



**Craighalbert Centre**  
Enabling Children to Achieve



# Parents' experiences in Scotland of accessing early learning & childcare for children with profound and multiple learning difficulties

## Snapshot

**62%**

of the parents of children with profound and multiple learning difficulties (PMLD) reported that their child was **NOT** able to access their full entitlement of ELC.

**59%**

of the parents of children with PMLD reported that their child's ELC provision was **NOT** able to meet all of their child's needs.

**52%**

of the parents of children with PMLD described the process of identifying and securing an ELC provision for their child as **VERY DIFFICULT** or **DIFFICULT**.



## Introduction

In Scotland there are estimated to be approximately 230 children aged 2-4 years with profound and multiple learning disabilities (PMLD) exacerbated by complex health needs which may be life-limiting or life-threatening. Such children experience a wide range of interrelated learning, health, communication, care and social challenges. Each child will have their own combination of care plans, drug regimens, specialist nutritional and feeding requirements, therapeutic and technological support.

In 2021 in Scotland there were approximately 2,630 individually registered early learning and childcare (ELC) providers of “funded” placements to support the delivery of the duty under Part 4 of the Children and Young People (Scotland) 2014 Act; 1,627 Local Authority and 1,003 partnership centres. Any one of these providers, in any part of the country, may be asked to fulfil the statutory right to 1140 hours of early learning and childcare for one of these children with highly complex needs.

Parents engaging with our Early Intervention Programme shared with us some of the challenges they were experiencing when trying to secure and sustain ELC placements for their children, prompting us to seek more information.

In early 2022 we partnered with national agencies to run a series of focus groups and distribute questionnaires throughout Scotland, to explore the recent lived experiences of ELC of the parents of children with PMLD exacerbated by complex health needs which may be life-limiting or life-threatening.

We found that Scottish children with PMLD are often not able to access their full entitlement to ELC from their parents' provider of choice, at a quality that is acceptable on a consistent basis.

To explore the potential inequality that these families experience we also surveyed a control group where children had no identified additional support need.



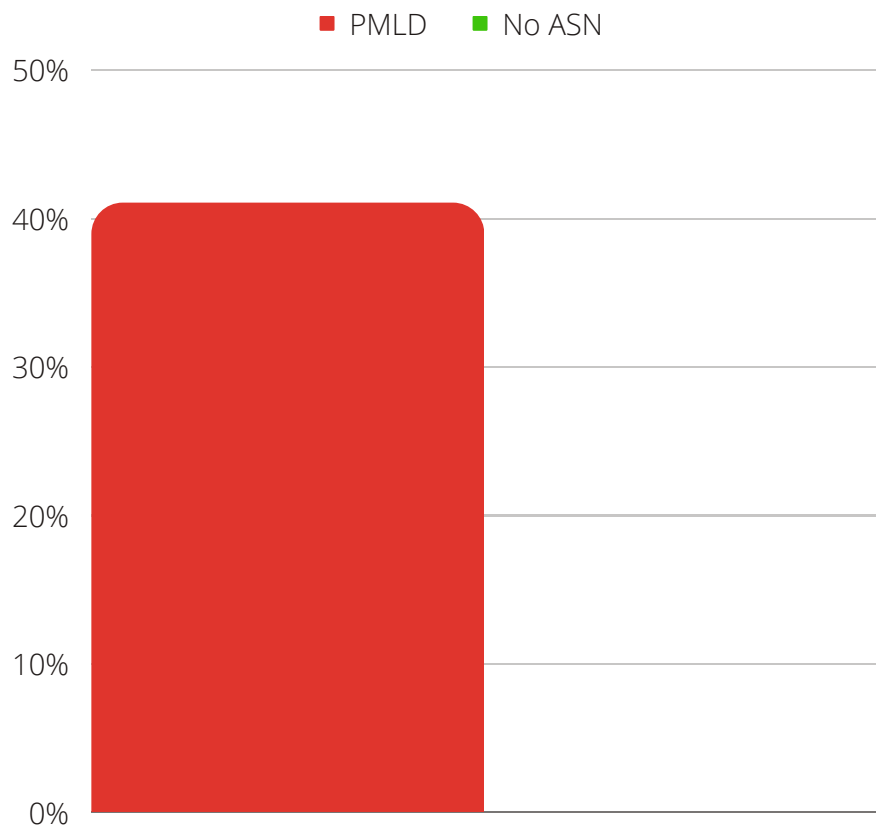


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## Survey findings

### Access to ELC provision of choice



### Key Facts

**41%**

of the parents of children with PMLD reported **NOT** securing the ELC Provision of their choice.

