'Parenting children and young people with complex needs’

An exploration of the additional challenges faced by parents of children and young people with exceptional healthcare needs and how professionals and services can best support families.

“How can we help families to rebuild expectations, give them back hope, and create dreams (that may be realised differently)........reclaim their ordinary life in the long term as well as in the short term?” (1)

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Jointly commissioned by NHS Highland and the National Managed Clinical Network for Children with Exceptional Healthcare Needs (NMCN CEN)

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www.cen.scot.nhs.uk
Acknowledgements

I want to thank all the parents who contributed to this project by agreeing to be interviewed. All the parents I interviewed spoke openly and frankly about their lives. I really appreciate their input.

Given the nature of this project individual parents are not identified. They came from diverse and socio-economically mixed backgrounds. Whilst their particular circumstances were unique to them they shared a number of challenges and supporting factors in common.

Thank you to Sally Amor, Child Health Commissioner for NHS Highland, for commissioning the project with NMCN and for inviting parents to be interviewed.

The report is of course only one part of this project and all the experiences that were shared will inform the practitioner’s workshop and future work of the network.
Table of Contents

1. Executive summary
2. Literature review
3. Purpose and objectives of the report
4. Parenting experiences – gathering information
   4.1 Methodology
   4.2 The ‘Family Asset’ Model
   4.3 Family-Centred Practice
   4.4 Recruitment of interviewees
   4.5 Data analysis
5. Context – the emotional impact of having a disabled child
6. Themes
   6.1 Supportive factors within families
       Individual factors
       Importance of wider family support
       Role of partner
       Parent to parent contact
   6.2 Supportive factors within communities
       Individual practitioners
       Policies and programmes
       Voluntary organisations
       Spiritual support
       Foster carers
7. Key messages
8. Recommendation
   Appendices
   1 – NMCN CEN criteria
   2 - Interview responses: Challenges
   3 - References
1. Executive summary

In October 2012 the Scottish government launched ‘The National Parenting Strategy: Making a positive difference to children and young people through parenting’ (2) The strategy focuses on valuing and supporting Scotland’s parents as one of the single biggest ways of giving children the best start in life. It seeks to champion the importance of parents to Scottish society by strengthening the support on offer to parents and by making it easier to access that support.

Emphasis is given to making it easier for parents to understand the positive difference they can make to their child’s development, help them to feel confident in their ability to care for their children; feel reassured that help is available if and when they need support and ultimately make parenting an even more rewarding experience. In this statement of why parenting matters the additional challenges for parents of disabled children are specifically referenced.

The ‘Getting It Right For Every Child’ (GIRFEC) agenda promotes a strength-based approach to supporting children and their families. The Parenting Strategy sits within this context and reflects the focus on supporting and developing resilience.

In ‘Better Health, Better Care’, 2007, NHS Scotland (NHSS) acknowledged the challenges facing Specialist Children’s Services. The National Managed Clinical Network (NMCN) for Children with Exceptional Healthcare Needs (CEN) was established in March 2009 with the aim to strengthen and develop these specialist services, including care closer to home for children with complex and exceptional healthcare needs in Scotland.

It is within this national context that the project was jointly commissioned by NHS Highland and the NNMCN CEN.

The Family Asset Model (3) and the core elements of Family-Centred practice (4) were used to develop an operating framework which reflected the desired strength-based perspective. This framework was used to develop the interview questions and the interview responses were mapped against it. Where quotes from the interviews are used in the report they are referenced to the Asset Model (shown below).

In NHS Highland and Argyll & Bute, there are 34 families with children who meet the criteria as defined by the NMCN CEN (appendix 1). Parents were invited to be interviewed by a letter from the Child Health Commissioner for NHS Highland.
The particular cohort interviewed were predominately parents of children pre-5, therefore close to diagnosis and adjusting to the ‘loss of child they thought they would have’.

The following are the main findings and themes discussed in the report:

Becoming a parent is a life-changing experience. For many people being a mother or father brings great rewards but there are also undeniable challenges. These include managing traditional gender roles, lack of time for one another and financial concerns.

