

Understanding local approaches to supporting parents with learning disabilities

Arlene McGarty, Angela Henderson, Deborah Cairns



University
of Glasgow

Scottish
Learning Disabilities
Observatory

Table of Contents

Definition of roles and glossary	3
Key Findings.....	4
Introduction.....	5
Method.....	10
Ethics	10
Data collection.....	10
Online survey:.....	10
Freedom of information requests:	11
Semi-structured interviews:	11
Data analysis.....	12
Involvement of people with lived experience	12
Results	13
Freedom of information request results	13
Outcomes for children.....	13
Support provided to parents with learning disabilities.....	14
Survey results	15
Support available for parents with learning disabilities.....	15
Gaps in provision for parents with learning disabilities	17
Decision making processes.....	18
Interview results.....	19
Developing and accessing support for parents with learning disabilities	19
Assessments and procedures not accessible.....	22
Complex legal system	25
Need for holistic approach to mental health support	27
Recommendations and discussion	28

Recommendation 1: More systematic collection of data on parents with learning disabilities across Scotland and outcomes for their children	28
Recommendation 2: More research is required to understand the types of support available across Scotland	29
Recommendation 3: Adaptation of parenting assessments for parents with learning disabilities.....	30
Recommendation 4: All information available in an accessible format.....	31
Recommendation 5: Inter-service training required for professionals	32
Recommendation 6: Advocacy and legal support offered to parents with learning disabilities when child welfare concerns are initially raised	33
Recommendation 7: Long-term mental health support available to parents with learning disabilities and their children/families.....	34
Recommendation 8: Systematically capture delivery of recommendations and outcomes from this report	35
Conclusion	36
References	38
Appendix 1: Online survey.....	40
Appendix 2: Freedom of information request	41
Appendix 3: Semi-structured interviews topic guide.....	42

Definition of roles and glossary

Children and families social workers aim to establish safe and stable environments for children. Their roles include assessing risk, protecting children, providing support to parents, and establishing relationships with all family members.

Adult social workers aim to help adults maintain and promote their independence by providing the required support and assistance. Adult social workers can specialise in working with people with specified needs, for example adults with learning disabilities.

Children in care refers to any child who has been in the care of the local authority for more than 24 hours and can include various placement types, such as respite care and fostering.

Health and social care partnerships (HSCPs) aim to integrate care services that were previously managed separately by NHS boards and local authorities. All HSCPs are responsible for adult social work but only some are responsible for children and families social work services (in some areas, children's services have not been integrated into the HSCP and are still overseen by the local authority). Scotland is divided into 31 HSCPs.

Local authority refers to the local government (councils). There are 32 local authorities, or councils, in Scotland.

NHS boards are responsible for population health and providing frontline healthcare services, for example, primary and secondary care. There are 14 NHS boards in Scotland

People First (Scotland) are a national disabled people's organisation run by adults with learning disabilities.

Key Findings

- Only three of the 31 HSCPs in Scotland reported offering a structured supported parenting programme for parents with learning disabilities. Most support provided is informally delivered through adult services.
- Flexible, supported parenting programmes need to be developed that are tailored to individual needs, focussed on the whole family, are non-judgemental, and can be accessed by parents without a formal diagnosis of learning disabilities.
- Most children with a parent(s) with learning disabilities are in care. Approximately 10% of children live with their birth parent(s).
- Parents with learning disabilities experience significant levels of stigma from professionals who often believe that people with learning disabilities cannot be “good enough” parents.
- Parents with learning disabilities and their children experience significant mental health impacts caused by child protection processes. Mental health support should be available for all parents and children who experience these processes.
- Parents with learning disabilities are not always given the advocacy, legal support, and accessible information they require to enable them to fully understand and engage with processes.
- A lack of knowledge about learning disabilities from children and families social workers often result in reasonable adjustments not being made for parents with learning disabilities, for example, in relation to parenting assessments, that would enable people to more accurately demonstrate their parenting skills.
- Information on the number of parents with learning disabilities within each HSCP and the outcomes for children are not routinely collected.

Introduction

People with learning disabilities have the same rights to be parents as those without disabilities. Article 23 of the United Nations Convention on the Rights of Person's with Disability—Respect for home and the family, specifies that people with disabilities of legal age who are able to fully consent, have the right to marry and have children, to decide on the number and spacing of these children, and to retain their fertility (United Nations: UN, 2006). Article 23 goes on to specify that member countries (which includes the United Kingdom) should provide “appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities” and “In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents”. Therefore, all people with learning disabilities in Scotland, who have the capacity to consent, have the legal right to be parents. Scotland, as part of the United Kingdom, is bound to provide the necessary support for parents. And, furthermore, children should not be removed from their parents due to any assumptions relating to parenting capacity arising from parental disabilities.

It is important to note, however, that the rights of people with learning disabilities to be parents needs to be balanced with the rights and safety of children. The rights of children are covered in the UN Convention on the Rights of the Child (1989), which includes rights relating to growing up in an environment where a child is safe, protected, respected, and has access to education, healthcare, and sustenance. This convention also states that families should be kept together where possible, but ultimately all decisions are made based on the best interests of the child. This aligns with The Children (Scotland) Act (1995) which details that the needs of the child and prioritising their welfare must come first. Therefore, although people with learning disabilities have the right to be parents, as with all parents, the standard of parenting provided must enable all the rights of the child to be met.

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, stimulation and encouragement, guidance, boundaries, age-appropriate responsibility and independence, and predictability of key routines to their child(ren). This guidance on “good enough” parenting stems from the standpoint that parenting is a challenging and difficult job and that no parent is perfect; in fact, parents need the freedom to fail and this “failure” is an expected and

necessary part of parenting. Although the concept of “good enough” parenting has been criticised in the academic literature for lacking in clarity and ambition (Choate & Engstrom, 2014), it provides a useful starting point for identifying and providing support and gives a benchmark for where intervention is required for parents who are having difficulties (Scottish Government, 2008). This acknowledgement that all parents (not just those with learning disabilities) may require support is also specified within [The National Parenting Strategy](#) (Scottish Government, 2012b) and [Getting it Right for Every Child](#) policy (GIRFEC; Scottish Government, 2012a). This demonstrates the widely accepted notion that *all* parents may need support and that all parents should have access to support.

The specific needs of parents with learning disabilities are captured through [The Keys to Life](#) (Scottish Government, 2013) and [The Refreshed Scottish Good Practice Guidelines for Supporting Parents with Learning Disability, entitled “Supported Parenting”](#) (Scottish Commission for Learning Disability; SCLD, 2015). The Keys to Life made the recommendation that: “by 2014 parents with learning disabilities should have access to local supported parenting services based on the principles of Supported Parenting and that the Scottish Good Practice Guidelines for Supporting Parents with Learning Disabilities are being followed by professionals working with parents with learning disabilities to ensure better outcomes for families” (Scottish Government, 2013, page 80). The Scottish Supported Parenting Guidelines (SCLD, 2015) describe the key features of good support provision for parents with learning disabilities as follows:

- 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.

