



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

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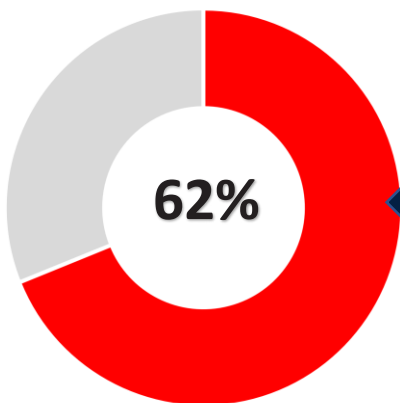
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"From August 2021, all three and four-year-olds, and a quarter of two-year-olds, will be eligible for around 30 hours a week of funded high-quality care and learning."
John Swinney MSP 2021

"Every child in Scotland has the right to good quality care that meets their needs and respects their rights."
Care Inspectorate 2021

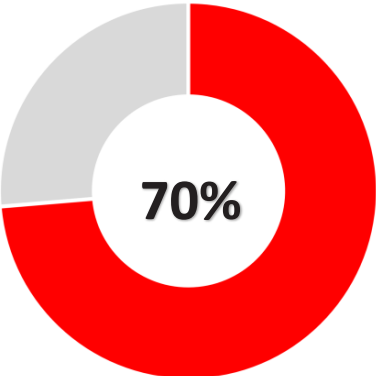
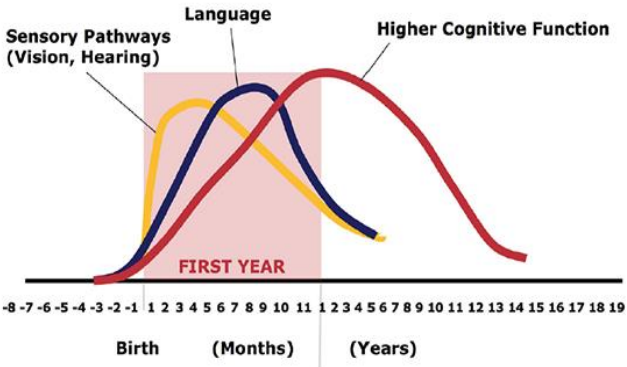


62% of the parents of children with profound and multiple learning disabilities (PMLD) reported that their child was **NOT** able to access their full entitlement of ELC.



Early intervention is important because of the ease at which new neural pathways can be formed during the critical period of neuroplasticity occurring between 0-5 years.
 (National Scientific Council on the Developing Child, 2014)

Human Brain Development
 Neural Connections for Different Functions Develop Sequentially



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

In this document **parent** refers to the mother or father of a child or young person, or to any foster carers, relative or friend who has been given responsibility for looking after or bringing up a child or young person. We will use the term parent or parents to refer to all parents and carers throughout this document.

Executive Summary Including Recommendations

Section 1	Introduction	1
Section 2	Scottish Legislative, Policy and National Guidance Framework	3
2.1	Introduction	3
2.2	Rights, Responsibilities and Duties	4
2.2.1	CYPA (Scotland) Act 2014	4
2.2.2	Equality Act (2010)	4
2.2.3	Children (Scotland) Act 1995	4
2.2.4	Education (Scotland) Act 1980	4
2.2.5	Human Rights Act 1998	4
2.2.6	Standards in Scotland’s Schools etc. Act 2000	4
2.2.7	United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) Non-discrimination, Equality of opportunity, accessibility, participation & inclusion	4
2.2.8	United Nations Convention on the Rights of the Child (UNCRC) (Incorporation) (Scotland) Bill	5
2.2.9	Education (Additional Support for Learning) (Scotland) Act 2004	5
2.2.10	Right help at the right time in the right place	6
2.2.11	All our Children and All their Potential	6
2.3	Summary of Section 2	6
2.4	Recommendations	7
Section 3	Population and Characteristics of Pre-school Children with Profound and Multiple Learning Disabilities and Life-Limiting or Life-Threatening Conditions	8
3.1	Prevalence of Disabled Children in Scotland	8
3.2	Children accessing ELC with Additional Support Needs	9
3.3	Children accessing ELC with Complex Additional Support Needs	9
3.4	Children accessing ELC with Profound and Multiple Learning Disabilities and Life-Limiting or Life-Threatening Conditions	9
3.4.1	Defining Children with Profound and Multiple Learning Disabilities with Life-limiting or Life-Threatening conditions	9
3.4.2	Data to inform the Prevalence of Children with Profound and Multiple Learning Disabilities with Life-Limiting and/ or Life-Threatening Conditions who are Eligible to access ELC	10
3.4.3	Estimated Prevalence of 2 – 4 years old in Scotland with PMLD and a Life -Limiting or Life-Threatening Condition	11
3.4.4	Estimated number of Children with PMLD and a Life -Limiting or Life-Threatening Condition Accessing Full or Part Time ELC Entitlement.	11
3.5	Summary of Section 3	11
3.6	Recommendations	11
Section 4	Meeting the Needs and Addressing the Barriers to Learning for Children with PMLD Accessing ELC	14
4.1	Brain Development, Learning and Neuroplasticity in the Early Years	14

4.2	Recognising, Understanding, Assessing and Responding to Changing Need and Opportunities for Development and Learning	15
4.3	Opportunities to Improve Communication in the Early Years	16
4.4	Opportunities to Improve Motor Learning in the Early Years	16
4.5	Improved Health and Quality of Life through Improved Postural Management	17
4.6	Summary of Section 4	17
4.7	Recommendation	18
Section 5	Understanding the Current Environment in Accessing and Providing ELC for the Families of Children with Profound and Multiple Learning Disabilities with Life-limiting or Life-Threatening Conditions.	19
5.1	Introduction	19
5.2	Registrations of Children with Disability for Funded ELC	19
5.3	Evidence from Recent Lived Experience	20
5.4	Parents' Perspective	21
5.4.1	Online Survey February 2022	21
5.4.2	Semi-structured Interviews with parents and carers of children with learning disability – Spring 2021	22
5.5	Evidence from Provider Organisations	23
5.5.1	Online Survey February 2022	23
5.5.2	Survey of ELC for children with learning disability – Spring 2021	24
5.6	Summary Section 5	24
5.7	Recommendations	25
Section 6	Delivery Challenges in Supporting Children with Profound and Multiple Learning Disabilities and a Life-Limiting or Life-Threatening Conditions Access their full ELC entitlement.	26
6.1	Introduction	26
6.2	Summary	27
6.3	Recommendations	28
Section 7	Final Words: Realising the Ambition and Delivering on the Legislative and Policy Framework	29
7.1	The Challenge and the Opportunity	29
7.1.1	Policy and Infrastructure	29
7.1.2	Children and Families	30
7.1.3	Early Years Sector	30
7.2	Impact	31
7.2.1	Impact on Scottish Government Policy Delivery	31
7.2.2	Impact on Children and Families	32
7.2.3	Impact on Local Authorities	33
7.3	Summary	34
7.4	Recommendation	34

Appendix I	Scottish Legislative, Policy and National Guidance Framework
Appendix II	Strategic Commissioning Group (NSCG) working description of children and young people with complex additional support needs
Appendix III	Disorders/ Conditions and Features that may be indicative of Children who have PMLD with associated life-limiting or life-threatening conditions
Bibliography	

Executive Summary

Section 1 Introduction

The life expectancy for many life shortening ‘childhood’ conditions has changed dramatically over the last 20 years; pre-millennium children affected by a wide range of conditions would have been expected to die in infancy or very early childhood. Children with these conditions are now surviving infancy into later childhood with many expected to live into adulthood and so efforts to optimise health and learning must go hand in hand with this changing trend. In Scotland there is an estimated prevalence of around 230 children two to four years old with profound and multiple learning disabilities (PMLD) whose needs are exacerbated through complex health needs, life-limiting or life-threatening conditions. However, there are approximately 2,606 individually registered early learning and childcare centres providing “funded” ELC placements to support the delivery of the duty under Part 4 of the 2014 Act; 1,621 Local Authority centres and 985 partnership centres (Scottish Government Early Learning and Childcare statistics 2022). Any one of these centres, in any part of the country, could be asked to fulfil the statutory right to early learning and childcare for one of these children.

Exploration of the current environment including primary and secondary research suggests that parents of children with profound and multiple learning disabilities often are not able to access their child’s full entitlement for ELC from their provider of choice, at a quality that is acceptable and that is a consistent and sustainable provision. The evidence suggests that there are significant inequalities between the experience of these children and parents when compared to families where the child has no recognised additional support need. Where children do access their full entitlement, consistently, from a provider of choice, at an acceptable quality, parents appear to be the main driver in securing the right education and care, at the right time in the right place rather than education authorities fulfilling the duty to make this available. This paper explores potential reasons for this and provides recommendations to support improvement.

Section 2 Scottish Legislative, Policy and National Guidance Framework

The Scottish Government’s legislative and policy landscape strongly promotes children’s rights, the rights of disabled people; statutory services taking action to meet the needs of disabled children and their parents; and providing equitable access to inclusive early learning and childcare of choice for children with profound and multiple learning disabilities whose needs are exacerbated through life-threatening and/or life-limiting conditions.

Current Scottish legislation, policy and guidance provides children, families, providers and commissioners with the rights, safeguards, authority, responsibilities and duties to ensure that children with PMLD, complicated by life-threatening and/ or life-limiting conditions can access their full entitlement to ELC from their provider of choice, at a quality that is acceptable and that is a consistent and sustainable provision. However, this web of interrelated and interdependent legislation, policy and guidance is complicated to navigate; this means that the practical application of rights, responsibilities and duties are often difficult to access and understand by those to whom they apply and are applied.

Scottish Ministers intent is to incorporate the United Nations Convention on the Rights of the Child into Scots law and give children and parents recourse to the Courts when these rights are not

upheld. When the Convention is brought into statute, this will strengthen the ability of parents to exercise their rights including to ensure that they can access their full entitlement to early learning and childcare for their child consistently, from a provider of choice, at an acceptable quality. If the current situation is not addressed, where frequently parents of children with profound and multiple learning disabilities whose needs are exacerbated through life-threatening and/or life-limiting conditions cannot equitably access early learning and childcare in their community, it could be viewed that Scottish Government was discriminating against children with disability in accessing ELC (Article 2); not acting in the best interest of the children (Article 3); that they were knowing not doing all they can to ensure that each child develops to their full potential in terms of gross and fine motor skills, communication, intellectual and social emotional development (Article 6); that they were not respecting the views of each child (Article 12); they could be inhibiting a children with disabilities freedom of expression (Article 15); that they were not supporting the parents of a disabled child in the development of that child (Article 18); that they were not supporting the disabled child to play an active part in the community (Article 23); that they were not supporting the child to have the best possible health (Article 24); that they were not supporting the child to have equal access to education (Article 28); and/or that the education being offered did not develop the child's personality, talents and abilities to the full (Article 29). Furthermore, the rights of other children in the family may be compromised by the demands for continuous parental care of the child with disabilities.

There is a need to simplify and make more accessible the complex web of interrelated law, policy and guidance that provides children, families, providers and commissioners with the rights, safeguards, authority, responsibilities and duties to ensure that children with PMLD, complicated by life-threatening and/or life-limiting conditions can access their full entitlement for ELC from their provider of choice, at a quality that is acceptable and that is a consistent and sustainable provision.

Recommendation

- (i) Scottish Government should undertake a review of policy and legislation that relates to children with complex needs in the early years and publish an accessible and coherent guide for parents, providers and commissioners to assist them in exercising their rights, responsibilities and duties.*

Section 3 Population and Characteristics of Pre-school Children with Profound and Multiple Learning Disabilities and Life-Limiting or Life-Threatening Conditions

There is patchy information on the prevalence, distribution, demographics of preschool children with PMLD and a life-threatening and/or life-limiting condition who are eligible to access ELC. Further there is wide variation in terms of learning, health and care needs of these children. What is clear is that these children have low incidence and high complexity conditions, and the estimated prevalence suggests a sparse distribution across local authorities and localities. In addition, the number of care providers (approximately 2600) outweigh the number of children (estimated 229) by a factor of more than 10 to 1. This would suggest it would be extremely difficult for any care provider, with the exception of a highly specialist service in a densely populated local authority, to develop and maintain the range of expertise necessary to provide an accessible high-quality experience for these children where they are enabled to achieve their full potential.