Having a disabled child is still the experience of a minority of parents and having a child with exceptional healthcare needs* is rarer still. Parenting a disabled child or young person therefore brings with it particular challenges. Parents caring for a disabled child do so in the face of considerable and varied pressures. In addition to those shared with other parents, they have to deal with grief over the loss of the ‘hoped’ for baby and the enduring process of adjusting to changes associated with the child’s condition as they grow older. This added dimension needs to be recognised and acknowledged. (5)

The emotional impact for families of having a child with exceptional healthcare needs is far-reaching. Many parents experience ‘chronic sorrow’ (6) throughout the life of their child. This level of emotional distraction can at times impact negatively on a parent’s comprehension, behaviours and management of their circumstances.

It can affect their relationships with friends and family as well as practitioners. It was clear when talking with some of the parents interviewed that there were unable to ‘hear’ some of what had been told to them about services and/or processes and could not therefore access or make use of what was offered to them. This needs to be recognised and understood as part of the process of adapting and adjusting that is going on for the parent. Frank Parkinson (1997) writing on post traumatic stress disorder (PTSD) refers to parents of disabled children as ‘experiencing trauma’ with all the attendant post-trama symptoms of rage, grief, intrusive thoughts, lack of control and anxiety(7). Given this is it any wonder that families need to be given information a number of times in a number of ways?

It is essential that practitioners recognise this impact and work in ways that enhance whole family functioning (8). That includes identifying with parents their strengths and working with colleagues to use the resources available creatively to support and build on these assets.
In the experience of this reporter and as identified in other NMCN projects there is a visceral need for many parents to tell their story and to express their fears and frustrations before it is possible for them to acknowledge what works well and to be able to identify what they draw on in themselves.

In interviewing these parents it was essential to listen and to acknowledge this part of their experience. Practitioners must recognise this is a necessary and ultimately helpful part of the process of developing a relationship with the family. Fundamentally the practitioner will gain a fuller picture of the family. The relationship can therefore become a collaborative one better suited to identifying the ‘right’ support for the whole family.

**Note:** For the purpose of this project, the term ‘parent’ means anyone with a parenting role and of children from the early year’s right through adolescence.

**2. Literature review**

In preparing for this project the following texts and articles were reviewed and are referenced throughout –

‘How is your Family’s well-being?’ - Lingren, H.E, 1982

‘Family Asset Mapping’ - Lingren, H. E, University of Nebraska-Lincoln, 2009

‘Developing Family Strengths’ - Staier, 2000


‘Supporting Parents: Messages from Research’ - Quinton, 2004
3. Purpose and objectives of the report

The overarching purpose of the report is to share the findings from a series of interviews with parents. These findings inform the training that has been developed.

The report and workshops are part of a specific education module for the CEN website www.cen.nhs.scot.uk. It also provides additional information and detail that can be used to inform the discussions between families, practitioners and service providers.

Specific objectives were to identify:

- the challenges and opportunities of parenting children with complex health needs
- what families identified as the supportive factors - both internal and external
- the elements of a workshop for practitioners

4. Methodology

The project involved the following processes –

- A literature review (see above)
- Identification of a ‘Family Asset Model’ as the framework for the interviews and their analysis
- Linking the core elements of Family-Centred Practice to the interview framework
- Development of an outline of the project, its objectives and how respondents could be involved
- Inviting potential interviewees through the office of the Child Health Commissioner
- Responding to interested volunteers and setting up interviews
- Interviewing twelve parents across Highland and Argyll & Bute and mapping their responses onto the framework
- Reviewing Family–Centred Practice as a context for developing the practitioner training
- Development of a workshop for practitioners informed by the findings of the research interviews
- Production of this report informed by the interviews

4.1 The 'Family Asset Model'
An explicit focus for this project was what parents reported as supportive and what they draw and build on within themselves and their family to manage their life circumstances.

Given this focus the ‘Family Asset Model’ developed by Professor H.E Lingren (9) was identified as a useful model for developing the interview framework.

Lingren identified ‘family assets’ as the strengths derived from or created within the family.

