Neil James describes how community nurses are ideally placed to assess parents and teach them parenting skills.

ALTHOUGH THE number of parents with a learning disability is not known, it is acknowledged that this population is increasing (Culley and Genders 1999, Tarleton et al 2006). Concerns continue to be highlighted over the high rate of removal of children from the homes of such parents (Elvish et al 2006), with estimates in the range of 50 to 60 per cent (Tarleton et al 2006). This rate of removal is compounded by the lack of investment in services to support these families (Booth 2000). Tarleton et al (2006) suggest that services for such parents need to improve and the societal prejudices need to be addressed. Although it is of paramount importance that children are protected from potential abuse and neglect, the rights of parents should not be disregarded.

The aim of legislation, social policy and service provision is to enable individuals who have a learning disability with greater opportunity to live as normal a life as possible (Department of Health (DH) 2001). Being socially valued means undertaking everyday activities alongside the rest of the community; living, working, shopping and spending leisure time in the same places as the majority population, developing relationships, getting married and having children.

However, when it comes to having children, it appears that stereotypical views prevail and, as a consequence, parents with learning disabilities can experience negative attitudes from the general public (McGaw and Newman 2005). The concerns that have been highlighted about parenting by people with a learning disability include a lack of ability to identify and meet the child’s basic physical and emotional needs, an increased risk of vulnerability to neglect and abuse, and a lack of skills in decision making, risk management and stress management (Booth et al 2005).

Learning disability nurses have a pivotal role in helping to identify and support the development of skills in parents who have a learning disability (Jenkins et al 2006). During pre-registration nurse training, learning disability nursing students develop skills in areas that ensure practice is undertaken in a person-centred and inclusive way (Table 1, page 14). Registered learning disability nurses can provide support to parents to help them meet some of their parenting roles.

Parenting abilities
Historically, many myths and misconceptions about people with a learning disability have led to degrading and debilitating legislative labels. These in turn contributed to their stigmatisation and lack of opportunities to live ‘normally’. The paternalistic approach to people with a learning disability is still apparent today with their parenting abilities being continually questioned (Wates 2003). Llewellyn and McConnell (2005) described the popular view held by society of people with a learning disability as

Summary
The number of parents with a learning disability is increasing, so it is important that the roles of professionals in supporting them are identified. The community learning disability nurse can assess, plan, implement and evaluate the support provided to parents with a learning disability to develop their skills. This article discusses issues relating to parenting and learning disability, including abuse and neglect, and ways of teaching parenting skills to people with a learning disability.

Keywords
Community learning disability nurses, parenting skills training, parental adequacy.
Mothers needed support in areas such as mother-child interaction, and understanding the care requirements of their child.
Table 1  Pre-registration nurse education

<table>
<thead>
<tr>
<th>Subjects</th>
<th>Overview of components</th>
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<tr>
<td>Contextual factors that influence service</td>
<td>Social, ethical, moral, cultural, spiritual, legal, political and economic.</td>
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<td>provision.</td>
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<td>Promotion of health and wellbeing.</td>
<td>A lifespan approach to the physical, social and psychological health of people with</td>
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<td>learning disabilities.</td>
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<td>Planning and delivering person-centred care.</td>
<td>Assessment of the spiritual and bio-psycho-social needs of individuals across the</td>
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<td></td>
<td>learning disability spectrum, person-centred care planning, working in partnership with</td>
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<td></td>
<td>clients, families/carers and other professionals, using an evidence-based approach to</td>
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<td>practice, evaluating the effectiveness of therapeutic interventions.</td>
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<td>Management and leadership skills.</td>
<td>Development of professional awareness, development of strategies to support personal</td>
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<td>and professional development, and strategies to develop decision making and problem</td>
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<td></td>
<td>solving, management of resources, personnel and care delivery. Working interprofessionally</td>
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<td></td>
<td>and assuring quality, managing change in line with service philosophies, local and</td>
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<td>government policies.</td>
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(Adapted from University of Glamorgan (2008) Learning Disability Branch Handbook)

being ‘child like’ or ‘childish’. People with a learning disability still appear to be deemed unable to take on responsible adult roles that include becoming and being a parent.

The assumed correlation between learning disability and parental incompetence or inadequacy appears to provide good enough reason to suspect that a child is at risk (Booth and Booth 1994, Feldman et al 2002). This is exacerbated by negative press coverage and reports that highlight inadequacies in parenting techniques and concern for the child’s welfare (Llewellyn 1995, Kroese et al 2002). As a result, parents with a learning disability may have to prove that they are capable of being a ‘perfect parent’ (Tarleton et al 2006). However, given the ever-changing views and standards in our society, the definition of what constitutes the ‘perfect parent’ or ‘good enough parenting’ is subject to debate (Reinders and Lievegoed 2008).

