Various tools can help to identify people with learning disabilities but more research is needed to find out how useful they are in identifying parents with learning disabilities.

Identifying parents with learning disabilities

In this article...

- Why timely support of parents with learning disabilities is vital
- The role of a learning-disability screening tool
- Tools that may help identify parents with learning disabilities

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Abstract: McKenzie K (2014) Identifying parents with learning disabilities. Nursing Times; 110: 22, 21-23. People with learning disabilities are likely to need additional support when accessing healthcare and, for those who are parents, receiving support at an early stage may help them to keep their child.

Health professionals who have contact with expectant mothers early on in their pregnancies are well placed to identify support needs. Providing timely support may be a challenge, particularly if the mother has not been known to learning disability services. This article discusses whether screening tools may offer nurses a quick, easy way of identifying people with learning disabilities.

Needs of people with learning disabilities

Levels of learning disability range from profound, in which the person has no verbal communication and relies entirely on others to meet their basic needs, to mild, in which the person functions well in daily life and needs only occasional support with specific tasks or in specific areas (BPS, 2000). It is the disabilities and related support needs of this second group that are likely to go unrecognised by nurses and midwives.

People with learning disabilities are at an increased risk of having additional, complex and, on occasions, unmet or inappropriately treated health problems (Mencap, 2007). For example, they may be less able to communicate that they are in pain, locate the source of pain or articulate why they are feeling unwell – although recent research suggests that some use pain vocabulary and gestures that can be recognised by other people as signifying pain and discomfort (McKenzie et al, 2013).

Several initiatives have been put in place over the years to help address the healthcare needs of this group, including liaison between acute services and specialist community services, and awareness raising (Buchanan, 2011). There are, however, some areas of healthcare provision where it is still challenging to identify patients who have a learning disability, often because they are accessing the service for the first time or are not known to learning disability services. One such area is maternity care.

Maternity care

The establishment of values-based community care policies in the UK, and the recognition that people with learning
disabilities have the right to sexual relationships and to be parents (United Nations, 2008) has coincided with a rise in the number of parents who have learning disabilities. Exact numbers are difficult to establish, with estimates varying between 23,000 and 250,000 in the UK (Department of Health and Department for Education and Skills, 2007).

Appropriate support is crucial for women with learning disabilities and is particularly important because they are likely to face additional challenges throughout pregnancy and into the postnatal period (Box 1).

The last point may extend to the health of the child, with some evidence suggesting mothers with learning disabilities may face an increased risk of pregnancy and birth complications, such as pre-term births (McConnell et al, 2008). Also, parents with learning disabilities have been found to have smaller support networks (Wilson et al, 2013).

The support that parents with learning disabilities receive from professionals and their social networks is considered to be central to their parenting success. Cleaver and Nicolson (2005) argued that the nature and length of professional support could be crucial in helping them to become “good enough” parents. These factors have also been highlighted by mothers with learning disabilities as influencing whether they will be receptive to help in the first place and whether it validates or undermines their identity as mothers (Wilson et al, 2013).

Both health visitors and midwives are well placed to identify, provide and facilitate support for new parents.

**Identifying individuals with a learning disability**

To provide timely and appropriate support, it is important to identify that an expectant mother or father has learning disabilities as early as possible.

There is evidence that parenting interventions can be successful at improving targeted skills (Wilson et al, 2014), but that interventions and support for this group may often occur in the context of a crisis (Ward and Tarleton, 2007) rather than being provided in a planned, proactive way; this then minimises the opportunities for parents to show they can be “good enough” (Porter et al, 2012). In this context, it is perhaps unsurprising that parents with learning disabilities are more likely than others to have their children removed from their care (Booth and Booth, 2005).

If an expectant parent is deemed incapable of providing adequate parenting and the child is to be removed from the parent’s care, early preparation, both practical and psychological, is crucial. The importance of early attachment relationships for babies has also influenced recommendations that, when a decision has been made to remove a child from his or her birth family, it should occur within six months of birth (Howe, 2005). Early preparation is therefore also crucial to ensure that a permanent carer for the new baby is identified as soon as possible.