However, Lingren recognised that families do not exist in isolation and that these assets must be strengthened and supported by ‘community assets’.

In addition, in exploring the impact of caring for disabled children on parental relationships, Glenn, 2007, identified a number of factors that sit well within the assets model (10). These were also incorporated into the framework.

<table>
<thead>
<tr>
<th>Parenting Project - operating framework</th>
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<tr>
<td><strong>Family assets</strong></td>
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<tr>
<td>Effective communication</td>
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<tr>
<td>Constructive approach to conflict</td>
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<tr>
<td>Problem solving</td>
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<td>Nurture of children</td>
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4.2 Family-Centred Practice

In the 1990s, the developing field of early intervention with young disabled children and their families adopted family-centred practice as its philosophical foundation (11). The GIRFEC agenda shows us how this continues to be of relevance today.

It includes three key elements –

1. An emphasis on strengths not deficits
2. Promoting family choice and control over desired resources
3. Development of a collaborative relationship between practitioners and parents

As far back as 1987, a set of core elements was identified for the care of children with special health care needs. These elements have been revisited and revised through successive policy programmes and service redesign including Care Co-ordination and currently within the GIRFEC agenda.

The nine core elements (12) very much echo Lingren’s model and emphasise the importance of the community assets in supporting those of the family.

- The family must be recognised as the constant in the child’s life
- Parent-Professional collaboration should be facilitated at all levels from individual care to programme development, implementation, and evaluation to policy formulation
- Respect for the racial, ethnic, cultural and socio-economic diversity of families
- Recognition of family strengths, individuality and different methods of coping
- Complete and unbiased information to be continually shared with parents in a supportive way
- Family-to-family support and networking to be encouraged
- Systems must take account of the developmental needs of children and families
- Implementation of comprehensive policies and programmes that provide emotional and financial support to meet the needs of families
- Service systems to be designed to be flexible, culturally competent and responsive to family-identified needs

A substantive body of evidence demonstrates that family centred practice can be linked to a wide range of benefits for children and families. Moreover, families report greater satisfaction with this approach than other models of practice (13).
4.3 Recruitment of interviewees

Parents within the Highlands were invited to participate by an invitation from the Child Health Commissioner. A letter was sent out to all families using the local health database. Parents were invited to contact the researcher directly by phone or email.

The majority of parents interviewed therefore selected themselves to be part of this project. One parent was also the link to a further four parents who had received the letter but not put themselves forward. She was involved in the last project and encouraged them to be interviewed.

In Argyll & Bute, health practitioners were asked to encourage families to become involved. The contact details for five parents were provided however, only one responded to the researcher’s direct contact. A face to face interview was arranged but only a brief telephone interview was possible as the child was unwell.

4.4 Data analysis

Analysis was done concurrently with the data collection and mapped onto the operating framework. Once all interviews were completed the material was reviewed again to identify any additional themes. The framework themes are presented in the report and are illustrated by anonymised quotes from parents.

5. The emotional impact of caring for a disabled child

5.1 Underpinning the work of the NMCN CEN is the recognition of the emotional impact on parents of having a child with exceptional healthcare needs. NMCN CEN has played an important role through its education programme of raising awareness of this impact and in encouraging understanding and compassionate practice.

5.2 As with the other projects parents interviewed reported that acknowledgement of the emotional impact by practitioners seems dependent on the individual’s own skills and confidence to address emotional issues. The parents interviewed talked about an inconsistent approach by practitioners across the services. This can be interpreted as a lack of a shared professional sense that this impact is a natural and understandable feature of having a disabled child.

5.3 Very important and healthy relationships do develop between parents and practitioners but the power balance is, certainly initially, an unequal one. Families are often dealing with a wide range of issues and feelings. They are looking to the practitioners to explain to them what has
happened and will happen. Some of what is being sought will be very much in the present but much will be at a very fundamental and painful level of finding themselves dealing with challenging and generally unexpected circumstances.

