



**Scoping Exercise on behalf of the Scottish Government,  
Keys to Life Change Fund**

# **Supporting Parents with Learning Disabilities in Scotland: Challenges and Opportunities**

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## Foreword

The Scottish Government wants to improve the lives of people with learning disabilities.

This report is one of a series commissioned by the Scottish Commission for Learning Disability on behalf of the Scottish Government to understand how we can achieve this.

Scotland's learning disability strategy, The keys to life, is based on a commitment to human rights, and seeks to improve the quality of life for people with learning disabilities so that they live longer, healthier lives, participate fully in all aspects of society and prosper as individuals.

People with learning disabilities should have the same rights to family life as anyone else and supporting parents with learning disabilities has a crucial role to play in making those rights real.

As this report demonstrates, people with learning disabilities face a myriad of challenges when they become parents. People with learning disabilities can and do become good parents. However, they may require additional support to to become the best parents they can be.

That support needs to be flexible. It will often need to be long term and intensive, particularly at key stages of a child's development. To be effective it has to be built around the needs of the whole family.

The Scottish Commission for Learning Disability has recently refreshed the Scottish Good Practice Guidelines for Supporting Parents with Learning Disabilities. This report maps the range of services available now and explores the extent to which parents with learning disabilities have access to services based on the principles of supported parenting.

It sets out clear thinking and detailed recommendations about providing support which reflects those guidelines, consistent recording across health and social care to ensure early identification and awareness raising. This will ensure good practice is adopted and embedded.

This will require close working with Integration Joint Boards and collaborative working across sector boundaries. Early identification and intervention is key to avoiding a crisis model of intervention which parents with learning disabilities have all too often experienced in the past.

Through our involvement in the Working Together with Parents Network, a collaboration with Learning Disability Wales and the Norah Fry Centre for Disability Studies at the University of Bristol, funded by the Esmee Fairburn Foundation, we will continue to drive improved policy and practice. This report provides an invaluable evidence base for that work.

Our objective must be to use every available opportunity to support parents with learning disabilities to secure better outcomes for them and their children.



**Chris Creagan**

Chief Executive, SCLD

A handwritten signature in black ink that reads "Chris Creagan".

## Executive Summary

### Background and aims of the study

The Scottish Government published *The keys to life* in 2013 (Scottish Government, 2013). It set out a national strategy for learning disability services and identified a number of priority areas including supporting parents with learning disabilities. Recommendation 38 stated that by 2014 parents with learning disabilities should have access to local supported parenting services based on the principles of supported parenting as outlined below:

- Support should be available from pre-birth onwards
- Support may need to be ongoing at every stage of the child's development
- Support must be based on respect for the parents and for the emotional bond for the parent and child
- 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.

It also recommended that the “Scottish Good Practice Guidelines for Supporting Parents with a Learning Disability” (SCLD, 2015) should be followed by professionals working with parents with learning disabilities to ensure better outcomes for families. *The keys to life* (Scottish Government, 2013) Implementation Framework and Priorities 2015-2017 highlighted the importance of the development of effective interventions for parents who have learning disabilities.

Unlike *The keys to life* (Scottish Government, 2013) and the refreshed Scottish Good Practice Guidelines for Supporting Parents with a Learning Disability, entitled ‘*Supported Parenting*’ (SGP; SCLD, 2015), there is no specific mention of (or guidance for working with) parents with learning disabilities within the National Parenting Strategy (Scottish Government, 2012b) although the Children’s and Young Person’s (Scotland) Act, 2014 sets out the duty that Local Authorities have to provide support to children and families where the child is at risk of becoming looked after.

The Scottish Good Practice Guidelines for Supporting Parents with a Learning Disability advise that the main features of good support provision for parents with learning disability are: accessible information and communication, clear and coordinated referral and assessment procedures and processes, eligibility criteria and care pathways, support designed to meet the needs of parents and children based on assessments of their needs and strengths, long term support where necessary and access to independent advocacy (SCLD, 2015).

It is not clear whether or not this level of support is available nationally (Scottish Government, 2013) and the extent of good practice in this area is largely unknown as are the outcomes of these approaches for the parents with learning disabilities for whom the services and supports are provided.

This scoping study therefore explored the progress made following the publication of *The keys to life* (Scottish Government, 2013) by addressing the following research questions:

- 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 Scottish Good Practice Guidelines for Supporting Parents with a Learning Disability?
- What outcomes are being achieved for parents with learning disabilities from the perspective of key contacts?

## Methodology

### **Stage 1 - electronic survey**

In order to gather baseline data an online survey was constructed using *Qualtrics* software to be distributed across all local authority (32) and health board (15) areas in Scotland. The aim was to identify services provided by the statutory sector alongside those commissioned services in the voluntary and private service. The survey was distributed via the following networks:

- Social Work Scotland Learning Disabilities Subgroup
- Social Work Scotland Children and Families Subgroup
- Working Together for Parents Network
- Heads of Midwifery Services
- Lead Nurses Group.

Exact figures cannot be provided on how many people the survey reached as it was not sent directly by the researchers but was sent via the bodies outlined above who were not always able to share details of their mailing lists to preserve the anonymity of respondents. A total of 42 completed surveys were returned. This limited response can be attributed to the use of external mailing lists where a significant number of potential respondents were no longer in post as well as a lack of centrally held data, for example for Community Learning Disability Teams.

The survey addressed the following key areas:

- The process of identifying parents with learning disabilities
- The range of services and supports available including identification of any gaps in provision
- Awareness of the Scottish Good Practice Guidelines and the extent to which these inform practice
- Understanding of supported parenting principles
- Identification of good practice.

## **Stage 2 – telephone interviews with key informants**

Based on an analysis of the responses to the survey, areas with significant levels of activity in supporting parents with learning disabilities were identified. Follow up telephone interviews were carried out with thirteen key informants across four geographical areas (Glasgow, Edinburgh, Fife and Ayrshire). In each of those areas attempts were made to ensure representation across social work, health and third sector staff. The following interviews were completed:

- Health (n=6)
- Social work (n=2)
- Third Sector (n=5)

The purpose of the interviews was to explore in more depth the key themes that emerged from the analysis of the survey and included issues around definitions of learning disability and eligibility criteria, the identification of parents with learning disabilities, opportunities for early intervention, the use of generic or specialist parenting services, issues around assessment of parenting capacity, identification of good practice and gaps in service provision.

### **Data Analysis**

The survey generated quantifiable data that was analysed statistically using basic descriptive statistics and the tools within the Qualtrics software designed for this purpose. A significant amount of the data collected was qualitative in nature given the aims of the survey to identify both good practice and gaps in provision. Data from both the survey and the key informant interviews was therefore analysed thematically (Miles and Huberman, 1984). The thematic analysis of the data from the survey informed the construction of the interview schedule for use with the key informants identified above to ensure the emerging data could be explored in more depth during the interview phase of the project.

### **Ethical Approval**

The methodology described above received ethical approval from the School of Social Work and Social Policy Ethics Committee at the University of Strathclyde. Careful consideration was taken to ensure the protection of participants from harm with a particular focus on the provision of information to ensure respondents were able to provide informed consent to participate in the study. The names of individuals have not been included in this report to protect their anonymity.

### **Literature Review**

The review aimed to scope research that incorporates the core elements of the principles of supported parenting identified above. The review found that evidence-based parenting support programmes, tailored for parents with a learning disability, provide the level of support parents with a learning disability need to help them parent more effectively (e.g. Bauer, 2014; Booth & Booth, 2003; Feldman, 2004). Examples of such programmes include home-based learning programmes, e.g. Self-directed Learning (SDL; Feldman, 2004), group-based learning programmes e.g. Supported Learning Parenting Programme (Booth & Booth, 2003), and a combination of both, e.g. Mellow Futures (Tarleton, 2014). Each programme is tailored for parents with learning disabilities but they vary in the age and stage of the children they are targeting and the

duration of the support they are providing. It was found that all of the programmes helped parents develop the skills they needed but there was limited evidence to support the long term effectiveness of the programmes with a further evidence gap identified in relation to outcomes for children. While some evidence exists that explores the possible impact of having a parent with learning disabilities, it is inconclusive and, similarly, research that looks at the effects of parenting programmes on the outcomes for children has also yet to be established (Wilson et al, 2013).

The literature review also identified the availability of accessible information as a key theme. It was found that parents with learning disabilities were not consistently getting access to the accessible information such as the CHANGE resources made available by NHS Scotland (Lewis et al 2011) partly due to the lack of awareness of professionals. In addition, Dale (2004) and MacIntyre and Stewart (2011) reported a lack of accessible information being made available to parents timeously during child protection proceedings. Advocacy support was found to assist with this alongside ensuring parents received appropriate support during child protection proceedings to ensure their voices were heard (Cox et al., 2015; Bauer, et al, 2014; McConnell & Bjorg Sigurjonsdottir, 2010).

The literature review emphasised the importance of partnership working in line with GIRFEC (Scottish Government, 2012) and the Scottish Government in the Public Bodies (Joint Working) (Scotland) Act 2014. 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 & Leonard, 2014). Hartworth (2012) reported difficulty in deciding which local authority service was responsible for providing support to families (i.e. Child or Adult services) and raised concerns about the conflict between addressing the support needs of the parent and safeguarding the child. This safeguarding/support conflict experienced by professionals is also reported in more recent research, e.g. Tarleton and Porter (2012) who refer to the distance between adult and children services as 'no-man's land'. Tarleton and Porter (2012) in an evaluation of the role of the Valuing Parents Support Service (VPSS), a specialist Parent with Learning Disability Team emphasised the benefits of the 'Think Family' approach adopted (Social Exclusion Taskforce, 2007).

## Findings

### ***Number of parents with learning disabilities***

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. The most recent statistical sources in Scotland, the Scottish Census 2011 and the Scottish Government Statistical Information for 2014 (Scottish Government, 2015) indicate that there are also challenges with the data that is collected around people with learning disabilities more generally (Scottish Learning Disability Observatory, 2016).

Many agencies who responded to the survey do not routinely record parental learning disability. Of those who do, figures range from five to six parents per year to over 40 in a single agency. However, evidence from this scoping study suggests that confusion over terminology (learning disability, learning difficulty, learning need, global

developmental delay) and inconsistent use of different diagnostic criteria means that data collected by individual organisations cannot be compared or collated accurately or effectively.

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). It is also suggested that there are more than 53,000 parents with a learning disabilities in England (Emerson et al, 2005) known to services. Extrapolating from this data in a Scottish context it is likely that there are around 5,000 parents with learning disabilities in Scotland. The Emerson et al study (2005) indicates that many more parents are not known to services and that the actual figure will be significantly higher. It therefore appears likely that this is a growing and often hidden population across the UK.

### **Definitions of learning disability**

To understand this lack of information around the number of parents being supported, it is necessary to understand what survey respondents understood by the term “learning disability” and how this translated to service provision and access to services. Different services had different thresholds for access with some only offering support to those with a diagnosed learning disability (predominantly by using an IQ of less than 70 as a measure) while others offered support to those with “*an assumed or suspected learning disability...or those with “learning difficulties” or “learning needs”*”.

The understanding of learning disability and its associated terms appears to vary according to professional background and training. Data from the survey suggested that some services did not use a test to establish the presence of learning disability and hence eligibility to the service while others did, introducing a lack of consistency that was thought to be driven by eligibility criteria.

### **Assessment of learning disability**

A number of different types of assessment were used to establish the presence of learning disability or not. These included IQ testing (IQ of less than 70) alongside a range of functional assessments. These IQ assessments were carried out by clinical psychologists who felt they often were expected to undertake a gate-keeping role to determine access to services. One psychologist reported that around 95% of those referred for assessment do not have a learning disability and that most fell into the borderline category with an IQ of just above 70. This has implications in terms of service provision and support and means the parameters of the populations remains vague. Where formal testing was not carried out, survey respondents reported using a range of measures or indicators to determine the likely presence of a learning disability, difficulty or need including previous service use, attendance at a special school, requiring “additional help” at school. There were benefits to this flexible approach in enabling work with those people who resisted having the label “learning disability” due to fear of the perceived stigma attached to the label. It was also more likely to include those at the borderline, with an IQ of just above 70.

### **Early identification of parents with learning disabilities**

The importance of early identification to promote preventative work has been acknowledged by Scottish Government and currently a specialist group (Early Identification Working Group) is exploring ways in which identification of parents with

learning disabilities can be improved. The work to date has focused on a number of key areas including the development of screening tools and awareness raising and training.

Some of the challenges noted in early identification were the need for self-identification as learning disabled or having additional support needs. Several respondents also felt that parents were unlikely to seek help at an early stage due to the perceived stigma attached to the label learning disability as well as fear of having their children removed from their care.

### ***Parenting referrals***

The majority of services operated an open referral policy and were willing to consider referrals provided that parents met their eligibility criteria. Others accepted referrals from social work only and others only from health with a growth in the number of organisations accepting self-referrals. The data from the interviews suggests that trigger points for referral, were primarily generated by Child Protection (CP) concerns rather than a focus on supporting the adult to parent prior to any CP concerns emerging. It could therefore be considered that the focus of much intervention with this group is largely based on the needs of the child alongside assessing and/or reducing risk associated with CP procedures. Whilst this is entirely understandable it does indicate that the needs of the parent could be being overlooked during periods of perceived crisis. There were however examples of where parents were identified during pregnancy, for example in Fife, using a specific screening tool developed in the local pre-natal pathway and this aided early intervention.

### ***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, although the impact on outcomes for children is less well explored. Avoiding crisis-focused and unplanned interventions was a goal for many of the respondents within this scoping study. A focus on crisis appeared to limit opportunities for strengths based approaches to be used with parents alongside reducing the time available for parents to develop their parenting skills.

Opportunities for early intervention were however available in some areas, a good example being the Special Needs in Pregnancy Service (SNIPS) available in a number of areas. The specially trained midwives in these teams were able to work directly with women during their pregnancy to consider potential support needs at an early stage.

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. These included the Barnardo's Family Health Project and the Early Years Centres in Edinburgh.

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
- 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.

### ***Services for parents with learning disabilities***

#### **Generic and Specialist Services**

The survey has found an intricate pattern of provision in terms of the different understandings of learning disability, whether a parent has to have a formal diagnosis to access a service, referral pathways, and in particular the point at which referral should take place. The survey has also revealed a complex picture of service provision with services available 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 debate around whether their needs were best met by specialist services that worked only with parents with learning disabilities or by those that worked with vulnerable parents more generally. There was some concern that generic services might not be best placed to meet the very specific requirements of parents with learning disabilities around accessible information, the need for repetition of information and practical opportunities for learning. There was also concern that when parents with learning disabilities were grouped with other vulnerable parents the pace of any intervention would be unsuitable and that they might be excluded because they lacked (or were assumed to lack) particular knowledge or experiences.

A number of suggestions were made as to the benefits of a dedicated specialist multi-disciplinary team to support parents with learning disabilities. 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 and that levels of support should depend on levels of need and issues of risk rather than prioritizing particular categories of parents such as those with learning disabilities or those who abuse substances.

#### **Type of support provided**

There has been a clear distinction made between services that work only with those with a diagnosed learning disability and services for all vulnerable parents. The survey also generated a significant amount of data on the *type* of support provided and it is suggested that a broad range of work was being undertaken by professionals working

in this field. The provision of support often goes beyond the parenting role itself to consider other aspects of the parent's life that might directly or indirectly impact on their parenting capacity such as housing support or general health and wellbeing. Analysis of the data suggests that assessment of parenting capacity, support to develop or maintain parenting skills and capacity and advocacy and representation are the most common activities undertaken.

### **Assessment of parenting capacity**

There is variable practice across the country in relation to whether generic or specialist assessment tools are used, how they are used and by whom. Respondents suggested that knowledge of specialist assessment tools was not widespread and that such tools were not always used.

The Parents Assessment Manual, (PAMs assessment tool) was valued for the level of detail it offered assessors in assessing parenting capacity. It was felt to offer greater opportunity to focus on the strengths of parents as well as areas for improvement and risk factors in a way that more generic assessment tools could not. The length of time taken to carry out the assessment (around fourteen weeks in total) was viewed as a positive feature (as well as a challenge) given the widely recognised need to allow parents with learning disabilities additional time to develop their capacity to parent.

It appears that awareness of 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. This is perceived to be because of the resource implications of using specialist tools in terms of time taken to complete the assessment, the financial costs associated with purchasing a licence and the cost of training staff.

Other important considerations identified by respondents related to completing the assessment in an environment that is familiar to parents (to allow for the modelling of behaviour) and ensuring that positives as well as negatives are emphasised to parents.

### **Support to develop or enhance parenting capacity**

Support to develop and enhance parenting capacity took many forms although it is possible to distinguish between;

- prenatal and postnatal services
- those services that focus primarily on the development of parenting skills and;
- those services that support the parent with issues around parenting in its broadest sense.

### **Support to prepare for the birth of the baby**

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 such as the SNIP team. Such support was primarily focused on preparing the mother for the birth of her baby with some limited postnatal support, usually for around six to twelve weeks after the birth of the child. While it was agreed that generic services should be flexible enough to meet the needs of all children, it was felt that it was "*a big ask*" to expect all midwives to support parents with learning disabilities. Likewise, for social workers, the

difficulties in developing expertise in relation to all the different groups of people they supported were acknowledged.

### **Parenting programmes**

Respondents felt strongly that generic programmes such as the Triple P programme offered across the Greater Glasgow and Clyde NHS Board area did not meet the needs of parents with learning disabilities as the course structure and materials were not fully accessible. Respondents valued specialist programmes such as the *Mellow Parenting* Programme, which it was felt, was flexible enough to meet the needs of parents with learning disabilities and designed specifically to be accessible. Analysis of the survey data suggests that the key elements required to make a programme suitable for parents with learning disabilities include:

- Adapting the pace to suit the needs of all parents
- Extending the length of the programme to provide support on a longer term basis
- Repetition of tasks and information
- Modelling of behaviour
- Social support
- Accessible information available in a range of formats, including video and online resources as well as verbal delivery of material.

