



Building Blocks



**Exploring the barriers and facilitators to early learning
and childcare provision for children with learning
disabilities in Scotland**

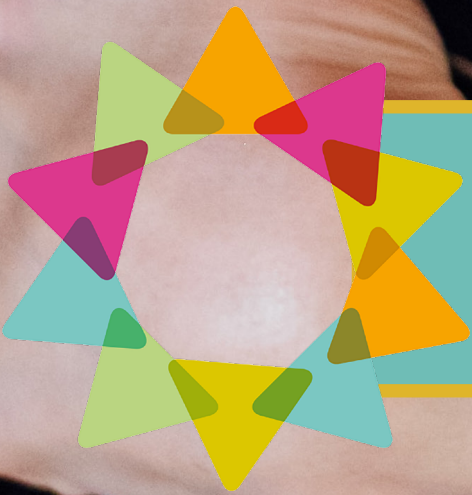
SCLD, MARCH 2022

Acknowledgements

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We are incredibly grateful to the early years leads, and others working in the early years sphere, for giving up their time so graciously as we navigated a policy area that was new to us. Our thanks must also go to those working in early years settings who took the time to fill in our survey.

Most importantly, this project would not have been possible without the parents and carers who told us their stories. To them we extend our enormous gratitude. And, for them, we hope that this report leads to a greater understanding of the needs of children with learning disabilities in the early years, and a commitment to real change in the future.



Executive Summary

1. Executive Summary

Background, policy context and research aims

- 1.1. The Scottish Government has long acknowledged the vital importance of the early years for a child's development, improved educational outcomes, as well as better health and employment outcomes in later life. Indeed, the policy landscape in relation to the early years in Scotland is well developed, with several legislative frameworks in place, and a stated ambition of giving every child the best start in life. Funded Early Learning and Childcare (ELC) is an important aspect of this, as well as a key enabler for parents to return to work. The numbers of funded hours parents are entitled to recently increased to 1140. Within this context, and against the backdrop of the passage into Scots law of United Nations Convention on the Rights of the Child (UNCRC), SCLD was keen to understand more about the specific experiences of parents of children with learning disabilities in accessing – or not – their funded ELC entitlement, to see if there were areas that should be the focus of changes to policy and practice.
- 1.2. The research was conducted using a qualitative approach, comprising:
 - A freedom of information request sent to local authorities regarding levels of uptake of funded ELC places for children with learning disabilities
 - Semi-structured interviews with parents and carers of children with learning disabilities
 - Semi-structured interviews undertaken with local authority early years leads
 - Semi-structured interview with a child development centre worker
 - A self-complete survey of childcare providers

Setting the context

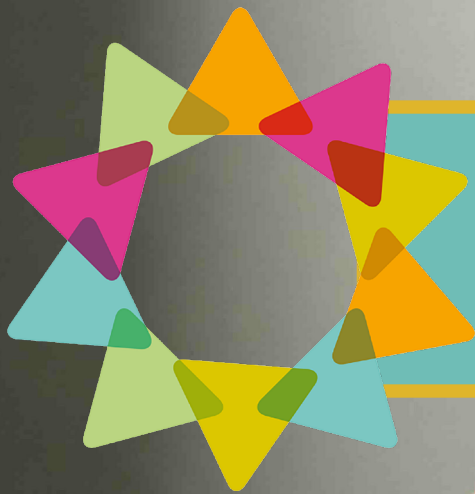
- 1.3. A freedom of information request supported the fact that current data collection does not allow us to assess the extent to which parents of children with learning disabilities are accessing their funded entitlement of ELC. Early years leads we spoke with were hopeful that health visitors would alert them to families who were not accessing their entitlement, though acknowledged that there was no way to know this for certain.
- 1.4. Early years leads we spoke with were passionate and dedicated to ensuring all children could benefit from funded ELC places, including children with learning disabilities. They identified unclarity on the part of ELC setting about their statutory duties of inclusion, inadequate resources for reasonable adjustments and the reduction of places within specialist provision as specific barriers for parents of children with learning disabilities taking up their funded entitlement. Factors that facilitated the uptake of places were engaging with families early to identify support needs, good relationships with NHS and social work teams to work together and get the right support in place, and utilising discretionary early entrant places for children with learning disabilities.
- 1.5. The research found that 57 % of local authority or partnership providers and 64 % of childminders who responded to a self-complete survey were confident in their ability to cater for children with learning disabilities. Those who felt confident cited previous experience, good training and good relationships with external specialists as key factors. Settings identified more training, more support from specialists and more staff as pivotal to instilling confidence, while inappropriate facilities were seen as a key difficulty in catering for children with learning disabilities.

Parents' perspectives

- 1.6. While a small qualitative study cannot do justice to the unique experience of each family, there were a number of common themes uncovered throughout the interviews with parents that serve to highlight the main experiences and challenges faced by parents when trying to find suitable early learning and childcare provision.
- 1.7. **Difficulties finding information about support and entitlements in a complex system:** Parents faced significant challenges finding out about their rights and what support was available to them, in a system that is complicated by the necessary involvement of many different services.
- 1.8. **The challenge to get the right support in place:** Parents spoke about how difficult it was to get the right support in place for their child to access and thrive in an ELC setting. This was down to a number of factors including the reduction in specialist provision and lack of one-to-one support for children attending mainstream settings.
- 1.9. **Inequity of provision for children with learning disabilities:** Parents detailed the lack of equity in provision available for children with learning disabilities. These included specialist nurseries not offering wraparound provision or access outwith term time, the unavailability of 'eligible 2s' places in specialist provision, local authorities not funding one-to-one support within the extended hours or allowing split/blended placements to include a mix of mainstream and specialist provision.
- 1.10. **The importance of good leadership and staff attitude in the setting:** Parents who reported that they and their child had a good experience within a mainstream ELC setting found that this was predicated on good leadership and staff attitude towards inclusion.
- 1.11. **Open, honest, equitable dialogue with parents:** It was clear from speaking with parents that openness and honesty on the part of the provider was a key component of a good ELC experience for parents and children. Parents appreciated feeling listened to and respected as an expert in their child's needs.
- 1.12. **The importance of well-trained staff:** Parents were clear that well-trained staff who understood their child's needs were an important factor in ELC settings. This was the reason some opted for specialist provision. Some worried that there was no mandatory training on inclusion for early years practitioners and that one-to-one support staff had no specific training to work with children with learning disabilities.
- 1.13. **Appropriately sized settings with the right staff ratios:** Another fundamental aspect of a good ELC experience for parents was finding a setting where class sizes were relatively small. Specialist nurseries by their nature are intimate settings with lower staff to child ratios, and this was a draw for parents when opting for this type of provision. However, some mainstream nursery classes can be very large, with parents feeling concerned that their child would not be happy, or indeed safe in such a setting.

Discussion and moving forward

- 1.14. The Scottish Government is clear in its ambition that all children and young people will get the support they need to reach their full learning potential. However, while some parents outlined a very happy experience of ELC for both themselves and their child, the overall picture from this research is one where, despite the best of intentions, we are simply not getting it right for every child. Proper resources will be a fundamental aspect of improving the situation for children with learning disabilities
- 1.15. While there is no silver bullet that will solve this complex issue, SCLD believes that on the back of this research, there are a number of actions to be explored in the short and medium term which could move us closer to getting it right for children with learning disabilities in the early years. To that end, SCLD has put forward a number of recommendations:
- Ensure children with learning disabilities are visible within the ELC Census
 - Provide clear, accessible information for parents about Enquire services
 - Ensure provision of early years support programmes specific to the needs of families raising a child with learning disabilities
 - Equip health visitors with knowledge to enable them to support and signpost families to information and advice
 - Reconsider how inclusion is assessed in the benchmark qualification for early years lead practitioners
 - Create an Open Badge for working with children with profound and multiple learning disabilities (PMLD) in mainstream settings
 - Early Learning and Childcare settings should introduce a more structured parental engagement process
 - Include children with learning disabilities in the first phase of the ELC expansion for 1- and 2-year-olds
 - Ensure all local authorities' 'split/blended placement' offer provides maximum flexibility, including a mix of mainstream and specialist provision
 - Replace the Early Learning and Childcare Inclusion Fund with ring fenced funding for local authorities for reasonable adjustments in early years settings
- 1.16. The COVID-19 pandemic has left people with learning disabilities and their parents and carers isolated and struggling to cope over the past 18 months. But their struggle is not new. This research has served to highlight that inequalities begin in the earliest years. And despite the best policy intentions, more information, support and resources are required for families and children with learning disabilities to enjoy equitable access to ELC settings, and, in turn, improved life-chances and better outcomes.
- 1.17. While the recommendations in this report could potentially move us closer to getting it right for children with learning disabilities in the early years, it is clear that the wholesale change that is needed to address the issues outlined in this report will require a concerted effort on behalf of policy makers, staff working in and around the early years sphere, as well as other professionals involved in the lives of children with additional needs.
- 1.18. Moving forward from COVID-19, the Scottish Government has committed to learn lessons from the pandemic, redouble efforts to tackle the wider inequalities that pervade our society, and embed equality, inclusion and human rights across Scotland. On this journey towards Scotland's recovery and renewal, we must make sure the voices of those who already experienced inequalities long before COVID-19 are front and centre. When it comes to ELC, these voices are telling us that we need wholesale change. Now is the time to listen. Now is the time to make them a priority. Now is our opportunity to create the fairer, more inclusive Scotland we all aspire to.