5.4 Many parents report a general lack of acknowledgement from practitioners (and others around them) of how all this feels. As other issues emerge and the child grows older parents continue to have to make decisions that have far reaching implications for them, their child and other family members. Each decision will elicit an emotional response and the impact of that may or may not be recognised by the practitioners involved. The cumulative effect of dealing with so much heightened emotion in relation to your child should not be underestimated. Moreover, how other people respond will also contribute to the impact.

5.5 Why does acknowledging the emotional impact matter? Parents tell us that the lack of it adds to their pain and stress. Children are part of a family and we must take account of the whole family. Supporting the parents enables them to continue parenting and to do so more effectively.

5.6 It is also important for practitioners. Practitioners want to do a good job and feel they have supported decisions that are beneficial for their patients and their families. Many recognise that providing emotional support is an important part of their role.

6. The importance of family and community assets in practice

The parents interviewed needed to describe those aspects of their life that they found challenging before being able to reflect on and identify their strengths.

6.1 The challenges

These are illustrated in appendix 2; however, the main issues include the following -

Lack of appropriate childcare to support maintaining the parents relationship with each other -

"There are no weekend options where we can do things together. If we want to go out it has to be separately now as there is no one else to look after the children"
Assumptions that wider family and friends will provide the extra support that families need -

“We moved to be closer to our families but actually the support didn’t transpire” and “it has been disappointing to see how little contact our friends will have with our son”

Problems with the health and social care systems -

“We have no choice as to where we live so to be so far away from the children’s hospital is very stressful. I lived with my son in the hospital for two months after he was born, effectively trying to manage two homes. There seemed to be very little advice and support or even acknowledgement of this and the strain it puts on you as a family. I know other parents who have had longer stays, how do they manage?”

Role of practitioners –

“Tends to be about the person not the role….. how can you be confident when someone new comes along?”

The enduring battles to get a child’s needs met even with ASL legislation and council policy of ‘presumption of mainstream’ -

“It was a fight to get him into the school, even though we made contact very early on and were upfront about his needs”

6.2 Supportive factors within families

The following themes were identified:

Individual characteristics - several parents were able to identify what personal resources they had to draw on and that they believed helped them to positively manage their circumstances.

“I have skills and knowledge that I can draw on from my training. I am a good organiser. It is important to me that I can use these skills in co-ordination to support my family”

“My own training and background as a paediatric nurse has been very helpful. I was not worried about the medical side of their care”
“We go into everything with an expectation that people will accommodate us and so far we have found this approach to work. We also know when to let go. We explore all the options before we go anywhere and ask questions and try to get people ‘on board’. We’ve always taken this approach to life so it’s not an issue for us”

“My involvement in a local group for parents has helped me use my organisational and facilitation skills to support other parents”

**Importance of wider family support** - support within the family, immediate and extended, was reported as a significant support and strength. Where this was missing (for two families interviewed) this was identified as a source of stress and isolation.

“My sister is an enormous support. I can talk to her...we talk through things together”

“Friends and family provide support on a day-to-day basis, this is essential”

“My husband’s cousin has helped us with the caring role and this is a great support, especially as our families are far away”

“I live with my mum and my brother is very supportive too”

“Our parents are around and can provide childcare for our younger child which is a great help”

“We are a family of health professionals; there has always been understanding and support”

“My mother lives here too and that is a great help. Other family are further afield but we see them regularly and our children are always included in family events.”

**Role of partner and the nature of the relationship** - ten of the twelve parents interviewed were mothers and two were single parents. For those parents with partners this relationship was seen as incredibly important to the parenting role and their own well-being. The Family Asset model puts much emphasis on how families communicate, their ability to problem solve and to offer a nurturing environment for their children. These elements were very much reflected in the interviews.

