If you had a four in ten chance of your baby being removed from you after birth, would you take the risk of having a child? Those are the odds facing a person with learning disabilities wanting to raise their own family. Yet with the right support at the right time and good communication between professionals – especially adult and children’s services social workers – many parents with learning disabilities can be supported to bring up their children successfully.

This article draws on some research evidence and good practice examples of providing parents with learning disabilities the sort of support they need to bring up their children. It is based on research done with the Working Together with Parents Network at the Norah Fry Research Centre, University of Bristol, and identifies some key messages for adult and children’s services social workers. Some practice examples of parents who have had the right support, published in the Working Together with Parents Network’s Stories of Positive Practice, are also included.

As a starting point for this debate, it is worth reflecting the fact that under the Human Rights Act 1998, parents with learning disabilities have the right – like any citizen – to marry, start a family, and not to suffer discrimination in pursuit of these rights. Children have a right, under the UN Convention on the Rights of the Child, to live with their parents, unless separation is necessary in the child’s best interests. When this happens, disabled parents have the right to support and information as other parents: public bodies, such as local authorities and the NHS, have a duty to promote equal opportunities for disabled people.

In England, the previous government’s learning disability strategy, Valuing People Now, stated that adults with learning disabilities should have the choice to have relationships, become parents and be supported to do so. The type of support to which they are entitled is set out in the Good Practice Guidance on Working with Parents with a Learning Disability (DH and DCSF 2007). This says that independent advocacy should always be provided where children are the subject of a child protection plan and care proceedings, and that advocacy and self-advocacy should be available to help parents engage with and access services.

In Scotland, the review, The same as you?, requires local authorities and the NHS to identify and meet the needs of parents with learning disabilities. The Scottish Good Practice Guidelines for Supporting Parents with Learning Disabilities describes what support should be provided to parents with learning disabilities in Scotland. In Wales, the Statement on Policy and Practice for Adults with a Learning Disability makes clear that authorities need ‘to review support and service arrangements as an individual’s needs may typically change over time, including, for example, when an individual with a learning disability becomes a parent.’

Figures from the Department of Health for 2003/04 indicated that one in 15 of almost 3,000 adults with learning disabilities interviewed in England, had a child. A broad estimate based on this sample suggests there could be 53,000 parents with learning disabilities in England, 1,700 in Scotland and around 680 in Wales. This excludes parents who have difficulties with their learning that haven’t been diagnosed, who may only come to the attention of social services when experiencing difficulties bringing up their child.

There is currently no reliable national data on numbers of parents with learning disabilities involved in child protection procedures, although there is evidence they have a higher chance of being involved in safeguarding proceedings, and of losing child custody. One study (Booth, Booth and McConnell, writing in the Journal of Applied Research in Intellectual Disabilities, 2005), for example, found that one in six of family court care proceedings in one English local authority concerned children with at least one parent with learning disabilities. In three out of four cases, children were removed from their family.

As with other dilemmas of practice, social
GOOD PRACTICE IN SUPPORTING PARENTS

- Provide information in plain language, broken down into small chunks.
- Have clear, co-ordinated referral and assessment procedures and processes, eligibility criteria and care pathways.
- Design support to meet the needs of parents and their children based on their strengths – what they can do, not just what they can’t.
- Put in support to meet needs over time – avoid short-termism, fire fighting.
- Give parents access to advocacy where available.

WHAT ADULTS’ SERVICES SOCIAL WORKERS CAN DO

- Talk to children’s services social workers.
- Make sure you know about all the support available to parents with learning disabilities – so you can tell people with learning disabilities who become parents.
- Ask your agency to provide information about universal and specialist services for parents with learning disabilities to others, eg: children’s services’ social workers, GP surgeries, employment services, day centres, colleges, and others.
- Give parents easy-to-understand information on their rights to support. This is important as many parents fear contact with a social worker will mean their child will be removed – not that they have rights to support to raise their child.

