

Working in Partnership through Early Support: distance learning text

Changing perceptions by Mark Brown and Olivia Trimbee



Introduction

Over recent years there have been a number of government initiatives regarding the needs of disabled children all of which emphasise the importance of working in partnership with children and their families. The most significant of these initiatives are the Revised SEN Code of Practice (2001), Every Child Matters and Standard 8 of the *National Service Framework for Children, Young People and Maternity Services*, which states:

“Children and young people who are disabled or who have complex health needs receive coordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, enable them and their families to live ordinary lives.”
(DfES, 2004).

This aspiration, this desire to be able to take the normal things in life for granted, lies at the heart of what disabled children and young people want. They want to play, to have friends, they want to go to the school that their brothers and sisters go to and for it to work. They want their health needs met in the most unobtrusive way possible and if they are going to have the agencies intruding in their lives they have a right to expect those agencies to avoid duplication and for that intervention to be appropriate and in keeping with their needs.

Much of the work around Early Support revolves around the effective coordination of service provision, whether based upon key worker systems¹, child centred team approaches² or some combination of both. But Early Support is not just about service provision – it is about changing the relationship between children, families and service providers from one that is currently too often disjointed and beset by conflict, to the development of a collaborative culture where the needs of the child are the central focus.

Mark Brown, parent: Context and background

The beginning: Making sense of it

It begins with the way in which we make sense of it – with the certainty with which we believe we understand what disability really means and the implications that this has for all whose lives are affected by it. For most of us, disability implies something that doesn't work, eyes that cannot see, ears that cannot hear or a brain that will not learn. It is a word given authority by its association with other words such as Rett's syndrome, autistic spectrum disorder or Down syndrome. And with this understanding of the term disability often comes an emotional response of sadness, tragedy and struggle. People speak of mourning the loss of a 'normal' child and of parents having to come to terms with their bereavement. This medically based conception of the word disability lies deep within our social fabric and more often than not will lie at the heart of a parent's soul at the time of a child's diagnosis.

But this isn't all that the term disability can mean? There is, of course, the social model which sees disability as something that society creates through its impact and intolerance of impairment. The simplest example of this is probably the way in which

¹ See Early Support distance learning chapter: Judith Cavet – *Best practice in key working: what do research and policy have to say?*

² See Early Support distance learning chapter: Peter Limbrick – *Team Around the Child*

the limited spread of sign language through out our society disables somebody with a hearing impairment; the disability being society's inability to share a language not an inability to hear. Yet society constructs disability in so many different ways and the idea that disability is either medically determined or socially constructed is sometimes unhelpful.

There are times when it is perhaps preferable to adopt an understanding of disability that is indeterminate, that changes over time and draws upon elements of the social **and** medical models and yet grounds that definition in the experiences and perspectives of the individuals whose lives are affected. Disability means different things to different people at different times in their lives. For a parent who has just finished suctioning a child or who has just received a diagnosis, disability is material; their child's impairment has an immediate and profound effect upon their day-to-day life – their focus will be on the language of disability as something medical. You cannot tell the parent of a disabled child that their 'grief' is derived out of the narrowness of our conception of what is normal. At such a time in our lives we live and breathe the medical model.

But for a child or young person with an impairment, with a list of achievements to match any other; their disability is often not about what they cannot do, but rather the attitudes and barriers to opportunity of a society that does not seem to understand, or seem to be able to adapt. That may express itself in poor access to employment and housing or in their parents' inability to accept their right to make their own choices and promote their independence. In such an instance, disability is defined by processes of exclusion that are principally social in nature, where people and institutions are unable to move beyond the idea of disability as a tragedy and the young person with an impairment as 'unable'.

This notion – that the meaning of 'disability' can change over time and according to views, needs and perspectives of the individuals concerned – lies at the heart of why working in partnership with the families of disabled children is so important. The inclusion of a young person with a disability in our society must begin with their place within their family. For any child to become a successful member of our society, we know that their well-being is based upon foundations of early love and acceptance, of strong relationships, of involvement and a sense of feeling valued.

Yet we know that the birth of a child with an impairment can be a traumatic experience and that children viewed through the looking glass of the medical model can come to be defined as a burden whose existence is mourned. Yet we need to help families to reconcile their emotional experience of disability as a tragedy with a child's emotional need for love and acceptance. There are no easy or simple answers but at the heart of it must come a shift in the way we see the child with a disability and an acknowledgement that at some point and at some time, a child has a right to be valued and accepted for who they are. In aspiring to do so we are supported by the principles underlying Every Child Matters.

Changing the vision: Every Child Matters

The phrase 'Every Child Matters' is a challenge to the notion that any child is somehow less valuable and less precious than any other. That challenge extends to all of us. This includes practitioners who attach labels to a child and who view them in terms of the demands they are likely to place on their service. It also encompasses parents who cannot yet see beyond what their child cannot do, whose vision and understanding of disability remains too narrowly focused upon the medical.

In this context, the words 'Every Child Matters' are not just title of a policy initiative but a call to shift the way in which we make sense of the word 'disabled'. We need to move from a definition which focuses upon the 'the broken' to one which centres upon the structures and processes of exclusion and then to go beyond those to the child that matters. If one of the key purposes of working in partnership with the families of disabled children is to strengthen the place of the child within the family, then one of the principle mechanisms for doing so is to help families to view their child more holistically.

Many parents will do this without having to read a word of government policy or attend a course on models of disability. They will do it because as parents their focus will inevitably turn to the needs of their child, and their view and understanding of their child will turn from the label to the person. Early Support can play a part in supporting that process.

The family's need for community and knowledge

Most of us seem to accept that we bring up a child in a social context and we are comfortable with idea that this is done with the formal and informal support of friends, neighbours, siblings, grandparents, childcare providers, schools, doctors, health visitors and wider community. But for a family with a young disabled child, the need for the support of the community is so much greater and yet, paradoxically, harder to sustain or achieve. In a study exploring the vulnerability of parents to a lack of support, Bryony Beresford pointed out:

"All parents in the study felt unsupported in some way – either by lack of support from formal agencies or from informal sources. It is important to acknowledge that overall the level of support to parents caring for a disabled child is inadequate." (Beresford, B. 1994, p114).