This demonstrates a recognition within policy specific to adults with learning disabilities that early and ongoing support is required, which aligns with existing research (MacIntyre, Stewart, & McGregor, 2019; Stmadova et al., 2017). Furthermore, when the necessary support is provided, parents with learning disabilities have the capacity to improve their skills and knowledge around parenting (Augsberger et al., 2021). However, the funding required to provide these services may not always be available, especially during times of austerity (Lymberry, 2012). The financial implications of providing these services should be viewed relative to the costs associated with removing children from their parents.

It is essential that supported parenting services are available to parents with learning disabilities, who often face more complexity in their lives. For example, parents with learning disabilities are more likely to experience a higher prevalence of trauma, isolation, poor mental and physical health, discrimination, and unemployment (MacIntyre & Stewart, 2012). These circumstances can make it more difficult for parents with learning disabilities to access help and may also make parents feel less able to ask for help. A common barrier faced by parents with learning disabilities is negative assumptions that are made regarding their parenting abilities due to them having learning disabilities. It has been extensively reported, from both the perspective of people with lived experience and professionals, that parents with learning disabilities are held to a higher standard than parents who do not have learning disabilities (MacIntyre & Stewart, 2012). Although parents with learning disabilities are often not considered to be causing deliberate harm to their child, service providers frequently view parents with learning disabilities as more likely to be neglectful to their child (MacIntyre & Stewart, 2012). Furthermore, many parents who have learning disabilities do not have a formal diagnosis due to the fear and stigma associated with this label, thus limiting their access to services (MacIntyre et al., 2019).

Due to the systemic barriers experienced, such as stigma from service providers and a lack of parenting support, parents with learning disabilities are often over-represented in the child protection system (Cox, Stenfort-Kroese, & Evans, 2015; MacIntyre & Stewart, 2019). Although challenging to estimate, it has been suggested that approximately 40-80% of parents with learning disabilities have had their child(ren) removed due to concerns about the standard of parenting they provide (Augsberger et al., 2021; Wilson et al., 2014).

Previous research has investigated the support available to parents with learning disabilities across each NHS health board and local authority in Scotland, prior to the establishment of the HSCP model (Stewart, MacIntyre, & McGregor, 2016). This project reviewed the extent to which practice was aligning with existing policy, specifically the recommendations made within The Keys to Life and Scottish Good Practice Guidelines for Supporting Parents with a Learning Disability by exploring: (i) the support available to parents with learning disabilities; (ii) whether services were aligned with the principles of supported parenting; (iii) the extent to which professionals followed The Scottish Good Practice Guidelines for Supporting Parents with a Learning Disability, and; (iv) outcomes achieved by parents with learning disabilities.

This report found that a high number of service providers (79%) used the Scottish Good Practice Guidelines in their work. The study reported that service providers had a focus on non-discriminatory practice and raising awareness of the issues faced by parents with learning disabilities. The report also identified numerous areas of good practice throughout Scotland. Areas of practice requiring additional focus were also identified, including the need for: provision of extensive and long-term support for families, early identification of parents with learning disabilities to enable intervention and support planning and provision when required, better advocacy and accessible information for parents as they progress through child protection processes, and improved working between different agencies. Overall, this report provides a somewhat positive perspective on the knowledge of professionals and the support available at that time, providing clear recommendations on how to implement the wealth of knowledge within existing guidelines, including The Keys to Life and Supported Parenting Guidelines.

The Stewart et al. (2016) study is now almost a decade old and there is a clear need for an updated review on the support available to parents with learning disabilities in Scotland, within the context of HSCP integration in 2016. These structural changes in the provision of health and social care, combined with other major challenges, including the COVID-19 pandemic and financial recessions, have had a major impact on public service delivery in Scotland. Therefore, there is a clear need to build on the important work of Stewart et al. (2016) and to update and better understand the availability of support for parents with learning disabilities in Scotland and understand outcomes for children. The Scottish Government's public consultation on the proposed Learning Disabilities, Autism and

Neurodivergence Bill (2023) also recognises the need to improve the supports and services for parents with learning disabilities and their children.

The overall objective of this project is to explore and strengthen the evidence on local approaches to supporting parents with learning disabilities, including scoping the extent to which children are maintained within the birth family. The aims of this project are to:

1. Investigate what support is available for parents with learning disabilities; how parents access parenting support services; and how many parents have accessed these services in the last 12 months.
2. Compile available data on the outcomes for the children of parents with learning disabilities
3. Understand decision making processes and the roles of different social care teams.
4. Consider how the information gathered can inform national policy development.

Method

Ethics

Ethical approval was received by the Medical, Veterinary, and Life Science College ethics committee at the University of Glasgow (reference: 200230340).

Data collection

Data for this report was collected via three complimentary methods: online survey, freedom of information request, and semi-structured interviews.

Online survey:

An online survey was designed using Qualtrics to gather information from key informants. To be eligible to participate, people had to work directly with families with parent(s) with learning disabilities, for example, children and families social work or adult social work. The survey was anonymous and collected no identifiable data from participants. Prior to entering the survey, participants had to confirm they met these inclusion criteria and that they had read and signed (using a check box) the online consent form.

The survey collected basic demographic information on profession, sector employed in, and locality of their service. Data on the types of support provided to parents with learning disabilities (if any) were collected, what this support consisted of, and how parents were referred to/accessed the available services. Data were also collected using free text response questions allowing participants to give their views on the gaps in services and other relevant information. The questions included in the survey are available in Appendix 1.

This survey was distributed via email to all HSCPs (N=31) in Scotland. The link was also advertised via online communications, including the social media channels of the Scottish Learning Disabilities Observatory and the eFocus newsletter distributed by the SCLD. A researcher also attended meetings held by the Social Work Scotland Learning Disability and Autism Group to discuss the survey and identify people who could share the survey with their networks.

Survey completion data from Qualtrics demonstrated that the survey took approximately 15 minutes to complete. The data collected by the survey was stored in Qualtrics under password protection. Only one member of the research team had direct access to data stored on Qualtrics.

Freedom of information requests:

Under the Freedom of Information (Scotland) Act 2002, people have the right to ask for, and to be given, information held by a Scottish public authority, including HSCPs (although certain conditions and exemptions apply). Public authorities have 20 working days to respond to a request and provide the information requested or set out why the information cannot be provided [with specific reference to the Freedom of Information (Scotland) Act].

Each HSCP has its own preferred process for submitting a freedom of information request, which can be found on their webpage. A freedom of information request was sent to all HSCPs (N=31) across Scotland using the preferred method described on the webpage. The aim of this request was to gather information relating to availability of supported parenting programmes, current caseloads, and outcomes for children of parent(s) with learning disabilities. The specific freedom of information request submitted is presented in Appendix 2.

Semi-structured interviews:

Semi-structured interviews were conducted with social workers to gain a better understanding of decision-making processes and gaps in provisions for parents with learning disabilities. The topic guide for interviews is presented in Appendix 3.

To be eligible to take part in an interview, participants had to currently work directly with families with parent(s) with learning disabilities and had to have a knowledge of decision-making processes. Participants were recruited via online communications. A researcher also attended meetings held by Social Work Scotland Learning Disability and Autism Group to discuss the interviews and speak with potential participants.

Potential participants were emailed an information sheet and asked to sign and return a consent form if they wished to take part. One researcher conducted the interviews and had no existing relationship with any of the participants. All interviews were conducted online using Microsoft Teams, were audio recorded, and then transcribed. Transcripts were anonymised and stored securely in a password protected file on a secure University of Glasgow server.

