University of Bedfordshire

GINGER GIRAFFE

Tilda Goldberg Centre
for social work
and social care

Re-imagining social care services in co-production with disabled parents

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Emily R. Munro and Maryam Zonouzi with Richard Fountain, Julie Harris, Dan Vale and a group of disabled parents

drill
Disability Research on
Independent Living & Learning

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Contents

Background and methodology

Historically studies of disability and parenting have tended to focus upon 'parental impairment – rather than social disablement – as the key variable of interest' (Olsen and Clarke, 2003, p.1). Moreover, they have tended to assume a correlation between impairments and negative impacts on children's wellbeing. In contrast, this Disability Research on Independent Living and Learning (DRILL) and Big Lottery funded research project aimed to re-imagine social care services for disabled parents and their children, and to:

- problematise the assumption that having an impairment necessarily impacts on the ability to care for a child
- use the Social Model of Disability to move away from talking about impairments and on to exploring the systemic, attitudinal and environmental barriers that may restrict disabled parents from meeting their parenting responsibilities
- work in co-production with disabled parents to develop potential solutions that aim to keep families together through independent living.

Aims and objectives

Researchers from the Tilda Goldberg Centre for Social Work and Social Care at the University of Bedfordshire engaged with disabled parents involved with Ginger Giraffe (a cooperative that brings together disabled people and those experiencing multiple disadvantage together with health and social care students on placement) to define the priorities for the research ('what do we want to explore?'). The parents had all been referred (or self-referred) to children's social care and had undergone an assessment to determine whether their child or children were in need or suffering, or likely to suffer, significant harm (under s.17 and s.47 of the Children Act 1989).

The central aims of the research were to:

- explore these six disabled parents' experiences of statutory assessments in children's social care services and subsequent service provision, including examination of:
    - the assessment pathway (how they accessed support)
    - the assessment itself (thresholds and eligibility criteria)
    - the principles guiding the assessment, and how these were experienced by disabled parents
- draw on disabled parents', child and family social workers' and researchers' knowledge and expertise to re-imagine how children's and adult social care might deliver holistic services which value the needs, assets and rights of the whole family.

Methodological approach

The methodological approach adopted was grounded in Participatory Action Research (PAR) that takes its first principles to be equality and reciprocity. PAR forefronts research with the voices of those most affected by the research (disabled parents) and seeks to research into an area or domain, which is of importance to the community (changing provision for disabled parents). Beyond the specified aims and objectives of the research, PAR seeks to address power imbalances between researchers through building a research community of equals, who become co-researchers on the project.

Alongside PAR, we introduced Appreciative Inquiry (AI) with a view to recommending positive changes to strengthen policy and practice. At its heart, AI is about the search for the best in people, their organizations, and the strengths-filled, opportunity-rich world around them. AI is not so much a shift in the methods and models of organizational change, but a fundamental shift in the overall perspective taken throughout the entire change process in order to ‘see’ the wholeness of the human system and to ‘inquire’ into that system’s strengths, possibilities, and successes (Stavros, Godwin and Cooperrider, 2015).

The two methodologies give rise to an approach known as Participatory and Appreciative Action and Reflection (PAAR) (Ghaye et al., 2008). PAAR was employed with the aim of overturning ‘deficit’ discourses surrounding disability and parenthood more specifically, and to developing an appreciative insight and understanding of what had worked to keep families together and ways of supporting this ambition going forward.

Within Appreciative Inquiry there is a methodological process which is adopted to guide the research process. The 5-D cycle includes: Definition (what do we want to explore), Discovery (stories about what is), Dream (imagining the best of what could be), Design (statements of intention) and Destiny (action planning) (Cooperrider and Whitney, 2000). Mixed methods were adopted across the 5-D cycle (see below for further details).

Co-production

Co-production was central to the project and the team included six disabled parents who were a) engaged in activities with Ginger Giraffe and b) had been assessed to determine whether their child or children were in need, or suffering, or likely to suffer, significant harm under s.17 and s.47 of the Children Act 1989. Further details about the parents who participated, including their impairments and subsequent social work intervention are provided in Annex 1)[1].

The team also included three academics with specialist knowledge of child and family social work, including a qualified social worker, as well as a disabled academic who has undertaken research on independent living and personalisation. The Executive Director of Ginger Giraffe also participated in the project.

Prior to data collection, the co-researchers both participated in and delivered training in line with the principles of co-production. Child and family social work co-researchers trained the parents in aspects of child welfare legislation, regulation and practice. Disabled parent co-researchers trained the group on adult social care, disability and equalities legislation and the Independent Living Movement. The academic researchers also provided training on focus groups and on data analysis and coding.

Methods

Between January and July 2018 over 25 meetings were convened to bring together the co-production team. Mixed methods were employed including: focus groups, service mapping and storyboarding (a process by which participants write their story against a timeline and present

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[1] The research team also tried to engage parents with learning difficulties in the project (via local organisations working with this group), but none agreed to participate.

the people in their stories including their thoughts and feelings), use of needs assessment mapping, service suitability mapping, concept reframing mapping, snap shot big picture, fishbone diagramming and role play. Table 1 provides a summary of these methods and activities and the timing of their use in the 5-D cycle.

Table 1: Summary of methods employed in the research

5-D phase	**Method or activity**	**Purpose**	**Overview of method or activity**
Discovery (stories about 'what is')			
	Creating personas	To present significant people in parents' stories of engagement with children's and adult services	Disabled parents created persona for each person in their account. Personas are used as a method in design thinking and give a person to connect with to bring a story to life (Cooper, 1999).
	Storyboarding	To assist the parents to share their journey (of involvement with children's and adult services).	A process by which participants write their story against a timeline and present the people in their stories, including reflections on their feelings and thoughts. Further details about the disabled parents' experiences were elicited using gentle questioning, prompting and probing (Bowling, 2002; Gray 2004).

	Empathy mapping	Develop an understanding of people in the disabled parents' stories and to illuminate what parents thought about their involvement at key points during their engagement with children's and adult services	Empathy mapping is a technique to help people develop deep shared understanding and empathy for other people and allowed the rest of the group to connect with the stories that were being told (Gray, 2017).
	Assessment of need mapping	Obtain parental reflections on what they thought social workers focused on during the	Parents were provided with a copy of the Assessment Triangle (a pictorial representation of the *Framework for the Assessment of Children in Need and their Families* so they could identify which dimensions of a child's development needs, parenting capacity and family and environmental factors they thought social workers had taken into consideration as part of the assessment (Department

		assessment	of Health, Department for Department for Education and Employment and Home Office, 2000).
	Service delivery mapping	Obtain parental reflections on which services were put in place and what was missing from the parents' perspectives	Researchers explored with parents which services children's and adult social services had put in place and whether they wanted these and felt they were needed. Parents were also asked whether there were additional services that they wanted but that were not offered. In order to make this visually interesting we invited parents to populate the template in a green, amber and red.
	Concept reframing mapping	Obtain parental reflections on the principles underpinning the Care Act 2014 and Children Act 1989.	Principles within Care Act 2014 and the Children Act 1989 were placed onto a target map. Parents and professionals were given red and green sticky dots. They were each invited to place their sticky dots on the target map. The green dots represented principles that the group were happy with and did not wish to change. The red dots represented concepts that were perceived to be problematic in respect of supporting disabled parents and their children.

5-D phase	Method or activity	Purpose	Overview of method or activity
Dream (imagining the best of what could be)			
	Creating new personas	Develop personas that reflect the characteristics that parents would like professionals to demonstrate in the future.	Parents decided from the discovery phase which personas they wished to take into dream. They subsequently developed a series of new personas to replace personas they did not wish to carry forward from the discovery phase.
	Empathy mapping	Develop an understanding of the new personas	Parents decided from the discovery phase which empathy maps they wished to take into dream. They subsequently developed a series of new empathy maps to replace personas they did not wish to carry forward from the discovery phase.

	Fishbone Diagram	Developing a goal to be achieved	Usually, fishbone analysis or ‘Ishikawa diagrams’ (1968) are used to find the root cause of problems. In Appreciative Inquiry, it can be used to do the opposite – an inclusive process to find the route to the Dream. In the ‘head’ of the diagram, disabled parents and professionals write the part of the Dream that they want to bring into reality. In the boxes at the end of each spine of the fishbone they write an area for which action needs to be taken to make the Dream happen. Along each spine of the fishbone, parents and professionals placed post-it notes with the actions that have to be taken, or the things that have to be in place, to make that area support the dream goal.