Recommendations

- (ii) Scottish Government should develop systems and processes to provide intelligence to support proactive locality, regional and national planning and provision of ELC that will enable children with PMLD and a life-limiting or life-threatening condition to access their full entitlement from their provider of choice, at a quality that is acceptable and that is a consistent and sustainable provision.*
- (iii) Scottish Government working with NHS Scotland should consider adapting the pre-school child health surveillance programme developmental assessment and reviews (6-8 weeks, 13-15 months & 27-30 months), their recording, reporting and information sharing to improve the identification and proactive planning for individual children, and locality and population planning for children with PMLD and a life-limiting or life-threatening condition.*
- (iv) Scottish Government working with NHS Scotland should consider further production and promotion of learning and development materials that support a better understanding of interagency, collaborative and holistic anticipatory planning for infants at risk of being affected by profound and multiple learning disabilities and a life-limiting or life-threatening e.g. further development and promotion of the elearning modules on the Turas system developed by the Managed Clinical Network for Children with Exceptional Healthcare Needs are accessible and applicable to all practitioners.*

Section 4 Meeting the Needs and Addressing the Barriers to Learning for Children with PMLD Accessing ELC

The period of intensive brain development in infancy and the early years creates the greatest opportunity for the brain to repair damaged areas and create or strengthen alternative pathways that can mitigate against congenital or infant acquired brain injury. This “neuroplasticity”, if exploited, may also help to mitigate against some progressive neurological impairment. For pre-school children with the most complex needs, those with PMLD and a life-limiting or life-threatening condition, there is often limited focus on the opportunity to mitigate brain impairment through intensive, sustained and tailored therapeutic support in the earliest months and years. The early years also offer the prospect of developing alternatives to speech communication alongside speech, e.g. use of eyegaze technology or Pragmatic Organisation Dynamic Display (PODD), allowing children the best chance to maximise on communication abilities. Furthermore putting in place and supporting sustained good posture in the early years will not only improve engagement, reduce pain and increase life expectancy of this population of children but also reduce the need for preventive and major corrective surgery including spinal and hip surgery as well as recurrent hospitalisation with respiratory illnesses related to aspiration and compromised lung function.

The opportunity offered through potential access to 1140 hours of ELC from age 2 years provides a vehicle for intensive early intervention to be provided. The opportunity to exploit neuroplasticity to develop alternative neural pathways begins at birth hence there may be an argument that where children are at risk of PMLD they are provided with access to the supports that will promote this development potentially changing their developmental trajectory. However, to capitalise on the opportunity offered while managing challenging care and health needs requires the 10 C’s”

from the team around the child; cooperation, collaboration, coordination, capacity, competence, capability, creativity, compassion, challenge and confidence, these must be set within a supportive, ambitious and agile environment. For many reasons it will not be desirable, possible or be in the best interest of many children to be in a specialist provision e.g. parental desire for inclusion, resultant separation from siblings, family circumstances, accessibility of provision making this unpracticable, etc. If practitioners in non-specialist ELC provisions are given access to expert context specific guidance, knowledge and skills to assist in planning, assessment, developing skills, and provided with access to expert healthcare advice when needed or as circumstances change, it is possible for these children to access their full entitlement for ELC from their provider of choice, at a quality that is acceptable and that is a consistent and sustainable provision.

At the age of 2 it is not possible to predict a child's future developmental potential or exact life expectancy and so it is all the more important that they are not denied the opportunity to reach that potential and to have the best possible life experience. These children may not 'grow up in Scotland' but Scotland should still be the best place for any child to live'.

Recommendations

(v) Scottish Government in partnership with NHS Scotland, Education Scotland, Early Years Scotland and key organisations who provide services and support for children with PMLD should collaborate to develop a campaign to raise awareness of the opportunities offered through neuroplasticity, developing alternative communication techniques and improved postural management in the early years.

Section 5 Understanding the Current Environment in Accessing and Providing ELC for the Families of Children with Profound and Multiple Learning Disabilities with Life-limiting and/ or Life-Threatening Conditions.

There is no systematic data collection on children with PMLD with a life-limiting or life-threatening condition who are accessing their full or partial entitlement to ELC or those who are not accessing their entitlement and the reason why not. However, data from Scottish Government, The Coram and, Children in Scotland all suggest that the proportion is significantly lower than that of the general population. Data from The Coram Group suggests this is partially a consequence of lack of sufficiency of childcare capacity in Local Authority areas for children with a disability.

An online survey of parents with recent lived experience (February 2022) of accessing Early Learning and Childcare for children with a life-limiting or life-threatening condition found that 70% of parents said they could not secure ELC when they requested it and when they did access it only 38% could access their full entitlement. Unfortunately, one in five parents reported that after securing ELC it was then withdrawn with 59% of parents saying that the provision they did access could not meet their child's needs. Almost four out of five parents told us that the process of securing ELC provision for their child or the provision that was provided meant that they had to give up work; prevented them from working; or necessitated them reducing their working hours. Similarly four out of five parents reported that the process of identifying and securing an ELC

provision for their child had a negative impact on their mental health and wellbeing and/or increased social isolation

An online survey (February 2022) of provider organisations seeking views on their experience in delivering ELC for children with PMLD and a life-limiting or life-threatening condition provides an insight into some of the challenges they are facing. 43% of ELC providers with experience of delivering learning and care for a child with learning disability said that they were not confident or were unsure about delivering this support. Three quarters of providers said that specialist equipment, guidance and training for staff were the most significant enabling factors. One in four said that staff capacity was a barrier to provision of full entitlement for children.

The parental view of children with PMLD with a life-limiting or life-threatening condition is clear; they are often not able to access sustainable ELC, their child's full entitlement (or the amount they wish), from their provider of choice, when they want it and at a quality they feel comfortable with. When comparing their experience with those where the child has no recognised additional support need the information available suggests that there are significant inequalities in accessing full entitlement, choice of provider, consistency in provision, meeting the needs of the child and meeting the needs of the parent. This infers that there is a planning, capacity and skills gap for the provision of early learning and childcare for these children. This is perhaps not surprising as it is not possible to plan for and provide responsive appropriate services and support for a highly dispersed population whose needs may only be made aware to the local authority on registration for ELC. Further, for individual providers and many local authorities the skill set, equipment and governance framework to assess and provide high quality ELC for a child with PMLD with a life-limiting or life-threatening condition is not readily available.

Recommendations

- (vi) Scottish Government in partnership with Local Authorities, NHS Scotland, Education Scotland, Early Years Scotland and key organisations who provide services and support for children with PMLD should further research, identify and take action to address the barriers children and families experience in accessing their full entitlement to ELC, when they wish to, from their provider of choice, consistently and that fully meets their child's needs.*
- (vii) Scottish Government in partnership with Local Authorities, Education Scotland, Early Years Scotland, National Day Nurseries Association and ELC providers should further research, identify and take action to address the barriers provider organisations experience in providing children with PMLD and a life-limiting or life-threatening condition their full entitlement to ELC consistently, when they are requested to, and that fully meets the child's needs.*
- (viii) The Scottish Government should ensure that the parents of children with PMLD and those whose child has a life limiting or life threatening condition are offered a safe and reliable peer support opportunity across Scotland to facilitate shared learning and experience in accessing ELC for their child.*

Section 6 Delivery Challenges in Enabling Children with Profound and Multiple Learning Disabilities with a Life-limiting or Life-threatening Condition to Access their full ELC Entitlement.

There is no single solution to the challenges faced nationally, by the sector and most importantly by the children and families themselves. It requires a truly integrated approach.

The integration of the specialist, professional skills, knowledge and understanding of the needs, development and learning of children with profound and multiple learning disabilities; those who support children with life-limiting and life-threatening conditions; and the professional expertise of early years practitioners could create a team with the ideal combination of leadership and operational experience to address some of the emerging challenges for the sector. The low volume, high complexity, varied nature of challenges and the high level of dispersal of these children in Scotland mean that the development of one or more centres of excellence will not in itself make a significant impact on addressing the challenges in an equitable way, what is required is access to expertise no matter where a child lives or learns. A package of national resources is required that can promote equality, children's rights, the rights of disabled people, through the provision of accessible, sustainable, efficient, effective, timely and high quality ELC for children with PMLD and a life-limiting or life-threatening condition.

Recommendations

(ix) Government should consider supporting the development of national resources to promote the inclusion of children with PMLD and a life-limiting or life-threatening condition in ELC settings these could include a national hub, best practice exemplars and a national network that will:

- share practice
- provide access to practical support for contextual holistic assessment for ELC placement planning
- improve and develop practice
- develop and share environmental appraisal, risk assessments, policies, procedures and protocols
- be a resource to trial and inform practice integration of new technologies
- be a resource to provide ELC contextual advice for providers throughout Scotland
- be proactive in developing practitioner collaboration, capacity, competence, capability, creativity, and confidence.
- provide equity of indemnity across public, private and not for profit ELC providers.

Section 7 Final Words: Realising the Ambition and Delivering on the Legislative and Policy Framework

The evidence shows that Scotland is currently failing in consistently providing the families of children with PMLD and a life-limiting or life-threatening condition with equality in terms of access to their full entitlement to ELC from their parents' provider of choice, when they want it, at a quality that is acceptable and reliably without significant disruption. At times it could be viewed that a number of these children's rights are being breached along with their rights as disabled people and at times we are failing to fulfil our statutory duties in a number of areas. Addressing these challenges requires a national response and the development of sustainable national

resources that can be equitably accessed by any provider to enable children and families of children with PMLD and a life-limiting or life-threatening condition to have the same opportunities no matter where they live. This would support the delivery of a wide range of Scottish Government policy and legislative commitments. Equally this approach would see benefits for local authorities, communities and children and families across Scotland through the enhancement of locality ELC provision. The model will also be a template for area wide, regional and national improvements in the provision of ELC for children with mild, moderate and complex learning disability and/or children with severe or complex health needs. Parents having confidence that their disabled child is accessing ELC that can consistently and sustainably meet their needs reduces their stress, improves emotional wellbeing, gives them the assurance they need to reengage or continue in employment, education or training and supports maintaining social contacts and often offers input from specialist therapists in an educational setting close to home.

Recommendations

- (x) Scottish Government should consider holding a roundtable discussion on the points raised by this paper with the aim of developing a working group and an action plan to address challenges raised and exploit the opportunities outlined.*



Section 1

Introduction

The life expectancy for many life shortening ‘childhood’ conditions has changed dramatically over the last 20 years; the National Records of Scotland Vital Events report for 2021 data showed that comparing the 5 years 2001 – 2005 to 2017 -2021, the death rate of those under 1 year fell by 37 % while the death rate for 1 – 4year olds fell by over 60%. Hence children with a range of rare, complex and life-threatening conditions are now surviving the neonatal period, infancy and into later childhood with many expected to live into adulthood and so efforts to optimise health, enablement and quality of life must go hand in hand with this changing trend to provide these children with an equal opportunity to achieve their potential.

This paper provides an insight into the provision of Early Learning and Childcare (ELC) in Scotland for children with profound and multiple learning disabilities (PMLD) whose holistic needs are exacerbated through complex health needs. The paper may be of interest to parents, providers, commissioners and policy makers. It provides recommendations for improvement including the strategic rationale and motivations for developing a Scottish Centre of Excellence in Inclusive Early Years Provision for children with PMLD complicated by life-limiting and/or life-threatening conditions.

Education Authorities [Local Authorities] have a duty under Part 4 of the Children and Young people (Scotland) Act 2014 (Part 4 of the 2014 Act) to ensure that 1140 hours of early learning and childcare (ELC) is made available to each eligible pre-school child. In delivering on this requirement, an education authority has a legal duty to “have regard to the desirability of ensuring that the method by which it makes early learning and childcare available is flexible enough to allow parents an appropriate degree of choice when deciding how to access the services.”

In Scotland there is estimated to be 229^{1 2 3} children two to four years old with profound and multiple learning disabilities (PMLD) whose needs are exacerbated through complex health needs, life-limiting or life-threatening conditions. These children experience a wide range of interrelated learning, health, communication, care and social challenges. Each will have its own combination of care plans (often including resuscitation and seizure plans), drug regimens, specialist nutritional and feeding requirements, therapeutic and technological support.

However, there are approximately 2,606 individually registered early learning and childcare centres providing “funded” ELC placements to support the delivery of the duty under Part 4 of the 2014 Act; 1,621 Local Authority centres and 985 partnership centres (Scottish Government Early Learning and Childcare Statistics 2022). Any one of these centres, in any part of the country, could be asked to fulfil the statutory right to early learning and childcare for a child with complex needs, including a child with profound and multiple learning disabilities (PMLD) whose needs are exacerbated through complex health needs, life-limiting or life-threatening conditions.

Exploration of the current environment including primary and secondary research suggests that parents of children with profound and multiple learning disabilities are often not able to access

¹ National Managed Clinical Network for Children with Exceptional Healthcare (CEN) Clinical Audit System (CAS) Prevalence Report (September 2021)

² The Children’s Hospices Across Scotland report – Children in Scotland requiring Palliative Care 3, Public Health Scotland (September 2000)

³ Congenital Anomalies in Scotland Statistical Report Public Health Scotland (October 2021), Data Files Accessed 01 March 2022
<https://publichealthscotland.scot/publications/congenital-anomalies-in-scotland/congenital-anomalies-in-scotland-2000-to-2019/>

their child's full entitlement for ELC from their provider of choice, at a quality that is acceptable and that is a consistent and sustainable provision. Where children do access their full entitlement, consistently, from a provider of choice, at an acceptable quality, parents appear to be the main driver in securing the right education and care, at the right time in the right place rather than education authorities fulfilling the duty to make this available. This paper explores potential reasons for this and provides recommendations to support improvement and the delivery of key Scottish Government policies including in relation to: Early Learning and Childcare; Children's Rights; Getting it Right for Every Child; Child Poverty; Inclusion; Equality; Attainment; Disability Rights; Health Improvement; Illness and Long-Term Conditions; Mental Health; and Employment.