The lack of support will often manifest itself in a multitude of ways. For example, grandparents may be reluctant to look after disabled children and getting 'practical support' from friends could be nigh on impossible. This lack of informal support is echoed in the difficulties that families have had in accessing more formal support. The Audit Commission report, *Services for disabled children: a review of services for disabled children and their families* (2003) stated:

"We found a lottery of provision. The services that disabled children, young people and their families are offered depend largely on where they live and on how hard their parents are prepared to push."

In addition to the provision being inconsistent they also found that it was often "too little and too late" and that "families would often have to struggle through a maze of information." (Audit Commission, 2003, pp2–3).

This difficulty in accessing information also indicates another aspect of what distinguishes a family with a disabled child. Whilst the parenting of most children does not require the skills and knowledge of particular groups of professionals, being the parent of a disabled child is harder to do without the skills and expertise of specialists. Indeed, research has shown (eg Honey et al, 2005) that having access to support and information from professionals will help families in developing their own coping strategies and strengthen their ability to manage the stress and isolation which are so often associated with bringing up a disabled child.

So perhaps the first principle of working in partnership with the families of disabled children would be to acknowledge that in contrast to other families, a family with a

disabled child is likely to have a specific need for support and professional expertise in order to function effectively as a family. This need will not be continuous and is likely to peak at certain junctures in a child's life. However, the purpose of that support is not so much to solve all the family's problems but rather to support them: "...[in] actively managing their situation rather than being passive recipients of an onslaught of stress." (Beresford, 1994, p111). However, there is a problem which, one way or another, lies at the heart of many of the difficulties practitioners may encounter in working with families – the power of expert discourse.

The power of expert discourse

The status of professionals within our society, and the power and authority of professional discourse, holds within it a number of inherent dangers. The first is that it can create a potential power imbalance between professionals and the families that they are seeking to support.

Most parents know how scary it is to bring home a new born child and how unprepared they feel taking on the task of caring for this new life. However, in spite of these feelings they quickly learn and become experts on their child. But, if you add the trauma of a diagnosis of disability, the complexity of a medical label and the confusion of service provision to that initial sense of experience, it becomes easy to fall into the trap of believing that only a specialist can understand your child's needs. You can come to feel that as a parent you could not possibly deal with your child's difficulties?

In such a situation, the power of professional discourse can have a significant and detrimental effect upon parents' abilities to make decisions based upon their own values and their own understanding of their child. It can disempower parents by creating dependence and a sense of inadequacy. Or, even worse, a particular theory may lead professionals to falsely attribute specific difficulties to parenting style – for example, the tendency in the Fifties and Sixties to attribute autism to a mother's inability to bond.

Professional knowledge is **not** absolute and will change as particular theories come to dominate a particular field of work. But that knowledge has the power to shape and change the lives of families of disabled children. Whether that knowledge undermines parents' understanding of their child, or whether that knowledge labels parents as problematic, its misuse can have a profound impact upon the lives of all concerned.

The misuse of professional discourse is not confined to professionals. How many children have been subjected to 'therapeutic regimes' which verge on the excessive because their parents believe that a particular 'treatment' for their child's disability is likely to effect some form of cure?

It is for this reason that we need to acknowledge the qualitatively different nature of parents' and professionals' knowledge about disabled children and that these forms of knowledge are complimentary. For example, a parent will quickly learn to respond to behaviour and gestures that only they will understand the significance of. Parents will learn to predict how particular situations will affect their child and events that may trigger particular difficulties. However, an experienced professional will be able to help a family to identify strategies for dealing with problem behaviours; their understanding of what may have worked for other families may help them find solutions to problems or to access a service that they as parents had not previously

considered. The input and support of professionals will greatly increase the range of strategies that are available to parents. This will enable parents to deal with the challenges that they are likely to be confronted with and to strengthen the personal and social resources that they will have at their disposal in order to meet them.

By adopting a partnership approach, families and professionals are more likely to develop a shared understanding of what can be done for a child rather than one of the parties imposing their particular view or body of knowledge over that of the other.

Beyond right and wrong: Good parent, bad parent

Most people don't have their parenting skills and decisions monitored that closely. However, if you are the parent of a disabled child your need to engage with the agencies will quickly open you up to formal and informal judgements of the decisions that you make. For example, if you fight to get the best for your child by taking an authority to tribunal, for instance, to make them pay for a particular educational programme, those with a responsibility for paying for that programme may view you as greedy and self-centred. You could also find that if you fight to secure your child a place in a residential school delivering a 24-hour curriculum, some people will equate your actions with putting your child in care and not acting in your child's best interests.

Judging the actions of our clients or customers is an integral part of providing any service – we all do it. It is easy to think that sending a 7-year-old child away to a residential school could be an expression of a parent not caring and an act of selfishness; or if a single mother one day just refuses to collect her child from respite, it's easy to condemn her for what we would see as an act of abandonment.

Being the parent of a disabled child can be incredibly difficult. If you have a child that smears, self injures, does not sleep, does not show affection and does not ever seem to change, seven, nine, fifteen years of this kind of emotional assault can batter you to a point of total exhaustion and despair. Sometimes it might not be challenging behaviour but it is the endless repetition that pushes you beyond your limit. For those on the outside looking in it is easy to judge, wonder why and condemn. They may compare you with parents who cope, parents who do not make unnecessary demands upon the system and label you as a bad parent. There are no good and bad parents just some who seem to make it and some who don't. Don't ever think you could do any better; just be grateful that you don't have to.

Working in partnership with the families of disabled children: *Together from the Start* and Standard 8

"Partnership working cannot take place in a systemic vacuum. Ultimately, the quality of the parent-practitioner relationship requires the development of systems and structures that enable services to deliver support that is appropriate to the needs of disabled children and their families."

