Supporting parents with learning disabilities and difficulties

Stories of positive practice
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Introduction

This booklet has been produced by the Working Together with Parents Network (www.right-support.org.uk). The Network was set up with funding from the Baring Foundation and the Esmée Fairbairn Foundation to support the development and sharing of positive practice in supporting parents with learning disabilities and learning difficulties.†

This booklet tells the stories of six families headed by a parent or parents with learning disabilities or difficulties, from England, Wales and Scotland, who have been enabled – with the right support from professionals – to look after their children and safeguard their welfare.

The six stories of positive practice aim to:

● give an insight into the complexities of the real lives of parents with learning disabilities and difficulties

● illustrate the positive impact on parents (and families) of professionals who believe in their abilities and provide appropriate, positive, flexible and co-ordinated support

● show how professionals involved with these families have supported parents to parent in a manner that ensures the welfare of their children

● provide services, and other people involved with parents with learning disabilities and difficulties, with strategies that may enable them to support other parents in positive ways.

The stories show that if parents are given support tailored to their particular learning styles and their family’s needs, they can parent effectively, despite the negative expectations and very real difficulties they face.

The work of the services and staff described in these stories illustrates how the aims and provisions of the Children Act 1989 (for England and Wales) and the Children Act (Scotland) 1995 – as set out in more detail in the Good practice guidance on working with parents with a learning disability (DH/DfES, 2007) and the Scottish good practice guidelines for supporting parents with learning disabilities (SCLD, 2009) – can be put into practice for the benefit of parents and children alike.

† Parents who do not have a diagnosed learning disability but who are regarded as having difficulties with their learning and their parenting are also included in this booklet.

†† All parents’ and children’s names have been changed to preserve their anonymity. The stories have been checked with them and the professionals involved in their lives.
The stories††

**Jack**
A single dad who has been assessed as being able to provide full-time care for his toddler daughter

**Maggi and David**
A couple with learning difficulties who are caring for their toddler daughter with support from their extended family and co-ordinated multi-agency support

**Steve**
A single dad who cared alone for his son for eight years from babyhood, before getting together with his current partner

**Sharon**
Mum to a six-month-old daughter, who has proved her parenting ability while living with her mother-in-law and through the use of a ‘virtual’ baby

**Cathy and Martin**
Parents to children (who are now teenagers or in their early twenties) who were removed from their parents 12 years ago, but have since returned to their care

**Alison and Richard**
Parents who had a previous child removed at birth and were therefore scared to contact social services for help with their second baby. They have been consistently supported by a voluntary organisation since the birth of their second child, who remains in their care
‘I have two children. My son, who is 12, lives with his mother, my ex-wife, but he has regular visits from me. We go to football practice and my son often has overnight stays. From another relationship I have a daughter, Sarah, who was removed from her mother after birth.

‘Social services assessed her mother and decided that Sarah should be adopted. I do not work any more and live in an upstairs flat. I struggled with money and had some debts. I had to ask to be assessed to care for my daughter.

‘At first, Sarah’s mother and me had supervised contact together. Then I got a solicitor, who suggested I had another assessment from an independent social worker. This assessment was good and said that “a plan should be considered to allow my daughter to grow up in her family of origin”. I felt that things were moving forward.

‘My relationship with Sarah’s mother ended, and it was agreed that I could have contact with Sarah on my own, for 20 hours a week, supervised. I had lots of assessments by different people. My community nurse (learning disabilities) helped the social worker to do an assessment that was specifically for parents with a learning disability. Finally it was decided that I could have my daughter for 47 hours a week, without supervision. Sometimes social workers would come to my house unannounced to make sure everything was okay.
‘Then, when Sarah was 16 months old, it was decided that she could live with me. On the day before she came home to me, I was told that court would have to decide before she could come home. I felt bad, so I telephoned my community nurse, who helped me to speak to my solicitor and my daughter’s social worker, and her manager, and then they decided Sarah could come home as planned. There will be more meetings and court hearings before it is definitely decided that she can stay with me.

‘Having Sarah at home with me has improved my life. I feel lots of self-satisfaction because I have done everything – all the steps I had to take to satisfy the social workers. Sometimes, I can’t see the point of having to do those steps, because I already have a son.

‘My family have helped me to get the flat decorated and they keep me right. I thought my community nurse was the first worker who tried to help me. All the other workers would contact her and she always told me what had been said.