Section 2

Scottish Legislative, Policy and National Guidance Framework

2.1 Introduction

Scottish Government have demonstrated through statute, policy and resourcing a strong commitment to a Scotland in which all children and young people can realise their potential with highest level of wellbeing achievable, regardless of where they live and learn, their social background or their learning needs, empowering them to flourish in life, learning and work. The statutory and policy framework in relation to preschool children affected by disability is extensive. Figure 1 highlights key legislation, policy and national guidance that impacts on pre-school children affected by complex additional support needs (ASN) including those with profound and multiple disabilities with life-limiting and/ or life-threatening conditions.

Figure 1 : Key Legislation, Policy and National Guidance Impacting on Pre-school Children Affected by Complex Additional Support Needs (ASN)

Key Legislation Impacting on Pre-school Children Affected by Complex ASN

- National Health Service (Scotland) Act 1978
- Education Act (1980)
- Children (Scotland) Act 1995
- Human Rights Act (1998)
- Standards in Scotland's Schools etc. Act 2000
- Education (Additional Support for Learning) (Scotland) Act 2004 as amended
- Equality Act (2010) and associated regulations
- Children and Young People (Scotland) Act 2014
- Carers (Scotland) Act 2016
- Education (Scotland) Act 2016
- Provision of Communication Equipment and Support: Part 4 of the Health (Tobacco, Nicotine etc. and Care) (Scotland) Act 2016
- United Nations Convention on the Rights of the Child (Incorporation) (Scotland) [not yet given Royal ascent]

Key Policy and Guidance Impacting on Pre-school Children Affected by Complex ASN

- Planning Improvements for Disabled Pupils' Access to Education - Guidance for Education Authorities, Independent and Grant Aided Schools (2014)
- Guidance on education for children and young people unable to attend school due to ill health (2015)
- Delivering Excellence and Equity in Scottish Education: A Delivery Plan for Scotland (2016)
- The right help at the right time in the right place: Scotland's Ten Year Strategy for the Learning provision for Children and Young People with Complex Additional Support Needs 2017 -2026 (2017)
- Additional Support for Learning: Statutory Guidance on the Education (Additional Support for Learning) Scotland Act 2004 (3rd edition 2017)
- Supporting children and young people with healthcare needs in schools Guidance for NHS boards, education authorities and schools (2017)
- National Improvement Framework (2019)
- Guidance on the presumption to provide education in a mainstream setting (2019)
- Support for Learning: All our children and All their Potential (2020)
- Realising the ambition: Being Me, National practice guidance for early years in Scotland (2020)
- Early Learning and Childcare Statutory Guidance (2021)
- Putting Learners at the Centre: Towards a Future Vision for Scottish Education (2022)
- Getting it right for every child policy (GIRFEC) (2022)

2.2 Rights, Responsibilities and Duties

There are a number of important rights, responsibilities and duties set out in the legislation, policy and guidance highlighted in Figure 1. However, the legal, policy and guidance framework that supports all children, preschool children and children with disabilities is complex and the interplay between these can be challenging to understand by those responsible for applying them and those to whom these apply. In relative terms, the commencement of the statutory duties in the 2014 Act in relation to education authorities/ local authorities' duties to secure ELC for children in their area is new and the interplay between these duties other duties, policy and guidance is still being worked through. Paragraphs 2.2.1 to 2.2.11 highlights some of the important rights, responsibilities and duties set out in the legislation, policy and guidance.

2.2.1 CYPA (Scotland) Act 2014

The Children and Young People (Scotland) Act 2014 places a duty on local authorities to secure 1140 hours of funded ELC for eligible children in their area.

2.2.2 Equality Act (2010)

Through the Equality Act (2010), pre-school children with profound and multiple disabilities have a right to equal opportunity to access their ELC entitlement and must not be discriminated against.

2.2.3 Children (Scotland) Act 1995

A disabled child is a "child in need" under this Act, this means that a Local Authority has a duty to promote the welfare of preschool children with PMLD within their area by providing a range and level of services appropriate to the children's needs. In doing so they have a duty to provide services that are designed to minimise the effect of the disabling impairment on the child and their family, and services should be designed to give those children the opportunity to lead lives which are as normal as possible

2.2.4 Education (Scotland) Act 1980

The Education Act 1980 places a duty on local authorities to secure provision of school education, including early learning and childcare, in their area. Education authorities are also empowered to provide discretionary early learning and childcare, over and above the statutory entitlement.

2.2.5 Human Rights Act 1998

The Human Rights Act 1998 provides a right to education, stating that "no person shall be denied the right to education". The 1998 Act also makes it clear that it is unlawful for a public authority to act in a way which is incompatible with this right.

2.2.6 Standards in Scotland's Schools etc. Act 2000

The presumption of mainstreaming (which came into force in 2003) enshrines the right of all children and young people with additional support needs to learn in mainstream early learning and childcare settings of their parents' choice.

2.2.7 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) Non-discrimination, Equality of opportunity, accessibility, participation & inclusion

The UK has been a party to the Convention since 2009. This means the Scottish Government has a responsibility to promote, protect and ensure the human rights of disabled people, including non-discrimination, equality of opportunity and access. Article 7 specifically references equality for disabled children and Article 24 references equal access to education.

2.2.8 United Nations Convention on the Rights of the Child (UNCRC) (Incorporation) (Scotland) Bill

The Scottish Government on 24th May 2022 restated its intention to amend and commence the UNCRC Bill. The Deputy First Minister made it clear that as far as is within the Scottish Government's power they will legislate to make it unlawful for a public authority to act in a way which is incompatible with the UNCRC requirements and to require them to take proactive steps to ensure the protection of children's rights in their service delivery.

He also stated that children, young people and their representatives would have a new ability to use the courts to enforce their rights.

In terms of supporting equitable access to ELC for children with PMLD and life-threatening and/or life-limiting conditions Local Authorities, Health Boards and Scottish Government may wish to consider if they are being proactive in ensuring that the following children's rights are being met:

- Article 2 - Non-discrimination of a child due to their disability;
- Article 3 – They are acting in the best interest of the child;
- Article 6 – Maximizing the development of the child;
- Article 12 - Respecting the views of the child;
- Article 15 – Providing a model of access to ELC that promotes freedom of association;
- Article 18 – Taking all appropriate measures to ensure that children of working parents have the right to benefit from child-care services for which they are eligible;
- Article 18 - Providing appropriate assistance to parents to support them in the development of their child;
- Article 23 - Doing all they can to support disabled children and their families by designing services to ensure that the disabled child:
 - has effective access to and receives education;
 - is provided with the specialist care necessary;
 - is socially integrated; and
 - has their individual development needs considered.
- Article 24 – Providing the best possible health care so a child can stay healthy;
- Article 28 – Supporting each child to have equal access to education; and
- Article 29 – Providing education that develops each child's personality, talents and abilities to the full

2.2.9 Education (Additional Support for Learning) (Scotland) Act 2004

The Act places a duty on an education authority to make appropriate arrangements for identifying "eligible" pre-school children who may have additional support needs and for providing the additional support required. For children under 3 years there is a duty to assess the needs and provide additional support to disabled pre-school children in their area when they are brought to

their attention and additional support needs are identified. That support is not confined to educational support but could include support from health, social work or voluntary agencies. Health Boards and other Local Authority Departments and other Local Authorities have a statutory duty under the Act to help an education authority deliver on their duties.

Parents of preschool children with additional support needs can ask for their child to attend ELC provision that is:

- delivered by their home Local Authority;
- with a private provider, where the home education authority have an arrangement for provision, normally referred to as a partnership nursery;
- an independent or grant-aided special school.

2.2.10 Right help at the right time in the right place

The “Right help at the right time in the right place” is Scotland’s ten-year strategy for the learning provision for children and young people with complex additional support needs. This strategy’s aim is to improve outcomes for children (3- 18 years), with complex additional support needs through strategic commissioning of services; with a particular focus on education services. It recognises that the funded ELC of 1140 hours for all children and for eligible two-year-olds has the potential to transform outcomes for children with complex needs in the early years. It proposes that services could be nationally commissioned to support:

- direct education, care and health services;
- research to provide evidence that will support national policy development and service provision;
- sustainable mechanisms to deliver learning, development and sharing of practice;
- broader services to support the education of children including those provided across authority areas, provided by local authorities or by voluntary organisations which may constitute a national need.

2.2.11 All our Children and All their Potential

The remit of the additional support for learning in schools review commissioned in 2019 included as part of its remit “*to consider the implementation of the Additional Support for Learning legislation and specifically how additional support for learning works in practice across early learning and childcare centres,*”. However, there is almost no reference to the ELC setting in the final report nor the recommendations. This is despite, that due to the high level of neuroplasticity in the brains of preschool children, the early years being a time that is widely recognised as a period when early and intensive intervention can be most effective in strengthening, changing and/or creating alternative neurodevelopmental pathways that can have a lasting if not life-long positive impact.

Expanded detail on the Scottish legislative, policy and national guidance framework is contained in appendix I.

2.3 Summary of Section 2

The Scottish Government’s legislative and policy landscape strongly promotes children’s rights and the rights of disabled people; statutory services taking action to meet the needs of disabled children and their parents; and providing equitable access to inclusive early learning and childcare

of choice for children with profound and multiple learning disabilities whose needs are exacerbated through life-threatening and/or life-limiting conditions.

Current Scottish legislation, policy and guidance provides children, families, providers and commissioners with the rights, safeguards, authority, responsibilities and duties to ensure that children with PMLD, complicated by life-threatening and/or life-limiting conditions can access their full entitlement to ELC from their provider of choice, at a quality that is acceptable and that is a consistent and sustainable provision. However, this web of interrelated and interdependent legislation, policy and guidance is complicated to navigate; this means that the practical application of rights, responsibilities and duties are often difficult to access and understand by those to whom they apply and are applied.

Scottish Ministers' intent is to incorporate the United Nations Convention on the Rights of the Child into Scots law and give children and parents recourse to the Courts when these rights are not upheld. When the Convention is brought into statute, this will strengthen the ability of parents to exercise their rights including to ensure that they can access their full entitlement to early learning and childcare for their child consistently, from a provider of choice, at an acceptable quality. If the current situation is not addressed, where frequently parents of children with profound and multiple learning disabilities whose needs are exacerbated through life-threatening and/or life-limiting conditions cannot equitably access early learning and childcare in their community, it could be viewed that Scottish Government was not acting in the best interest of the child (Article 3); that they were knowingly not doing all they can to ensure that each child develops to their full potential in terms of gross and fine motor skills, communication, intellectual and social emotional development (Article 6); that they were not respecting the views of the child (Article 12); that they were not supporting the disabled child to play an active part in the community (Article 23); that they were not supporting the child to have the best possible health (Article 24); and/or that they were not supporting the child to have equal access to education (Article 28). Furthermore, the rights of other children in the family may be compromised by the demands for continuous parental care of the child with disabilities.

There is a need to simplify and make more accessible the complex web of interrelated law, policy and guidance that provides children, families, providers and commissioners with the rights, safeguards, authority, responsibilities and duties to ensure that children with PMLD, complicated by life-threatening and/or life-limiting conditions can access their full entitlement for ELC from their parents' provider of choice, at a quality that is acceptable and that is a consistent and sustainable provision.

2.4 Recommendation

- (i) Scottish Government should undertake a review of policy and legislation that relates to children with complex needs in the early years and publish an accessible and coherent guide for parents, providers and commissioners to assist them in exercising their rights, responsibilities and duties.

Section 3

Population and Characteristics of Pre-school Children with Profound and Multiple Learning Disabilities and Life-Limiting or Life-Threatening Conditions

3.1 Prevalence of Disabled Children in Scotland

Statistics on how many children in Scotland are disabled are inconsistent (Figure 2). However, it has been noted that statistics that report on population childhood disability show that the reported prevalence of disability in the population significantly increases between infancy and early school years. It is unlikely that the increased prevalence seen in the reporting of disability as children get older can be explained by increased incidence alone and may, to some degree, be reflective of low recognition or reporting of disability in younger children. This makes it difficult for services to be planned at national, regional, local authority and locality levels, particularly for children in their early years.

Many disabled children have a rare disease condition, a rare disease condition is defined as a condition that is present in 1 in 2,000 people however there are actually 7,000 different rare conditions. So individually these conditions are rare but collectively not uncommon. Further we know that 81% of rare disease conditions are present in childhood that is around 5,700 conditions. Many children with PMLD and a life-limiting or life-threatening condition have a rare condition.

Figure 2 Key Statistics Relating to Children with Disabilities

Scottish Government Summary of Statistics for Schools in Scotland 2022

34% (2241,639) of all pupils had a recorded additional support need and that 2.8% (19,554) of children were assessed or declared disabled.

Additional Early Learning and Childcare Tables

The number of registrations for funded ELC from children with an additional support need is 18% (16,500) and for children assessed or declared to have a disability it is around 1.5%, (1,410 children).

UK Government Family Resource Survey 2019 -2020 (2021)

Estimate that 8% of children are disabled, National Statistics –Disability Data Tables.

Growing Up in Scotland, The Impact of Disability on the Lives of Young Children (2013)

12% of children were reported as having a disability at ten months of age. This increased with age; by age six years, 19% of children were reported to have a disability. 2% of children were reported to have a life-limiting disability at age two years. This had increased to 5% at age six years.