5-D Phase	Method or activity	Purpose	Overview of method or activity
Design (statements of intention)			
	Focus groups		A series of focus groups were conducted around the following themes: help seeking, the assessment, the service, service closure/continuation and outcomes and the principles of assessment.
	Snap shot big picture	Designing new principles to support best practice in working with disabled parents and their children	Browolski (2018) created the snap shot big picture method. The snapshot of the big picture is designed to clarify what individuals and teams are experiencing right now and to help them envision the desired future and create an action plan to get there. The snap shot big picture tool was used after the concept reframing mapping. The snap shot big picture enabled the group to think about the principles they wanted professionals to practice. Parents and professionals worked together to reimagine the principles they had highlighted as requiring reframing through the concept reframing

			mapping.
	Fishbone diagram	Developing a goal to be achieved	Parents and professionals used the Fishbone diagram to map out the characteristics and strengths of the new personas they had created in the dream phase

Analysis

Data analysis occurred iteratively after each phase of the data collection process and informed the subsequent one. As the research was underpinned by PAAR, the methods employed were designed to be accessible and to provide an opportunity for the parents to engage in the data analysis process[2].

A grounded theory approach was employed to analyse the data, informed by Strauss and Corbin's (1990) four step process, as summarised, below.

Step 1: Theoretical sensitivity

The aim of this step is to build up a list of relevant topics that have arisen and that are considered essential to the subject under investigation. These indexes are constructed and reconstructed following an exhaustive analysis of the text.

Step 2: Constant comparative coding

Three types of coding were used:

1) *Open coding* - where co-researchers segmented the transcribed data into similar groupings that formed preliminary categories of information about our study.
2) *Axial coding* (focussed coding) - following intensive open coding, co-researchers bring together the categories they identified into groupings. These groupings resemble themes which enabled us new ways of seeing and understandings.

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[2] Ten data analysis sessions were held with the disabled parents.

3) *Selective coding* (theoretical coding) - co-researchers organise and integrate the categories and themes in a way that articulated a coherent understanding and theory.

Step 3: Theoretical saturation

The analysis process continues until saturation is reached, the point at which there were no new ideas or insights from the data.

Step 4: Development of theory[3]

The results of a grounded theory study are expressed as a substantive theory, that is, as a set of concepts that are related to one another in a cohesive whole. The research design, data collection and data analysis are interlinked and iteratively build on each other to construct the development of theory (p.12-14).

Ethical considerations

Ethical approval for the research was obtained from the Institute of Applied Social Research (IASR) Ethics Panel at the University of Bedfordshire.

In line with the principles of co-production, the disabled parents were remunerated for taking part in the research, taking into account the National Institute for Health Research guidance on involving the public in social care research (INVOLVE). This included paying for accessible transport and a support worker to provide assistance during meetings.

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[3] This fourth step was not undertaken because this was not the purpose of this research project.

Pseudonyms have been used throughout the report to minimise the likelihood that participants can be identified. However, the small number of research participants involved in the project and the rich data that they supplied means that friends and family, or the professionals involved in their cases, may be able to identify them even though they have not been named. This was discussed with the parents and they have all reviewed the final report and given their informed consent to include their case studies and quotes being included in the report.

Strengths and limitations of the research

The sample size for the study is small and a number of policy and practice developments have occurred over the period that these parents were involved with children's services. On this basis we make no claims about the generalisability of the research findings, but we do suggest they raise questions about service responses to meet the needs of disabled parents and their children that warrant further examination. We also echo Dale's (2004) reflection that the views of parents 'can extend beyond the biases of their particular experiences and consequently can offer sophisticated and insightful contributions that are of much value in relation to the development of good practice' (p.138).

The 'dream' of an alternative model of service provision sought to address a number of the barriers and challenges that the parents' stories illuminated. These ideas are intended to provoke discussion and debate in the disabled community and amongst policy makers and health and social care professionals. We see this as the start of a conversation about approaches to protect and promote the wellbeing of disabled parents and their children, not the final destination. It would be valuable to hear the voices of a larger group of disabled parents, as well their children. In addition, there is a need to hear from professionals and to consider whether conditions are in place to maximise the likelihood of the proposals being adopted in practice (see for example, Bostock, 2018).

Learning from disabled parents’ experiences

National and international research provides rich insights into parental experiences of child and family assessments and child protection practice (see among others, Buckley, Carr and Whelen, 2011; Dale, 2004; Dunbrill, 2006; Gallagher et al., 2011; Gaffar, Manby and Race, 2012; Harris, 2012). However, to date minimal attention has been directed to eliciting disabled parents’ views of the assessment process and subsequent interventions.

The six disabled parents who participated in the research were assessed by children’s social care services to determine whether their child or children were in need, or suffering, or likely to suffer, significant harm (as defined under s.17 or s.47 of the Children Act 1989)[4]. These assessments took place between 2002 and 2018. This chapter provides an overview of each of their stories, in their own words, and then goes on to illuminate commonalities and differences in these disabled parents’ experiences. Particular attention has been given to the following: referral pathways and help seeking, experiences of assessments from children and adult services, service provision, specifically the issue of substitute parenting, and the relationship between agencies and environmental barriers. Pseudonyms have been used throughout.

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[4] Parents were unclear about what type of assessment was conducted, or their subsequent status and the classifications are based on the social work researchers’ analysis of the information supplied during the course of the research.

The parents' stories: In their own words

Amanda

I am a mother of four children: three daughters and one son. We have faced many challenges as a family and our experiences have enabled our resilience on many occasions. My first introduction to adult mental health services was over 30 years ago when I was diagnosed with postnatal depression after the birth of my first child. Some months later I was diagnosed with having bipolar affective disorder.

Children's services became involved in our lives in May 2014 and continue to intervene. I was invited to attend a Child Protection Case Conference. My child was in respite accommodation due to a recent relapse in mental health and due to physical ill-health. Initially my son was placed with his father. My son then made an allegation of abuse and I was taken out of hospital to attend the Child Protection Case Conference meeting. His father was exonerated at the first meeting. Children's Services then placed their focus on me and said that my son needed protection. To me it seemed this was because I was mentally unwell. They asked me many questions about my mental illness and I did not have an advocate.

I initially believed that support was going to be put in place to help me parent and to keep the family together. A family intervention service was offered, but this did not help me and my son did not want the service.

What I needed:

- Support in understanding and managing my son’s diagnosis of special educational needs (SEN) and Attention Deficit and Hyperactivity Disorder (ADHD).
- Support for my other children who were affected by the impact of my mental health relapses and inpatient hospital admissions
- A service that would engage with the whole family, including those who are labelled as ‘difficult to engage’
- Opportunities as a family to explore our strengths and be enabled.

Sadly, we did not get what we needed and we are no closer to getting it.

Cliff and Gloria

My name is Gloria my partner is Cliff. We have been together since 2006. We are both wheelchair users with spinal cord injuries. Before 2004 I was a non-disabled single mother of two. In 2004 I had a spinal cord accident. Overnight my life changed. I was in hospital for seven months. In this time my children were looked after by my best friend. It was only when the hospital wanted to discharge me that they realised I had children. They wanted to send me to a nursing home and then realised the children could not come with me. The council gave me a two bedroom flat. I shared a room with my daughter, Irene, and my son, Wayne, had his own room. I got a care package from Adult Social Services to help me but this did not include help with the kids. They offered me meals on wheels but did not offer to provide this for my children. I managed as best as I could and relied on my friends and neighbours, especially for school runs or used taxis to drop them off. I thought I was coping well and then I got a knock at the door from children's social services. I asked why they had come and they said it's because you are disabled. Initially I was very frightened and so I asked Cliff to come to the meetings so they could see that we were just a normal family. I did not know what was going on and I was not involved in the assessment. In the end, they came and said that my daughter Irene needed to be taken out, so they sent a lady called 'Sarah'. Sarah took Irene to the cinema, the park and out shopping but I wasn't allowed to go. My son was not given anything: they said this was because he was 15 years old. The Adult Services wanted my children to be my carers and I said no to them. I needed some basic help with cooking, cleaning, school runs but this did not happen. I struggled for many years relying on neighbours and friends and felt embarrassed. It was not a good time but we survived.

Noor

My name is Noor. I am a wheelchair user and I have had progressive muscular dystrophy since birth. I am married to Mustapha. We have one daughter called Duaa, who is now 11-years-old.

As a result of my past personal experience, I got involved in this project that focuses on social care for disabled parents.

I went through a very difficult phase in my life when I was pregnant and I I was dealing with Children's Services. As a result of my disability, the attitude of the social care worker was intimidating. Social services treated me as though I was not fit to look after my child or able to be a caring mother because of my disability. My experiences were contrary to my expectation that social workers would show empathy and offer adequate support. When I delivered my baby at the hospital I was placed in a non-accessible ward and I experienced discrimination from some of the hospital nurses. They were all undermining my ability to be a good parent. They refused to discharge me from the hospital until a meeting took place in which they questioned my ability as a parent.

Due to all this, I was left with no other option but to take my daughter abroad and leave her in the care of my parents for several months until children's services closed the case (when my daughter was aged one).

Sahar

My name is Sahar and I am a wife to Omar and a mother to Ali. Omar and I married 15 years ago. I have been disabled and in a wheelchair for many years. The doctors are not sure about my exact diagnosis but it effects my mobility which means I need help with everyday activities. Before I got a Personal Budget I used to live with my mum and she helped me a lot.

