



SHROPSHIRE Parent  
And  
Carer  
Council

**healthwatch**  
Shropshire

## Executive Summary:

“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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## 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 1<sup>st</sup> 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.