

# Health and Social Care Alliance Scotland

## Response to the Education and Skills Committee Inquiry

15 May 2020



The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social organisations, as well as disabled people, people living with long term conditions and unpaid carers. We manage the Getting to Know Getting It Right for Every Child (Getting to Know GIRFEC) programme<sup>1</sup>, delivering information sessions, workshops and continuously updated material to practitioners, carers, third sector organisations, families, children and young people.

As part of the programme, the ALLIANCE's Getting to Know GIRFEC team relies on an Advisory Group which meets regularly and comprises of several third sector organisations which work with **disabled children and young people, children and young people with long term conditions and complex additional support needs**.

**This response will address this category of vulnerable children**, as defined in the Conveners email to key organisations<sup>2</sup>. It is submitted by the ALLIANCE but based on feedback from our members, the members of the Getting to Know GIRFEC Advisory Group and informed by what they have shared with us. It does not offer a complete picture, but aims to highlight the main concerns which have been raised by them.

### General concerns

The ALLIANCE welcomes the prioritisation of the wellbeing of vulnerable children and young people during the Coronavirus outbreak as one immediate focus of work for the Education and Skills Committee. We also recognise the strain that responding to the pandemic places on the Scottish Government, NHS, local authorities and Health and Social Care Partnerships, as well as the deep impact for children and young people living with long term conditions, disabled children and young people, unpaid carers and organisations that work for and with them.

As we have already stressed in our briefing on 'COVID-19 - A Framework for Decision Making and Further Information'<sup>3</sup>, COVID-19 does not have the same

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<sup>1</sup> <https://www.alliance-scotland.org.uk/policy-into-practice/getting-to-know-getting-it-right-for-every-child/>

<sup>2</sup> <https://www.parliament.scot/parliamentarybusiness/CurrentCommittees/114986.aspx>

<sup>3</sup> <https://www.alliance-scotland.org.uk/wp-content/uploads/2020/05/ALLIANCE-Briefing-on-COVID-19-A-Framework-for-Decision-Making.pdf>

impact on everyone. It is already disproportionately affecting some individuals and groups within society, among them disabled children, children with long term conditions and additional support needs.<sup>4</sup>

Regarding education, three challenges affect how families, carers and organisations working with and for children and young people are capable of ensuring continuity of education and development:

1. Disabled children, children with long term conditions and additional support needs require support from multiple policy areas (e.g. education, health, social work). These need to be engaged with to ensure the rights of disabled children and young people are considered and protected. This creates additional complications for families, carers, children, young people and the organisations which work for and with them. For example, several concerns have been raised about messaging, which is not always clear, updated, coordinated and circulated across policy areas (which have been described as “silos” in one instance). In addition, stress is exacerbated having to identify and deal with multiple points of contact. Messaging about how to shield and protect against the virus should also be considered from the perspective of families with disabled children and young people. There is, however, sign of good practice: PAMIS<sup>5</sup>, who is part of our Advisory Group, raises the example of the organisation, social work, NHS and education working together to support families through difficulties. They also recognise that education staff are not just providing support for education and are also facing difficulties.
2. As paid carers are shielding or avoiding physical contact, some families are taking on a 24/7 caring role (other family members are being asked by care agencies to be the 2<sup>nd</sup> carer of the child). This is a real struggle for unpaid carers who are exhausted and concerned about their mental health, their own wellbeing and that of their child or young person. They have also lost the protective environment of school services, can have reduced support packages, and many have additional children requiring home schooling support. PAMIS raises that some families are at breaking point and that urgent action is required to support this group. In such cases, continuity of education is not necessarily a priority nor a possibility for families and carers, putting additional pressure on them as they feel they are “failing”. One organisation has even taken steps to reassure families and ensure they do not pressure themselves too much. Support needs to be provided on this issue, risk assessments carried out and solutions found to allow for respite.