Together from the Start (DfES, 2003) outlines in some detail the key elements of working with disabled children and their families and these elements are in turn incorporated into the *National Service Framework for Children: Standard 8* and the *Early Support Materials* (DfES, 2004). As you might expect, the focus is very much on the practical objectives of developing and delivering services to disabled children and their families. These include:

- ⇒ Communicating the news of a child's disability in a way that values the child and respects parents and families. Detailed advice on good practice for this process, can be found in Scope's *Right From the Start* guidance (2003).
- ⇒ Early intervention and assessment leading to the development of an Early Support family service plan.
- ⇒ That where possible service providers should coordinate the assessment process so as to minimise stress and duplication.
- ⇒ Different ways of working in partnership including the establishment of key worker services, which promote the development of collaborative relationships between parents and professionals.
- ⇒ The importance of working in partnership in a way that is non-judgemental acknowledges the importance of parental expertise.
- ⇒ Providing information to families that is accessible and appropriate to their particular situation and needs.
- ⇒ Providing practical support around a range of needs including children with complex disabilities.

This advocates an approach to service development which focuses both upon the practical needs of children and families as well as the development of what we might term a 'collaborative culture'. It puts in place the framework for service developments which will greatly improve outcomes for disabled children and young people and prevent the long-term isolation of the child and their family within the community.

The next section examines some of the experiences of families as they seek to cope and respond to the demands that are being placed upon them. These stories illustrate many of the themes and issues outlined in *Together from the Start*. Finally, the section considers the implications that these experiences have for the development of family-centred services.

Olivia Trimbee, parent and practitioner: The experiences of families

Motherhood and the disabled child

Before launching into writing about the role of motherhood and the parenting of a disabled child, I shall first introduce myself and my daughter to you. I am a single mum in my early forties, and my daughter is a gorgeous 16-year-old with severe learning difficulties, poor mobility and wildly uncontrollable epilepsy. She requires one-to-one support all through her waking hours in order to keep her safe, at home or in school. Sometimes I work when her health allows me to and my stress levels are manageable. Over the last three years I have a new partner who – although he does not live with us (I don't want him to run away!) – has given me physical support with caring and emotional support for the worry. By sharing the jobs we have managed to get laughter back in our lives.

When I started to think about the role of being a mother to a disabled child I realised I first had to think about how women 'know who they are or what they do'. It seems to me that many women living in Western Society today take their cues as to who they are from the way that others perceive them. By 'others' I mean anyone who is in a 'relationship' with the said woman – this could include a child, a manager, a partner, her friends or extended family. 'Others' also means the media, the church, her

cultural background, any place or medium that narrates the woman's experiences and gives her feedback on who she should be.

This led to me wondering if mothers of disabled children receive different feedback and hear different stories to other mothers about how to be a mother? What stories are told in regard to the different resources they might need to do a job that has been done by women since time began? Perhaps we develop different sensitivities to the way we listen to the stories? Do we hear what is being said about our mothering and our child and interpret messages differently?

As mothers we are searching for the best way forward for our family in what seems like an alien world and we are very sensitive to the language and expertise of professionals. Yet front-line community workers often seem to feel de-skilled when asked for support from mums in my position and unsure of the best 'advice', often preferring to refer on to a higher authority. Mothers in turn can be ambivalent to 'advice,' as it confirms that their child is different, or we may feel that the 'advice' is generic and doesn't fit our family. From there a 'dance' begins between professionals and mothers. Sometimes this 'dance' can be a barrier to working in partnership, with both parties feeling there is a lack of understanding of the other's position.

Over the last decade much has been written about working in partnership with parents and most of it is very supportive and useful (Mitchell and Sloper, 2000; Beresford et al, 1996; and Davies, 1993). However, over the next few pages I would like to take partnership working to the next level and introduce some insight into how mothers of children with disabilities experience and make sense of their world. To do this I have elicited the help of other mothers – Anna Skinner, Julie and Louise. They have shared their thoughts and ideas with me and I am very grateful for their input and generosity in letting me use their words in this story.

In the beginning – stories around diagnosis

"They sort of pushed her in to the room in her little incubator, then sat me up and asked me if I noticed anything different about her, and I ... [hesitates] and I lifted up her head and she looked at me and I looked at her and I just knew it's not just a case of she's got no hole in her bum and they can fix it, it was a case of oh... my... God... I've got a little Down's baby." (Anna Skinner)

This story was told in the context of this mum feeling she was lucky, as she knew from day one what her daughter's difficulties were. She described focusing on the practical stuff, of her daughter needing immediate surgery and didn't give any thought to what it might mean for the future. This mum's thinking about the future was more shaped by this following extract describing the emotional reaction of people around her rather than her feelings toward her daughter.

"It was all very sad... I remember everyone – and I mean everyone – being very sad and telling me how sorry they were and I didn't really like it cos I didn't feel sorry, I thought first and foremost I've had a baby. Friends and family were really sad but so were the hospital staff that had looked after me cos I'd been ill during the pregnancy so they had nine months getting to know me. I just kept thinking what's the matter with you all why haven't you bought me any flowers or cards." (Anna Skinner)

The experience of mothers varies widely in terms of receiving a diagnosis but the one constant factor is the experience of everyone feeling sad and that it is a disaster to have to have child with a disability. Looking back now I feel that this response is more a reflection of the value society puts on the lives of disabled people. However, it is important that people realise that this response is partially responsible for shaping the mother's experiences of the birth of her child and is the first step on the road to isolation and separation from the everyday experiences of others. It begins your induction into the world of the professionals.

In the middle – realising you are on your own

For many families, regardless of disability, babies are just babies and the majority of mums get on with doing mum things. For many of us though, financial worries creep in early on. The ability to return to work, a normal expectation for most people in today's society, is often no longer an option due to appointments, and suitable childcare is unavailable. A new story soon emerges from friends, families and providers: "You are the only person who is competent enough to care for your child and other people have no idea how you cope." Mothers know this story as the 'there ain't no way you're leaving them with me' story.

At this time we seem to have reached a point where we realise that the umbilical cord, so vital for the life of the unborn baby in the womb, remains in place and now serves to keep the mother and child joined closely together in life. Some may argue that mothers themselves choose that position but for most it is not a choice. A new culture develops in the home and in the family, the daily routine of coping matures and evolves to meet the changing needs of the family as it does in all families but in ours many of the tasks don't change. What changes is the child grows and the environment has to alter to keep them safe.

