

Position Statement

The Rights of Children and Young People with Health Conditions to School Age Education and Healthcare in School

Children's Health Scotland is the leading Scottish children's health charity. We promote the healthcare rights of all children and young people across Scotland and are committed to ensuring that the best possible healthcare is provided for all children and young people to improve their life experiences; in particular, when they experience physical or mental health challenges, or are affected by long-term health conditions.

In promoting links and collaboration between the various primary and specialist health services and the wide spectrum of educational provisions and personnel, Children's Health Scotland makes a valuable contribution to children and young people's holistic care and development. Their work is underpinned by the European Association for Children in Hospital (EACH Charter), which states the rights of children and young people in health care services, and their corresponding rights in the United Nations Convention on the Rights of the Child (UNCRC).

LEGISLATIVE CONTEXT

Children and young people who are experiencing challenges surrounding their health and wellbeing continue to have the same educational rights given to all children and young people to '*adequate and efficient*' educational provision that is '*directed towards the development of the personality, talents and mental and physical abilities of the child or young person to their fullest potential*' (**The Education (Scotland) Act 1980; Standards in Scotland's Schools Act 2000; and The Education (Scotland) Act 2016**). The Standards in Scotland's Schools Act 2000 states that for children with prolonged ill-health, for whom the pupil is unable, or it would be unreasonable to expect the child to attend an educational establishment, special arrangements must be made for the pupil to receive education elsewhere, such as in the home, or at hospital.

The Equality Act 2010 defines a disability as a '*physical or mental impairment which has a substantial and long-term adverse effect on your ability to carry out normal day-to-day activities*.' This may include walking, getting dressed, using public transport, being able to concentrate or understand, or being able to form social relationships. Further stating, '*whether or not a person has a disability is to be regarded as an aspect of that person's health*.' This therefore recognises that adults and children who have, or have had, health conditions may also legally be considered disabled.

The Additional Support for Learning (Scotland) Act 2004 states that ‘A child or young person has additional support needs for the purposes of this Act where, for whatever reason, the child or young person is, or is likely to be, unable without the provision of additional support to benefit from school education provided.’ Further referencing ‘provision’ as ‘additional to, or otherwise different from, the educational provision made generally for children... in schools... under the management of the education authority for the area to which the child or young person belongs’. Thus, highlighting that some children and young people may require additional educational support that is classified as different from the ‘norm’. This may include protective measures put in place, whether that be in the school, home, hospital, or other educational establishments.

The Children and Young People (Scotland) Act 2014, begins by discussing the duty of the Scottish Parliament to make provisions for the rights of children and young people, following the rights and obligations set out in the **United Nations Convention on the Rights of the Child (UNCRC)**. The 2014 Act additionally supported the **Getting It Right For Every Child (GIRFEC)** approach to improve children and young people’s health and wellbeing, by believing that that everyone involved in a child’s life must work together in the best interests of the child. In March 2021, the Scottish Parliament unanimously passed the **United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Bill 2021** with aim to incorporate the UNCRC into Scots law. These steps taken further strengthen a child or young person’s rights, specifically surrounding their health and wellbeing, in relation to educational provision and practices within an educational establishment best suited to their needs at the time.

WHY IS ACCESSING THESE RIGHTS IMPORTANT?

- Receiving full access to educational entitlements, including healthcare in school and additional support for learning if needed, enhances children and young people’s ability to benefit from their education and to improve their educational attainment.
- It assists children and young people to fulfil their potential, gain qualifications, and therefore improve their future life prospects.
- It allows children and young people to learn and socialise with friends in schools, or to maintain contact through other support streams whilst in hospital, or other educational establishments, separate from their friends. This can reduce isolation and offer normality in what may be a stressful or traumatic time; and therefore, have a positive impact on their mental health and wellbeing.
- Participation in the holistic and individually focussed approaches of Scotland’s **Curriculum for Excellence** enhances children and young people’s resilience and capacity to self-manage their lives, including aspects surrounding their health.