‘She would read letters and reports to me because I cannot read or write very well. She helped me to realise that it was other people’s problem to give me information that I would understand, and not my problem for not being able to understand. She reminded me of appointments and times. She helped me with any problems I had with social workers, and she helped me to make telephone calls. She came to my solicitor’s with me and to court and explained things to me and for me. I did some assertiveness work with my community nurse that made me plan my life in a different way, and to think differently. I was honest with workers. I understood that my community nurse was there for me and the social worker was there for my daughter.

‘I had two different social workers and thought that they were honest with me about what they expected, and they would tell me if I did anything wrong. My solicitor was good at explaining things to me, and she would always write letters to my community nurse as well as me, to make sure I understood what was happening. The health visitor did not know I could not read and write very well, but when she found out she gave me information that I could understand.

‘My daughter is nearly two years old now, and the recommendation for the final court hearing is that my daughter remains in my care. Me and my son feel dead chuffed, and my ex-wife feels proud of me for what I did.’

What helped?

The community nurse says that what helped her in supporting Jack was:

- believing that, with support, Jack would be able to adequately care for his daughter
- following the Good practice guidance on working with parents with a learning disability (DH/DfES, 2007)
- supporting other professionals with how to communicate with a parent with a learning disability
- listening and hearing what Jack had to say
- ensuring that he understood all written information
- not judging
- working in partnership with everyone involved
- Parent Assessment Manual (McGaw et al., 1998)
- accessible information, such as You and your baby (Affleck and Baker, 2004) provided by CHANGE (www.changepeople.co.uk).
Maggi and David have been married for three years and, in Maggi’s words, ‘unusually for where we live we didn’t have a child until after we were married’.

Their daughter, Anne, is 19 months old, well advanced in her language development (according to their health visitor) and loves any kind of loud musical toy, wires and keys. Maggi and David moved into their new house two days before their daughter was born. They have a ‘loopy’ dog called Louise. The couple are both mainly at home with their daughter, although David plans to go into business full-time and perhaps get a market stall when Anne starts nursery.

Maggi and David were planning a trip to New York when Maggi got pregnant. Maggi and David were initially shocked – ‘David needed a pint!’ – put the holiday on the back-burner and started to prepare for a baby. Neither Maggi nor David had a social worker at the time, but they were involved with KeyRing, a housing support organisation. Their supporter at KeyRing was ‘absolutely brilliant’. ‘When we told her we were pregnant, she asked if we wanted any help.’ She supported them to ask for a social worker (which was a long wait), helped them apply for the ‘maternity grant’ and put them in touch with Flying Start.† The KeyRing supporter continued to believe in them and ensure that they were fully informed on what was expected of them, why there were concerns about how things were going with the baby and how to overcome these.

Maggi and David were also supported by workers from Flying Start during the pregnancy, and an antenatal package of care was planned. However, the early arrival of Anne meant this didn’t happen: Maggi had pre-eclampsia during pregnancy and had Anne a month early, weighing just five pounds and two ounces.

After the baby was born, Maggi and Anne’s discharge from hospital was delayed, at KeyRing’s request, while Maggi and David were assessed on their ability to care for her appropriately.
When they came home from hospital, they were visited by professionals from the Flying Start team twice daily, seven days a week for the first three weeks. These visits spanned both day and evenings, to ensure that support was available when needed. Maggi and David were shocked by the extremely negative attitudes of some of the professionals they came into contact with and the number of ‘hoops to go through’. They report being told by one social worker that they ‘should have got rid of the baby’ and that because they have learning disabilities, their daughter will have too.

Maggi and David have had excellent support from their midwife at the maternity hospital, then from the Flying Start health visitor, as well as from KeyRing and from their large extended family. Maggi is one of six children; David is one of four sons. Anne is the first grandchild on David’s side and her paternal grandparents are besotted with her. Extra support from KeyRing and the Flying Start family support worker encouraged the housing department to get the family a house quicker than usual and in the location they needed, so they could support David’s parents, who have medical problems.

Maggi describes the hospital midwife as a ‘superstar’. She supported them with Anne’s feeding, and then liaised with their ‘wonderful health visitor from Flying Start’, when they brought Anne home from hospital at ten days old. Their Flying Start health visitor helped a number of times with weaning Anne, taking them through from the premature baby milk, to standard baby milk, and then on to solid food. Maggi feels confident to ring her health visitor whenever she has a question or concern.