After I got married I became pregnant. It was not until Ali was born that I experienced some difficulties, especially with feeding him, as my arms are not strong enough to hold him. The health visitor visited me and she said that she was going to contact Children's Services. I didn't know about Children's Services then. When the social worker came she questioned me about my movement and being able to feed my baby. I explained I needed help and some equipment. She did not know what to do, so I contacted Adult Social Services and they sent me an occupational therapist. I was given a feeding board. This did not work.

The children's social worker kept coming to the house and asked lots of questions. I felt like she was watching me, rather than being there to t help me. I became upset. After a few visits she said that another lady 'Ms Fatma' would come and take Ali out. I don't know why this was but she came every week and took Ali out. I did not go with them. Eventually when Ali went to nursery she stopped coming. The social worker also referred me to Home Start. The staff there were nice and friendly to me.

Overall, even though my mum and my husband were helping with Ali the the social worker still seemed to think I couldn't manage, but she did not ask me about my family and how they helped. I was not involved in the assessment. This was a very painful time for me. Since my son went to nursery and we got a wheelchair accessible flat the social worker has stopped coming.

Stephanie

My name is Stephanie and I am wife to Steve and mother to Chrissie. Steve and I got together 27 years ago and got married 17 years ago. On the honeymoon I became pregnant with Chrissie.

I have had a long history of involvement with psychiatric services and 27 years ago was given a diagnosis of paranoid schizophrenia which is applied to me to date. For all this time I have been on psychiatric medication, so when I decided to have a baby this needed to be factored in. Prior to having Chrissie I'd had a number of admissions to psychiatric units but on getting married had been 'well' for a number of years.

During pregnancy, and for the first two months after Chrissie's birth, I was fine. I cared for Chrissie and the home. Unfortunately, due to the lack of sleep from having a small baby my mental health deteriorated and I went onto the Mother and Baby unit with Chrissie when she was about three months old. On being discharged we were allocated a child minder but…I became unwell again and I had another couple of admissions which is about the time that Marian became involved. I think she was classed as a respite foster carer, although her exact role was never made clear to us. At one point Chrissie went to stay with Marian every weekend.

We had children's services involved in our lives for a couple of years and eventually they pulled out when Chrissie started nursery and following a Family Group Conference. It strikes me as ironic that children's social services' remit is apparently to keep families together whereas by keeping sending Chrissie away to Marian's they tore our family apart. Why couldn't they allocate someone to stay at the house with me and/or Steve so we could get enough sleep? I am convinced this is the main reason I ended up unwell as it is a known fact that one of the indicators for psychosis is lack of sleep! Since their involvement ceased Steve and I have had no admissions to hospital and they have not been involved again.

Referral pathways and help seeking

Four parents spoke to health or adult services professionals to request support to help them fulfill their parenting responsibilities. In each case parents were either told to get in touch with children's social care direct, or the professional concerned offered to make a referral. The responses in each of these cases suggested that health and adult social care professionals did not view any aspect of child care support to be within their purview. Noor recounted how she had spoken to adult social care when she was two months pregnant, as she anticipated she would need an increase in support and the adult social care worker said:

> 'Regarding the baby, you will need to contact Children's Social Services', so she only helped me to the extent just to do with my care package, as a disabled person.

Further, the worker was reported to have said '*we only assess the needs of the individual or disabled person and that's it'*. In the later stages of the pregnancy a nurse at the hospital offered to make a referral to children's social care on Noor's behalf. At the time, Noor said she saw this as a positive thing, but that her view soon changed. No 'support' was offered but 'monitoring' ensued. From Noor's perspective:

> The only thing she [the social worker] was concerned with was that because I'm disabled, there's a risk, full stop, that's the only thing she could see.

Sahar also made a modest request for equipment via the health visitor to make it easier for her to change her son's nappy and to assist with other practicalities. Children's services were reported to have said they were unable to provide what Sahar had requested. Subsequently, Sahar experienced an increase in visits (or 'surveillance') from social workers from children's services. They subsequently put in a child minder to take her son out for a couple of hours per week. The family was also referred to Home Start.

Amanda and Stephanie also requested support in response to changes in their mental health. Although they were both ambivalent about asking for help, for fear of being labelled as ‘not coping’, they also recognised that they required additional support. Stephanie spent three months on a psychiatric mother and baby unit with her daughter and, shortly before discharge, she asked for a few hours support to be put in place. This was provided but step-down support for children’s services post-discharge was short-term (for a matter of weeks) and Stephanie was subsequently re-admitted to a psychiatric unit. Amanda requested support to meet the needs of her son who has mental health needs and behavioural issues, but support was not provided at the time.

> I believe the reason for my relapse was that I didn’t get the support that I’d been asking for. I’d approached services…asking for an assessment. I actually asked for an assessment even though I know my [previous] history with the services hadn’t been too fantastic, but I knew I needed some support. I did what I thought a good parent would do when you know, you’re not coping.

Stephanie and Amanda both reflected that had more intensive support been put in place earlier then emergency admissions to hospital and relapse might have been avoided, which would have been in their whole family’s best interests.

Although the parents acknowledge that they would benefit from help they were also fearful about having contact with children’s services.

> You don’t want to call social services. You are scared to call them because they might think you are incapable of looking after the child. So you have to struggle with what you have because you are scared to call to ask for help because then they will say, ‘we told you she’s disabled, she can’t look after her child’, so there’s always that element of fear, of ‘shall I or shall I not?”

Finally, in Gloria’s case her role as a parent went unacknowledged for seven months while she was in a rehabilitation unit following a spinal injury. During this time her two children were cared for informally by a family friend. It was not until she was about to leave that her children became ‘visible’ again. There was no discussion about a referral to children’s services and then, as Gloria explained, without warning:

> Somebody knocked on the door and they said they were a children’s social worker. I panicked, I thought ‘what did I do wrong for them to come in?’, and I asked, ‘who sent you here?’ and they said ‘Oh it’s because you are disabled’.

Subsequent experiences, as outlined below, served to reinforce rather than ameliorate parents’ initial fears about the involvement of children’s social workers in their families’ lives.

Assessments and meetings with children’s social care

All the families’ assessments were undertaken after the *Assessment for Children in Need and their Families* was implemented (Department of Health, Department for Education and Employment and Home Office, 2000). The Assessment Framework acknowledges the need to obtain an understanding of:

- the developmental needs of children
- the capacities of parents or caregivers to respond appropriately to those needs
- the impact of wider family and environmental factors on parenting capacity and children (ibid, p. 17).

These are described as inter-related domains which have a number of inter-related dimensions that need to be explored during the assessment to contribute to understanding how they affect the child or children in the family (see Figure 1 below).

Figure 1: Assessment Triangle

Source: Department of Health, Department for Education and Employment and Home Office (2000).

> Underpinning principles of the Assessment Framework include (but are not limited to) the following:
>
> - Adopting an ecological approach
> - Working *with* children and families
> - Building on strengths as well as identifying difficulties
> - An inter-agency approach to the assessment and provision of services (Department for Health, Department for Education and Employment and Home Office, 2000, p.10).

Parents' accounts suggest that a number of these principles were not evident in practice. First, although the principle of work in partnership with parents is enshrined in the Children Act 1989, and working with parents is recognised as being of central importance, none of the parents felt they had been given enough information about the purpose of the assessment. They also reported that their voices were not heard and that their knowledge and expertise in relation to their own impairments was not adequately understood or recognised. Poor communication and lack of clarity about the social work processes they were the subject of, served to heighten anxiety about children's services intervention in their lives. Cliff explained that:

> [My partner] didn't even know what was happening because nobody ever explained it to her. 'This is Children's Social Services and this is why we are doing this assessment and we are doing this assessment because of this'. Nothing was explained so she was just in darkness.

He also reflected that this meant she '*was quite timid because she didn't know whether the idea was they do an assessment to take away her* *daughter*'. Based on the information presented it was clear to the social work researchers that the case was not close to meeting the threshold for removal.

Noor was initially positive about meeting the children's social worker as she anticipated that this was the gateway to support. In retrospect she described her optimism as naïve. She recounted that at the first visit the social worker said '*bluntly there's no support we can offer at all'*. Then:

> At the end when our conversation got heated, she said the only option is that once the child is born, 'there is a risk that she will be removed'. And then my husband said: 'So you are suggesting that if the child is removed, you are willing to spend all the Social Services money on looking after her in a foster home but at the same time, you're not willing to give an hour of support that my wife has asked for? And she said: 'Yes, we don't support in that way, we only remove the children if we feel there is a risk'.

Again, Noor's first encounter with a children's social worker was not conducive to building effective working relationships. Rather than seeking to understand the family's perspectives on their needs, circumstances and desired outcomes, the social worker exerted their power and authority. The power imbalance, and failure to provide adequate information to parents to facilitate their meaningful engagement, is also reflected in Amanda's story.