For me, it means that now my daughter is 5 feet tall there are very few places she can't reach. All the ornaments are long gone, the fire guards been strengthened by a smithy, doors have locks on them or have been sawn in half to stop her entering rooms – this still allows me to see her. Gone is the relaxing bath, replaced by a wet room and her delightful hand painted wooden bed has been replaced by one with plastic padded sides. All of these things we have accepted as best we can as part of our normality but what I don't think I will ever fully adjust to is the mundane nature of doing the caring tasks over and over again, every day with no likelihood of change, the need to constantly follow your child around, the fear of going to the toilet in case she falls while I'm gone and hurts herself or has a seizure... the list is long, I could go on. The complete mother-child life cycle has ground to a halt and the wheels are coming off.

I asked other mothers about how they saw their roles as carers for their child and this made me think about my use of the word 'carer'. I wondered when I had become a carer to my daughter rather than her mother? For me that felt like quite a loss and I couldn't quite remember when it happened. I kept trying to remember but like many other mothers I don't like to examine my feelings about finding myself in this position too closely for fear of the floodgates bursting open – I might not be able to crank them shut again. Often I think we are lost in the monotony of our lives while skimming along on the surface of our existence. This may be why it only takes some thing small to make us feel as if we are teetering on the edge of a precipice, feeling emotional and wondering why not being able to get a box of latex gloves on prescription can make us feel so devastated.

All the mums had some ambivalence about being thought of as a carer and one in particular said she preferred to think of herself as a caring parent. Here are some thoughts:

“Taila’s only ten, she will be starting secondary school next year. I do feel that I am on the cusp, I am changing from being this child’s mother to being this child’s carer. You expect your children to use the bathroom, to wash their faces, to grow up, to grow off-hand but with our children they stay babies forever. You know I am still having to cut up her food, feed her, change her nappy, wash her face, so she is still the baby. It is hard to say that I am her carer cos I’m her mum and it just comes natural for me to want to do that to look after her and to love her but as she is getting older I am looking for her to go off and do things in her own right so that then makes me a carer and I’m not so much the mother.” (Anna Skinner)

“I have to take on board lots of different needs for this child and not all of them should be met by the parents.” (Louise)

“Because it gets tiring when you have to do something every single day of the week without any break whatsoever, and I don’t mean school. I have never considered school as part of my respite. They go to school cos they go to school any kid goes to school, it’s when they get home and you still have to watch them like a hawk to make sure they don’t hurt themselves or that they don’t get hurt, you know, or even to just let them out – they don’t just have friends and make friends – their friend’s mum takes them out for tea (ha ha ha ha ha!) can you imagine! We just don’t get that. That’s when the caring bit I think comes in cos that’s when you have to do things above and beyond the call of duty.” (Anna Skinner)

For me, along with the caring role comes a sense of isolation, partly positioned there by stories of what is required to look after our children, most of whom increase in their dependency and vulnerability as they grow up to become teenagers. We are to some extent isolated from friendships. These are the close nurturing relationships that many women cherish and make use of, not only in times of despair but also in celebration. Slowly, over the years I have seen my friendships wither away, I tell myself many stories to explain why – perhaps I am responsible for not working hard enough to keep in touch? Perhaps I became too needy? Perhaps I cancelled once too often? Perhaps they feel too bad that they have children in ballet class, doing GCSEs, going to discos or playing football? What I do know is that we used to have lives on parallel paths and while I am still held in high esteem by my old friends, the paths have diverged too much to bridge the gap. It’s either that or I just don’t have energy to try. Two weeks ago I went out for dinner with some of my oldest friends (I have managed to avoid seeing them for 18 months). I was nearly sick before we left, knowing my daughter and her current needs would be the main topic for the evening’s discussion. These are lovely people and they care for me very much but for me it means there is no escape from being reminded of how different we have become, often financially, as well as in our hopes and dreams for the future.

One mum I spoke to had been to a ‘back-to-work conference’ organised by the local authority. I know this mum has wanted to return to work for a few years but she found “it rubbed salt in her wounds” and left her an “emotional wreck”. Despite her best attempts she believes that “no employer would be that understanding.”

Speaking as a mum who was able to work for a few years, I really relished the opportunity to have another focus for my life. However, childcare, especially in holiday times, was a nightmare; coupled with running a home this left me frequently physically and mentally exhausted. Many more mothers would like to go to work, mostly on a part-time basis. I think it is important to note here that working gives you a kind of feedback that can help mums feel as if they are still a person in their own right and not surgically attached to their child. One mum used to tell me her job was “a kind of respite.” (Louise)

Now and for the future?

A lot comes down to our relationships with professionals. When other supports are not available or drift away over the years, the one thing that remains consistent is the fact that most of us will have significant contact with a range of services. I am really pleased that in recent years professionals have begun to adopt a position that the parent is the expert – and in many cases that expert will be the child’s mother.

Personally I have been lucky to receive some good support and some good respite services over the last few years and I don’t want to end by rubbishing people’s efforts when I think that most are very genuine caring people trying their best to provide services and support.

What I would like to do is to give a voice to some of the things mothers find very difficult and to put these in the context of how they make us feel about ourselves as mothers.

For example, two weeks ago I needed to talk to a health care professional about my daughter’s incontinence pads – it was awful, I just felt she didn’t listen to me. She started the conversation by suggesting I should be grateful for the product I received and it went down hill from there. What might not be obvious to the ‘outside’ observer is how hurt and let down I felt. It’s bad enough that your 16-year-old needs to wear pads at all, that’s enough to make me want to cry, but I never succeeded in getting my needs across which was that I would run out of product before my next delivery.

This conversation replayed on a loop in my head for days and nights. I examined it very closely and wasted hours thinking about how it could have gone so wrong and what my part might have been in that misinterpretation. This is the side of mothering a child with a disability that I don’t think people are aware of. It links with the story I was telling you earlier about how it’s the little things that send us over the edge like when your calls aren’t returned, or you come to point where you feel you have to shout and scream.

“It was in the middle of Tesco’s car park. I had to shout at her down the phone because nothing was happening, there I was ranting away, everybody was looking at me. It was so embarrassing but I just had to make sure she realised how serious it was.” (Julie)

People don’t realise that sometimes we have to go against the advice of the medical profession.