On the day of the interview for this story, Anne has a virus and Maggi has been in contact with her GP, the Flying Start health visitor and her mum, who is a matron of an old people’s home, for advice.

The Flying Start team gave Maggi breastfeeding and other parenting advice using visual aids, pictures, posters and a book to enable the family to establish good routines and ensure home safety. Maggi describes their support as ‘ace’ and ‘worth their weight in gold’. Maggi and David are still involved with Flying Start, and attend a parenting group, which provides contact with other parents, advice and trips out in the summer holidays.

A new package of care has just been initiated, because their needs for support fluctuate as Anne’s developmental needs change. The current involvement is around supporting age-appropriate play for six weeks, in the home. However, regular telephone calls and support within the group will continue to provide a wrap-around provision for this – and every – family in Flying Start.

What helped?

Key points for services were:

- early support from KeyRing
- ongoing involvement from Flying Start, acting as the main point of contact for both the parents and the other professionals involved
- positive ongoing relationships with the parents from before the baby was born, with work aimed at preventing potential future problems as early as possible
- the availability of practical advice and support, which was easily accessed by the parents and which they felt they could ask for without their parenting capacities being questioned
- clear explanations to the parents about why there were concerns about their parenting and the type of parenting expected of them
- belief in the parents’ ability to care for their child – with the right support.

† A Welsh Assembly Government project providing antenatal, health visiting and other support to families in the most disadvantaged areas of Wales (see page 19 for more details).
Steve’s story

As told by Steve to an interviewer

Steve works at a national disability organisation and has lived with his current partner for some time. He has two children by previous partners.

His eldest child – a daughter – is now in her twenties and lives round the corner. He sees her regularly. She was brought up by her mum after the divorce, but Steve saw her most weekends.

Steve brought up his son George, who is now 18, on his own for eight years, before getting together with his current partner. When George was 16, he moved into a residential place for young people with learning difficulties, so he could be supported with his behavioural problems. Steve sees him at weekends when George is not busy with his friends (generally every other weekend) and phones him a couple of times a week. According to Steve, George has ‘just had a Goth phase because of a girl he fancies’.

Steve and his then partner had been together for a year when George was born. Steve had never been in contact with social services before, while his partner had always had a social worker. Steve was not working at the time, because of health problems. When the baby arrived, they were supported by the midwife, then by their health visitor and Steve’s mum.
When George was three months old, he was placed on the ‘at risk register’ for 18 months, as a result of an incident with the child’s mother. Steve had gone to visit friends for a few hours and came back to find the baby crying on the floor. As they didn’t have a phone, he ran across a busy road to call an ambulance. When they got to hospital, the doctors said that the baby’s injury had been deliberate. Social services became involved and George was placed in foster care.

Steve didn’t know that his partner had had a previous child who had been adopted because of harm from her. Steve split from George’s mother and said that he wanted to take care of his son.

As Steve was not married to George’s mother, he had to prove he had got parental responsibility for George.† Steve did a 12-week parenting assessment to prove his parenting skills and competence. He completed the course successfully within eight weeks, though he says he felt that the assessment was looking for things he did wrong, rather than recognising his abilities.

Steve’s mother fully supported him through this and helped him to gain parenting skills. Having his mum’s support meant that Steve understood what was expected and had the confidence to get through the assessment. Steve went to court and ‘won my son back’. The child was taken off the ‘at risk register’ after being back with Steve for nine months.

Steve had good support from his ex-partner’s social worker during this time and also had a great advocate. The advocate helped him understand what was happening in court. Steve firmly believes that parents with learning difficulties should get an advocate as soon as they know they are expecting a baby, so that they understand everything that is going on. He believes there would be fewer problems if this happened.

When George returned home, Steve was visited once or twice a week by his son’s social worker to see he was ‘keeping things going all right and that George was going to nursery’. These visits got less frequent and gradually focused on helping with his son’s behaviour, rather than monitoring Steve’s parenting.

Steve was also supported by a local voluntary organisation, which helped ‘make sure I was doing things right’, like paying the bills. This was generally short-term support for larger things, such as decorating the house.

What helped?

Key points for services are:

- to involve an advocate as early as possible if there are concerns about a child’s welfare
- to involve supportive family members throughout the process of planning support
- to engage local family support services that can provide ongoing support.
Sharon is in her late thirties and lives in a flat on her own. She has been together with her partner, Mike, for nearly two years. They have just got engaged and plan to get married and live together, when they have saved up in a year or two. Sharon and Mike have a baby girl of six months, called Summer, who does not currently live with them.