Data analysis

Data collected via the survey and freedom of information requests were analysed descriptively. Qualitative data from the interviews were analysed using thematic analysis (Braun & Clarke, 2021). Due to the small sample size, no direct quotes or demographic data of the participants has been included to ensure anonymity.

Involvement of people with lived experience

People First (Scotland) Parent Group were involved in all aspects of this project. The group contributed to development of the methods, including providing input into the topics to be included in the semi-structured interviews. Meetings were held every 1-2 months with the group. During data collection, the group were updated on study progress and preliminary results. At the conclusion of data collection, the group were involved in the interpretation of the results and contributed to the recommendations given. Feedback from the group is included in this report; this is clearly stated throughout.

Results

Data will be presented separately based on the three data collection methods for clarity . This will enable differences in findings between methods to be highlighted and potential reasons for these differences presented.

Freedom of information request results

Outcomes for children

Eleven HSCPs provided data on current case numbers: Aberdeenshire, Argyll and Bute, Dumfries and Galloway, East Dunbartonshire, East Renfrewshire, Edinburgh City, Orkney, South Ayrshire, West Dunbartonshire, West Lothian, and Western Isles. Due to the small case numbers and risk of identifying individuals, the full breakdown of results will not be presented, only summary data will be provided. As some data were provided in the form of “less than” figures, e.g. <5 children in a placement type, all data presented are approximate (~) figures. Furthermore, when interpreting data, it should be acknowledged that these figures are only representative of children who have parents with a formal diagnosis of learning disabilities who are known to social work, and due to the small number of HSCPs who provided information, the results may not be representative of Scotland as a whole.

The total number of children with a parent(s) with learning disabilities, who are known to social work, ranges from zero (Western Isles) to 1,838 (Edinburgh City). The most common outcome for children is to be in care (~49%), with more children living outside the family home compared to the number who live with their birth parent(s). Approximately 12% of children are in kinship care, 2% have been adopted, and ~27% are in “other”, not specified, placement types outside the family home. Only ~10% of children live with their birth family.

Where data were not provided, it was reported by the remaining 20 HSCPs that they do not collect or hold information on parents with learning disabilities. Therefore, as information is not held and would require the creation of new information [Section 17(1)(b)] and that the HSCP estimates that the cost of providing this information would exceed £600 [Section 12(1)], these HSCPs were legally exempt from providing any information. However, one area reported

in their response that they would amend their recording system to enable them to record and collate information on parents with learning disabilities moving forward.

The number of children taken away from their family because they have a parent with learning disabilities needs to change. The high number of children taken away is because professionals still believe we can't be good parents. This goes against our rights.

People First (Scotland) Parent Group

Support provided to parents with learning disabilities

In relation to the data on support available for parents with learning disabilities collected through the freedom of information requests, only three HSCPs reported providing dedicated parenting services for people with learning disabilities (Dundee City, East Lothian, and West Dunbartonshire). Three HSCPs (Angus, Midlothian, and Perth & Kinross) did not provide any information, citing that the information is not held and would require the creation of new information [Section 17(1)(b); Angus and Perth & Kinross]. The remaining 25 HSCPs responded that they do not provide or commission any form of dedicated supported parenting services for parents with learning disabilities.

The support provided and the numbers accessing these services are provided below:

Dundee City work in partnership with a specialist learning disability nursing service to support parenting assessments, interventions and supports where a parent has learning disabilities. This includes work with parents where a pre-birth assessment and post-birth support is required via the New Beginnings Team. In the 12-month reporting period, 12 parents have accessed this service.

East Lothian have a learning disabilities pathway through their Community Learning Disability Team that provides dedicated support for parents who have learning disabilities. No dedicated support is provided for parents with learning disabilities through adult social work nor children's Services. In the 12-month reporting period, 22 parents have accessed this specialist support.

West Dunbartonshire reported that they provide dedicated support for parents with learning disabilities; however, no details were provided on what this support entails. Furthermore, no parents have accessed this service in the last 12 months.

More support is needed for parents with learning disabilities. And this has to be available to parents all over Scotland. If one area can provide support to parents with learning disabilities, why doesn't every area?

People First (Scotland) Parent Group

Survey results

Forty-five participants completed the survey. As highlighted in Table 1, responses were captured from 17 distinct geographical areas (including those self-identifying as working in HSCPs, local authorities, and NHS health boards). Respondents reported that they worked in the following professional areas: adult social work (N=25), nursing (N=8), speech and language therapy (N=2), clinical psychology (N=2), children and families social work (N=2), and not specified "other" (N=6).

Support available for parents with learning disabilities

In relation to support provided for parents with learning disabilities, a greater level of support was captured through the survey than the freedom of information request. Participants reported that support was provided to parents with learning disabilities in 10 areas of Scotland. Provision of support to parents with learning disabilities was most commonly reported by participants who worked in adult social work teams.

The following key components were specified as part of the support provided: respite care, practical support (e.g. assistance with tasks and organising appointments), guidance on parenting, mental health and emotional support, signposting (e.g., information and groups/clubs), providing easy read information, legal information, and help with accessing other required services. All participants reported that support was available during pregnancy, at birth, and throughout childhood. All support was available to both parents, with 50% of the

services described being open to external family members as well. In relation to accessing services, 50% of participants reported that parents with learning disabilities could self-refer to get support and all services could be accessed through referrals from social work or health care services.

Interestingly, within five HSCPs responses of both “yes” and “no” were recorded in relation to whether support for parents with learning disabilities was provided. Furthermore, within 4 out of 5 of these occurrences, participants with different responses identified as working in the same area within the HSCP, e.g. in the role of adult social worker. This could suggest that more informal support is provided to parents with learning disabilities, as opposed to a more structured parenting programme. Or it may be a limitation with the study methods whereby supported parenting programmes were not clearly defined.

Table 1. Survey respondents by area

Area	Number of respondents
Aberdeen council	5
Aberdeen HSCP	13
Angus HSCP	1
Dundee City Council	3
Dundee HSCP	3
East Dunbartonshire HSCP	6
Falkirk HSCP	1
Fife HSCP	1
Fife NHS	1
Forth Valley NHS	1
Highland NHS	2
Perth & Kinross HSCP	1
Renfrewshire HSCP	1
Scottish Borders council	2
Tayside HSCP	1
West Lothian Council	2
Western Isles HSCP	1
TOTAL	45

Gaps in provision for parents with learning disabilities

All N=45 participants responded that there was a lack of support available for parents with learning disabilities within their local area. The following areas of support were identified as being important to provide for parents with learning disabilities:

- early intervention work on sexual health and relationships
- parenting skill development (e.g. child safety, managing personal care, modelling positive behaviour, ensuring suitable boundaries)
- parent support groups
- structured parenting education
- 24-hour support available with outreach (e.g. a helpline or online chat function).
- Respite services (including overnight)
- Training on additional support needs for parents (as many have children also have additional support needs).
- Support with providing safe accommodation
- Support for parenting children over 16 years who chose to return to their parent(s) home after being removed at a younger age.
- Independent advocacy
- Whole-family wellbeing approach
- Adult foster care type placements (e.g. Shared Lives model)
- Accessible information

It was also widely reported by survey participants that to support the implementation of more structured supported parenting, there were wider changes that had to be made, specifically relating to legislation, funding, and training.