Introduction and Methods



2. Introduction and methods

Background and policy context

- 2.1. The Scottish Government has long acknowledged the vital importance of the early years for a child's development, improved educational outcomes, as well as better health and employment outcomes in later life. Indeed, the policy landscape in relation to the early years in Scotland is well developed, with several legislative frameworks in place, and a stated ambition of giving every child the best start in life.¹²³
- 2.2. Legislative recognition that high quality, state funded early learning and childcare (ELC) is a key factor for getting it right in the early years came in 2014 with the introduction of the Children and Young People (Scotland) Act,⁴ and a commitment to provide 600 funded hours of ELC for all three- and four-year-old and eligible two-year-olds. The term ELC was introduced by the Act, with the intention to emphasise that the care and education of very young children are not two separate things.
- 2.3. In 2016, the Scottish Government announced it would double the funded entitlement to 1140 hours by August 2020.⁵ The stated aims of the expansion were improving children's outcomes, increasing family resilience, and supporting parents into work, study, or training. Though delayed by the COVID-19 pandemic the expansion was completed in August 2021, and the latest Programme for Government⁶ sets out an ambition to provide the same funded early learning and childcare entitlement to all one- and two-year-olds, beginning in this Parliament with those from low-income households.
- 2.4. The Scottish Government also explicitly recognises the importance of getting it right in the early years for children with learning disabilities. Indeed, supporting the early years development of children with learning disabilities is an important priority identified in **The keys to life** implementation framework 2019-2021.⁷ In particular, the framework commits to ensure the needs of children with learning disabilities are reflected in the implementation of the Play Strategy. This has implications for ELC settings, as the Strategy aims to ensure children enjoy high quality play opportunities daily, including in ELC settings.⁸
- 2.5. However, children with learning disabilities will only enjoy all the benefits that come with their funded ELC entitlement where they are accessing provision that meets their needs. As part of an equality impact assessment (EQIA) of ELC expansion, the Scottish Government acknowledged that current data collection does not allow it to assess whether uptake of funded ELC is different for families with protected characteristics, though it aims to address this by moving to an individual child-level ELC Census by 2022.⁹ The EQIA did however recognise that there were a number of potential barriers to access to ELC for children with disabilities and/or additional support needs, including lack of parental confidence in the knowledge and ability of staff within settings and lack of flexibility of provision that can meet their children's needs.¹⁰ The introduction of the £2 million ELC Inclusion Fund in 2018 was an attempt to break down some of these barriers by allowing settings to access funding for reasonable adjustments.
- 2.6. It is important to highlight that ensuring equitable access to funded ELC for children with learning disabilities is not simply a good idea. It is their legal right. The Education (Additional Support for Learning) (Scotland) Act 2004 (as amended) places duties on local authorities to identify and, most importantly, meet and continue to review the needs of all children and young people. This includes children under the age of three if they have a disability. Moreover, the Equality Act (2010) places a duty on local authorities to make reasonable changes to the care and learning environment to meet any additional support needs that a child may have.¹¹

1 Scottish Government (2010) [The Curriculum for Excellence](#)

2 Scottish Government (2006) [Getting it right for every child](#)

3 Scottish Government (2009) [The Early Years Framework](#)

4 [The Children and Young People \(Scotland\) Act \(2014\)](#)

5 Scottish Government (2016) [A Blueprint for 2020](#)

6 Scottish Government (2021) [A fairer, greener Scotland: Programme for Government 2021-22](#) (page 6)

7 Scottish Government (2019) [The keys to life Unlocking futures for people with learning disabilities: Implementation framework and priorities 2019-2021](#)

8 Scottish Government (2013) [The Play Strategy: Our action plan](#)

9 Scottish Government (2019) [Equality Impact Assessment: Expansion of early learning and childcare](#)

10 Ibid

11 [Equality Act \(2010\)](#)

- 2.7. Though the Scottish Government’s **Getting it right for every child (GIRFEC)** approach fully embraces the United Nations Convention on the Rights of the Child (UNCRC), the recognition of children’s rights was further bolstered by its passage into Scots law via the UNCRC (Incorporation) (Scotland) Bill in March 2021.¹² This direct incorporation will place a binding commitment on all public agencies to respect, protect and fulfil children’s rights. Article 23 of UNCRC creates a legal obligation to: **“ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child’s achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.”**¹³
- 2.8. Despite strong legislative underpinnings, and attempts to create equitable access, concerns are consistently expressed about the availability and appropriateness of provision for children with additional support needs from the early years through to high school. Though focussed on experiences of children during the primary and secondary years, the Additional Support for Learning review¹⁴ identified several key difficulties that are relevant to ELC provision. These include fragmented and inconsistent support, a focus on academic attainment, poor attitudes towards those with additional support needs from teachers, and under-resourcing in the context of austerity. This creates a gap between the intention of the legislation and the reality on the ground.
- 2.9. The Scottish Government’s Programme for Government accepts the Review recommendations in full. The **Towards Transformation** plan also acknowledges the findings from the Review, and commits to working with partners to improve educational experiences and outcomes for children with learning disabilities. This includes plans to develop more appropriate indicators of progress, introduce guidance on restraint and seclusion and look at ways to support parents to be equal partners in their child’s education.¹⁵
- 2.10. Within this context, SCLD was keen to understand more about the specific experiences of parents of children with learning disabilities in accessing – or not – their funded ELC entitlement. Most research in this area has focussed on school aged children, and while undoubtedly many of the issues will be similar in ELC settings, SCLD was keen to explore whether there were any barriers – or indeed drivers – to access that were specific to these early years. SCLD is of the belief that getting it right for every child must start with getting it right for children with learning disabilities. If we can get it right for children with learning disabilities, then we can get it right for everyone.

Research aims, methods and objectives

- 2.11. The overarching aims of this research were to understand as far as possible the levels of uptake of funded ELC places for children with learning disabilities, and to understand the issues that influence parents’ decisions to access – or not - these places. This would allow SCLD to develop a set of recommendations to take to the Scottish Government in terms of ensuring equity of access to funded early learning and childcare places. The research was conducted using a qualitative approach, comprising:

- A freedom of information request sent to local authorities regarding levels of uptake of funded ELC places for children with learning disabilities
- Semi-structured interviews with parents and carers of children with learning disabilities
- Semi-structured interviews undertaken with local authority early years leads
- Semi-structured interview with a child development centre worker
- A self-complete survey of childcare providers

¹² On 6th October 2021 the UK Supreme Court ruled that some provisions of the Bill were ultra vires and so the Bill has been returned to the Scottish Parliament for further consideration

¹³ United Nations [Convention on the Rights of the Child](#) (1990)

¹⁴ Scottish Government (2020) [Support for Learning: All our Children and All their Potential](#)

¹⁵ Scottish Government (2021) [Learning/Intellectual Disability and Autism: Towards Transformation](#) (Actions 22-27)

Freedom of Information Request (FOI) to determine any data held on the levels of uptake of ELC for children with learning disabilities

- 2.12. An FOI was submitted to all 32 local authorities in December 2020 to determine whether they held information on how many children with learning disabilities aged 3 to 4 were eligible for 600 hours of early learning and childcare, and of those children, how many were registered with early learning and childcare providers. Local authorities were invited to give this figure as a percentage of children eligible if this could potentially be disclosive.

Semi-structured interviews with parents and carers of children with learning disabilities

- 2.13. Fourteen semi-structured interviews were conducted with parents of children with learning disabilities. Participants were recruited by advertising through SCLD's networks. Interviews lasted between 1 – 2 hours and were conducted over Zoom/Teams or over the phone. One interview took place over the chat function in Facebook messenger at the participant's request. All interviews were structured loosely around a discussion guide, but allowed for parents to discuss what they felt was most important to them. The discussion guide was shared with parents prior to the interview.