Much of the research that has been carried out has centred on parental inadequacies of people with a learning disability and risks to the child, rather than on their capabilities (Campion 1995, Wade et al 2008). Many studies are flawed due to:

- Non-specification of the degree of learning disability.

- Small sample sizes.

- The lack of agreed standards and definition of parental competence.

- What constitutes child abuse and neglect.

Booth and Booth (1994) indicated that most participants in early studies came from an institutional background, which constituted a sampling bias that culminated in the presentation of some of the most pessimistic outcomes. This has resulted in a lack of consideration for those people with learning disabilities who are not known to the service and who are coping and managing with parenthood in the community (Woodhouse 1997).

Issues of abuse and neglect

Booth (2003) emphasised that abuse by parents with a learning disability is rare. Most concerns that are raised are in relation to neglect. This neglect and/or lack of parenting skills may be a result of their own upbringing, what they have learned through observation, and their own history of treatment and abuse (McGaha 2002).

Parents with a learning disability are commonly affected by poverty, deprivation and social disadvantage, all of which can influence parenting techniques (Booth 2000, McGaha 2002). These conditions can also lead to unemployment and poor social support networks. The benefits of having positive social support systems have been highlighted for mothers with a learning disability (Booth and Booth 1997, Llewellyn et al 1999). The social support received, for example, from family and friends, can influence how the child develops and enhance parental competence (Booth and Booth 2000).

Feldman et al (2002) reported an inverse correlation between social support and stress of mothers with a learning disability, indicating that an increase in social support can reduce the effects of stress.

By collaborating with other services using a multi-agency approach any concerns or issues that are identified about the welfare and vulnerability of the child and/or the parents can be minimised and managed by effective communication, co-ordination and delivery of support tailored to individual needs. This should include the assessment and implementation of appropriate protective measures that provide support, and safeguards for the parents and the child.

As a member of this multi-agency team, the community learning disability nurse can share information and have a shared responsibility for the assessment and delivery of appropriate levels of support. Tarleton et al (2006) provide some useful
guidelines for the planning and delivery of effective multi-agency support for parents with a learning disability. These include:
- Regular face-to-face meetings.
- Ongoing contact between professionals.
- Training that is jointly attended.
- Roles and boundaries made clear.
- The development of trusting relationships between professionals where communication is open and honest.

Supporting parents
Keltner (1992) found that mothers with a learning disability needed professional support in areas such as mother-child interaction, feeding skills and understanding the care requirements of their child. Results from other studies show that offering training to parents with a learning disability can improve their competence in providing a safe nurturing environment (Tymchuk 1991a, Tymchuk and Andron 1992, Booth and Booth 1994). Parents may also need support with practical issues, such as accessing health services, community facilities, financial management and emotional support.

Topics that have been covered in other parent-training programmes include handling a small infant, child growth and development, nutrition and feeding, parent-child interaction, recreation and discipline, health and safety issues and the use of healthcare and community resources (Greene et al 1995, Feldman and Case 1999, Llewellyn et al 2003). Hanna and Ebdell (1992) described a successful intensive mothercraft programme for women with a learning disability that they took before leaving hospital with their newborn babies. It aimed to help them and their partners to acquire skills such as feeding, settling, dressing and playing. Llewellyn et al (2002) also reported the benefits of using a home-based parent education programme to teach child health and safety issues.

Service delivery
Tarleton et al (2006) found that parents expressed dissatisfaction about service delivery. Goodinge (2000) and O’Hara and Martin (2003) suggest that there is no consistency in services nationally, which has led to a disparity in the level and type of services and support that parents with learning disability are offered. Commissioners and managers can seek guidance from Good Practice Guidance on Working with Parents with a Learning Disability (Department for Education Skills (DfES) and DH 2007) and from the work of Tarleton et al (2006). The Disability Discrimination Acts (1995 and 2005) and the National Service Framework for Children, Young

Much of the research that has been carried out has centred on parental inadequacies of people with a learning disability

People and Maternity Services (DfES and DH 2004) also need to be considered. The benchmarks set out in Good Practice in Learning Disability Nursing (DH 2007) should also be used by nurses, educators and their employers to ensure that the provision of any identified support to parents with a learning disability is effective.

Community learning disability nurses require education about how to assess parental competence and about the law relating to child protection. They should be aware of the resources and agencies that provide support, and how to teach everyday practical skills to parents with learning disabilities (Culley and Genders 1999).

Role in the community
The education and role of learning disability nurses has evolved in line with service delivery and social policy for people with a learning disability. They now work in community, residential and continuing care services, providing advice, support and interventions. They are able to develop effective and long-term relationships, and have an understanding of the abilities of individuals. Community learning disability nurses are in a strong position to support parents with a learning disability. Genders (1998) found that community nurses working with parents required a multiplicity of skills and were involved in many activities that required them to work collaboratively with other members of the multidisciplinary team. However, their part in supporting parents needs to be defined clearly (Genders 2000). It is therefore proposed that one of these roles is in the development of parenting skills classes.