WHAT CHILDREN’S SERVICES SOCIAL WORKERS CAN DO

- Explain to parents in easy-to-understand words what their responsibilities as parents mean in practice, what they must do, and what support they can expect.
- Be aware that parents who are struggling may have learning difficulties, even if they have never come to the attention of services before. Refer them to other specialist services if appropriate.
- Write plans and other communications in plain language. If you need help writing in plain language, ask for training, or consult the CHANGE website.
- Give parents information about why any assessment is being done for the court, who’s involved, and what may happen.
- Check parents understand what’s going on in court proceedings.
- Make sure parents can take part in any meetings, and that they are respected and listened to.
- Involve the children in assessments of their needs, dependent on their age and understanding.

Parents with learning disabilities may struggle on without receiving any support, learning may never have been diagnosed. They may have learning difficulties, even if they have never come to the attention of services before. Refer them to other specialist services if appropriate.

Understanding the barriers parents with learning disabilities face in bringing up their own children is a first step. These range from negative stereotyping (for instance, a belief that parents with learning disabilities are doomed to fail), to difficulties accessing healthcare and other services generally, to chronic long-term poverty. A parent with a learning disability asking for help may be seen as unfit to care for their child: another parent might be viewed as more able. Parents may not be known to services; their difficulties with learning may never have been diagnosed. They may struggle on without receiving any support, before being referred to services at crisis point, by which time the support needed may come too late.

Chapters of practice, approach and thinking can do much to tackle these barriers. Early assessment of needs, accessible information, and honest, clear communication are the building blocks of effective social work practice with parents with a learning disability.

If concerns arise and safeguarding procedures are used, parents will need legal, practical, and possibly other help, to take part in any enquiry process. Throughout, the child has the right to be protected from neglect or harm: their interests are paramount. If the enquiry outcome is that the child is not at risk, then assessment is needed to find out what help the family may need to support them.

If the case goes to court, parents may find it hard to understand why court proceedings have been initiated and feel disadvantaged by the court process. Assessments of parenting skills presented to the court need to be competence-based, focused on what the parent can do, and the support they need to tackle deficits in parenting.

The fragmentation of social work education, training and practice may mean that adult services social workers lack confidence dealing with the needs of parents; while social workers in children’s services may lack specialist skills needed to deal with adults with learning disabilities. Children’s services may struggle to provide the flexible practical support parents say they need. Research shows the focus of much children’s social work is on mothers, with much less attention to supporting the role of fathers and the extended family in maintaining the family unit. Yet the recently published Stories of Positive Practice illustrates the vital part grandparents can play in supporting the family, and the need for careful, committed input by professionals and services to support parents.

In one example from this research, Jack received support from his community nurse and from his extended family to care for his two year-old daughter, Sarah. The local authority had considered initiating adoption proceedings after Sarah was born. Over time, however, Jack built up his unsupervised care of Sarah to 47 hours a week. What helped Jack was accessible information about parenting provided by CHANGE, the equal rights organisation led by disabled people, and the support of his community nurses, who read and explained legal and official papers to him. Jack had help to understand that the social worker’s job was to make sure Sarah was safe; for their part, social workers were straight with him about what they expected. The court has recommended that Sarah, now two, stays with her dad.

In a second example from the book, Sharon and Mike are parents to Summer, who was subject to a child protection plan after she was born. Sharon and Mike, and Mike’s mother, share parental responsibility for the baby. As well as help from Mike’s mother, Sharon had an advocate who helped her to develop her parenting skills. Summer now stays with Sharon and Mike, with the constant support of her grandmother.

Stories of Positive Practice show how giving the right support to people with learning disabilities to bring up their children means, as one professional said, the “work is through the parents, but reflects the needs of the children”.

Dr Angie Ash was a part-time research fellow at the Norah Fry Research Centre, University of Bristol. She is a registered social worker, and principal of the research consultancy Angela Ash Associates.