Interviews with local authority early years leads

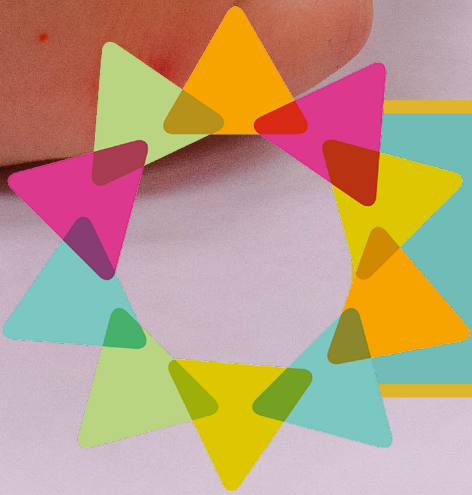
- 2.14. To contextualise the findings of the research conducted with parents, five interviews were carried out with local authority early years leads across local authority areas. Participants for the research were recruited with the help of the Scottish Government Early Years team. All interviews were loosely structured around a discussion guide, which was shared with participants prior to interview. The team also interviewed one worker from a child development centre who approached them.

Survey of ELC settings

- 2.15. A short online self-complete survey was undertaken to capture the views and experience of people working in early years settings, including child minders, providing ELC to children with learning disabilities. The survey was distributed to all ELC providers via email with the help of the Care Inspectorate. 73 responses were received.

Interpreting the findings

- 2.16. This small-scale qualitative project is not intended to produce an exhaustive exploration of the experience and attitudes of all parents of children with learning disabilities in relation to early learning and childcare. Each child is an individual with unique needs and living within specific circumstances. Therefore, it is impossible within the parameters of such a project to do justice to each individual experience. However, it aims instead to explore the common themes within their experience of accessing childcare, assuming that the common issues affecting the participants are likely to be similar in the wider population.



Setting the Context

3. Setting the context

- 3.1. This chapter sets the context for the interviews with parents. It explores some of the key challenges in identifying the population of children with learning disabilities to understand whether they were utilising the free early learning and childcare offer. It also explores the view of local authority early years leads about some of the challenges for children with learning disabilities accessing their early learning and childcare places, and indeed the challenges for settings themselves.

Levels of uptake of ELC: ‘You don’t know what you don’t know’

- 3.2. The Scottish Government has acknowledged that current data collection does not allow it to assess whether uptake and accessibility to funded ELC is different for families with protected characteristics, though it aims to address this by moving to an individual child-level ELC Census by 2022.¹⁶ SCLD was keen to understand whether this information, or information that could indicate the extent to which parents of children with learning disabilities were accessing their funded places, was held at a local level by individual authorities. To that end, a freedom of information request (appendix 3) was submitted to each local authority.
- 3.3. Thirty-one local authority areas, out of a possible thirty-two, provided a response to SCLD’s freedom of information request. Responses support the fact that there is a lack of available data in relation to the uptake of funded early learning and childcare places for children with learning disabilities. Twenty-one local authorities explicitly stated that they did not hold the information. Three local authorities pointed to the Scottish Government’s pupil census data collection, which does not in fact hold the information requested.
- 3.4. A few of the more in-depth responses also point to some of the challenges local authorities face in collecting and reporting this data. In particular:
- Perth and Kinross Council reported the number of children who were referred to the Early Years Inclusion service. This includes a range of support needs, not just children with learning disabilities. In its response it outlined that one of the specific challenges for reporting is that a learning disability may not be diagnosed at this age.
 - East Dunbartonshire Council outlined that all children with additional support needs for whom early learning and childcare was requested received it, but that it did not hold records for those who did not make a request.
 - Midlothian Council outlined that it does not hold complete information of the additional needs of children under five, except for the purpose of their early learning and childcare place. Once at primary school, they are able to identify all children and can retrospectively examine whether they attended nursery. Of the current children in primary one in Midlothian with additional support needs, 94 % took up an ELC place in 2019, though this was not broken down by support need.
 - Edinburgh City Council outlined that it may be able to provide the information if SCLD was able to define learning disabilities.
 - Dundee City Council was able to identify that 13 children who were enrolled in ELC at the time of the 2019 census had learning disability recorded as an additional support need, but did not know that as a percentage of those children who had learning disabilities in Dundee because there is not an independent count of this.
- 3.5. During the interviews with early years leads, participants were asked whether they had any information on the levels of uptake of ELC places for children with learning disabilities. All stated that their belief was the numbers of children with learning disabilities not accessing an ELC place they were entitled to was very small, though they did not have data to state this definitively. As stated by one participant “you don’t know what you don’t know.” Participants acknowledged that they would not know of children whose parents had opted not to apply for a place, but their hope was that health visitors would be in touch with the early years team to make them aware of this.

¹⁶ Scottish Government (2019) [Equality Impact Assessment: Expansion of early learning and childcare](#)

Professionals' perspectives on the drivers and barriers faced by parents of children with learning disabilities

3.6. Section 4 covers the barriers and facilitators to ELC among parents who were interviewed as part of the research. However, to set the context of the research, early years leads were also asked their views on what they thought were the main challenges in terms of getting early learning and childcare right for children with learning disabilities, as well as the things that have helped, or could help, to do so. There was a general sense that the early years teams were doing well for children with learning disabilities in terms of ELC provision, but that they can always – and strive to – do better.

- **The importance of engaging with families early:** All early years leads expressed the view that early identification of support needs was crucial in getting it right for children with learning disabilities. This allowed time to work alongside parents to prepare and plan for the child coming into the service. It could be challenging to get the right support in place where additional needs were only discovered when a child entered an ELC setting. This tended to happen when individuals had moved from outwith the local authority area and had no prior relationship with services before attending an ELC setting when they turn three as part of their funded entitlement.
- **Good relationships with NHS and social work teams:** Relatedly, early identification of support needs relied on close working relationships, in particular with the NHS, to identify all children who will be eligible for funded ELC places, as well as their support needs even before referrals are made for additional support. There was acknowledgement that while health visitors played a pivotal role in this as they are often the first point of contact with families, they have generally faced increasing caseloads over recent years.
- **Utilising 'eligible 2s' places:** Another key aspect of early intervention and identified good practice in relation to increasing uptake of places, was the utilisation of spare capacity of eligible 2s places for children with learning disabilities. Eligibility criteria for the 2-year-old offer are set out in The Provision of Early Learning and Childcare (Specified Children) (Scotland) Order 2014. However, local authorities have a discretionary power to provide ELC beyond statutory eligibility to support families to meet local priorities. In one instance spare capacity was being used creatively to provide a more holistic service where the parent and child could attend together. Most areas spoken to were using spare capacity for children with learning disabilities, with some having protected capacity and budget for 2-year-olds with additional support needs that pre-dated the statutory entitlement. There was a recognition that because the 2-year-old settings tended to be smaller in numbers, children and parents felt this was supportive, and allowed time and space to get used to being in this type of setting.
- **Clarity with ELC providers over their duties:** While local authority early years teams work with providers to understand their duties under the Additional Support for Learning Act, it was suggested that more still needs to be done to increase providers' understanding of their duties in relation to equality and inclusion. It was thought that current guidance is often framed in 'policy speak' and jargon which can make it inaccessible and difficult for providers to understand their obligations. One local authority also suggested that a specific ring-fenced fund for appropriate adjustments would be useful.
- **Implications of roll out of 1140:** Some leads drew attention to the fact that the extension of the funded hours had inadvertently resulted in the reduction of choice for parents of children with learning disabilities because within specialist provision, the number of available places had halved as the entitlement for children already accessing places doubled. This was also mentioned by one parent during the interviews.

Childcare providers' experience of catering for children with learning disabilities

- 3.7. A short self-complete survey was distributed to early years providers to gain an insight into their experience of, and confidence in, providing childcare to children with learning disabilities within their settings. In recognition that childminding services are a very different setting as compared with local authority and other funded providers, their responses are reported separately.

Local Authority and Partnership Nursery Provision

- 3.8. Of the 37 providers who responded, all had experience of providing care for a child with a learning disability within their service. 21 of the 37 (57%) said that they felt confident that their setting was able to cater for children with learning disabilities. For those who were not confident, or who were unsure, the majority outlined that more training for staff on how to care for children with learning disabilities would enable them to feel more confident. Providers felt that support from external specialists, such as speech and language therapists and occupational therapists, was not as proactive or robust as it could be, but that this support would be very welcome. Providers also felt that grants should be provided that would enable training to be undertaken within work hours, with additional staff in place to take care of the children.
- 3.9. The majority also suggested that they would need more staff to feel confident to cater for children with learning disabilities. Many felt that the staff ratios within the service did not adequately consider the specific needs of children with learning disabilities, in particular those that required one-to-one support.
- 3.10. Some providers said that they simply did not have appropriate facilities to cater for the needs of children with learning disabilities, in particular where settings were large and open plan. One setting described challenges they face keeping children safe, who would attempt to leave the setting via an exit door with a large push bar.
- 3.11. Providers who were confident in their ability to cater for children with learning disabilities highlighted good training and continuing professional development, as well as close working relationships with external specialists as key enablers. Additionally, previous experience of catering for children with learning disabilities was highlighted as a reason for provider confidence.

