Parenting and people with learning disabilities

What kind of support is available to parents who have learning disabilities?
Diana Neaves reflects on the issues that arose during a community placement

On a recent community placement, I had the opportunity to work with Elizabeth (not her real name). Her story and that of her family need to be brought to a wider audience.

Elizabeth is 30 and has been married for about 11 years. She has a mild learning disability and epilepsy. Until the age of three, Elizabeth had been a healthy child but she then developed mumps, which led to meningo-encephalitis. When she was five, epilepsy was diagnosed and, subsequently, learning disabilities.

Elizabeth and her husband have two children who where taken into care in 2001 after being placed on the child protection register. They are currently being adopted. Elizabeth’s husband was the main carer for her and the children, especially their daughter, who was born with a major cerebral malfunction.

Elizabeth and her husband did not receive any support when the children were born, or after, and the learning disability community team was only informed about Elizabeth after the children were removed.

Elizabeth and her husband both admit that their relationship at the time was volatile and that he drank too much alcohol. Both felt this caused the main problems in their relationship. Having suffered three family bereave-ments in the space of six months, finding out that their daughter had a disability, coupled with a worsening of Elizabeth’s epilepsy, undoubtedly put even more pressure on them. They both had counselling with Relate and saw a psychologist for ‘wishes and feelings’ group-work.

Elizabeth admits she did not bond with her children after they were born. She feels this was because she was reluctant to hold them as babies for fear of dropping them if she had a seizure. Elizabeth’s epilepsy does affect her lifestyle. She feels the need to have a wheelchair when she is shopping as she is scared of having a seizure while away from home. She limits her trips out and will only go if she feels well enough on the day.

Elizabeth is clinically obese and feels her weight exacerbates her injuries if she falls during a seizure. Because her epilepsy is refractory to treatment, vagus nerve stimulation has been suggested by her consultant. Elizabeth states that her main focus and aspiration in life is to have a ‘baby girl with no disability’.

Elizabeth’s seizures

Elizabeth has complex partial seizures where the area of the brain affected by the seizure is larger than the area in a simple partial seizure. Three things are affected by such seizures: the person’s consciousness, their response and their memory. In addition to complex partial seizures, Elizabeth has atomic seizures, which cause the muscles in the body suddenly to go ‘floppy’ and the person to fall forward. These seizures may be referred to as ‘drop attacks’ as they cause a sudden fall to the ground. The person usually recovers quickly, but may be injured during the fall (National Society for Epilepsy 2008).

Most people with epilepsy will have restrictions on their lifestyle opportunities. Some, like Elizabeth, do not want to be left on their own for any length of time or may be reluctant to go out without a companion. In Elizabeth’s case, even general household chores can be limited. She will not do the cooking, washing-up, vacuuming or dusting for fear of having a seizure and injuring herself.

Planning a family may require far more consideration for women with a condition like Elizabeth’s. According to a health professional from the local NHS trust, for women with epilepsy who become pregnant, the pregnancy will be consultant-led rather than midwifery-led as a change in medication is required. Anti-convulsive medication can affect an unborn child, causing hair lip and cleft palate. Before and during the pregnancy, extra folic acid is recommended and at 36 weeks vitamin K injections are given until birth. This is because anti-epilepsy medication absorbs vitamin K and

Keywords
- Family
- Learning disabilities: rights
- Parenthood
These keywords are based on the subject headings from the British Nursing Index. This article has been subject to a double-blind review.
without these injections the essential amount required by the baby would be reduced. Lack of oxygen during a seizure in pregnancy can also affect an unborn child, as can a fall. For these reasons a woman with epilepsy requires close monitoring through pregnancy. Women without a learning disability may realise they need this advice before falling pregnant. But those with learning disabilities will not necessarily seek advice before becoming pregnant.

Asked about the advice given once the baby has been born, a health visitor told me she would inform all new parents of the changes a baby will cause to their lifestyle. Having epilepsy increases the effects of those changes, and taking prescribed seizure medication, getting enough sleep and exercise, and eating healthily can be beneficial. The support recommended to those with epilepsy is to maintain contact with their neurologist, general practitioner and health visitor. But with parents with epilepsy and a learning disability, things are different.

