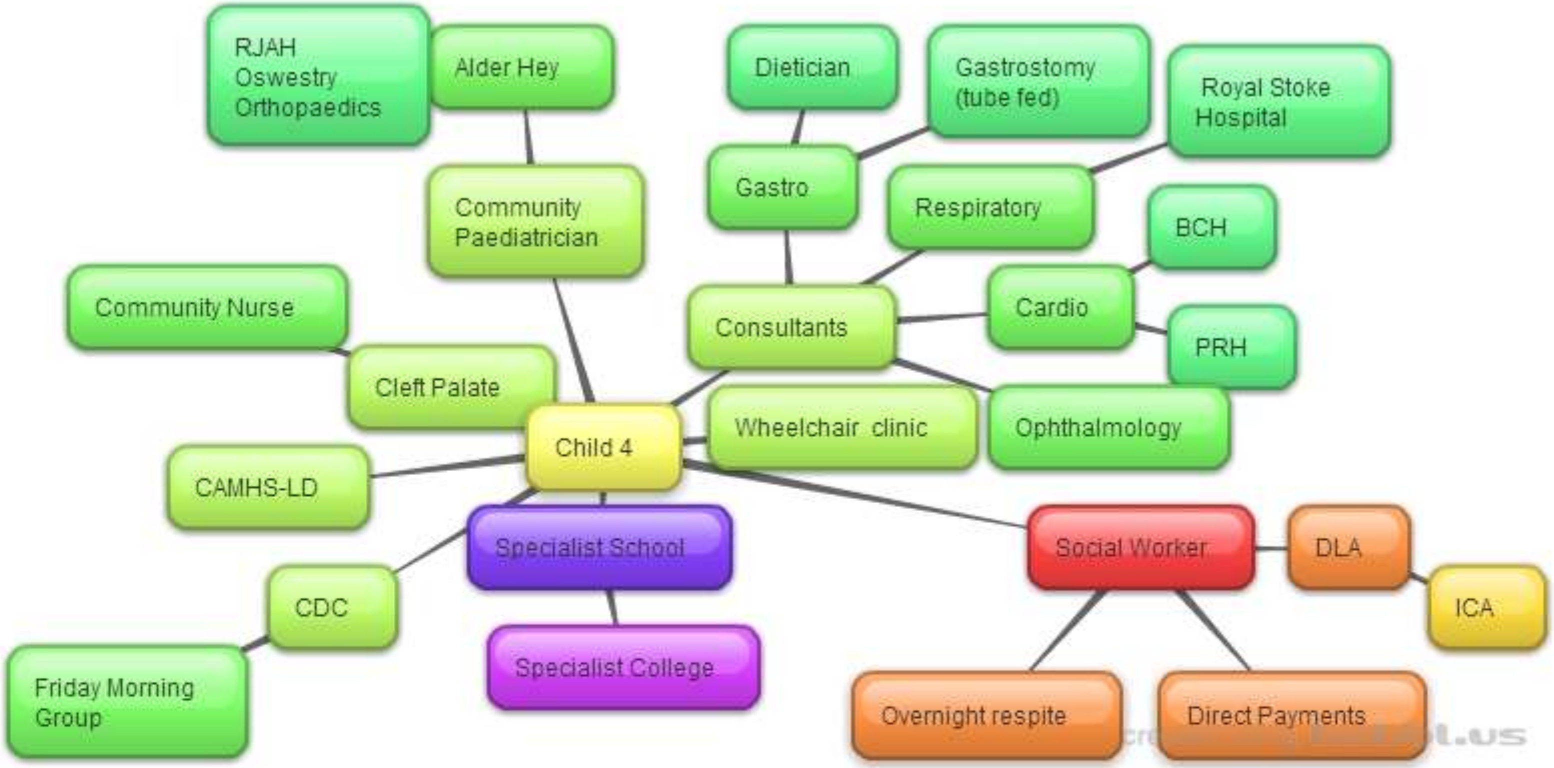
Child 1’s Mind map of Services



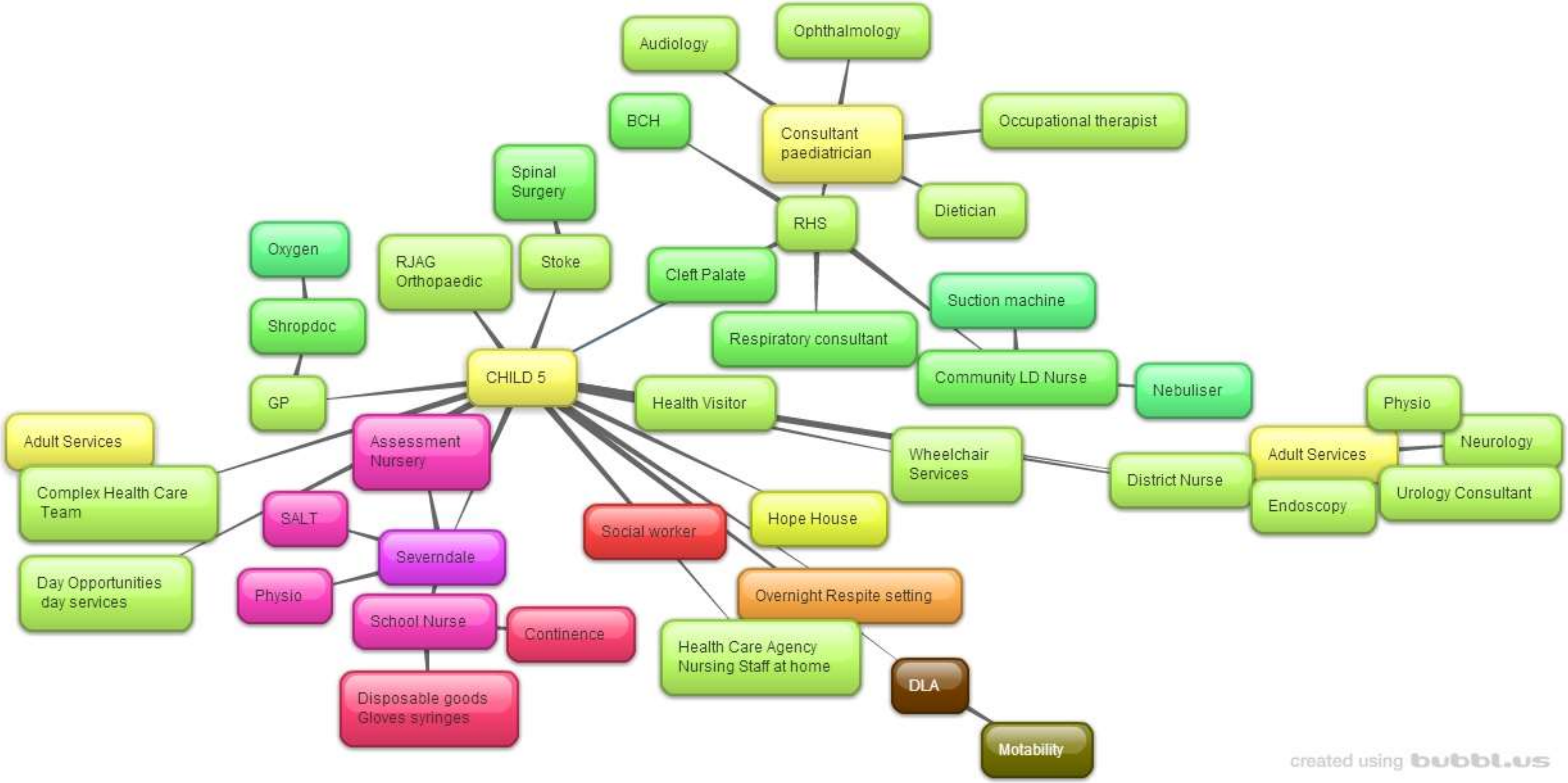