Childminders

- 3.12. Of the 36 childminders who responded to the survey, 26 (72%) had experience of providing care for a child with a learning disability in their service. 23 out of the 36 (64%) said they were confident that their setting was able to cater for children with learning disabilities. Of those who were not confident, or were not sure, many said that it would depend on the nature of the learning disability. Most said they would be happier once they had experience of catering for a child with learning disabilities. Childminders also said that more training would help them to feel confident.
- 3.13. Logistical issues were noted as a particular barrier in childminder settings. An example given was a child requiring the use of a non-standard buggy may lead to the childminder being unable to cater for any babies or toddlers on the same day as there would not be a suitable buggy to allow this.
- 3.14. As with local authority and partner providers, childminders outlined that they derived their confidence from good training as well as good relationships with external specialists. Interestingly, many childminders said that they felt confident in their ability to cater for children with learning disabilities as they had experience of children with learning disabilities in their personal lives.



Parents' Perspectives



4. Parents' perspectives

- 4.1. Children with learning disabilities are not a homogenous group. All children are unique with different needs and living within their own set of circumstances. Because of this, it is not possible to do justice within this report to each individual experience. Despite this, there were several common themes threaded throughout the interviews, which serve to highlight the main experiences and challenges faced by parents when trying to find suitable early learning and childcare provision. These themes are explored below.

Difficulties finding information about support and entitlements in a complex system

- 4.2. A significant challenge faced by the parents we spoke with, was finding out about their rights, as well as what support services and provision were available for them and their child with a learning disability in their early years. There was an overall feeling that managing to get the right support in place, and access appropriate ELC provision, often came down to a parent's prior knowledge of the system and/or the ability to navigate the system. The extent of this challenge was highlighted by one participant who said that despite a professional life spent working in the sector, they still found it hard to know their entitlement.
- 4.3. Even though support is not meant to be 'diagnosis led', parents who were aware of their child's learning disability pre-birth or had a definitive 'diagnosis' soon after birth reported receiving better information about what support was available to them. They were also more likely to be able to access support from allied health professionals, and find appropriate ELC provision, consequently. Many children will not be formally 'diagnosed' as having a learning disability until they are 6 or 7 years old. One parent of a child with Down's syndrome outlined that they were able to make the case that their child needed a place in specialist provision because they had a parent-to-parent support worker from a charity who worked with community nurses.

“You have to fight, and I'm lucky that I know how to fight, but lots of people don't. I just feel for children who are born into this from a disadvantaged background and don't have the support to know what they are entitled to. You really have to work to find it.”

- 4.4. A particularly striking example of the difficulty accessing information, specifically related to ELC entitlements, was the complexity surrounding eligibility for 'eligible 2s' places. These early entrant places were noted by early years leads as being of pivotal importance for getting the right support in place for children with learning disabilities in early years settings. Many parents who had a good experience of ELC within a mainstream setting also mentioned early entrant places as having played a key part in that. However, for those who had not met the national eligibility criteria through their entitlement to certain benefits, finding out about whether their local authority offered discretionary early entrant places for children with learning disabilities seemed to come down to luck and persistence.

“My health visitor mentioned that there was funding for eligible 2s. I know others who have applied and have been told it is means tested so they are not getting it. If the health visitor hadn't mentioned it, I wouldn't have had a clue, so I'd have been struggling until he could get his pre-school funded place. I feel very fortunate to have got it since others now aren't.”

- 4.5. A few of the interviewees felt that being appointed someone, such as a mentor or key worker, to help parents of children with learning disabilities would be useful to help navigate the complexity, and help parents understand the different options available to them.

“You need parent advocates. Almost a parent advisory group of parents who have been through it and know exactly how it works and can support other parents.”

“I think when you get a diagnosis you should get post diagnostic support. When you’re diagnosed with dementia you get a year of post diagnostic support. Even if you have global developmental delay, you should be allocated someone to help you through the system.”

The challenge to get the right support in place

- 4.6. One of the most remarkable aspects of the interviews was the strength of feeling from parents that getting ELC provision that was appropriate for their child’s needs across the board was very difficult, and at times, impossible. Parents whose children were accessing specialist provision were clear that this was the best setting for their child, and that the care and specialist knowledge offered there could not be met in mainstream provision with support in place.

“Specialist provision is hugely important for children with additional needs, because they are small nursery classes. It’s a maximum of six children. You’ve got all the agencies within the school. You’ve got teachers who are trained medically as well, and know how to teach children in the best way.”

“I would always have been an advocate for mainstream, but when someone’s needs are so complex... now I feel if he went to mainstream with support he would be in a little bubble with his support. Whereas now every teacher’s got the skills and knowledge to aid his communication, and they all do sign along. It’s funny how your views change.”

However, not all parents we spoke with who sought specialist provision were able to access it, with places often reserved only for those with the most complex needs, including medical care needs.

“At the child’s plan meetings, it was agreed that mainstream wasn’t suitable for him. The fact he had been getting one-to-one but was still struggling was evidence of that. The choice was made not to send him to mainstream nursery. We applied for the only specialist provision, and he was denied a place there. So, knowing he couldn’t go into mainstream he’s been at home ever since.”

- 4.7. While many interviewees were clear about the benefits of specialist nurseries, some parents described a difficult choice between mainstream and specialist settings. Parents often weighed up what they saw as the different benefits that each setting offered, with some understandably concluding that a specialist nursery was better placed to keep their child safe and meet their health needs. However, some felt that specialist settings, while undoubtedly staffed with highly trained specialists, were less able to provide the same peer socialisation benefits as a mainstream nursery.

“I want community, and the social aspect for him growing up, but I think [in going to mainstream] I’ve had to sacrifice his support in terms of academic learning and whether he might have got more speech therapy. It’s like a balance, and I decided the social part and the community part was the most important bit.”

One interviewee outlined their perception of the specialist nursery as a place where their son would simply go to undertake his physiotherapy in a different setting, when what they wanted was a more holistic nursery experience for him.

“We were offered a place at the special needs nursery, but we said no. We had been taking him to groups every day, but then we saw the nursery and it was this wee lass lying on her side being peg fed, with no engagement, and it looked like hell on earth. I was worried they would strap him to the mat and leave him. I just want him to have had a nice day, learned some stuff and made friends. The education side just seemed like a token gesture there.”

- 4.8. Many parents shared the view that mainstream provision was particularly beneficial for their child’s social development. However, getting the right support in place to allow their child to thrive in a mainstream setting was not guaranteed. Many told of a battle, and often parents felt they had to compromise. There was widespread agreement that one-to-one support was fundamental to their children’s developmental and educational needs, and ensuring they were safe in a mainstream setting. However, despite this, the provision of one-to-one support is rare.

“I didn’t think it was an unreasonable expectation that he would be safe, and he’d need a person. He can’t hold his head up. The minute they said there wasn’t one-to-one support and he’d be catered for in the rota I was like, well he’s going to come back dead. So we shut down.”

“I am perfectly aware of my son’s needs. He would need a one-to-one. It wouldn’t be a case of the budget doesn’t cover it.”

Where parents were able to secure one-to-one support for their child, sometimes this person was used by the nursery to ensure they had the appropriate staff/child ratio within the setting, which restricted what they were able to do with the child.

“She said she couldn’t leave the room because there were no other staff and she needed to be there. Well, is she his one-to-one, or an early years practitioner? They are so nice so I said it was fine, but it does feel like she was used by the school.”

- 4.9. Another parent, who had a good experience with a mainstream provider, told that getting the right support staff in place had been down to luck, and that going forward, the funding level is not guaranteed.

“At the nursery it just so happened that there was another child with additional needs applying for a place when we were applying, and didn’t end up taking it, so they already had the funding in place for the people. So she pretty much has a one-to-one though it’s not classed as a one-to-one as such. Again, it’s luck! We might get the funding going forward but it’s not guaranteed.”

- 4.10. A key aspect of getting the right support in place in ELC was having professional support and input from an early stage. Though the experience was mixed, many felt that having an understanding and supportive health visitor helped them to access further support from allied health professionals. There were clear benefits where the right people were involved in a child’s care from the start, through multi-disciplinary team (MDT) meetings, and where these professionals worked well together.

“I suppose [a key thing] was having the MDT meetings right from the start. That was what kicked everything off so they could get the training to meet his needs. Physio, the speech and language therapist and the epilepsy nurse were there. They took each other’s details and they’ve had epilepsy and Makaton training and physio. Because he had a walker, it was about whether he would have it at home or nursery so they went out and said it would be better for it to be there. And they’ve been back out to check up.”

“The health visitor was quite integral in getting the support he needed when he went to the nursery as well.”

- 4.11. Parents told of other issues that arose in ELC settings for their children. One interviewee explained that they had removed their child from a special needs playgroup due to the use of inappropriate physical restraint. The parent felt that mainstream nurseries as well as some specialist nurseries were not accommodating to the needs of neurodiverse children, but instead focussed on trying to recondition them to be neurotypical.