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<sup>4</sup> [https://www.improvementservice.org.uk/\\_data/assets/pdf\\_file/0013/16402/Poverty-inequality-and-COVID19-briefing.pdf](https://www.improvementservice.org.uk/_data/assets/pdf_file/0013/16402/Poverty-inequality-and-COVID19-briefing.pdf)

<sup>5</sup> PAMIS (Promoting A More Inclusive Society) is the only organisation in Scotland that works solely with people with profound and multiple learning disabilities and their families for a better life. <http://pamis.org.uk/>

3. The vulnerability of disabled children, children with long term conditions and additional support needs, their parents, families and carers can be increased by other factors (e.g. financial difficulties, lack of Internet access, lack of access to a vehicle, language barriers). This can mean:
  - 3.1 Having problems accessing education hubs and emergency respite as public transport is unavailable (in some local authorities, transport drivers have been furloughed). This is when there are places on offer in education hubs;
  - 3.2 Being unable to access technology, which is crucial when education resources and support are moved online, and when classmates and friends are missed and inaccessible to a population who thrives on physical contact (e.g. touch can be an important part of communication for disabled children and children with long term conditions). Adapting online learning to specific needs and coordinating allocation of equipment between policy areas are key;
  - 3.3 Having parents and carers which themselves can be disabled and have long term conditions, including learning disabilities, which can make home-schooling more difficult;
  - 3.4 Being affected by poverty. As mentioned in a recent open letter to the First Minister calling for a direct financial boost for all families living on low incomes to support them through the coronavirus crisis, signed by over 100 charities including the ALLIANCE, “an out of work family with two children is still being left with an income 20% below the poverty line, a poverty line that in itself is well below the income the general public believe is needed for a minimum socially acceptable standard of living. The families that many of our organisations work with are reporting increased financial stress and associated anxiety, loneliness, and more complex mental health problems. The charitable hardship funds many of us operate have come under massively increased pressure, with, for example, a 1400% increase in demand for Aberlour’s Urgent Assistance Fund.”<sup>6</sup> This is also true for families and carers of disabled children and children with long term conditions, and accentuates their troubles (e.g. 3.1 and 3.2, being unable to access a car or technology). We think the solutions highlighted in this open letter would contribute to ease the difficult situation of these families.

In addition to these general concerns, we have outlined some specific concerns shared by our Advisory Group.

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<sup>6</sup> <https://www.povertyalliance.org/campaigners-call-for-emergency-cash-boost-to-prevent-child-poverty-crisis/>

## **Focus: Ensuring the physical wellbeing of children with profound and multiple learning disabilities (PMLD) during school closure**

In this section, our response is built mainly on the expertise, contributions and direct feedback from PAMIS.

One of the first concerns was that shielding letters were not coming out to children, young people (but also adults) with PMLD, perhaps because the primary diagnosis may be a learning disability and the complex other disabilities were not being noted. Some families have children with at least one of the priority trigger conditions but still have no letter. This is an issue when it comes to help and support but also paints a poor picture of how this group feels it remains hidden and unsupported.

All children with profound and multiple learning disabilities are now at home with their families and many are not receiving any educational or therapeutic interventions from school staff or Allied Health Professionals. There has been concern about what processes are being put in place to mitigate the regression and deterioration physically, socially and emotionally for these young people. Some member organisations are now ensuring their services are available online, including multi-sensory storytelling, creative sensory art therapy or music therapy<sup>7</sup>. Much of this virtual support is provided through the third sector.

Additionally, children with PMLD often cannot move their own bodies independently and need physical support and intervention ordinarily provided in school by education staff, physiotherapists and occupational therapists to maintain and improve movement where possible. Resources should be shared with family carers and social care providers to enable the continuation of movement during school closure to protect the mobility of these young people, and support given to social care staff to help maintain the physical integrity of these young people.

Families of children and young people with PMLD are left with limited educational support and cannot rely on the care provided by Self-directed Support (SDS) funding as it is not always delivered. As parents seek appropriate alternatives to the use of SDS funding (e.g. buying sensory equipment to stimulate and engage), they cannot get responses from social work teams to enable these purchases. Social work teams should receive direction and support to approve changes of use in SDS funding.

### **Focus: Returning to school**

Disabled children, children with long term conditions and additional support needs can often be part of the shielding group. It should also be considered that their parents and/or carers can be as well.