Before planning for, and having, Summer, Sharon was a cleaner, working three days a week in local offices. Sharon likes going to Gateway club (a social club for people with learning disabilities) on a Tuesday evening, to drama group and out to the pub for karaoke on Saturday night. Sharon and Mike plan to take it in turns to go out when Summer is with them full-time.

Sharon used to live in supported living flats for people with learning difficulties but ‘they don’t take people with babies’, so she moved out when she was pregnant. The flat she now lives in is owned by a housing association. Sharon had her own social worker to help her move and get the right support in her new flat.

When Summer was born, Sharon was not allowed to be on her own with her, as children’s services were concerned about Sharon’s ability to bond with the baby and care for her appropriately. Sharon has a 17-year-old son who lives with her mum and dad, because she had difficulty bonding and with the practicalities of caring for him.
Children’s services were also concerned about Mike’s use of drugs and alcohol. So when Summer was born, Sharon, Mike and Summer went to stay at Mike’s mum’s house for about three months. This was part of the child protection plan for Summer and provided Sharon with support and supervision. Mike’s mother was given shared parental responsibility for Summer by the court.

Summer is now six months old and everyone involved with the family agrees that Sharon has bonded with the baby, is really attentive to her and is capable of looking after her on her own.

Summer is with Sharon every day and stays with her two nights a week. The rest of the time, Summer is with her grandmother. Sharon goes to collect her from there on the bus and takes her back to her own flat. Sharon is now fully responsible for Summer’s care when she is with her, but she must be present and oversee Mike when he is with his daughter. Sharon and Mike hope that when they go back to court, this rule will be dropped.

Sharon attended a parenting group at the local People First organisation (an organisation of people with learning disabilities). People First provided advocacy for Sharon during the child protection proceedings. Sharon’s advocate suggested the use of a ‘virtual’ baby†, so Sharon could show that she had the skills to look after a baby. The advocate felt able to ask for this, and for initial supportive supervision, because the local authority had a disabled parents protocol (or agreement) which she was able to cite.

People First put Sharon in touch with a local pregnancy crisis centre, which has a project using a virtual baby. Sharon looked after the baby for a few weekends. She says: ‘It was all right … It helped us learn a lot with knowing about a baby until it ran out of batteries! It cried when it wanted a feed and a nappy change.’

Spending time with the virtual baby showed that Sharon had appropriate responses to its cries and so on. This information contributed to the decision that Summer could remain with her parents, but with the constant support and supervision of her grandmother.

Sharon has also been provided with ongoing, positive support from Mary, a children and families support worker. Mary comes to see Sharon twice a week and has shown her how to bath, dress, feed and play with Summer, as well as how to sterilise bottles.

What helped?

Key points for services are:

- to use the Good practice guidance on working with parents with a learning disability (DH/DfES, 2007) in England, the Scottish good practice guidelines for supporting parents with learning disabilities (SCLD, 2009) in Scotland, or the disabled parents protocol (if there is one locally), to work together and open up communication between adults and children’s services
- to involve the extended family, if they are supportive and available
- to support the development of trusting relationships between parents and support staff.

† ‘Virtual’ babies are generally used as an educational tool. They are, however, increasingly being used as an educational tool and part of the assessment process for adults with learning difficulties who are becoming parents. ‘Virtual’ babies are said to be just as demanding as real babies, and provide those using them with the most realistic parenting simulation available. The ‘babies’ need feeding, burping, rocking and nappy changing and require their heads to be gently supported. The carer has to determine the precise care needed.
My name is Cathy and I am nearly 44 years old. I am married to Martin, who is nearly 48 years old. We both have learning disabilities and I have a physical one as well.

We both have children from previous marriages. I have three: one girl and two boys. Martin has three girls and one boy. But we do not have any between us. We would have liked to, but the situation being as it was at the time, the new baby more than likely would have been taken off of us.

My children are now teenagers. When they were taken into care by the social services in August 1997, we did not agree with the decision. At the time they were two, five and six. This was because my eldest daughter had fallen off her bicycle and social services thought that Paul [my then husband] had intentionally injured her and fractured her rib. They gave me a choice of leaving my husband and keeping my children, but I did not think that I could cope, because of my disabilities. Paul does not have contact with his children at present.