Inequity of provision for children with learning disabilities

- 4.12. Another theme that was clear from the interviews was that ELC provision for children with learning disabilities was not equitable with provision for children who did not have any additional support needs. For example, often specialist nurseries do not offer provision for 50 weeks of the year, or wraparound provision, like some of their mainstream counterparts.

“Mainstream nurseries adopted a 50-week approach. And those nurseries have wraparound provision to enable parents to work. So you go in from 8 in the morning and have breakfast and can stay until 6. But at the specialist provision the difficulty was you had nursing staff and teaching staff. And the nurses wouldn’t move from their 39-week contracts, and the extended hours came in. So because of that failing of staffing, the places were reduced. There is a solution to every problem but they chose not to find one because when you look at children with additional needs and disabilities the presumption is that parents are not going to work.”

- 4.13. This inequity was also demonstrated by the fact that the eligible 2s places that so many parents found to be a pivotal part of their good experience with ELC, were not available in specialist provision.

“The local authority relaxed the criteria for the eligible 2s places in January because they didn’t have the uptake. But if we’d taken up the offer it would have jeopardised our application for the special needs school. Because they don’t offer 2-year-old places. So what about children with additional support needs that need a 2-year-old place?”

- 4.14. Further, some parents whose children were receiving one-to-one support felt that they would not benefit from the extension of the funded hours, because the local authority would not extend funding for one-to-one support for these hours.

“We had a one-to-one three days a week. We applied for him to go five days but that was refused. That was at a nursery where they do the 1140 hours. I don’t think it’s great that if he’d been a typical child he can go from 9-3 every day, but they refused his one-to-one for five days a week, but agreed to four.”

Indeed, where parents had secured one-to-one provision, difficulties getting this support funded for the right number of hours was a common experience among the interviewees.

“It’s difficult to get the right amount of hours. A full nursery week is 30 hours. But the Council only fund 25. We’re not looking at children holistically we are looking at them academically. There’s 25 hours of academic support. But they are actually at nursery longer than that so who fills the gap? Well, nobody. You have to remove them for those amount of hours.”

- 4.15. Parental choice is a key driver of the extension of the funded hours. As part of this, local authorities offer different models of ELC provision for parents, including blended placements, where a child can spend part of their funded entitlement in one setting, and another part in a different setting. However, interviewees expressed frustration that these blended placements did not extend to specialist provision in all local authority areas.

“We used to have split placements in nursery, before my child started in specialist provision. In the placement the child could experience both [mainstream and specialist], which is a good tool to look at where the child will go in future for school. You can see if they are managing in the mainstream environment. And then they stopped that and now it’s one or the other. That’s not really helpful.”

“I asked about a split placement but was told that wasn’t available anymore.”

“But the other thing I think going forward, which would be really beneficial, would be a split placement, but they will not support that in this area. If we want to do it, it will be a massive fight and effort on our part. I don’t know why they don’t do it – the council down in the borders do it.”

As mentioned by some early years leads, it was also noted that in some areas, the doubling of funded hours was resulting in the number of places available in specialist settings being halved.

“When the nursery hours increased you lost 18 children’s places. The places went down to 18 instead of 36.”

The importance of good leadership and staff attitude in the setting

- 4.16. Parents who reported that they and their child had a good experience within a mainstream ELC setting found that this was predicated on good leadership and staff attitudes towards inclusion. Good leadership and attitude resulted in good relationships between parents and ELC settings, fostering open communication and co-operation that was beneficial to children's experiences. Indeed, many parents were clear that the right attitude was the single most important thing that an ELC setting could demonstrate.

“It was the positive attitude of the manager from the start. She is always striving for what's best, and an inclusive environment.”

“Ultimately for me it's about attitude. The nursery just had a really positive attitude. They are nurturing. She gets stuck in, but they are always bringing her along.”

“For me personally it's the attitude of the staff and them seeing equality for what it is, and just having equipment that is accessible for all aspects of her learning. For me it's really the people.”

In one instance a parent described the situation where staff were asked whether they wanted to be trained in peg-feeding to be able to provide this for her child, and almost every member of the team volunteered and was trained. This meant that there was no difficulty ensuring that a trained member of staff was available when the child was attending.

“Ten members of staff volunteered. So that shows the commitment of the staff and how much they cared for [child].”

- 4.17. Parents outlined the importance of ELC leaders demonstrating the fact that their child was welcome and would be included by being pro-active in seeking input into their child's support from external specialists, as well as from parents themselves.

“They've gone above and beyond, contacting the physio to ask how they can support him at nursery, and occupational therapy to get seats so he can be included as part of the group sitting round the table for arts and crafts and other things.”

- 4.18. Sadly, the interviews told of instances where parents were made to feel like their child with a learning disability was not welcome within mainstream nurseries. This was demonstrated in some cases by providers simply stating that they would be unable to provide a suitable placement for their child as they had no prior experience. It was also demonstrated in more subtle ways, such as parents being requested to leave a child's wheelchair outside of the classroom.

“The attitude of the nursery when I would pick up my older child was stinking. They expected me to leave his buggy at the door so he wouldn't be safe. That was my first experience going into the nursery. My older child was welcome because she could zip up her jacket, but he was looked down on.”

Open, honest, equitable dialogue with parents

- 4.19. Relatedly, it was clear from speaking with parents that openness and honesty on the part of the provider was a key component of a good ELC experience for parents and children. Parents demonstrated pragmatism, understanding that getting things right often involved some trial and error. They also understood that providers did not all have experience of working with children with learning disabilities, and so making sure their child was included and thriving within a setting might include a learning curve for the staff.

“The biggest thing is engaging with us, with his team, and being open and honest and not being afraid to say what training they need.”

“We’d want them to be honest and be open to listening to us when we say what to do but also ask us to show them again if they forget or tell us what isn’t working.”

Where there was open dialogue, and parents felt listened to, they reported good outcomes for them as well as their child.

“It used to bother me that my child couldn’t tell me the children’s names. I mentioned this and they put that into the GIRFEC meeting as one of the standards. Within a week she was able to tell me who the children were. The manager at the time just really took it on board. It could have been easy for the nursery to overlook it. It was just through this open conversation and then they actioned that and asked all the teachers to focus on it. I don’t know how they went about it but they made it a priority.”

- 4.20. Parents expressed frustration that often they were seen as being a nuisance to the provider or being unreasonable when they were simply striving to ensure their child had the best experience possible in ELC. Where experiences were poor, this often came down to providers thinking that they knew best and did not respect parents’ role as experts in their children’s needs.

“One of the biggest things is that parents are not listened to. They say it’s important that parents are listened to but it’s not happening, and it’s very frustrating. In the playgroup I had a meeting and she said, ‘I’ve done this for 20 years, I know what I’m doing’.”

“The fact she wasn’t speaking didn’t concern them. They were confused with the term inclusion in the sense that they were treating her like every other child, which isn’t what inclusion is. They were just leaving her to it with free flow play and she was choosing not to. I spoke and wrote emails to the nursery and they just brushed me off saying she was fine, we’ve got 20 years’ experience.”

The importance of well-trained staff

- 4.21. As explored above, though not everyone's preferred choice, the appeal of specialist provision derived from the fact it was staffed by well trained professionals who parents could trust to look after their children. Parents felt safe in the knowledge that staff there had not only the training but the desire to work with children with additional support needs, which was sometimes found to be lacking in mainstream settings.

“I had one day in a private nursery in the morning to try and give us a bit of respite, but it was all they could manage because they didn't have the staff or training and they didn't know how to cope. It wasn't their fault. I know why parents are not taking this up. They'll be getting a choice of two or three nurseries and they'll be mainstream because there isn't enough additional support needs nurseries. It's more hassle than it's worth. I was working full time and getting phoned 3 or 4 times a day to get him, and it was totally disruptive.”

- 4.22. Some parents who had managed to secure a one-to-one within a mainstream setting still expressed concerns that they did not have specific training to work with their children.

“We have always had one-to-one support, but the main issue is making sure the one-to-ones are confident with him. They get no training. We found that the one-to-one helped to control his behaviour but didn't help him to move forward and learn.”

“Pupil Support Assistants are great if you have a good one, but you don't need a qualification to be one. You really want someone who will take the time to do therapy and speech and language. If you have someone with very little experience you are going to need to spoon-feed them what to do with this child. You should be going through robust training.”

- 4.23. In some instances, those providing one-to-one support were having to give up their own time to undertake training to support the communication needs of the child they were supporting.

“The Pupil Support Assistants (PSA) did get sign along training but it was out of hours. So it really depends what your PSA can do. They don't get any prep time in work hours.”

- 4.24. A number of interviewees were of the opinion that early years practitioners should have some form of mandatory qualification or training for working with children with learning disabilities.

