

INSIGHTS

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37

Parents with learning disabilities

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Key points

- Parents with learning disabilities can and do become good enough parents when appropriate supports are in place
- Parents with a learning disability often have very complex needs as a result of a range of issues including poverty, discrimination, depression and poor self-esteem
- Families where the parent has a learning disability are often over-represented in the child protection system
- There is a lack of clarity over the number of parents with learning disabilities currently living in Scotland
- Early identification of parents is crucial to allow preventative work to take place, however crisis intervention still dominates
- Tools exist to assess parenting capacity, however, many are unsuitable for parents with learning disabilities and need to be adapted
- Parenting programmes are available across Scotland, including home and group-based learning programmes, and programmes that incorporate both elements
- Parenting programmes that meet the needs of parents with learning disabilities provide: accessible information, advocacy support and effective joint working
- Effective partnership working that takes a whole family approach is crucial when providing support for families

Introduction and policy context

Families where one or both parents have a learning disability can often have very complex needs as a result of a range of issues including poverty, discrimination, depression, poor self-esteem, and unemployment (Macintyre and Stewart, 2012; Wade, Mildon and Matthews, 2007). These families are often over-represented in care proceedings (Cox, Kroese and Evans, 2015) due to a perception that the parent(s) do not possess the skills and knowledge necessary to parent effectively rather than them being purposefully neglectful or abusive (Feldman, 2004). Parenting capacity assessments are often triggered when there are concerns about the welfare of a child. It has been suggested that parents with learning disabilities have to meet stricter criteria than other parents to demonstrate their ability to parent (Tarleton, 2007). It is also estimated that between 40% and 60% of parents with a learning disability have their children removed from their care due to being assessed as unable to provide an adequate standard of parenting (Wilson and colleagues, 2013).

According to the Scottish Government (2008), being a 'good enough' parent requires parents to be able

to provide basic physical care, love and affection, security, guidance, boundaries, and age-appropriate responsibility and independence. Some parents with learning disabilities require support to develop some of these 'good enough' parenting skills including:

- The ability to provide a safe home environment, adequate nutrition, and positive and nurturing interactions
- Being able to recognise and treat medical emergencies
- Having a basic understanding of child development (Feldman, 2004)

When provided with appropriate support, many parents with a learning disability can improve their skills and knowledge and learn to parent more effectively (Murphy and Feldman, 2002; Coren, Thomae and Hutchfield, 2011). Ensuring that parents with learning disabilities have access to services based on the principles of supported parenting was a key recommendation in the Scottish Government's learning disability strategy, *The keys to life* (Scottish Government, 2013). The strategy recommended that the *Guidelines for supporting parents with learning disabilities* (SCLD, 2015) be used by professionals to

ensure positive outcomes for families. The guidelines are built on the principles for supported parenting:

- Support should be available from pre-birth
- Support may need to be ongoing and required at every stage of a child's development
- Support must be based on respect for parents and for the emotional bond between them and their children
- Parents should be viewed as a resource and not the problem
- Support should be for the family as a whole rather than individuals
- Parents should be supported to be in control and to experience being competent
- Support should focus on building strengths
- Families are best supported in the context of their own extended families, neighbourhoods and communities

More recently, Section 12 of the Children and Young People (Scotland) Act 2014 places a duty on local authorities to secure services for children at risk of becoming looked after, thus highlighting the needs of parents with learning disabilities in mainstream legislation and policy.

This *Insight* aims to bring together the key research findings on supporting parents with learning disabilities to aid practitioners in considering approaches for working with this group of vulnerable parents. Examples of good practice from a recent scoping exercise carried out on behalf of the Scottish Government, commissioned by SCLD and written by the authors (Stewart and colleagues, 2016) is drawn on throughout.

Who are the parents?

There is a lack of clarity over the number of parents with learning disabilities in Scotland (SCLD, 2016; MacIntyre and Stewart, 2016). There are thought to be around 27,218 adults with learning disabilities known to Scottish local authorities, however, the number of parents within this group is not recorded (SCLD, 2016). English data (Emerson and colleagues, 2005) suggests that there may be around 5,000 parents with a learning disability in Scotland. Inconsistency in terminology used (learning disability, learning difficulty, learning need, global developmental delay) and the use of different diagnostic criteria means that data that is collected by individual organisations cannot be compared or collated accurately (MacIntyre and Stewart, 2016; Cooper and colleagues, 2016).

In addition, many parents and pregnant women may be reluctant to accept the label ‘learning disability’ for fear of discrimination and negative assumptions around capacity to parent.

What does the research tell us about support?

EARLY IDENTIFICATION OF PARENTS

Early identification of parents is crucial (MacKenzie, 2014), although much work remains focused on crisis intervention rather than preventative work that supports parents to develop parenting capacity (Ward and Tarleton, 2007). The Early Identification Working Group convened by the Scottish Government is exploring ways in which identification of parents with learning disabilities can be improved via the use of screening tools and awareness raising and training. Currently, a number of different types of assessment are used to establish the presence of learning disability, including IQ

testing (IQ of less than 70) alongside a range of functional assessments. Most parents with learning disabilities fall into the borderline category with an IQ of just above 70, meaning they cannot access a range of services due to strict eligibility criteria (McGregor and colleagues, 2017).