**0%**

of the parents of children with no ASNs reported not securing the ELC Provision of their choice.



## Survey findings

## Access to ELC provision of choice

### The parents of children with PMLD said:

"We haven't been able to find a suitable ELC provision for our daughter."

"Transfer distance to school is a risk factor and transport unable to manage our son's high risk health needs, however our preferred provision, closer to home, is a non-local authority resource and was refused."

"There is no longer a nurse [based in local ASN nursery] and my daughter is considered too complex to attend without a nurse on-site."

"Although allocated our placement of choice, our daughter is unable to attend because the local authority will not provide anyone to support her trachea management."

"My daughter should have been allocated a specialist placement in the first instance rather than being set up to fail in a mainstream setting."

"There is no local provision for a 2-year-old child unless their parents have limited income, even if they have additional support needs requiring early intervention."

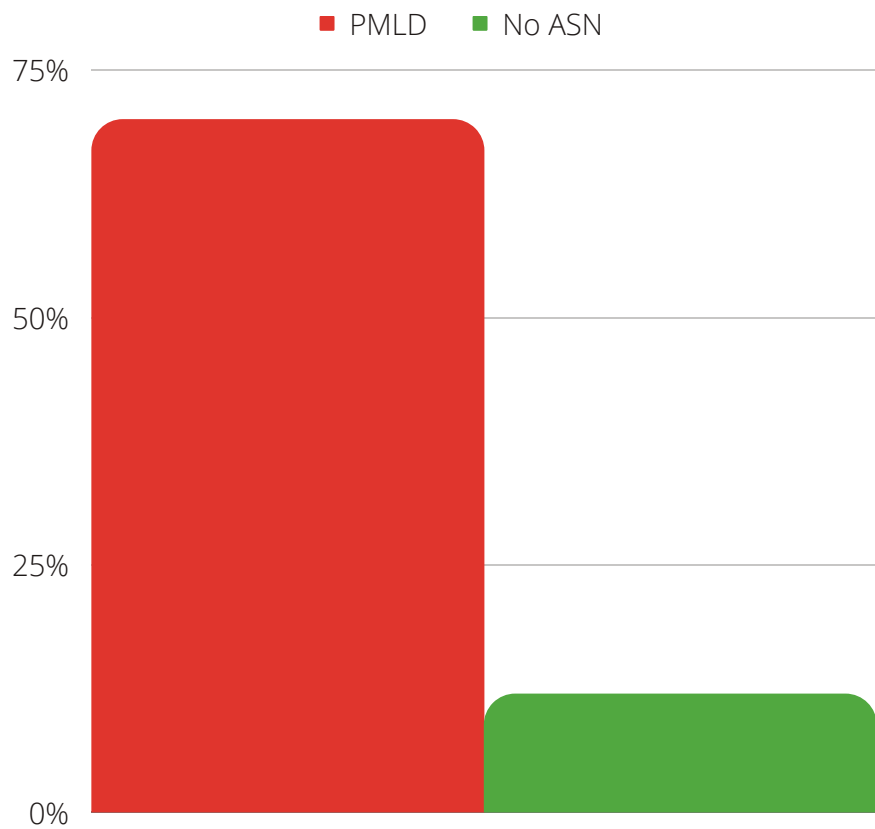
"As an eligible 2-year-old our daughter was not able to access ELC because there was not an appropriate provision locally."





## Survey findings

### Access to ELC Provision at age of choice



### Key Facts

**70%**

of the parents of children with PMLD reported **NOT** securing an ELC provision for their child at the age of their choice.

**12%**

of the parents of children with no ASNs reported not securing an ELC provision for their child at the age of their choice.



## Survey findings

## Access to ELC provision at age of choice

### The parents of children with PMLD said:

"It took us around 4 months, maybe longer, to get our son into nursery due to training and insurance mainly."

"Our daughter hasn't been able to start a placement even though we were advised that she was entitled to start a year ago, aged 2."

"We wanted our daughter to attend . . . but this was out of our catchment area. We had to go to tribunal and pay for a lawyer. We were eventually successful . . . but she missed all her nursery years bar a couple of terms."