### **Support to develop parenting capacity in its broadest sense**

There was recognition among many respondents 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. As a result, respondents reported *“working with parents to address those issues that are likely to impact directly on their capacity to parent”* such as support around housing, support related to health and wellbeing, financial support and social support to access local resources. This might incorporate practical support with household tasks such as cooking, cleaning and shopping but primarily appeared to be about supporting parents to access relevant support from other sources.

### **Advocacy support or other forms of representation**

A key source of support reported by respondents was the provision of advocacy support to ensure that parents had their voices heard in relation to the care of their child and legal representation to ensure they could access their legal rights. This support was thought to be crucial for parents, particularly in relation to child protection proceedings.

### **Support for children**

Three respondents described the work that they did with children which focused primarily on child development and attachment. One respondent structured this work around the five to thrive principles which is described as an “attachment based approach to positive parenting” and is based on talking, playing, relaxing, cuddling and responding ([www.fivetothrive.org.uk](http://www.fivetothrive.org.uk)). Other work with children involved ensuring

children met their developmental milestones and providing social opportunities to prevent social isolation and to promote interaction with other children.

### **Accessible information**

The provision of accessible information was also identified as crucial for parents with learning disabilities. 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’.

Overall, it was acknowledged that a parent’s information needs should be assessed on a case by case basis but that everyone could benefit from information being presented in a clear and accessible way. Time and financial pressures and a lack of specific knowledge on the needs of parents with learning disabilities meant that poor practice could still be identified by respondents.

### **Joint working**

Joint working was noted as crucial to effectively support parents with learning disabilities yet problems with joint working, particularly between adult and children social work teams were noted consistently as an area of concern. The focus of concern was that parents with learning disabilities often fall between the gap in services. As they are often not eligible for a service in their own right from adult services, they fall under the radar of children and family services until a child protection concern is raised by which point the opportunity to focus on the parent’s abilities and skills, which is often the focus of early intervention service, can be lost. It was noted however that services such as advocacy, can become usefully involved at this stage to ensure that the parents voice is heard in any subsequent child protection proceedings and that those proceedings are explained in a way that the parent can understand. Joint working with third sector organisations can be helpful in ensuring that the needs of the parents are taken into consideration.

The input of third sector organisations is highly valued because of the additional time, flexibility and resources they can put in place to support parents. Another particular advantage of joint working with the voluntary sector highlighted by a number of respondents was the independent nature of the organisations, which was viewed as being crucial. For parents who are subject to significant scrutiny over their ability to parent, an independent organisation providing assessment and support can promote engagement, confidence and trust.

## Discussion

### **Scottish Good Practice Guidelines**

One of the aims of this scoping study was to consider the extent to which the Scottish Good Practice Guidelines have influenced service provision for parents with learning disabilities across Scotland. The survey indicates that 87% of respondents were aware of the guidelines and that 79% used them in their everyday practice.

Respondents believe that the guidelines have influenced their practice in a number of ways, with a particular focus on ensuring that practice is non-discriminatory and safeguards the rights of parents and their children. This can involve ensuring meaningful participation for parents, the provision of accessible information alongside practical support to enable parents to attend meetings such as the availability of crèche facilities or provision of transport.

The guidelines have proved useful in raising awareness of the particular issues faced by parents with learning disabilities and have promoted “*an acknowledgement that the parent’s rights are as important as the rights of the child*”. The guidelines have also been used to promote good practice with other professionals.

### **Progress towards supported parenting**

#### **Support should be provided pre-birth**

Good progress has been made in this area and the study has identified a number of examples of good practice in supporting parents to prepare for the birth of a child. A number of challenges remain in ensuring that parents are identified at an early stage with respondents noting reluctance amongst some professionals to label parents as having a learning disability as well as a reluctance amongst some parents to come forward to access support for fear of having their child removed. Concern over the required resources may also limit consideration of early intervention.

#### **Support should be ongoing**

While it was recognised that this long term support was essential to enable parents with learning disabilities to parent effectively, it was often not available and was identified as a major gap by many of the respondents. The lack of available support services to refer people onto after short term intensive interventions ceased was thought to be particularly problematic. Undermining the gains that had been made during a period of early intervention and the creation of further crisis was of specific concern. Postnatal services in particular were felt to require further development and it was acknowledged that as children move through the stages of development, support is required to help parents adapt their parenting strategies. This gap was likely due to the resource implications of providing often intensive support on an on-going basis as well as a lack of clarity around whose responsibility it was to fund and provide this support.

#### **Support should be strengths based**

Given the challenges identified in promoting a model of early intervention for parents with learning disabilities, the support that is often provided tends to be crisis driven resulting in a deficit model being adopted that focuses on what a parent cannot do as opposed to what they can. Grouping together a number of the supported parenting principles suggests that a strengths based approach should be taken. This involves:

- respect for parents
- viewing the family as a resource rather than part of the problem
- parents being in control and experiencing being competent
- building on strengths.

Some respondents suggested a reluctance to put such support in place *“if the child is going to end up being removed anyway...we are just building up false expectations”*. This suggests negative attitudes towards parents with learning disabilities ability to parent remain. Specialist assessment tools allow professionals to identify the strengths a parent or family can bring to the parenting relationship but they do not necessarily allow for the provision of support to tackle any gaps that are identified. Residential settings to provide parents with intensive support as their parenting capacity was assessed were considered appropriate by a number of respondents. Advocacy was also considered to be a way of ensuring the parent’s strengths were clearly identified and communicated. Appropriate parenting programmes such as Mellow were also considered to aid in identifying parent’s strengths and building on them.

### **Support should be for the whole family**

Evidence from the literature review, the survey and the key informant interviews suggests that support that focuses narrowly on one aspect of parenting or on one member of the family is unlikely to result in positive outcomes, hence a whole family approach that focuses on the needs of the parent’s within their social context as well as the needs of the children is strongly advocated for.

Such an approach would also allow staff to focus on the developmental needs of the child *and* the parent without perceiving this to be a conflict of interests. Parenting programmes that incorporate a social aspect and encourage the development of peer-to-peer support outside of class were very highly valued by respondents. For a whole family approach to work a level of joint working is required, the barriers to which have been well rehearsed. Some respondents advocated the creation of jointly funded multi-disciplinary teams that would allow the staff to develop appropriate levels of expertise and skills to support families affected by parental learning disability. It would also allow for the appointment of staff from a range of disciplines, ensuring the appropriate skills mix within the team.

## Conclusion

Bringing together evidence from the literature review, the survey and the key informant interviews identifies a number of very clear messages. 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 will be resource intensive as “good enough support” is likely to be long term and, at times, intensive as children reach particular developmental milestones.

Unless such extensive support is available for the *whole family* parents with learning disabilities will be unlikely to have their children living with them. Using the supported parenting principles as a guide it has been possible to evidence progress towards providing appropriate support for parents with learning disabilities and many examples of good practice have been identified. This support is thought to have a number of key characteristics including the following.

- Support must be long term in nature
- It can 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.

There appears to be a growing body of knowledge and expertise around supporting parents with learning disabilities in Scotland and this is invaluable. 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 learning disabilities. To this end, a training need has been identified as many staff do not yet have this knowledge base, which appears to be developing in an ad hoc way, progressed by champions. This should be viewed as problematic as it can result in inequitable access to high quality support services for parents.

Although this report brings together evidence from a range of sources to highlight good practice, many of the practices or services outlined have not been formally evaluated and so there is a lack of empirical evidence that establishes positive outcomes for parents or children as a result of these interventions. In addition, there are different opinions as to what a positive outcome for a parent with learning disabilities might look like. For example, if a parent’s child is removed from their care but they feel that they were respected and listened to in the process can this be viewed as a positive outcome? Further discussion about what outcomes should be considered is required.

It is recognised that further development is needed to ensure that adequate postnatal support is available at a national level. Currently, much of the good practice that has developed pre-birth and in the early stages after birth is undermined when there is no suitable postnatal support to refer on to. Further challenges exist in relation to the provision of early intervention support which is complicated by the different understandings of learning disability and different definitions that are currently being operationalised across different professional groupings. This may mean that parents have difficulty accessing services or fall between the gaps in services. Other barriers to early intervention include the perceived stigma attached to the label learning disability that is shared by parents and staff alike and the fear that seeking help will result in children being removed from their parents' care.

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. By working together, these teams will be able to offer more consistent support to families and will share consistent messages with parents so that they have a much better understanding of what is expected of them in relation to their parenting role. Such teams will work in close partnership with third sector organisations that already have a proven track record in providing intensive and flexible support to families that traditional health and social work services have been unable to provide.

Alongside the development of these specialist multi-disciplinary teams, 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 disabilities as it currently stands. These pathways must be based on the best available evidence in terms of what works in supporting parents with learning disabilities and while the evidence base in this area is growing, more robust evaluation is needed that focuses on outcomes for parents and children.

## Recommendations

### Prevalance

1. There is a need to establish more accurate prevalence rates of parents with learning disability currently living in Scotland to allow for more effective service planning and delivery. This process may include consideration of standardised coding and reporting across the key stakeholders.
2. A better understanding of the different definitions of learning disability in use is needed in order to gain a clearer sense of the population in question. Targeting identification of those individuals most at risk of receiving little or inadequate support (likely to have an IQ of just above 70) is required. This would help to ensure that a model of crisis intervention is avoided, allowing for intervention at an earlier stage.

### Support Provision

3. A clear, evidence-based pre and post-natal care pathway, which can measure impact and improvement and has been tested by parents should be established. This will minimise the current complex, geographically variable and ad hoc provision that is available.
4. Longer-term, parent centred support that is reflective of individual child development milestones should be developed. This support is likely to be intensive at times, particularly at points of transition, for example during the transition from baby to toddler when a range of new parenting skills and support requirements will be necessary. The current lack of effective long term postnatal support has the potential to undermine the good practice that has been established prenatally and in the early days following the birth of the child.
5. This support should take a whole family approach that focuses on the needs of both the parent and the child. This support must take account of the broader structural and social factors that impact on a person's ability to parent effectively.
6. The best way to structure and organise whole family support is via the creation of jointly funded multi-disciplinary teams involving social workers, community learning disability nurses, nursery nurses, health visitors, midwives, psychologists and occupational therapists. The teams should work in partnership with experienced third sector providers. Such an approach would help to prevent families affected by parental learning disability from falling between the gaps in service provision and should promote better use of early intervention strategies. Existing models of jointly funded support for families should be explored and lessons for good practice identified and disseminated.
7. It is essential to build on the knowledge and expertise that has been established in this area, particularly by third sector organisations. While it is recognised that parents with learning disabilities should be supported to access mainstream services where appropriate, their very specific support needs as well as the value of working together with parents who are experiencing similar issues must be acknowledged and specific targeted interventions developed.

8. A clear, adequately funded accessible information strategy should be put in place to help better meet the information needs of parents with learning disabilities. This strategy should acknowledge the excellent work that has been carried out by individual practitioners and organisations to translate information but should also recognise the piecemeal way in which this work has developed. The strategy should have a governance framework and utilise evidence based materials, where available.

### Awareness raising

9. Greater awareness of the very specific support needs that parents with learning disabilities have is required. This includes the need for specialist tools to assess parenting capacity, accessible information, flexibility, repetition and the modelling of good practice. The good practice identified in this report should be disseminated widely.
10. Specialist training on the needs of parents with learning disabilities and their families should be provided to frontline practitioners, many of whom have limited experience of working with this group. This training should be offered as part of qualifying programmes for social workers, midwives and health visitors but should also be offered as CPD for those professionals wishing to develop additional specialist knowledge.

### Further research

11. Further research is required to establish long term outcomes for families affected by parental learning disability. However careful consideration and discussion of the outcomes to be measured will be required beforehand to ensure that indicators of successful are reasonable and realistic.
12. Additional research is required to illicit the views of parents with learning disabilities about the factors that promote or hinder their ability to parent at a national level.

## Background and aims of the study

The Scottish Government published *The keys to life* in 2013 (Scottish Government, 2013). It set out a national strategy for learning disability services and identified a number of priority areas including supporting parents with learning disabilities. Recommendation 38 stated that by 2014 parents with learning disabilities should have access to local supported parenting services based on the principles of supported parenting as outlined below.

- Support should be available from pre-birth onwards
- Support may need to be ongoing at every stage of the child's development
- Support must be based on respect for the parents and for the emotional bond for the parent and child
- 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.

It also recommended that the “Scottish Good Practice Guidelines for Supporting Parents with a Learning Disability” (SCLD, 2015) should be followed by professionals working with parents with learning disabilities to ensure better outcomes for families. *The keys to life* (Scottish Government, 2015) implementation framework highlighted the importance of the development of effective interventions for parents who have learning disabilities.

These recommendations must be understood in the context of the Children and Young People (Scotland) Act, 2014, Section 12 of which places a duty on Local Authorities to secure services for those children deemed at risk of becoming looked after. The Act states that Local Authorities must secure services for:

- each eligible child living in their area
- a qualifying person in relation to such child
- each eligible pregnant woman residing in its area
- a qualifying person in relation to such women.

An eligible child is described as any child deemed at risk of becoming looked after and a qualifying person is deemed to be someone who is related to the child, who has any parental rights or responsibilities towards the child or someone with whom the child has been or is living. Given what is known about the children of parents with learning disabilities outlined below and in more detail in the literature review of this report, it is likely that there will be circumstances under which these children will be eligible for support under this legislation.

The Act states that any relevant service includes:

- providing information on a matter
- advising or counselling about a matter
- taking any other action to facilitate the addressing of a matter by an individual.

In relation to the third point above, this might include the provision of support to support a parent with learning disabilities to develop their parenting skills or capacity or the provision of advocacy support for example.

Evidence suggests that families where a parent has a learning disability can often have very complex needs due to a large variety of factors including poverty, discrimination, depression, poor self-esteem, and unemployment (Macintyre & Stewart, 2013; Wade, Mildon & Matthews, 2007). In addition to having complex needs, there is a propensity for parents with learning disabilities to be over-represented in care proceedings (Cox, Kroese & Evans, 2015). Many families that include a parent with learning disabilities are involved with social services and child protection agencies. This is often due to a perception that the parent does not possess the skills and knowledge necessary to parent effectively, rather than 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 a stricter criteria than other parents (Tarleton, 2007) and it is estimated that between 40% and 60% of parents with learning disabilities have their children removed due to them being assessed as being unable to meet an adequate standard of parenting (Wilson et al., 2013). This standard of parenting is often referred to as 'good enough parenting' (Choate & Engstrom, 2014), which acknowledges that parents are not perfect and they can make mistakes.

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. Whilst 'good enough parenting' has been criticised for lacking in clarity (Choate & Engstrom, 2014), it recognises the need for establishing a baseline for assessing parents existing parenting ability, which in turn, provides the opportunity to identify areas where skills and knowledge can be nurtured and developed (Scottish Government, 2008). Several of the skills and knowledge synonymous with being a 'good enough parent' have been found to be lacking in some parents with learning disabilities including the ability to provide a safe home environment, adequate nutrition, positive and nurturing interactions, being able to recognise and treat medical emergencies and having a basic understanding of child development (Feldman, 2004). Yet, when provided with enough support, many parents with learning disabilities can improve their skills and knowledge and learn to parent more effectively (Murphy & Feldman 2002; Coren, Thomae & Hutchfield, 2011).

The National Parenting Strategy (Scottish Government, 2012ba) and Getting it Right for Every Child (GIRFEC; Scottish Government, 2012b) both acknowledge that parents and families should be provided with the support they need at the earliest opportunity. However, unlike The keys to life (Scottish Government, 2013) and the refreshed Scottish Good Practice Guidelines for Supporting Parents with Learning Disability, entitled '*Supported Parenting*' (SGP; SCLD, 2015), there is no specific mention of (or guidance for working with) parents with learning disabilities within the national strategy.

The Scottish Good Practice Guidelines advise that the main features of good support provision for parents with learning disabilities are:

- accessible information and communication
- clear and co-ordinated referral and assessment procedures and processes eligibility criteria and care pathways
- support designed to meet the needs of parents and children based on assessments of their needs and strengths
- long term support where necessary
- access to independent advocacy.

(SCLD, 2015).

Yet in practice, it is not clear whether or not this level of support is available nationally (Scottish Government, 2013). There is however a range of good practice being undertaken with parents with learning disabilities across Scotland. This work includes but is not limited to: the development of easy read material associated with assessment and the children's hearing system, models of early intervention to promote preventative practice and the creation of care pathways to support parents with learning disabilities throughout their journey (for example the pre-natal pathway in Fife). The extent of this good practice is largely unknown as are the outcomes of these approaches for the parents with learning disabilities for whom the services and supports are provided.

This study will therefore explore progress made following the publication of the national strategy by addressing the following research questions:

- 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 Scottish Good Practice Guidelines for supporting parents with learning disabilities?
- What outcomes are being achieved for parents with learning disabilities from the perspective of key contacts?

## 4. Methodology

### 4.1 Stage 1- collection of baseline data

At the time of undertaking the research there was no information held nationally about the range of supports and services that were available for parents with learning disabilities. In order to gather baseline data an online survey was constructed using *Qualtrics* software to be distributed across all local authority (32) and health board (15) areas in Scotland. The aim was to identify services provided by the statutory sector alongside those commissioned services in the voluntary and private service. Work was carried out in advance of the distribution of the survey in collaboration with members of the Working Together with Parents Network in Scotland alongside the Learning Disability sub-committee and the Children and Families sub-committee of Social Work Scotland to identify key contacts in each agency. The survey was distributed via the following networks:

- Social Work Scotland Learning Disabilities Subgroup
- Social Work Scotland Children and Families Subgroup
- Working Together with Parents Network
- Heads of Midwifery Services
- Lead Nurses Group.