**Caring for children**

*Adults with Learning Difficulties in England* (Department of Health (DH) 2005) found that just over half (52 per cent) of parents with learning disabilities looked after their children at home. In 67 per cent of cases, support came from partners. 16 to 21 per cent had help from parents or relatives, and only 7 per cent had help from social services.

Physically, Elizabeth has been able to conceive and carry a baby full term but her learning disability, epilepsy and attention-seeking behaviour had a dramatic impact on her parenting skills. But what is a good parent? Booth and Booth (1994) state: ‘There is no agreement on what constitutes minimal acceptable standards of good-enough child care. While children are known to need care, supervision, nurture and stimulation, the minimal requirements defining parental competence in these skills are unspecified.’

According to the Children Act, the five desired outcomes for children are to be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic wellbeing. *The Framework for The Assessment of Children in Need and Their Families* (DH et al 2000) is an assessment tool used to help safeguard and promote children’s welfare. It covers the child’s developmental needs – health, education, emotional and behavioural development, identity, family and social relationships, social presentation and self-care skills – as well as environmental factors and parenting capacity.

From this framework, it is clear that Elizabeth and her husband meet less than half the criteria. To promote the welfare of her children, Elizabeth considered basic care, housing, income and education to be important. But she was unable to bond with her children due largely to her epilepsy, and she required constant attention herself and considered this above her children’s needs. This is echoed in Booth and Booth’s (1994) findings, which suggest that the problems parents with a learning disability encounter when bringing up children are lack of sensi-
tivity to the child’s development, little contribution to a stimulating environment that encourages learning and play, a disregard for physical safety, maintaining discipline, and conveying feelings of love and affection. Elizabeth and her husband loved their children, cared for them, dressed them and fed them. However, it could be argued that as the children where taken into care because of physical abuse, as parents they did not keep them safe.

**Parental pressures**

According to Booth (2000), not only do parents with learning disabilities have lives that are inhibited by poverty, debt, tenancy difficulties, poor education, troubled relationships and victimisation, they also know that as parents they are under the watchful eye of child protection organisations, which can only add extra pressure to family life. However, those who experience these cultural issues but who do not have a learning disability do not have the added pressure of child protection organisations checking on their progress as a parent. Research by Cleaver and Nicholson (2007) states: ‘Social workers felt that the learning disability was an obstacle to parents’ full involvement, both in terms of their ability to understand complex issues and their ready acquiescence.’

Is this because people with a learning disability do not have the ability to fight for their children? Parents suffering from mental health problems do not appear to be examined as closely. Are those with drug and alcohol problems or those in violent relationships scrutinised in the same way as parents with a learning disability?

It has been suggested by Barnardo’s that children who have disabled parents can experience social exclusion, and have difficulty accessing schools, health care and employment (Barnardo’s 2005). This could be why such a high percentage of children who have parents with learning disabilities are taken into care. But with eight out of ten children in care gaining no qualifications and nearly half those in care not supported at school events, bullied at school and not having a representative at parents’ evenings (BBC News 2006), one could argue that being in care is not beneficial to the child in the long term. By contrast, Elizabeth and her husband attended all school events and encouraged their children at such events.

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It could be suggested that people who have a learning disability are unable to parent because, like Elizabeth, they did not have parenting skills instilled in them as children. Booth and Booth (1994) argue that many parents’ problems ‘stem more from their own upbringing than from their learning difficulties’. However, there are plenty of people without learning disabilities who were not parented themselves and who face the same difficulties, but without the children’s team from social services watching them.

A Life Like Any Other? (Joint Committee on Human Rights 2008) states that decisions are constantly being made regarding the future of these children without sufficient information or support to encourage parents to show their ability. The report also states that adult and children’s social services teams do not always work well together to support these families.

**Support for families**

This became apparent when I was on my placement. Not all parents with a learning disability are known to adult services and only seem to be referred to them by children’s teams once there is a crisis; the crisis being that the children have already been taken into care. The support should start with professionals working together, as highlighted by McMillan (2006), who wrote that: ‘Professionals working in services for adults with learning disabilities [need] to be trained in child protection issues, while those in children services need to know more about dealing with adults with learning disabilities and their support needs.’

Research has shown that there are a number of parents who feel they did not have the support they needed until it was too late (Joint Committee on Human Rights 2008). And good practice guidance on working with parents with a learning disability states: ‘People with a learning disability have the right to be supported in their parenting role, just as their children have the right to live in a safe and supportive environment.’ It adds: ‘While children have the right to be safe from harm, children’s needs are usually best met by support from their parents, to look after them’ (Joint Committee on Human Rights 2008).