“My husband has a strong sense of family. We negotiated and discussed every aspect of how we would manage our circumstances”
“Although my husband is away a lot with work when he’s here we are united together”

“When we got the pre-natal diagnosis we committed to our son and to each other”

“My new partner has a relaxed attitude which helped me to adjust to having someone in my life and to develop trust......the true extent of my son’s needs and the impact on family life hit him when he moved in but he has learned to do all the procedures and is totally supportive”

“My husband has always been very supportive including when I had a major episode with anxiety and basically collapsed”

“He often offers me helpful psychological insights as to why people might be acting the way they are......when I just feel they are blocking things”

“We made a commitment together to do this and we use each other as a sounding board”

“We went into this with our ‘eyes wide open’ and as far as you can be, a realistic sense of the potential challenges ahead”

“My partner has formed a good relationship with my other child. This has really helped as there is no doubt about it I neglected him at times because of the needs of my disabled child”

“We are determined to do ordinary things, have holidays and do stuff as a family”

**Parent to parent contact** - the parents interviewed drew a lot from their contact with other parents. The new technologies play an important part here too in helping to reduce their sense of isolation and as a source of information.

“Contact with other parents through the internet and the condition website has been very helpful”

“I use a condition specific forum to post questions, vent my feelings and get feedback. I feel I get understanding and support here”

“Talking with other parents – one parent takes a mentor role, this has been so supportive”

“I use ‘Face book’ to keep in touch with friends and other parents. This is really all that’s possible for me given my day-to-day life”
“I read a lot about my child’s condition use the internet and support organisations’ websites, listen to other parents’ experiences and learn a lot from listening to other parents”

5.3 Supportive factors within communities

In describing what they found helpful and supportive outside of family and friend networks most parents expressed some ambivalence. The need to access services and work within additional systems is entirely due to their child having exceptional healthcare needs. Therefore, whilst some expressed gratitude most parents were compromised by their emotions when thinking about the level and nature of professional involvement with their families.

Notions of ‘partnership working’ within GIRFEC and other policy frameworks need to be alert to the ‘reluctant’ and ambivalent feelings of parents. Loving and caring for a child with exceptional healthcare needs does not mean welcoming all that comes with meeting that child’s needs. When parents regularly report experiencing barriers and obstacles in trying to carry out their parental responsibilities then a whole-hearted endorsement of community services shouldn’t be expected.

Other work for the NMCN has shown that some practitioners fail to recognise fully the implications of this and can be defensive when parents complain about “their service”. Acknowledging the context for families can help planners and commissioners develop services that more meaningfully meet the needs of their users. Acknowledgement and understanding can also help practitioners better support the families they work with.

**Individual practitioners** - most parents reported that individual practitioners were supportive but generally regard the systems and processes for support as “over-complicated and impersonal”.

This feedback about individual practitioners emphasises the importance of the relationship. Parents want to feel a real interest and understanding from practitioners of their personal circumstances. However, it also raises concerns of an inconsistency of practice and service delivery. If practitioners within a service and/or discipline are not working to the same set of values and principles of practice then this leads to confusion for families and potentially discriminatory service delivery.
“We now have a social worker for children with complex needs. Her role has been invaluable”

“The Family Support woman at the Army Welfare service has been very supportive”

“I was provided with counselling through CHAS this was incredibly supportive. I felt understood.”

“The community children’s nurse and the social worker have been helpful”

However, there were concerns expressed by some of the parents interviewed that services were not delivered “in the same way to all families”. In discussing this further, parents reported feeling judged on occasion and assumptions being made about their “ability to cope”.

**Policies and programmes** - only one of the parents interviewed was aware of the policy environment including the GIRFEC agenda, in relation to disabled children and/or those with exceptional healthcare needs. Two had heard of the CEN National Managed Clinical Network and had visited the website and one had contributed to a previous project. One parent was aware of the Child Health Commissioner’s role and had shared her understanding with other parents involved in securing the accommodation for the local playgroup.

One family reported involvement in the Self Directed Support programme. They found the system overly complex and bewildering but a difficult summer “without any support” had led them to the CAB and to begin the process.

All parents reported that they had depended on someone else to help them to find the information that they needed and that “other parents” were usually the source. The Social Worker for Children with Complex Needs and a Community Children’s Nurse were specifically referred to as being helpful here but not every family had their input. This demonstrates a real issue in terms of equity in information provision.