Firstly, respondents said that parenting support requires a more robust, legislation-based pathway, that is cohesive and easy for professionals to understand, with a move away from the more informal support provided that varies greatly between HSCPs.

Funding was also noted as a major issue, with a current lack of forward planning and investment to support parents long-term and a focus only on short-term outcomes. Respondents also identified the need for funding to implement structured supported parenting programmes.

Finally, training was highlighted as being essential for implementing supported parenting programmes, in particular training on learning disabilities for children and families social workers. Joined up working between adult learning disability teams and children and families teams has to be implemented and utilised. It was reported that when healthcare professionals observed “learning disabilities” on a parent's case file this led to biased thinking towards the parent who would then be routinely assumed to not be a capable parent; this stigma was considered unhelpful. Capacity for parents with learning disabilities to be effective parents is often assumed not to be present. One participant suggested a potential approach to address this is that learning disability service providers can attain care commission registration enabling them to work with both the adult and the child.

Decision making processes

All processes relating to welfare or safety concerns of a child are implemented and led by children and families social work. The children and families team will invite other services to be involved based on their assessments. Other teams involved in these processes usually include adult/learning disabilities social work, community learning disabilities teams, and parental advocacy. Wider teams involved will depend on the needs and risks assessed; for example, the police will be involved for any situations where there has been criminality. The age of the child will also impact who is involved; for example, midwives for pre-birth, health visitors for recently born children, or education services for school-aged children. The role of learning disabilities teams in these processes is to provide a balanced view of how the parent’s learning disabilities impact their parenting skills and to recommend independent advocacy for the parent.

Although they are called “children and families” social workers, they don’t focus on the “families”. They only see a child with a parent who has learning disabilities and quickly decide they need to remove our children. If they focussed more on the families and got to know us, they would see we can be great parents.

People First (Scotland) Parent Group

Interview results

Five interviews were conducted. All participants were social workers who worked with adults with learning disabilities. Participants worked within West (N=2), Central (N=2) and East (N=1) Scotland. The following themes and sub-themes were identified.

Developing and accessing support for parents with learning disabilities

In summary, this theme describes that there is currently limited support available for parents with learning disabilities, in relation to supported parenting programmes. And where support is available, either through supported parenting schemes or social work more broadly, parents with learning disabilities are cautious of asking for help due to the stigma they experience and fear that their children will be removed. More training is required for children and families social workers to understand learning disabilities and to know when to include other services to support parents. However, more funding is required to do this.

Limited support available

All interview participants viewed that there is limited support available for parents with learning disabilities and that there is a significant need for this support to be provided. Specialised support for parents is not a new concept, with supported parenting services more widely available for parents with differing needs, for example, to those with addiction. Due to the lack of tailored support for parents with learning disabilities, one participant discussed that some parents with learning disabilities have been referred to other supported parenting services; for example, parents with learning disabilities being signposted to supported parenting services for people with addiction issues, because no learning disabilities specific support was available. Participants suggested that existing supported parenting programmes, such as the [Shared Lives model](#), could be implemented more widely.

The needs of parents with learning disabilities are unique and support may be required throughout the parenting journey. Participants identified that parents with learning disabilities need more intensive support to help them with the ever-changing demands of parenting and the frequent milestones that children go through. Support needs to be a specialised service so that parents can have their own needs met and this support should be available 24/7. However, it was noted by participants that simply providing a service will not ensure that parents will use it due to fears of raising awareness of their situation. Parents may be unsure of accessing services in case it causes critique of their parenting and that not accessing services will prevent questions on their parenting being raised by social work. Due to this stigma, it is common that when parents are offered an adult social work referral, for example for additional support or a formal assessment/diagnosis of learning disabilities, it is often refused. Therefore, parents would benefit from more services offering support in a different way. i.e. providing guidance for everyday problems they have, without the need to be open to social work and having a complete assessment undertaken.

Parents without a formal diagnosis not accessing services or support

Participants emphasised the need for supported parenting services to be open to parents who do not have a formal diagnosis of learning disabilities or are borderline. Some parents may be unsure of attending an assessment to receive a formal diagnosis as they fear how the label of “learning disabilities” might impact how they are viewed as parents. Participants suggested that children and families social workers who visit a child and think a parent has additional support needs, should make a referral to the adult learning disabilities team. Participants also emphasised the need for parents to be made aware that the adult learning disabilities social worker is there to support them; many parents with learning disabilities (without a formal diagnosis) can go through child protection procedures without having an adult learning disabilities social worker or advocacy present to support them.

Teams working together

Due to the differing remits, participants acknowledged that social workers in adult learning disabilities services often have a lack of understanding about how children and families

services work, and visa versa, which highlights the importance of these teams working together. There is a sense that children and families social workers routinely collaborate with other teams, such as mental health and addiction teams, but less so with learning disabilities teams. However, participants said that increased knowledge sharing and training between teams could help children and families social workers to understand that parents with learning disabilities can be effective parents.

Specific training for children and families social workers around parents with learning disabilities was also suggested by participants as a way to support identification of parents who may have learning disabilities who would benefit from onward referral to the adult learning disabilities team. As all social workers use the same system, it is possible to share information between teams when social workers have the capacity to do so. It was suggested by one participant that opportunities for adults learning disabilities and children and families social workers to shadow each other for a period of time to better understand how each team works would be highly beneficial.

Time demands were also reported by all participants as impacting on the ability of teams to work together. Processes around child protection can move very quickly which can limit teams working together. For example, adult social work teams may not always be included in parenting assessments that are led by the children and families team. This may quickly result in the onset of legal proceedings and this is often the point at which adult learning disabilities services are informed. More coordination between teams early-on could ensure that parents with learning disabilities are given the support required from the start. Furthermore, team working should include services that can further support parents with learning disabilities, for example occupational health and learning disabilities nursing.

When teams are working together, however, it was highlighted by participants that financial issues are common, as children and families services and adult services work from different budgets. This can cause delays when support is required and issues arise between services in relation to who pays for the support and which budget it comes from; for example, if a parent needs transport support to enable attendance at an appointment with the child, discussions on whether this is an issue related to the adult or child and ultimately who pays for it can cause hold-ups and stress for parents. As budgets are small, social work teams can be very unwilling to use their funds if they are not certain it is within their domain. More streamlined

budgets specific to supported parenting that cover the whole family could help implement support quicker.

We would like to have additional support available, such as practical support to develop parenting skills and support children as they grow. For example, help with schoolwork.

However, many parents who encounter social work try to hide that they have learning disabilities. They don't want to be judged or viewed as not good parents. So, they don't feel able to ask for the support they need.

People First (Scotland) Parent Group

Assessments and procedures not accessible

In summary, this theme describes that there is a lack of reasonable adjustments for parents with learning disabilities. This includes a lack of accessible information, limited adaptations for assessments, and a lack of clarity around service providers and their roles. This creates confusion for parents, but they are fearful of asking for help or clarity as they perceive children and families social workers have a negative bias towards them and hold them to a higher standard.

Lack of adaptations for parenting assessments

Parenting assessments and functional skills tests for parents often do not account for the needs of people with learning disabilities. One participant explained that parents with learning disabilities who are capable of completing tasks in their own home may perform poorly in tests that take place outside their home environment; for example, not being familiar with a different brand or style of kitchen appliance. This can make parents appear less capable than they are due to the lack of reasonable adjustments. This is one example where the involvement of a wider team, such as occupational health, can help make adaptations for these types of assessments to enable parents with learning disabilities to perform better.