A snowballing technique was also used and the survey was sent to relevant people as recommended by initial respondents. Exact figures cannot be provided as the survey was not sent directly by the researchers but was sent via the bodies outlined above, who were not always able to share details of their mailing lists to preserve the anonymity of respondents. A total of 42 completed surveys were returned. This limited response can be attributed to the use of external mailing lists where a significant number of potential respondents were no longer in post as well as a lack of centrally held data. For example, there is no centrally held information about community learning disability teams across Scotland. In addition, the survey was distributed during a key holiday period, with a very tight turnaround time making it difficult to follow up potential respondents as persistently as would have been possible otherwise.

The survey addressed the following key areas.

- The process of identifying parents with learning disabilities;
- The range of services and supports available including identification of any gaps in provision;
- Awareness of the Scottish Good Practice Guidelines and the extent to which these inform practice;
- Understanding of supported parenting principles;
- Identification of good practice.

Respondents were given ten days to respond to the survey and were reminded after a further seven days. The researchers were as flexible as possible in their attempts to increase the number of responses, urging those who had responded to pass the details of the survey onto other relevant sources as noted above.

## **4.2 Stage 2 - telephone interviews with key informants**

Based on an analysis of the responses to the survey, areas with significant levels of activity in supporting parents with learning disabilities were identified. Follow up telephone interviews were carried out with thirteen key informants across four geographical areas (Glasgow, Edinburgh, Fife and Ayrshire). In each of those areas attempts were made to ensure representation across social work, health and third sector staff. The following interviews were completed:

- health (n=6)
- social work (n=2)
- third sector (n=5).

The purpose of the interviews was to explore in more depth the ways in which the principles of supported parenting and use of the Scottish Good Practice Guidelines underpin the services and supports currently being provided. This enabled the identification of good practice as well as identifying areas for further development. The interviews enabled key informants to expand upon the key themes which emerged from the analysis of the stage one data. This allowed the researchers to explore the extent to which the emerging themes from the survey made sense to respondents from a practice perspective. This included issues around definitions of learning disability and eligibility criteria, the identification of parents with learning disabilities, opportunities for early intervention, the use of generic or specialist parenting services, issues around assessment of parenting capacity, identification of good practice and gaps in service provision.

## **4.3 Data Analysis**

The survey generated quantifiable data that was analysed statistically using basic descriptive statistics and the tools within the software designed for this purpose. A significant amount of the data collected was qualitative in nature given the aims of the survey to identify good practice and gaps in provision. Data from both the survey and the key informant interviews was therefore analysed thematically (Miles and Huberman 1994). This involved taking a middle order approach that involved working with the themes that emerged from the review of literature and from the questions asked in the survey and using these as a framework to organise the data. The data was then interrogated to identify further themes and sub-themes contained therein. This analysis informed the construction of the interview schedule for use with the key informants identified above to ensure the emerging data could be explored in more depth during the interview phase of the project. These telephone interviews were partially transcribed and further thematic analysis was undertaken in order to confirm and illustrate themes already identified and highlight further emerging themes.

## 4.4 Ethical approval

The methodology described above received ethical approval from the School of Social Work and Social Policy Ethics Committee at the University of Strathclyde. Careful consideration was taken to ensure the protection of participants from harm with a particular focus on the provision of information to ensure respondents were able to provide informed consent to participate in the study. Care was also taken to ensure that the confidentiality of respondents was protected at all times. To this end, the names of individuals have not been included in this report, and quotes have not been directly attributed to particular participants. Where examples of good practice have identified a particular service or locality, appropriate permissions have been sought from those involved to reproduce the data. This is also the case for the range of services identified in appended templates.

## 4.5 Limitations

Whilst every attempt has been made to contact all relevant agencies who may provide services to parents with learning disabilities, centrally held data is not available for a number of services – such as community learning disability teams. It is acknowledged therefore that the survey may not have reached every potential respondent. It should also be acknowledged therefore that the responses to the survey and consequent interviews were limited. This means that the findings from the scoping exercise may not be generalizable. In addition, due to resource and time constraints it was not possible to include the views of parents with learning disabilities in this scoping exercise. Further research is required to redress this balance.

## Literature review

A review of the literature was carried out to identify what is known about supporting parents with learning disabilities. The review focused on identifying examples of good practice as well as providing evidence of what worked in supporting parents. An initial search for articles using a number of different terms for example 'parents with learning disab\*', 'learning difficult\*', 'parent skills programme', 'parenting intervention', on different databases including Strathclyde library online search facility, ebsco, BPS journals, learning disability practice, British journal of learning disabilities, google scholar. Following this a snowball technique was used. Thereafter the research articles found on the initial search were screened for their relevancy. A note was taken of any other relevant studies mentioned within the relevant papers and then searched and screened. Therefore, the technique used could be characterized as an initial targeted search followed by a snowball search.

As mentioned in the introduction to this report, the principles of supported parenting are as follows.

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

The refreshed Good Practice Guidelines also advised that the main features of good support provision for parents with learning disabilities are; support that is tailored for each family's needs and strengths, the provision of accessible information and communication, having access to long-term support and independent advocacy, and partnership working between agencies involved with the family (SCLD, 2015). Yet in practice, this level of support does not tend to happen (Scottish Government, 2013). This literature review therefore aims to scope research that incorporates the core elements of the principles of supported parenting, namely evidenced based parenting support programmes, accessible information provision, access to long-term support and independent advocacy and partnership working between agencies involved with a family.

## 5.1 Evidence based supported parenting programmes

In terms of existing literature, supported parenting can be seen in evidenced-based parenting support programmes that are in place to develop parents existing skills. Evidence-based parenting support programmes, tailored for parents with learning disabilities, have been shown to provide the level of support parents with learning disability need to help them parent more effectively (e.g. Bauer, 2014; Booth & Booth, 2003; Feldman, 2004). The importance of evidenced-based parenting programmes is to ensure that support provided to families is based on sound empirical research, theory and best practice (Gow, 2000). Examples of such empirically based parenting programmes include home-based learning programmes, e.g. Self-directed Learning (SDL; Feldman, 2004), group-based learning programmes e.g. Supported Learning Parenting Programme (Booth & Booth, 2003), and a combination of both, e.g. Mellow Futures (Tarleton, 2014). Each programme is tailored for parents with learning disabilities but they vary in the age and stage of the children they are targeting and the duration of the support they are providing.

SDL is a self-directed skills-based parenting programme that targets families with children aged from birth until 5 years old. The programme builds on existing skills that parents have, provides accessible information to help with parent's understanding of the skills being taught and repetition and support for the skills that parents are struggling to learn. The programme aims to reach a large number of families and, because it removes the need for intensive training and support, it is said to be cost effective. SDL was part of a Parent Enhancement Program (PEP) developed by the Surrey Place Centre in Toronto, which provides community services to people with intellectual disability (based on the DSM-IV definition of mental retardation and including an IQ less than 70). The programme was implemented by PEP therapists, who had undergraduate or graduate degrees in either psychology, nursing or early childhood education. Feldman (2004) summarises the results of three studies that implemented an SDL programme (i.e. Feldman & Case, 1997; Feldman & Case 1999; Feldman et al., 1999). A combined total of 33 families with a parent with learning disability (30 mothers, 5 fathers) were involved, 79% of whom were known to child protection services.

The SDL programme involved parents undertaking a parenting skills assessment to establish their existing strengths and identify their current needs (by having their baseline performance monitored), being provided with a handbook to support their SDL and having their skill development monitored. The handbook incorporated checklists for 25 basic childcare skills, that were pertinent for children from birth to 5 years old (e.g. preparing a bath), and manuals with pictorial instructions relating to those skills. The use of pictures is one of the main features of easy-read guidelines for making information more accessible. In addition to pictorial checklists, audio tapes were also given to parents with literacy difficulties. Initial training was provided to all parents on the use of the handbook (and audio where applicable).

Skills were monitored weekly, until the 80% criterion level was reached over two consecutive visits (the level of skill was measured by dividing the number of correctly performed steps from the skill checklist by the total number of steps, multiplied by 100). However, if parental performance did not improve within seven visits, full teacher-led training was provided (i.e. prompting, modelling, praise and feedback).

Across all three studies, 31 out of 33 parents reached criterion on at least 1 skill through self-learning alone and parents achieved a high degree of success with 96% of the skills being reached without additional teacher-led training being required and the vast majority of parents quickly meeting a performance level comparable to known competent parents. Prompts were used with 12 parents due to performance either dropping below the criterion level or due to parents not using the manual, and full training was provided to 2 parents to help them meet the criterion level.

Follow-up only began once the criterion had been reached, during such time the monitoring of skills was gradually reduced from weekly to every 6 months. In follow-up across the 3 studies, the criterion level was maintained over a number of months (the level means ranging between 82 to 91% over 4 to 11.9 months). At follow-up, 30 parents managed to maintain criterion on at least one skill via self-learning, two parents were unable to maintain criterion on any skill via self learning and one parent required full training to reach criterion levels.

Whilst self-directed learning may be able to reach a wide number of parents due to cost efficiency and is successful in parental skills development, it is unknown what impact it has on other aspects of the parents lives (e.g. their parent-efficacy, self-esteem) or additional skills (e.g. managing their child's behaviour) or indeed how it impacts on their children's lives. Furthermore, self-directed learning on its own does not provide the peer social support that group-interventions can provide, which is an aspect that has been found to be very important for parents with learning disabilities (Booth & Booth, 2003; Tarleton & Porter, 2012). In addition, whilst the programme established what the parents learning need was, it was not explicit in how it worked with the parents strengths.

As well as self-directed home-based learning programmes, there are also programmes built around group-based interventions. The Supported Learning Parenting programme (SLP; Booth & Booth, 2003) provided group-based support to 31 mothers with learning disabilities (18 mothers were involved for 18 months or longer and 4 joined 6 months before the end of the project) to help them with parenting, their self-advocacy development (e.g. to be more assertive and to help them recognise their own strengths), and to meet the needs of their children (age and stage of children not specified). Mothers were targeted due to parents with learning disabilities tending to be mothers who either are lone parents or are with a partner without learning disabilities. The programme consisted of weekly learning support groups, day or evening courses and activities, guidance and support for accessing educational courses, and also fostered mentoring support between the mothers. 28 of the mothers (16 of which attended regularly) attended the weekly support group and/ or group activities (there were 680 held in total with an average of 41 being attended by regular participants) and 20 mothers participated in learning activities (e.g. cookery classes, driving lessons and assertiveness classes).

The weekly support group was run by parents for parents, the learning activities were conducted outwith the group and attendance was determined by each mother's own circumstances and preferences, e.g. only five women attended any sessions of a 10-week assertiveness class, which was fully completed by two parents. Whilst there was no discussion about home-based interventions versus group-based interventions,

the outcomes specific to the group setting were the relationships fostered with other mothers, the support received from the group and, due to 'getting out of the house', life being more enjoyable. Each mother's portfolio, which was updated at least weekly with each mother being encouraged to help maintain their own, was used to assess the gains each mother achieved from the SLP and whilst 15 mothers joined college courses, six gained employment, six gained voluntary experience and seven moved into a house of their own (either through separation from a partner or leaving their parental home). Booth and Booth (2003) suggest that whilst most of the progress made may have appeared minor e.g. being able to shop on their own, going on holiday or taking driving lessons, its true impact can only be fully understood when considering it within the context of each parent's life. Whilst the study was not explicit about how it worked with the mothers' strengths, it did give consideration to each parent's individual needs by providing flexibility around which groups mothers wished to attend. The social aspect of this intervention has shown success in helping mothers transition into education and employment and illustrates the benefits that group work can have in developing the confidence and social skills to make that transition.

Another parenting programme built on group-based learning but also incorporated home-based support is Mellow Futures, which has been designed by Mellow Parenting, a Scottish based charity that delivers six programmes from pre-birth to help vulnerable parents and families who may have parent-child relationship problems, mental health issues, social care needs and child protection issues (Mellow, n.d.). As well as Mellow Futures, the programmes include Mellow Bumps (pre-birth), Mellow Bumps and Dad Matters, Mellow Babies (birth to 18 months), Mellow Toddlers (18 months up to 5 years), and Mellow Mums and Dads, with each programme having its foundation in attachment and social learning theory. Whilst the evidence base for the Mellow programmes is still developing (e.g. Macbeth et al., 2015; Puckering et al., 2010; Scourfield et al., 2014), they have been shown to improve parent and child interactions, child development, behaviour and language acquisition for children and the wellbeing, effectiveness, self-esteem and confidence of parents (Mellow Parenting, n.d.).

Mellow Futures has been tailored specifically for parents with learning disabilities and/or difficulties and is a perinatal programme, in that it runs antenatally for 2 hours per week for 6 weeks and 1 day per week for 14 weeks postnatal, and uses a combination of mentoring and peer support to address the issues that parents with learning disabilities face (Mellow Parenting, n.d.). Tarleton (2014) conducted an interim evaluation of the Parents as Pioneers project that implemented a Mellow Futures pilot incorporating Mellow Bumps (6-week antenatal course) and Mellow Babies (14-week postnatal course) across two areas in England. The Mellow Futures pilot entailed the parents attending a weekly group session as well as each parent being paired up with a volunteer mentor who would support parents in their own homes with their learning and connect them with local community supports. The evaluation consisted of mothers being interviewed by the researcher up to 4 times during the course of the pilot and Tarleton (2014) advises there will be a further final interview at the programme reunion, which has yet to be reported. Fourteen mothers (out of 17) participated in the evaluation, five (out of five) of whom completed Mellow Bumps and nine (out of 13) completed Mellow Babies. Three of the mothers completed both programmes. All but one mother enjoyed the Mellow Bumps programme, they liked and trusted the facilitators and enjoyed friendships with other mothers, albeit they did not keep in

touch with each other during the 3-month break between Mellow Bumps finishing and Mellow Babies beginning (during which time the Mellow Bump mothers had given birth and were adjusting to their new babies).

All mothers viewed the Mellow Babies programme positively and fostered good relationships with the facilitators, they felt the programme helped them understand their babies better, helped them address past and current issues in their lives, increased their confidence, and they valued the peer support from other mothers in similar situations. Whilst the majority of mothers felt their relationship with their mentor was supportive, two did not 'see the point' of them and did not want to engage, with one criticising their mentor for not being a parent themselves. The role of the mentor was also unclear for one parent who thought they were there for their child as opposed to them. The materials used for the programme's activities were, in the main, accessible, but some were felt as 'babyish' by some parents, e.g. using pass-the-parcel as a means for parents to say something positive about themselves each time it was their turn to unwrap the parcel.

The common outcome running through each of the parenting programmes discussed above is that they have all shown positive relatively short-term results in helping parents to develop the skills they need and have been relatively successful in supporting parents with learning disabilities and/or difficulty in different aspects of their lives. However, the successes being reported are short term with some results actually being reported during the course of the intervention (e.g. Tarleton, 2007) and others being reported around 7 months after the intervention was implemented (Feldman, 2004).

## 5.2 Long-term outcomes

Whilst there is an increasing, albeit limited, evidence base surrounding the short-term benefits of supporting parents with learning disabilities in their role as parents, there is a dearth of research regarding the longer-term outcomes especially for programmes specific to parents with learning disabilities. One study reporting both short-term and long-term outcomes (follow-up 1 year later), albeit not specific to parents with learning disabilities, was the Parenting Early Intervention Programme Evaluation (PEIPE) conducted by Lindsay et al (2011). They aimed to evaluate the effectiveness of five parenting programmes that were selected by the UK Government to be implemented within 150 local authorities in England between 2008 and 2011; 43 local authorities participated in the evaluation. The programmes were aimed at parents of children aged 8-13 (either with behavioural problems or at risk of them) due to that age range being judged as tending to have lower levels of support available to them as younger or older age groups. The mean age for 5,605 (out of 6,143; data was missing for 538 children) children involved was 8.3 years old (SD 3.9 years) so whilst local authorities prioritised this age range some included younger children (54% were in the prioritised 8-13 age range).

The project used questionnaires to collect pre-programme data from 6,143 parents, post-programme data from 3325 parents and to conduct a one-year follow-up with 212 parents (representative of those who completed the programmes). The parents involved were considered to be more disadvantaged than the general population, e.g. living in poverty and isolation, single parent and low education. These disadvantages are similar to those that some parents with learning disabilities experience.

The programmes involved were the Positive Parenting Program (Triple P; Age Range 0-16 years; originated from Australia), the Incredible Years (Age Range 8-13 years; originated from USA), Strengthening Families Programme (SFP; Age Range 10-14 years; originated from USA), and Strengthening Families, Strengthening Communities (SFSC; Age Range 3-18 years; originated from USA) and Families and Schools Together (FAST; Age Range 3-18 years; originated from USA). However, FAST was excluded from their final analysis due to the lack of questionnaires returned.

The four remaining programmes (Triple P, SFP, SFSC and The Incredible Years) showed improved outcomes for parents and their children, which were maintained up to 1 year after the project ended and the outcomes were positive for parents of both older and younger children. The overall short-term outcomes saw improvements in parent's mental well-being (79% of parents), in parenting 'laxness' (74% of parents), a reduction in over-reactivity (77% of parents) and a reduction in the number of parents that had previously considered their child as having serious behavioural issues (19% less parents). The majority of parents found the group helpful (98%). The programme helped them deal with their problems (95%), helped with their children's behaviour (95%) and they experienced fewer problems since the programme completed (98%). In the 1-year follow-up, the longer-term outcomes were the maintenance of improvements in parent 'laxness' and child behaviour, and parents' mental well-being still remained higher than at the beginning of the programmes but had shown a small reduction. Although, it is concerning that parents' mental well-being had already started to show a decline, it is positive in that the majority of the parents were still benefitting one year on from the support they received during the programme. However, research generally has been criticised for being deficient in data regarding the impacts of parenting programmes on children (Wilson et al., 2013).