Amanda's son was placed with his birth father following her emergency admission to a psychiatric ward. Her son then made an allegation against him which precipitated a child protection case conference. She explained:

> I'd recently been discharged from the psychiatric ward and I had to attend the meeting. I thought it was going to be a small, little meeting…I walked into one of these big meeting rooms…loads of people sitting around the table. I was quite overwhelmed...I thought the meeting was about the allegation…I didn't know that in the meeting and subsequent meetings it was going to be about me. I felt like a layer of flesh was coming off every time somebody spoke…it was all about my mental health…I was ill-prepared. I didn't have advocacy…my daughter broke down and she was in her 20s, she broke down because at one point the social worker, who was new to us, new to the family, she was saying, 'you've used services before'…[and] that shouldn't have been disclosed…She [the social worker] used it to illustrate a history of service intervention…It was very unkind.

At the same meeting the Chair was reported to have said:

> 'I hope you don't mind us discussing your personal history at the meeting? I'm aware Mr. J [my son's dad] and his wife are at the meeting. I'm sure that there's nothing that…' You know she assumed that he knew all about me even though we'd be separated for a long period of time. I'd never once discussed my mental health with him in all the years that I'd known him, so for her to start disclosing all that information about me in the meeting and to ask for my consent at the meeting, once it's already convened, I found that very unfair.

Second, all the parents highlighted that, contrary to the principles of the Assessment Framework, assessments were risk focused and deficit orientated and that the primary focus was parental (in)capacity. Parents' accounts suggested that parental disabilities tended to viewed as posing a risk to children and that their strengths and resilience were not the focus of attention. One of the reasons for this was perceived to be societal attitudes towards people with disabilities and the predominance of the medical model of disability. One of the parents said:

> I do think that people look at your disability first…they label you…because you're a disabled person, it's a synonym of being incapable so they undervalue your ability, even if other things are positive.

Another reflected that:

> The professionals, when they asses us, they already have a negative perception and it's an ideological barrier. In the back of their mind they assess based on preconceptions…They have a negative attitude that you will remain disabled all your life, there's no cure, hence you are always a risk…You are seen and labelled as 'cared for', rather than as a 'caregiver'.

In Noor's case her discharge from hospital following her daughter's birth was postponed until a meeting was held, at which:

> Children's services were present, the Occupational Therapist, the nurse and other people whom I had never met…The lady who facilitated the meeting said they had concerns about me because of my disability and they said I cannot wash my daughter etc. and I said, 'What are you talking about? I clean my daughter on my lap or on the bed, but how am I supposed to take my daughter to the basket in the [hospital] bathroom when the table is almost two

> meters high…when I was in a wheelchair that doesn’t go up and down.

At the meeting Noor highlighted that she had been expected to demonstrate her ability to provide basic care for her daughter on an inaccessible hospital ward[5]. She observed that the nursing staff and social worker appeared to have little understanding that the ward was not accessible but that at home, with adaptations, she would be able to operate differently. The role of her husband in providing care, as well as the wider support available to Noor, also appeared to be disregarded in discussions. It was agreed that Noor and her daughter would be discharged, but that the situation would be monitored. Noor recalled that the nurse said in a very cruel tone ‘*Don’t worry if it all turns out to be a complete failure’*.

Sahar also felt that her assessment was driven by assumptions about what she could not physically do, and that the important role of her extended family in providing care was not taken into account in the assessment process.

The two parents with mental health diagnoses also said that professionals focused on their weaknesses and, as one explained:

> It’s not about enabling my mental health. They were focusing on my weaknesses, not on my capacity or strengths or anything that enables mental well-being. It’s about the impact of my weaknesses on the family, not on my strengths.

Featherstone and colleagues (2018) have also highlighted that:

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[5] The Equality Act 2010 places a duty on all public authorities to make reasonable adjustments.

> Services and processes are infused with an emphasis on deficits. This is a contradiction at the heart of service design and planning; partnership rests on respect and mutuality, but our current service design and processes are preoccupied with what doesn't work, what risks must be avoided and how best to manage failure (p.77).

Service provision

Children's social care provision

One of the purposes of assessment is to inform decisions about the provision of support services to improve a child's outcomes and welfare, and where necessary to make them safe (HM Government, 2018). Table 2, below provides a summary of the services that parents wanted from children's social care services, as well as what was offered and subsequently provided.

Table 2: Services that parents wanted from children's social care and subsequent provision

Parent(s)	**Service parents wanted from children's social care**	**Service provided by children's social care**
Amanda	To be included and involved in the assessment and support for her son to help to manage his behavior.	Foster placement Residential care placement Family Intervention worker (but son 'did not engage')
Cliff and Gloria	One to two hours of support per day	Support worker once a week After school activity
Noor	One to two hours of support	None (child moved abroad)

	per day	due to parents’ fear that she would be removed/placed in care
Sahar	One to two hours of support per day	Child minder to take son out every week
Stephanie	6-8 hours of support during the night to allow Stephanie to sleep	Foster care (weekends)

As Table 2 shows, there was a mismatch between the services and support that parents perceived would be helpful and what was available and offered to them. First, the parents highlighted that the services that were provided did not serve to support them to fulfill their parenting responsibilities but instead involved providing substitute care which separated them from their children rather than bringing the family unit closer together.

Cliff, Gloria and Noor requested help and support with practical tasks. Cliff and Gloria said they wanted support with shopping, cooking, cleaning, laundry and school runs. Instead they were offered a support worker to take their youngest daughter out on activities and after school clubs:

> Children’s services, they provided my daughter with Sarah, about six hours a week, so [my daughter] can do what she wants. Then, one of the managers said ‘I would like her to do something else after school’ so they found her Sylvia Young, she went to Sylvia Young for a little bit which was amazing but it was only part time, like an after school club.

Gloria highlighted that she was not supported to be able to do the activities with her daughter.

> ‘I wish you could come as well’ but I couldn't, only on one occasion near the Christmas time they invited me to go shopping with them because I was using the card, so they needed me for shopping!

She also reflected that:

> it’s not what I wanted, they say to me ‘this is what we offer, what other parents are doing’.

Noor felt that in admitting that she needed help with practical tasks she was assessed to be a potential risk to her daughter. Children’s social care stated to her that if she could not manage that they could provide a foster placement instead of practical support to enable her to carry out the parenting tasks.

Stephanie also wanted practical support. Sleep is important to the management of her condition but sleepless nights are common when you have a baby. The medication that the psychiatrist put Stephanie on made her even more exhausted, but, as she pointed out, she was ‘stuck between a rock and a hard place’ as ‘non-compliance’ with medical advice would have been ‘reckless’, yet compliance made it harder to care for Chrissie. Children’s social care provided respite foster care but Stephanie was clear that it would have been more appropriate for a carer to come to her home, rather than separating her from her child.

Second, the parents reflected that time-limited support was not helpful when parental impairments are long term. Both Amanda and Stephanie, who have mental health issues, emphasised that their conditions fluctuate but that early help would be preferable to crisis interventions once difficulties have escalated. They also reflected that support should be reduced over time rather than being terminated abruptly. Their experiences also highlight how gaps in assessment of the wider family and environment created additional stress rather than alleviating problems when they were unwell. Stephanie was discharged from hospital to a flat with no provision for her or her child:

> I was discharged to an empty house, so I had no carpet, no oven, no bed, no cot, nothing, nothing... within four weeks of being in that house I was hearing voices, I was hallucinating.

The parents also drew attention to differences in the informal rules of engagement in adult services compared with children's services. Parent felt they were recognized as experts on their own impairments in their dealings with adult services. They were also conscious that, in the context of resource constraints, they needed to articulate what they could not do to avoid reductions to their care packages. Parents highlighted that adopting a similar approach during discussions with children's services had the potential to secure them support services but it could also have the unintended consequences of heightening the children's social care services' concerns regarding their parenting capacity. Stephanie explained that:

> In mental health, I hate the terminology but their recovery model - you can't recover unless you understand you've got a problem, so you go to them wanting help but the only way you're going to get help is by saying 'I have a problem. The Children's Services rock up and say, 'You've got a problem, therefore you can't parent', so you are kind of doomed.

Overall, parents signalled that walking this tightrope – demonstrating that they deserved and were eligible for assistance – but not too needy for children's social care to deem them to be a risk – would not be necessary at all if adult services provided them with support to fulfil their parenting responsibilities.

Adult' services provision and the relationship between agencies

At the time the majority of the parents were undergoing assessment the *Fair Access to Care Services: Guidance on eligibility criteria for adult social care* (Department of Health, 2003) was in place. This stated that:

> As presenting needs are fully described and explored, the individual and professional should consider and evaluate the *risks to independence that result from the needs both in the immediate and longer-term*. This evaluation should take full account of how needs and risks might change over time and the likely outcome if help were not to be provided. The evaluation of risks should focus on the following aspects that are central to an individual's independence:
>
> - Autonomy and freedom to make choices
> - Health and safety including freedom from harm, abuse and neglect, and taking wider issues of housing and community safety into account
> - The ability to manage personal and other daily routines.
> - *Involvement in family and wider community life*, including leisure, hobbies, unpaid and paid work, learning, and volunteering (Department of Health, 2003, p.9, emphasis added).