Again, this finding reflects similar reports for the Early Expectations project. In interviewing practitioners for that project it was clear that levels of awareness and understanding of policy and its implications for practice also varied enormously amongst individuals and disciplines. This can be understood as issues of leadership and communication and these
are identified as key factors in the sporadic implementation of Family–Centred practice (14).

**Voluntary organisations** - generally the involvement of voluntary organisations, particularly local offices, was seen as positive. Parents reported feeling ‘part of something’ and getting to meet other parents in similar circumstances. This was seen as especially helpful in the early days of coming to terms with their child’s healthcare needs and very much reflects findings from the Early Expectations project (NMCN CEN, 2012).

“Being part of this group has been so positive. I learn things from the other parents and feel part of something”

"Attending the group has given me support and confidence”

"Going to the group got me out. It helps me to feel positive and that I have something to offer other parents from my experience”

“This local group provides activities and days out. We get to meet other parents, get some respite and time together as a family”

"Our oldest daughter goes to Brownies and has a support worker. They were not necessarily very informed at first but certainly welcoming”

“Direct Childcare run a play scheme providing activities one day a week during the holidays, this is a great help”

Parents are however, aware that many voluntary organisations have funding concerns and are affected by the current climate of uncertainty and financial constraints.

“At times we have felt some pressure from the staff there – no one knows the future of the centre and it is not the holistic place it once was, the insecurity for the staff sometimes comes through onto us at the group”

**Spiritual support** - all the parents were asked about this aspect of life but only two identified their faith and the support of a church community as a source of both family and community strength.

“We are members of two church communities. Both have been welcoming of us and the children. This is a hugely important part of our lives.”
**Foster carers** - three of the parents identified themselves as foster carers.

One parent made the following comment -

“We feel very supported. We also know from speaking to other families that should we move from fostering to adopting we would lose a lot of that support. It is because of the support that we are able to provide the love and care for the children and are committed to doing so on a lifelong basis”

This reflects the fact that foster carers are entitled to respite and paid holiday whereas birth parent carers are not guaranteed either within the current benefit and respite allocation systems.

#### 7. Key messages

From this project and other work in this area we are reminded of a number of important messages as service providers and practitioners.

7.1 Having a disabled child affects *every* aspect of family life – a ‘whole family’ approach is a necessity if we are to better support children at the centre and make best use of limited resources.

7.2 As practitioners we need to listen to and accept the experience of the parent and family. This acknowledgment and acceptance not only enables the parent to focus on what is positive and working well for them but supports the development of constructive relationships. When as a practitioner you have earned the trust of the parent you will be able to raise difficult issues (for you and for them) and have these issues ‘heard’.

7.3 An important process in building a collaborative relationship is to support the parent to identify what their strengths are and what they can build on. This helps to build parental confidence and acknowledges their expertise in relation to their own child.

7.4 Increasingly services are required to identify and deliver stated outcomes. We need to recognise that the inconsistency of practice, skills and attitudes amongst professionals in terms of supporting families is a key factor in failing to meet those outcomes.
8. Recommendation

A workshop for practitioners is a key output of this project. In the first instance it will be delivered locally in the NHS Highland area. NMCN will be sharing the learning through its website and e-learning platform. It will also be incorporated into future training and development days hosted by NMCN on a regional basis in 2014.

Take-up of similar workshops hosted by the network over the last five years has been strong and feedback has been very positive. This can be interpreted as a keenness and openness on the part of many practitioners to access training which incorporates parental experiences and opportunities for reflection.

Children’s plans need to take full account of the elements of family-centred practice. Furthermore, given that support is so vital as a protective factor for sustaining parenting and family life the child’s plan process has to also demonstrate equity of outcome. As we know, there are often considerable additional costs when families break down, committing to these supportive approaches within the plan fits well with the preventative spend agenda.

The workshop is designed to reflect and build on the findings of this report and includes an exercise to audit current practice in developing the child’s plan against the core elements in line with these agendas.

It is recommended that all practitioners working with families of children with exceptional healthcare needs access this workshop and senior management commitment and support is therefore essential.