### **5.3 Impact of parenting interventions on children**

Evidence relating to outcomes for children of parents with learning disabilities is limited and unclear. Whilst, a few studies suggest that living with a parent with a learning disability can have adverse consequences for children, such as having an increased risk of child developmental delays and speech and language problems (Emerson & Brigham, 2014), health, developmental and behavioural problems (Feldman, 2004), these outcomes can be dependent upon a number of other different factors and not necessarily down to parental learning disability. Collings and Llewellyn (2012) conducted a literature review focussing on the outcomes for children with parents with learning disabilities. They highlight that research tends to focus on children under five years whose parents may already be displaying difficulties and vulnerabilities in their parenting role. They found that research is very limited, lacks longitudinal studies, and tends to focus on children's cognitive development, health and behaviour. They also found a lack of consensus in the results with some studies suggesting that having a parent with a learning disability can have a negative impact for their children whereas other studies suggest this is influenced by other factors including parents' own childhood experience of parenting, poverty and isolation. Whilst one of the main findings were that children experienced social exclusion, bullying and stigma, only one study included reports from the children themselves and only included a small number of children (i.e. Faureholme, 2010).

Faureholme (2010) conducted a longitudinal qualitative study on 23 Danish children of parents with learning disabilities over a 10-year period (1994 to 2004), with each child being interviewed twice. The children were aged 8-12 years at the first interview and 18-22 at the second interview. Six children were moved into permanent foster care and most received an element of special education, which was held outwith the classroom of their peers. Some children reported feeling 'humiliated' at being removed from the classroom and 'degraded' for not learning the same subjects at the same time and pace as fellow pupils and this resulted in many advising of the additional effort they expended in an attempt to help their siblings avoid experiencing special education, e.g. encouraging siblings to do their homework. The children also spoke about experiencing bullying, isolation and stigma within the education system. Overall, while some evidence exists that explores the possible impact of having a parent with a learning disability, it is inconclusive and, similarly, research that looks at the effects of parenting programmes on the outcomes for children has also yet to be established (Wilson et al, 2013).

#### **5.4 Provision of accessible information for parents with learning disabilities**

Another disadvantage parents with learning disabilities can face is not having access to information that is presented in a way that they can understand, and the information not being issued timeously. In reference to parents having access to accessible information, the Scottish Good Practice guidelines advise that services should make communication and information accessible to parents with learning disabilities and, under the Equality Act (2010), services also have a legal obligation to do so. NHS Scotland took the step to make the three easy-read CHANGE resources available to parents with learning disability free of charge (Lewis, Wood & Cruikshank, 2011). The CHANGE resources, *'My pregnancy, my choice'* and *'You and your baby 0-1'* were available from 2009 and *'You and your little child 1-5'* from 2010, and they are the easy read equivalent of *'Ready Steady Baby!'* (pregnancy to 1 year old) and *'Ready, Steady Toddler!'* (1 to 5 years old), which are free resource guides already provided to mothers by midwives and health visitors (Lewis et al, 2011; Reece & Porter, 2011). An evaluation on the use and implementation of the CHANGE resources was conducted by Lewis et al., who interviewed 11 parents with learning disabilities and held a focus group with an additional seven parents. They found that parents were not getting access to the CHANGE resources as readily as NHS Scotland intended with only five parents having received a copy (two of which did not receive the next stage of the resource as their child developed). However, all parents were positive about the resources and most commented on the inaccessible nature of the *'Ready Steady...'* resources. Lewis et al, (2011) also found that professionals involved with parents had a lack of awareness regarding the resources and there was no clear distribution pathway for the resources.

The lack of accessible resources means that parents with learning disabilities may be missing crucial advice and guidance and may therefore not be as informed and forewarned as other parents regarding issues surrounding pregnancy and parenting young children. Furthermore, the lack of accessible information also has the potential to have considerable implications for parents to understand and fully engage with processes that can have life-altering outcomes for them and their children.

In relation to information not being issued timeously, Dale (2004) and MacIntyre and Stewart (2011) report that information issued to parents regarding the child protection process can be high in volume, difficult to understand and issued at short notice, with some information even being handed over during meetings with the expectation parents will absorb it there and then. Information being handed over for comment during meetings of such importance is very concerning considering the parent receiving it may not be able to understand it or have time to absorb it or its implications. To this end, MacIntyre and Stewart (2011) not only recommend the input of additional services such as advocacy to support parents through the child protection process but also for supports to be long term where needed.

## 5.5 Support to navigate different care arrangements and proceedings

Children of parents who have learning disabilities and/or who need support with parenting can be seen as vulnerable. In Scotland, vulnerable children supervised by the local authority are known as 'looked after' children and are the subject of a supervision requirement either with or without residence restrictions. A supervision requirement *without* residence restrictions is also known as a Home Supervision Requirement (HSR) and is unique in Scotland (Gadda & Fitzpatrick, 2012). The HSR means that children can remain in their own homes with their parent or guardian but a social worker will ensure that the terms of the requirement are met (Gadda & Fitzpatrick, 2012). In cases where children are unable to remain in the family home, a supervision requirement with restrictions (SRR) means that children will be accommodated elsewhere, e.g. foster care or residential homes. Under Section 25 of the Children (Scotland) Act 1995, an SRR can be voluntary or enforced on the parent by the local authority (Scottish Government, 2012c). A voluntary agreement is when a parent agrees to their child being removed until such time as it is appropriate for them to be returned or, in some instances, until the child is eventually permanently placed elsewhere if the supervision requirements are left unmet. In relation to enforced removal, parental consent is not required and involves the local authority applying to have a child removed from their family home due to them being perceived as being at risk from significant harm (McGhee & Francis, 2003). Enforced removal is granted either through the Children's Hearing system or through a warrant from the Sheriff Court (Scottish Government, 2012c).

If a looked after child cannot remain under the care of the parent, the local authority may place them in the care of family or friends, this is known as Kinship care. Aldgate and McIntosh (2006) conducted a study of children who were in kinship care in Scotland. The study comprised of a national survey of the policies and practices for children in kinship care across the 32 local authorities in Scotland, and a study of 30 children within 5 local authorities who were living in long-term kinship care in 24 families. Children were placed in kinship care due to neglect through substance misuse ( $n=20$ ), neglect/abuse unrelated to substance misuse ( $n=3$ ), the death of a parent ( $n=3$ ) or parent mental health issues ( $n=4$ ). The majority of carers were grandparents (16 out of 24) and over half of all carers were living on benefits. It found that carers were motivated to keep their kin out of 'stranger' care and by their familial obligations to support the parents by looking after their children. Kinship care allowed children to keep in contact with their families and siblings and minimised the shock of separation from their parent.

Regardless of whether a child is looked after at home or elsewhere, the child protection process can be long, complicated and involve many stages (McRae, 2006). It is therefore important that parents fully understand why they are subject to child protection proceedings, what steps they can take to improve their situation for themselves and their children, what the process involves and what the implications of each stage of the process are. Unfortunately, research has shown that parents with learning disabilities often do not receive enough support in protection hearings (Cox et al., 2015; McConnell & Bjorg Sigurjonsdottir, 2010). Therefore having access to support services like advocacy, that can help parents understand information that can be difficult and complex, is vital for some parents with learning disabilities.

## **5.6 Access to independent advocacy**

Access to advocacy services is also a recommendation of the SGP guidelines. Advocacy can help parents in many aspects of their lives including the child protection process, and has not only been shown to be cost effective (Bauer et al, 2014) but has also been shown to help improve outcomes for parents with learning disabilities. Macintyre and Stewart (2011) conducted a mixed methods pilot study to investigate the role of advocacy on the lived experiences of parents with learning disabilities by issuing a questionnaire to service providers and conducting interviews with five parents with learning disabilities and their advocates (interviews with advocates were conducted separately). They found that advocates played a key role in helping parents understand information, have their voices heard, and feel more confident in challenging decisions.

However, access to advocacy for parents with learning disabilities has been found to be variable. Hartworth (2012) found there to be a reduction in the number of advocacy services available to support parents with learning disabilities within Newcastle upon Tyne. They found that this group of parents primarily need support with child protection proceedings, which are lengthy and time intensive for advocacy staff. However, funding cuts and the scarcity of available funding sources has meant advocacy services are less able to take on lengthy advocacy cases (Hartworth, 2012). This therefore 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. In Scotland there is a legal duty to provide advocacy services for adults subject to certain compulsory measures (such as a compulsory treatment order under the Mental Health (Care and Treatment) (Scotland) Act, 2003) and it is considered good practice to ensure advocacy provision is available for other vulnerable groups, such as parents with learning disabilities (Stewart and MacIntyre, 2013). The Scottish Independent Advocacy Alliance provide detailed information about advocacy provision across Scotland.

## **5.7 Partnership working between agencies**

All services supporting parents, whether it is advocacy, social work, NHS or education, should be working in partnership. As well as being one of the main features of the Scottish Good Practice Guidelines, partnership working between agencies is also one of the ten key components of GIRFEC (Scottish Government, 2012) and is promoted legislatively by the Scottish Government in the Public Bodies (Joint Working) (Scotland) Act 2014. Partnership working helps professionals to develop a shared understanding,

within their own organisations and across other agencies involved with the families, of the needs of the children and their families. In addition, effective communication and shared recording across all partners helps to reduce the overall risk as all services are informed of the whole picture and not just their own particular area. However, effective partnership working takes time to develop that is not necessarily afforded to social workers, especially in times of austerity, and can result in relationships between social workers, other services and service users being underdeveloped, contributing to poor decision making (O'Connor & Leonard, 2014). Unfortunately, the issue of time pressures is common across NHS and local authority services, and is not necessarily exclusive to social workers.

As well as partnership working within their own organisations, staff should be trained in the needs of parents with learning disabilities in order for them to understand and appreciate the issues they face and their complex needs (Cox, Kroes & Evans, 2015). Cox et al., interviewed 11 legal professionals (8 solicitors and 3 legal executives) with experience of representing parents with Learning Disabilities to child protection hearings in England and Wales, and held a focus group with six of those interviewed. The legal professionals raised concerns about the key role social workers and their assessments play in care proceedings as it was felt that, whilst there were some excellent social workers, there were also those with a negative attitude and who lacked the skills, knowledge and experience of working with parents with learning disabilities and these influenced their assessments. It was also suggested that the process was prejudiced against people with learning disabilities and some social workers seemed to be biased in their evidence selection by tending to choose evidence supporting their case whilst ignoring evidence that did not. The study recommended for professionals involved with parents with learning disabilities to undergo specific training in order to alleviate the bias towards removing children from their parents. This not only highlights the relevance of the role independent advocacy could have in the child protection process (as mentioned earlier), but also highlights the importance of partnership working so that a fuller picture of the family circumstances can be established rather than just relying on one viewpoint.

GIRFEC guidelines stipulate that partnership working between professionals is essential for enabling early intervention support for families when they first experience difficulty, rather than when they have reached crisis. GIRFEC also recommends the selection of a lead professional to 'co-ordinate and monitor multi-agency activity' (p.7). However, deciding on who the lead professional should be is not necessarily straightforward, and even more basic issues can exist with regard to identifying appropriate sources of support. Hartworth (2012) found that health professionals based in Newcastle upon Tyne found it difficult to decide which agency should provide services (i.e. health or local authority) to parents with a learning disability and which professionals within those organisation should be involved, e.g. nurses, health visitors, and social workers. Similarly, the local authority professionals reported difficulty in deciding which local authority service was responsible for providing support to families (i.e. Child or Adult services) and raised concerns about the conflict between addressing the support needs of the parent and safeguarding the child. This safeguarding/support conflict experienced by professionals is also reported in more recent research, e.g. Tarleton and Porter (2012) who refer to the valley between adult and children services as 'no-man's land'.

## 5.8 A whole family approach

Tarleton and Porter (2012) conducted an evaluation of the role of the Valuing Parents Support Service (VPSS), a specialist Parent with Learning Disability Team. VPSS is a joint project between child and adult services of Medway Council in Kent. The VPSS service uses a 'Think Family' approach (Social Exclusion Taskforce, 2007) and was developed in accordance with the Good Practice Guidance on Working with Parents with Learning Disabilities (Department of Health and Department for Education and Skills, 2007) and Finding the Right Support? (Tarleton et al., 2006). The service is aimed at parents with learning disabilities with children under 8 years old, with a view to providing a holistic approach to family support that considers the needs of the whole family and includes assessment, intervention and support. The service evaluation consisted of a Matching Needs and Services audit, which focused on the child and covers five areas of their lives, i.e. living situation, relationships, behaviour, health and education. The audit compared the outcomes of children and families receiving support from the VPSS to those receiving support from Assessment Service in children's services. In addition, two focus groups were held with 12 parents who were supported by VPSS only (and not the Assessment Service) and twelve professionals also provided feedback via focus groups (7 professionals), telephone interviews (2 professionals) or written responses to questions posed in focus groups (3 professionals).

The focus groups highlighted that parents received support in a range of areas including parenting skills, household support (e.g. shopping, safety and cleanliness), advocacy, facilitating access to mainstream parenting groups, helping parents engage with factors influencing their ability to parent (e.g. domestic violence, housing and grief of having children removed) and signposting to external services where needed. The Matching Needs and Services audit found that children supported by the VPSS had better outcomes than those supported by the Assessment Services, partly due to the tri-level positive partnership working that was implemented in the project, i.e. between the VPSS team and parents, between parents and other services, and between services. The success of the partnerships was attributed to VPSS staff being matched to parents and being described by parents as 'respectful, honest and kind'. VPSS staff were also able to support parents to engage with a wide range of mainstream services including play groups, mother and baby groups, housing and legal services and counselling. These findings were supported in the focus group discussions they had with parents and professionals. Whilst the evaluation reports of using 'easy information' to explain the purpose of the evaluation and consent to those participating, it does not mention accessible information in relation to the support the VPSS provide for parents. In addition to this, an element in the support provision that parents identified as being missing from the VPSS was the need for an on-going parenting group where parents could seek support from parents in similar situations as themselves.

Nonetheless, what is unique about the VPSS parenting service is not only were they able to cross the '*no man's land*' between adult and children services but they have also worked successfully in it. The service provided a holistic support to parents that included elements of advocacy, tailored support provision and partnership working all of which are recommended within the Scottish Good Practice Guidelines for Supporting Parents with a Learning Disability. However, what we do not yet know is the impact that this service and other parenting projects have in the longer-term for parents and their families.

It is clear that if vulnerable parents, regardless of whether they have a learning disability or not, do not get the support they need, it can result in their families being more likely than their peers to experience adverse outcomes (Social Exclusion Taskforce, 2007). Having access to support can provide parents with the opportunities they need to be successful parents. Having the right support has been shown to provide the opportunity for parents to develop their parenting skills and knowledge (e.g. Feldman, 2004), engage with services (e.g. Tarleton & Porter, 2012), and increase their self-esteem and confidence (e.g. Booth and Booth, 2003). There are parenting programmes available that support parents from pre-birth and at earlier stages of children's development (e.g. Mellow Parenting), however there is a dearth of research that discusses ongoing support or support for parents with older children particularly.

## 6. Findings

The findings that are reported below are drawn from the survey data and from the in-depth interviews with key informants. Given the small number of key informant interviews conducted and the small number of specialist services represented, the quotes have not been attributed to particular participants or sectors in order to preserve the anonymity of those involved.

The literature review has highlighted the key aspects of supported parenting that are necessary to promote positive outcomes for parents with learning disabilities while acknowledging the lack of available evidence with regard to longer term outcomes. The provision of tailored support, advocacy services, accessible information, partnership working and peer and social support has been identified as being particularly important. The remainder of this report will assess the extent to which these features are apparent in current service provision across Scotland, identifying examples of good practice as well as gaps and areas for further development. The findings are presented thematically and based on an analysis of data collected as outlined in the methodology section of this report.

### 6.1 Context

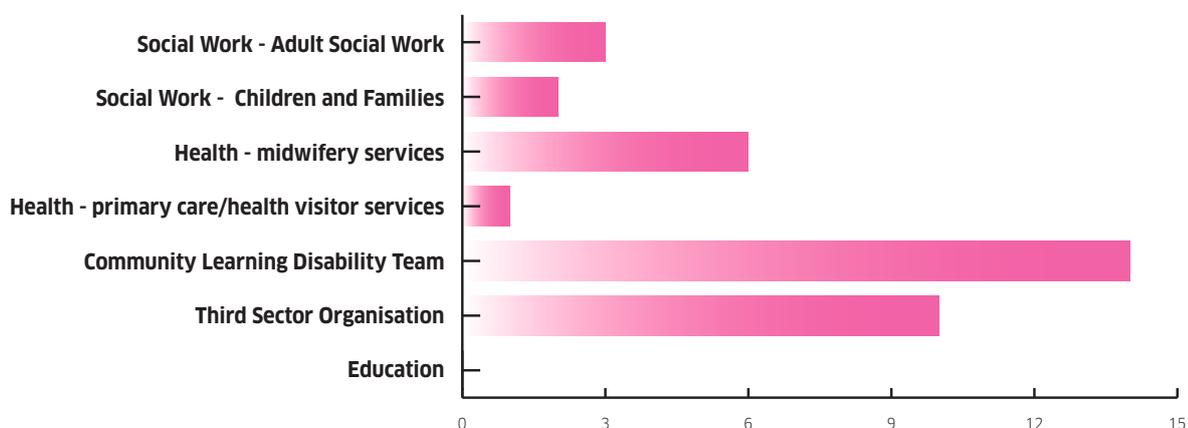
Before considering the key findings, it is necessary to provide contextual information around the completion of the survey. Analysis was based on 42 completed returns from which there was a fairly good spread of disciplines (for example social work, psychology, midwifery, law) and job roles (development manager, frontline practitioner) as well as a fairly even split between those providing generic services targeted at *all* parents (or mothers) or all vulnerable parents (or mothers) and those targeted specifically at those parents with learning disabilities.