"Our son started at 3. We were told he didn't qualify for a placement at 2."

"Because we didn't have a diagnosis early enough, we could not start our daughter at 2, although she was eligible, and had to wait until she was 3."

"Due to having to wait for a panel decision, our daughter did not start her ELC placement until she was 2 years and 8 months."

"Over 8-months delay to starting nursery due to delays in equipment arriving and staff being trained."

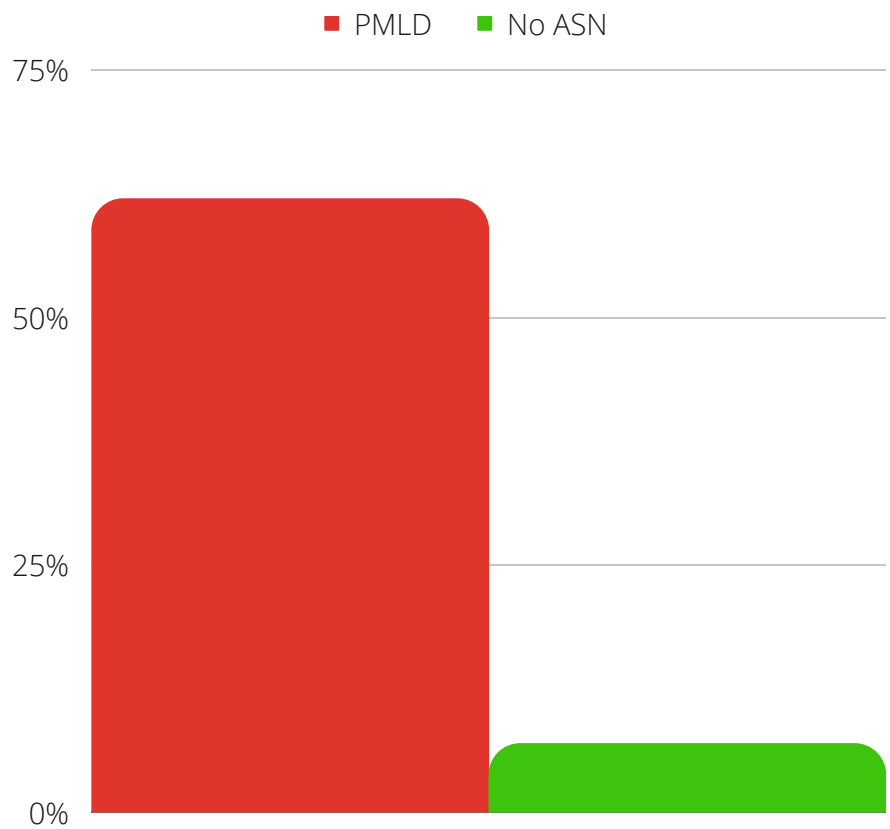
"There was around a 6-month delay in enrolling our son due to insurance needs despite applying to the nursery 6 months in advance of his requested start date to give them notice."





## Survey findings

### Access to full entitlement of ELC



### Key Facts

**62%**

of the parents of children with PMLD reported that their child was **NOT** able to access their full entitlement to ELC.

**6%**

of the parents of children with no ASNs reported that their child was not able to access their full entitlement to ELC.



## Survey findings

## Access to full entitlement of ELC

### The parents of children with PMLD said:

"We are only allowed to take it over 2 days, 8.00-18.00 and every other Friday but our son is not able to cope with being in ELC for 10 hours a day . . . he is only there for 3.5 hours per day."

"I do not get to use even 600 of the 1140 hours."

"Our local nursery does not have the capacity to provide all those hours."

"Our daughter has received around 10% of her entitlement."

"Local authority unwilling to facilitate out-of-school term-time option, which is available to all other children. Currently involving MSP to fight for this."

"The specialist school in our local authority only provided 2.5 - 3 hours sessions and only during term time. These sessions were so limited my daughter was not able to access a session every day."

"My son's hours have been limited due to staff availability."





## Survey findings

**ELC provision did not meet child's needs**



### Key Facts

**59%**

of the parents of children with PMLD reported that their child's ELC provision was **NOT** able to meet all their child's needs.

**0%**

of the parents of children with no ASNs reported that their child's ELC provision was not able to meet all of their child's needs.