Child 2's Mind map of Services



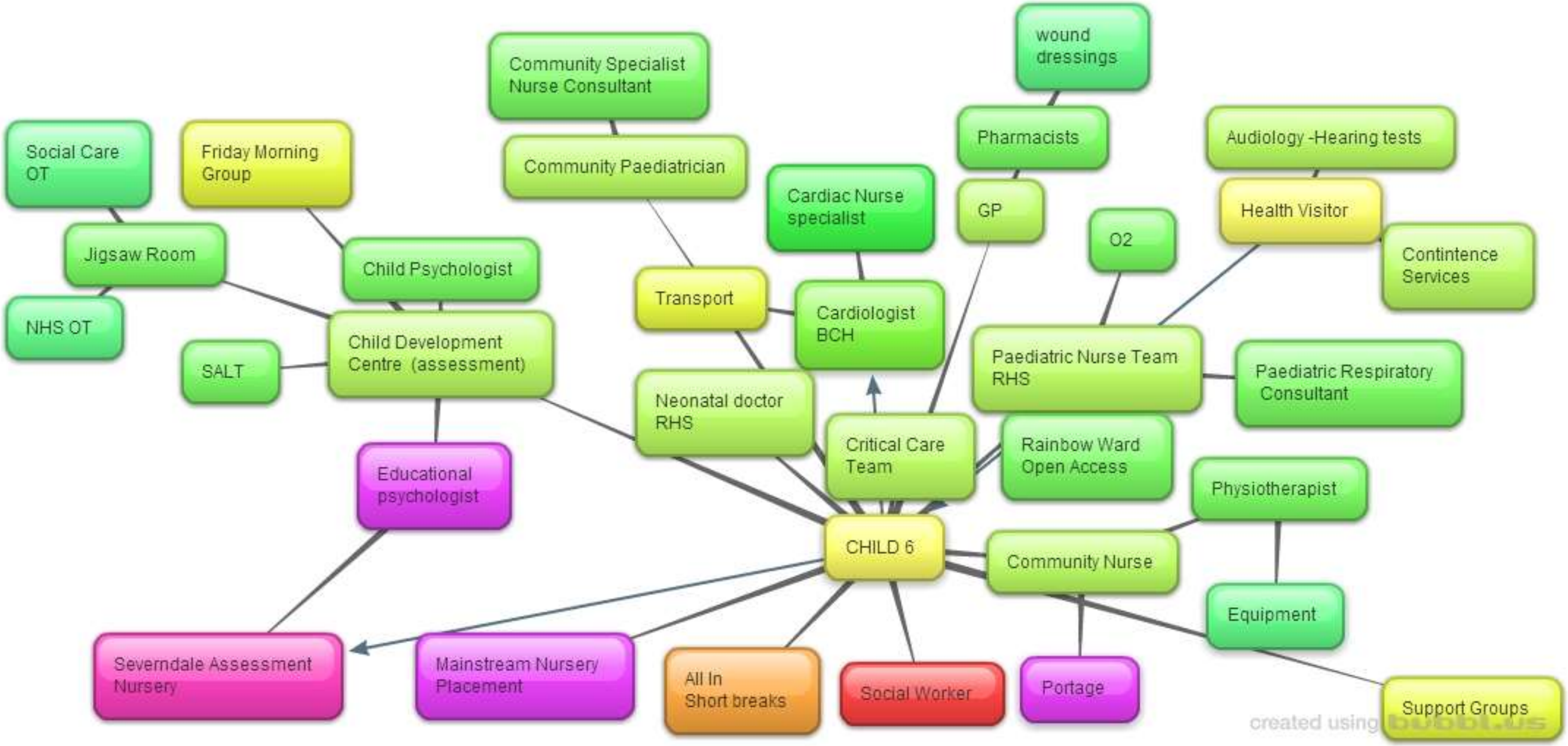
Child 3's Mind map of Services