3.2 Children accessing ELC with Additional Support Needs

Although 34% of children in schools were recorded as having an additional support need in 2022, only 18% (16,500) of children registered with an ELC provider were recorded as having an additional support need. The proportion of registrations in ELC for children with an assessed or declared disability, is lower than the proportion of school age pupils recorded on the pupil census with assessed or declared disability: 1.5% in ELC and 2.8% in school age children (Scottish Government 2022)⁴.

3.3 Children accessing ELC with Complex Additional Support Needs

Scotland's ten-year strategy for the learning provision for children and young people with complex additional support needs (including those who are 3 -5 years) says that a rigorous, clearly bounded and universally accepted definition of complex additional support needs is extremely difficult to formulate because of the multiplicity of factors and the impact of specific contexts in different local authorities. For that reason, the National Strategic Commissioning Group (NSCG) is using a working description rather than a definition of children and young people with complex additional support needs (Appendix II). The 2015 Scottish Government Qualitative Research Report, Strategic Commissioning for Services for Children with Complex Additional Support Needs (Part of the "Doran Review") surveyed local authorities in 2015 and using their reported data they estimated that 9% of children with additional support needs had complex additional support needs. Applying this to the reported 16,500 children with additional support needs registered with an ELC provider in 2022, this would suggest that an estimated 1,485 children accessing ELC had complex additional support needs. If the prevalence of complex additional support needs in ELC was the same as in schools, i.e. 34% rather than the reported 18% then the number of children with complex additional support needs accessing ELC could be as many as 2,834.

There is no data on how many children with complex additional support needs were not accessing ELC or of the children with complex additional support needs how many were accessing their full entitlement.

3.4 Children accessing ELC with Profound and Multiple Learning Disabilities and Life-Limiting or Life-Threatening Conditions

3.4.1 Defining Children with Profound and Multiple Learning Disabilities with Life-limiting or Life-Threatening conditions

Children with Profound and Multiple Learning Disabilities with life-limiting or life-threatening conditions are a subset of those with complex additional support needs. For similar reasons, because of the multiplicity of factors that contribute to being identified in this grouping, there is no definitive definition of this group of children. In Scotland PAMIS is the most recognised charity that support people with profound and multiple learning disabilities, their families, carers and the practitioners who support them. They describe people with PMLD as *a group of individuals with learning disabilities in the profound range and who have a number of healthcare needs. Their disabilities can present challenges for them and those providing care.* PMLD Link, a UK charity, describes people with PMLD as those with *profound intellectual and multiple disabilities, very*

⁴ Scottish Government Summary Statistics for Schools in Scotland 2022 including Additional Early Learning and Childcare Tables (December 2022)

severe communication problems, often extreme physical and/or sensory disabilities, and complex health needs. Together for Short Lives, a UK Charity, describes life-limiting conditions *as those for which there is no reasonable hope of cure and from which children will die. Some of these conditions cause slow deterioration over time rendering the child increasingly dependent on parents and carers.* They describe life-threatening conditions as *those for which curative treatment may be feasible but can fail.* Appendix III provides information on examples of disorders, conditions and features that may be indicative of children who have PMLD with associated life-limiting and/ or life-threatening conditions. It should be noted that there is wide variation in terms of learning, health and care needs between children with different conditions, disorders, severity/ stage, co-morbidities and stability of health. Each child is unique. For children with PMLD with life-limiting or life-threatening conditions the complex interaction of learning, health and care needs means that practitioner experience in working with one child may be of some benefit when working with different children with PMLD and life-limiting and life-threatening conditions but is unlikely to fully equip an individual or team to provide high quality integrated learning, therapy and care for each child.

3.4.2 Data to inform the Prevalence of Children with Profound and Multiple Learning Disabilities with Life-Limiting and/ or Life-Threatening Conditions who are Eligible to access ELC

Available databases cannot give precise details about the numbers and circumstances of pre-school children with PMLD i.e. children who live with complex learning needs and health needs of a life-limiting or life-threatening nature. It is therefore necessary to consider a range of reports that may give some insight into this population of children and families.

The Children's Hospices Across Scotland (CHAS) report – Children in Scotland requiring Palliative Care 3 was delivered by Public Health Scotland in September 2020, this report specifically focuses on children with life-limiting and life-threatening conditions. The report suggests, through its inclusion criteria, there were 1,098 children in Scotland aged 2-4 years in 2018/19 who have a life-limiting or life-threatening condition. From their report it can be estimated that for 263 of these children the main impairment is neurological. Hence this could suggest up to 263 children with PMLD and a life-limiting or life-threatening condition.

Using significantly different inclusion criteria and methodology the *National Managed Clinical Network for Children with Exceptional Healthcare Needs (CEN)*, in March 2022, identified 79 children 2-4 years registered on its Clinical Audit System (CAS). It is noticeable that the prevalence of children registered for each Health Board on the CEN CAS is significantly different to population distribution across Scotland. This could suggest variation in recording rather than significantly differences in prevalence. There may also be differences among health boards in the timing and personnel involved in the assessment, inter-professional formulation and interpretation of the findings and how they are recorded in infancy.

The Congenital Anomalies and Rare Diseases Registration and Information Service for Scotland (CARDRISS) Public Health Scotland 2021 report's supporting data could suggest that there could be up to 378 children aged 2-4 years with major nervous system, genetic syndromes and micro deletions. These do not include chromosomal conditions such as Down Syndrome or Turner syndrome. This number is based on birth data and it is reported that an unknown number of these children will die before age four and this is likely to be higher than the number who are diagnosed

later, who develop or who acquire profound and multiple learning disability through disease or injury.

3.4.3 Estimated Prevalence of 2 – 4-year-olds in Scotland with PMLD and a Life -Limiting or Life-Threatening Condition

The number of 2 – 4 years old in Scotland in 2022 with profound and multiple learning disabilities with a life -limiting or life-threatening condition is likely therefore to be no less than 79 and possible as high as 378. The mid-point between these is 229 children, close to the 263 estimated from the CHAS/ Public Health Scotland report of 2020. As there is no definitive definition or register of children with profound and multiple learning disability with a life-limiting or life-threatening condition, to allow us to explore need and potential workable models to address need we will use the estimate of 229 children as our population of children 2-4 years. Figure 3 provides an illustrative representation of the distribution of the estimated 229 two to five years olds across the 32 Local authorities; the distribution is based on the National Records of Scotland population estimates mid-2021 and adjusted for 2022. This illustrates how potentially highly dispersed this population of low incidence high complexity need is across Scotland. It should be noted that this distribution, based on the estimated distribution of 2–4-year-olds living in the areas, differs significantly from a distribution based on all ages population.

3.4.4 Estimated number of Children with PMLD and a Life -Limiting or Life-Threatening Condition Accessing Full or Part Time ELC Entitlement.

There is no data on how many children with profound and multiple learning disabilities with a life -limiting or life-threatening conditions are accessing their full entitlement for ELC from their provider of choice, at a quality that is acceptable and that is a consistent and sustainable provision. This is because there is no systematic identification of this population of children and no systematic recording of why children are not accessing their entitlement.

3.5 Summary of Section 3

There is patchy information on the prevalence, distribution, demographics of preschool children with PMLD and a life-limiting or life-threatening condition who are eligible to access ELC. Further there is wide variation in terms of learning, health and care needs of these children. What is clear is that these children have low incidence and high complexity conditions, and the estimated prevalence suggests a sparse distribution across local authorities and localities. In addition, the number of care providers (approximately 2,600) outweighs the number of children (estimated 229) by a factor of more than 10 to 1. This would suggest it would be extremely difficult for any care provider, with the exception of a highly specialist service in a densely populated local authority, to develop and maintain the range of expertise necessary to provide an accessible high-quality experience for these children where they are enabled to achieve their full potential.

3.6 Recommendations

- (ii) Scottish Government should develop systems and processes to provide intelligence to support proactive locality, regional and national planning and provision of ELC that will enable children with PMLD and a life-limiting or life-threatening condition to access their full entitlement from their provider of choice, at a quality that is acceptable and that is a consistent and sustainable provision.

- (iii) Scottish Government working with NHS Scotland should consider adapting the pre-school child health surveillance programme developmental assessment and reviews (6-8 weeks, 13-15 months & 27-30 months), their recording, reporting and information sharing to improve the identification and proactive planning for individual children, and locality and population planning for children with PMLD and a life-limiting or life-threatening condition.
- (iv) Scottish Government working with NHS Scotland should consider further production and promotion of learning and development materials that support a better understanding of interagency, collaborative and holistic anticipatory planning for infants at risk of being affected by profound and multiple learning disabilities and a life-limiting or life-threatening e.g. further development and promotion of the elearning modules on the Turas system developed by the Managed Clinical Network for Children with Exceptional Healthcare Needs and accessible and applicable to all practitioners.





Figure 3 Estimated Local Authority distribution of children 2-4 years with PMLD and a life-limiting and/or life-threatening condition

Section 4

Meeting the Needs and Addressing the Barriers to Learning for Children with PMLD Accessing ELC

4.1 Brain Development, Learning and Neuroplasticity in the Early Years

A child's early years are integral to their physical, emotional, behavioural, and cognitive development. Early childhood is a time of tremendous brain development. The young brain literally changes shape and size in response to everything encountered in the early years. New environments, life experiences, carers, and relationships can all affect the way complex brain circuits are wired. This network of synaptic connections will ultimately determine brain function. This process is generally similar for children with Profound and Multiple Learning Disabilities.

An infant's brain at birth has roughly 86 billion brain cells (neurons), almost all the neurons the human brain will ever have. Although a new-born has about the same number of neurons as an adult, it has only 25% of the adult brain size. Infant's neurons are connected by only roughly 50 trillion neural connections, called synapses, whereas an adult brain has about 500 trillion of them. By age 3, the synaptic connections have grown to 1000 trillion. A child's brain volume reaches 90% completion roughly by age 5. For children with PMLD this unique period in their life cycle offers an opportunity to develop parts of the brain and neural connections that may reduce or mitigate the impairing effect of their neurological disorder.

To understand how we can use education to promote learning we must first understand and provide the best opportunity and environment for a child to develop. From birth we utilise play to promote development and over many centuries have learned what works for most children most of the time. However, children with PMLD require different strategies to promote development and play that are often non-linear in terms of the different domains⁵ of child development and early learning when compared to commonly understood development pathways.

Domains of Child Development and Early Learning:

- Cognitive Development
- General Learning Competencies
- Socioemotional Development
- Physical Development and Health.

Within early childhood, developmental timing is important. There are windows of time when different regions of the brain become relatively more sensitive to both positive and negative experiences. These are called critical periods of childhood brain development. During a critical period, synaptic connections in certain brain regions are more plastic and malleable. Connections are formed or strengthened given the appropriate childhood experiences. After the critical period has passed, the synapses become stabilised and less plastic. During adulthood, the synaptic density will be half that of a toddler at age two. Hence the opportunity to develop new, alternative or stronger pathways is highest in the early years. For example, language learning, the foundation for verbal communication and literacy development, is much easier in the early years than for older children and most challenging for adults.

⁵ Transforming the workforce for children birth through age 8: A Unifying Foundation, Institute of Medicine and National Research Council of The National Academies (2015)

Hence the brain is most flexible, or “plastic”, early in life to accommodate a wide range of environments and interactions, but as the maturing brain becomes more specialized to assume more complex functions, it is less capable of reorganizing and adapting to new or unexpected challenges. For example, by the first year, the parts of the brain that differentiate sound are becoming specialized to the language the baby has been exposed to; at the same time, the brain is already starting to lose the ability to recognize different sounds found in other languages. Although the “windows” for language learning and other skills remain open, these brain circuits become increasingly difficult to alter over time. Early plasticity means that where there is or suspected to be neurological impairment, it’s easier and more effective to influence a child’s developing brain architecture in the early years to try to rewire parts of its circuitry and reduce or mitigate impairment than it is as the child gets older.

What we know about children with PMLD, is that there is limited focus on the opportunity to mitigate against antenatal, perinatal and infant brain damage through intensive, sustained and tailored therapeutic support in the earliest months and years. With such significant focus on the immediate health challenges and parental adjustment to their new world, the opportunity, in these early years, to exploit neuroplasticity and develop new neural pathways reassigning tasks meant for injured areas to parts of the brain that remain unscathed (brain rewiring) is most often missed. [See “Neuroplasticity in children and adolescents in response to treatment intervention: A systematic review of the literature”]. Addressing this earlier, we know, has the potential to influence outcomes in the medium to long term.

4.2 Recognising, Understanding, Assessing and Responding to Changing Need and Opportunities for Development and Learning

Before accessing an ELC provision every child will have experienced a unique journey from prebirth and will be living within their own unique context of family and community, hence each will require, at a minimum, a “tweaking” of the typical curriculum to meet their learning and development needs. Children with PMLD have complex additional support needs and experience atypical learning and children with life-limiting or life-threatening conditions have additional health related barriers to learning.

Access to highly specialist expertise will be required frequently to maximise the opportunity for a child with PMLD and complex health needs to meet their potential. However, it should not be assumed that a child’s needs are best met by attending a highly specialist ELC provision exclusively. If we look at how a preschool child’s complex health needs are supported through a network of practitioners from universal (Health Visitor), general (General Practitioner), specialist (local child health/ paediatric team) and highly specialist (specialists at children’s hospitals) and we apply the same principles to meeting the child’s highly complex learning needs we may find a model for ELC provision that will meet the needs of children with PMLD and complex health needs in Scotland giving them the best opportunity to achieve their potential while most often remaining within their local community.

