



Supporting Parents with Learning Disabilities in Scotland: Challenges and Opportunities

Key findings

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What is the issue?

Between 40% and 60% of parents with learning disabilities have their children removed as a result of being assessed as not meeting a satisfactory standard of parenting. Therefore, ensuring that parents with learning disabilities have access to supported parenting services based on the principles of supported parenting was a key recommendation in the Scottish Government's learning disability strategy *The keys to life* (2013).



Additionally the strategy stated that the SCLD (2015) Scottish Good Practice Guidelines for Supporting Parents with Learning Disabilities should be followed by professionals working in this area to ensure positive outcomes for families. These recommendations should be understood in the context of the Children and Young Person's (Scotland) Act 2014 Section 12, which places a duty on local authorities to secure services for children at risk of becoming looked after.

The National Parenting Strategy (Scottish Government, 2014) promotes early intervention to support vulnerable families, allied with more effective joint working between agencies. However, there is no specific mention of parents with learning disabilities that details their particular support requirements.

Aim of the Scoping Exercise

The aim of this scoping exercise was to explore the progress made since the publication of the Keys to Life (Scottish Government, 2013) by examining the following:

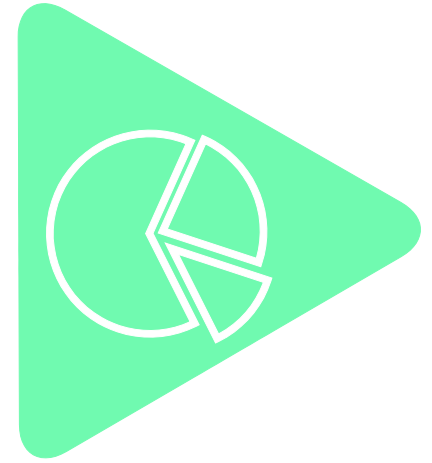
- What range of services is available to support parenting for parents with learning disabilities across Scotland?
- To what extent do parents with learning disabilities have access to services based on the principles of supported parenting?
- To what extent are professionals following the supported parenting good practice guidelines?
- What outcomes are being achieved for parents with learning disabilities by key members?

It did this by undertaking a literature review, an electronic survey and follow up interviews with key stakeholders.

What does the scoping exercise tell us?

Respondents were very keen to highlight that parents with learning disabilities can and do become “good enough parents” with the right support. However, the support that they need to do so may be resource intensive as “good enough support” is likely to be long term and, at times, intensive as children reach particular developmental milestones.

Evidence from the scoping highlights that there are challenges around a number of key areas of current support provision:



1. Partnership Working

The importance of partnership working across professional support teams has been highlighted as key in The Scottish Good Practice Guidelines (SCLD 2015) and GIRFEC Guidelines (2012) which state that partnership working allows for support to be provided to families before a crisis develops. This has been promoted legislatively in the Public Bodies (Joint Working) (Scotland) Act (2014). Moreover, communication and shared recording between those professionals involved in support can help to reduce the risk of crisis, as services are aware of a family’s whole circumstances.

The survey revealed a complex picture of service provision with available services ranging from those only for people with a diagnosed learning disability (including parents) to those for vulnerable parents more broadly where no such diagnosis is required. There were a range of views around whether this mixed pattern of service provision was appropriate to meet the needs of parents with learning disabilities. There was some concern that generic services might not be best placed to meet the very specific requirements of parents with learning disabilities.

A number of times the benefits of a dedicated specialist multi-disciplinary team to support parents with learning disabilities were stated. Specialist services were thought to be more likely to offer intensive and long term support for parents. Yet the general view was that ALL services should be responsive enough to meet the needs of parents with learning disabilities.

Survey respondents highlighted that working in tandem with the third sector was useful due to the extra time, flexibility and resources they can offer. Partnership work with the third sector was valued due to their independent nature which allows them to develop trust with parents.

However, difficulties in joint working across public services was demonstrated. In some areas adult learning disability services and children services work independently of one another, thus creating disputes about who is offering what support and when.

2. Early Intervention

The importance of early intervention for parents with learning disabilities has been clearly established and there is evidence of the benefits of this. A focus on crisis appeared to limit opportunities for strengths based approaches to be used with parents, as well as reduce the time available for parents to develop their parenting skills. Opportunities for early intervention were however available in some areas.

A number of respondents felt that early intervention was beginning to happen on a more regular basis and a number of examples of good practice were identified.

Barriers to early intervention remain and those identified by survey respondents included:

- women not realising they are pregnant until very late in the pregnancy
- women being reluctant to approach their GP or other sources of support for fear of their child being removed
- pregnant women not being identified as having a learning disability or as needing extra support
- perceived cost of providing potentially long term support viewed as prohibitive by service providers
- lack of a clear diagnosis of learning disability
- lack of effective joint working
- lack of understanding of the needs of parents with learning disabilities.

3. Assessment of parenting capacity

Knowledge of specialist assessment tools was not widespread and that such tools were not always used. It appears that awareness of such specialist assessment tools is growing yet their use is not widespread, with social work in particular being viewed as using inappropriate assessment tools at times.