Moreover, the eligibility framework recognised the risks to independence and other consequences, if needs were not addressed and included ‘impact on family and other social roles and responsibilities’ (p.4). Morris and Wates (2007) also identified the following as features of good practice in working together to support disabled parents:

- Needs arising from the impairment/illness and/or disabling barriers were addressed before making judgements about parenting capacity
- There were good working relationships between agencies and disciplines
- Service development and delivery were characterized by a partnership between agencies and disciplines
- There was a continuum of prevention (p. 10).

Based on the stories and experiences outlined above, it appears that these principles were not consistently embedded in practice. The accounts all suggested that adult services were minded to assess the disabled parent as an ‘individual’ without any reference to their parental role and associated support needs. For example, Noor was told that:

> ‘Regarding the baby, you will need to contact Children’s Social Services’, so she only helped me to the extent just to do with my care package, as a disabled person.

She was also told:

> ‘In the Adult Social Services, we only assess the needs of the individual or disabled person and that’s it.’

Gloria found out that adult services were planning to discharge her from hospital to a nursing home until an accessible flat became available. *Nobody had thought where are the children going to go?* She was also assessed as needing practical support with cooking following her spinal injury. She was offered meals on wheels but this offer was not extended to her children. Noor was also awarded a personal assistant to help her with cooking and cleaning but was told that they could not cook or clean for her daughter. Amanda also highlighted that adult services did not appear to take into account her parenting responsibilities when she was sectioned under the Mental Health Act. She recalled that:

> On admission to the ward I was asked questions like ‘Do you have pets? Everything’s locked?’ and they didn’t ask me about my children and who was looking after my children and I find that quite strange…I understood that there was a need for me to be in hospital but who was going to step into my place? Especially with my son’s needs.

Overall, there was little evidence of joint working between children’s social care and adult services, and there was a mismatch between the services and support that was wanted and what was offered. Specialist, low-level parenting support needs were rarely addressed to prevent unnecessary problems from arising, even though the importance of working together and a preventative approach is acknowledged in policy and procedure documents (Department of Health, 2010; 2014; SCIE, 2013).

Many of the stories gathered from parents and discussed above predated implementation of the Care Act 2014. Under the Care Act 2014, an adult's needs meet the eligibility criteria if:

> (a) the adult's needs arise from or are related to a physical or mental impairment or illness
>
> (b) as a result of the adult's needs the adult is unable to achieve two or more of the outcomes specified in paragraph (2), and
>
> (c) as a consequence there is, or is likely to be, a significant impact on the adult's well-being.

One of the specified outcomes that is explicitly mentioned is 'carrying out any caring responsibilities the adult has for a child' (Care Act 2014 and Care and Support (Eligibility Criteria) Regulations 2014). However, since the legislation has been enacted, two of the parents have made specific requests for adult services to meet these needs but have been refused, even though they meet the eligibility criteria. It appears, therefore, that adult services are failing to fulfil their duties under the Care Act 2014, and are instead signposting parents to children's social care.

> I was recently assessed. I think it was four, five weeks ago. And I mentioned in the assessment to the social worker that one of my needs was my role as a parent etc. and I needed some level of support. Now I'm not as worried as before, when my daughter was a baby, so I was more confident and especially because it's written in the Care Act. The quick response from her; she said 'No, you need to go and contact Children's Services' because we don't deal with that'.

Nothing. I’ve had untold crisis plans and care plans and Care Programme Approaches and never once has there been any reference made to the fact that I’ve got a child, never once.

Re-imagining social care services to support disabled parents and their children

Drawing on learning from disabled parents' experiences the co-production team moved on to imagine what an ideal model of support for disabled parents and their children might look like. The 'dream' of an alternative model of service and support sought to address a number of the barriers and challenges that the parents' stories illuminated. It is important to note that our ideas about what could be done differently are intended to provoke discussion and debate amongst key stakeholders. We see this as the start of a conversation not the final destination. Currently, statutory duties under the Care Act 2014 also need to be upheld.

Beyond silos: Developing a specialist service

Parentability: The Disabled Parents' Partnership

Parents' accounts of current models of service delivery revealed a number of issues, including the following:

- Limited acknowledgement of the environmental barriers that disabled parents routinely face and how these limited their full participation in their children's lives
- Gaps in professionals' knowledge and understanding about impairments and disabilities and appropriate supports to assist parents as they raise their children
- Adults' services' failure to provide support to help parents to carry out their caring responsibilities

- Lack of service coordination and unresponsiveness
- Children's services' involvement provoked fear and was seen to be stigmatizing.

In order to overcome these problems, the parents were keen establish a new dedicated and specialist service called 'Parentability': The Disabled Parents' Partnership, to assess and meet the needs of disabled parents and their families. They recommended pooled funding from the Department of Health, Department for Education and the Department of Work and Pensions to 'avoid arbitrary cut-offs' and gaps in care provision. They also thought it was important for the new service to sit outside current service structures and to be embedded in the community in order to help overcome entrenched attitudes and models of working in adult and children's services. One parent expressed the dream as:

> A service that caters holistically for the whole of the family, which is inclusive, rather than changing and reshaping existing statutory services and then trying to shift their mind-set and their way of practice…

Another said:

> My dream is something to do with the family not this dualism and split between children and adults…New training would also be developed.

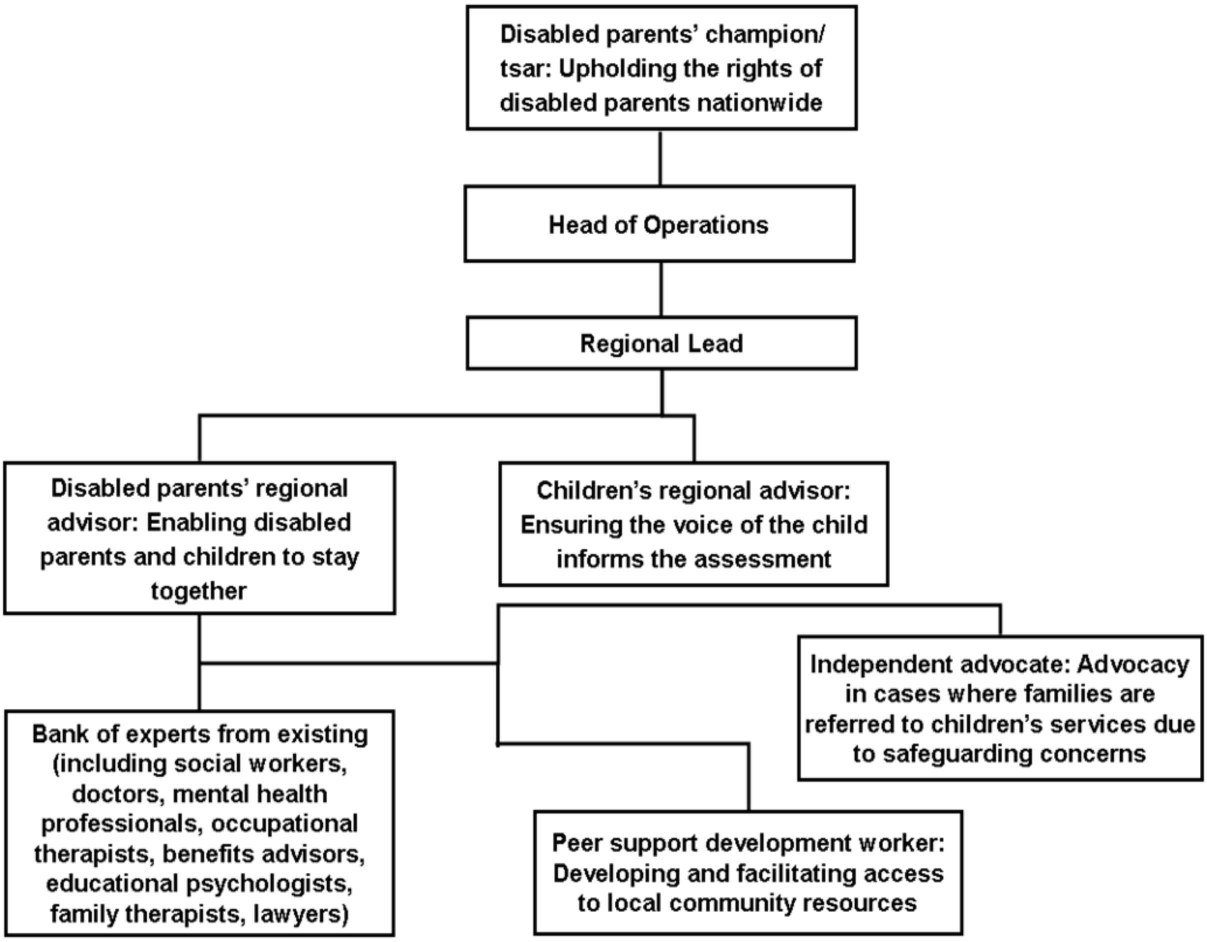
Being 'outside' children's and adult services was perceived to be important to minimise fear and stigma. The parents also recommended that around 70% of the staff should be disabled. Both these developments were seen as important vehicles to alter power dynamics and to '*allow disabled parents to hold some of the power in the decision making process'*.