As we have discussed above and earlier, the learning, care and health needs of individual children within this group can change rapidly providing opportunities, challenges and risks. The exceptional, potentially life changing opportunities offered for child development in the early years through neuroplasticity must not be underestimated however to capitalise on these while

managing challenging care and health needs requires the 10 C's" from the team around the child; cooperation, collaboration, coordination, capacity, competence, capability, creativity, compassion, challenge and confidence, these must be set within a supportive, ambitious and agile environment. Access to expert knowledge and skills will be necessary to assess holistic needs; develop a learning, therapy and care plan; be available to assess what may be rapidly developing capabilities or alternatively changing barriers to learning; advise on potential next steps or alternative development opportunities; provide advice on adaptations and communication equipment, some of which may be highly specialist and require frequent adjustment to minimise the barriers to learning, maintain challenge and provide a supportive environment for achievement.

4.3 Opportunities to Improve Communication in the Early Years

Every day, children who cannot speak face social and educational isolation as well as significant frustration because they are unable to communicate their necessities, desires, knowledge and emotions.⁶ Research shows that as many as 85% of two year old children with cerebral palsy present with communication impairment, with only 10% expected to outgrow their delay by 4 years of age.⁷ The beginning period of language development is rich with opportunities for the young child to develop comprehension and communication skills; emerging speech production skills in infants with cerebral palsy can be positively influenced through the use of a combination of interventions focused on capitalising on early periods of plasticity when language learning is most sensitive. The challenge is to provide children with complex communication needs with access to the magic and power of communication at the earliest possible age to mitigate or even circumvent the negative effects of communication disabilities. Evidence of the effectiveness of early intervention for children with complex communication needs who require substitute, aided or electronic communication systems (Augmentative and Alternative Communication -AAC) is building; in a systematic review of AAC use with infants and toddlers across 12 studies improved communication was reported in 97% of participants. Research also indicated that the earlier intervention begins, the better the outcome may be, maximising the opportunities to enhance the development of children with complex communication needs, reducing the potential for continued delay, increasing quality of life, for the child and the family and decreasing cost(s) of later intervention⁸. Furthermore the use of AAC by peers to support communication has been associated with stronger language growth of children with complex communication needs.⁹

4.4 Opportunities to Improve Motor Learning in the Early Years

Children with cerebral palsy reach 90% of their gross motor potential by age 5, with most potential achieved in the first 2 years¹⁰. Neuroplasticity literature suggests that intensive, task-specific intervention ought to commence as early as possible and in an enriched environment, during the

⁶ Augmentative Communication and Early Intervention – Myths and Realities, MaryAnn Ronski & Rose A. Sevcik , *Infants and Young Children* V18 No.3 pp 174-185 (2005)

⁷ Implementation of an Early Communication Intervention for Young Children with Cerebral Palsy Using Single-Subject Research Design Roslyn Ward et al, *Journal of Clinical Medicine* 12, 232 (2023)

⁸ Effects of AAC Interventions on Communication and Language for Young Children with Complex Communication Needs, Kathryn Drager, Janice Light and David McNaughton, *Journal of Pediatric Rehabilitation Medicine: An interdisciplinary Approach* 303-310 (2010)

⁹ Support for AAC Use in Preschool, and Growth in language Skills for Young Children with Developmental Disabilities, R Michael Barker et al, *Augmentative and Alternative Communication* 29(4) 334-346 (2013)

¹⁰ Rosenbaum, P.L., Walter, S.D., Hanna, S.E., Palisano, R.J., Russell, D.J., Raina, P., Wood, E., Bartlett, D.J. and Galuppi, B.E., 2002. Prognosis for gross motor function in cerebral palsy: creation of motor development curves. *Jama*, 288(11), pp.1357-1363

critical period of neural development and that neuroplasticity is harnessed through high-intensity or high-dose training^{11 12}.

While motor skills develop naturally for most typically developing pre-schoolers, young children with disabilities often experience delays in this area. Therefore, it is essential to intervene, providing direct and intentional motor programmes for children with disabilities during their early years when fundamental motor skills such as locomotion and manipulation develop. These skills form a foundation for skill development in other developmental areas¹³. Through the promotion of early perceptual-motor behaviours i.e. the integration of sensory and motor abilities to carry out physical activities, more global developmental advancements can be facilitated and future delays can be minimized across domains for infants and children with special needs. The goals of these interventions should be not only to advance targeted perceptual-motor skills in the moment but also to more broadly advance future abilities and meet the early intervention goal of maximizing children's learning potential¹⁴.

4.5 Improved Health and Quality of Life through Improved Postural Management

Children who suffer with cerebral palsy (CP) and similar conditions have a significant chance of developing scoliosis (abnormal twisting and curvature of the spine) during their early years. The development of this scoliosis is closely associated with the severity of the neuromuscular disability. Without timely therapeutic intervention, scoliotic curves will continue to progress and cause impairment in function and increased risk of poor health including pain; reduced respiratory function; and the requirement for spinal and/ or hip surgery¹⁵. It should be noted that there is a potential for negative effect if postural care information is given without full support and monitoring eg producing body shape distortion, aspiration etc. Hence it is critical that expert support is available no matter where the child is learning or being cared for¹⁶.

4.6 Summary of Section 4

The period of intensive brain development in infancy and the early years creates the greatest opportunity for the brain to repair damaged areas and create or strengthen alternative pathways that can mitigate against congenital or infant acquired brain injury. This “neuroplasticity”, if exploited, may also help to mitigate against some progressive neurological impairment. For pre-school children with the most complex needs, those with PMLD and a life-limiting or life-threatening condition, there is often limited focus on the opportunity to mitigate brain impairment through intensive, sustained and tailored therapeutic support in the earliest months

¹¹ Jackman, M., Lannin, N., Galea, C., Sakzewski, L., Miller, L. and Novak, I., 2020. What is the threshold dose of upper limb training for children with cerebral palsy to improve function? A systematic review. *Australian occupational therapy journal*, 67(3), pp.269-280

¹² Morgan, C., Novak, I., Dale, R.C. and Badawi, N., 2015. Optimising motor learning in infants at high risk of cerebral palsy: a pilot study. *BMC pediatrics*, 15(1), pp.1-11

¹³ Favazza, P.C., Siperstein, G.N. (2016). Motor Skill Acquisition for Young Children with Disabilities. In: Reichow, B., Boyd, B., Barton, E., Odom, S. (eds) *Handbook of Early Childhood Special Education*. Springer, Cham. https://doi.org/10.1007/978-3-319-28492-7_13

¹⁴ Michele A. Lobo, Regina T. Harbourne, Stacey C. Dusing, Sarah Westcott McCoy, *Grounding Early Intervention: Physical Therapy Cannot Just Be About Motor Skills Anymore*, *Physical Therapy*, Volume 93, Issue 1, 1 January 2013, Pages 94–103, <https://doi.org/10.2522/ptj.20120158>

¹⁵ Cloake, T, Gardner, A (2016) The management of scoliosis in children with cerebral palsy: review, *Journal of Spinal Surgery* v 2(4) 299 – 309, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5233861/>

¹⁶ Hill, S, (2011) A One Year Postural Care Training Programme for the Workforce Supporting the Needs of those with Complex and Continuing Healthcare Needs: Project Evaluation, <https://www.choiceforum.org/docs/pcsh.pdf>

and years. The early years also offers the prospect of developing alternatives to speech communication alongside speech, e.g. use of eyegaze technology, Pragmatic Organisation Dynamic Display (PODD) or intensive baby signing, allowing children the best chance to maximise on communication abilities. Furthermore putting in place and supporting sustained good posture in the early years will not only improve engagement, reduce pain and increase life expectancy of this population of children but also reduce the need for preventive and major corrective surgery including spinal and hip surgery as well as recurrent hospitalisation with respiratory illnesses related to aspiration and compromised lung function.

The opportunity offered through potential access to 1140 hours of ELC from age 2 years provides a vehicle for intensive early intervention to be provided. The opportunity to exploit neuroplasticity to develop alternative neural pathways begins at birth hence there may be an argument that where children are at risk of PMLD they are provided with access to the supports that will promote this development potentially changing their developmental trajectory. However, to capitalise on the opportunity offered while managing challenging care and health needs requires the 10 C's" from the team around the child; cooperation, collaboration, coordination, capacity, competence, capability, creativity, compassion, challenge and confidence, these must be set within a supportive, ambitious and agile environment. For many reasons it will not be desirable, possible or be in the best interest of many children to be in a specialist provision e.g. parental desire for inclusion, resultant separation from siblings, family circumstances, accessibility of provision making this unpracticable, etc. If practitioners in non-specialist ELC provisions are given access to expert context specific guidance, knowledge and skills to assist in planning, assessment, developing skills, and provided with access to expert healthcare advice when needed or as circumstances change, it is possible for these children to access their full entitlement for ELC from their provider of choice, at a quality that is acceptable and that is a consistent and sustainable provision.



At the age of 2 it is not possible to predict a child's future developmental potential or exact life expectancy and so it is all the more important that they are not denied the opportunity to reach that potential and to have the best possible life experience. These children may not 'grow up in Scotland' but Scotland should still be the best place for any child to live'. Early access to supported Early Learning reduces parents' anxiety that their child with PMLD has not missed the window of opportunity for better developmental outcome.

4.6 Recommendation

- (v) *Scottish Government in partnership with NHS Scotland, Education Scotland, Early Years Scotland and key organisations who provide services and support for children with PMLD should collaborate to develop a campaign to raise awareness of the opportunities offered through neuroplasticity, developing alternative communication techniques and improved postural management in the early years.*

Section 5

Understanding the Current Environment in Accessing and Providing ELC for the Families of Children with Profound and Multiple Learning Disabilities with Life-limiting or Life-Threatening Conditions.

5.1 Introduction

As discussed in Section 3 there is no systematic recording of the number of preschool children with PMLD with a life-limiting or life-threatening condition, hence it is not possible to obtain a full understanding of families' experiences of accessing ELC with different needs and in different communities, equally obtaining a comprehensive understanding of provider's experience of enabling access is not possible. Acknowledging these limitations, there has been some recent research that provides an insight into both families' and providers' experiences. Further, some of the regularly collected data can help to provide indicative information on those children with complex needs accessing their ELC entitlement.

The Voice of Parents

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

"He had to leave his first nursery as the 3-5 provision was upstairs. Our alternative choice refused him a place."

"Unable to manage health care risks, therefore receives 1 hour of home teaching per week and 2 half hour visits to nursery per week."

"Our private nursery said they could no longer meet his needs."

5.2 Registrations of Children with Disability for Funded ELC

The proportion of registrations in ELC for children with assessed or declared disability, is lower than the proportion of school aged pupils recorded on the pupil census with assessed or declared disability, i.e. 1.5% Vs 2.8% (Scottish Government 2022). There are several possible explanations for this. Some disabilities are difficult to identify at an early age (e.g. dyslexia) or as a result of an impact later in childhood (e.g. accident or illness that results in long term impairment). It also may be that some children with disabilities are not accessing their entitlement. The Coram - Family and Childcare Trust Annual Report on their Childcare Survey 2021 reported that of the 15 Scottish Local Authorities who responded to the question 'did they have sufficient childcare capacity for disabled children' around 59% said they had sufficiency in all areas and around 41% said they had sufficiency in some areas. Just over half of Local Authorities did not answer questions on sufficiency of childcare for children with a disability indicating "data not held" or "cannot tell". This suggests that there is a capacity gap for the provision of childcare for children with disability and a data gap for the majority of local authorities. It is not possible to provide appropriate services and support for a population the size of which is unknown and where the baseline skill set and resources of providers is unclear.

In their response to the consultation on the ELC service model for 2020¹⁷, 'Children in Scotland' provided similar feedback on access to ELC for children with ASN. Through their role in managing Enquire, the Scottish advice service for additional support for learning, they are aware of barriers that children with additional support needs face due to a lack of capacity or resources to support them. They have examples that illustrate that children with additional support needs are being offered less flexibility and choice of provision and that some families are struggling to find an ELC placement that will meet their child's needs. They called for more staff knowledge and training to support all children and reinforcement of the laws and duties already in place.

5.3 Evidence from Recent Lived Experience

The Voice of Parents

"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.

The private nursery placement, partially funded by the council, was withdrawn when my son was 2 as he was getting harder to move around and needed more equipment. I also think they realised that they did not really know what to do with him and how to help him develop."

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

"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."

In partnership with national agencies the Scottish Centre for Children with Motor Impairments (SCCMI) has carried out research across the sector including:

- Desk research to help identify available data on uptake, access and experiences of children with PMLD with a life-limiting or life-threatening condition access their entitlement to ELC.
- An online survey of parents and their experience past and present of accessing ELC for their child with PMLD with a life-limiting or life-threatening condition or broader ASN.
- An online survey of parents and their experience past and present of accessing ELC for their child where there is no known additional support need.
- An online survey of ELC providers and their experiences of providing ELC for children with PMLD
- A series of focus groups with parents to explore some of the above in more detail
- Interviews with practitioners from the ELC sector and those who support children with ASN.

An important factor to note in the input and observations from parents is that most of these parents would describe themselves as articulate, educated and actively engaged in formally advocating for their child's rights.