The table below provides a breakdown of those who completed the survey (not all respondents answered this question):

Job role	Number
Clinical psychologist	2
Development officer/ coordinator/ manager (third sector)	3
Social work team leader/ manager	4
Occupational therapist	2
Community Learning Disability Manager/ Team Leader	2
Service Manager (Health)	2
Project worker (third sector)	1
Social worker/ Local Area Coordinator	3
Midwifery Manager	1
Midwife	1
Solicitor	1
Community Learning Disability Nurse	4
Health improvement worker	1

**Table 1: Job role of those who completed the survey**

Respondents described the sector they worked in in the following way:



**Table 2: Employment Sector of respondents**

In terms of geographical spread, there was representation from Glasgow, Edinburgh, Fife, Aberdeen, Renfrewshire, Perth and Kinross, Orkney, Shetland, Angus, Tayside, South Ayrshire, East Ayrshire, West Dunbartonshire and South Lanarkshire.

## 6.2 Number of parents with learning disabilities in Scotland

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 population may in fact impact on the availability and range of services provided. The most recent statistical sources in Scotland, the Scottish Census 2011 and the Scottish Government Statistical Information for 2014 (Scottish Government, 2015) indicate that there are also challenges with the data that is collected around people with learning disabilities more generally (Scottish Learning Disability Observatory, 2016). The report of the Scottish Learning Disability Observatory (2016) noted that the discrepancy between different sources was related to the range of definitions used by professionals, alongside dependence on self-reporting either by the individual themselves or by a carer. This discrepancy is further exacerbated by the fact that in some situations, for example whilst at school, there can be advantages in having a 'label' of learning disability to secure additional supports, which might diminish at different points across the life course. Conversely where a 'label' may be viewed as a disadvantage, for example as a parent or a pregnant woman, then adults may resist the 'label' for fear of discrimination. In addition, the statistics collected by Scottish Government on those with learning disability relate solely to those known to local authorities (Scottish Government, 2015). This does not include those where the diagnosis is unclear, those for whom there is no formal diagnosis but an assumption of learning disability or those who are simply not receiving services or supports from local authorities, partly as a result of increasingly high eligibility criteria which may mean people are no longer entitled to support. These concerns regarding reliable statistical data were reflected by respondents in this scoping study, particularly for those concerned with commissioning services.

While some respondents were able to provide information around the number of parents with learning disabilities they supported, the data collected indicates that many agencies do not routinely record parental learning disability. Of those who do, figures range from five to six parents per year to over 40 in a single agency. However, evidence from this scoping study, as discussed in more detail in Section 4.3 of this report, suggests that confusion over terminology and inconsistent use of different diagnostic criteria means that data collected by individual organisations cannot be compared or collated accurately or effectively.

In more general terms, 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). These adults were either 16/17 and in full-time education or aged 18 and over. The most robust figures available suggest that there are more than 53,000 parents with learning disabilities in England (Emerson et al, 2005), although these figures are now somewhat dated. Extrapolating from this data in a Scottish context it is likely that there are around 5,000 parents with learning disabilities in Scotland. The English study on which the parental data is based indicates that many more parents are not known to services and that the actual figure will be significantly higher. It therefore appears likely that this is a growing and often hidden population across the UK. Evidence from an audit of referrals to community learning disability teams in England, supports this assertion (Elvish et al, 2006) by reporting a significant increase in referrals to support parents with learning disabilities.

### 6.3 Definitions of learning disability

To understand this lack of information around the number of parents being supported, it is necessary to understand what survey respondents understood by the term “learning disability” and how this translated to service provision and access to services. Different services had different thresholds for access with some only offering support to those with a diagnosed learning disability (predominantly by using an IQ of less than 70 as a measure) while others offered support to those with “*an assumed or suspected learning disability...as most of our parents have never been formally assessed*”. Others also worked with those with “learning difficulties” or “learning needs”, acknowledging the complexity of life circumstances that were likely to affect this group:

*Some of the people I work with might not have a formally diagnosed learning disability but they are vulnerable because of their lack of understanding...a lot of the girls I work with cannot take in or retain information and they wouldn't be able to concentrate for long enough to read a social work report for example, but they do not necessarily have a formal learning disability*

It is likely that understanding of learning disability and its associated terms varies according to professional background and training and data from the survey suggested a complex referral system that was dependent on the flexibility of the service regarding the need for formal diagnosis or not. Some services did not use a test to establish the presence of learning disability and hence eligibility to the service while others did, introducing a lack of consistency that was thought to be driven by eligibility criteria.

### 6.3.1 Assessment of learning disability

A number of different types of assessment were used to establish the presence of learning disability or not. These included IQ testing (IQ of less than 70) alongside a range of functional assessments. These formal assessments were carried out by clinical psychologists who felt they often were expected to undertake a gate-keeping role to determine access to services. This put psychological services under significant amounts of pressure in terms of workload, hence colleagues from other organisations reported that *“getting the test done in the first place can be really challenging”*. One psychologist who was interviewed for the study reported that around 95% of those referred for assessment do not have a learning disability. Most fall into the borderline category with an IQ of just above 70. This has implications in terms of service provision and support and the psychologist reported that:

*If they do come out of that [the assessment] with an indication that they don't have a learning disability, we can still write the report but we can't work with them going forward. The service is just not available for people where the diagnosis is not given.*

Another psychologist from a different part of the country confirmed this by explaining that:

*If it is a borderline case then we wouldn't see them, we start with cognitive assessment, but if their IQ is above 70 we won't be able to work with them... Colleagues will say they are over stretched so it just isn't possible...They will then be referred back to social work and...are likely to fall through the cracks because of the eligibility criteria...As a clinician I have a duty of care to people so I find it really difficult.*

Where formal testing was not carried out, survey respondents reported using a range of measures or indicators to determine the likely presence of a learning disability. These included:

- previous service use
- attendance at a special school
- requiring “additional help” at school.

In such cases the criteria for access to the service was likely to be wider than formal diagnosis recognising that the category of “learning difficulty” was much broader. There were some benefits to this in terms of enabling work with those people who resisted having the label “learning disability” due to fear of the perceived stigma attached to the label. It was also more likely to include those at the borderline, with an IQ of just above 70. Some organisations or professional disciplines were also reluctant to label people in this way with social work, for example, more likely to use the terms “learning need” or “global developmental delay”.

One respondent suggested that younger people were less likely to have received a formal diagnosis of learning disability as they were less likely to have attended a special school:

*It goes back to their school experience...they are less likely to have picked up a formal diagnosis if they didn't attend a special school...if they were just quiet and bumbling along, the educational psychologist may have classed it as global delay... we see folk who we think have survived through the system without being given a diagnosis.*

The data suggests that the position of those on the borderline, without a formal diagnosis of learning disability is uncertain and they appear more likely to present in crisis. Some services such as the community learning disability team or the adult learning disability team (social work) have been clear that they cannot work with those without a formal diagnosis (and an acknowledged IQ below 70). Other services (such as Equal Say for Parents) have taken a more flexible approach to enable those on the borderline to receive support. Some respondents suggested that the onus should be on services to adapt the support on offer to suit the needs of those on the borderline regardless of formal diagnosis:

*If the parent is able to have some input from the learning disability teams either in health or social work that gives the other services information about exactly what is required for the person, for example, make sure you communicate in a particular way. We don't want to exclude people, so we don't demand a formal label. A lot of people maybe went to a special school but there isn't any record of a formal diagnosis.*

*When you get to know someone you can tell [if they have a learning disability] like the woman I was working with today never even considered herself to have a learning disability...She has had two kids removed as she was targeted by an abusive partner and was thought to be complicit in the abuse of her children... she was actually in jail...no one ever thought to check [whether or not she had a learning disability].*

*Even if someone turns out not to have a learning disability...we can't just say if their IQ isn't under 70 we won't work with you...We have had a couple with drink/drug problems who we are not quite sure about whether they have a learning disability but we would still work with them.*

While this might be helpful in ensuring that those who need support are able to access appropriate services, it makes it more difficult to plan the delivery of those services as there is less certainty about the number of people likely to access them. As noted above this variety of approaches to determining whether or not a learning disability, difficulty or need is present, creates challenges in determining the parameters of the population.

## 6.4 Early identification of parents with learning disabilities

The issue of early identification has been acknowledged by Scottish Government and currently a specialist group (the Early Identification Working Group) is exploring ways in which identification of parents with learning disabilities can be improved. Their work to date has focused on a number of key areas and these are incorporated in the findings reported below.

### 6.4.1 Screening Tools

An exploration of screening tools as a way for midwives and health visitors to identify parents with learning disabilities (diagnosed or not) has taken place. It was agreed that these professionals are in a better position than anyone (except possibly GPs) to identify parents at an early stage. A number of screening tools have been examined with a focus on efficacy, and training needs associated with their use. A proposal has been made to incorporate screening tool questions within the set of questions that all midwives complete as part of the Scottish Women's Handheld Medical Record. This will be transformed into an electronic record in the near future, and the opportunity to review all the questions will be taken at that time.

### 6.4.2 Awareness raising and training

Data from the current survey suggests that awareness of parents with learning disabilities and the issues they face is fairly poor across disciplines. Analysis indicates that there is a significant impact on parents with learning disabilities when professionals have a limited awareness of what learning disability means. Impatience and a lack of understanding with regard to the time required for parents to develop appropriate skills, when a more realistic timeframe might produce more positive results, is just one example.

Training offered to midwives and health visitors on learning disability was explored by the Working Group on Early Identification to consider ways of raising awareness of the key issues faced by parents with learning disabilities. *Compassionate Connections* is considered a good online learning tool used by this workforce, but there is no learning disability component. The group will continue to explore options for developing this aspect of the tool.

The current study identified a significant training need for professionals working with parents with learning disabilities. A particular concern about limited awareness across professions that was reported was that some professionals start from a point of assumed incompetence as soon as they hear the term learning disability. One psychologist interviewed within the current study noted:

*If we had the time I would love to go to our local teams and do a proper training event so they know exactly what the issues are and how you identify this. To be able to do this for other practitioners would be excellent and so valuable.*

Particular concerns were raised regarding the awareness levels of social workers about the issues faced by parents with learning disabilities and there was a perception that it had been challenging to gain access to social work teams to provide training.

*We have to raise awareness with social workers...more case studies would help to illustrate how we can work with parents. Yes, there are concerns but they can be managed. Showing all workers that it can be managed but it does require specific and consistent focus that I think a specialist team would be better placed to provide. Most social workers have too much on their plate to be experts in every situation they are confronted with.*

Where training was provided it was perceived to have a positive impact as the following quote suggests:

*We've been involved in training with the Royal College of Midwives along with People First...that was great, it went really, really well they responded well to the information and seemed grateful to get the help.*

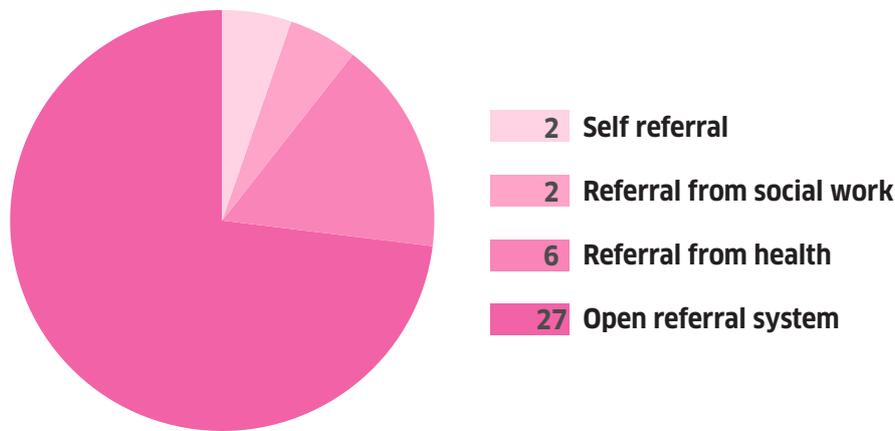
### **Good Practice: Joint training - Local Area Coordinator (LAC) and colleagues, Edinburgh City**

A local area co-ordinator and colleagues in Edinburgh City put together a joint training course for social work staff in Edinburgh City, identifying some of the key issues faced by parents with learning disabilities. They used a power point presentation drawing out key themes, such as the high percentage of children accommodated, disparity from those children whose parents do not have a learning disability, and examples of what works in supporting parents. They provided examples of how best to work with people with learning disabilities including the provision of accessible information, visual timetables and reminder texts for meetings. A key message delivered was that using these techniques might make the difference to the parents' understanding of what was being asked of them. Evaluations were undertaken before and after the training, using a confidence scale and very positive outcomes for staff were reported.

Some respondents considered that awareness of the issues for parents with learning disabilities had increased and as one respondent put it, *'a head of steam is building up'*. Organisations may have one or two members of staff who have experience of working with parents with learning disabilities and they become a source of information for others within the organisation, building capacity. To complement this increase in individual knowledge, organisations such as Equal Say for Parents are being used more frequently as a source of expertise. For example, they may be asked to provide advice on particular issues such as communication and to identify appropriate resources such as the most effective parenting programmes or specialist assessment tools. A recent evaluation of Equal Say for Parents found that one of the most valued aspects of the service was the body of expertise and knowledge that had been built up within the agency over a number of years (MacIntyre and Stewart, 2016).

## 6.5 Parenting referrals

As discussed above, the early identification of parents with learning disabilities was thought to be important as it would allow appropriate services to be targeted effectively at as early a stage as possible. It is therefore important to consider how people were referred to the service and the likely trigger points for these referrals. Services reported accepting referrals from the sources identified in diagram one. The key point to note here is that the vast majority of service providers suggested that they operated an open referral policy (although this did not guarantee that an individual would then meet the criteria to receive a service).



**Diagram 1: Sources of referral**

In terms of trigger points for referral, analysis of both the survey and interview data suggests that referrals were primarily generated by Child Protection (CP) concerns rather than adopting an early intervention approach that involves supporting the parent to develop their parenting capacity prior to any child protection concerns arising. It could therefore be considered that the focus of much intervention with this group is largely based on the needs of the child alongside assessing and/or reducing risk associated with CP procedures. Whilst this is entirely understandable it does indicate that the needs of the parent may be being overlooked during periods of perceived crisis. There is a clear view expressed within the data that a focus on preventative work would ensure that the needs of the parents were included in any assessment of need, were this not being driven by CP procedures and the attendant timescales associated with this work.

There were, however, examples of where parents were identified during pregnancy, for example in Fife, using a specific screening tool developed in the local pre-natal pathway. Midwives were trained and supported to use this tool to identify parents with learning disabilities at this early stage to ensure a clear pathway for support was developed. However, a number of respondents noted that this type of early identification did not necessarily mean that appropriate supports were put in place. For example, one respondent noted that they were often contacted when a woman was 32 weeks or more pregnant, providing limited time to support the parent to prepare for the birth of the child and for them to assess for or assist in the development

of parenting skills. Thus the opportunity and potential to prevent future crisis was compromised.

There were also examples of self-referral within the data, particularly within voluntary sector provision. This did provide the opportunity for parents themselves to seek early support. However, challenges noted with this process were the need for self-identification as learning disabled or having additional support needs alongside the perception that many self-referrals were predicated upon crisis associated with CP procedures. Several respondents also felt that parents were unlikely to seek help at an early stage due to the perceived stigma attached to the label learning disability as well as fear of having their children removed from their care.

## 6.6 Early Intervention

The importance of early intervention for parents with learning disabilities has been clearly established in the literature review and there is evidence of the benefits of this, although the impact on outcomes for children is less well explored. Avoiding crisis-focused and unplanned interventions was a goal for many of the respondents within the current study. A focus on crisis appeared to limit opportunities for strengths based approaches to be used with parents alongside reducing the time available for parents to develop their parenting skills. Respondents noted a number of concerns about crisis led interventions and in particular its relationship with child protection proceedings.

*Where inputs are crisis led the focus is more likely to be on child protection and that drowns everything else out...we need to reintroduce more intensive early support.*

Opportunities for early intervention were however available in some areas, a good example being the Special Needs in Pregnancy Service, available in a number of areas. Where these teams were available, great value was attached to the opportunities for intervention they provided. The specially trained midwives in these teams were able to work directly with women during their pregnancy to consider potential support needs.

### **Good practice: Special Needs in Pregnancy Service**

The Special Needs in Pregnancy Service (SNIPS) provides support to a range of women with additional support needs and social problems during pregnancy. Initially focused on those women who misused substances or had mental health issues, the service targets any vulnerable women where there are likely to be child protection concerns requiring a multi-agency response. The service was jointly planned by health and social work and involves midwives working in partnership with addiction workers, mental health specialists and social workers to plan individually tailored packages of support for parents that will improve outcomes for children. SNIPS offers a “one stop” service where women can get support on a range of issues that are likely to affect their pregnancy including financial and practical help as well as emotional and medical support. Women are allocated their own key worker who can develop a personalised support plan to meet their specific needs. This also allows women to quickly access other forms of support such as addiction and psychiatric services.

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 alongside the SNIPS service outlined above. These included the Barnardo's Family Health Project, which will be discussed in more detail later in the report and the Early Years Centres in Edinburgh. These centres offer support, advice, groups and classes for all vulnerable families with children up to 8 years old. Services provided can range from nursery to outreach. Evidence suggests that staff work hard to communicate with parents with learning disabilities including different formats of information provision and developing awareness of the specific needs of this group.