Currently, the local community learning disability team (CLDT) highlights those parents having difficulties and help, in the form of Homestart, Sure Start and advocacy, is then offered. Homestart is a support scheme where volunteers provide advice and support to those families with children under five. Sure Start aims to give every child the best start in life. It assists in education, child care, health and family support, but it is unclear how it would support a family with parents who have a learning disability, if indeed it does.

**How advocacy can help**

The need for advocacy for parents has been highlighted by Booth and Booth (1998) in a research project funded by Joseph Rowntree Foundation. It appears that parents are sometimes snubbed and offloaded onto other services by people who should be able to offer them advice and support. The study showed that advocacy can help parents who find themselves in difficult situations, and explain child protection court proceedings.

Booth (2000) states: ‘Being there is not about arguing for parents but about lending them authority. It’s about keeping agencies on their toes and reducing the risk of a minor difficulty turning into a crisis.’ Some of these agencies are the organisations that should be there to offer advice and support, and should not be dependent on an advocate to point out their shortcomings.

There are a number of organisations such as Change and the Norah Fry Research Centre
that express a need for parenting projects to support people with learning disabilities. These should push for more advice, accessible information and educating, not just in parenting but in building relationships (Change 2005). The Norah Fry Research Centre aims to establish a parent network that encourages parents and professionals to work together and discuss ideas, and create leaflets that explain child protection and court proceedings.

**Buying power**

Direct payments, the main financial support offered, can help the parents to buy the service they feel will assist them most. Independent living funds are another way of offering financial support to those with a learning disability. These entitle the person to purchase care or pay for assistance to help them live their chosen lifestyles. The latest initiative is individualised budgets, which have recently undergone a pilot scheme. They give the service user more choice and control over how the money is spent. Any of the above would help parents find the right support and put together their own package, and can be seen as person-centred planning approaches.

Furthermore, there has to be a change in the way parents with a learning disability are assessed. There should be an assessment that looks at what the parent can and cannot do for the child, and then a plan of care and support should be put in place either by the team or by other support networks. The CLDT in North Tyneside suggests that the service should provide parent support groups, personal development programmes, advocacy support, parenting skills assessments, parent care plans, outreach support, and adult and child protection and training (Arnold 2003).

The attitudes of some professionals need to be addressed, too. The negative attitude of some children’s nurses can create stigma for parents. And communication can cause problems for professionals and parents, leading to negativity on both sides (Kenny and Tagg 2006).

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Perrin and Nirji, cited by Booth and Booth (1994), ask how far the principle that people should be enabled to enjoy ‘the same rights, responsibilities and opportunities as are available to others’ can be applied to parenthood? The fact that documents and legislation such as A Life Like Any Other (Joint Commission on Human Rights 2008), the Disability Discrimination Act and Valuing People (DH 2001) are in place, indicate that parents with a learning disability should be given the same opportunities as everyone else. Yet it could be argued that to receive payments to help develop a package for support does not constitute normalisation (Wolfensberger 1972). After all, most people without a learning disability do not receive payments to provide extra support to look after their children. But extra finance could give families such as Elizabeth’s the option of employing someone to take care of the children or house and, in Elizabeth’s case, reduce concerns regarding the safety of her children if she has a seizure. However, the philosophy of normalisation is often abused and used to deny access to services and opportunities that most people take for granted (Bank-Mikkelsen, cited by Gates 2002).

**Signposting**

Having a disability affects a person’s lifestyle opportunities. The role of the learning disability nurse should be to act in the way of an advocate and explain, using good communication skills, the policies and guidelines that enable clients to have the same rights as every citizen. This can then help nurses to promote a person-centred approach.

There are many families that have difficulties just like Elizabeth’s and it is to be hoped that guidelines on supporting parents with a learning disability can be used to assess each case on its merits and to help them maintain their ideal lifestyle. The emphasis in the role of the learning disability nurse should be on providing the necessary support and education to people like Elizabeth and her husband, and on signposting them through the maze of services. In doing so, the learning disability nurse not only empowers clients but also presents opportunities for them to achieve their chosen lifestyles.

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**References**


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