“Even a few years ago the consultant was talking about a ‘pull through’ and an ‘ace’ procedure for my daughter. I had to **really, really** put my foot down and say... look... you know.... her learning disability will not allow her to tend to herself, so I will have to tend to her and that will not make for an easy life. You have got to make life

easier and happier for us, as long as she is pain free and happy I can't expect or ask for any more." (Anna Skinner)

It is important to me that the courage and strength of mothers is never underestimated. If you start from the premise that all of us are doing the very best we can with the resources we have – both emotionally and physically – and just accept that like in any role, strengths and capacities vary and they are evolving every moment of every day.

I think the mother's role is very clearly summed up below – no one can say that anyone other than a person with the closest emotional ties and commitment could say this.

"It was like me and the surgeons and the consultant all sitting round the table ... me actually listening to what they were saying but them having to listen to what I said, and I wouldn't let them hold her down for up to 40 minutes and put lines in everywhere, those days are over, they are long gone. As she has got older I don't allow anybody to do anything without me thinking about the consequences of it. I'm always thinking about the safest, kindest, pain free-est way of doing it. You as their mother have to find the voice somewhere within you to say 'no, I'm sorry but I am not going to let you do that to my child' and explain to them why then they can't fault you." (Anna Skinner)

Siblings: Aaron's story (aged 15)

Living with a sister who has a disability could be said to be rather like a going on a rollercoaster ride – it has its ups and downs! Most of these times are good, brilliant even, and I would not swap them for the world. However, the bits that are not so good can be very, very hard and I sometimes find these times very difficult to cope with.

My sister is now ten years old and has complex needs, but happily is fighting fit and healthy, and ever since I can remember she has had the most cheeky and cheery personality imaginable. She always has a smile on her face, well nearly always, but just recently she has started to blossom, and her 'ten-year-old' personality has really started to shine through.

I believe that a lot of this is because of the school she currently attends. My sister goes to an absolutely wonderful Scope school which specialises in conductive education. The children are all encouraged to be as independent as possible, and to develop as individuals – "each of us are just one part of a jigsaw" – whilst learning from each other. Of course, as well as all the amazing staff at the school, special equipment plays a very important part, and while the school is very well equipped, we at home are not!

One of the major issues we have which crops up time and time again at home is equipment and the ongoing battle with social services to do anything about it. Every mealtime for example, my sister has to eat her food reclined like a baby while sitting on my mum's lap because she doesn't have anything as simple as a chair to sit in! The help we receive as a family can only be described as very, very disappointing. I don't think that 'normal' people realise just how hard times can get. Even what might seem like small things to others are often huge problems to us – such as mobile people parking in the disabled spaces at the shops, theatre, cinema etc. My sister is quite big now and carrying her is no longer possible except for short

distances, plus we need room around the car to lift her in and out. Good luck to the clampers I say.

Do people not realise, or do they just not care? (I do have a supply of stickers for car windscreens, which point out the mistake they have made though!). If I had just one wish, it would probably be that all families without disabled children had to live with a disabled child for a week, just to see how difficult it can be...

... For example, the other day we went to Brighton to do our Christmas shopping, which my sister absolutely loves, being a shopaholic, but the only problem is that when we go away for the day we have to take several changes of clothes for her – she is very dribbly. Now you tell me how it can possibly be acceptable to be changed, top and bottom, in a cold and very public car park... how humiliating. But there are no other facilities available. We could always just stay at home I suppose. Another thing that really does get me down is people staring at my sister in the street. This is the 21st century after all, so why can't people just accept each person for who they are and realise that everyone is different in some way. I used to stare back, but just recently mum brought my sister a 'Vicky Pollard' badge which says, very loudly, 'don't go giving me evils' – brilliant. She also has a key ring attached to her buggy which says, 'I understand, I just don't care'.

There are many other small things like that which I could do without and I'm sure my sister could do without them too, but I would still not be without her for a moment. She is wonderful and I love her to bits, after all she is not the problem it's everything else that we have to deal with.

When I am eighteen I am planning to move to London to attend college. I'm really worried about just how my mum will cope on her own, my sister will be thirteen then and it's hard enough now with two of us at home.

Mark Brown, parent: Fathers

Many of us have an idea of men as the ones who find it harder to adjust to the birth of a disabled child. I seem to be stuck at the beginning. The first step we are told, is to mourn the healthy child who was not born and nurture the damaged one who was. I wonder how anyone can accept the unacceptable (Robertson, in Meyer, 1995).

There often seems to be a perception that men are either disengaged or angry, but like most things in life the reality is probably more complex.

“Four years later, battle scared, war toughened, wiser for the experiences, I still find immeasurable joy in holding my angelic child and coaxing her into a grin. And when the rough spots hit – and they hit relentlessly – I simply take a deep breath, ask myself who is really suffering, and then do what has to be done.” (Dale, in Meyer, 1995).

Being the father of a disabled child changes everything. Personally, I always thought I'd take my children, sailing and hiking. That my sons would go to university. That we could go camping and skiing and discuss the finer points of social theory... I know, no child would talk to their father about the finer points of social theory and most would only go sailing and hiking under duress or for huge amounts of cash. But the problem is my son is 10 years old and the only thing we've talked about today is *Teletubbies* and his obsession with the BBC 2 logo.

Luckily I've got a really bad memory, so the hard bits tend to disappear deep into my subconscious, but there is one that might be worth sharing for reasons that will become apparent.

I think he must have been about two and a half years old. It was after the diagnosis and a few weeks later, I took him to the phlebotomy department so that blood could be taken for some tests. As with any child, especially one on the autistic spectrum, I was expecting a bit of a fight, so it was no great surprise that after not very long I had a screaming kicking child fighting to get out of the room. The problem was that the phlebotomist couldn't find a vein and the more she tried the more he struggled and the more I had to pin him down, he screamed and sobbed and after what seemed like an age a now traumatised phlebotomist decided that we would need to get a paediatrician off the ward.

So I waited with my sobbing child, who although exhausted was still fighting to get out until the paediatrician came and it all began again. He screamed and fought and I pinned him down and after a long while the blood was taken. The paediatrician left with barely a word and the phlebotomist was consoled by her colleagues on the other side of the room. Nobody spoke to me, I dressed my son, apologised as I left the room and cried with him as I left the building.