Furthermore, participants argued that, where possible, parenting assessments should be conducted in the parent's own home.

Number of services and people involved can cause confusion

Participants reported that the number of people and services involved, and understanding their roles, can be challenging for parents with learning disabilities. For example, for one family, there could be a children and families social worker, parents may have their own social worker (if both parents have learning disabilities, they will likely have a different social worker), parents and children could also be supported by a range of other professionals, such as support workers, midwives, and specialist learning disabilities community health workers. This can be overwhelming for parents with learning disabilities to keep abreast of who everyone is and what their roles and responsibilities are.

Participants explained that it was common for parents with learning disabilities to feel scared to ask for clarification and explanations in case this is viewed by social workers as an example of them not being capable. Each of these people can be telling parents different things, leaving parents further unsure of whose advice to listen to. So, although larger teams can be beneficial to help support parents with learning disabilities, for example, the inclusion of occupational therapists in making adaptations for parenting assessments as previously noted, this has to be done in a way where parents are fully informed of who people are and what their roles are. Furthermore, it highlights the need for parents with learning disabilities to have a specialised advocacy worker to help understand these situations and someone who can give parents independent support and advice.

Parents with learning disabilities are held to a higher standard

A further barrier highlighted by participants was that parents with learning disabilities are often held to a higher standard than parents without learning disabilities, especially by children and families services. Participants described that parents with learning disabilities were not able to make common parenting mistakes without being viewed as unfit parents, and that social workers often held the view that adults with learning disabilities are more prone to lead chaotic and unstable lifestyles. Examples included, being in unhealthy

relationships, being more vulnerable, and having a higher prevalence of mental health problems and past trauma. Although these concerns are not applicable to all parents with learning disabilities, they can often be the main causes of child protection concerns. However, one participant described that in their experience, parents with learning disabilities who they worked with almost always felt that any child protection issues raised were about their learning disabilities. The participant suggested that greater transparency from social workers about their specific concerns could help parents with learning disabilities to understand reasonings and potentially enable them to make the changes required.

Lack of accessible information

Participants highlighted that limited information is available to parents in an easy read or accessible format. This leads to various issues for parents with learning disabilities, especially around their understanding of processes. Furthermore, if children and families social workers are not aware of the need for accessible information, they may leave written information/instructions that parents with learning disabilities are not able to understand or follow. Parents may not feel able to tell the social worker that they are unable to read that information as they worry it may make them look less capable as a parent. This can have a knock-on effect as parents may not complete tasks described in the written information, such as attending an appointment. This will be marked as a negative against the parent, but it does not reflect their ability as a parent, only their ability to understand and follow complex written information.

Parenting assessments feel like they are designed to “catch us out” and show all the things social work view we can’t do. It feels like we are set up to fail. They watch you, take notes, but don’t tell you what they write. It is so intimidating and upsetting.

They don’t give us information in a way we can understand. It feels like they don’t want us to know what’s going on. We can’t ask for information again because it makes us look bad. And not everyone can read, so written information isn’t always good. We should have access to all information online in video/audio format without having to ask for it.

People First (Scotland) Parent Group

Complex legal system

In summary, this theme describes that the initial processes and legal proceedings around child welfare are extremely complex. Adult social workers, specifically those working with parents with learning disabilities, do not fully understand these processes and therefore cannot always provide the support and information that parents require. More cross-service training and joint working is required to increase adult social workers' knowledge of these proceedings. In addition, work has to be done to reduce the stigma associated with learning disabilities to increase the likelihood that children can continue to live with their parents, where it is safe to do so. Parents with learning disabilities should also be offered advocacy and legal support as early as possible and not just when court proceedings begin.

Adult learning disabilities teams' knowledge of child protection processes

The legal aspects of child protection are extremely complex and all participants recognised they had limited knowledge of these processes. Children and families teams lead these processes, including initiating the parenting assessments. All services involved can input on a decision at the case conference, but ultimately the power lies with the children and families service to make legal applications through the courts for any child protection issues. Children and families social workers receive extensive training on child protection and children's hearing processes. However, adult social workers do not receive training on this and, therefore, many adult social workers do not fully understand the legal processes surrounding child protection. This can limit the support they can provide to the parents they work with. It was recommended by participants that more crossover training would help adult learning disabilities services to support parents with learning disabilities. It would also increase the understanding of children and families services to know when it is also beneficial to bring in other services, such as occupational therapy and learning disabilities nursing, to provide information at different hearings in support of the parent.

Parents lack of understanding of rights

Parents with learning disabilities are often not fully aware of their legal rights. Furthermore, participants discussed that most parents do not receive advocacy or legal services at the early

stages of any potential child protection issues. The required support given at the correct time could help parents make informed decisions. A combination of themes already discussed can also impact parents' understanding of their rights. For example, parents have a fear of asking questions when they do not understand the processes or the information they have been given. They are scared this will also make them look unfit as parents. Information on legal rights is not available in an easy read or accessible format – information is available online that is called “easy read”, but it is a plain English summary and not easy read.

Limited effort to return children to live with parents with learning disabilities

Once a child is removed from their birth parent(s), they often get limited time with the child, and often under supervision. In the experience of participants, once a child is removed, it is almost always permanent and there are limited attempts by children and families social workers to return the child to the family home. This is unusual in comparison to parents with other issues that affect their child, such as addiction, where children are more likely to be returned to the family home. Participants discussed that as learning disabilities cannot be “cured”, unlike other issues such as addition or mental health problems, children are less likely to remain with their birth parent(s) with learning disabilities.

It can be really difficult for parents to understand what is going on and what rights we have. It's hard to know who to listen to when it feels like everyone is against you. Having a lawyer is really important. Sometimes social workers say you have to do certain things, but the lawyer can tell you what you need to do and what you don't need to do.

Every parent should have a lawyer from the start as they are on your side. But sometimes it can be hard to find a lawyer who has experience of working with parents with learning disabilities.

People First (Scotland) Parent Group

Need for holistic approach to mental health support

Participants recognised that removing children is a traumatic experience for both parents and their children. As many parents with learning disabilities have experienced trauma in their lives, the experience of having their child removed can be a tipping point for their mental health. Support, such as counselling, needs to be offered to both parents and children. But offering this immediately will not always be effective, as parents may be in the process of grieving and not ready to use a service. However, a holistic and long-term mental health service should be available once the parent and child are ready to access the service.

How parents are treated by professionals can be very damaging to our mental health. We can be lied to, tricked, and situations twisted to make us look bad. Having a child removed is traumatic for children and parents. A social worker can arrive unexpectedly, and you get 10 minutes to pack a bag for your child and say goodbye. There is no care or compassion shown. That leaves a lasting impact.

But once your child is taken away, you are forgotten about. You have no support. This can be a crisis point for many parents. We need to be seen as people with emotions and given the support to deal with what we are feeling.

Children need support to deal with this trauma too. The knock-on effects of how parents with learning disabilities are dealt with is creating generational damage.