“The perfect setting in my eyes would have a Special Educational Needs (SEN) worker in every classroom. That a SEN diploma was mandatory to any early years practitioner.”

“Even things like making it part of your training that you should do one day in an additional needs nursery.”

Appropriately sized settings with the right staff ratios

- 4.25. Another fundamental aspect of a good ELC experience for the interviewees was finding a setting where class sizes were relatively small. Specialist nurseries by their nature are intimate settings with lower staff to child ratios, and this was a draw for parents when opting for this type of provision. However, some mainstream nursery classes can be very large, with parents feeling concerned that their child would not be happy, or indeed safe in such a setting.

“The number is important. I wouldn’t want her in with 60 kids. It just wouldn’t work.”

“If it was a massive nursery I would have looked for specialist provision.”

“The setting was very small and contained. It was perfect. There were 4 adults to the 10 children.”

“The ideal nursery would have lower numbers. It would be based on the space, not the staff. But then you think of the staffing for the space.”

- 4.26. A number of parents raised concerns about the fact that staff ratios only took account of chronological age, with no account taken of their child’s developmental age.

“Pupil Support Assistants cover about 4 children, and don’t take the cognitive age into consideration for the ratios.”

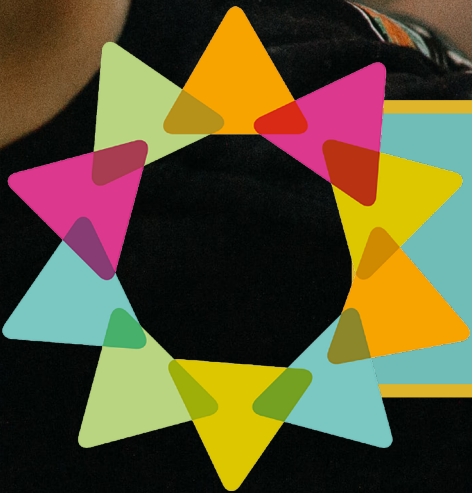
Relatedly, some parents told of good experiences where ELC settings were willing to be flexible in response to their child’s needs, and deliver stage appropriate education rather than focussing on chronological age.

“She was in the baby room. She got on well because the other children were doing baby activities so it was a safe environment and the staff were good and supportive.”

“[Teaching should be] stage appropriate not age appropriate – this isn’t highlighted enough. Practitioners feel like they can’t use a birth to 3 curriculum with a 4-year-old.”

Other issues

- 4.27. While the focus of the interviews was specifically on people’s experience accessing their funded ELC entitlement, several related issues emerged in the course of the conversations. Parents highlighted difficulties accessing wrap-around care that was appropriate for their child, both at nursery and school age. Wraparound childcare is a very strong focus in the Scottish Government’s Programme for Government 2021, and it will be important to include families of children with learning disabilities in discussions about how the offer can be designed to work for them.
- 4.28. Some parents also discussed difficulties faced when their child was transitioning from ELC into primary school, specifically not being well informed about different options or having time to consider these. Improving transitions is an important element of the Scottish Government’s *Towards Transformation* plan and it is imperative that the transition between early years and primary school is included within this.
- 4.29. One parent also discussed the use of inappropriate restraint when her son was in primary school. The misuse of restrictive practices in educational settings has been raised as an area of significant concern at the Restraint Reduction Scotland (RRS) meetings. The Scottish Government is in the process of developing new guidance on the use of restrictive practices in schools with a particular focus on restraint and seclusion. It is critical that early years settings are not overlooked in this process.



Discussion and Moving Forward

5. Discussion and Moving Forward

Discussion

- 5.1. The Scottish Government is clear in its ambition that all children get the best possible start in life. This is underlined by a commitment to provide high quality, flexible early learning and childcare that is accessible and affordable for *all* families. Practice guidance for ELC drafted in 2014¹⁷ acknowledges the importance of equality of access, when it states: ***“Additional Support for Learning and issues of equality and diversity, although not specifically noted, are taken as being implicit throughout the text and are integral to the delivery of high quality early learning and childcare.”*** Local authority early years leads who we spoke to were clearly passionate about the benefits of ELC for all children, and passionate about ensuring that those benefits were available to all children, including those with learning disabilities. However, while some parents that we spoke with outlined a very happy experience of ELC for both themselves and their child, the overall picture from this research is one where, despite the best of intentions, we are simply not getting it right for children with learning disabilities.
- 5.2. Instead, what the research demonstrates is a complex, fragmented ‘system’ that is difficult to navigate and find out what support is available. Part of the complexity is due to the fact that the right support for many children with learning disabilities will require early input from allied health professionals, educational psychologists, social work, and others, which can be overwhelming for new parents to navigate. Good experiences were often predicated on these multidisciplinary teams working well together, but this is not always guaranteed. The way in which health and social care delivery structures interact with children’s services and education varies from local authority to local authority, adding more complexity to the overall picture.
- 5.3. Parents face an uphill struggle to get the right support in place that would ensure their child can access their funded ELC placement and allow them to thrive. Some were hesitant to call it such, but the reality is that for many it is a battle. Many had made compromises. Some had taken fewer hours than they would like. Others had to send their child far from home to access appropriate provision. Some were simply unable to access appropriate provision at all.
- 5.4. It is important of course to acknowledge that there are many passionate, dedicated professionals working within ELC settings and in the wider early years system. The survey of ELC settings highlighted that most childcare providers want to include all children in their settings, but lack of training, resources and staff hinder their ability to do so.
- 5.5. Through the interviews it was clear that good attitudes and well-trained staff who understood inclusion were two key components where parents reported a good experience of accessing their funded entitlement in mainstream settings. Indeed, some interviewees went to great lengths to outline how staff working with their children went above and beyond to make sure they were included and thriving. However, the fact that parents describe staff going above and beyond is indicative of the fact that having their child with learning disabilities included and thriving is not something that happens as a matter of course. In fact, some interviewees highlighted very poor attitudes from staff in settings, which reminds us that sadly not all professionals are fully signed up to the principles of inclusion.
- 5.6. It is also important to acknowledge the role of proper resources in many of the barriers faced by parents we spoke to, as well as the key enablers. While there are particular considerations for children with learning disabilities, inappropriate staff ratios and settings that are too large in particular are two important factors that many parents express concerns about in relation to their children’s experience in nursery. Similarly, while for many parents we interviewed inequity of provision for children who require additional support as compared to those who do not was felt acutely, different models of provision between local authority areas often mean there is inequity in provision all across Scotland.

17 Scottish Government (2014) [Building the Ambition: National Practice Guidance on Early Learning and Childcare: Children and Young People \(Scotland\) Act 2014](#)

- 5.7. The introduction and expansion of funded early learning and childcare in Scotland, while a significant investment, has taken place entirely within the context of austerity. This has impacted the availability of resources for local authorities and the NHS. At the time of writing, the full financial impact of the COVID-19 pandemic also remains to be seen. For many children with learning disabilities, a mix of reducing resources in education and health and social care, an increasing number of children and young people attempting to access their rights to support under the Additional Support for Learning Act, and a reduction in specialist staff is putting them to the back of the queue when it comes to meeting their needs. Undoubtedly, adequate resourcing will be the cornerstone for getting the ELC offer right for children with learning disabilities.
- 5.8. It is perhaps not surprising that many of the themes uncovered in this research were similar to those found in the Additional Support for Learning Review. The Scottish Government has accepted the review findings and committed to fully implementing the recommendations put forward, to close the gap for children and young people with additional support needs. This is a very welcome step, and SCLD is fully supportive.
- 5.9. However, the Review's focus was understandably shaped by those who engaged with it, and thus centred its report and recommendations on the primary and secondary years. Though there are many overlaps, the focus of this research on the early years for children with learning disabilities allows us to understand more fully the barriers – and indeed facilitators - to accessing appropriate ELC places. It is important that as we move forward, the early years are not seen as distinct from primary and secondary education, but as a foundation stone for a move towards learning for life. Getting it right at this stage will pave the way for it to be right throughout people's lives. And if we can get it right for children with learning disabilities, we can get it right for everyone.

Moving Forward

- 5.10. Getting it right for every child is a worthy ambition. However, this research has demonstrated that for some children with learning disabilities and their families, this can feel more like empty rhetoric than meaningful policy. Getting it right for **most** children is not good enough. While there is no silver bullet that will solve the myriad issues uncovered in this report, SCLD believes that on the back of this research, there are a number of actions to be explored in the short and medium term which could move us closer to ensuring equality of access to ELC for children with learning disabilities.