Making sense of our experiences

There is a distinct perception among service providers and perhaps amongst many mothers that fathers are a problem. Researchers in the field often represent fathers as 'hard to reach' and peripheral; they often perceive their role within the family with a disabled child is at best one of supporting the principle carer and at worst, to quote a friend of mine, 'useless ****tards'. Of course, I'm not totally comfortable with that notion, but I'd be the first to admit there are some issues around working with disabled children and their fathers, and in particular their relationship with the agencies.

The difficulty in engaging the fathers of disabled children would seem to be:

- ⇒ That the nature of traditional male identities represses emotion and caring and that this can lead to difficulties in coming to terms with the birth of a disabled child.
- ⇒ That the nature of service provision is not adapted to meeting the practical difficulties that fathers have in engaging with them. For example, the fact that most meetings are set during working hours and that men are often unable to attend.
- ⇒ The popular theory based on the concept of the bad father, that is, when the going gets tough the men get going.

The likelihood is of course that all of these issues are factors in the marginalisation of the fathers of disabled children. But is this all that is going on; or do we need to ask ourselves questions about what actually happens within families when a disabled child is born or diagnosed? We hope you will forgive us if we indulge in a little theorising about some of the dynamics that we believe may develop in some instances in some families.

A reassertion of traditional gender identities

As we all know, we live in a world where all identities are under pressure and subject to rates of change unheard of through history. This process of change is as valid for mothers and fathers as it is for any other type of identity. Although there are debates about the extent to which men have changed, the traditional view of the father is challenged by new identities of new caring men pushing buggies and changing nappies. Mothers are no longer queens of the domestic but have become magicians somehow able to hold down a career, do most of the chores and liberate themselves from any dependency upon men.

Until, that is, a disabled child is born. At which point the new man and woman are gone and the expectation is that the mother adopts alone, and for herself, an identity based upon traditional concepts of motherhood. Whilst for the father there is a reassertion of traditional male identities based upon self-reliance and the non domestic sphere, without necessarily adopting other traditional elements of male identities such as obligation and a sense of duty. But for the mother, as Olivia put it in her section on 'Motherhood and the disabled child':

“At this time we seem to have reached a point where we realise that the umbilical cord so vital for the life of the unborn baby in the womb, remains in place and now serves to keep the mother and child joined closely together in life. Some may argue that mothers themselves choose that position but for most it is not a choice.”

There is an expectation that a 'good mother' will selflessly adopt the identity of mother as nurse, mother as carer and mother as saint. An expectation that I suspect we all indulge in, mothers, fathers and professionals, and you might argue that such a reassertion is only natural. Perhaps, perhaps not; but what this reassertion of traditional identities does do is re-establish a traditional division of responsibilities within the family and with it comes the foundations of a mother's isolation and the marginalisation of the father.

The division of responsibilities in families with disabled children³

(The chapter by Barry Carpenter and Jo Egerton also discusses the roles of family members, focusing on international as well as national research.)

Research has shown (Pelchat et al, 2003) that in most families with a disabled child primary caring responsibilities are the preserve of the child's mother, whilst at best fathers come to adopt a support role, working, caring for the carer and supporting the needs of the siblings. This tendency is often exacerbated by the needs of the disabled child and the intensity of the relationship that develops within the mother-child dyad. When children have medical needs, it is usually the mother that provides the nursing care and becomes expert in their delivery. Where children are non-verbal, the principle carer will develop an intimate understanding of the meaning of particular gestures and behaviors. The result is:

- ⇒ That a father's attempts at communication may be met with less success than that of the mother.
- ⇒ The child may come to prefer interaction with her over that with the father.

³ The Early Support distance learning chapter by Barry Carpenter and Jo Egerton – *Family Structures* – also discusses the roles of family members, focusing on international as well as national research.

- ⇒ Ultimately a father may cease to attempt to interact intensively with the child, fearing criticism and rejection, both from their child and from their partner.

As Pelchat points out when speaking about mothers' views of their partners' roles: "They feel that the father is not capable of providing adequate care for the child or that they are simply more qualified for this important task." (Pelchat, 2003, p238).

In itself there is nothing wrong with this type of process, and in many ways these concerns about the father's role as a caregiver are the same for all families. As with other families, it's understandable if a family divides itself so it is able to meet the needs of the disabled child and their siblings. The problem is that this division of labour may have a number of consequences for the family of a disabled child, namely:

- ⇒ To make the mother the child's exclusive carer.
- ⇒ To marginalise the concerns of other members of the family.
- ⇒ To divide the family into two parts: one centered around the needs of the disabled child and the mother, the other around the rest of the family.

⁴Bray et al (1995) also reported that among fathers finding it difficult to accept that anything was wrong with their child, the quality of early contacts with medical personnel was critical to their ability to deal with the intense emotions accompanying the birth of their child. In Bray's study, fathers described an almost immediate worry about their child's long-term future. Fathers in the different studies described adverse coping strategies they had adopted to deal with their emotional trauma, which included consuming more alcohol more frequently (Bray et al, 1995), working longer hours and withdrawing emotionally from their families (Carpenter and Herbert, 1995; Herbert and Carpenter, 1994). West (2000) concluded that the fathers whom she interviewed felt they were just shadows. Although there is some evidence that professionals are beginning to consider fathers' needs, four themes constantly recur throughout research and are of major significance within any effective early intervention programme: the absence of someone to talk to; very little direct advice, for example, on behaviour management; poor information; and professionals' reluctance to discuss their child's future.

Professionals can adopt practices which include fathers. In a Welsh study, Jones and Ware (1995) describe the commitment of a particular health professional to involving fathers:

"What I have tried to do...is to involve the dads. I rarely meet the dads. There is one who is keen to talk to me, and I try to organise my visits to fit in with his shift work. A way of overcoming this problem for the others is to try to leave something with the parents, even just a sheet of paper, that they could talk about. I try to make clips of video that the parents could look at together and try to discuss their ideas." (Jones and Ware, p6).

The mother-child dyad and the rest

As the mother becomes absorbed in the needs of her child, the right of the whole family to have normal concerns, normal problems and for these to be heard within

⁴ The closing paragraphs of this subsection were provided by Barry Carpenter – see also the Early Support distance learning chapter by Barry Carpenter and Jo Egerton.

the context of the family is undermined. In the early days of diagnosis and adjustment these issues are unlikely to be a problem, but as time moves on this division of the family into the mother-child dyad and the rest, may have the effect of destabilising and undermining its long-term viability.