## Survey findings

### ELC provision did not meet child's needs

#### The parents of children with PMLD said:

"The ELC was able to keep my son safe but there was a general lack of training provided to his key worker and 1:1 support assistants."

"We attended TAC meetings every quarter but they were of limited use; although we were able to review our son's progress and set new goals, most of what was agreed was never implemented."

"Not enough support for visual impairment."

"No access to SLT at nursery."

"This didn't happen if the trained member of staff was absent."

"My son was not provided with a 1:1 assistant . . . there was no-one who really knew him to read what he was trying to communicate and act accordingly and timely."

"My son could not play with 90% of the toys in the nursery and staff were not trained to help him interact with other children."

"There was very little floorspace . . . my son needed safe rolling mat time but was at risk of getting squashed."

"Due to limited hours available, there was little opportunity for my daughter to use the hydrotherapy pool, sensory room etc. and limited access to physiotherapy, occupational therapy and speech and language therapy in the ELC setting."

"Some days there are not trained staff to feed our son so we have to keep him at home."





## Survey findings

### ELC provision altered or withdrawn



### Key Facts

**55%**

of the parents of children with PMLD reported that their child's ELC provision was **ALTERED** or **WITHDRAWN**, with 31% of placements altered and 24% withdrawn.

**0%**

of the parents of children with no ASNs reported that their child's ELC provision was altered or withdrawn.



## Survey findings

### ELC provision altered or withdrawn

## The parents of children with PMLD said:

"Our son had to leave his first nursery as the 3-5 provision is upstairs."

"There were regular changes to our son's 1:1 support meaning that the new person would have to spend time learning about him and how to work towards his goals."

"Our first nursery said they could no longer meet our son's needs."

"The main issue is the delay in getting things in place, due to the local authority and bureaucracy."

"It is under constant review."

"Knowing that this can happen does make us anxious."

"Altered due to staff training needs after my son had been in hospital for a long time . . . staff seemed wary / scared."

"Spent 2 months at nursery and then lockdown happened . . ."

"Change of days due to other children or staff changes."

"Current nursery unable to provide reasonable adaptations to accommodate my daughter once she turns 3."





## Survey findings

### Process of identifying or securing ELC provision



### Key Facts

**52%**

of the parents of children with PMLD described the process of identifying and securing an ELC provision for their child as **VERY DIFFICULT** or **DIFFICULT**.

**1%**

of the parents of children with no ASN described the process of identifying and securing an ELC provision for their child as very difficult or difficult.



## Survey findings

## Process of identifying or securing ELC provision

### The parents of children with PMLD said:

“Ensuring that everything was in place to support my son in nursery was extremely difficult.”

“I had to go to court to fight for my son’s placement.”

“It was a shock to discover our son wasn’t able to go to the ELC provision we wanted for him.”

“We had to engage a private lawyer to help us secure funding for our daughter’s ELC provision. It was a horrible experience to go through.”

“Nobody took responsibility for making things happen . . . there were lots of different people with different timescales and agendas and in the middle of all that was my son, missing out on learning opportunities and my mental and physical health deteriorating.”

“Utterly terrible.”

“We felt like we were treated like second-class citizens by our local authority.”

“Utterly arduous and stressful.”

“It took months and months after our initial contact with the nursery for our son to start.”