We have had to go over a lot of obstacles over the years. At one time “the powers that be” said my children would never come back home. I was told that they would be adopted. If it had not been through me asking my children’s social worker at the time, if they could look into me getting help of some kind, I would never have known about the special parenting team. But as soon as they came on the scene, ours and our children’s lives could not be better.

They not only got us going in the right direction, but also told me of the Parents Opening Doors [college] course, which helps parents with parental issues, like healthy living, keeping children safe, bonding and play, and managing behaviour. The course helps us to build up our confidence, with budgeting and learning to read and write better. We have had teaching on children’s rights, parents’ responsibilities and child protection. I have met many friends here who have similar problems to ours. We would not be where we are today, if it had not been for the special parenting team and the college course. Also, the social worker we have got now is good. My children have had quite a lot of social workers over the years.
'The special parenting team assessed the family when my eldest son was 13 years old. They gave us support to help us have him back at home by teaching us about behaviour management and responsibility and independence. The college course also helped us with parenting. We learned about healthy living (eating healthily and exercise), setting boundaries for teenagers, dealing with teenage problems and talking to the teachers at school. The special parenting team talked regularly to the social worker and we had meetings together to explain our needs and what things would help us (transportation for appointments, visitations for our youngest son and help with medical appointments).

'When my daughter (who is nearly 20) started getting older, it was decided for her to go to independent living instead of returning home to live with us. This was because she had various behaviour problems, which was felt at the time that I and her stepfather might not be able to manage. She has gone to college, and is either going into music, or writing.

'My oldest son, who is now nearly 19, came back home to live with us when he was 14 and he still lives with us at present, but is hoping to go in the armed forces later this year.

'My youngest son was 13 at the time when he came back home to live with us in November 2008. He is now 14. He has not made up his mind what he wants to do when he leaves school. He has mentioned he wants to be a cook. He has disabilities like me. We still have a great relationship with his last foster carers, who I have always been able to call when I need advice. They continue to have him visit at their home and I have been to conferences about disabilities with them.

'The special parenting team did another assessment update when he first came home. We are now having a support programme from them that helps us to teach him to be more independent – helping him to learn to tell the time and go to the shops on his own. They are helping me to manage my stress better and I attended their stress management and relaxation group. I am also helping them to give training to social workers and other professionals on how to work best with parents with learning difficulties.

'So all we can say is, if you work hard long enough and stick at it, even though you might not see the light at the end of the tunnel, you will. All I can say is, do not put barriers up – work with them. The turning point in our life came when I worked with them – social services and all the rest.'

What helped?

Key points for services are:

- a dedicated team of workers to support parents with learning difficulties
- to engage parents through support which enhances their competence
- to support parents to increase their parenting skills, independent living skills and confidence
- ongoing contact between parents, a specific key worker and other multi-agency professionals, to identify needs, provide practical support and improve communication
- to develop/use parent-focused, holistic assessments for parents with learning difficulties
- adapted parenting courses and individual home-based support
- accessible teaching and support paced at parents’ level of understanding – visual aids, demonstrations, modelling, step-by-step instruction
- to involve parents with learning difficulties in staff training.

A specialist service dedicated to working with parents with learning difficulties
Alison and Richard have had a tough life. They got together when they were young, and within a couple of years their first child, Margi, was born.

However, because the hospital had concerns about the couple’s abilities to bring up Margi safely, Margi was taken away and placed in foster care. Alison says she wasn’t even allowed to hold Margi when she was born.

Alison and Richard were distraught and say that no-one offered them any support to make sense of what had just happened to them. Alison said that what made it worse was a social worker telling her: ‘If you ever get pregnant again, you must have an abortion’. So when Alison found out she was pregnant again in 2007, she was very frightened. She knew she needed support, but also felt she couldn’t go to the social work department.

Instead, she contacted a service provider that she’d heard of: ENABLE Scotland (a voluntary sector organisation). She also found a lawyer. The lawyer instructed a report of the couple’s parenting needs. ENABLE asked the local authority to address the recommendations in this report, so that Alison and Richard could have the support they would need to take their baby home and look after her. The authority did not respond, but ENABLE Scotland provided unpaid support for Alison throughout the rest of her pregnancy.

When their daughter, Tracey, was born, Alison and Richard were told they were not allowed to take her home. An emergency meeting was called by the social work department, and, because the baby was born on a Friday, Alison and Richard had the whole weekend to worry about whether they would be able to keep their child or not.
They found it was terrible being in limbo and Richard refused to hold his baby, saying, ‘I’m not going to bond with her, because who’s going to have her on Monday?’