People First (Scotland) Parent Group

Recommendations and discussion

This section provides recommendations related to policy and practice based on the findings of this project (Aim 4). The People First (Scotland) Parent Group suggested that the recommendations from this project are fully discussed and justified as a standalone section within this report, rather than presented as bullet points at the end of the report. The aim of this section is to highlight the importance of these recommendations, discuss where these recommendations sit in relation to existing knowledge, and demonstrate the need for action to help support parents with learning disabilities in Scotland.

Recommendation 1: More systematic collection of data on parents with learning disabilities across Scotland and outcomes for their children

Response rates within this project were not fully representative of Scotland as a whole. Therefore, it was not possible to provide nationally accurate data on the number of parents with learning disabilities and the outcomes for their children. It was widely reported in the results from the freedom of information requests that HSCPs do not routinely collect data relating to the number of parents with learning disabilities in that area, nor the outcomes for their children. Although the information collected in the project provides an important starting point, if parenting programmes are to be developed and implemented throughout Scotland, there is a need to accurately understand the numbers of parents with learning disabilities, the context of their child's care, and the distribution of parents across each HSCP. This is essential for developing programmes and allocating funding. The Learning Disabilities, Autism and Neurodivergence Bill consultation (2023) also recognises the importance of data collection and reporting of the number of parents with learning disabilities and their children as the foundation to improving services for these groups.

Recommendation 2: More research is required to understand the types of support available across Scotland

There is a clear need for supported parenting programmes to be designed specifically for parents with learning disabilities and available to parents and families throughout Scotland. The small number of existing programmes identified through the freedom of information request were not well used, which suggests that the design or accessibility of the programmes does not suit the needs of parents with learning disabilities.

When parents with learning disabilities are provided with the support they require, parents can improve their parenting skills, improve the home living environment, and children are more likely to remain in the care of their parents (Augsberger et al., 2021). Therefore, providing accessible support is essential for positive outcomes for parents and children. Support provided needs to be tailored to the needs of each parent and could include training, practical support with parenting tasks, social support, and focussed on the whole family (Koolen et al., 2020). Therefore, a flexible whole-family programme should be developed with parents with learning disabilities and piloted, prior to national roll-out.

An important area of note was that less formal support for parents with learning disabilities was identified in the present study, in comparison with previous work on this topic in Scotland (Stewart et al., 2016). In comparison with this previous research, it is a great concern that the support available to parents with learning disabilities has reduced in the last ~10 years, while the evidence base for the need for this support continues to grow. Therefore, it is essential that additional research is conducted to fully capture the support available and to understand if this difference in reported support is based on programmes no longer being available (and, if so, why), or whether there is a lack of knowledge on the supported parenting programmes available. Furthermore, the People First (Scotland) Parent Group highlighted that they are aware of community-run programmes, for example through churches and disability organisations, which are unlikely to have been identified in the present study.

Recommendation 3: Adaptation of parenting assessments for parents with learning disabilities

Processes, especially relating to parenting assessments, are usually conducted with limited adaptations for parents with learning disabilities. As these assessments are led by children and families services, this is likely due to a lack of understanding about the needs of parents who have learning disabilities. If adult learning disabilities services are included prior to these assessments being conducted, it provides the opportunity for the needs of the parents to be met. The inclusion of a wider team, such as occupational therapists and learning disability nurses, could input on reasonable adaptations that could be made to ensure parents are comfortable and able to complete the assessment to their full ability.

Recommended adaptations need to be made based on the individual needs of parents. However, the following broad adaptations are likely to benefit all parents with learning disabilities: assessments conducted in their own home, when safe to do so; information should be provided in an accessible format; the aim of the assessment has to be clearly explained, and; the assessor needs to be aware of the needs of parents with learning disabilities. This need for adaptations in relation to parenting assessments has previously been described within the Supported Parenting guidelines (SCLD, 2015). Since the publication of these guidelines in 2015, nothing has changed in practice in relation to the support and adaptations provided to parents with learning disabilities during assessment processes.

Implementing these adaptations to enable parents with learning disabilities to demonstrate their parenting skills is essential. These assessments play a key role in deciding whether parents are able to care for their child. It has previously been estimated that between 40%-80% of parents with learning disabilities are deemed to not be meeting an adequate standard of parenting as a result of parenting assessments, which results in their children being removed from their care (Augsberger et al., 2021; Wilson et al., 2014). Therefore, this raises the question of how many children are being removed from their parents, not because the parents cannot provide “good enough” care, but because they cannot complete the parenting assessment.

As previously discussed, the Scottish Government (2008) define being a “good enough” parent as providing basic physical care, love and affection, security, stimulation and

encouragement, guidance, boundaries, age-appropriate responsibility and independence, and predictability of key routines to their child(ren). Parents should also have the flexibility to make mistakes, fail, and learn from this. However, the previously discussed stigma associated with learning disabilities results in parents being held to a higher standard (MacIntyre et al., 2019). Therefore, reasonable adaptations will create a more equitable system where parents with learning disabilities can better demonstrate their parenting skills.

Recommendation 4: All information available in an accessible format

Information is not consistently provided to parents in an easy read or accessible format. This includes information relating to legal procedures, as well as information provided by social workers. It was identified in this study via the survey and interviews that social workers develop and provide easy read information to give to parents. These individual examples of good practice have been identified in previous research (SCLD, 2015). However, this also highlights a significant gap whereby parents who are not known to social work have limited access to accessible information without asking for it. This is not a fair or consistent model for ensuring parents with learning disabilities are provided with the information they require to make informed decisions. Although providing accessible information will require funding, it will also reduce the burden on individual social workers. Furthermore, not providing information in an accessible format does not align with the Equality Act 2010 [Disability Discrimination Act 1995] and therefore it is essential this is addressed.

As discussed by the People First (Scotland) Parent Group, accessible information must go beyond easy read. Audio information and videos should be made widely available, and freely available online and in social work offices, so that parents can access information without having to disclose having learning disabilities or any associated issues, such as problems with reading. The Supported Parenting guidelines (SCLD, 2015) already recommend accessible information and communication and specifies that this can include: easy read, large print, CD or DVD, accessible websites, face to face meetings, and support from an advocate to help with these. Furthermore, these guidelines suggest that information is available “when” required by parents. However, as identified in the present study, it is also important that information is freely available so that parents are not required to ask for it.

Recommendation 5: Inter-service training required for professionals

It was identified that services had a limited working knowledge of other services and their respective fields. Children and families social workers had a lack of knowledge around learning disabilities, which impacted their behaviour towards parents with learning disabilities and the views they had around capacity for parenting. On the other hand, adult learning disabilities services had a lack of knowledge on the policy and legislation relating to children and families social work, in particular around child protection procedures. This limited the support they could provide to the parents with learning disabilities they worked with.

There is a need for services to receive training to address these gaps in knowledge. This can be implemented in various ways and should be included in both formal and informal training, i.e. child protection training also being offered to adult learning disability services. Training for children and families social workers should include people with lived experience to break down barriers and reduce conscious and unconscious bias towards people with learning disabilities. The People First (Scotland) Parent Group currently deliver this type of training on a request basis, but this could be rolled out to be mandatory for all services who may encounter parents with learning disabilities. In addition, a social worker who participated in the interviews suggested that small case studies could be conducted within teams to test the effectiveness of firsthand training in the form of shadowing colleagues. It was also suggested that an increased knowledge on learning disabilities from children and families teams could help identify parents who may have learning disabilities and provide them with support, if required. The benefits from this increased training could have significant implications for the outcomes of children.