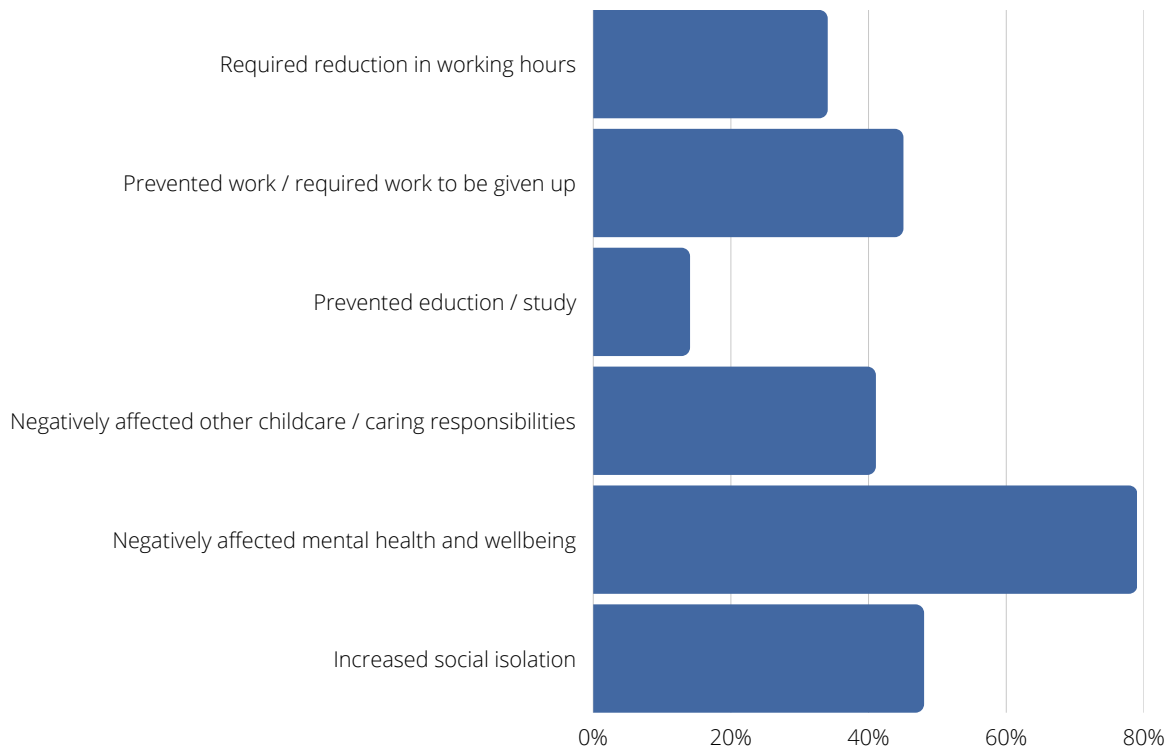
“A very long . . . stressful process.”





## Survey findings

### Impact of the process of identifying or securing ELC provision on parents



### Key Facts

**79%**

of the parents of children with PMLD reported that the process of identifying an ELC provision for their child had a **NEGATIVE IMPACT** on the mental health and wellbeing.

**79%**

of the parents of children with PMLD reported that the process had **AFFECTED THEIR ABILITY** to work, preventing them from working, requiring them to reduce their working hours and/or requiring them to give up work.

**48%**

of the parents of children with PMLD reported that it had **INCREASED** their social isolation.

**41%**

of the parents of children with PMLD reported that it had a **NEGATIVE IMPACT** on their other childcare / caring responsibilities.



## Survey findings

### Impact of process of identifying or securing ELC provision on parents

#### The parents of children with PMLD said:

"I ended up on the sick for 7 weeks whilst my son was waiting to actually start nursery because he doesn't sleep and I was with him 24/7 and I was beyond exhausted."

"Very disappointed with the ELC options in our local authority. We feel unsupported and that we have been forgotten about. We have had to do our own research to find possible ELC options for our daughter."

"On top of caring for our daughter with such complex needs, securing a nursery placement was financially, emotionally and physically crippling."

"The whole system is wrong and does not work on the principal of getting it right for every child."

"One of the most difficult things was witnessing agencies bargaining about which agency was responsible for paying for what."

"Decision-makers should be more aware of the impact of these processes . . . parental burn-out."

"I feel massively let down by the whole situation."

"The local authority was utterly useless in identifying my son's needs . . . it was exhausting talking to people over and over again who didn't understand what its like to have a child with such complex needs."

". . . detrimental impact on physical and mental health."

"The cost of battling with the local authority was unacceptable."