¹⁷ Children in Scotland – Early Learning and Childcare Service Model for 2020 Consultation Response (2018). https://childreninscotland.org.uk/wp-content/uploads/2018/08/ELC_Service_Model.pdf

5.4 Parents' Perspective

5.4.1 Online Survey February 2022

An online survey of parents with recent lived experience (February 2022) of accessing Early Learning and Childcare for children with PMLD and a life-limiting or life-threatening condition provides an insight into some of the challenges parents are facing. As a comparator group the same survey questions were asked of parents whose child had no reported ASN. The survey obtained responses from parents accessing ELC in 16 of the 32 Scottish local authorities as follows:

- 70% of parents of children with PMLD and a life-limiting or life-threatening condition (PMLD & LL/ LT C) said they could not secure ELC when they requested it, in contrast only 12% of parents surveyed of a child with no identified ASN (no ASN) reported this.
- 41% of parents (PMLD & LL/ LT C) could not secure ELC provision from their provider of choice, whereas no parent of a child with no reported ASN said they could not secure ELC from their provider of choice.
- 62% of children (PMLD & LL/ LT C) could not access their full entitlement to ELC this compared to 6% of children with no identified ASN.
- 59% of parents (PMLD & LL/ LT C) believed that the provision they did access did not meet their child's needs; this compares to no parent of a child with no identified ASN reporting that the provision secured did not meet their child's needs.
- 52% of parents (PMLD & LL/ LT C) that responded to the survey, described the process of securing ELC provision for their child as difficult or very difficult.
- 79% of parents (PMLD & LL/ LT C) reported that the process of identifying and securing an ELC provision for their child had a negative impact on their mental health and wellbeing and/or increased social isolation.
- Some parents had to use the Tribunal process to secure their place of choice, others were unable to secure their place of choice and accepted shorter hours in alternative provision, and some had to wait long periods for resources to be put in place.
- 59% of parents (PMLD & LL/ LT C) believed that the provision they did access did not meet their needs as parents; this compared to 4% of parents whose child had no identified ASN.
- 55% of parents (PMLD & LL/ LT C) reported having their child's ELC provision altered or withdrawn, with 34% of placements altered and 21% reporting their child's ELC provision was withdrawn due to an inability to meet their needs.
- 79% of parents (PMLD & LL/ LT C) who responded told us that the process of securing ELC provision for their child or the provision that was provided meant that they had to give up work; prevented them from working; or necessitated them reducing their working hours.

The Voice of Parents

"Being told the placement was ending in a meeting of 20 people was very difficult. I was on maternity leave with my second child, so I ended up with both all the time which was difficult and left me less time with my new baby. Fighting for a setting that was right for my son was exhausting."

"She started at 3; we were told we didn't qualify for a place at 2 years old. Private childcare options were not able to meet his needs due to lack of resource, so I had to leave my job."

"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 but very few do."

These findings are not isolated, new or unusual. In 2013 Growing Up in Scotland (GUS) found that “Parents of disabled children were more likely to say they were not using childcare because their child needed special care”.

The same report also found that at 10 months there was no significant difference between the proportion of disabled children and non-disabled children in the bottom quintile for equivalised household income. However, at age five disabled children were 40% more likely than non-disabled children to be living in households in the lowest income quintile. Highlighting the lived experience of parents that the impact is not only on the child but the parents and the wider family too.

The Voice of Parents

“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.”

“The council were utterly useless in identifying my son’s needs. There was not a single person who was responsible to make things happen. It required coordination of lots of different people with different agendas and timescales and at the centre of it all was my son missing out on learning and social interaction and my mental and physical health deteriorating.”

“They no longer have a nurse on site and my child is too complex to attend without.”

“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.”

5.4.2 Semi-structured Interviews with parents and carers of children with learning disability – Spring 2021

In spring 2021 the Scottish Commission for People with Learning Disabilities (published March 2022) carried out semi-structured interviews with parents and carers of children with learning disability. This qualitative study highlighted the main experiences and challenges faced by parents when trying to find suitable early learning and childcare provision to be:

- Difficulties finding information about support and entitlements in a complex system
- The challenge to get the right support in place
- Inequity of provision for children with learning disabilities
- The importance of good leadership and staff attitude in the setting
- Open, honest, equitable dialogue with parents
- The importance of well-trained staff
- Appropriately sized settings with the right staff ratios.

The SCLD report comment that:

"...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."

The Voice of Parents

"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."

"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."

"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."

5.5 Evidence from Provider Organisations

5.5.1 Online Survey February 2022

In February 2022, an online survey was carried out of ELC provider organisations to obtain views on their experience in delivering ELC for children with PMLD and a life-limiting or life-threatening condition. The survey obtained responses from providers in 8 of the 32 Scottish local authorities as follows:

- 87% of ELC providers described the experience of providing ELC to children with PMLD and a life-limiting or life-threatening condition as challenging.
- 50% of ELC providers reported that the increase in funding from 600 to 1140 hours per year had had a negative effect on their ability to support a child with PMLD and a life-limiting or life-threatening condition access their full entitlement
- 75% of providers said that specialist equipment, guidance and training for staff were the most significant enabling factors
- 25% identified staff capacity as a barrier to provision of full entitlement.

The Voice of Providers

"Nothing was put in place before they started due to lack of information from health."

"No support from local authority. Only support from NHS PT team."

"Requests have been put in for specialist support but still waiting . . ."

5.5.2 Survey of ELC for children with learning disability – Spring 2021¹⁸

Of the 37 nursery providers who responded, all had experience of providing care for a child with a learning disability within their service. 16 of the 37 (43%) said that they were not confident or were unsure about catering for a child with learning disability, 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.

The Voice of Providers

'You don't know what you don't know'

"Along with zero additional staffing we still do our best to get it right for that child. We may question if we have done it right at times and it can knock your confidence but we are trying our best."

"Partner providers are unable to apply for additional funding to accommodate children with complex needs therefore we cannot put adequate systems in place for them to attend."

5.6 Summary Section 5

There is no systematic data collection on children with PMLD with a life-limiting or life-threatening condition who are accessing their full or partial entitlement to ELC or those who are not accessing their entitlement and the reason why not. However, data from Scottish Government and The Coram, Children in Scotland all suggest that the proportion is significantly lower than that of the general population. Data from The Coram Group suggests this is partially a consequence of lack of sufficiency of childcare capacity in Local Authority areas for children with a disability.

The parental view of children with PMLD with a life-limiting or life-threatening condition is clear; they are often not able to access sustainable ELC, their child's full entitlement (or the amount they wish), from their provider of choice, when they want it and at a quality they feel comfortable with. When comparing their experience with those where the child has no recognised additional support need the information available suggests that there are significant inequalities in accessing full entitlement, choice of provider, consistency in provision, meeting the needs of the child and meeting the needs of the parent. This infers that there is a planning, capacity and skills gap for the provision of early learning and childcare for these children. This is perhaps not surprising as it is not possible to plan for and provide responsive appropriate services and support for a highly dispersed population whose needs may only be made aware to the local authority on registration for ELC. Further, for individual providers and many local authorities the skill set, equipment and governance framework to assess and provide high quality ELC for a child with PMLD with a life-limiting or life-threatening condition is not readily available.

¹⁸ Building Blocks: Exploring the barriers and facilitators to early learning and childcare provision for children with learning disabilities in Scotland – Scottish Commission for People with Learning Disabilities (March 2022)

5.7 Recommendations

- (vi) Scottish Government in partnership with Local Authorities, NHS Scotland, Education Scotland, Early Years Scotland and key organisations who provide services and support for children with PMLD should further research, identify and take action to address the barriers children and families experience in accessing their full entitlement to ELC, when they wish to, from their provider of choice, consistently and that fully meets their child's needs.
- (vii) Scottish Government in partnership with Local Authorities, Education Scotland, Early Years Scotland, National Day Nurseries Association and ELC provider should further research, identify and take action to address the barriers provider organisations experience in providing children with PMLD and a life-limiting or life-threatening condition their full entitlement to ELC consistently, when they are requested to, and that fully meets the child's needs.
- (viii) The Scottish Government should ensure that the parents of children with PMLD and those whose child has a life limiting or life threatening condition are offered a safe and reliable peer support opportunity across Scotland to facilitate shared learning and experience in accessing ELC for their child.

Section 6

Delivery Challenges in Supporting Children with Profound and Multiple Learning Disabilities and a Life-Limiting or Life-Threatening Conditions Access their full ELC entitlement.

6.1 Introduction

The evidence from analysis of the current environment highlights a number of concerns and challenges that must be addressed if the policy and legislative intent is to be realised:

- The intention of the legislation to make available 1140 hours as an inclusive offer, open to all 3- and 4-year-olds and some 2-year-olds is currently not being met.
- Despite a presumption of inclusive access and commitment to UNCRC and children's rights, we lack practical guidance on, examples of and professional learning in truly inclusive approaches, to support existing provision.
- Children with PMLD and a life-limiting or life-threatening condition commonly cannot access a place that meets their needs in their locality of choice.
- The perception of the sector is that specialist and additional resources are required to be able to offer these places and whilst to some extent this is true, improved availability of information and resources on integrated ELC alongside better professional understanding could influence the subtle culture shift required to transform the broad general approach and response to Inclusive ELC.
- Direct support in early years settings from health professionals such as AHPs and Community Children's Nurses offers learning opportunities for education staff and ancillary staff while ensuring the child with PMLD receives essential therapies.
- Confidence is low in the mainstream early years sector and professional knowledge has a wide range of gaps in relation to provision of ELC for children with complex needs.
- The reality that legislation behind the statutory offer focuses on children 3-5 and some eligible 2-year-olds, despite the knowledge that 75% and 90% of brain development happens by the age of 3 and 5 years, respectively. Whilst the intention to extend the offer to under 3s is welcomed, it is acknowledged that it will take time to achieve this even for children without additional needs. However, for families with a child with complex needs, this may be further off and not as easy to overcome.
- With confidence and knowledge levels as they stand, alongside availability of places, we are seeing the policy messaging conflict with the reality.
- Parents and families of children with PMLD and a life-limiting or life-threatening condition are much more likely to experience the challenges of poverty and poor wellbeing than other families and yet their access to the placements that could support this is lower.

These challenges tell us that doing more of the same is no longer an option. We must be more innovative in our approach, to make a positive difference, address the challenges with purpose and a collaboration of expertise.

- There is a need for increased numbers of places that are accessible to children with PMLD and a life-limiting or life-threatening condition and provide flexible and high quality early learning and childcare experiences alongside their peers.
- The real risk of further inequity of children with profound and multiple learning disabilities and a life-limiting or life-threatening condition.
- The reality that left as is, many of these children and families will not be able to exercise their right to 1140 hours ELC and what is a transformational policy becomes a catalyst to greater inequity.
- Covid has negatively impacted the attainment gap as outlined in the Closing The Poverty Attainment Gap Progress Report 2016-2021 and as such requires innovative and creative approaches for all children and families.
- Research by the Child Poverty Action Group, Family Fund CONTACT, and Kindred has indicated that the pandemic has had a disproportionate negative impact on families with children with complex needs, failure to be able to access their ELC entitlement is serving to continue this impact beyond the Pandemic. This included the loss of access to therapies that were best provided in the education setting.

6.2 Summary

There is no single solution to the challenges faced nationally, by the sector and most importantly by the children and families themselves. It requires a truly integrated approach.

The integration of the specialist, professional skills, knowledge and understanding of the needs, development and learning of children with profound and multiple learning disabilities; those who support children with life-limiting and life-threatening conditions; and the professional expertise of early years practitioners could create a team with the ideal combination of leadership and operational experience to address some of the emerging challenges for the sector. The low volume, high complexity, varied nature of challenges and the high level of dispersal of these children in Scotland mean that the development of one or more centres of excellence will not in itself make a significant impact on addressing the challenges in an equitable way, what is required is access to expertise no matter where a child lives or learns. A package of national resources is required that can promote equality, children's rights, the rights of disabled people, through the provision of accessible, sustainable, efficient, effective, timely and high quality ELC for children with PMLD and a life-limiting or life-threatening condition. The Covid 19 pandemic has highlighted the potential for incorporating remote access to specialist healthcare expertise that may offer new opportunities to support the early years providers in any part of Scotland.



6.3 Recommendations

- (ix) Scottish Government should consider supporting the development of national resources to promote the inclusion of children with PMLD and a life-limiting or life-threatening condition in ELC settings these could include a national hub, best practice exemplars and a national network that will:
- share practice
 - provide access to practical support for contextual holistic assessment for ELC placement planning
 - improve and develop practice
 - develop and share environmental appraisal, risk assessments, policies, procedures and protocols
 - be a resource to trial and inform practice integration of new technologies
 - be a resource to provide ELC contextual advice for providers throughout Scotland
 - be proactive in developing practitioner collaboration, capacity, competence, capability, creativity, and confidence.
 - provide equity of indemnity across public, private and not for profit ELC providers.