Holistic and knowledgeable approaches are particularly important, since many children and young people may experience both physical and mental health conditions, with one sometimes impacting upon the other. It is not uncommon, for instance, for children and young people who have had extended absence because of poor physical health, or who have experienced traumatic illnesses or injuries, to present with symptoms of anxiety and depression. They may experience difficulty attending school regularly, or at all. Some may become recognised as ‘school refusers’ or ‘poor attenders’. They may underachieve significantly in their educational outcomes, fall behind or as a last resort, drop out of education. A further issue is that disabled children with additional support needs have a higher risk of poor physical and mental health; this risk further increases for children and young people with complex disabilities.

Children’s Health Scotland actively engages with The Scottish Government, and a range of agencies such as Enquire, the National Scottish Advice Service for Additional Support for Learning, to advocate for the rights of children and young people with health conditions. Children’s Health Scotland has helped to develop Scottish Government guidance on **‘Guidance on education for children and young people unable to attend school due to ill health’** and **‘Supporting children and young people with healthcare needs in schools: Draft guidance for NHS boards, education authorities and schools’**. As well as Enquire publications such as, **‘Supporting Children and Young People with Healthcare Needs’**.

THE GAP BETWEEN LEGISLATION AND GUIDANCE, AND ACTUAL PRACTICE IN THE FIELD

Findings from families, and health and education professionals recommend a multidisciplinary approach between families and health and education professionals to ensure that children and young people receive the necessary support required; this is highly important when waiting for assessment and diagnoses. During this time, the impact of health on education is often underestimated, and limited knowledge on the family’s situation may result in miscommunication and often unnecessary strain on already struggling families. The child, therefore, may not be receiving educational provision that equates with their statutory rights, in terms of quantity or quality, despite legislation and guidance defining and raising the awareness of their rights.

Some children and young people may experience periods in which they receive no education, whilst others have had to be withdrawn by their parents or carers because appropriate healthcare had not been made available in their educational establishment. This is illustrated in an Additional Support Needs Tribunal (Scotland) case, in which a young child with Type 1 diabetes was reported by his mother as not being adequately supported in the administration of insulin in school, after the teacher refused to continue the administration. The correct and timeous administration of insulin was necessary not only for his health and safety but also for his education and socialisation with his friends. The child was unable to attend school from December 2012 – March 2013. The Tribunal said that the Council had unlawfully discriminated for the period of the child’s absence from school.

THE KEY BARRIERS TO CHILDREN AND YOUNG PEOPLE WITH HEALTH CONDITIONS ACCESSING THEIR FULL EDUCATIONAL RIGHTS

- The COVID-19 pandemic has caused enormous educational disruption to children and young people across Scotland. We know that during the pandemic education was not equally accessible, with digital exclusion and exam cancellation, which disproportionately affected groups of children and young people. The pandemic also led to a significant reduction in hospital services, where some children and young people may receive their education; this means that at an extreme view, their rights may have been compromised. Reports by the Scottish Parliament show that the demand for specialist services will increase as the longer-term impacts of the pandemic emerge, and is likely to remain a prominent issue in Scotland for the foreseeable future.
- Research emerging regarding the Cost-of-Living Crisis show that families with higher energy needs, such as larger families, or households where someone is disabled or has a long-term health condition are being severely impacted. It cannot be disputed the damage this crisis will have on children and young people's physical and mental health, and the damage this consequently will have on their education in both the short-term and long-term. It is well known that children and families living in poverty suffer greater health and social inequalities, as well as larger negative impacts on educational outcomes and attainment. In the recent **Tackling Health Inequalities in Scotland Report 2022** it states that *"about 75,000 children went without food on a day during the past year."*
- The above report, further highlights the difficulty in lack of accessible nursery and childcare for those caring for disabled children, arguing that this has effectively excluded the families from accessing free childcare provision provided by the Scottish Government.
- The legislation and guidance cited are lengthy and complex documents. While Enquire produces succinct and lucid summaries of these documents, a full understanding of children and young people's rights can only be grasped from perusal of the documents themselves, which takes a considerable amount of time and resource.
- It is of our opinion and expertise, and from speaking with the families that we work with, that some Education Authority Officers, and school staff (whether of local authority or independent) appear to have insufficient awareness of the educational rights of their pupils with health conditions, of the laws underpinning those rights, of Scottish Government guidance, or of their own responsibility to deliver and facilitate individually appropriate educational provision and healthcare in, or out, of school. An example of this is **The European Association for Children in Hospital (EACH Charter)** with Article 7 stating *'Children shall have full opportunity for play, recreation and education suited to their age and condition and shall be in an environment designed, furnished, staffed and equipped to meet their needs.'*