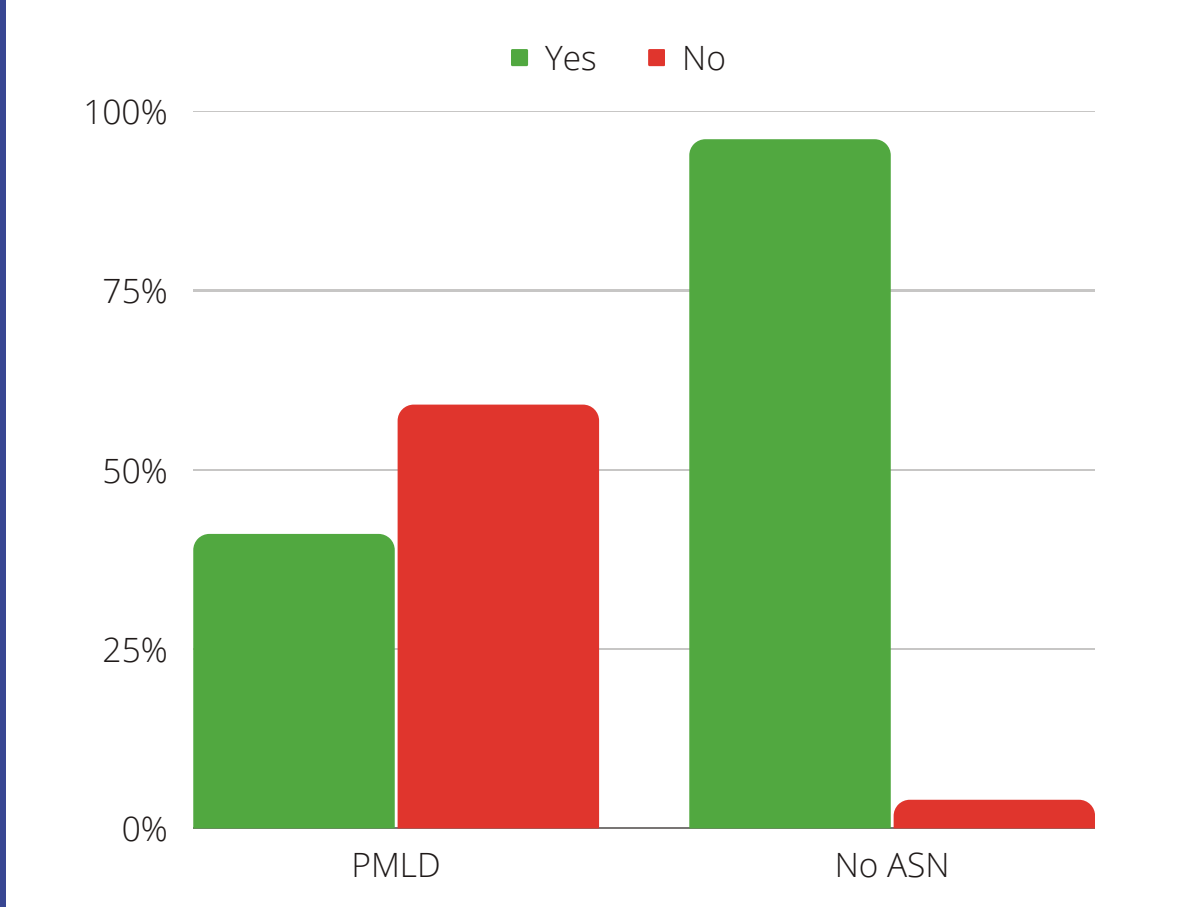
"ASN nurseries should provide the same 1140 hours in line with mainstream nurseries; children with ASNs are no less worthy of the entitlement."





## Survey findings

### ELC Provision met parents needs



### Key Facts

**59%**

of the parents of children with PMLD reported that their child's ELC provision did **NOT** meet their needs as parents.

**4%**

of the parents of children with no ASN reported that their child's ELC provision did not meet their needs as parents.



## Survey findings

### ELC Provision met parents needs

## The parents of children with PMLD said:

"I continue to be called regularly to collect my son because he is upset. Fortunately, I have flexible working which allows me to collect him."

"I have had to give up my pharmaceutical career."

"The hours as they are mean I still can't work as my son only gets 10.5 hours per week and we aren't able to access additional ELC due to his needs."

"The system is discriminatory and is keeping families with disabled children in the poverty trap."

"Because I couldn't secure sufficient hours in the local nursery, I gave up work . . . it was all getting too much."

"I am still on call at all times because of my son's seizures."

"I have clung onto my 3 working days throughout my son's pre-school days because I have a very supportive family."

"As a parent, I undertook most staff training (the CCN team were only able to provide one-off sessions on e.g. feeding / stoma care)."

"I spent the first 4 months of my daughter's nursery placement with her, settling her in. I also could not leave her until all staff were CPR trained."

"Local authority unwilling to facilitate out-of-school term-time option which is available to all other children; currently involving MSP to fight this."

"With very limited (next to nothing really) specialist nursery provision I had to give up work completely as my family couldn't continue to help as our daughter's needs increased."