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<sup>7</sup> [https://www.alliance-scotland.org.uk/blog/case\\_studies/pamis-adapts-its-services-during-covid-19/#expanded](https://www.alliance-scotland.org.uk/blog/case_studies/pamis-adapts-its-services-during-covid-19/#expanded)

There has been concern on provisions being made for children and young people who are in the shielding group and/or who have Special Educational Needs on how they will get the same support when their classmates return to school<sup>8</sup>. For example, if schools reopen progressively by blending in-school and at-home learning, the continued inclusion of parents and carers of children and young people in the shielding group should be ensured. Furthermore, the coordination and the additional work it will require for parents and carers of children and young people with Special Educational Needs should be examined.

This also raises the issue of families who want their children or young person to stay home even if they do not have to shield under government guidance, as they are anxious about virus circulation in a school setting. One organisation stressed that children and young people themselves had great fear about leaving their house to return to school, while another highlighted the fact that some families faced dilemmas, having a child which needed shielding and anxious about what the situation will be when their siblings are allowed back to school. Support and understanding should also be provided in these cases. Third sector organisations are already providing such support, for example by creating and sharing material on how to deal with anxieties or putting in place “kindness calls”.

Many children and young people with additional support needs (e.g. PMLD, Autism Spectrum Disorder and other complex healthcare needs) require intimate care, moving and handling and have specific equipment needs and communication needs. These require close interaction and contact. We need to ensure that parents, teachers support staff and others supporting children and young people returning to school, are confident and reassured about how these issues are being considered and addressed as part of coordinated and collaborative planning across policy and organisations.

Children and young people that may be transitioning into primary or secondary education in the new school year have not had the opportunity to engage in their new environments and with their new staff. Virtual introductions are not always appropriate, and there is a question about what plans will be developed to support these children and young people in their transition.

In general, as PAMIS suggests, working with family carers is key. Family carers have spent their lives keeping their child safe and as healthy as possible; they are the experts on this, and a partnership approach is needed to explore possibilities of reintroduction in to school and communities in general. Children and young people with PMLD, for example may need a different approach – services and government needs to be responsive to some of these unique groups – one approach will not fit all!

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<sup>8</sup> <https://www.alliance-scotland.org.uk/wp-content/uploads/2020/05/ALLIANCE-Briefing-on-COVID-19-A-Framework-for-Decision-Making.pdf>

## **Focus: Transitions to adult services**

Lack of social work input and assessment regarding transition, reported in some areas, has put family carers in a difficult position as they are becoming more and more concerned and stressed regarding the future packages of care for their young person leaving children's services and entering adult services.

This raises many concerns, which have been addressed in another publication by ARC Scotland and the Scottish Transitions Forum<sup>9</sup>: while *“there has been no formal ECD [Education Closure Direction], on 18 March 2020 the Scottish Government announced schools would close. Other impacts might be from a change in term times and holidays depending how the pandemic plays out through social distancing measures. This might change transitions processes and pathways quite drastically in the coming year. What this means for young people moving into further or higher education is not known at the moment. The Scottish Youth Parliament has written to the SQA asking to be involved in decisions around the new grading arrangements.”* Clarification on this and any legal precedents should be provided as quickly as possible to young people and their families.

Concerning health transitions, there is concern about whether adult services are going to be ready for young people with complex healthcare needs given the focus and resource is currently on COVID.

## **Focus: Inclusive Communications**

Children and young people with sensory loss and complex communication support needs have faced huge challenges during the COVID-19 lockdown. The struggle to communicate has caused a lot of stress from carers and individuals and further complicates the understanding of messaging.

Throughout any planning and process, inclusive and accessible communication must be paramount for all. Children and young people must have agency and input within the process, and decisions should be made with people, and not for people. To this end, a framework of inclusive practice should be central to the process.

As previously mentioned, for many children and young people with sensory loss and complex communication support needs, tactile language, or communication within the bodily tactile modality is essential. In this regard, appropriate risk assessments, guidance and PPE should be in place for all communication partners and education professionals.

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<sup>9</sup> <https://scottishtransitions.org.uk/blank/wp-content/uploads/2020/04/COVID-19-legislation-FINAL.pdf>

The management of the risks of COVID-19 mean that the importance of routine, education and respite for families must be balanced against the critical need for effective communication and that the safety of all stakeholders is paramount.

## Contact

If you would like to discuss any of the topics raised within this response, or to request any further information, please contact:

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## About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 2,900 national and local third sector organisations, associates in the statutory and private sectors and individuals. Many NHS Boards, Health and Social Care Partnerships and Medical Practices are associate members.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self-management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.