

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

Briefing Notes

Thank you for your interest in our report, below is a copy of our expanded press release with quotes from parents with lived experience, and supporters of the report. You are welcome to use the information provided for promotion on your social media channels. Please use our hashtag #LetsDoBetter.

Concerns that children with disabilities are unable to access nursery.

A new report highlights widespread failings, as children with highly complex disabilities and intensive health care needs are unable to access their right to nursery placements across Scotland.

Every 3 and 4 year old in Scotland has a legal right to 1140 hours of free nursery or alternative early learning and childcare. However, the report highlights that children with highly complex disabilities and intensive health care needs, who would hugely benefit from inclusive play, communication and learning 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.

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, and 79% said that the process of securing nursery provision for their child or the limitations of the provision that was provided meant that they had to give up work; prevented them from working; or required them to reduce their working hours.

The Scottish Centre for Children with Motor Impairments and Indigo Childcare Group have released this new report today [Wednesday 29th March 2023] into the provision of Early Learning and Childcare for children with highly complex disabilities and intensive health care needs. They say 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.

Bob Fraser CEO of the Scottish Centre for Children with Motor Impairments said "We are talking about around 230 children in Scotland with the most complex needs who have very rare conditions or multiple conditions where the science tells us that they would particularly benefit developmentally from nursery. However, parents tell us they can't access their entitlement to reliable nursery placements that consistently meet their child needs when they want it and where they want it, if they can access a placement at all."

Although this report focuses on children with profound and multiple learning disabilities with a life-limiting or life-threatening condition, the challenges faced by these children and families in accessing Early Learning and Childcare are also faced by many other families affected by childhood disability.

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The report calls for the development of a national hub, best practice exemplars and a national network to support families and those who work with children with highly complex disabilities and intensive health care needs.

Parent Lynsey McLuckie said:

“The appeal process has caused our family a great amount of stress. We have been told our application was at one point ‘incompetent’ and that we were not entitled to ask for the educational route we wanted for our daughter. The process has meant that we have had to concentrate on all the negativity’s in our life regarding our daughters condition and only talk about what she can’t do. This has meant that as parents we have been incredibly upset and distressed at times which in turn has an affect on our daughter.”

A nursery placement doesn’t just mean that our daughter will have an education , but it means that she is included in activities with children with similar abilities, support in feeling safe and nurtured with people other than her parents and the opportunity to be more active and achieve skills that may seem otherwise impossible.”

Parent Kate McMaster said:

“Our daughter only attended nursery at Craighalbert for 6 months before starting primary one. This was how long it took to get agreement and funding from Glasgow City Council. There is no system in Glasgow to request a placement out of the Glasgow Council area. We had to do everything ourselves. It cost us time, money and a lot of stress. She missed out on her early years nursery and vital therapy.

Not only were we trying to come to terms with her devastating diagnosis, but also fighting a non-existent system to try to get her what she needed to have with regards to education and therapy with no help. It’s a dreadful experience and has definitely taken its toll on all of us.”

Parent Grace Dennison White said:

“We are based in the Cairngorms and our daughter, is due to start nursery in August. We recently visited a couple of local mainstream nurseries to see if they could be a suitable option for her. Unfortunately, there are no specialist provisions local to us, the nearest being an hour’s drive away.

There’s so much to consider when choosing an educational setting for our daughter, including facility and bathroom adaptations, staffing ratios, staff training, travel time and catering for her blended diet. It’s imperative that each aspect is assessed on her individual needs.

She deserves to have the opportunity to learn and develop the same as every other child, in whichever setting we see best for her and us as a family.”

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Early Years Scotland said:

Early Years Scotland (EYS) fully supports the findings of this report. Difficulty in accessing and sustaining a place within an ELC setting can be further exacerbated for children with additional support needs. It is often the case that there are not enough specialist staff, or adequate resources, in order to support children within settings. It is essential that children who require additional support are not discouraged or excluded from accessing mainstream ELC. The recent focus on the importance of outdoor play and learning, particularly during the pandemic where fresh air is essential, must also include appropriate support measures for ASN children. All children should have the same level of access to beneficial outdoor play and learning. Our organisation agrees with the calls for the development of a national hub, best practice exemplars and a national network to support families and those who work with ASN children, and would provide support in the establishment of these important policy levers. The findings of this report also align with the UNCRC, the implementation of which EYS is fully behind. It is unacceptable that there are children who face significant barriers to accessing the Scottish Government's flagship policy on the expansion of early learning and childcare and, as such, EYS fully supports the asks outlined within this vital piece of work.

Scottish Commission for People with Learning Disabilities (SCLD) said:

"SCLD welcomes this incredibly important report. SCLD's own research into ELC last year found that we are simply not getting it right for children with learning disabilities in their earliest years, and the findings from this report really drive home how far we have to go to make ELC accessible for children with PMLD and complex health needs."

Children's Health Scotland said:

"The presence of complex disabilities and intensive healthcare needs should never be a barrier to young children enjoying the same rights (UNCRC 24 - Health, 28 - Education and 23 - Disability and inclusion) as any other child. These children have the same rights to benefit and thrive in a nursery or early learning setting providing the opportunity for brain development, communication, socialisation and physical development.

Children's Health Scotland, as a leading Scottish children's health charity, is dedicated to upholding the healthcare rights of ALL children and young people across Scotland regardless of condition or setting. We welcome this report and support the recommendations made within it. We call upon the Scottish Government to address this inequality and provide funding and appropriate resources to meet the needs of children with complex disabilities and intensive healthcare needs so that they may, along with their peers, realise their true potential."

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Iain Nisbet, Consultant Solicitor, Cairn Legal said:

“The law provides an entitlement to early learning and childcare for all pre-school children, regardless of their disabilities. For this group of children to be effectively shut out from their entitlements is of great concern – and may well amount to unlawful discrimination. Nursery providers, particularly larger providers (in the public and private sectors alike) need to respond to the challenges in this report and make sure their provision is accessible for all children, including those with highly complex disability and intensive health needs.”

Cheryl Ward, CEO, Family Fund said:

“Family Fund recognises that families of disabled children want to see the significant barriers they face to accessing appropriate care and support addressed. Given the multiple benefits of access to early learning and childcare provision for this particular cohort of children and their families, we wholeheartedly welcome the publication of this important report and its recommendations. “

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