Section 7

Final Words: Realising the Ambition and Delivering on the Legislative and Policy Framework

7.1 The Challenge and the Opportunity

To realise our collective ambition for Scotland to support each and every child to achieve their full potential, we must deliver on our comprehensive legislative and policy framework for children. It is not good enough to deliver for most of the children most of the time when often it is the same children who are not enabled to access their entitlements. Children with profound and multiple disabilities with a life-limiting or life-threatening condition have a very low prevalence in ELC and to attend a “mainstream” provision usually require a package of new skills, higher staffing ratio, specialist equipment, new policies, procedures or protocols. Often, due to a lack of anticipatory planning, these children are not able to access their full entitlement to ELC from their provider of choice, when they want it, and at a quality that is acceptable and reliably without significant disruption. The low prevalence in each local authority making it impossible for most local authorities to maintain the wide range of skills necessary so that they are accessible when required. At times it could be viewed that a number of these children’s rights are being breached along with their rights as disabled people and at times we are failing to fulfil our statutory duties in terms of the ELC legislation (CYP Act 2014), Equality Act, Human Rights Act, ASL Act, Children (Scotland) Act, Education (Scotland) Act and potentially other statutory entitlement, responsibilities or duties (see Section 2).

This is a national challenge and requires a comprehensive national response to ensure that all children realise their human, equality, children’s and education rights. We must plan for success if we are going to meet the needs of children, parents and practitioners in relation to children with complex needs in the early years to give them the best chance of achieving their potential. The following is a suggested positive vision for the future and hence also a self-evaluation framework.

7.1.1 Policy and Infrastructure

- Early years policy *and* practice align and generate information, resource and outstanding examples of fully inclusive ELC, that is ahead of practice in any other country and acknowledged internationally.
- A sustainable national resource that will support robust, inclusive practice development and can demonstrate impactful and innovative models and strategies for inclusive early years practise for all children no matter where they live or learn.
- Research and evaluation of early years practice with all children provides a robust framework to inform future policy and practice development.
- Reduced medium to longer term impact on statutory services as a result of robust, focused early intervention, including sustained intensive intervention where this will improve long term outcomes.
- A robust early years sector, confident in providing inclusive early years learning and childcare for all children, supported by partner agencies where they collaboratively promote the achievement of highest level of wellbeing for each child.

- A reliable national database of prevalence of childhood disabilities with consistent definition and analysis of the data to support planning and resourcing of the services from all agencies

7.1.2 Children and Families

- Children with profound and multiple learning disabilities (PMLD) with a life-limiting or life-threatening condition can access their ELC entitlement, alongside their peers and siblings in their own communities.
- Broader access to specialist skill sets for all children giving the potential to contribute to closing the attainment gap. (e.g., access to speech and language therapists with advanced technical knowledge about language and communication development that can develop the competencies, capabilities and confidence of ELC practitioners to the benefit to all children they encounter).
- Children without PMLD have stronger early years experiences, improved language and communication skills and improved medium to longer term outcomes.
- Improved knowledge and understanding of diversity the benefits that it can bring to all children.
- Increased engagement with children with a wider spectrum of abilities.
- Families of children with PMLD/ complex health needs/ life-limiting or life-threatening conditions, can access the same benefits of ELC as other families.
- Families of children with PMLD/ complex health needs/ life-limiting or life-threatening conditions may lessen some of the additional financial burden they experience reducing economic disadvantage and providing increased opportunity to fully engage with work.
- Families of children with PMLD/ complex health needs/ life-limiting or life-threatening conditions have reduced medium to longer term challenges to face as a result of a strong early years' experience.
- Families of children with PMLD/ complex health needs/ life-limiting or life-threatening conditions have reduced stress.

7.1.3 Early Years Sector

- Practitioners are confident in providing fully inclusive early years experiences for *all* children including those with profound and multiple learning disabilities (PMLD) whose needs are exacerbated through complex health needs, life-limiting or life-threatening conditions.
- Practitioners have access to models and resources that can support this.
- Practitioners can access specialist advice and guidance to support person centred holistic planning for children with PMLD/ complex health needs/ life-limiting or life-threatening conditions as they progress through ELC, their needs change and at transitions.
- Common resources, consistent advice and guidance are available and accessible throughout Scotland.
- Develop leading practice locally and share nationally and internationally, having pride in and celebrating success.

7.2 Impact

7.2.1 Impact on Scottish Government Policy Delivery

The model of national inclusive ELC for children with PMLD and a life-limiting or life-threatening condition being articulated through this paper will contribute significantly to the following Scottish Government policy and legislative commitments:

- **Early Years Expansion**, in particular providing access to entitlement for children with profound and multiple learning disabilities, particularly those with complex health needs with a life-limiting or life-threatening conditions.
- **Inclusive education (The Right Help at the Right Time in the Right Place)** – providing a safe equitable and sustainable model of inclusive ELC that will support equitable offer of ELC in local communities.
- **Delivery of Getting It Right For Every Child** policy into practice.
- **Child poverty** – The Tackling Child Poverty Delivery Plan: Third Year Progress Report (2021) reported that the relative poverty rate for children in households with a disabled child was 27%, compared to 24% for all children. However, if disability benefits are excluded, as these are provided to mitigate against impact of the disability, then the relative poverty rate for these families jumps to 31%. Families of children with PMLD and life-limiting or life-threatening conditions are finding it significantly more difficult to access their child’s entitlement to appropriate ELC in a sustainable way where, when and for how long they wish; hence they are being further disadvantaged by being restricted in their capacity to secure and maintain work, further training or education, potentially trapping them and their family in poverty.
- **UNCRC Incorporation** – As Scotland works to enshrine the UNCRC into law, there are crucial rights that must be considered in ensuring children with disabilities can access their entitlement to ELC including; Article 2 – Non-discrimination; Article 3 – Best interests of the child; Article 6 – life survival and development; Article 12 – Respecting the views of the child; Article 15 – Freedom of association; Article 18 – Providing parents with assistance in the development of their child; Article 23 – rights of children with a disability; Article 24 – Providing the best possible healthcare; Articles 28 and 29 right to education and goals of education.
- **Equality Act 2010**; This ELC provision will promote equality of opportunity for all, giving every individual the chance to achieve their potential, free from prejudice and discrimination. – addressing structural inequalities and discrimination and unintended institutional discrimination.
- **Policy development**; Qualitative and quantitative data collection built into the modelling in relation to access, equality, user experience, outcomes, resource implications and sustainability will provide a growing information source to inform policy and practice development.
- **Evidencing Scotland as the best place to grow up**; Initial research at national and European level including through the European agency has indicated that such progress would place Scotland at the forefront of inclusive ELC practice, contributing to Scotland’s vision of being the best place to grow up, for all.
- **Internationally relevant research**; A national practice development, service delivery and research resource focused on developing best practice for inclusive ELC for children with PMLD will have on-going international relevance.

7.2.2 Impact on Children and Families

More children with profound and multiple learning disabilities with a life-limiting or life-threatening condition will:

- be able to access their entitlement and right to ELC alongside their peers and siblings in their local community.
- be included in their local community through the knock-on effect from local friendships and accessing local resources.
- have the opportunity to improve their life chances from an earlier stage.
- experience a smoother and more informed transition to primary school.
- have the potential to achieve higher degrees of independence and quality of life moving forward.

More families of children with profound and multiple learning disabilities with a life-limiting or life-threatening condition will:

- have improved opportunities to engage with education, training and employment.
- have reduced family stress.
- have the opportunity to experience a more balanced experience as a parent compared to fulfilling the role of carer/advocate.
- have improved family experience as siblings will be able to enjoy protected time with parents while their disabled sibling enjoys the experience of high quality ELC.
- have the opportunity to access contextual expertise that is specifically targeted on inclusive ELC for their child.
- be able to access a network of parents and children in similar circumstances across Scotland.
- Will have increased confidence in local services that are supported by national expertise.
- will at the earliest stage be supported to engage with professionals constructively in the best interests of their child easing the pressures on the family and transition experiences.
- will be supported to have confidence in participating in the Realistic Medicine approach to Patient partnership with health professionals.

Children with mild, moderate and complex learning disability and/ or children with severe or complex health needs will:

- through the learning gained in developing a sustainable model to provide high quality, accessible and inclusive ELC for children with profound and multiple learning disabilities with a life-limiting or life-threatening condition it should be possible to use this as a template for the improvement of ELC provision for children with mild, moderate and complex learning disability and/ or children with severe or complex health needs.
- through the development gained by practitioners including in anticipatory planning, assessment, improved systems, processes and procedures for inclusion, development of knowledge, skills and experience will have added value for children with mild, moderate and complex learning disability and/or children with severe or complex health needs who are accessing ELC.

Families of Children with mild, moderate and complex learning disability and/or children with complex health needs will through the learning and development gained:

- will experience improved anticipatory planning, reduced delays in accessing services and more sustainable service provision.
- have less risk of an impact on their opportunities to engage with education, training and employment.
- have less requirement to directly support practitioners in their child's ELC provision.
- will have increased confidence in local services that are supported by area wide, regional and national expertise.
- have reduced family stress including stress on siblings.

Children in general will:

- have access to high quality ELC and all its benefits with staff teams who are trained to a higher level.
- experience enhanced opportunities to develop high levels of communication and all the attributes that brings with it.
- through the experience, gain the benefits of inclusive diversity from an early age.
- have an ELC experience strengthened by the expertise of an integrated multi-agency approach.

Families in general will

- experience all the benefits of accessing high quality ELC that underpins the policy commitment.
- have an improved understanding of diversity and benefit from the experience of an inclusive ELC setting in their local community.
- benefit from enhanced knowledge and understanding of practitioners supporting children in an inclusive setting including potential access to relevant specialist advice as part of the integrated approach.

7.2.3 Impact on Local Authorities

Local communities will:

- have more resilient, inclusive, diverse and tolerant communities.
- have more families engaged in core services.
- have more families who feel empowered to influence their future and give their family the best possible start.
- experience reduced pressures on support services through increased employment and learning of parents.
- see increased numbers of economically active families.

Local authorities will benefit from:

- reduced demand for specialist ELC provision and transport to distant ELC sites when local services are empowered to provide for every young child's needs in their own community.
- reduced financial pressures on services and waiting lists.
- more inclusive education experiences.
- delivering statutory commitments in ELC to a wider range of families through existing resources.
- less tribunals and complaints from families who believe their child's rights are being denied.

- realising the longer-term benefits to children potentially requiring less statutory support in the future through inclusive community support.

Schools will benefit from:

- a more informed and prepared transition of children into primary and secondary school, especially for children with PMLD.
- established multi agency relationships and communication channels particularly for children with complex additional support needs, freeing up significant amounts of teaching and administrative time to focus on the child and family.
- increased capability and confidence in working with children and young people with PMLD who have complex health needs that are potentially life-threatening or life-limiting.

7.3 Summary

The evidence is that Scotland is currently failing to consistently provide the families of children with PMLD and a life-limiting or life-threatening condition with equality in terms of access to their full entitlement to ELC from their provider of choice, when they want it, and at a quality that is acceptable and reliably without significant disruption. At times it could be viewed that a number of these children's rights are being breached along with their rights as disabled people and at times we are failing to fulfil our statutory duties in a number of areas. Addressing these challenges requires a national response and the development of sustainable national resources that can be equitably accessed by any provider to enable children and families of children PMLD and a life-limiting or life-threatening condition to have the same opportunities no matter where they live. This would support the delivery of a wide range of Scottish Government policy and legislative commitments. Equally this approach would see benefits for local authorities, communities and the children and families who will learn alongside children with PMLD and a life-limiting or life-threatening condition.

7.4 Recommendations

- (x) Scottish Government should consider holding a roundtable discussion on the points raised by this paper with aim of developing working group and an action plan to address challenges raised and exploit the opportunities outlined.

Scottish Legislative, Policy and National Guidance Framework

Scottish Government have demonstrated through statute, policy and resourcing a strong commitment to a Scotland in which all children and young people can realise their potential, regardless of where they live and learn, their social background or their learning needs, empowering them to flourish in life, learning and work. The statutory and policy framework in relation to preschool children affected by disability is extensive. Figure 1 highlights key legislation, policy and national guidance that impacts on pre-school children affected by complex additional support needs (ASN) including those with profound and multiple disabilities with life-limiting and/or life-threatening conditions.