Practice
It is important not to assume that all people with a learning disability lack parenting skills. Assessment should cover a range of physical and psychological factors that can affect a parent’s wellbeing and ability to function in this role.

Using appropriate assessment instruments and resources, such as the Parent Assessment Manual (McGaw et al 1998), issues can be identified that need to be addressed as part of a comprehensive care plan. The Norfolk Area Child Protection Committee has produced a manual for practitioners on the assessment of parents with a learning disability (Morgan and Goff 2004). This assessment
The needs of people with a learning disability should continue to be incorporated in the common foundation programme

should be undertaken as part of a multidisciplinary and multiprofessional approach to form part of a collaborative work ethic. Tymchuk (1991b) highlighted the benefits of using assessment tools to identify issues such as emergency responses, and preventing and reducing dangers and accidents.

The information acquired from assessments can be used to develop training packages to increase parents’ ability to deal with particular situations. Using teaching strategies in which the parent contributes to the planning process, such as ‘shaping’, ‘forward chaining’, ‘backward chaining’, ‘task analysis’ and ‘incidental teaching’, can promote skills development and independence (James and Wheeler 2006). Skills training in the home has also been found to be effective (Llewellyn et al 2002) and this could further support the generalisation of skills that may have been taught in group sessions.

The nurse can develop aids to help parents remember what has been taught, including illustrations, notices, checklists, diaries or videotapes. The use of accessible books, such as those produced by the equal rights organisation CHANGE (Affleck and Baker 2004), can help the nurse in skills teaching. The nurse will then monitor the effectiveness of any training given to parents.

Community nurses can use a variety of learning strategies to develop structured parenting classes. These can be run in a variety of settings, including clinics, community centres or the parents’ homes. Tuition can be on a one-to-one basis or as a group. Groups can enable parents to pass on information to one another, and also help them to build a social network, all of which can contribute to their psychological wellbeing (Murphy and Feldman 2002).

The content and guidelines for these classes can be adapted from the topics highlighted in other parent-training programmes (see, for example, Hanna and Ebdell 1992, Llewellyn et al 2002, Tymchuk and Andron 1992). Interventions may also need to be planned and implemented that encourage and provide support for parents in accessing resources available to other parents, such as antenatal classes, family planning clinics, leisure facilities, self-help groups and community programmes (Booth and Booth 1994).

Culley and Genders (1999) identified health promotion advice, accessing resources to support parents, referral to other health professionals, parenting skills, assessment of parenting skills and advice on legal issues as being roles undertaken by community learning disability nurses. In addition, because of their knowledge of behavioural issues, they can provide parents with the support to understand and manage their child’s behaviour in partnership with health visitors and other appropriate professionals. The nurse will also be able to provide counselling, advice and referral to other professionals.

Nurses will have a role to play in advocacy and in providing support to those parents who have had their children removed from their care. This support may be in dealing with separation and loss, and developing social and coping skills. Finally, they should be contributors and advocates for the development of appropriate policies and guidelines that support professionals in their roles.

Research and education

Research in the area of parent training interventions is limited. Further studies need to be undertaken on the effectiveness of courses and interventions to identify the impact they have had on the short- and long-term ability of parents. The effectiveness of policies and procedures that have been implemented to support professionals and parents in their roles also needs to be reviewed.

Further research on how socioeconomic conditions affect how parents cope and what strategies can be used to alleviate these factors should also be undertaken. Community learning disability nurses need to be active in research by undertaking studies, either individually or collaboratively, by being participants or by highlighting areas requiring further research.

Raising awareness about learning disability issues and parenting will help other healthcare professionals such as midwives, paediatric nurses and social workers, to be more sensitive to the needs of parents with learning disability. One of the ways that this could be achieved is by teaching on other professionals’ pre- and post-registration courses. This will also help identify professional boundaries so that good multi- and interprofessional working can be promoted and implemented. The needs and rights of people with a learning disability should continue to be incorporated in the common foundation programme of pre-registration nurse education programmes.

Learning disability nurses should have an active role in influencing policy development at an organisational, local and national level. Therefore they need to be attentive to the agendas of professional regulators, and local and national
government bodies. Opportunities for sharing good practice should be pursued in networks such as the UK Health and Learning Disability Network, the National Network for Learning Disability Nursing and the Working Together with Parents Network.

Conclusion

Community learning disability nurses can help to support parents with a learning disability by developing and delivering parenting skills classes. This role is multifaceted, incorporating a variety of skills, and requires effective collaboration and team working with a range of other professionals in a structured and comprehensive service to meet the needs of parents. It is imperative that community nurses use networking to promote best practice and shared aims that ensure consistency of service delivery across the UK to all parents. It is also crucial that community nurses continue to work in a way that enables and empowers parents to develop their confidence and competence so that they are able to care for their children.

References


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