4. Support to develop or enhance parenting capacity

Support to develop and enhance parenting capacity took many forms although it is possible to distinguish between 3 different types:

- prenatal and postnatal services

Support to develop parenting skills was often provided by midwives prenatally either as part of a generic service or as part of a specialist team. Respondents felt that expecting all midwives to have the skill and confidence to support parents with a learning disability was a 'big ask'. Similarly, the difficulties in developing expertise in relation to all the different groups of people they supported were acknowledged.

- those services that focus primarily on the development of parenting skills

Respondents felt strongly that generic parenting programmes did not meet the needs of parents with learning disabilities as the course structure and materials were not fully accessible. Some of these, such as Mellow Parenting, have been adapted to be accessible to this population of parents and have good outcomes for the families that attend.

- those services that support the parent with issues around parenting in its broadest sense.

Many respondents stated that focusing on the development of parenting skills alone was not sufficient to enhance the parenting capacity of parents with learning disabilities.

Parents with learning disabilities are likely to experience poverty and poor housing, poor physical and mental health and may be affected by abuse and substance misuse. Therefore, some services currently are working with parents to address those issues that are likely to impact directly on their capacity to parent. Primarily this appeared to be about supporting parents to access relevant support from other sources.

5. Accessible Information

The Equality Act (2010) makes accessible information a legal obligation.

Survey respondents felt that accessible information was crucial for parents. There was also a general agreement amongst respondents that accessible information was good for everyone, not just individuals with learning disability.

A number of components, outlined below, were viewed as being important.

- Provision of graphic or other visual information.
- Avoid giving too much information at one time - information should be provided in “bite size” chunks.
- Repetition of key messages to ensure learning.
- Providing the opportunity to talk over information that is provided in written format.
- Offering the opportunity, perhaps via advocacy for materials and processes to be ‘translated’.

However that there is a need for improvement in providing accessible information. In their evaluation of NHS Scotland CHANGE Resources Lewis et al (2011) demonstrated that professionals working with parents had a lack of knowledge of these resources.

6. Data collection and Research

There is limited information available on the numbers of parents with learning disabilities in Scotland and the data from this scoping study suggests that this lack of knowledge of the breadth of the population may in fact impact on the availability and range of services provided. Difficulties in collating reliable data include:

- Some organisations not recording parental learning disability
- Definitional issues (what constitutes a learning disability?)
- Inconsistent use of terminology e.g. learning difficulty, learning disability, additional support need

The most recently available statistics suggest that there are 25,842 adults with learning disabilities known to local authorities currently or in the past three years in Scotland (Scottish Government, 2015). Using this figure and extrapolating from an English study Emerson et al study (2005), it is likely that there are around 5,000 parents with a learning disability in Scotland.

What has been shown to work?

1) Whole Family Approach

A holistic approach to family support that considers the needs of the whole family and includes assessment, intervention and support” (Stewart, MacIntyre & McGregor, 2016, p.36).

This approach has been reviewed by Tarleton and Porter (2012) who carried out a Matching Needs and Services Audit that compared the outcomes produced for children by general assessment services and the Valuing Parents Support Service (VPSS), which takes a whole family approach. The audit found that VPSS provided better outcomes for children as a result of working with parents and linking with other services.

2) Pre and postnatal pathways

NHS Fife Barnardo’s Family Health Project has been successful in promoting relationship building between key workers and parents which provides social parenting support from the twenty-second week of pregnancy until the child is twelve weeks old. Between 60 and 70% of parents who have engaged with this project have had their children removed from the child protection register.

3) Accessible Information

The free information service, Parenting across Scotland have produced an easy read information booklet on starting school. The feedback on the book from parents was positive, however, due to a perception that the production was time-consuming and costly the organisation has no further plans to produce more easy read material.

Moving forward

Unless the right support is available for the *whole family*, some parents with learning disabilities will continue to struggle to parent their children effectively, and their children may struggle to achieve their potential.

This support has a number of key characteristics including the following:

- Support must be long term in nature.
- It may be intensive at times, particularly during child development milestones.
- Support must be flexible.
- Support takes a whole family approach that focuses on the needs of the parent and the child.
- Appropriate assessment tools and processes should be used and appropriate support should be provided alongside these to develop parenting skills on an ongoing basis.
- There needs to be accessible information to ensure meaningful participation.



- Specialist parenting programmes should use appropriate teaching and learning methods that involve the use of visual and graphic material, opportunities for repetition, modelling of behaviour and longer timeframes for learning.

Parents are most likely to benefit from specialist support where staff have a clear awareness and understanding of the particular issues faced by parents with a learning disability. To this end, a training need has been identified as many staff do not yet have this knowledge base.

It is suggested that the solution to these challenges is the provision of jointly funded, multi-disciplinary teams that take a whole family approach, thus prioritising the needs of parents as well as children. Such teams will understand parenting and the capacity to parent in its broadest sense and will develop increasing awareness, skills and expertise as they support families affected by parental learning disability.

In addition, clear pre and post-natal pathways require to be developed to reduce the complex and ad hoc nature of support provision for parents with learning disability as it currently stands.

Some excellent practice has already been developed in Scotland and further afield, including the development of a pre-natal care pathway. This good practice should be widely disseminated to facilitate consistently high provision of service.

Local information strategies should be developed and implemented to ensure that the information needs of parents with learning disabilities are met.

Local service provision should be underpinned by more consistent and comprehensive collection of data. This depends on developing a shared definition of 'learning disability' and improved data sharing between agencies.