Parentability: Functions and professional roles and responsibilities

The parents proposed that Parentability should fulfil the following functions:

- Upholding the rights of disabled parents
- Hearing the voice of both disabled parents and their children
- Keeping disabled parents and their children together
- Enabling strengths and unlocking assets
- Promoting disabled parents and their children's full participation in mainstream society.

The parents considered the skills and competencies that professionals would need to possess in order to meet the ambitions of the new organisation. The organisational chart below outlines the proposed structure for Parentability and the roles of the professionals that would be appointed.



Parents wanted the professionals in Parentability to exhibit a range of strengths and skills to support the conduct of holistic family assessments[6]. These are summarised in Figure 2 below.

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[6] The strengths and attributes that parents felt that the professionals in Parentability should possess were developed drawing on work by Nicolson (2014) to support organisational development. The theoretical underpinnings for that method lie in strength and asset based approaches developed by McKnight and Block (2010).

Figure 2: Strengths Parents Recommended Professionals Should Exhibit

Disabled Parents Regional Advisor
Creativity, critical thinking, fairness, honesty, hope, humility, kindness, leadership, perspective, perseverance, zest

Children's Regional Advisor
Bravery, creativity, critical thinking, fairness, hope, humour, love, kindness, perspective, perseverance

Disabled Parents Champion
Bravery, creativity, critical thinking, higher purpose, honesty, leadership, perspective, social intelligence, teamwork

Peer Support Development Worker
Creativity, critical thinking, honesty, hope, humility, love of learning, kindness, perspective, perseverance, self-regulation, social intelligence, teamwork, zest

Independent Advocate
Bravery, creativity, critical thinking, curiosity, fairness, kindness, perspective, perseverance, social intelligence, teamwork, zest

Re-imagining the assessment process

The ‘discovery’ phase of the project served to highlight that parents were unclear about the purpose of assessments and the processes children’s social care followed to reach decisions and the ultimate outcomes. Moreover, they felt that they were not treated as experts on their own impairments and that children’s social care professionals equated ‘disability’ with ‘incapacity’ and ‘risk’. Both the appointment of professionals with different roles and functions and a new Parentability assessment process was recommended. They envisaged embedding a process that included more opportunities for professionals to build relationships and rapport with disabled parents and their children, to facilitate the conduct of a holistic family assessment. It was anticipated that this would mean that the support packages that were developed would provide services that were appropriate and that enabled parents to be parents, rather than providing substitute care. The Parentability Assessment Process is outlined in Table 3. The parents were clear that if safeguarding concerns arose these should be referred to children’s social care.

Table 3: The Parentability Assessment Process

Stage	**Purpose**	**Experience**
Help seeking	Access to support	Accessible: Multiple routes to access support, including the Citizens Advice Bureau and disability charities Discussions with professionals that parents already know (and ideally trust) Non-stigmatising
Initial contact with Parentability	Enabling parents to have a voice and articulate what they need	Professional interest Not intimidating '*It's a tailored organisation and so they'd ask the nature of your enquiry. They ask you to give them your views, rather than having a checklist of questions that you answer. They'd go at your pace'*
Initial conversation with the disabled parents regional advisor	Exploring parents wants and needs Informing parents about what services	The advisor has a good understanding of disability and parenting, as well as of the services and supports that are available to meet diverse needs *'The enquirer may not know what support they can get, or they*

	are available	*may be confused, so probably the regional advisor could give options and ideas'* *'Recognising family strengths and things that you might like support with and how do you think they'd be able to support you, [considering] your own ideas about the support you require and what you think it might look like'.*
First meeting	Pre-assessment face to face meeting to build rapport and explain the assessment process	Professionals are honest and kind and invested in building relationships with the family. Advisors clearly articulate the purpose of the visit and explain what each professional will be doing. Advisor seeks permission from parents to speak to the child. It should be made clear that if safeguarding concerns emerge during the course of the assessment then a referral would be made to children's services.
Holistic family assessment	Assessment underpinned by the principles outlined in the Disabled Parents and Families Assessment Honeycomb (see	Rights-based approach which values process and outcomes rather than the achievement of professionally established goals. Strengths based not deficit orientated Disabled parents and children are active participants in the

	below for further details)	process Support for parents to assist them to fulfill their parenting responsibilities rather than the provision of substitute care which conveys the message that they are not capable parents.
Approval and service agreement	Professionals and family agree the package of support, with input from a Bank of Experts (where applicable).	Shared ownership of the service and support plan. Accessible, written summary of the agreement provided to the family.
Referral to peer support and advocacy	Bringing disabled parents together and advocacy	Community of disabled parents and promotion of informal support networks Advocacy for disabled parents, including support for any families who have been referred to children's services because there are concerns that children are in need, or suffering, or likely to suffer significant harm *'They're supporting, informing our choices, enabling us to have a voice... Having representation at meetings where you're amongst a variety of professionals, and informing their knowledge base. So, we may feel intimidated at those meetings but the advocate who knows your journey, knows*

		your narrative will be there to support you. Sometimes that support will make all the difference'.
Review service provision	Contact with the family after three and six months to check that the service and support plan is working as intended	Responsive and flexible provision.
Reassessment of need	Reassessment of needs on an annual basis, or earlier if circumstances change	Understanding that needs and circumstances change and the need to respond accordingly.

Guiding principles for the assessment of disabled parents and their children

As Chapter 2 showed, parents' experiences of assessment were rather different to the principles that are espoused in the *Framework for the Assessment of Children in Need and their Families* (Department of Health, Department for Department for Education and Employment and Home Office, 2000). Parents felt that current practices served as barriers to independent living and that alternative principles need to be embedded in practice to counteract the multiple barriers they face in fulfilling their parenting roles, and to improve outcomes for the whole family.

The snap shot big picture diagram, below, outlines how parents view the 'current reality' and their recommendations for alternative guiding principles to support best practice.[7] As the diagram shows, parents were keen to move from what they experienced as a risk focused and deficit orientated system which assesses what they cannot do, to a model of assessment that recognises parental capabilities and strengths. As one parent explained, professionals should look at:

> Parental assets, strengths, skills and accomplishments and what we are able to do, not just from our perspective, but from the perspectives of others looking in…Strengths based is looking at your skills and strengths and then acknowledging where you need support.

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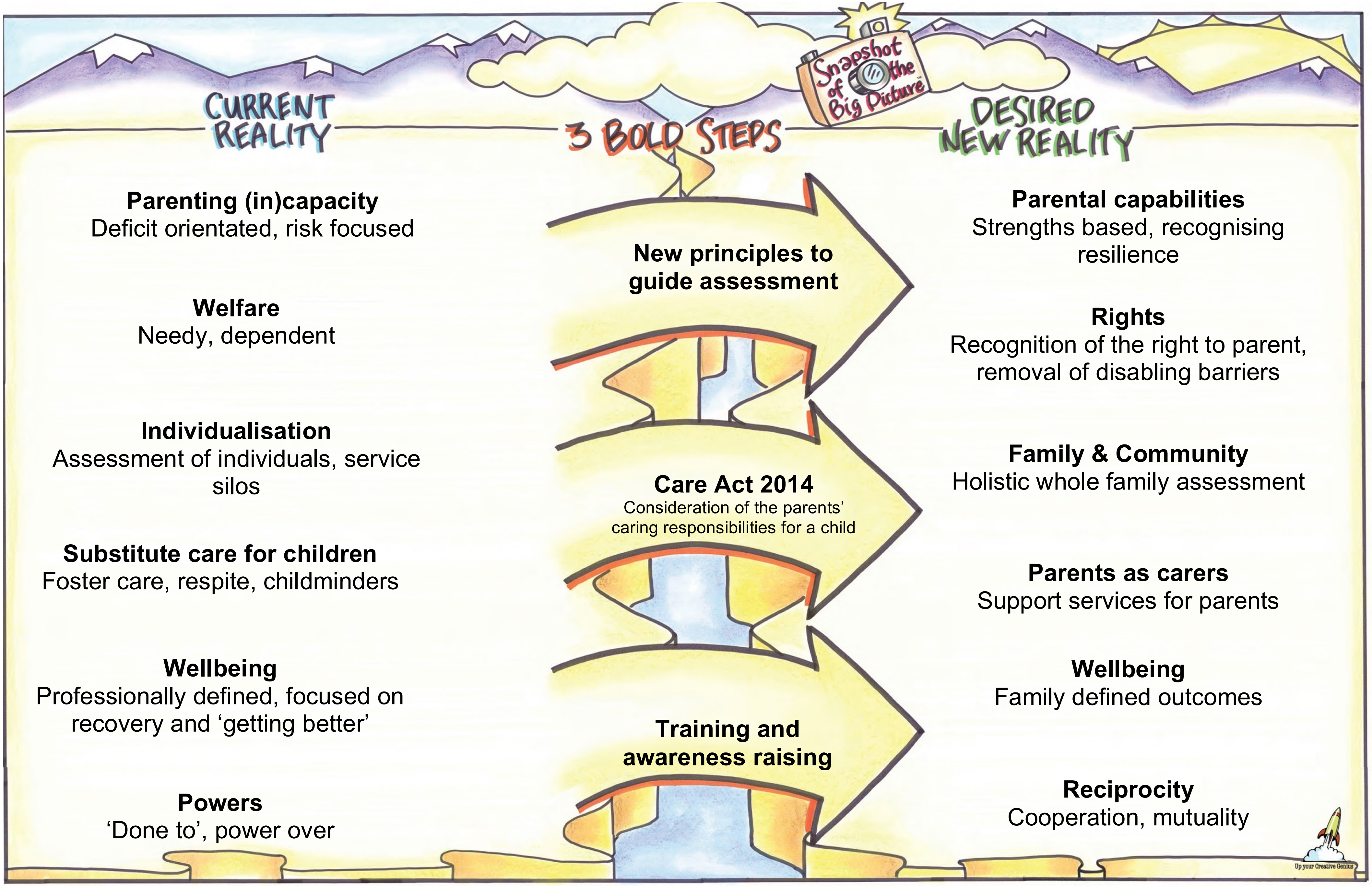
[7] The snap shot big picture template was created by Browolski (2018) for general use

