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Happy families. Research-based good practice in supporting parents with learning disabilities

Angie Ash

Parents with learning disabilities have a disproportionately high risk of having their child removed from them. That is why the Baring Foundation commissioned the Norah Fry Research Centre at the University of Bristol to find out what could be done to support parents with learning disabilities to look after their own children successfully. The publication, *Finding the right support?*, followed in 2006, and paved the way for the development of the *Working Together with Parents Network*. The *Network*, involving partners in England, Wales and Scotland, and counting over 500 and professionals and many parents in its membership, set out to develop and share positive practice about supporting parents with learning disabilities.

This article, then, tells the stories of some parents who *have*, on the whole, had the right support so far to bring up their children. These and other *Stories of Positive Practice* have recently been published by the Norah Fry Research Centre.

Numbers and needs

It is estimated that over 55,000 adults with learning disabilities in England, Wales and Scotland have a child or childrenⁱ. This is a conservative figure: it does not include parents with undiagnosed difficulties with learning who may not come to the attention of services. The research for *Finding the Right Support?* indicated many parents with learning disabilities had children removed from them: often, it appeared, services had failed to provide the support they needed to be good enough parents.

In England, the 2001 White Paper, *Valuing People*, committed to “supporting parents with learning disabilities in order to help them, wherever possible, to ensure their children gain maximum life chance benefits” (DH 2001:127); a commitment strengthened eight years later in *Valuing People Now* (DH 2009). The review of services for people with learning disabilities in Scotland, *The Same as You?*, called on local authorities and NHS Trusts to identify, and meet, the needs of parents with learning disabilities and their children. In England, the first page of the government’s *Good practice guidance on working with parents with a learning disability* was unambiguous: “... people with learning disabilities have the right to be supported in their parenting role ... their children have a right to live in a safe and supportive environment”ⁱⁱ.

Nonetheless, research evidence indicates that families where one or both parents have a learning disability face many problems bringing up their own child. They often live in unsatisfactory housing in poor neighbourhoods where they are harassed, excluded or exploited. They may lack access to information about child care and parenting they need, in formats they can understand. They may be judged negatively by some professionals who doubt they will ever be good enough parents. Parents, in turn, may be hostile, untrusting and threatened by contact with services, and hence behave in ways that alienate professionals.

What helps?

So what works to support parent with learning disabilities bring up their own children? It’s the accounts of parents themselves that highlight the types and timing of support that can help families headed up by a parent or parents with learning disabilities.

To mark the ending of the *Working Together with Parents Network* project, six sets of parents shared their stories about the support they have had to raise their children. These have been published in the new Norah Fry Research Centre booklet, *Supporting parents with learning disabilities and difficulties. Stories of positive practice*. Here are two stories from the booklet:

Maggi and David's story

Maggi and David have been married for three years; their daughter Anne was 19 months old when her mum and dad recounted their story. Neither Maggi or David had a social worker at the time Maggi became pregnant, but they were involved with KeyRing, a housing support organisation.

Maggi describes her support worker at KeyRing as 'absolutely brilliant'. She supported the couple to ask for a social worker (which took some time to secure), put them in touch with Flying Start (a support service in parts of Wales for families with children under 4), helped them apply for the maternity grant, and to learn about parenting.

Maggi and David were also supported by workers from Flying Start during the pregnancy. An ante-natal package of care was planned; however Anne's premature arrival put paid to this. After the baby was born, Maggi and Anne's discharge was delayed, at Keyring's request, while Maggi and David's abilities and skills to care for her appropriately were assessed.

When Maggi, David and Anne 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 the day and evenings to meet the needs of Anne and her parents.

Maggi and David were shocked by what they found to be very negative attitudes of some professionals they had contact with, recalling they were told that because they 'have learning disabilities their daughter will have too'. They have, however, had good support from their midwife, the Flying Start health visitor, as well as their extended family and KeyRing. Maggi describes her hospital midwife as a 'super-star'. She supported them with Anne's feeding, which was difficult to begin with as Anne was so small. The midwife liaised with their 'wonderful Health Visitor from Flying Start' when they brought Anne home from hospital, at ten days old.

Extra support from KeyRing and the Flying Start Family Support Worker helped housing allocate housing speedily to Maggi and David a house quicker than usual and in the location they needed so they could support David's parents who have medical problems.

The Flying Start Team gave Maggi breast feeding and other parenting advice, using visual aids, pictures, posters, and the "Choices" book, which was used to enable the family to establish good routines and ensure home safety.

Maggi describes the team's support as 'ace' and says they were '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.

What helped – Key points for services

- A lead professional who is the main point of contact for the parents and other professionals involved.
- Positive on-going relationships with the parents from before the baby is born, with work aimed at preventing possible future problems as early as possible.
- Availability of practical advice and support, easily accessed by parents and which they feel they can ask for without their parenting capacities being questioned.
- Clear explanations to parents about why there are concerns about their parenting and the type of parenting expected of them.
- Belief in the parents' ability to care for their children with the right support.

Alison and Richard

Alison and Richard 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 Margi up safely, she was placed in foster care. Alison said she wasn't allowed to hold her baby when she was born. Alison and Richard were distraught, saying they were not offered support to make sense of, or understand, what had happened to them.