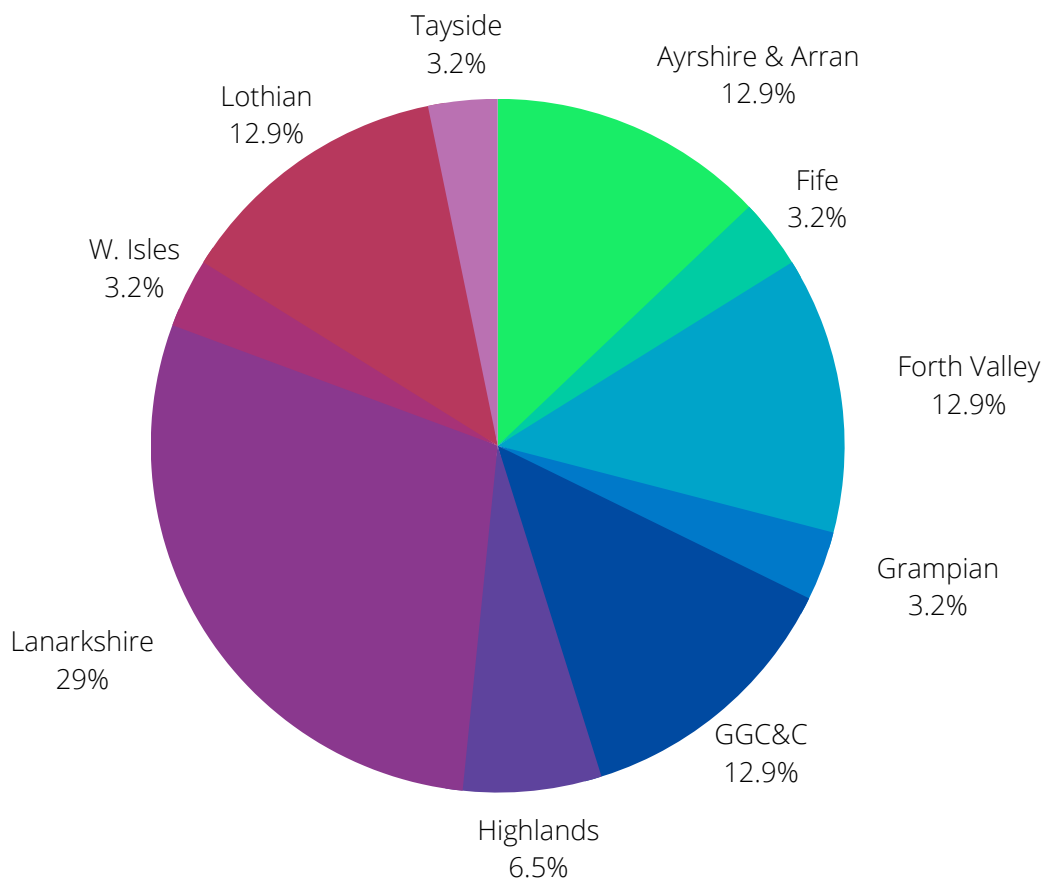






## Survey findings

### Location of respondents by Scottish NHS Board



## Key Facts

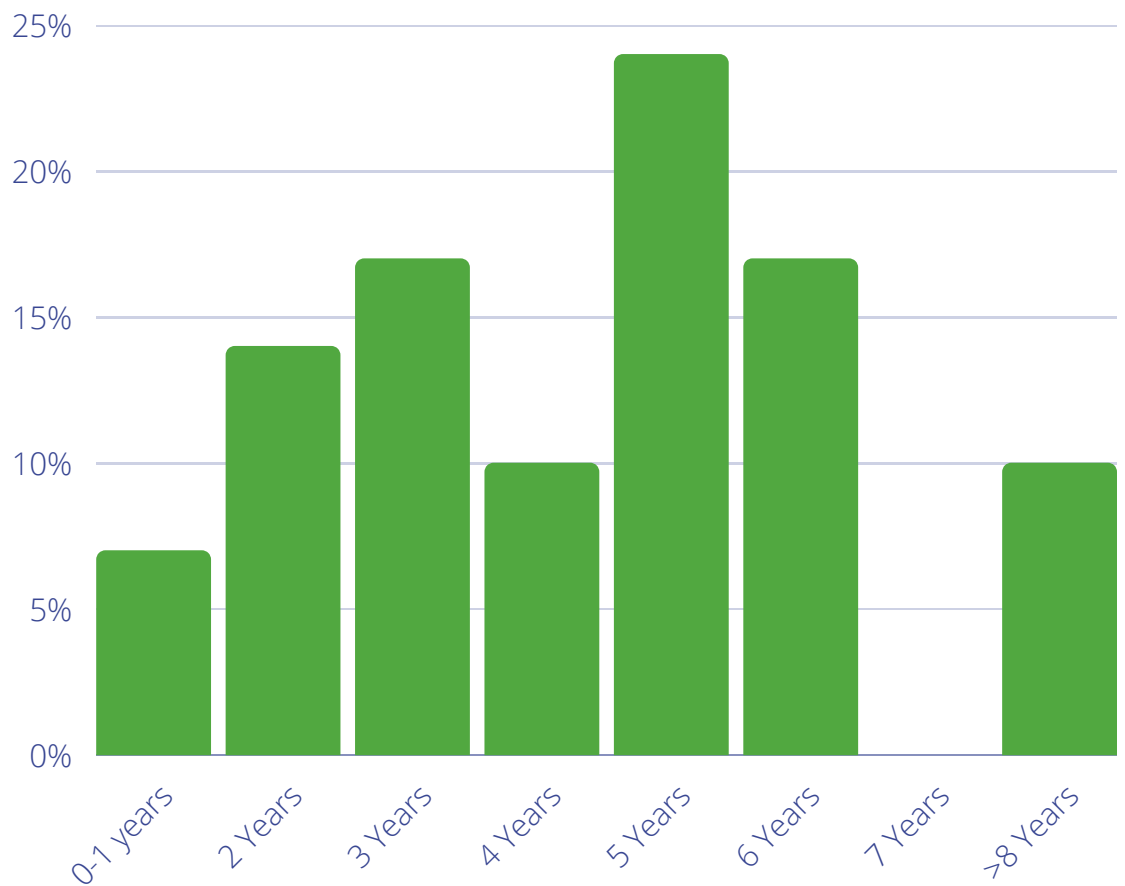
**71%**

of NHS Boards were represented in the responses from the parents of children with PMLD, indicating the widespread / national nature of the challenges relating to the provision of ELC for children with ASN.



## Survey findings

### Current age of respondents' children



## Key Facts

**58%**

of the parents of children with PMLD reported on recent or current experiences of ELC provision.

The current age range of the respondents' children is indicative of long-term challenges in the identification, allocation and provision of ELC for children with a wide range of ASNs and their lasting impact on the wellbeing of their parents.

## Survey findings

### Summary



## Summary

There are an estimated 230 children 2-4 years with profound and multiple learning disabilities (PMLD) exacerbated by complex life limiting health needs and around 2,600 providers of ELC in Scotland. The learning and health needs of these children vary significantly due to the severe low incidence nature of their conditions. These children are highly dispersed throughout Scotland and any ELC provider in any location could be asked to provide ELC for one of these children.

This report outlines some of the inequalities, challenges and impact experienced by families of children with profound disability in trying to consistently access their entitlement to early learning and childcare, at an acceptable quality from their provider of choice.