Three workshops (12 participants per workshop) will be delivered across NHS Highland in March 2014. Learning from this piloting of the workshop will inform the next stage of this project - the development and delivery of ‘Training for Trainers’ course to build capacity into the CPD programme.
Appendix 1 – NMCN CEN criteria

The six impairment categories used for assessing the children and young people are:

- learning and mental functions
- communication
- motor skills
- self care
- hearing
- vision

A child or young person (up to the age of 19) is defined as having exceptional healthcare needs if they have:

Severe impairment recorded in at least 4 categories together with enteral/ parenteral feeding

OR

Severe impairment recorded in at least 2 categories and requires ventilation/CPAP

AND

The impairments are sustained and ongoing or expected to last for more than 6 months.
### Appendix 2 - Parent interviews: challenges

Every parent interviewed needed to describe the challenges that they had faced or were currently facing. The following quotes are presented as they sit within the framework of the Asset model.

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<thead>
<tr>
<th>Internal</th>
<th>‘Family Assets’</th>
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<tbody>
<tr>
<td><strong>Relationship with partner</strong></td>
<td>&quot;There are no weekend options where we can do things together. If we want to go out it has to be separately now as there is no one else to look after the children”</td>
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<td>&quot;We are not as fun-loving and carefree as we were, even thinking about how we changed in becoming new parents with our first child…….there’s almost no comparison”</td>
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<td></td>
<td>&quot;My husband has to work all the time. I cannot work outside the home because of our son’s health. I feel I have really changed. I am exhausted and very isolated”</td>
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<td><strong>Wider family</strong></td>
<td>&quot;Moved to be closer to our families but actually the support didn’t transpire”</td>
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<td>&quot;We have no family here – as refugees we can’t go home but we talk sometimes on the phone. Maybe that makes me more upset”</td>
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<td><strong>Friends</strong></td>
<td>&quot;It has been disappointing to see how little contact they will have with our son”</td>
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<td>&quot;We don’t get invitations to things anymore as clearly his behaviour causes anxiety …..couldn’t really face it anyway now”</td>
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<td><strong>Parent to parent contact</strong></td>
<td>&quot;This has not been helpful for me as often the children are much older and I can’t look at that yet……other than our children [having complex needs] we have nothing else in common”</td>
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<tr>
<td><strong>External</strong></td>
<td><strong>‘Community Assets’</strong></td>
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| **Health system** | “My son has a very rare condition and requires constant monitoring. It is very frightening and waiting for the doctor to hear back from Glasgow as to what meds adjustments need to be made is very stressful”  
“We have no choice as to where we live so to be so far away from the children’s hospital is very stressful. I lived with my son in the hospital for two months after he was born, effectively trying to manage two homes. There seemed to be very little advice and support or even acknowledgement of this and the strain it puts on you as a family. I know other parents who have had longer stays, how do they manage?”  
“My son had to go to Yorkhill soon after birth. I had to go by train on my own just one day after giving birth in very traumatic circumstances. Whenever, I mention this I get expressions of outrage but I think this still happens to other mums” |
| **Practitioners** | “Tends to be about the person not the role….. how can you be confident when someone new comes along?”  
“Some therapists visit when it suits them not us”  
“The focus is on the child, not our needs as a family”  
“I’m the one who brings everyone up to date, there is no co-ordination or communication that I can see”  
“She basically withdrew from us. I had to instigate all the routine tests he needed and find out about them from the internet – no one told me” |
| **Community play groups** | “I went to a baby massage class. None of the other mums would come near us. It felt awful” |
| **Respite** | “I get one overnight a week but the carer can’t give meds so if they are needed I get woken up” |
| **Education system** | “It was a fight to get him into the school, even though we made contact very early on and were upfront about his needs” |
Appendix 3 - References


2. ‘Growing together or drifting apart’, Glen, F, 2007


4. ‘Parental and professional views of the needs of families with a child with severe physical disability’, Sloper, P, Turner, S, 1991


6. ‘How is your Family’s well-being?’, Lingren, H.E, 1982

7. ‘Family Asset Mapping’, Lingren, H. E, University of Nebraska-Lincoln, 2009


10, 11, 12, 13 & 14