The parents also highlighted the need to dispel ill-conceived assumptions that disabled parents are needy, dependent and cared for, and that they have to be provided for by the state and/or by their own children.



CURRENT REALITY

Parenting (in)capacity
Deficit orientated, risk focused

Welfare
Needy, dependent

Individualisation
Assessment of individuals, service silos

Substitute care for children
Foster care, respite, childminders

Wellbeing
Professionally defined, focused on recovery and 'getting better'

Powers
'Done to', power over

3 BOLD STEPS

New principles to guide assessment

Care Act 2014
Consideration of the parents' caring responsibilities for a child

Training and awareness raising

DESIRED NEW REALITY

Parental capabilities
Strengths based, recognising resilience

Rights
Recognition of the right to parent, removal of disabling barriers

Family & Community
Holistic whole family assessment

Parents as carers
Support services for parents

Wellbeing
Family defined outcomes

Reciprocity
Cooperation, mutuality

As Kosher and colleagues (2016) outline:

> Needs-based approaches typically arise from charitable intentions…[but] judgements are cast by elites regarding who is deserving and who is not based on criteria that serve to perpetuate existing social, economic and political relationships…Needs-based approaches prioritize the achievement of professionally established goals over the process of developing the goals, and, too often, the failure of outcomes is attributed to…individuals or groups who receive assistance (p. vii).

Instead, the parents called for a rights-based approach which ‘places equal value on process and outcomes’ (Kosher et al., 2016, p vii). The parents suggested that:

> Rights should be the unifying culture. I should not have to fight for my rights.

And that,

> It’s about putting the necessary support in place to adhere to the law…

They were keen to see evidence that service providers were actively considering their family and caring responsibilities (as required under the Care Act 2014) and providing services that uphold their rights[8]. Featherstone and colleagues (2018) have also argued that ethics and human rights need to be at the heart practice. Drawing on Melton's (2010) work they emphasize that:

> None of us are simply free-floating individuals but are part of, and enmeshed in, relationships – rights are therefore exercised relationally and choices are considered contextually (p.20).

The parents also wanted to challenge the tendency towards narrow and individualised service responses. They were concerned that their children were seen as invisible or irrelevant in assessments of their needs as adults (except as providers of care to reduce demand on social care services). Also that children's services focused on establishing whether they posed a risk and constructed them as the problem, without reference to the social and economic contexts of their families' lives (see also Bywaters et al., 2018; Featherstone et al., 2018).

The parents' accounts revealed that children of disabled parents were being labelled as their parent's carers by both adult and children's services. Within adult services, children were sometimes seen as a resource to be tapped into to reduce demand on statutory services.

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[8] Slasberg and Beresford (2014) highlight that the Care Act is still essentially needs-based and that 'need' is often defined by resource availability. Collingbourne (2014) also notes that allocation of resources in individual cases continues to be dependent on the application of eligibility criteria, and in response to long-term systemic underfunding local authorities have increasingly raised the threshold of eligibility (Collingbourne 2014, p.6).

Gloria explained that:

> [adult services] they came and said that my children should be my carers. I said ‘no, they are my children not my carers’.

Amanda’s son was assessed and subsequently labelled a young carer following an assessment that she had not consented to, and that was undertaken without her knowledge. She reflected that:

> My son is 15 he does nothing but the cruel irony is that he has been referred as my carer… at no point did anyone ask if I was the carer. They have not looked at me in that regard, they just looked at me as a disabled parent.

The parents wanted to be recognised as parents, and for their children to be allowed to be children. They viewed the fact that professionals were expecting children to take on caring responsibilities as a failure of the state to protect them and meet their legal obligations towards parents.

Noor reflected that:

> As a parent you have parental responsibilities, whether you are disabled or not…that parental role you should be in control of, even if you need support you are the parent and care giver…the child should be seen as a child…

She also emphasised the damage that a destructive and disabling ideology can have:

> It’s destructive for my daughter to be labelled or seen as a young carer. I feel that the term young carer is wrong because it puts me in a position that I am vulnerable, as if my life is not worth living. It puts me under pressure as I am seen as ‘cared for’ by my own child, regardless of her age…It is undermining of me as a parent…If my daughter is having to support me it is because of the lack of service and because adult services are not meeting my needs.

A hallmark of good practice is to first meet the needs of disabled parents before making judgments about parenting capacity (Department of Health, 2003; Morris and Wates, 2007). However, recent research has highlighted a significant increase in the number of young people providing care for an ill or disabled parent (BBC News and Nottingham University, 2018). The Children and Families Act 2014 extended the right to a needs assessment for young carers, but the parents in our research felt strongly that children should not be expected to provide a high level of care. Instead, they highlighted the need for adequate funding for adult social care, so that parents could access services and support to help them to parent themselves. High thresholds for service provision were identified as having unintended and detrimental consequences for the whole family.

As outlined in Chapter 2, there was a mismatch between the services and support that disabled parents wanted and needed and what was provided. The *Munro Review of Child Protection* (Munro, 2011) identified that:

> Services have become so standardised that they do not provide the required range of responses to the variety of need that is presented (Munro, 2011, p.6).

Amanda and Stephanie both received ‘late help’ in the form of short breaks in residential care and foster care for their children, rather than longer term community based support which would have kept the family together and reduced the likelihood of their conditions deteriorating in the first place. Stephanie, reflecting on the experiences of the group said that:

> The attitude was ‘we have given you this support what more do you want? You are not grateful and you are not getting any better’ but *you are not giving me what I need*. I use the analogy of the broken leg…You go to hospital with a broken leg and they put your arm in a cast.

Overall, the parents ‘dream’ was cooperation based on the principle of mutuality and holistic whole family assessments and community based provisions that help to keep families together and promote the wellbeing of disabled parents and their children.

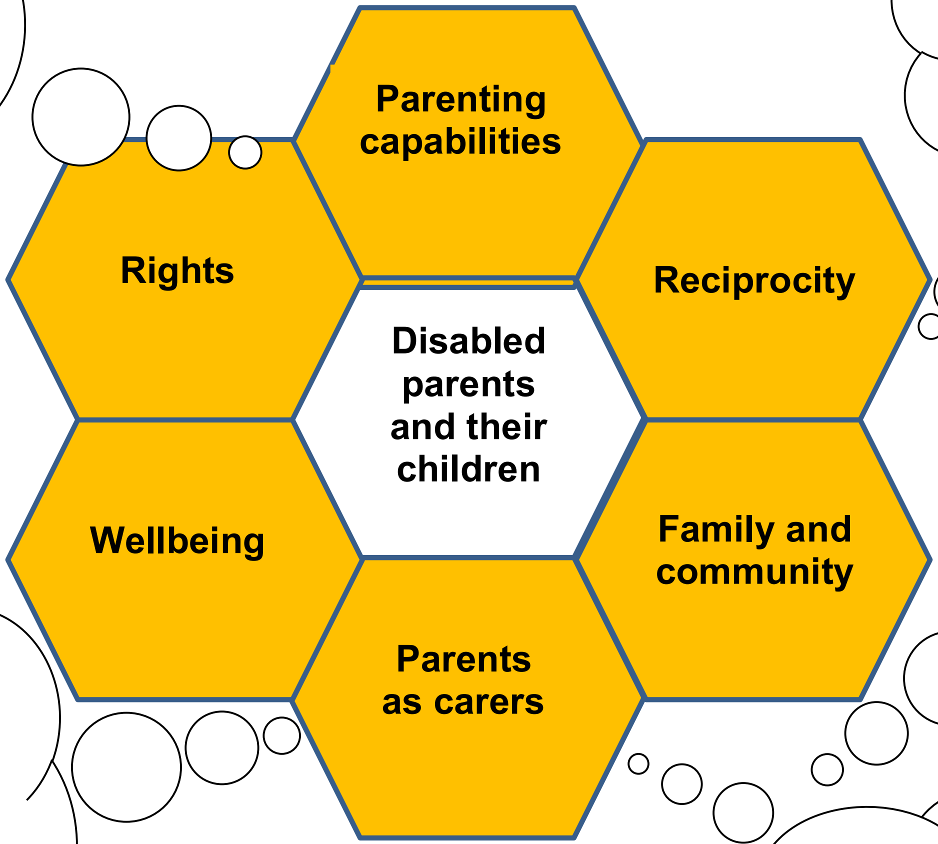
> It’s about mapping out the support that the disabled parent may have…looking at those support networks and meet the needs of the parents by filling the gaps in that support network…It’s about keeping the family together. You deal with the family as a whole not as adults and children separately.