ASSESSING PARENTING CAPACITY

Evidence suggests that variable practice exists around the country in terms of whether generic or specialist assessment tools are used to assess parenting capacity and that knowledge of specialist tools is limited (Stewart and colleagues, 2016). The most commonly used specialist tool is the Parents

Assessment Manual (PAMs) (McGaw, 1998). This tool provides a comprehensive assessment of parenting capacity identifying strengths, as well as areas where further support is needed, by observing parents undertaking a range of tasks. The length of time taken to complete the assessment (usually around 12-14 weeks) is viewed as a positive feature (as well as a challenge)

Many parents and pregnant women may be reluctant to accept the label ‘learning disability’

given the widely recognised need to allow parents with learning disabilities additional time to develop their capacity to parent (Tarleton and Ward, 2007). However, the resource implications in terms of time taken to complete the assessment, the financial costs associated with purchasing a license and the cost of training staff to use the tool, all act as barriers (Stewart and colleagues, 2016). The evidence reviewed identifies good practice in assessing parenting skills:

- Early assessment to be completed to allow a preventative approach to be taken focusing on positive and negative aspects of parenting
- Ensuring that any report produced contains clear recommendations based on the principles of supported parenting
- Ensuring that when gaps in parenting capacity are identified, multi-disciplinary support is provided to fill these gaps (Stewart and colleagues, 2016)

Models of support

EARLY INTERVENTION

Early intervention is crucial and provides a range of benefits for parents (Bauer and colleagues, 2014;

Feldman, 2004; Booth and Booth, 2003). It allows for the needs of parents to be taken into account at an early stage and involves a shift away from a model that is crisis driven to one which allows preventative work to take place, providing an opportunity to work with parents before they become subject to child protection measures. Good practice examples include the Special Needs in Pregnancy Service (SNIPS) that involves specially trained midwives as part of a multi-disciplinary team that works directly with women during pregnancy to consider potential support needs.

Barriers to early intervention remain:

- Women not realising they are pregnant until very late on in the pregnancy
- Women being reluctant to approach their GP in case their child is removed
- Perceived cost of supporting parents as this is likely to be long-term and at times intensive
- Lack of clarity over learning disability means that parents often fall between the gaps in services
- Lack of effective joint working between children and families and learning disability services
- Lack of understanding of the needs of parents with learning disabilities

PRE-BIRTH SUPPORT

Pre-birth, time-limited programmes that provide support until the child is between six and twelve weeks old are well established. Support is often provided by midwives either as part of a generic service or as part of a specialist team. Such support is primarily focused on preparing the mother for the birth of her baby with some limited postnatal support. There are mixed views in the literature as to whether this support should be provided by

Focusing on parenting skills alone is not sufficient to enhance the parenting capacity of all parents with learning disabilities

specialist or generic teams (Stewart and colleagues, 2016). Generic programmes do not always meet the needs of parents with learning disabilities as course structures and materials are not fully accessible (McGregor and colleagues, 2017). Specialist programmes such as the Mellow Parenting Programme are flexible enough to meet the needs

of parents with learning disabilities and designed specifically to be accessible. Key elements are required to make a programme suitable for parents with learning disabilities:

- Adapting the pace to suit the needs of all parents
- Extending the length of the programme
- Repetition of tasks and information
- Modelling of behaviour
- Social support
- Providing accessible information in a range of formats, including video and online resources, as well as verbal delivery of material (MacIntyre and Stewart, 2016)

Focusing on the development of parenting skills alone is not sufficient to enhance the parenting capacity of all parents with learning disabilities as they are also likely to experience poverty and poor housing, poor physical and mental health and may be affected by abuse and substance misuse (MacIntyre and Stewart, 2012). The provision of support must therefore incorporate practical support with household tasks such as cooking, cleaning and shopping and should signpost parents onto other relevant support providers. The Barnardo's Family Health Project in Fife

(Barnardo's, 2017) is a good practice example of a service that provides practical support to parents with learning disabilities.

SUPPORTED PARENTING PROGRAMMES

A range of parenting programmes is available, targeted at pregnant women and at families in the weeks and months after birth. A number of programmes is also available to support families with toddlers and older children. Most of these services are time limited, and there appears to be a significant gap in relation to the provision of longer term, flexible support. Programmes can be grouped according to three broad types:

- **Home-based learning programmes** eg Self-directed Learning (Feldman, 2004) that involves building on existing skills that parents have, and providing accessible information, repetition and support to help parents understand the skills being taught.
- **Group-based learning programmes** eg Supported Learning Parenting Programme (Booth and Booth, 2003) usually involves regular learning support groups; day or evening courses and activities; guidance and support for accessing educational

courses; and fosters peer support. Booth and Booth (2003) found that the relationships fostered between parents, the support received from the group and 'getting out of the house', were particularly important.

- **A combination of both** eg Mellow Futures (Tarleton, 2014) has been tailored specifically for parents with learning disabilities and/or difficulties and is a perinatal programme. It uses a combination of mentoring and peer support to address the issues that parents with learning disability face (Mellow Parenting, n.d.).