This need for cross-service training and working to support parents with learning disabilities has been identified in previous research and guidelines (SCLD, 2015; Stewart et al., 2016) and could be an effective method of reducing the bias and stigma identified in this study towards parents with learning disabilities. Stigma from social workers in relation to the abilities of parents with learning disabilities, identified in the present study, aligns with previous research. For example, family courts are more likely to view parents with learning disabilities as less able parents resulting in the unjust removal of their children (Sigurjónsdóttir & Rice, 2017). Furthermore, social workers have been shown to demonstrate prejudice to parents

with learning disabilities, to the extent that they believe mothers with learning disabilities should terminate their pregnancy rather than become a parent (Strnadova et al., 2017).

The need for partnerships and cross-service working is not a new concept but is at the core of all existing guidelines relevant to this topic. For example, the need for public agencies and services to work together is specified within Government legislation [e.g. Public Bodies (Joint Working) (Scotland) Act 2014] and is a key component within the GIRFEC policy (Scottish Government, 2012a). Therefore, services that are involved in the care of families and parents with learning disabilities should be working more closely together. Furthermore, it is also important for services to work in partnership with the third sector, in particular organisations that can provide advocacy for parents with learning disabilities (Stewart et al., 2016).

However, as highlighted in this study, there are practical reasons that could limit services working together; for example, relating to funding and the need for a more streamline funding model to support a whole-family approach, and the capacity of social workers to find the time for additional training. Therefore, these barriers need to be addressed to enable services to work better together and receive cross-service training, which will provide a more effective context for supporting parents with learning disabilities and their children.

Recommendation 6: Advocacy and legal support offered to parents with learning disabilities when child welfare concerns are initially raised

This project highlighted how complex child protection processes are and that these usually involve multiple agencies. This can result in parents with learning disabilities not fully understanding the processes and assessments involved, for example: who different people are and what their roles are, and not knowing what their (and their child's) rights are in different situations. Therefore, it is essential that parents can always access advocacy and legal support. Services who work with adults with learning disabilities will often advise parents to seek advocacy when child welfare concerns have been raised. But as adult services are not always involved in these processes from the start, parents with learning disabilities often do not have an advocate or legal support until court proceedings have begun. It is essential that all services, in particular children and families social work, are aware of the need for advocacy and can advise parents of this at the first opportunity, as well as ensuring

learning disability services are involved as early as possible. As highlighted by the People First (Scotland) Parent Group, children and families social work could work better with “families” – as a key part of the family, parents with learning disabilities should be advised to seek independent support.

Independent advocacy is a legal right for people with learning disabilities under the Mental Health Care and Treatment (Scotland) Act (2003). Having an advocate has been shown to be effective at helping parents engage and have their voices heard during the processes relating to child protection, and to make them more confident in challenging decisions (Atkin & Kroese, 2021). Due to these benefits, advocacy is recommended in existing guidelines relating to supporting parents with learning disabilities (SCLD, 2015; Stewart et al., 2016) and therefore should be widely implemented.

In addition to the barriers identified previously, such as parents not being made aware of their right to access an advocate or legal support, other barriers also exist in relation to accessing advocacy. The People First (Scotland) Parent Group highlighted that many advocacy organisations have closed, and existing organisations may have limited capacity. The group also highlighted that it can be difficult to find legal support from a lawyer experienced in dealing with cases involving parents with learning disabilities. Therefore, early signposting for advocacy may provide parents with enough time to identify a suitable advocate and legal counsel to support them throughout the impending processes.

Recommendation 7: Long-term mental health support available to parents with learning disabilities and their children/families

The assessments and processes surrounding child protection can be unpredictable, i.e. sometimes moving quickly, sometimes more slowly, and can include numerous phases, such as parenting assessments and temporary removal of a child. This uncertainty and the fear that their child could be permanently removed from their care can cause a high level of stress to parents (and children). Parents mental health can also be impacted because of having learning disabilities and the resulting stigma they experience.

People with learning disabilities also have a higher prevalence of mental health problems and trauma than the general population (McNally, Taggart, & Shevlin, 2021; McMahon & Hatton, 2021). Subsequently, parents with learning disabilities experience a higher prevalence of low self-esteem, low confidence, and social isolation and therefore require additional support. The Supported Parenting guidelines recommend that parents with learning disabilities are provided with emotional support due to these factors (SCLD, 2015). However, due to the impacts on mental health caused by experiencing child protection processes, combined with the higher prevalence of existing mental health problems, this support needs to extend beyond emotional support to mental health support, such as access to counselling services.

As highlighted by interview participants and the People First (Scotland) Parent Group, the mental health impacts are significant and parents and children are left feeling isolated and without the support required to process their experiences, in particular when children are permanently removed from the family home. Additional research needs to be carried out to understand the long-term mental health implications on families where children have been removed.

Recommendation 8: Systematically capture delivery of recommendations and outcomes from this report

As previously discussed, this report has identified areas of focus for parents with learning disabilities that are similar to the gaps in knowledge and provision identified in previous work on this topic in Scotland (SCLD, 2015; Stewart et al., 2016). Therefore, there is a need for action, specifically in relation to the implementation of the recommendations within this report. This requires the development of a government led working group that has oversight for driving forward the recommendations in this report.

Conclusion

The combined results from this project demonstrate that parents with learning disabilities in Scotland are not being provided with the support and reasonable adjustments they require to be “good enough” parents. Parents still experience a high level of stigma and negative bias towards their parenting skills due to having learning disabilities. This results in many parents with learning disabilities having to experience the stress and trauma of child welfare processes, which almost always results in their child being permanently removed. Based on the data available, only ~10% of children with a parent(s) with learning disabilities are cared for with their birth family. The findings from this study suggests that the number of children removed from their parents is unnecessarily high and that parents with learning disabilities can provide the level of parenting required to keep their child in their care when given the right support.

Support for parents needs to include supported parenting programmes that are flexible to the needs of parents, focussed on the whole family, are non-judgemental, and can be accessed by parents without a formal diagnosis of learning disabilities. Parents also need to be given the advocacy, legal support, and accessible information they require to enable them to fully engage with proceedings, know which processes are mandatory or optional, and be given the confidence to challenge decisions. The stigma associated with parents with learning disabilities is a significant issue and needs to be addressed as a matter of urgency; this negatively contributes to outcomes for children and has significant impacts on the mental health of parents and children.

Reducing the stigma experienced by parents with learning disabilities could be achieved through cross-service training and training delivered by people with lived experience. Learning disabilities services could also benefit from an increased knowledge on the processes involved with child protection. There is also a need for focussed research to be conducted to better capture the number of parents with learning disabilities in Scotland, the outcomes for their children, and the support provided to parents that is informal.

Many of the findings identified in this study align with the results and recommendations presented within previous work in this field (SCLD, 2015; Stewart et al., 2016). This is concerning as it highlights that no progress has been made in relation to supporting parents

with learning disabilities in Scotland in the past 10 years. In fact, the findings from this project suggest that the situation for parents has gotten worse, including identifying fewer supported parenting programmes compared to Stewart et al. (2016). Therefore, there is an urgent need for action to be taken and findings implemented so that parents with learning disabilities are supported to be the best parents they can be.