Yet a number of barriers to early intervention remain and these can create challenges for parents and staff:

*What we see is that we are getting referrals much earlier now so I think that is changing but I don't think enough time is put in early enough to do assessments... getting to know parents. The idea that we'll do a pre-birth assessment at week 32 is clearly too late. So even with that kind of planning its not enough time... The consequence of that is that there is not enough clear information about the parents' support needs or their parenting capacity. The only other option is for social work to look after the baby in the short term but that means the parents don't get to develop the skills early and attachment with the child can be damaged.*

Barriers to early intervention identified by survey respondents include:

- women sometimes do not realise they are pregnant until very late on in the pregnancy
- women are reluctant to approach the GP in case their child is removed
- fear of social work prevents women from approaching for support at an early stage
- cost of provision of support to parents was viewed as prohibitive as this was likely to be long term and intensive and consequently expensive
- lack of a clear statement about the status of the adult, e.g. learning disability, learning need or learning difficulty means that they 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.

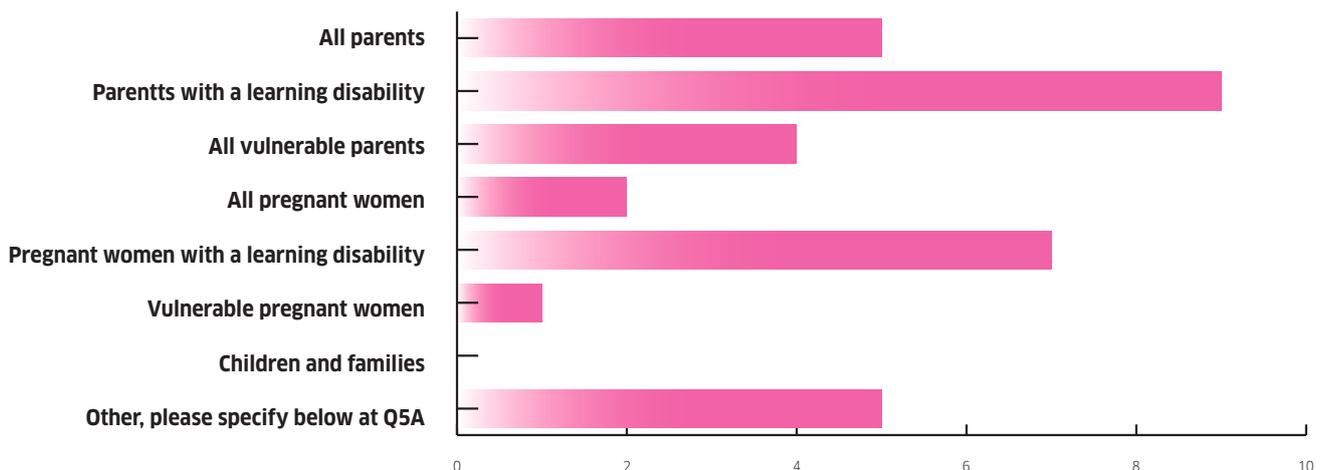
Despite the barriers identified above, early intervention was seen as the most effective way of ensuring that the needs of parents with learning disabilities as well as those of their children are met appropriately. Early intervention can allow preventative work to take place that focuses on the strengths of parents. It provides an opportunity to work with parents before they become subject to child protection measures with the associated negative messages about their ability to parent. This was viewed as being highly valuable by respondents.

*We like to start from the point that this person can parent...we don't want to be taking the position that there is no point wasting time on this because we need to start planning to remove this child as they won't ever be able to do this [parent their child effectively]...changing our starting point makes all the difference in the world to parents.*

## 6.7 Services for parents with learning disabilities

### 6.7.1 Generic and specialist services

The survey has painted a fairly complex picture both in terms of the different understandings of learning disability and whether someone has to have a formal diagnosis to access a service and in terms of referral pathways, and in particular the point at which referral should take place. When considering the types of services people are referred to the survey has revealed a fairly complex picture of service provision with services available 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. According to table 3 below, services were represented as follows:



**Table 3: Types of service provision**

Other types of service included those targeted at *all* people with a learning disability therefore the focus of the service was not primarily on parenting but on broader aspects of learning disability such as the community learning disability team.

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 with some debate around whether their needs were best met by specialist services that worked only with parents with learning disabilities or by those that worked with vulnerable parents more generally. There was some concern that generic services might not be

best placed to meet the very specific requirements of parents with learning disabilities around accessible information, the need for repetition of information and practical opportunities for learning. There was considered to be a risk that when parents with learning disabilities were grouped with other vulnerable parents the pace of any intervention would be too fast and they would be left behind or that they might be excluded because they lacked (or were assumed to lack) particular knowledge or experiences. Data from the survey and the individual interviews suggests that some respondents felt that social work in particular did not understand the need for repetition and duplication for people with learning disabilities, although the demands on social work were recognised as significant. In addition, there was a concern that the ability of some groups to communicate their needs more effectively might result in parents with learning disabilities missing out on the support they need. A number of suggestions were made as to the benefits of a dedicated specialist multi-disciplinary team to support parents with learning disabilities. It was noted that:

*If you only come across a parent with learning disabilities occasionally then that expertise does not get built up in individuals and organisations.*

Similar to disability teams for children where social workers are working with families every day, a body of expertise is built up, that would be helpful for parents with learning disabilities. 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 and that levels of support should depend on levels of need and issues of risk rather than prioritising particular categories of parents such as those with learning disabilities or those who abuse substances. As one respondent said:

*It's more to do with the service rather than the person...the onus should be on the service to meet the needs of the person effectively...they should be flexible enough to adapt accordingly...and some of the things that work for parents with learning disabilities will work for everyone, like accessible information is helpful for everyone...a service needs to be equipped to respond to a variety of needs.*

## **6.8 Type of support provided**

There has been a clear distinction made between services that work only with those with a diagnosed learning disability as well as between specialist provision for parents with learning disabilities and services for all vulnerable parents. The survey also generated a significant amount of data on the type of support provided and this can be categorized as follows:

<b>Type of support provided</b>	
Assessment (both of cognitive ability and capacity to parent)	6
Raising awareness of support available and signposting to appropriate services	2
Support to improve parenting capacity or parenting skills (including the provision of parenting programmes)	7
Provision of advocacy or other forms of representation	5
Pre-natal care	4
Post-natal support	6
Practical tasks for daily living	1
Health promotion activities	2
Provision of accessible information (including the adaptation of existing materials)	2
Whole family work	1
Group work with parents (not only about parenting role)	3

**Table 4: Types of support provided**

This highlights the broad range of work undertaken by professionals working in this field and suggests that the provision of support often goes beyond the parenting role itself to consider other aspects of the parent's life that might directly or indirectly impact on their parenting capacity such as housing support or general health and wellbeing. This suggests a whole family approach is required to support parents and this is considered in more detail later in this report. Analysis of the data suggests three main categories of work with parents – namely assessment of parenting capacity, support to develop or maintain parenting skills and capacity and advocacy and representation.

## **6.9 Assessment of parenting capacity**

One of the core tasks carried out by survey respondents was either the requesting of or completion of parenting capacity assessments. Although a specific question on parenting capacity assessments was not asked as part of the survey, analysis of the data suggests there is variable practice across the country in relation to whether generic or specialist tools are used, how they are used and by whom. Respondents suggested that knowledge of specialist assessment tools was not widespread and that such tools were not always used.

The Parents Assessment Manual, widely known as the PAMS assessment tool was specifically mentioned by a number of respondents. This is a specialist assessment tool that was developed by Dr Susan McGaw, a clinical psychologist with expertise in working with parents with learning disabilities, in 1998. The manual provides the assessor with tools to make a comprehensive assessment of parenting capacity. The

assessment includes observing parents undertaking a range of parenting tasks, as well as assessing their knowledge across a number of areas. The manual also includes a parenting booklet which contains a series of simple cartoons to assist the assessor to assess parenting skills that are not easily observable. An initial parenting questionnaire and an “I need help” worksheet are also available. Parents are assessed across a number of parenting domains including feeding, independent living skills and health care. Respondents who used the manual provided positive feedback, in line with a previous evaluation carried out by the authors on behalf of Aberlour Childcare Trust (MacIntyre and Stewart, 2015).

In particular, this specialist manual was valued for the level of detail it offered assessors in assessing parenting capacity. It was felt to offer greater opportunity to focus on the strengths of parents as well as areas for improvement and risk factors in a way that more generic assessment tools could not. The length of time taken to carry out the assessment (around fourteen weeks in total) was viewed as a positive feature (as well as a challenge) given the widely recognised need to allow parents with learning disabilities additional time to develop their capacity to parent. In addition, the use of cartoons to assess knowledge and skills in relation to parenting was thought to be more inclusive and accessible overall. Despite the greater accessibility of the manual, all respondents who reported using the manual also reported making adaptations to the materials to suit their needs and those of the parents. While this can be viewed positively in making the assessment process more meaningful for parents with learning disabilities, the adaptation of validated tools in this way can raise questions around both the validity and the *consistency* of the assessment that is carried out. A number of examples were given by respondents where assessment tools were adapted or combined:

*I've observed folk using the PAMS manual so they used bits of it and used other assessment tools alongside. Experience of sitting in on assessment meetings and what we see is that it really comes down to the individual worker carrying out the assessment and to their attitude and awareness of the key issues for the parent where there is a learning disability...*

*PAMS is not great - it tends to focus on knowledge rather than skill, it uses knowledge as a framework...I have taken bits of it and adapted it...Have adapted history/ family background bit...I have developed my own semi-structured interview based on maternal advantages and risks...also use the Parenting stress index and the Change resources...nurses use them because they are free...we should all use them I think...I have only dipped in and out of them...fine for what I needed.*

It appears that awareness of specialist assessment tools is growing – often as a result of the work of dedicated individual staff with expertise of working with parents with learning disabilities – “*I bang the drum at every opportunity*”. Yet, their use is not widespread with social work in particular being viewed by some respondents as using inappropriate assessment tools at times. This is perceived to be because of the resource implications of using specialist tools in terms of time taken to complete the assessment, the financial costs associated with purchasing a licence and the cost of training staff. Respondents suggested that at times assessors felt that making minor adjustments to existing tools was sufficient:

*They [social workers] say that they give bite sized information and pictorial information and they think that's enough.*

Respondents emphasised the skills required to undertake specialist parenting assessments with parents with learning disabilities:

*None of it is difficult but if you are not routinely working with parents with a learning disability then you don't recognise it [the learning disability and associated support needs]. Their [social work's] understanding of the parent's learning disability and what that might mean requires quite a sophisticated analysis of their needs to adapt existing assessment tools. For example, hypothetical questions often don't work with parents with learning disabilities... this relies on the worker being flexible, understanding and making appropriate adaptations.*

Other important considerations identified by respondents in relation to carrying out parenting assessments related to allowing sufficient time to complete the assessment (usually over a period of several weeks or months), completing the assessment in an environment that is familiar to parents (to allow for the modelling of behaviour) and ensuring that positives as well as negatives are emphasised to parents, alongside ensuring that the parent has a clear understanding of what is being assessed and what is expected from them.

*Constantly being told you are failing to meet the required standard, particularly when you don't really know what the standard is and you are not being assessed in a way you can relate to or that is really relevant to your needs, can really undermine a parent's confidence and self-esteem.*

Related to this is the provision of support for parents with learning disabilities who are being assessed. However, local authority eligibility criteria mean that it is not clear who should provide this support. One respondent suggested that in her experience children and families social work teams will not support someone with a learning disability, while adult services will not provide support for the child. In an example of good practice, Edinburgh City Council has funded two packages of care jointly in order to support the whole family. This was as a result of the children's panel requesting specialist assessments of the mother and fathers' parenting capacity.

### Good practice: assessing parenting capacity

One psychologist described her approach to assessing parenting capacity. She emphasised the following as being important:

- Allow enough time to complete the assessment. Often parents do not seek help until the child is at risk of being removed, making early assessment difficult
- Provide a balanced view focusing on positive and negative aspects of parenting (parental advantages and disadvantages)
- Ensure that any report produced contains clear recommendations based on the principles of supported parenting
- Where gaps in parenting capacity are identified work with others to provide support to rectify these gaps (for example the provision of “top up” sessions by midwives)
- If assessment takes place post natally provide some advice around contact and identify goals for these sessions, ensuring structure and progress towards clear outcomes.

## 6.10. Support to develop or enhance parenting capacity

Alongside assessing parenting capacity, a number of survey respondents discussed their role in supporting parents to develop or enhance their parenting capacity. Such support took many forms although it is possible to distinguish between:

- prenatal and postnatal services
- those services that focus primarily on the development of parenting skills and those services that support the parent with issues around parenting in its broadest sense.

### 6.10.1 Support to prepare for the birth of a baby

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 such as the Special Needs In Pregnancy Team (see page 46 for details). Such support was primarily focused on preparing the mother for the birth of her baby with some limited postnatal support, usually for around six to twelve weeks after the birth of the child. As mentioned earlier in the report there was some debate around whether this support should be provided by generic teams or by specialists with expertise in learning disability. While it was agreed that generic services should be flexible to meet the needs of all children, it was felt that it was “a big ask” to expect all midwives to support parents with learning disabilities. Likewise, for social workers, the difficulties in developing expertise in relation to all the different groups of people they supported were acknowledged:

Social workers do not have the time or resources to deal with or become experts in the broad range of need with which they are presented and that includes parents with learning disabilities.

### **6.10.2 Parenting programmes**

The literature review identified three specific parenting programmes that are evidence based. Survey respondents also identified a number of parenting programmes that were used with parents with learning disabilities in order to develop their parenting capacity. Respondents felt strongly that generic programmes such as the Triple P programme offered across the Greater Glasgow and Clyde NHS Board area did not meet the needs of parents with learning disabilities as the course structure and materials were not fully accessible. Respondents valued specialist programmes such as the *Mellow Parenting* Programme, which it was felt, was flexible enough to meet the needs of parents with learning disabilities and designed specifically to be accessible. Analysis of the survey data suggests that the key elements required to make a programme suitable for parents with learning disabilities include:

- adapting the pace to suit the needs of all parents
- extending the length of the programme to provide support on a longer term basis;
- repetition of tasks and information
- modelling of behaviour
- social support.

There was recognition that social support was particularly important for parents with learning disabilities who were often socially isolated. Three survey respondents reported providing social support in a group setting where the focus was broader than the parenting role). One respondent described adapting a mainstream parenting programme run in her locality to make it more suitable for parents with learning disabilities. She had worked in partnership with a community development colleague to “translate the programme” to make it more accessible. This involved translating ideas around child development into more user friendly language.

### Good practice: Mellow Parenting

The Mellow Futures Programme has been adapted from the Mellow Bumps and Mellow Babies Programmes in partnership with MENCAP to specifically meet the needs of parents with learning disabilities. It is a relationship based programme that focuses on developing the relationship between parent and child. The adapted programme recognises the need to be flexible enough to take things at the pace of the parents in the group within a structured environment and provides parents with the support of a volunteer to transfer the learning from the group to their own home situation. The programme also recognises the importance of social support and peer learning from other families where the parent has a learning disability.

### 6.10.3 Support to develop parenting capacity in its broadest sense

There was recognition among many respondents that focusing on the development of parenting skills alone was not sufficient to enhance the parenting capacity of parents with learning disabilities. It was acknowledged that parents with learning disabilities are often highly disadvantaged and marginalised and live extremely complex lives (MacIntyre and Stewart, 2012). They are likely to experience poverty and poor housing, poor physical and mental health and are likely to be affected by abuse and substance misuse. As a result, respondents reported “*working with parents to address those issues that are likely to impact directly on their capacity to parent*” such as support around housing, support related to health and wellbeing, financial support and social support to access local resources. This might incorporate practical support with household tasks such as cooking, cleaning and shopping but primarily appeared to be about supporting parents to access relevant support from other sources. One respondent explained that:

*There needs to be recognition of the things that might have an impact on parents' capacity to parent...One of the things that services have got involved in is thinking about how other things affect pregnancy - quite often the parent is not in good housing stock, or is not able to manage financially, so its about supporting parents with those sorts of things, things like applications for housing, budget management... So what we are finding is that services with a primarily clinical focus are straying into all sorts of other areas, it isn't enough to talk about pregnancy, we need to have an understanding of relationships, partner, family, friends, living circumstances, what support they have...*

### **Good Practice: Barnardo's Family Health Project, Fife**

Barnardo's Family Health Project is funded by NHS Fife and provides a coordinated pathway for vulnerable families from the twenty second week of pregnancy until the child is around twelve weeks old. The project has a specialist worker who works with parents who have learning disabilities or difficulty. Her primary focus is to work with parents to develop their parenting skills but as her relationship with the parents develops she supports them with a range of tasks including working with social work and housing as well as providing support with practical tasks. The support provided is flexible and is not restricted to a set number of hours or days each week. Much will depend on the particular circumstances of the family. Mums do not have to have a diagnosed learning disability to access the service but are likely to have difficulty with processing or retaining information. If particular concerns about learning disability are raised by midwives as part of their initial screening, a referral can be made to psychological services for an assessment to be completed. Part of the role involves signposting clients to other sources of support but there can be difficulties with this as it is not always clear what other support is available. The project has a strong link with local advocacy services who can provide support to parents to ensure their voices are heard during social work meetings and so on. Most parents do not want the support to come to an end when the baby reaches twelve weeks old and a significant gap has been identified in terms of a lack of follow on support to refer on to. The service is thought to have made a difference in relation to parents' lifestyle, confidence and understanding and between 60 and 70% of the parents whose children were on the child protection register at the start of the intervention had their child removed from the register. Some of the success of the project has been attributed to confidence building for the parents, which in turn inspires the confidence of social workers in their ability to parent.

### **6.11. Advocacy support and other forms of representation**

The other key source of support mentioned by respondents was the provision of advocacy support to ensure that parents had their voices heard in relation to the care of their child and legal representation to ensure they could access their legal rights. This support was thought to be important for parents, particularly in relation to child protection proceedings. Other research carried out by the authors (MacIntyre and Stewart, 2016) suggests that having the opportunity to participate in formal proceedings such as children's panel meetings or case conferences was valued by parents, regardless of the eventual outcome. What appeared to be important was that families felt that they had been listened to and treated with respect. Support in the form of representation was also thought to improve the relationship between parents and the professionals involved in their cases (MacIntyre and Stewart, 2016).