Ensure children with learning disabilities are visible within the ELC Census

- 5.11. Addressing this issue begins by understanding its extent. While the professionals SCLD spoke with believed that children with learning disabilities were accessing their funded ELC entitlement, they acknowledged that currently there is no way to know this for certain. It is important to be able to monitor the uptake of ELC for children with learning disabilities, to identify whether new policy interventions are needed to enable parents to access their entitlement.
- 5.12. The Scottish Government has established a data transformation project to improve the quality of the data in the ELC Census, recognising that the current collection does not allow for measurement of uptake against all protected characteristics. However, it is imperative that the data transformation project also uses this opportunity to improve the categorisations of additional support needs. Unlike the School-Pupil Census, the ELC Census does not include learning disability as a reason for needing additional support.
- 5.13. SCLD understands that there are numerous issues that make this categorisation difficult, particularly in the earliest years, including the different terminology used across services. Universally recognised definitions and descriptors are an important long-term goal, that will allow us to calculate uptake as a percentage of children with learning disabilities. However, SCLD believes in the short term, updating the ELC Census to be in line with the School-Pupil Census will go some way to allowing us to monitor uptake of ELC for this group over time.

Provide clear, accessible information for parents about Enquire services

- 5.14. Overcoming the difficulties faced for parents when trying to find out about their rights to additional support for their child, the various duties on ELC settings and what services are available will require a concerted effort on the part of education authorities as well and health and social care services. SCLD welcomes the report from the Scottish Government's Short Life Working group on Coordinated Support Plans¹⁸ and hopes that the Additional Support for Learning Implementation Group (ASLIG) will consider the findings from this research when taking this work forward.
- 5.15. SCLD believes that the Scottish Government should consider the inclusion of an information leaflet within the Baby Box that signposts parents to Enquire.¹⁹ Enquire is a national service run by Children in Scotland which provides easy to understand advice and information about additional support for learning and helps families to find local education and support services. Feedback from parents about Enquire services shows a very positive impact on families, in understanding their rights to additional support for learning, but that parents tend to only find out about Enquire by chance. Most expectant parents in Scotland sign up to receive a Baby Box and so inclusion of a leaflet within this would provide an opportunity to draw their attention to Enquire's services.

Ensure provision of early years support programmes specific to the needs of families raising a child with learning disabilities

- 5.16. Though this project was focussed on access to funded early learning and childcare places, it is impossible to isolate those experiences from the wider experience of raising a child with learning disabilities in the earliest years. It was clear through the interviews that families need access to evidence-based, practical information, as well as social and emotional support specific to their particular circumstances and experiences. Interviewees spoke of the value of peer support and opportunities to access both professional expertise and expertise gained from lived experience.
- 5.17. SCLD believes that the wellbeing and resilience of families would be improved by offering new parents access to programmes specific to the needs of families raising a child with learning disabilities. One such programme is Early Positive Approaches to Support (E-PATs). E-PATs is an 8 session co-produced support programme for groups of families who have a child under 5 years with a learning disability, that is co-facilitated by trained family carers and professionals working in partnership. The programme supports wellbeing for family carers, proactive service access and positive development and behaviour for children through a low-cost, flexible approach.²⁰

Equip health visitors with knowledge to enable them to support and signpost families to information and advice

- 5.18. Though people's experiences were mixed, local authority early years leads were clear that they viewed health visitors as key partners, liaising with them about children with additional support needs. Some parents we spoke to talked of the important role the health visitor played in helping them access other services and supports, and in turn, their ELC places.
- 5.19. As the first point of contact for most families, health visitors must be equipped with the relevant training and knowledge to enable them to support parents of children with learning disabilities, to signpost them to wider information, advice, and services, including Enquire, to maximise access to rights and support. Knowledge of relevant legislation alongside close partnership working with other professionals will be an important part of this.

¹⁸ Short Life Working Group on Coordinated Support Plans (2021) [Final Report](#)

¹⁹ [Enquire About Enquire - Enquire](#)

²⁰ E-PATs is lead by Dr Nick Gore and Dr Jill Bradshaw, Tizard Centre University of Kent, has been piloted in Scotland, throughout the UK and is the subject of a recent Feasibility Randomised Control Trial: Coulman, Gore et al. (2021) [Early Positive Approaches to Support \(E-PATs\) for families of young children with intellectual disability: A Feasibility Randomised Controlled Trial](#)

Reconsider how inclusion is assessed in the benchmark qualification for early years lead practitioners

- 5.20. Leadership is one of eight key elements which is critical in developing inclusive practice in schools and ELC settings.²¹ And demonstrating a commitment to inclusion is the first benchmark for the Standard for Childhood Practice.²² This research has highlighted that good leadership around inclusion is a key ingredient where children with learning disabilities have a positive experience in mainstream ELC settings, but, sadly, that it is not a given.
- 5.21. SCLD understands the difficulties practitioners face demonstrating this benchmark, particularly where they may have had little experience of children with additional support needs. However, consideration must be given as to how this benchmark is assessed meaningfully, encouraging practitioners to consider how their own setting can work towards delivering key strategic drivers, such as wraparound childcare, in an equal and inclusive manner.
- 5.22. Ensuring staff in ELC settings have the necessary training, tools, and support to achieve genuinely inclusive practice for children with the most complex needs is a clear challenge. One approach which SCLD believes may merit greater attention in this context is Positive Behaviour Support (PBS). In adopting a person centred and rights-based approach which seeks to understand behaviour and communication PBS seeks to improve support and change structures, cultures, and environments. While SCLD recognises the difficulties of mainstreaming this, we believe it offers considerable potential to engender more inclusive practice in ELC settings for those with the most complex needs.

Create an Open Badge for working with children with profound and multiple learning disabilities (PMLD) in mainstream settings

- 5.23. Some parents of children with PMLD we spoke with were very clear that specialist provision was the most appropriate setting for their child. However, the Scottish Government is clear that the principle of presumption to mainstream is not under review. In any case, many parents would prefer their child to access a mainstream place with the appropriate support. SCLD believes that an Open Badge for working with children with PMLD would be a useful qualification to create and advertise for early years practitioners.
- 5.24. An Open Badge would provide a quick and easily accessible qualification that could act as a baseline to help practitioners feel more confident about working with children with PMLD who come into their setting. Ensuring appropriate content would require close working with PAMIS and the families they work with.

Early Learning and Childcare settings should introduce a more structured parental engagement process

- 5.25. Many parents we spoke with told us that their expertise by experience was not respected by professionals working in settings. It is pivotal that parents and carers are involved as truly equal partners in their child's early years education. The need for cooperation between schools and parents was a strong theme highlighted in the Additional Support for Learning Review. SCLD welcomes the fact that the Scottish Government has committed to several actions on this, including consideration of opportunities to gather evidence of effective relationships between parents and professionals, and promote good examples of joint working between parents, local authorities, and schools. It is important that ELC settings are considered as part of this work.
- 5.26. SCLD believes that clear structures for regular communication would go some way to promoting positive relationships between parents and settings. In person meetings at regular intervals would create a more open dialogue and promote cooperation, including regular opportunities for issues to be aired and considered.

²¹ Scottish Government (2019) [Guidance on the presumption to provide education in a mainstream setting](#)

²² Scottish Social Services Council (SSSC) (2015) [The Standard for Childhood Practice Revised](#)

Include children with learning disabilities in the first phase of the ELC expansion for 1- and 2-year-olds

- 5.27. The Scottish Government committed in its Programme for Government to expand free early learning and childcare to all 1- and 2-year-olds, and to start in this Parliament with children from low-income households. Given the importance of early entrant places for many of the children with learning disabilities we spoke with, SCLD believes that children with learning disabilities should be included within the extension in this Parliament.
- 5.28. A pivotal component of these early entrant places was small class sizes, which enabled children time and space to settle into their ELC placement. Eventually free ELC will be expanded to all 1- and 2-year-olds. However, SCLD believes including children with learning disabilities within the first phase of the national roll out will allow authorities and providers to understand more clearly what needs to be put in place to ensure these placements are successful for children with learning disabilities, and embed this in preparation for full roll out.
- 5.29. This could be done in the first instance by piloting the expansion in some areas that are currently utilising their discretionary early entrant places in this way, with the learning from this shared more widely. Importantly, the Scottish Government must listen to families as they design how the new offer will work in practice, and use this learning in the design of an inclusive system of wraparound childcare.

Ensure all local authorities' 'split/blended placement' offer provides maximum flexibility, including a mix of mainstream and specialist provision

- 5.30. Underpinning the 'Funding Follows the Child'²³ approach, which accompanies the roll out of 1140 hours, are the principles of parental choice, and getting it right for every child. Inflexibility of provision, including lack of suitable provision locally and appropriate wraparound care were highlighted by parents. Moving forward, it is pivotal that the intended flexibility is built into the system to allow adequate choice for all parents. The interviews highlighted in particular that many parents were not being allowed to split their child's time between specialist and mainstream placements.
- 5.31. For some children with learning disabilities and their parents, specialist provision will be the right placement type to allow them to thrive. Additionally, specialist nursery provision is not available in all local authority areas due to historical decisions about such provision. That notwithstanding, our research has found that for many parents being able to split their child's time between specialist and mainstream provision would allow them to experience the benefits of both.
- 5.32. As we move beyond COVID-19 and split/blended placements are no longer seen to increase transmission risk, the Scottish Government should publish guidance that makes it clear that a mix of specialist and mainstream provision is allowed within such placements, including across local authority boundaries.