While the need for mainstream professionals to be better prepared to identify and provide support has long been recognised, the early identification of parents with learning disabilities remains a challenge. This may particularly be the case in those who have had no contact with learning disability services. For a diagnosis of learning disabilities to be made, the person must undergo assessment by an appropriately qualified applied psychologist. This involves an assessment of intellectual functioning, adaptive functioning and a developmental history to ascertain whether the person has:

- Significant impairment in intellectual functioning (commonly an IQ of <70);
- Significant impairment in adaptive functioning;
- Childhood onset of these impairments (BPS, 2000).

**The role of screening tools**

Diagnostic assessments are time consuming to administer and accessing an appropriately qualified psychologist to carry out the assessment may take time, leading to delays in diagnosis. This has led to an interest in using screening tools in a range of settings to help identify patients who may have learning disabilities.

Ward and Tarleton (2007) highlighted the need to identify parents with learning disabilities as the first in a list of strategies to support them. Similarly, it has been recommended that midwives use a screening tool during antenatal care to help identify women who may have learning disabilities (NHS Greater Glasgow and Clyde, 2009). There have been some attempts to put this into practice.

Porter et al (2012) provided midwives with a list of indicators of potential intellectual disability, for example having attended a special school, to help guide their decisions about supplying an accessible pregnancy information pack. Likewise, in Hertfordshire, a protocol for the assessment of parents with learning disabilities provides some screening items for use by staff (Hertfordshire County Council, undated).

McDonnell and Hames (2005) reported on a pilot study of a screening tool comprised of a short reading passage and associated questions, which was developed specifically to identify parents with learning disabilities. Unfortunately, there has been limited research into the validity and reliability of the checklists or screening tools. While McDonnell and Hames (2005) reported promising results from their tool, the small sample size limited the extent to which conclusions about its psychometric strength could be made.

As with the assessments used to give a diagnosis, screening tools should be proven to be reliable and valid, even though they only provide initial indicators of whether a person might have learning disabilities.

The Learning Disability Screening Questionnaire has been found to have good psychometric properties and to distinguish between those with and without learning disability accurately in clinical settings (McKenzie and Paxton, 2006). The LDSQ has seven “Yes/No” questions, covering literacy, self-care and previous support needs. It was designed to be used by a range of people without any specific particular professional qualification and takes approximately five minutes to complete, so it is a quick and easy way in which to identify people who may have a learning disability.

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**BOX 1. CHALLENGES FACED BY MOTHERS WITH LEARNING DISABILITIES**

Mothers with learning disabilities often face additional pre- and postnatal challenges:

- More likely to experience poor socioeconomic conditions (Cleaver and Nicholson, 2005)
- May be subject to disapproving and critical attitudes from others (Mayes et al, 2006)
- At increased risk of poor psychological wellbeing and physical health (Aunos et al, 2008; O’Keeffe and O’Hara, 2008)

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**QUICK FACT**

23,000-250,000 Estimated number of parents who have learning disabilities in the UK
disability. However, to date, no research has been done on how well it identifies par-
ents with learning disabilities. Future work may help evaluate whether it is useful for this purpose.

Conclusion
Nurses are likely to meet people with learning disabilities in a range of settings. The growing number of parents with learning disabilities means staff working in maternity services will be increasingly called upon to support this group. Early identification of whether a woman has learning disabilities can be crucial to ensuring that she and her partner receive appropriate support.

Screening tools have been highlighted as one way of gaining an early indicator of whether an individual has learning disabili-
ties but existing checklists and tools that have been used with parents with learning disabilities have limited information about their psychometric properties. The LDSQ has good psychometric properties but has not yet been evaluated with parents. Future research is needed to ascertain whether or not it offers a helpful means of early identification of parent with learning disabilities. NT

References


Hertfordshire County Council (undated) Protocol for the Assessment of Parents with Learning Disabilities. tinyurl.com/HertsProtocol