### Good Practice: Equal Say for Parents

Equal Say for Parents offers a range of services to support parents with learning disabilities. These include Mellow Parenting Classes for those parents with children under 5. This offers a 10-week programme to support parents to develop their parenting skills in a safe and appropriately tailored programme that includes support between classes provided by parent supporters who work with parents to transfer the learning from class to their own home environment. The service also offers direct advocacy support via full time staff and volunteers depending upon the needs of the parent. A recent evaluation of the service found that it was valued by both parents and referrers as offering a clear opportunity for parents to develop their skills, to have their voices heard in formal proceedings and to have those proceedings explained to them appropriately both verbally and in writing. The involvement of an advocate was also thought to lead to better engagement with formal services thus resulting in better relationships between parents and professionals such as social workers. Professionals reported being reminded about how to communicate with parents with learning disabilities and about the provision of accessible information as a result of advocacy involvement (Macintyre and Stewart, 2016).

## 6.12. Support for children

Survey respondents were asked whether they provided direct support for children. Three respondents described the work that they did with children which focused primarily on child development and attachment. One respondent structured this work around the *five to thrive* principles which is described as an “attachment based approach to positive parenting” and is based on talking, playing, relaxing, cuddling and responding ([www.fivetothrive.org.uk](http://www.fivetothrive.org.uk)). Other work with children involved ensuring children met their developmental milestones and providing social opportunities to prevent social isolation and to promote interaction with other children.

### Good Practice: Aberlour Family Service Children’s Group

This children’s group within the Aberlour Family Service in Girvan, provides the children with the opportunity to socialise with other children and to undertake stimulating play such as within the Dina Dinosaur programme. This programme uses dinosaur themed learning materials to promote children’s social, emotional and academic skills. The training strengthens children’s social and emotional skills such as understanding and communicating feelings, developing problem solving skills and strategies, managing anger, practising appropriate classroom behaviour (for children of school age) and developing friendships. An evaluation of the Aberlour Family Service completed by MacIntyre and Stewart in 2014 suggested that children who participated in the programme enjoyed the group activities although less data was available around longer term outcomes such as improved attendance or behaviour at school.

Interestingly, one respondent felt that working directly with children might represent a conflict of interest:

*We did run parenting groups in the past where we would provide advice on parenting skills based on the parent's cognitive ability but it was difficult because effectively the child became our client and then it's like straying into other folk's territory...*

This quote perhaps illustrates some of the difficulties around joint working that will be discussed later in the report.

One of the key features highlighted by respondents when discussing the supports they provided for parents with learning disabilities was the need to ensure that this support was available on a long term basis. Making a direct comparison with parents with physical disabilities, one respondent described the challenges in meeting the needs of families where the parent has a learning disability. It was felt that where there was a physical disability, level of need was likely to remain stable for a longer period of time than if the parent had a learning disability, which was in fact often not the case. Respondents were very clear that “*we can't just go in and provide a service for six months and then remove it again*”. It was felt that, at times, support would need to increase as the needs of the parent and the child changed. The following case example is illustrative:

*We are working with one mum where the children have remained on the register for a long time as things keep changing as the support tails off then something else arises, it might be something minor, like the level of extended family support changes and then the support goes up and they don't come off the register. Or it might be that the needs of the children change so as the children are getting older and they don't want to go in the buggy we need a whole new set of strategies for walking the children to school. Parents need to see someone else getting it done, so it's like modelling behaviour so they can see exactly what it is they need to do. Without ongoing flexible practical support around these changing needs, that's going to be difficult and its assumed the parents have failed, rather than this being a failure of support to be flexible enough.*

### **6.13. Accessible information**

Alongside the provision of long term support, survey respondents identified the provision of accessible information as crucial for parents with learning disabilities. A number of components 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
- providing the opportunity to talk over information that is provided in written format
- offering the opportunity, perhaps via advocacy for material and process to be ‘translated’.

Many respondents discussed their own attempts to translate information provided to parents into a more accessible format and the survey identified a number of examples of good practice. These ranged from individuals undertaking training to ensure they can communicate in a more accessible way (for example training in the use of talking mats), to using an Ipad to watch video clips as a direct alternative to providing information in writing. NHS Choices was identified as a useful source of information, providing video clips on a range of parenting tasks such as feeding and bathing. Likewise, the Change Resources (*My Pregnancy, My Choice; You and Your baby, 0-1; You and Your Little Child*) were viewed extremely positively, although there was a perception that these resources were not being provided to all parents with a learning disability, despite it being recommended by Health Scotland that:

- midwives give out My Pregnancy, My Choice
- midwives give out You and Your Baby, 0-1 at the 28 week appointment
- health Visitors give out You and Your Little Child (1-5) when the child turns one([www.healthscotland.com](http://www.healthscotland.com)).

This gap may be the result of the lack of clarity over which parents have a learning disability, outlined earlier in this report, as well as the reluctance of some professionals to label people in this way alongside the reluctance of some parents with a learning disability to seek support until the later stages of their pregnancy.

There was a growing view amongst respondents that all information should be provided in easy read format although there was perceived to be some resistance towards this, particularly within the education system. It was thought that the cost of translating information into an easy read format was viewed as prohibitive by some. Others were concerned that the provision of information in an easy read format might be considered patronising. Yet despite these barriers, easy read information should be considered good practice:

*We have been trying to get things in easy read, it's a massive hassle but we are getting there, we are trying to promote the idea with everything that we do...we have been translating a handbook for schools and that has been a big battle...it would be a perfect job for a modern apprentice to do...social workers should have access to templates so that all of the information they provide parents can be done in an easy read format...all parents would benefit from this, not just parents with learning disabilities.*

Overall, it was acknowledged that a parent's information needs should be assessed on a case by case basis but that everyone could benefit from information being presented in a clear and accessible way. Despite this message, time pressures and a lack of specific knowledge on the needs of parents with learning disabilities meant that poor practice could still be identified. One example provided was of a learning disability social worker photocopying material from a standard parenting manual and posting it through the letter box of a parent. The respondent who reported this incident noted that:

*This parent did not read well and really needed an explanation of what the information actually said, images were much more useful with her. But even with that you had to take the time to go over all of the information verbally...the practical stuff needed to be modelled with her in her own home. We went over the same things again and again... you have to tailor what you are doing to that individual parent, otherwise it's just pointless.*

### **Good Practice: Parenting Across Scotland**

Parenting Across Scotland is a national information service that is available to all parents across Scotland. The service brings together a range of parenting resources, support networks and helplines on a range of topics. The information is free and covers all age groups from pregnancy and birth, to babies, toddlers and teenagers. There is also specific information available for dads. The service is very aware of the need to provide accessible information for parents with learning disabilities and is clear about the need to make messages clear and accessible. This involves a consideration of practical matters such as font size and layout as well as ensuring that the key messages being conveyed are expressed in simple terms. Testing out material with parents with learning disabilities is viewed as being crucial in determining what works. The service produced one of their most popular information booklets on starting school in an easy read format to make it more accessible for parents with learning disabilities. This involved consulting with parents with learning disabilities to find out what they needed and a designer was then employed to produce a coloured booklet in an accessible format. The feedback was very positive but the production of the booklet was hugely time consuming and costly and there are no plans to produce further information in this way. Parents are very disappointed as they want information from birth until their child reaches the age of eighteen and this simply is not available. The organisation now focuses on signposting parents with learning disabilities to other sources of accessible information.

### **6.14. Joint working**

The literature review identified that joint working was crucial to effectively support parents with learning disabilities yet problems with joint working, particularly between adult and children social work teams were noted consistently as an area of concern for all respondents. The focus of concern is that parents with learning disabilities often fall between the gap in services. As they are often not eligible for a service in their own right from adult services, they may fall under the radar of children and families services until a child protection concern is raised by which point the opportunity to focus on the parent's abilities and skills, which is often the focus of early intervention service, can be lost.

*What we see often is that when there is a child protection concern there can be supports put in place then it stops...so if the child protection concern is dealt with the support is removed and then if things change parents can find it difficult to cope with the different transitions that children go through. So a second crisis is created. So the parents and the child can go through the same process again and a feeling of failure is created.*

*Our local learning disability team are really challenging, the team won't assess the parents whilst they are pregnant (the concern is that their hormones are everywhere, so won't be reliable), only after the baby is born. Which prevents anything being done in advance, so we are talking permanence planning with babies under six months because we've waited too long to provide a service. The two services work so separately and the two practices don't work well together and there is always a bit of a dispute about who does what and when.*

At the point when child protection concerns are raised, risk to the child becomes the pre-dominant factor and there is often limited or no ongoing support for the parent. However, it was noted that services such as advocacy, can become usefully involved at this stage to ensure that the parents voice is heard in any subsequent child protection proceedings and that those proceedings are explained in detail in a way that the parent can understand.

Joint working with third sector organisations such as Aberlour can also be helpful in ensuring that the needs of the parents are taken into consideration. Aberlour use the PAMS assessment tool (discussed above) in a number of their projects, including the family service in Girvan and Aberdeen to assess the level of parenting skill and capacity exhibited by the parent and to provide training or teaching programmes to address any identified gaps. The input of third sector organisations is highly valued because of the additional time, flexibility and resources they can put in place to support parents. Another particular advantage of joint working with the voluntary sector highlighted by a number of respondents was the independent nature of the organisations, which is viewed as being crucial. For parents who are subject to significant scrutiny over their ability to parent, an independent organisation providing assessment and support can promote engagement, confidence and trust.

One suggestion to potentially alleviate some of the pressures created by poor joint working practices would be to create multi-disciplinary teams perhaps along the lines of the Special Needs in Pregnancy Service discussed earlier in the report as the following quote suggests:

*We have long campaigned for joint multi-disciplinary teams with a good skill mix there needs to be a nursery nurse, a children's social worker and an adult social worker but don't think its seen as sexy enough given adult mental health waiting lists, people with learning disabilities always seems to be at the bottom of the pile.*

## 7. Discussion

### 7.1 Scottish Good Practice Guidelines and their influence on practice

One of the aims of the survey was to consider the extent to which the Scottish Good Practice Guidelines discussed in more detail earlier in the report have influenced service provision for parents with learning disabilities across Scotland. Given that the guidelines aim to:

- help services to improve their support for parents with learning disabilities and their children
- increase the chances of the children of parents with learning disabilities continuing to live with them in a positive and supportive environment that meets the children's needs
- increase the changes of avoiding family breakdown which has enormous social and financial consequences.

it was important to get a sense of how they were influencing practice. The survey indicates that 87% of respondents were aware of the guidelines and that 79% used them in their everyday practice. Respondents were also asked to indicate how their practice had been influenced by the guidelines and what key lessons they felt had been learned. This was also followed up where appropriate in the individual interviews that were undertaken. It should be noted, however, that it is likely that the people who have completed the survey and participated in the interviews are those most likely to have awareness of the guidelines and this should not be taken as an indication that they are widely known about or used, outside of specialist services. SCLD undertook a review of the ways in which the guidelines were being used in 2014 (SCLD, 2014). This review found that of the 25 respondents who completed the survey, 60% were using the guidelines in their work, suggesting an increase in use at the time of the current scoping exercise. The SCLD review suggested that those who did not use the guidelines did not find them necessary to undertake clinical work or were likely to refer on to a specialist rather than consult the guidelines. The review also suggested that the majority of those who did use the guidelines only passed on the easy-read version to parents that they worked with "occasionally", suggesting that important information about what to expect from support services may not be reaching parents with learning disabilities.

Data from the current survey indicates that respondents believe that the guidelines have influenced their practice in a number of ways, with a particular focus on ensuring that practice is non-discriminatory and safeguards the rights of parents and their children. It was felt that this can be achieved by ensuring meaningful involvement for parents in service provision and support. This can involve the provision of accessible information alongside practical support to enable parents to attend meetings such as the availability of crèche facilities or taxis. Respondents also highlighted clear joint care pathways that have been tested by parents as being particularly important. This sat alongside an acknowledgement that any work was likely to be long-term and should ideally be preventative in nature.

The guidelines have also proved useful in terms of raising awareness of the particular issues faced by parents with learning disabilities and has promoted “*an acknowledgement that the parent’s rights are as important as the rights of the child*”. Interestingly the guidelines have been used to promote good practice with other professionals groups - one example is the development of Good Practice Guidelines produced for psychology staff (British Psychological Society, 2011).

### **7.1.1 Progress towards supported parenting**

The principles of supported parenting have been used in this section to identify progress towards supporting parents with learning disabilities, drawing from the findings above, as well as identifying any gaps that remain.

### **7.1.2 Support should be available pre-birth**

Good progress has been made in this area and the survey has identified a number of examples of good practice in supporting parents to prepare for the birth of a child. Working with parents, often the mother, prior to the birth of the child allows professionals to focus on supporting the parent to develop their parenting skills, whilst acknowledging the additional factors such as poverty, poor housing and abuse that are likely to impact on their ability to parent. While this pre-birth support can often be crisis driven (with child protection concerns being raised prior to the birth of the child) there is often scope to work with the parent over a longer period of time, particularly if they are identified during the early stages of pregnancy.

A number of challenges remain in ensuring that parents are identified at an early stage with respondents noting reluctance amongst some professionals to label parents as having a learning disability as well as a reluctance amongst some parents to come forward to access support for fear of having their child removed. These difficulties are exacerbated by the confusion and different understandings of the term learning disability that remain which can result in those parents viewed as being on the borderline (perhaps with an IQ of just above 70) falling between the gaps in service provision. Creating further confusion is the interchangeability of the use of terms, learning disability, learning difficulty, learning need and global developmental delay.

Early intervention was also thought to be prohibited by the resource implications associated with working with a parent or family at an early stage of pregnancy. Eligibility criteria may mean that parents do not actually qualify for support because their learning disability is not severe enough to access support from adult social work services or the community learning disability team. Therefore, the trigger point for intervention comes from children and families social work services when a child protection concern is raised.

Interestingly there was a suggestion by a small number of respondents that it may be appropriate to provide input to schools for young people with learning disabilities *before they become parents* to explore what it means to be a parent and to highlight the potential challenges involved. This type of early intervention could also focus on consideration of when the right time might be to have a child and appropriate planning

processes for pregnancy and parenthood. Knowledge given to young adults with learning disabilities about what it means to be a parent was therefore considered to be limited.

Some good practice in relation to the early identification of pregnant women was identified during the research with midwives in Fife adapting their initial screening tool to incorporate questions on learning disability for example. This scoping study also identified a need for greater awareness both in relation to the identification of parents with learning disabilities along with greater knowledge of good practice in working with this particular group of parents. Respondents identified a need for staff that work with parents with learning disabilities to have greater awareness of their very specific need, as often parents are very skilled at masking their limitations.

*...sometimes it depends on individual children and families and adult social workers...the outcome might be the same but you want to be sure that you have at least given everyone a fair and equitable chance.*

### **7.1.3 Support should be ongoing**

The literature review highlighted the need for ongoing long term support for parents and this message was reinforced strongly and consistently by survey respondents and interviewees:

*This work is never going to be short term...parents are going to need support at every stage of their child's development*

*A lot of my girls need forever support.*

While it was recognised that this long term support was essential to enable parents with learning disabilities to parent effectively, it was often not forthcoming and was identified as a major gap by many of the respondents. The lack of available support services to refer people on to after short term intensive interventions ceased was thought to be particularly problematic and could potentially undermine the gains that had been made during a period of early intervention. Respondents expressed frustration at this gap in the support pathway for parents. Postnatal services in particular were felt to require further development and it was acknowledged that as children move through the stages of development, support is required to help parents adapt their strategies, for example ensuring a safe journey to nursery whilst a child is in a buggy and the attendant changes once a child can walk. This gap was likely due to the resource implications of providing often intensive support on an on-going basis as well as a lack of clarity around whose responsibility it was to fund and provide this support. Yet when ongoing support was available it was thought to alleviate the need for repeated crisis driven interventions and so could potentially save money in the longer term.

*Issues are more around how effective services are at key milestone points - birth, toddler, teenager and how do we respond to each of the milestones? I can think of an example where the social worker said that the parent would not be able to parent after the child's second birthday. So what do we do about that?*

*Funding is a challenge when thinking about the provision of long term support - so we have secured a funding stream for our prenatal service for the foreseeable future...but for the postnatal and early years...I'm not sure where it will come from and what it will look like.*

#### **7.1.4 Support should be strengths based**

Given the challenges identified in promoting a model of early intervention for parents with learning disabilities, the support that is often provided tends to be crisis driven resulting in a deficit model being adopted that focuses on what a parent cannot do as opposed to what they can. Grouping together a number of the supported parenting principles suggests that a strengths based approach should be taken. This involves:

- respect for parents
- viewing the family as a resource rather than part of the problem
- parents being in control and experiencing being competent
- building on strengths.