References

- Augsberger, A., Zeitlin, W., Rao, T., Weisberg, D., & Toraif, N. (2021). Examining a child welfare parenting intervention for parents with intellectual disabilities. *Research on Social Work Practice, 31*(1), 65-74.
- Braun, V., & Clarke, V. (2021). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology, 18*(3), 328-352.
- Choate, P. W. & Engstrom, S. (2014). The 'good enough' parent: implications for child protection. *Child Care in Practice, 20*(4), 368-302.
- Koolen, J., van Oorsouw, W., Verharen, L., & Embregts, P. (2020). Support needs of parents with intellectual disabilities: Systematic review on the perceptions of parents and professionals. *Journal of Intellectual Disabilities, 24*(4), 559-583.
- Lymberry, M. (2012). Social Work and personalisation. *British Journal of Social Work, 42*(4), 783–792.
- MacIntyre, G., & Stewart, A. (2012). For the record: the lived experience of parents with a learning disability—a pilot study examining the Scottish perspective. *British Journal of Learning Disabilities, 40*(1), 5-14.
- MacIntyre, G., Stewart, A., & McGregor, S. (2019). The double-edged sword of vulnerability: Explaining the persistent challenges for practitioners in supporting parents with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 32*(6), 1523-1534.
- McMahon, M., & Hatton, C. (2021). A comparison of the prevalence of health problems among adults with and without intellectual disability: A total administrative population study. *Journal of Applied Research in Intellectual Disabilities, 34*(1), 316-325.
- McNally, P., Taggart, L., & Shevlin, M. (2021). Trauma experiences of people with an intellectual disability and their implications: A scoping review. *Journal of applied research in intellectual disabilities, 34*(4), 927-949.
- Scottish Consortium for Learning Disability. (2015). Supported Parenting: Refreshed Scottish Good Practice Guidelines for Supporting Parents with a Learning Disability. Glasgow: SCLD. Retrieved from: https://www.sclد.org.uk/sdm_downloads/good-practice-guidelines-for-supporting-parents-with-learning-disabilities/
- Scottish Government. (2008) Final report from the parenting task group for the early years framework. Edinburgh: Scottish Government.
- Scottish Government (2012a). A guide to Getting it right for every child. Edinburgh: Scottish Government. Retrieved from: <http://www.gov.scot/Resource/0045/00458341.pdf>
- Scottish Government (2012b). National Parenting Strategy. Edinburgh: Scottish Government. Retrieved from: <http://www.gov.scot/Resource/0040/00403769.pdf>
- Scottish Government (2013). The keys to life – Improving quality of life for people with learning disabilities. Edinburgh: Scottish Government. Retrieved from:

<https://www.gov.scot/publications/keys-life-improving-quality-life-people-learning-disabilities/>

Scottish Government. (2023). Learning Disabilities, Autism and Neurodivergence Bill: Consultation. Edinburgh: Scottish Government. Retrieved from: <https://www.gov.scot/binaries/content/documents/govscot/publications/consultation-paper/2023/12/learning-disabilities-autism-neurodivergence-bill-consultation/documents/learning-disabilities-autism-neurodivergence-bill-consultation/learning-disabilities-autism-neurodivergence-bill-consultation/govscot%3Adocument/learning-disabilities-autism-neurodivergence-bill-consultation.pdf>

Sigurjónsdóttir, H. B., & Rice, J. G. (2017). 'Framed': Terminating the parenting rights of parents with intellectual disability in Iceland. *Journal of Applied Research in Intellectual Disabilities*, 30(3), 543-552.

Stewart, A., MacIntyre, G., & McGregor, S. (2016). Supporting Parents with Learning Disabilities in Scotland: Challenges and Opportunities. Glasgow: SCLD. Retrieved from: <https://www.sclld.org.uk/wp-content/uploads/2016/11/Parenting-Report-FINAL-14.11.16.pdf>

Strnadova, I., Bernoldova, J., Adamcikova, Z., & Klusacek, J. (2017). Good enough support? Exploring the attitudes, knowledge and experiences of practitioners in social services and child welfare working with mothers with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 30(3), 563–572.

United Nations. (2006). Convention on the Rights of Persons with Disabilities: Article 23 – Respect for the home and the family. Retrieved from <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-23-respect-for-home-and-the-family.html>

Wilson, S., McKenzie, K., Quayle, E., & Murray, G. (2014). A systematic review of interventions to promote social support and parenting skills in parents with an intellectual disability. *Child: care, health and development*, 40(1), 7-19.

Appendix 1: Online survey

Q1. Please tell us the name of the HSCP that your organisation is in

Q2. Profession of person completing survey

Q3. Which department are you in:

1. Adult social work team
2. Children and families social work team
3. Third sector organisation
4. Education
5. Other, please state

Q4. Does your organisation provide supported parenting services?

If yes, how many parents with learning disabilities are supported by your organisation?

Q5. Does your organisation provide dedicated support to parents with learning disabilities?

If yes, how are people referred to this service?

1. Self-referral
2. Social work referral
3. Health care service referral
4. Walk-in
5. Other, please state

Q6. At what stage in the parenting journey is support available to parents with learning disabilities?

- During pregnancy
- At birth
- Post-birth
- Throughout childhood

Q7. Can you briefly describe the type of support that is provided? (For example, respite care, information and advice, practical support with day-to-day parenting, emotional support)

Q8. Who is this supported parenting service available to?

- Mother only

- Both parents
- Extended family members

Q9. Do you think there are gaps in provision of support for parents with learning disabilities in your area?

If yes, what types of services do you think are needed?

Q10. When a decision needs to be made for a child of parents with learning disabilities [e.g. suggesting a voluntary care arrangement (under section 25), whether to refer the child to the Reporter, or whether a child protection investigation needs to take place], which teams would typically be involved in these conversations? What determines who is involved?

Appendix 2: Freedom of information request

Question 1: Does your adult social work team, children and families social work team or other relevant department provide or commission dedicated supported parenting services for parents with learning disabilities? If yes, how many parents have accessed this service in the previous 12 months.

Question 2: How many children (who have at least one parent with learning disabilities) were in the following placement types on 29th February, 2024:

- Cared for with birth family (with a Compulsory Supervision Order)
- Kinship care (including under section 25; voluntary arrangement)
- In care
- Adopted
- Other, please specify

Appendix 3: Semi-structured interviews topic guide

Below is a topic guide used to guide the semi-structured interviews:

- Current case load
- Awareness / use of Principles of Supported Parenting
- Outcomes for the children of parents with a learning disability
- Decision-making processes

This report was authored by:

Dr Arlene McGarty, University of Glasgow

Angela Henderson, Scottish Government

Professor Deborah Cairns, University of Glasgow.

Report submitted to Scottish Government, April 2025.

For enquiries regarding this report, please contact:

Dr Arlene McGarty
Scottish Learning Disabilities Observatory
Mental Health & Wellbeing , School of Health and Wellbeing
College of Medical, Veterinary and Life Sciences
University of Glasgow, Charity number SC004401

Clarice Pears Building
90 Byres Road
Glasgow
G12 8TB
Email: Arlene.McGarty@glasgow.ac.uk



Leading research | Improving health | Tackling inequalities