When Alison found out she was pregnant again, she was very frightened. She knew she needed support, but also felt she couldn't go to the social work department.

Instead Alison contacted a service provider that she'd heard of, ENABLE Scotland. 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 provided unpaid support for Alison throughout the rest of her pregnancy.

When their daughter Annie was born, Alison and Richard were told they could not take her home. An emergency meeting was called by social workers and, because the baby was born on the Friday, Alison and Richard had the weekend when they worried about whether they would keep their child.

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

Alison and Richard say that the support they had from the service was consistent and positive; ENABLE found Alison and Richard to be motivated and determined. Together, they were able to ensure that Annie had a good start.

The quality of their housing made life very tough. Their flat was in a poor state, damp and often needing repairs. The family did not feel safe there: "we've had the windows smashed in, and the door kicked in once". After they were rehoused to a flat that was bright, comfortable, well-appointed and safe, the couple felt a huge difference. Both parents were less stressed; Richard felt confident going out and taking his child to the park. The flat is closer to Alison's father's house, which means more contact with the extended family.

Alison and Richard now have limited support from ENABLE Scotland; a worker drops by each week, to be on hand should there be any problems. The health visitor calls every month, to offer advice and encouragement.

The staff team anticipate that at some point they may have to be more hands-on again, as Annie's needs change. But at the time they told their story, Alison and Richard were doing well, and Annie thriving.

What helped – key points for services

- Early intervention is important, giving the parent or parents the best chance to learn, and to be supported.
- Support should be tailored to meet individual need. It is mainly about supporting the mother or couple take part in, for example, ante-natal classes, health appointments and parenting classes.
- Information about appointments should always be reviewed again with the couple at home, so that fears or gaps can be addressed. This helps the parent learn and gain confidence, and be ready to look after their baby when she or he arrives.

Taken together, the stories give an insight into the complexities of the lives of parents with learning disabilities; they illustrate many barriers parents with learning disabilities may face. These include the negative expectations and stereotypes others have of them; and the psychological impacts (such as feelings of deep and enduring loss, anxiety, anger and fear) of having had other children removed from them. They may also face long standing and corrosive social problems of poor housing, isolation and poverty, as they try to raise their children.

The stories also demonstrate the positive impact of professionals who believe in the parents' capacities, and who provide constructive, flexible and coordinated assistance. The accounts show that with support tailored to their particular needs and circumstances, parents with learning disabilities can parent effectively, despite negative expectations others may have of them, and very real difficulties they face.

Looked at overall, the stories highlight the types of practical, service and professional support that can make a significant difference to the lives of families headed up by a parent or parents with learning disabilities, including:

- professionals' belief in parents' abilities, as well as parents' belief in themselves – these are closely connected;
- advocacy: an advocate that walks in the parent's shoes, and provides the assistance and guidance that's needed along the way;
- clear explanations to parents from professionals about the exact concerns they have about the child's welfare, and the specific expectations they have of the parents;
- pro-active intervention as early as possible in pregnancy; competency-based assessment of parental skills and the support they need to parent;
- positive and constructive support from an extended family, ie, support that is available, appropriate and consistent;
- multi-agency support co-ordinated by a named or lead worker, and provided by honest, consistent and trusted workers;
- helping parents to tackle barriers in their lives, such as poor housing and low self esteem.

The parents who told their stories showed they wanted the best for their children. They recognised the need to work with services to secure the best outcomes for the family. And they demonstrated that with the right help, at the right time, they could be good parents to their children.

ⁱ Personal communication, Professor Linda Ward, Chair, Supporting Parents with Learning Disabilities National Taskforce.

ⁱⁱ Department of Health and Department for Education and Skills (2007). *Good Practice Guidance on Working with Parents with a Learning Disability*. London: DH/DfES (also available in easy-read format).

<http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_075119>

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All the parents and children's names have been changed.

Dr Angie Ash was a part-time Research Fellow at the Norah Fry Research Centre. She is a registered social worker, and Principal of the research consultancy *Angela Ash Associates*.

Published copies of *Supporting parents with learning disabilities and difficulties. Stories of positive practice* are available, £5 inc. postage and packing, from Sammantha Cave, Norah Fry Research Centre, University of Bristol, 3 Priory Road, Bristol BS8 1TX, tel: 0117 331 0987.

The *Stories* are also available for download at
<<http://www.bristol.ac.uk/norahfry/right-support/>>

Further information

Information about the *Working Together with Parents Network* and supporting parents with a learning disability is available at www.right-support.org.uk.

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Flying Start is a Welsh Assembly Government scheme, which aims to make a decisive difference to the life chances of the under-4s in the localities in which it operates.

http://wales.gov.uk/topics/educationandskills/policy_strategy_and_planning/104009-wag/flyingstart/?lang=en. Accessed: 12 March 2010.

ENABLE Scotland is a charity run by its members. ENABLE campaigns for a better life for children and adults with learning disabilities and supports them and their families to live, work and take part in their communities. www.enable.org.uk

Department of Health and Department for Education and Skills (2007). *Good Practice Guidance on Working with Parents with a Learning Disability*.

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KeyRing helps members of its Living Support Networks exercise choice and take responsibility for their own homes. People living in around ten dwellings in a neighbourhood are provided with flexible part-time support from a KeyRing community living worker.

www.keyring.org/