The problem for service providers is that traditionally service provision is targeted at the primary care giver, in most instances the mother. In addition to the knowledge of their child that they develop as a result of the intimacy of their relationship, the divide with the rest of the family is intensified by the fact that most of the knowledge which service providers feed into the family is done through the principle carer – the mother. This has the effect of strengthening the expertise of the mother but also of re-enforcing the skills imbalance and entrenching the division of the family.

So what happens when families become divided in this way? Sometimes nothing, sometimes it works; sometimes the individuals within the family are able to reconcile the divisions and the choices that they make. Sometimes those on the periphery create their own centre and begin to lead parallel lives to the disabled child and the primary carer. But more often than not the mother becomes isolated by the needs of her child and her own success in meeting them and the father moves further and further toward the periphery. This has a huge impact upon the stress levels that mothers have to deal with.

Gender, stress and coping

Most studies which compare men's and women's ability to cope with stress usually presume that they are comparing a father's and a mother's response to the same set of stressors. However, as Gray (2003) has argued:

“Research on gender and coping often has assumed that men and women are necessarily experiencing the same problems when exposed to the same stressful life events. However, this assumption may be incorrect, as their different roles may require them to cope with different problems.”
(Gray, 2003, p632).

As we have argued, and in support of points made by Gray, the division of labour in a family with a disabled child is very much along the lines of a traditionally gendered division of labour. Gray goes on to argue that the stress levels for mothers are so much greater because it is they who are dealing with the child's disability on a daily basis. To quote one of the fathers from his study:

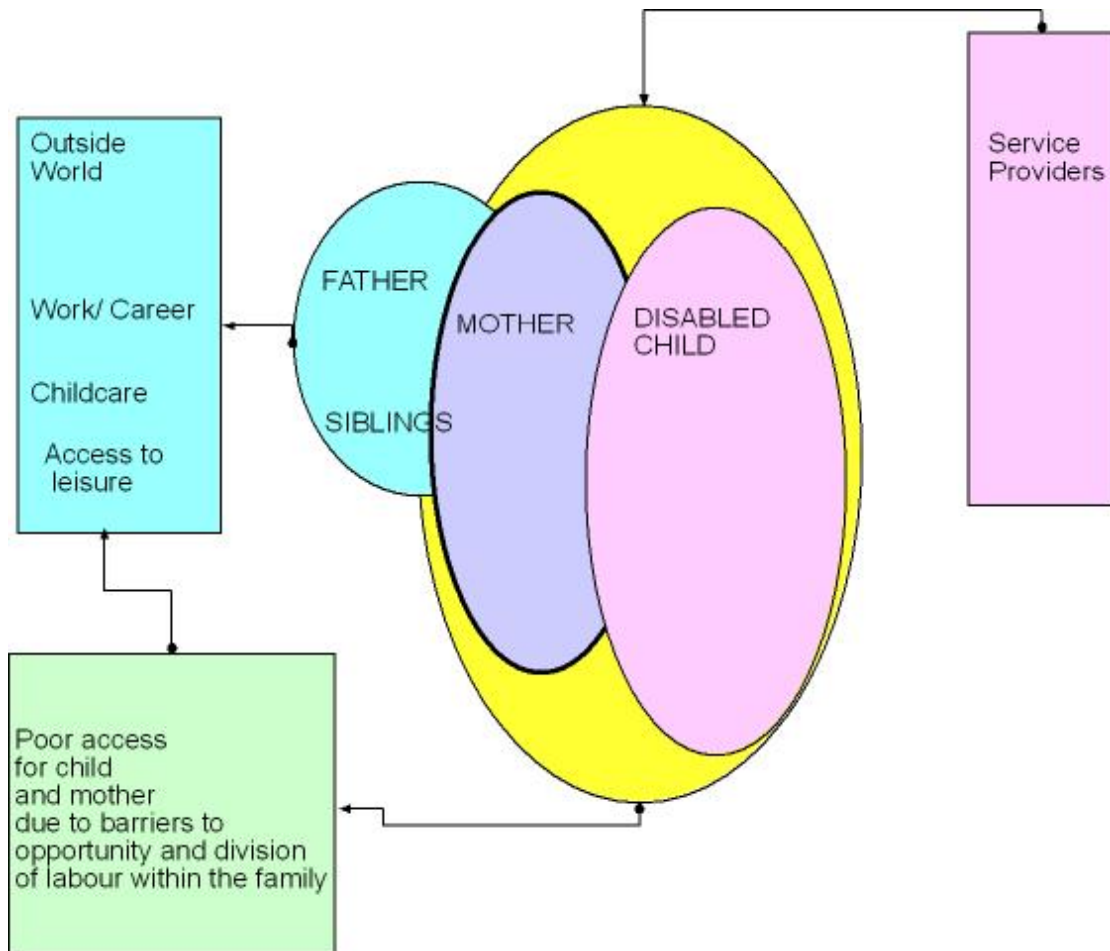
“Nine times out of ten it's the mother who is [caring for the child] day after day, hour after hour ... A lot of the burden is put on the mother because the father is working ... The father essentially has respite care five days a week.”

Whilst the mother becomes absorbed in the day-to-day concerns and difficulties of meeting the child's needs the traditional division of responsibilities within the home means that fathers are able to remain focused upon concerns outside of the home and are less directly affected by their child's disability. Often the difficulty for fathers was more the effect of the child upon their partner, and the realisation that upon returning home they will have to deal with their partner's distress. Unfortunately, the fathers taking part in Gray's study admitted that their child's disability 'might have encouraged a greater commitment to their work'. All of this has the effect of adding to the stresses that mothers are confronted with and undermines the resources and strategies that are available to them in coping with them and in maintaining their personal sense of well-being and worth.

For those who like to visualise concepts, and as I attempt to show in the following diagram, the mother and disabled child are unable to access work and leisure opportunities in the way that other members of the family are able to. They become increasingly isolated, not so much by the intrinsic nature of the child's needs but by the combined effect of:

- ⇒ The division of roles within the family.
- ⇒ The barriers to inclusion which disabled people within our society face.
- ⇒ The tendency of service providers to support the mother-child dyad rather than the whole family.