At the meeting, ENABLE Scotland proposed supporting the family at home, and liaising with the local authority children and families social workers. This was agreed, and Richard, Alison and their new baby Tracey went home the same day.

ENABLE Scotland found that Alison and Richard were motivated and determined. Together, they were able to ensure that Tracey had a good start. However, none of this support was paid for by the local authority but by ENABLE Scotland.

The one thing that made life very tough was their flat. It was in a poor state, damp and often needing repairs. What’s more, the family didn’t feel safe there: ‘We’ve had the windows smashed in, and the door kicked in once’.

In June 2009, however, Alison and Richard moved into a housing association flat in Paisley. It’s bright, comfortable, well appointed (fitted kitchen, laminate flooring), and above all, safe: it’s one floor up, with a security buzzer on the main door. The area is much better too. There is nobody hanging around the flat, no vandalism, and the neighbours are all fine: ‘Everyone just keeps themselves to themselves’. It’s only five minutes’ walk to the shops and everything else in the town centre. This better housing has made all the difference in the world. Both of them are less stressed, and Richard feels more confident about going out: ‘He’s out all the time now with the wee one, down at the park’. The flat is closer to Alison’s dad’s house as well, so there is more contact there too.

They now need very little support from ENABLE Scotland. Someone drops by each week for a short time, to be on hand should there be any problems. The initiative for this came from Richard and Alison, but the service provider has agreed with the level of support needed. The health visitor continues to visit once a month, and gives advice to Alison on how to encourage Tracey’s speech development, as well as on more routine things.

All in all, the family is doing well, and Tracey is thriving. Everyone agrees that Alison and Richard would never have got to this point without ENABLE Scotland’s support. The staff team anticipate that at some point in the future, they might have to be more hands-on again, as Tracey’s needs change. But right now, Alison and Richard and their daughter are doing well.

**What helped?**

**Key points for services are that:**

- early intervention is best, as this gives the mum (or couple) the best possible chance to learn, and be supported, in the run-up to the birth of their child

- support should be tailored to meet individual need, but is mainly about supporting the mum (or couple) to engage with things like maternity appointments, health appointments and parenting classes

- information from appointments should be gone over with the couple at home, and any fears or gaps addressed, so that the couple can both learn and grow in confidence and be ready to look after their baby when it arrives

- a ‘support the parent’ model is adopted, as opposed to a ‘child protection’ stance. The best and most effective way to do this is to ensure that the three points above are at the forefront of any work carried out.
Summary

The stories of positive practice in this booklet show the complexities of the lives of six families headed by parents with learning disabilities or difficulties in different parts of the UK. They are among the most vulnerable members of our society and are entitled to support with their parenting under the Children Act 1989 and the Children (Scotland) Act 1995.

The stories show that parents with learning disabilities, and learning difficulties, continue to face a number of barriers in trying to bring up their children, including:

- negative expectations and stereotypes of parents with learning difficulties, which the parents feel are still all too widespread
- the emotional impact of having had previous children removed from them.

They also face other problems not related to their parenting abilities, such as poor housing, social isolation and relationship difficulties, while trying to ensure their children’s happiness and welfare.

The real stories of these real parents illustrate vividly both the normality and the complexities of their lives as adults grappling with the challenges of living in society today.

The stories also show that, with the provision of the kind of support advocated by the Good practice guidance on working with parents with a learning disability (DH/DFES, 2007) in England and Scottish good practice guidelines for supporting parents with learning disabilities (SCLD, 2009) in Scotland, adults with learning disabilities and learning difficulties can parent in a way that ensures the welfare of their children.
The support provided in these stories includes:

- belief in the parents’ abilities
- advocacy, including clear information and explanations of any concerns about their children’s welfare and the processes in which they are involved
- proactive intervention as early as possible in pregnancy or babyhood
- competency-based assessment of skills and strengths and of the support required
- positive family support, where this is appropriate
- co-ordinated multi-agency support led by a keyworker or lead professional
- support from honest, consistent and trusted workers
- following a local disabled parents protocol or policy where available
- enabling parents to overcome the barriers in their lives, such as poor housing and low self-esteem.