This research provides evidence that indicates that families in Scotland of children with profound and multiple learning disabilities where there are complex health needs experience widespread inequalities in access, choice, quality and sustainability of early learning and childcare compared to children where there is no identified additional support need.

The consequence of these inequalities not only directly impact on the child's health, learning and inclusion, they also have a negative impact on the mental health of parents and restrict their ability to be economically active.

The evidence that families experience inequalities, challenges and negative effects throughout Scotland suggests that a national approach is required to support families, providers and those that enable providers to ensure that all children can access their full entitlement of ELC, consistently, from their provider of choice and at a quality that is acceptable.





## Survey findings

## Next Steps

### Next Steps

- Bring together key stakeholders to explore findings of the research and their views on how the inequalities, challenges and the effects highlighted could be eliminated, reduced or mitigated against.
- Engage with providers and those that enable them, to explore in depth the barriers to equitable access, choice, quality and sustainability of ELC for children with profound disability and the opportunities to reduce, mitigate or eliminate these barriers..
- Recognising the low prevalence, highly dispersed and varied nature of these children's needs, explore with Scottish Government the opportunity to develop a national approach to provide direct practice support for ELC providers throughout Scotland and in the development and sharing of best practice.



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# THANK YOU TO ALL THE PARENTS WHO SHARED THEIR EXPERIENCES WITH US!



Published August 2022



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