The Assessment Honeycomb

In order to embed best practice in the assessment and delivery of services for disabled parents and their children, the parents recommended embedding the principles from their desired new reality into the assessment process.   The Disabled parents and children's regional advisors would use the Assessment Honeycomb to guide the conduct of holistic whole family assessments, as Figure 3 below illustrates. Quotes from parents have also been included to capture the intent of the principles from the parents' perspectives.

Disabled Parents' Assessment Honeycomb

Disabled parents' recommendations on principles to underpin assessments of disabled parents and their children



Parenting capabilities

Rights

Reciprocity

Disabled parents and their children

Wellbeing

Family and community

Parents as carers

Parental assets, strengths, skills [need to be recognised] and there needs to be acknowledgement of what we are able to do. Strengths based is looking at the strengths we have and then acknowledging where we need support.

Uphold the rights of disabled parents to parent

Having a sense of worth, confidence and esteem in the presence of professionals when working towards solutions and being part of the decision-making process enables my wellbeing. Also, being allowed to say how I want things to be and not being judged because of my circumstances. Wellbeing for me is a life without stigma.

It's about shifting the power dynamic…it's about professionals allowing disabled parents to hold some of the power in the decision making process

It's about mapping out the support that disabled parents may have and looking at those support networks…it's about keeping the family together and thinking about family as whole, not adults and children separately

Recognise us as parents (not simply as people who need to be cared for) and provide services to support us to fulfill our parenting responsibilities

Final Reflections

> *Families carry with them the hope offered by humane encounters and the hurt created by careless professional responses* (Featherstone et al., 2018, p.72).

The voices of six parents have been at the heart of this project. Their vivid accounts raise questions about the design and delivery of services and support for disabled parents and their children. What we still need to understand is how many other disabled parents have experienced similar difficulties securing adequate support to carry out their parenting responsibilities. We also need to hear from others who play a central role in their stories, including their children, family, friends and professionals.

It is perhaps telling that there are gaps in the data on disabled parents, the support they do (or do not) receive from adult services, or on the number of disabled parents who are referred to children's social care services. As these data are not routinely collected the scale of this issue and the human and financial costs to families and wider society are unclear. What is clear from the accounts presented in this report is that there is scope to do things differently in order to more effectively protect and promote the wellbeing of disabled parents and their children, to challenge 'othering' and to ensure that their rights are upheld.

Messages from the disabled parents in this study are broadly consistent with national and international research exploring service users' experiences of child and family assessments and child protection practice (see among others, Buckley, Carr and Whelan, 2011; Dale, 2004; Dunbrill, 2006; Gaffar, Manby and Race, 2012; Gallagher et al., 2011; Harris, 2012). Findings revealed that the involvement of children's social care provoked fear and anxiety and that parents felt that they were under surveillance and being monitored and judged rather than offered support. There was limited evidence of health and social care services working together to provide support for the whole family. Instead, there was a mismatch between the support that parents wanted and needed for their family (practical support) and what was available and offered (short term support and/or substitute care).

The research served to illuminate specific barriers and challenges facing disabled parents. First, we found that a lack of accessible housing, equipment, schools, hospital wards and transport adversely affected disabled parents' ability to support their children and that these disabling barriers were not addressed (even though these matters should be addressed before making judgements about parenting capacity) (Morris and Wates, 2007). Second, parents highlighted how societal attitudes towards disabled parents meant they were generally perceived to be needy and dependent and judged on their incapacities, rather than on their strengths and resilience. Third, the findings revealed that health and adult social care professionals did not appear to view any aspect of child care support to be within their purview, even though family life and caring responsibilities should be taken into account under the Care Act 2014. It was acknowledged that austerity measures meant that thresholds for services and support were (too) high and that this had detrimental consequences for disabled parents and their children. They called for tailored and preventative support services to avoid the escalation of difficulties (rather than short term crisis interventions and use of substitute care which separates children from their parents, rather than supporting parents to fulfill their parenting responsibilities).

Re-imagining services and support

Rather than focusing simply on ‘what is wrong with the system’, this research project sought to draw on the wisdom and expertise of those who had encountered it, to imagine alternative ways of working. Our suggestions and ‘dreams’ about what could be are intended to foster discussions and debate about models of delivery and principles to support best practice.

In re-imagining services’ responses to protect and promote the wellbeing of disabled parents and their children, the parents placed rights (rather than needs and resource led decisions) at the heart of practice. They called for greater recognition of the social, economic and environmental realities of disabled peoples’ lives, whilst also drawing on the strengths and resources within local communities. They aspired to see greater recognition of their parenting capacities and strengths and for professionals to work *with them* to provide tailored packages of support for the whole family. These suggestions are not intended to be the last word, but part of a wider debate on supporting families. It is worth noting that the proposals resonate with wider calls to re-imagine child protection and to adopt more humane and strengths and rights based practices which promote social justice (Featherstone et al., 2018).

Recommendations

- Routine collection of statistical data to establish the number of disabled parents in the UK and to establish the nature and extent of service provision to support these families

- Further research to examine the degree to which adult and children’s social care are meeting their statutory responsibilities towards disabled parents and their children
- Acknowledgement that disabled parents and children are ‘experts in their own lives’
- Recognition of parental capabilities and strengths
- Greater attention given to the economic, social and cultural barriers faced by disabled parents and the impact these have on the whole family
- Rights-based rather than needs-led and resource driven decision-making
- A clear and integrated assessment pathway that moves beyond service silos
- Moving beyond individually-orientated, reactive and crisis driven approaches to meeting needs
- Tailored and preventative support services to prevent the escalation of difficulties (rather than short term crisis intervention or the provision of substitute care which separates children from their parents, rather than supporting them to fulfil their parenting responsibilities)
- Coordinated support that meets the needs of the whole family
- Local services that promote family and community engagement.

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Annex 1

Table 4: Summary information about the disabled parents, their families, and children's social care involvement in their lives

Parents engaged in research	**Family composition**	**Impairment(s) of parents engaged in the research**	**Additional information about impairments**[9]	**Age of children at time of referral to children's services**[10]	**Assessment/status**[11]	**Children's services response**
Amanda	Single parent	Mental health diagnosis	Bipolar	Son: 13 years Daughter 15 years Daughter 16 years	Son: Looked after	Initial involvement of the children with disabilities team as Amanda's son has a diagnosis of Attention Deficit Hyperactivity

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[9] Unless otherwise specified partners do not have any impairments

[10] Excludes children who were not living at the family home

[11] Highest level of intervention in family life

						Disorder and has behavioural issues. Her son was placed in foster care and residential when Amanda was admitted to hospital (mental health and physical health admissions). Access to outside activities (sports)
Cliff and Gloria	Couple from 2014	Spinal cord injury (1990 and 2004 respectively)	Both Cliff and Gloria's mobility is restricted and	Daughter: 8 years Son: 15 years	Daughter: Child in need Son: No further action	Daughter: worker took Gloria's daughter out

			they both require support with practical and physical tasks including personal care, domestic support, cooking, cleaning, laundry and carrying out external activities for example with shopping, banking and social activities			for four hours every Saturday Access to outside activities (theatre school)
Noor	Married	Progressive impairment (type of muscular dystrophy)	Wheelchair user (motorised) Noor’s mobility is restricted and she requires a high level of support with practical	Daughter: Pre-birth	Daughter: Assessment to determine whether child was in need or suffering, or likely to suffer significant harm	Noor and her husband placed their daughter in the care of the grandparents (abroad) until the case was

			and physical tasks including personal care, domestic support, cooking, cleaning, laundry and carrying out external activities for example with shopping, banking and social activities.			closed by children's services.
Sahar	Married	Progressive impairment	Wheelchair user (motorised) Sahar's mobility is restricted and she requires a high level of	Son: Pre-birth	Son: Child in need	Provision of a child minder to take Sahar's son out to the park and to play group. Attended

			support with practical and physical tasks including personal care, domestic support, cooking, cleaning, laundry and carrying out external activities for example with shopping, banking and social activities.			Home Start
Stephanie	Married	Mental health diagnosis	Schizophrenia Amanda' husband also has similar diagnosis	Daughter: 6 months	Daughter: Looked after	Foster care (weekends)