These principles sit well with social work values (Payne, 2005) but the crisis driven nature of many interventions with parents with learning disabilities make promoting a strengths based approach more challenging for staff. The survey did however identify progress towards the provision of support that is underpinned by these principles. Assessment of parenting capacity using specialist assessment tools that allow the assessor to highlight a parent's strengths as well as the challenges to their parenting capacity are a helpful starting point. However, data from this scoping study suggests that awareness and use of these specialist tools is still not widespread and is currently being implemented on an ad hoc basis. In addition, respondents identified a gap when areas for development were identified during the course of an assessment but no measures were put in place to support parents to develop their skills in these areas. Some respondents suggested a reluctance to put such support in place *"if the child is going to end up being removed anyway...we are just building up false expectations"*. This suggests negative attitudes towards parents with learning disabilities ability to parent remain with a starting point of assumed incompetence taken by some staff. The case example below illustrates some of the points made here well:

*I am aware of a mum going through STEPS assessment, her baby is in foster care and is brought to the nursery for assessment. She is being assessed but no one has filled in gaps in her knowledge - they observe her but they don't fill in gaps so if they see she doesn't know how to do something they don't tell her how to do it so how can they expect her to learn - I don't know whose job that is. I have found that there is reluctance to provide support as they don't think she will get the child home anyway...the referral has already been made to the permanency panel as they do it that far in advance...I think that morally that's wrong.*

Specialist assessment tools allow professionals to identify the strengths a parent or family can bring to the parenting relationship but they do not necessarily allow for the provision of support to tackle any gaps that are identified. Support providers such as Aberlour Childcare Trust have developed services that attempt to fill this gap by providing individualised support or training to parents alongside the assessment process. This dual function should be considered an example of good practice and can help to ensure a strengths based approach is taken. Other respondents advocated the use of residential assessments to provide parents with intensive support as they undertook an assessment of their parenting capacity. Such residential support could provide the space and time for families to develop effective strategies for childcare as well as to test out in a safe space, with dedicated well informed support, routines to take into their own homes. There are already some examples of this type of service provided for vulnerable families, such as the Lillius Graham Trust in Thornhill and Richmondhill House in Aberdeenshire and both have offered support to parents with learning disabilities in the past.

*Residential unit would be great we would know very quickly how successful the parenting could be and the assessment process wouldn't be so protracted.*

Advocacy support was also identified as a way of ensuring that parents are treated with respect, particularly within formal childcare proceedings, ensuring that their voices are heard and their rights upheld. As identified earlier in the report the advocacy service provided by Equal Say for Parents is considered an example of good practice and has been shown to strengthen relationships between parents and the other professionals that they work with. The service is particularly valued for the knowledge and expertise that the staff have built up in supporting parents with learning disabilities as well as for its independent nature which allows staff to challenge decisions and provide support in a way that might represent a conflict of interest for staff employed by the Local Authority or NHS board. Equal Say for Parents have been able to request that information be provided to parents in a timely and accessible manner and have been able to support parents by translating information into a more user friendly format, thus ensuring their meaningful participation in decisions that affect their child.

Equal Say for Parents have also been able to deliver the Mellow Parenting Programme thus addressing another perceived gap in service provision, namely the lack of availability of specialist parenting programmes. There was considered to be a lack of suitable and accessible parenting classes other than the Mellow programmes which was not available in all areas. The specialist nature of this provision, including the knowledge and expertise of staff, the content of the group work, the length of time given for parents to develop their skills (over 10 weeks), increased value placed upon the parents own expertise and the significant levels of support between the group work that forms the core of the programme have been found to be particularly effective for parents with learning disabilities (Macintyre and Stewart, 2016).

### 7.1.5 Support should be for the whole family

Evidence from the literature review, the survey and the key informant interviews suggests that support that focuses narrowly on one aspect of parenting or on one member of the family is unlikely to result in positive outcomes. Therefore a whole family approach that focuses on the needs of the parents as well as the children is strongly advocated for. As highlighted above current provision that does not acknowledge the needs of the parent as someone with a learning disability, is unlikely to offer early intervention or ongoing support needed to prevent crisis situations from arising in the first place. Whilst it is clearly acknowledged that the needs of the child are paramount where there is concern about their safety and wellbeing, a whole family approach was thought to accommodate this risk within a broader paradigm that enabled consideration of support to the parent which could reduce the risk and limit the requirement for statutory measures.

A whole family approach acknowledges the family within its broader social context and as discussed in the previous chapter, enables exploration with parents about the range of factors that might impact on their capacity to parent alongside their parenting skills. Such an approach would also allow staff to focus on the developmental needs of the child *and* the parent without perceiving this to be a conflict of interests. Taking a whole family approach would also enable staff to focus on the social needs of the family, recognising that both parents and children living in families affected by parental learning disability are at risk of social exclusion and isolation. The provision of social support, working with families to access local community resources such as Bookbug classes at the local library was viewed as being particularly important. Parenting programmes that incorporate a social aspect and encourage the development of peer-to-peer support outside of class were very highly valued by respondents.

For such an approach to work however, joint working is required, the barriers to which have been well rehearsed earlier in this report. Some respondents advocated the creation of jointly funded multi-disciplinary teams that would allow the staff who worked there to develop appropriate levels of expertise and skills to support families affected by parental learning disabilities. It would allow for the appointment of staff from a range of different backgrounds ensuring the appropriate skills mix within the team. The following case example, illustrates the ways in which a whole family approach might work in practice.

*I am currently supporting a young couple with learning difficulties to develop their parenting skills and building their informal networks. During pregnancy the couple engaged in a full assessment of need. This process ensured the couple had the level of support required to allow them the opportunity to parent their child and to continue to develop their parenting as the baby's needs changed. Intensive family support was available and essential in enabling the parents to develop their skills and supervision took place within the home so the parents did not have to deal with an artificial environment... Social work resources provided three two hour supervised sessions to assess and develop their parenting capacity. This level of support allowed for reinforcements in terms of their learning needs. The pre-birth assessment took account of their learning difficulties and their capacity to learn as far as reasonable and practical to do so. This involved sharing of information between all agencies and previous reports from their time in education.*

## Conclusions

Bringing together evidence from the literature review, the survey and the key informant interviews identifies a number of very clear messages. Respondents were very keen to highlight that parents with learning disabilities can and do become “good enough parents” who love their children and want to be the best parents they can be, with the right support. Having a learning disability does not necessarily mean that parents cannot learn appropriate parenting skills or develop their parenting capacity. However, the support that they need to do so will be resource intensive as “good enough support” is likely to be long term and, at times, intensive as children reach particular developmental milestones. Indeed, the provision of such support is now legally mandated under Section 12 of the Children and Young People (Scotland) Act 2014, and given the status of many children of parents with learning disabilities as “at risk” of becoming looked after this would appear to be particularly relevant. It seems crucial that the guidelines currently being drafted around the provision of support under this Act takes cognisance of the particular support needs of families affected by parental learning disabilities that are clearly identified in this report.

The evidence suggests that unless such extensive support was available for the *whole family* that parents with learning disabilities would be unlikely to have their children living with them. Using the supported parenting principles as a guide it has been possible to evidence progress towards providing appropriate support for parents with learning disabilities and many examples of good practice have been identified. This support is thought to have a number of key characteristics including:

- long term in nature
- can be intensive at times
- support must be flexible
- takes a whole family approach that focuses on the needs of the parent and the child
- uses appropriate assessment tools and processes and provides support alongside these
- provides accessible information to ensure meaningful participation
- parenting programmes 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.

Services are also required to view the parent as a person in their own right recognising the broader social factors that might impact on their ability to parent. For many parents, their “*vulnerability*” is caused by factors other than their learning disability and the survey provided a number of examples of mothers who had been specifically targeted by abusive partners for example. Any service that does not take account of these broader structural and environmental factors is unlikely to be successful.

Although it is necessary to view parents in their wider social context, drawing on generic services to provide support and advice where appropriate, evidence from the survey also suggests that the growing body of knowledge and expertise that is developing around supporting parents with learning disabilities is invaluable and that parents are most likely to benefit from specialist support where the staff have a clear awareness and understanding of the particular issues faced by parents with learning disabilities. To this end, a training need has been identified as many staff do not yet have this knowledge base, which appears to be developing in an ad hoc way. At present, good practice appears to depend on the attitudes and skills developed by individual members of staff and this should be viewed as problematic as it can result in inequitable access to high quality support services for parents.

As highlighted above good practice has been identified across a number of areas and pre-birth support, advocacy services, the production of accessible information and support that recognises the parenting role in its broadest sense were singled out for particular attention. However, although this report brings together evidence from a range of sources to highlight good practice, many of the practices or services outlined have not been formally evaluated and so there is a lack of empirical evidence that establishes positive outcomes for parents or children as a result of these interventions. In addition, there are different opinions as to what a positive outcome for a parent with a learning disability might look like. For example, if a parent's child is removed from their care but they feel that they were respected and listened to in the process can this be viewed as a positive outcome? Further discussion about what outcomes should be considered is likely to be needed.

A number of gaps have also been identified and it is recognised that further development is needed to ensure that adequate postnatal support is available at a national level. Currently, much of the good practice that has developed pre-birth and in the early stages after birth is undermined when there is no suitable postnatal support to refer on to. Further challenges exist in relation to the provision of early intervention support which is complicated by the different understandings of learning disability and different definitions that are currently being operationalised across different professional groupings. This may mean that parents have difficulty accessing services or fall down the gap between services. As mentioned above, other barriers to early intervention include the perceived stigma attached to the label learning disability that is shared by parents and staff alike and the fear that seeking help will result in children being removed from their parent's care. Services would also appear reluctant to take on the responsibility of providing support to a parent or child before they deem it strictly necessary. Yet failure to do so has been shown to result in a greater number of crisis driven interventions that are likely to be more resource intensive and financially prohibitive in the longer term.

The solution to these challenges as outlined above is the provision of jointly funded, multi-disciplinary teams that take a whole family approach, thus prioritising the needs of parents as well as the 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 continue to support families affected by parental learning

disability. By working together, these teams will be able to offer more consistent support to families and will share consistent messages with parents so that they have a much better understanding of what is expected of them in relation to their parenting role. Such teams will work in close partnership with third sector organisations who already have a proven track record in providing intensive and flexible support to families that traditional health and social work services have been unable to provide.

Alongside the development of these specialist multi-disciplinary teams, clear pre and post natal pathways need to be developed to reduce the complex and ad hoc nature of support provision for parents with learning disabilities as it currently stands. These pathways must be based on the best available evidence in terms of what works in supporting parents with learning disabilities and while the evidence base in this area is growing, more robust evaluation is needed that focuses on outcomes for parents and children.

An important gap in this respect is the absence of the voices of parents and children in the current scoping exercise. While the authors have developed a substantial knowledge base that includes the views of parents with learning disabilities around what supports and undermines their capacity to parent, it was not possible to include their views in the current work due to time constraints and other pragmatic considerations. Further work is needed to establish their views at a national level and to incorporate this vital data into the evidence base going forward.

To conclude, it is important to return to the research questions that this scoping study aimed to address.

- What range of services is available to support parenting for parents with learning disabilities across Scotland?

The range of services identified by this scoping exercise can be considered across a continuum from specialist parental learning disability services to generic parenting services. Types of support provided include; individual advocacy, home care support with routines, information and advice on parental learning disabilities for practitioners, use of specialist assessment tools that support learning and skill development and long term (14 week) detailed parenting programmes. There appear to be 'pockets' of good practice that have developed in Glasgow, Edinburgh, Ayrshire, Fife and Tayside.

- To what extent do parents with learning disabilities have access to services based on the principles of supported parenting?

The survey identified a number of examples of good practice and areas where good progress is being made towards the principles of supported parenting, particularly in the areas of pre-natal support, in the use of specialist assessment tools, in the development of specialist parenting programmes and in the provision of advocacy support. As noted above, whilst there are examples of specific and specialised support for parents in a number of areas across Scotland, pockets of expertise appear to have developed in Glasgow, Edinburgh, Ayrshire, Fife and Tayside. This work is driven by champions whose expertise is now a considerable resource. Although this report brings

together evidence from a range of sources to highlight good practice, many of the practices or services outlined have not been formally evaluated and so there is a lack of empirical evidence that establishes positive outcomes for parents or children as a result of these interventions.

- To what extent are professionals following the Scottish Good Practice Guidelines for Supporting Parents with Learning Disability?

The survey indicates that 87% of respondents were aware of the guidelines and that 79% used them in their everyday practice. Respondents believe that the guidelines have influenced their practice in a number of ways, with a particular focus on ensuring that practice is non-discriminatory and safeguards the rights of parents and their children. This can involve ensuring meaningful participation for parents, the provision of accessible information alongside practical support to enable parents to attend meetings such as the availability of crèche facilities or provision of transport. The guidelines have proved useful in raising awareness of the particular issues faced by parents with learning disabilities and have promoted *“an acknowledgement that the parent’s rights are as important as the rights of the child”*. The guidelines have also been used to promote good practice with other professionals. It should however be noted that participants in this scoping study are those more likely to have awareness of and to use the good practice guidelines and this should not be taken as an indication that they are widely used across all services.

- What outcomes are being achieved for parents with learning disabilities from the perspective of key contacts?

There are different opinions as to what a positive outcome for a parent with a learning disability might look like. For example, if a parent’s child is removed from their care but they feel that they were respected and listened to in the process can this be viewed as a positive outcome? Further discussion about what outcomes should be considered is essential. Analysis of the data collected within this scoping study suggests that there have been positive outcomes for parents including having their children remain in their care and increased self-confidence and self-esteem through developing their parenting skills and having their voices heard in statutory processes. However, there is a significant gap in the evidence base regarding parents own views and that of their children.

## Recommendations

### Prevalance

1. There is a need to establish more accurate prevalence rates of parents with learning disability currently living in Scotland to allow for more effective service planning and delivery. This process may include consideration of standardised coding and reporting across the key stakeholders.
2. A better understanding of the different definitions of learning disability in use is needed in order to gain a clearer sense of the population in question. Targeting identification of those individuals most at risk of receiving little or inadequate support (likely to have an IQ of just above 70) is required. This would help to ensure that a model of crisis intervention is avoided, allowing for intervention at an earlier stage.

### Support Provision

3. A clear, evidence-based pre and post-natal care pathway, which can measure impact and improvement and has been tested by parents should be established. This will minimise the current complex, geographically variable and ad hoc provision that is available.
4. Longer-term, parent centred support that is reflective of individual child development milestones should be developed. This support is likely to be intensive at times, particularly at points of transition, for example during the transition from baby to toddler when a range of new parenting skills and support requirements will be necessary. The current lack of effective long term postnatal support has the potential to undermine the good practice that has been established prenatally and in the early days following the birth of the child.
5. This support should take a whole family approach that focuses on the needs of both the parent and the child. This support must take account of the broader structural and social factors that impact on a person's ability to parent effectively.
6. The best way to structure and organise whole family support is via the creation of jointly funded multi-disciplinary teams involving social workers, community learning disability nurses, nursery nurses, health visitors, midwives, psychologists and occupational therapists. The teams should work in partnership with experienced third sector providers. Such an approach would help to prevent families affected by parental learning disability from falling between the gaps in service provision and should promote better use of early intervention strategies . Existing models of jointly funded support for families should be explored and lessons for good practice identified and disseminated.
7. It is essential to build on the knowledge and expertise that has been established in this area, particularly by third sector organisations. While it is recognised that parents with learning disabilities should be supported to access mainstream services where appropriate, their very specific support needs as well as the value of working together with parents who are experiencing similar issues must be acknowledged and specific targeted interventions developed.

8. A clear, adequately funded accessible information strategy should be put in place to help better meet the information needs of parents with learning disabilities. This strategy should acknowledge the excellent work that has been carried out by individual practitioners and organisations to translate information but should also recognise the piecemeal way in which this work has developed. The strategy should have a governance framework and utilise evidence based materials, where available.

### Awareness raising

9. Greater awareness of the very specific support needs that parents with learning disabilities have is required. This includes the need for specialist tools to assess parenting capacity, accessible information, flexibility, repetition and the modelling of good practice. The good practice identified in this report should be disseminated widely.
10. Specialist training on the needs of parents with learning disabilities and their families should be provided to frontline practitioners, many of whom have limited experience of working with this group. This training should be offered as part of qualifying programmes for social workers, midwives and health visitors but should also be offered as CPD for those professionals wishing to develop additional specialist knowledge.

### Further research

11. Further research is required to establish long term outcomes for families affected by parental learning disability. However careful consideration and discussion of the outcomes to be measured will be required beforehand to ensure that indicators of successful are reasonable and realistic.
12. Additional research is required to illicit the views of parents with learning disabilities about the factors that promote or hinder their ability to parent at a national level.

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## Appendix 2 – Change Fund Projects

### Keys to Life Development Fund Projects

NHS Fife/Aberlour Learning Exchange

NHS Fife have run a successful pre-natal project for mothers with a learning disability. Aberlour Childcare trust run a successful project in South Ayrshire supporting parents with learning disabilities at home. This project allows the two staff teams to learn from each other with a knowledge exchange that includes multi-disciplinary visits to each other's sites. Workers also get the chance to speak to parents from the other site, to learn about the impact each project has made.

### Bright-Lights

Bright Lights offer therapy to parents with a learning disability, either one to one, or as couples, or as a family together with their children and other relatives. The aim of this therapy is to strengthen relationships so that they understand each other more, communicate well, are best placed to overcome life's challenges as individuals and as a strong family unit. We will support them to understand what is happening in their lives, to look at key challenges they are struggling with and plan how to overcome them, enable family members to express and explore how they are feeling, understand each other's experiences and views, listen to each other, appreciate each other's needs, to build on family strengths and make useful changes in their relationships and lives.

### Firsthand Lothian

Firsthand Lothian offers home support to parents with a learning disability, to work alongside the parents and their children to help and encourage parents to be more able and confident and provide a good standard of parental care for their children, creating a stable home environment, developing, establishing and maintaining routines that will help them in their parenting role; they aim to show parents how to interact with and understand their child/rens needs and support parents to engage positively with other agencies regarding their family and their children which would benefit the family as a whole.

### Mellow Parenting

Mellow devise and deliver parenting programmes across Scotland. They have already developed programmes for parents with learning disabilities who are expecting a child or who have babies. This piece of work consists of developing, alongside parents themselves, a new programme for parents of toddlers, and piloting this new programme. Part of this programme involves a volunteer mentor supporting parents to put in place the parenting strategies they learn during the course.

### East Ayrshire Advocacy Service (EAAS)

EAAS will establish and support a number of local collective advocacy groups for parents with learning disabilities. They will also provide one to one support for parents who need specific support at different times. The aim of this project is to develop a sustainable long-term support structure for parents with learning disabilities within the communities of East Ayrshire.





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