The parents who generously shared their own stories for this booklet all wanted the best for their children. They recognise that parents with learning disabilities or learning difficulties need to work together with services to achieve the best outcomes for their families – they just need support and understanding to be able to do so. We hope that their stories will inspire other people to provide that support for other parents in similar situations, so that they too can live happily and safely with their children.
Organisations that can help

Working Together with Parents Network

The Working Together with Parents Network is run by a consortium of partner organisations and individuals:

- the Norah Fry Research Centre, University of Bristol
- CHANGE, an organisation of and for people with learning disabilities
- Family Action (formerly the Family Welfare Association)
- the Scottish Consortium on Learning Disability
- Learning Disability Wales
- Jenny Morris, an independent consultant.

This network for professionals, frontline workers and anyone else involved with parents with learning difficulties is free to join. It provides an informative website and online/email updates about new policy or practice developments or issues concerning parents with learning disabilities or difficulties. The interactive website provides a forum for discussion of current issues across the UK and sharing of ideas on good practice.

Working Together with Parents Network
c/o Norah Fry Research Centre
University of Bristol
3 Priory Road
Bristol BS8 1TX
Tel 0117 331 0987
Email right-support@bristol.ac.uk
www.right-support.org.uk

CHANGE

There is also a free network for parents with learning disabilities or difficulties themselves, hosted by CHANGE. This aims to link individual parents and parents’ groups to share experiences and keep updated on issues related to parents with learning disabilities or difficulties.

CHANGE
Unit 41
Shine
Harehills Road
Leeds LS8 5HS
Tel 0113 388 0011
Email info@changepeople.co.uk
www.changepeople.co.uk

Scottish Consortium on Learning Disability

The Scottish Consortium on Learning Disability hosts a network for parents and professionals in Scotland, as well as participating in the UK-wide Working Together with Parents Network.

Scottish Consortium for Learning Disability
Adelphi Centre Room 16
12 Commercial Road
Glasgow G5 0PQ
Tel 0141 418 5420
Email administrator@scld.co.uk
www.scld.org.uk
Learning Disability Wales

Learning Disability Wales hosts a network for parents and professionals in Wales, as well as participating in the UK-wide Working Together with Parents Network.

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Cardiff CF14 5GG
Tel 029 2068 1160
www.learningdisabilitywales.org.uk

ENABLE Scotland

ENABLE Scotland is a dynamic charity run by its members, campaigning for a better life for children and adults with learning disabilities and for support for them and their families to live, work and take part in their communities. ENABLE runs a growing range of flexible person-centred services.

ENABLE Scotland
2nd Floor, 146 Argyle Street
Glasgow G2 8BL
Tel 0141 226 4541
Email enable@enable.org.uk
www.enable.org.uk

KeyRing

KeyRing enables members of its Living Support Networks to exercise choice in, and take responsibility for, their own homes. A Living Support Network usually includes ten ordinary properties scattered around a small neighbourhood, with nine flats or houses for people with learning disabilities. The tenth flat is for KeyRing’s community living worker, who provides part-time support on a flexible basis.

National Office
1st Floor, Impact Centre
12–18 Hoxton Street
London N1 6NG
Tel 020 7749 9411
Email enquiries@keyring.org
www.keyring.org/site/keyring_splash.php

Life Choice Ltd

To find out more about ‘virtual’ babies, or to buy one, contact:

Life Choice Ltd
6 Woodway Court
Thurby Road
Bromborough
Wirral CH62 3PW
Tel 0151 334 6151
www.lifechoice.co.uk

Flying Start (Wales)

Flying Start is a Welsh Assembly Government project providing a four-element approach to families in the most disadvantaged areas of Wales. The four elements commence antenatally with packages of care, and progress through intensive health visiting, with support packages delivered on a multidisciplinary basis. Basic skills and parenting programmes are also available to all parents in a Flying Start area. These programmes may be delivered in the home on a 1:1 basis or in a group setting. At the age of two years plus, each Flying Start child receives a free quality childcare place for three terms, before entering the Welsh Early Education Programme.

For more information, see www.childreninwales.org.uk/areasofwork/earlyyears/flyingstart/index.html
References


This booklet has been produced by the Working Together with Parents Network, which aims to support the development and sharing of positive practice in supporting parents with learning disabilities and their children, and the wider group of parents with learning difficulties.

This booklet shares the stories of six families headed by a parent or parents with learning disabilities or difficulties, whose stories (or at least parts of their stories) are seen as a success by them and the professionals involved in their lives.