PROVISION IN SCOTLAND OF EARLY LEARNING AND CHILDCARE FOR CHILDREN WITH PROFOUND AND MULTIPLE LEARNING DISABILITIES WITH LIFE-LIMITING OR LIFE-THREATENING CONDITIONS

(ABBREVIATED VERSION)



Introduction

A new report highlights that although the Scottish Government's flagship policy of access to free nursery care for 3 and 4 year olds is working well for most families in Scotland, significant challenges remain in ensuring that those with complex needs can access their entitlement.

Every 3 and 4 year old in Scotland has a legal right to 1140 hours free nursery or alternative early learning and childcare. That's around 30 hours per week.

Recent advances in medicine, therapy and care mean that children with highly complex disability and intensive health needs are living longer and longer. Many children who would only have lived a few months in hospital 15 years ago are now at home and expected to live long into childhood and potentially into adulthood.

Government statistics tell us that children who would not have survived till age five are now 2.5 times more likely to be ready to start school. That means many more children with needs we have rarely or never seen in nurseries are turning up at their local nursery and asking for a place. Although these children have very severe and complex disability, doctors, scientists and educators are all telling us that with consistent skilled interaction in the early years, while their brains are developing, there are real opportunities to rewire parts of their brain so that the effects of their disability may be reduced. So not only do they have the chance to live longer but also better quality lives.

We are talking about around 230 children in Scotland with the most complex needs who have very rare conditions or multiple conditions who would benefit hugely from nursery and have a right to it. However, parents tell us they can't access reliable nursery placements that consistently meet the needs of their child when they want it and where they want it, if they can access a placement at all.

In this summary report we have replaced the term "profound and multiple learning disabilities (PMLD) with life-limiting or life-threatening conditions" with "complex disability and intensive health needs" for ease of reading and wider communication.

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- Research indicates that parents of children with highly complex disability and intensive health needs are rarely able to access their child's full entitlement to nursery when they want it, from the provider of choice, that meets their needs consistently and is reliably available.

"It was a shock to discover that he was not able to go where we wanted him to."

- Parent

- 70% of parents of children with highly complex disability and intensive health needs surveyed said they could not access a nursery placement for their child when they asked for it.

"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."

- Parent

- Around 2 out of 3 parents surveyed said their child with highly complex disability and intensive health needs was not able to access their full entitlement.

"The nursery was unable to manage health care risks, therefore (child) receives 1 hour of home teaching per week and 2 half hour visits to nursery per week."

- Parent

- 3 out of 5 parents surveyed of children with highly complex disability and intensive health needs said the provision offered could not meet their child's needs.

"Our child was made to fit a local authority provision rather than a child with complex needs being provided with an individualised plan... a coordinated approach was difficult due to poor communication and inconsistency."

- Parent

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- These children are known to health professionals in particular from infancy however there appears to be an almost universal failure to plan ahead for their nursery provision.

"Over 8 months delay to starting in a mainstream nursery due to delays in equipment arriving and staff being trained – manual handling, epilepsy, tube feeding. Also delay in receiving risk assessment for storage and giving of blended diet in nursery"

- Parent

- Apart from the obvious and immediate inclusion, equality, children's rights and disability rights issues, missing out on nursery is likely to have a long term negative effect on children's brain development, communication, socialisation and physical development as well as concerning effects on parental mental health and their ability to work, potentially driving them into poverty.

"I wanted to return to work when my son was 1 but no private nursery would consider taking him . . . There should be more provision for complex needs kids from a younger age. Just because you've unfortunately had a child with a genetic condition does not mean you should have to give up your career; indeed it's more important that you continue so that you can have some normality in your life and somewhere you cannot be the carer all the time."

- Parent

- So, children with highly complex disability and intensive health needs, who would largely benefit from nursery are often not able to access this entitlement and are missing out on potentially life long benefits while their parents are experiencing mental health problems, isolation and are unable to work.

"I feel massively let down by the whole situation. It has caused my family additional stress on top of what is already a stressful situation. Everyone says that they are here to help buy very few do."

- Parent

- Parents are telling us that this is a problem throughout Scotland.

Asks

- Many organisations can help to resolve the challenges hence in the first instance we would ask that Scottish Government host a round table discussion so that all key stakeholders can share their experience and consider improvements.

- We believe that meeting the needs of children with complex disability and intensive health needs is a long term national challenge so our main call is for Scottish Government to back the development of a national hub, best practice exemplars and a national network to support families and those who work with them.

- It is critical that we raise awareness of the amazing opportunities in the early years to rewire brains and we would ask that Scottish Government support a campaign to do this, benefitting a wide range of children with brain injury and brain disorders.

- Put in place a system for early identification of children with complex disability and intensive health needs by local authorities so that they can plan for the provision of a nursery placement that meets the needs of the child.
- Access for all nurseries to training, development and support to enable them to provide placements for children with complex disability and intensive health needs.

- More accessible information for parents on their rights and their child's rights and how to exercise them.

- The learning from getting it right in the early years for children with complex disability and intensive health needs is transferable to the planning and delivery of services for thousands of children with significant but less complex needs. If we can get it right for these children in the early years, we should be able to get it right for any child.



Thank you for reading.

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A copy of the full report and parent survey findings are available from:

www.craighalbert.org.uk/ELC-PMLD

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