In the long-term this isolation of the mother may play a role in the higher divorce rates that we see with families with disabled children; and have as a consequence the need for the agencies to adopt the role of corporate father.



Mark Brown, parent: Working in partnership and parent participation

So to summarise what are for us the key principles that underpin working in partnership with parents:

- ⇒ That we live in a society that sees the birth of a disabled child as a tragedy, yet disabled children have a right to be loved, valued and respected, above all by their parents. Parents will have to make an emotional journey which will take them from the former to the latter. The

principle objective of your work will be to support and empower them in that process.

- ⇒ As part of that journey families need early support and care coordination providing access to the following:
 - Information
 - Emotional support
 - Service coordination and planning
 - Financial support
 - Advocacy.
- ⇒ Professional knowledge and parental expertise should be used to empower and to support collaborative solutions to the needs of disabled children and their families; and to help families in developing their own personal resources and coping strategies.
- ⇒ Families who make choices you don't agree with have a right to be respected and not condemned or judged.

The experiences of families tell us:

- ⇒ Whilst families have common concerns that often revolve around the detailed elements of service delivery such as equipment, individual members of the family have to deal with different issues and differing levels of stress.
- ⇒ That mothers are often isolated by their role as carers both from the community and within the family.
- ⇒ That we need to develop approaches to working with families which acknowledge the needs of all members of the family and yet challenges the traditional division of labour within the family which may lead to the isolation of the mother/principle carer.

Throughout this chapter we have referred to the principle of working in partnership with disabled children and their families without elaborating more precisely on what working in partnership actually means. The principle reason for the omission is either:

1. That we forgot;
2. That the meaning is actually not that straightforward and we didn't want to confuse things.

We'll let you guess which is true. However, be that as it may, the definition of the term that we are using has its roots in three separate strands of children's services provision. The first is the type of definition that Hilton Davis uses to describe an approach to working with families that:

“... recognises that many people have a potential role in providing help and support, while at the same time taking account of the expertise and self determination of parents.” (Davis et al, 2002).

Its purpose is to strengthen parents' resilience and their ability to cope with stressful situations, helping them to develop their own personal psychological resources and strategies.

The second finds its origins in the *Warnock Report* (1978), *The 1981 Education Act*, the *SEN Code of Practice* (2001) and the work of the country's parent partnership services. Its origins in the *Warnock Report* acknowledge the contribution that parents make to meeting the educational needs of their children, but in an educational context the phrase 'working in partnership' has associations of conflict minimisation.

Whilst most parents who use Parent Partnership schemes acknowledge their usefulness and value their support (Wolfendale and Cooke, 1997; Vernon, 1999), the relationship between parents and the education system remains one that is beset by the language of the battlefield (Duncan, 2003) rather than partnership.

The third sense in which we are using the term is in the context of service evaluation, policy consultation and user involvement. Here the participation and involvement of children, young people and parents is based upon the principle that services are more effective if they are designed in such a way that it draws upon the knowledge and expertise of users. In such a case, services are more likely to:

- Have the confidence of users
- Meet the needs of users
- Generate a sense of shared ownership and collaboration.

These principles are integral to Every Child Matters and the Core Standards of the National Service Framework for Children, Young People and Maternity Services, in particular Standard 3:

“Children and young people and families receive high quality services which are co-ordinated around their individual and family needs and take account of their views.” (DoH, 2004).

There are three strands to the process of working in partnership with disabled children and their families:

- ⇒ Empowerment and resilience as an outcome of working in partnership.
- ⇒ Conflict minimisation through parent participation in meeting a child’s SEN; and
- ⇒ Service development through consultation and user involvement.

These are at the core of what we believe working in partnership with disabled children and their families is about, and that the success of any single strand is dependent upon the implementation of all three. Therefore, an approach to working in partnership which functions at these three levels is one which supports families in adjusting and coming to terms with the challenges that they face – helping to shift the vision and conception of the child from one which focuses upon the label to one which sees the whole child. From this basis, built upon principles of shared expertise and non-judgemental practice, comes a foundation upon which a relationship based upon trust and conflict avoidance can be developed.

This is not to say that families who have been supported to develop their own self-reliance and coping strategies will not go to tribunal, but rather that if they do they will do so as an act of choice rather than desperation. However, where working in partnership has functioned effectively at a strategic level and where service provision is family-centred and responsive to the needs of service users in keeping with the core principles of the NSF, then another building block for collaborative working will have been put in place and the likely effectiveness of service provision increased.

But that partnership has to be genuine. Consultation has to be meaningful and has to make a difference. If carried out for its own sake it will create fatigue and disillusionment and sour the relationship between providers and users. You might argue that you have been consulting and working in partnership for years and that your organisation already has a collaborative relationship with its children and families. Perhaps you are right but it might be worth looking at the following quote from the *SENDIST⁵ Annual Report for 2003–2004*.

⁵ SENDIST is the Special Educational Needs and Disability Tribunal

“On 31 August 2004 the Tribunal completed 10 years working as an independent judicial body to decide disputes between parents and LEAs in SEN issues and since 2002, in disputes between parents and schools in disability discrimination issues we have received nearly 25,000 SEN cases.” (SENDIST, 2004).

As a measure of the extent to which partnership working and the development of collaborative approaches needs further work, it is fairly convincing.

But the reason we need to do so is not just so that we can reduce the amount of money we waste through conflict between parents and service providers it is because, to quote what I said in the foreword to the distance learning text:

“We will need you to help us to adjust and adapt to our changed situation. You will need to help us to access those services that will enable us to remain valued members of the world in which we live, supporting us in the challenge of our changed expectations. You will need to help us to protect our children from disadvantage because we need to recognise and value disabled children for who they are. You will need to help us to move from the difficulties of those early days, from our grief and confusion; because the child’s right to demand that we should try is beyond doubt. The academic and disability rights activist, Tom Shakespeare, once said:

“There is a need for disabled people ... to establish themselves as subjects, each with a voice and rights which are rich enough to respect their individuality while recognising them as a member of the community.

“That process begins within their family and with a child’s right to acceptance, love and respect...”

But that’s not where it ends.

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