- This insufficiency extends to many parents, carers, children, and young people themselves, who may not know what to ask of the Education Authority and school. Equally, other families with greater awareness may, understandably, be too preoccupied with their children and young people's health and wellbeing to enter a lengthy struggle for their educational rights.
- The concepts of 'ill health', 'long-term', or 'chronic conditions' are rarely mentioned in important educational documentation; with many documents in desperate need of an inclusive update to correlate guidance for the current crisis. The **Supporting Children's Learning: Draft Code of Practice (3rd Edition) 2017**, **Technical Guidance to Schools in Scotland 2014** (in relation to the Equality Act 2010), and **Initial Teacher Education Content Analysis (2017)**, make little reference to additional support needs and/ or disability. The Initial Teacher Education document highlights that during some PGDE Secondary Programmes, some spent as little as 13 contact hours dedicating teaching time to health and wellbeing. With the endless Scottish Government documentation promoting the improvement of children's health and wellbeing, it is disappointing, but not surprising, that education teams have insufficient knowledge surrounding children's educational rights. This lack of connection can lead to the impression that mental or physical health conditions and healthcare needs are primarily matters for families and medical professionals and have little to do with schools and their staff. This in turn can lead to some children and young people with very significant challenges to their health and wellbeing failing to access the rights in education to which they are fully entitled under the criteria used to identify children and young people who have Additional Support Needs or are Disabled.
- Significant disparities also exist between the various Education Authorities and their linking Health Boards in the educational provision and arrangements made and, in the services, offered to children and young people with health conditions. These disparities are evident both when children and young people are in school and when they are absent for a prolonged period, or frequently for shorter periods, due to ill health. Within each Education Authority the approaches taken by individual schools may vary, and further disparities exist in the attitudes and practices of the spectrum of staff working within individual schools. Children and young people with health issues are effectively subject to a postcode lottery, with some faring very well indeed and too many others being ill-served and deprived of their rights.
- Thus, with evidence of some children and young people's educational rights being neglected and the national picture showing such disparities across Education Authorities and schools, it appears that there has been insufficient focus on children and young people with health-related issues by Authorities' Quality Improvement Officers and by His Majesty's Inspectorate.

- The need for additional and joint training for both education and health staff is evident, at initial professional education and in-service levels, although pressures, both on time for further training and on programme content, are already overwhelming.
- There is evidence nationally of falling numbers of qualified learning support, specialist teachers and of classroom and school assistants. These staff may work with primary class teachers and secondary subject teachers in supporting pupils with additional support needs of all kinds, including those that are health-related and who may require healthcare in school and/or support for their learning. The increasing numbers of reported pupils with additional support needs appear to reflect an increase in numbers but they may also reflect the pressure on school resources, both human and material, in the current economic climate. The benefit of an increase here, may reflect the deeper societal understanding we have gained in the last decade of additional support needs.

Summary Statistics for Schools in Scotland 2020 and 2021 and statistics noted in the **Report of the May 2017 meeting of the Scottish Parliament's Education and Skills Committee** and include:

Numbers of Pupils with Additional Support Needs in Scottish Schools	2010	69,587 (10.3%)
	2016	170,329 (24.9%)
	2017	183,491 (26.6%)
	2020	226,838 (32.3%)
	2021	232,753 (33%)
Numbers of Additional Support for Learning Teachers	2010	3,518
	2016	2,990
	2017	2,838

Children's Health Scotland is committed in its current work to make significant contributions as the leading Scottish children's health charity, and in collaboration with other relevant agencies, to reduce these barriers. We want to ensure that children and young people with health conditions, and/ or during times of illness, along with their families, including carers, are empowered in knowing their needs and rights to access appropriate services. We want a range of training and resources to be made available to ensure that there is equity of access to education for all children and young people who are absent from school due to their health. Through this they are able to benefit from their education, whilst their health and wellbeing is supported in an individually appropriate and timeous way.

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