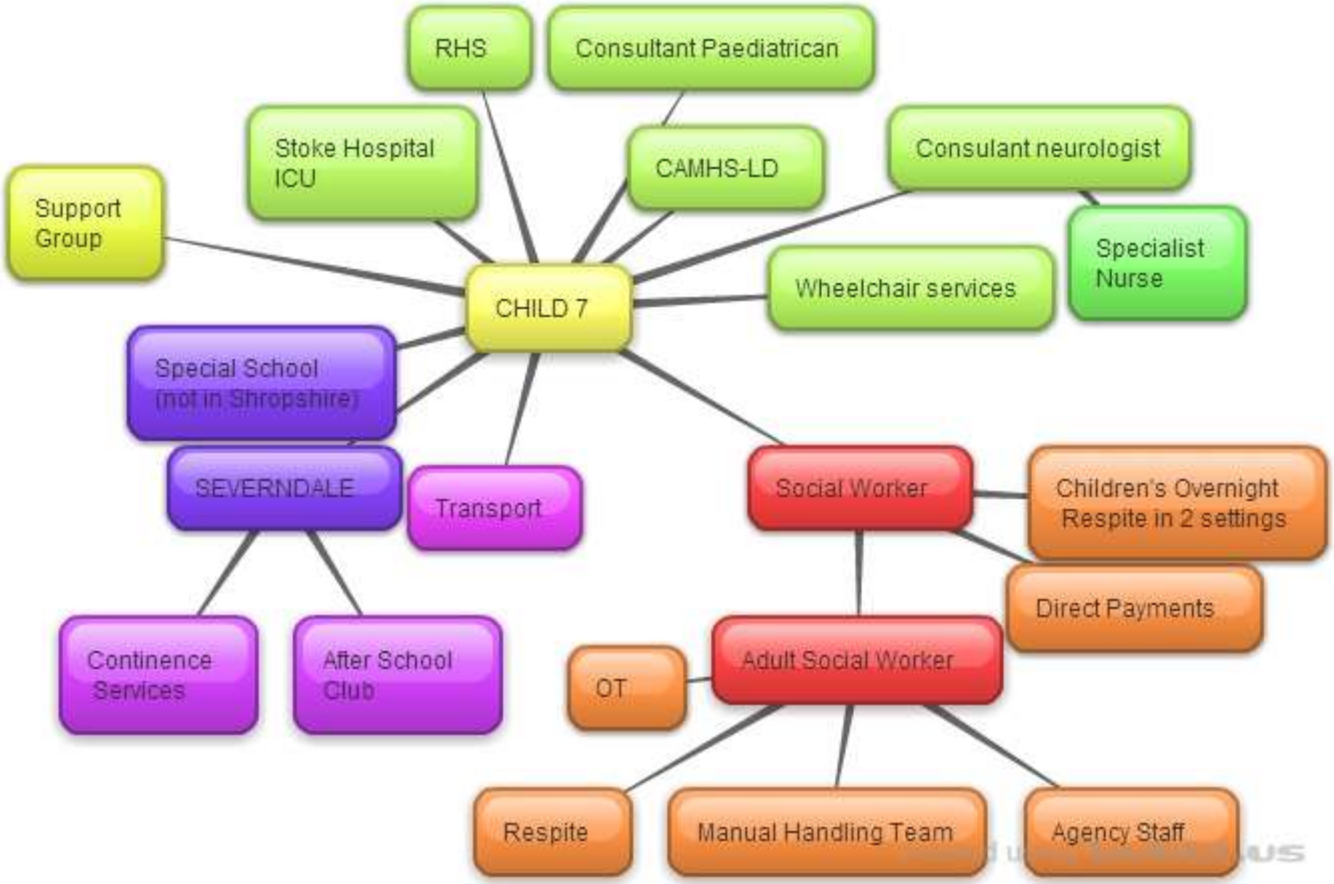
Child 4's Mind map of services



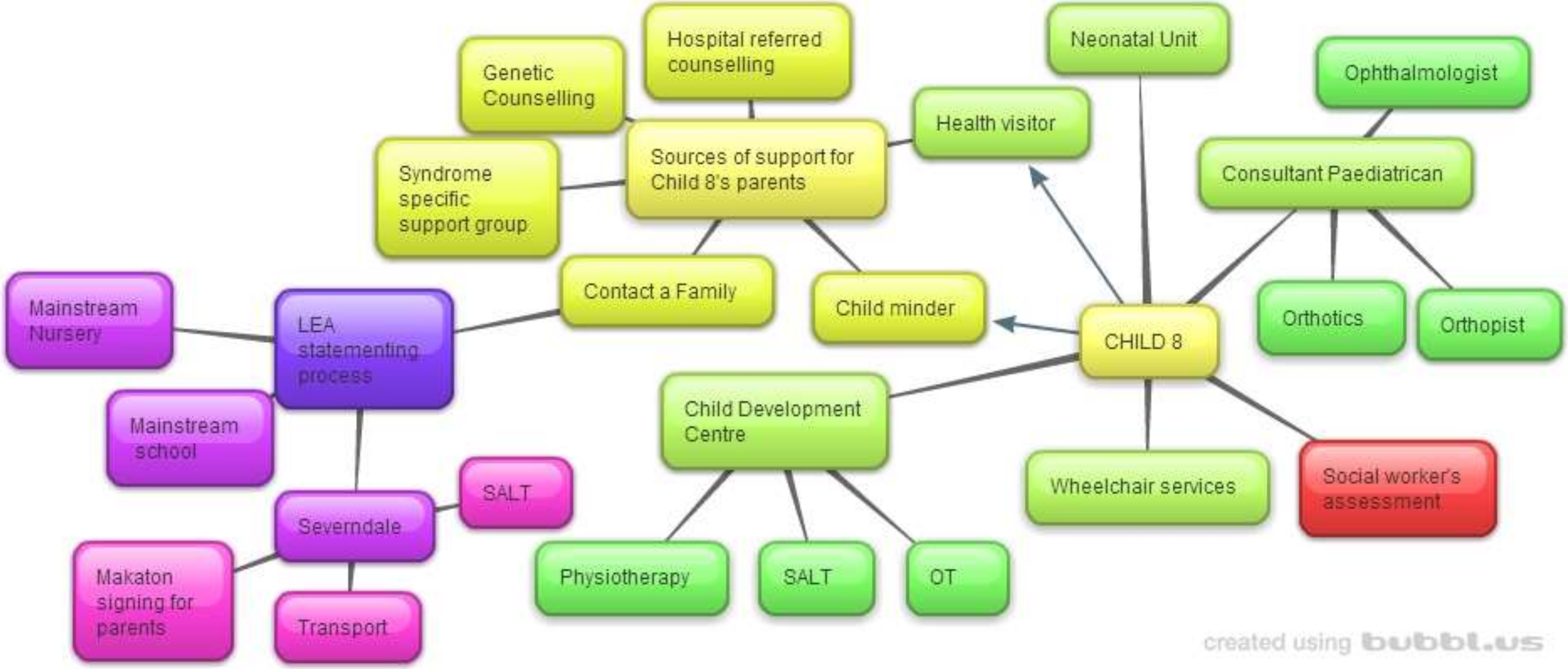
Child 5's Mind map of Services



Child 6's Mind map of services



Child 7's Mind map of Services



Child 8's Mind map of Services