Evidence suggests that these specialist programmes help parents develop parenting skills. They share a number of common features:

- Provision of accessible information
- Provision of advocacy support – particularly in relation to child protection issues
- Effective joint working practices

There is limited evidence of the long-term effectiveness of the programmes. A further evidence gap has been identified in relation to outcomes for children (Wilson and colleagues, 2013).

ACCESSIBLE INFORMATION

Accessible information for parents with learning disabilities is crucial, yet evidence suggests that they are not consistently accessing specialist information such as the CHANGE resources made available by NHS Scotland (Lewis and colleagues, 2011), partly due to a lack of awareness among professionals. In addition, Dale (2004) and MacIntyre and Stewart (2012) reported a lack of accessible information being made available to parents timeously during child protection proceedings, reducing their ability to participate meaningfully in, or to effectively understand these often complex proceedings. A number of components are viewed as being important:

- Graphic or other visual information to enhance understanding and participation
- Provide information in bite-size chunks
- Repeat key messages
- Provide the opportunity to talk over information that is provided in written format
- Offer the opportunity, perhaps via advocacy, for material and process to be 'translated'
- Do not use smaller than a 14-point font in any printed material (Jarrett and colleagues, 2017; Stewart and colleagues, 2016)

ADVOCACY SUPPORT

Advocates play a crucial role in translating information for parents to enable them to participate more meaningfully in discussions about their child(ren). This is particularly important during child protection proceedings (MacIntyre and Stewart, 2016; Cox and colleagues, 2015; Bauer and colleagues, 2014; McConnell and Bjorg Sigurjonsdottir, 2010). A recent evaluation of Equal Say for Parents identified a number of key roles played by advocacy workers. These included:

- Ensuring that the voices of parents were heard
- Supporting the development of trusting relationships
- Improving relationships between parents and other professionals
- Providing representation and support during child protection proceedings
- Raising awareness of the specific needs of parents with learning disabilities (MacIntyre and Stewart, 2016)

Access to advocacy for parents with learning disabilities is variable with more provision available in some parts of the country than others (Hartworth,

2012). This can leave parents, who may struggle with information and who may not fully understand the child protection process, to navigate it on their own without independent support.

Access to self-advocacy groups can also provide effective support to parents with learning disabilities. Groups such as People First and Equal Say for Parents promote self-advocacy skills in parents with learning disabilities that have led to improved confidence in participating in formal proceedings (MacIntyre and Stewart, 2012).

Partnership working

Effective partnership working takes time to develop and that is not necessarily afforded to public sector workers, especially in times of austerity. This lack of time can result in relationships between social workers, other services and service users being underdeveloped, contributing to poor decision-making (O'Connor and Leonard, 2014). Hartworth (2012) reported difficulty in deciding which local authority service was responsible for providing support to families (ie child or adult services) and raised concerns about the conflict between

addressing the support needs of parents while safeguarding children. This safeguarding/support conflict experienced by professionals is also reported by Tarleton and Porter (2012), who refer to the distance between adult and children services as 'no-man's land'. They explain that there is a risk of families where one or both parents have a learning disability falling between the gap in services. This is confirmed by Stewart and colleagues (2016) who suggest that, often, parents with learning disabilities are not entitled to support or services in their own right. As a result, services only become involved when child protection concerns are raised at which point the scope to undertake preventative work is limited.

Implications for practice

Practitioners working with parents with learning disabilities and their families need to:

- Ensure the provision of accessible information to parents. This is important in all interactions, but particularly crucial in matters relating to child protection proceedings.
- Ensure clarity of roles and responsibilities across health and social work and between children

and families and adult services to ensure parents have access to appropriate supports through developing joint protocols. These roles should be clearly explained to parents.

- Make use of supported parenting principles. These should underpin all intervention with parents with learning disabilities.
- Ensure that appropriate assessment tools are used when assessing parenting capacity.
- Identify and/or develop clear pathways of care and support that promote early identification of parents (including appropriate screening tools), taking a strengths-based approach.
- Promote the use of independent advocacy to ensure the voices of parents are heard.
- Self-advocacy can also promote increased participation and confidence for parents.

The lives of parents with learning disabilities are likely to be characterised by marginalisation and disadvantage

- Consider the use of specialist parenting programmes which have been proven to provide more effective outcomes for parents with learning disabilities than standard programmes.

Conclusion

Little is known about how many families are affected by parental learning disability in Scotland and the UK and there are a number of challenges in establishing prevalence rates. It is clear, however, that the lives of parents with learning disabilities are likely to be characterised by marginalisation and disadvantage and they are likely to be disproportionately represented in the child protection system. There is a growing body of evidence that suggests that parents with learning disabilities can and do become good enough parents when the right support is in place. This support should be based on the principles of supported parenting set out by SCLD in 2015. Evidence suggests that good progress has been made in providing this support, particularly peri-natally. However, geographical variation remains across the country and further work is needed to ensure that support is available on a longer-term basis with flexibility around key transition points in the life of the child and parents.

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