Figure 1 : Key Legislation, Policy and National Guidance Impacting on Pre-school Children Affected by Complex Additional Support Needs (ASN)

Key Legislation Impacting on Pre-school Children Affected by Complex ASN

- National Health Service (Scotland) Act 1978
- Education Act (1980)
- Children (Scotland) Act 1995
- Human Rights Act (1998)
- Standards in Scotland's Schools etc. Act 2000
- Education (Additional Support for Learning) (Scotland) Act 2004 as amended
- Equality Act (2010) and associated regulations
- Children and Young People (Scotland) Act 2014
- Education (Scotland) Act 2016
- United Nations Convention on the Rights of the Child (Incorporation) (Scotland) [not yet given Royal Assent]

Key Policy and Guidance Impacting on Pre-school Children Affected by Complex ASN

- Planning Improvements for Disabled Pupils' Access to Education - Guidance for Education Authorities, Independent and Grant Aided Schools (2014)
 - Guidance on education for children and young people unable to attend school due to ill health (2015)
 - Delivering Excellence and Equity in Scottish Education: A Delivery Plan for Scotland (2016)
 - The right help at the right time in the right place: Scotland's Ten Year Strategy for the Learning provision for Children and Young People with Complex Additional Support Needs 2017 -2026 (2017)
 - Additional Support for Learning: Statutory Guidance on the Education (Additional Support for Learning) Scotland Act 2004 (3rd edition 2017)
 - Supporting children and young people with healthcare needs in schools Guidance for NHS boards, education authorities and schools (2017)
 - National Improvement Framework (2019)
 - Guidance on the presumption to provide education in a mainstream setting (2019)
 - Support for Learning: All our children and All their Potential (2020)
 - Realising the ambition: Being Me, National practice guidance for early years in Scotland (2020)
 - Early Learning and Childcare Statutory Guidance (2021)
 - Putting Learners at the Centre: Towards a Future Vision for Scottish Education (2022)
- Getting it right for every child policy (GIRFEC) (2022)

Equality Act (2010) - Right to equal opportunity for preschool children with PMLD

The Equality Act (2010) recognises that a person can be disabled at any age and it is the effect of the impairment on the individual that should be considered. The effects of impairments may not be apparent in babies and young children because they are too young to have developed the ability to carry out activities that are normal for older children and adults. However, Regulations provide that an impairment to a child under six years old is to be treated as having a substantial and long-term adverse effect on the ability of that child to carry out normal day-to-day activities where it would normally have a substantial and long-term adverse effect on the ability of a person aged six years or over to carry out normal day-to-day activities. Hence pre-school children with profound and multiple disabilities are deemed to be disabled under the Equality Act. This then gives them legal rights against discrimination, hence pre-school children with PMLD should have equal opportunities as to their peers who are not disabled. To avoid substantial disadvantage in accessing early learning and childcare there is a duty to make reasonable adjustments for disabled children in the provision of services. Fulfilling this duty is not only an education authority responsibility but also a Scottish Government responsibility to ensure that their statutory framework is able to be delivered equitably.

Children (Scotland) Act 1995- Duty to promote the welfare of preschool children with PMLD

In addition to duties under the Equality Act, Section 93 (4) (a) of the Children (Scotland) Act 1995 makes it clear that a disabled child is a “child in need”. This means that under this Act (sec 22) a Local Authority has a duty to promote the welfare of preschool children with PMLD within their area by providing a range and level of services appropriate to the children’s needs. In doing so they have a duty to provide services that are designed to minimise the effect the disabling impairment on the child and their family, and services should be designed to give those children the opportunity to lead lives which are as normal as possible (sec 23). In promoting the welfare of disabled preschool children, a Local Authority has a duty to do this in a way that safeguards, promotes and supports their wellbeing and in assessing wellbeing they must do so by referencing the extent to which the child is safe, healthy, achieving, nurtured, active, respected, responsible and included (sec 23 A).

Education (Scotland) Act 1980, CYPA (Scotland) Act 2014, Equality Act 2010 & Human Rights Act 1998

Rights of preschool children with PMLD to Education & ELC

Education (Scotland) Act 1980

Section 1 of the Education Act 1980 places a duty on local authorities to secure provision of school education, including early learning and childcare, in their area.

Children and Young People (Scotland) Act 2014

Part 6 of the Children and Young People (Scotland) Act 2014 places a duty on local authorities to secure 1140 hours of funded ELC for eligible children in their area. Eligible children are:

- Under school age but 3 years or older
- Is two years or older:
 - is looked after, care experienced or in kinship care
 - their parent is receiving a wide range of benefits but does not include Disability Living Allowance (DLA) or Personal Independence Payment (PIP)

Equality Act 2010

The Equality Act 2010, says that disabled persons must not be discriminated against and reasonable adjustments must be made for them to access service, this includes access to ELC.

Human Rights Act 1998

Human Rights Act 1998 provides a right to education, stating that “no person shall be denied the right to education”. The 1998 Act also makes it clear that it is unlawful for a public authority to act in a way which is incompatible with this right.

Education (Scotland) Act 1980

Discretionary powers for Education Authorities (Local Authorities) to provide early learning and childcare for disabled children

Under section 1 of the Education (Scotland) Act 1980, education authorities are empowered to provide discretionary early learning and childcare, over and above the statutory entitlement. This power could be utilised to support provision to disabled children in need. Supporting Local Authorities to fulfil their duties under section 22, 23 and 23 A of the Children (Scotland) Act 1995

Standards in Scotland’s Schools etc. Act 2000

Presumption to provide education in a mainstream setting (Guidance 2019)

The presumption of mainstreaming (which came into force in 2003) enshrines the right of all children and young people with additional support needs to learn in mainstream early learning and childcare settings of their parents choice. The 2019 updated guidance, sets out its key expectations as:

- All children and young people should learn in environments which best meet their needs
- All children and young people should be fully engaged in the life of their school [ELC Provision], through the inclusive ethos, culture and values of the school [ELC Provision]
- All children and young people should receive a full time education including flexible approaches to meet their needs

The legislation states that it only be in exceptional circumstances that provision further states that it shall be presumed that those circumstances arise only exceptionally. The key principle is that the decision that is reached, regardless of whether that decision is for placement in a mainstream, special school or for the use of flexible provision, must be about meeting the child’s needs, with a continued focus on reaching that individual’s full potential.

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) Non-discrimination, Equality of opportunity, Accessibility, Participation & Inclusion

The UK has been a party to the Convention since 2009. This means the Scottish Government has a responsibility to promote, protect and ensure the human rights of disabled people. Although the Convention does not form part of Scotland's domestic law directly, it can be used to help interpret the rights that are contained in the Human Rights Act 1998. The general principles of the convention include:

- Non-discrimination
- Equality of opportunity;
- Accessibility;
- Full and effective participation and inclusion in society;
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; and
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Article 7 refers to the rights of Children with Disabilities directly and states that parties to the convention shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children. And that in all actions concerning children with disabilities, the best interests of the child shall be a primary consideration. Further Article 24 states that parties must recognise the right of persons with disabilities to education. With a view to realising this right without discrimination and on the basis of equal opportunity and that they must ensure an inclusive education system at all levels.

United Nations Convention on the Rights of the Child (UNCRC) (Incorporation) (Scotland) Bill

The Scottish Government on 24th May 2022 restated its intention to amend and commence the UNCRC Bill. The Deputy First Minister made it clear that as far as is within the Scottish Government's power they will legislate to make it unlawful for a public authority to act in a way which is incompatible with the UNCRC requirements and also require them to take proactive steps to ensure the protection of children's rights in their service delivery.

He also made it clear that children, young people and their representatives would have a new ability to use the courts to enforce their rights.

In terms of supporting equitable access to ELC for children with PMLD and life-threatening and/or life-limiting conditions Local Authorities, Health Boards and Scottish Government may wish to consider if they are being proactive in ensuring that the following children's rights are being met:

- Article 2 - Non-discrimination of a child due to their disability;
- Article 3 – They are acting in the best interest of the child;
- Article 6 – Maximizing the development of the child;

- Article 12 - Respecting the views of the child;
- Article 15 – Providing a model of access to ELC that promotes freedom of association;
- Article 18 – Taking all appropriate measures to ensure that children of working parents have the right to benefit from child-care services for which they are eligible;
- Article 18 - Providing appropriate assistance to parents to support them in the development of their child;
- Article 23 - Doing all they can to support disabled children and their families by designing services to ensure that the disabled child:
 - has effective access to and receives education;
 - is provided with the specialist care necessary;
 - is socially integrated; and
 - has their individual development needs considered.
- Article 24 – Providing the best possible health care so a child can stay healthy;
- Article 28 – Supporting each child to have equal access to education; and
- Article 29 – Providing education that develops each child’s personality, talents and abilities to the full
- Article 31 – The right to play and relax.

Education (Additional Support for Learning) (Scotland) Act 2004

Early years: Provision of Additional Support

The Act places a duty on an education authority to make appropriate arrangements for identifying “eligible” pre-school children who may have additional support needs and for providing the additional support required. For children under 3 years there is a duty to assess the needs and provide additional support to disabled pre-school children in their area when they are brought to their attention and additional support needs are identified. That support is not confined to educational support but could include support from health, social work or voluntary agencies. Health Boards and other Local Authority Departments and other Local Authorities have a statutory duty under the Act to help a education authority deliver on their duties.

Parents of preschool children with additional support needs are able to ask for their child to attend ELC provision at:

- an ELC provision delivered by their home Local Authority;
- an ELC provision where the home education authority have an arrangement with a private provider, normally referred to as a partnership nursery, in that home or host education authority area;
- an independent or grant-aided special school, the managers of which are willing to accept the child; and
- a school in England, Wales or Northern Ireland providing wholly or mainly for children people with additional support needs, the managers of which are willing to accept the child.

Similar to the rights of disabled school age children with additional support needs, parents have a right to appeal an Education Authorities decision to refuse a placing request and refer this decision to the Additional Support Needs Tribunal.

[From ASL Code of Practice Chapter 3 & 4]

Right help at the right time in the right place

The “Right help at the right time in the right place” is Scotland’s ten-year strategy for the learning provision for children and young people with complex additional support needs. This strategy’s aim is to improve outcomes for children (3- 18 years), with complex additional support needs through strategic commissioning of services; with a particular focus on education services. It recognises that the funded ELC of 1140 hours for all children and for eligible two-year-olds has the potential to transform outcomes for children with complex needs in the early years. It proposes that services could be nationally commissioned to support:

- direct education, care and health services;
- research to provide evidence that will support national policy development and service provision;
- sustainable mechanisms to deliver learning, development and sharing of practice;
- broader services to support the education of children including those provided across authority areas, provided by local authorities or by voluntary organisations which may constitute a national need.

All our Children and All their Potential

The remit of the additional support for learning in schools review commissioned in 2019 included as part of its remit “*to consider the implementation of the Additional Support for Learning legislation and specifically how additional support for learning works in practice across early learning and childcare centres,*”. However there is almost no reference to the ELC setting in the final report nor the recommendations. This is despite early years being widely recognised, due to the high level of neuroplasticity in preschool children, as a period when early and intensive intervention can change/ create alternative neurodevelopmental pathways that can have a lasting if not life long positive impact.

Strategic Commissioning Group (NSCG) working description of children and young people with complex additional support needs

1. Those in receipt of a Co-ordinated Support Plan as defined in the Education (Additional Support for Learning) (Scotland) Act 2009, i.e. where: -
 - a. an education authority are responsible for the school education of the child or young person,
 - b. the child or young person has additional support needs arising from-
 - I. one or more complex factors, or
 - II. multiple factors,
 - c. those needs are likely to continue for more than a year, and
 - d. those needs require significant additional support to be provided-
 - I. by the education authority in the exercise of any of their other functions as well as in the exercise of their functions relating to education, or
 - II. by one or more appropriate agencies (within the meaning of section 23(2)) as well as by the education authority themselves.
2. Children and young people aged 3-18 who do not have a co-ordinated support plan but who have been assessed as stage 3 or 4 by a local authority under a staged intervention model as recommended by the Supporting Children's Learning Code of Practice.
3. Children and young people aged 3-18 who attend a grant aided or independent special school

Disorders/ Conditions and Features that may be indicative of Children who have PMLD with associated life-limiting or life-threatening conditions

Disorders/ Conditions (Some are primary conditions others commonly associated comorbidities)	Challenges
<p>Genetic: Ehlers-Danlos syndromes, Rett syndrome, SWAN (Syndromes without a name), Fragile X, Cri-duchat, Rubinstein-Taybi Syndrome, Patau Syndrome (Trisomy 13), Edwards's Syndrome (Trisomy 18)</p> <p>Metabolic: mitochondrial disorders, Congenital disorders of glycosylation, fatty acid disorders, lysosomal storage disease,</p> <p>Neurological e.g. Cerebral palsy, complex epilepsy, seizures, anencephaly, encephalocele, microcephaly, arhinencephaly/ holoprosencephaly, brain injury,</p> <p>Neuromuscular disorders e.g. muscular dystrophy, myotonic dystrophy, spinal muscular atrophy, peripheral neuropathies, Krabbe disease</p> <p>Sensory e.g. Anophthalmos / microphthalmos, severely sight impaired, severe hearing impairment</p> <p>Circulatory e.g. Congenital heart defects,</p> <p>Respiratory e.g. congenital and acquired lung and respiratory tract defects</p> <p>Digestive system e.g. oesophageal atresia, duodenal atresia</p> <p>Urinary e.g. renal agenesis including Potter syndrome, bladder exstrophy and / or epispadia</p>	<p>Unstable or deteriorating complex health conditions</p> <p>Children with considerable impairment of:</p> <ul style="list-style-type: none"> • development and learning • communication • motor skills/ movement • hearing • vision <p>Use of a ventilator to support breathing</p> <p>Enteral feeding - nutrition is administered through a feeding tube placed into the stomach or intestines.</p> <p>Parenteral feeding - nutrition is administered through a drip directly into a vein</p> <p>Frequent and or life-threatening seizures/ Seizure management plans</p> <p>Respiratory compromised or risk of respiratory arrest/ Respiratory management plans</p> <p>Risk of sudden death or collapse/ Resuscitation plans</p> <p>Complex pharmaceutical support/ Complex drug regimens</p> <p>Significantly restricted movement/ – requirement for postural management plan and or pressure sore prevention plan</p> <p>Frequent hospital admissions, surgery, post operative therapeutic support/ proactive planning to minimise/ mitigate interrupted learning including provision/ support for blended learning.</p>

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