Replace the Early Learning and Childcare Inclusion Fund with ring fenced funding for local authorities for reasonable adjustments in early years settings

- 5.33. The Scottish Government's Early Learning and Childcare Inclusion Fund distributed £2 million over four years, to support children with additional support needs to access their funded entitlement. The fund will end in March 2022, however, there is still a lot of work to be done to ensure that all children are able to access their entitlement.
- 5.34. SCLD believes that the Scottish Government should consider the provision of ring-fenced funding to local authorities for adjustments in ELC settings to support them to fulfil their duties under the Additional Support for Learning Act and the Equalities Act when the ELC Inclusion fund ends. As well as physical adjustments, such funding would finance the provision of training, extra staff, and the provision of communication in alternative formats, among other things.

23 Scottish Government (2018) [Funding follows the child and the national standard for early learning and childcare providers: principles and practice](#)



Concluding Comments

6. Concluding Comments

“When things come apart, there is always the opportunity to put them back together differently. We can work together to design the Scotland we want to emerge from this crisis.”

(Scottish Government)²⁴

- 6.1. As we move forward from COVID-19, the Scottish Government has committed to learn lessons from the pandemic, redouble efforts to tackle the wider inequalities that pervade our society, and embed equality, inclusion and human rights across Scotland. If we truly are to ‘build back better’ – or preferably, build forward better - this commitment must be taken seriously. People with learning disabilities and their parents and carers have been left isolated and struggling to cope over the past two years. The impact of the closure of schools and nurseries, and reduction or removal of support has been significant. The huge pressure on family carers, in particular, has led many to reach breaking point.
- 6.2. But their struggle is not new. This research has served to highlight, once again, that inequalities begin in the earliest years. And despite the best policy intentions, more information, support and resources are required for families and children with learning disabilities to enjoy equitable access to ELC settings, and, in turn, improved life-chances and better outcomes.
- 6.3. While the recommendations in the previous section could potentially move us closer to getting it right for children with learning disabilities in the early years, it is clear that the wholesale change that is needed to address the issues outlined in this report will require a concerted effort on behalf of policy makers, staff working in and around the early years sphere, as well as other professionals involved in the lives of children with additional needs.
- 6.4. As we move towards Scotland’s recovery and renewal, we must make sure the voices of those who already experienced inequalities long before COVID-19 are front and centre. When it comes to ELC, these voices are telling us that we need wholesale change. Now is the time to listen. Now is the time to make them a priority. Now is our opportunity to create the fairer, more inclusive Scotland we all aspire to.

²⁴ Scottish Government (2020) [Coronavirus \(COVID-19\): framework for decision making](#)

Appendix 1: Interview Discussion Guide – Parents and Carers

Background on participants circumstances

- Which local authority area do you live in?
- Who do you live with and can you tell me a bit about your circumstances at the moment?
- If you are comfortable, can you tell us a little about what life has been like since you found out your child had a learning disability?

Potential Barriers to ELC

- When you heard about the provision of funded early learning and childcare did you apply for a place?
- There are high uptake rates for free ELC, but anecdotal evidence tells us that many parents of children with learning disabilities do not take up the offer, and we are interested to find out why this might be. Can you tell us a bit about the reasons that you [did/did not] take up the offer?
- Can you think of any reasons why uptake of free ELC might be lower for parents of children with learning disabilities?

Perception of benefits and difficulties

Benefits

- In general, what do you think might be the benefits of free ELC?
- And what do you think the benefits might be for children with learning disabilities in particular?

Difficulties

- So in general, what do you think might be some of the difficulties of ELC?
- What about difficulties for children with learning disabilities in particular?

COVID-19

- Can you tell us a bit about how the COVID-19 pandemic has impacted on childcare for your child in general?
- Do you have any specific worries about how this might impact your child over the coming months and into the future?

Ideal childcare

- To finish off, what would the ideal nursery or Early Learning Centre look like to you?

Close

That's all of the questions I wanted to ask you today. Before we finish off, is there anything else you would like to say or ask that we haven't covered?

Appendix 2: Interview discussion guide – stakeholders

Background and involvement in ELC

- Could you briefly tell me a little bit about your background and your current role?
- And in relation to the introduction, implementation and expansion of free Early Learning and Childcare, what has your role/involvement been?
- How does your ELC application process work – and is this the same for children with additional needs?

Data on Uptake

- As you know, we are interested in understanding the particular barriers faced by children with learning disabilities in accessing ELC places. We've had difficulties ascertaining levels of uptake, as most local authority areas don't collect specific data on children with learning disabilities. Do you have any knowledge of the uptake levels for children with learning disabilities specifically?
- When we were trying to ascertain levels of uptake, we found that there was often a misunderstanding of learning disability and a tendency to include learning difficulties such as dyslexia. Do you think this is the case in your area?
- More generally, how have levels of uptake been in the local authority area?

Barriers to uptake

- What do you think the main barriers are for parents accessing free ELC places?
- While we are finding it difficult to ascertain the levels of uptake for children with learning disabilities, anecdotal evidence tells us that parents are not taking up their places. Can you think why that might be? Are there specific barriers that they face?
- What do you think about barriers for parents of children with profound and complex needs?

Good practice examples

- Do you know of anything in particular that has worked well in your area to encourage uptake for children with additional support needs? Anything specific to children with learning disabilities?
- Have you worked with any partner agencies or organisations locally to target increasing the uptake among children with learning disabilities?
- Are you aware of anything in other areas that has worked well?

COVID-19

- Can you tell us a bit about how the COVID-19 pandemic has impacted ELC in your area? Do you have any specific worries about the consequences of the pandemic over the coming months and into the future?

Close

That's all of the questions I wanted to ask you today. Before we finish off, is there anything else you would like to say or ask that we haven't covered?

Appendix 3: *Freedom of Information Request: submitted via email to 32 local authorities on the 18th of December 2020*

Good morning,

I am writing to you under the Freedom of Information (Scotland) Act 2002 to request the following information:

1. How many children with learning disabilities (as differentiated from specific learning difficulties such as dyslexia) aged three and four in the local authority area were eligible for 600 hours of funded early learning and childcare at the time of the Early Learning and Childcare Census in September 2019?
2. Of those three and four year olds with learning disabilities aged three and four who were eligible, how many were registered with early learning and childcare providers at the time of the Early Learning and Childcare Census in 2019?

If numbers are so small as to be disclosive, or you are unable to provide exact numbers, I am happy to receive an estimate detailing the percentage of children with learning disabilities aged three and four who were registered with early learning and childcare providers in September 2019 of those who were eligible.

If it is not possible to provide the information requested due to the information exceeding cost of compliance limits, please provide advice and assistance as to how I can refine my request.

If you have any queries please don't hesitate to contact me via email or phone and I will be very happy to clarify what I am asking for and discuss the request, my details are outlined below.

Thank you for your time and I look forward to your response.

Appendix 4: *Survey of ELC Providers*

The extension of free Early Learning and Childcare hours from 600 to 1140 hours should provide all children with the potential for improved outcomes, as well as offer parents more opportunity to take up work. However, anecdotal evidence suggests parents of children with learning disabilities are not accessing provision.

This survey hopes to find out about the experience early learning and childcare providers have of working with children with learning disabilities. By learning disability we mean:

A significant, lifelong condition that starts before adulthood, affects development and leads to help being required to:

- Understand information
- Learn skills
- Cope independently

For the purposes of this research we do not mean children with specific learning difficulties such as dyslexia.

Survey of ELC Providers

1. What local authority area are you based in?

2. Which of these options best describes your early learning and childcare setting?

- Local authority Private business Voluntary sector
- Self-employed (*childminder*)
- Other (please specify) _____

3. Do you have a process in place to determine the support needs of children looking to access the service?

- Yes No Not sure

4. If yes, could you give a short description of the process?

5. Do you have experience of providing care for a child with a learning disability in your service (either now or in the past)?

- Yes No Not sure

6. Do you feel confident that your setting is able to cater for children with learning disabilities?

- Yes No Not sure

7. If no, what would help you to feel more confident?

8. If yes, what gives you that confidence?

9. Can you think of any reasons why a parent of a child with a learning disability might have reservations about enrolling their child in a mainstream early learning and childcare setting?

10. Have you applied to the Early Learning and Childcare Inclusion Fund?

- Yes No Not sure

11. If yes, what type of adaptation(s) did you apply for funding for?

- Physical adaptations Equipment Training Resources
- Other (please specify) _____

12. Is there anything else you would like to tell us?



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