

## Enquire briefing: Transitions of young disabled people and their parents

### Summary of evidence

#### Background

Enquire, like many services and organisations within the sector, continues to hear that young disabled people and their families often face difficulties at the transition between children's and adult services in Scotland. We feel strongly that more can be done to improve this transition and that improving transitions to adulthood will have a positive impact on the lives and outcomes of disabled people and their families.

This paper restates our concerns about how transitions are currently managed, shares data and case studies from the families we advise, and updates evidence we have previously shared following the impact the pandemic has had on children, young people and their families.

#### Case study

“A parent called about their young person who is 18 with significant needs (young person has learning disabilities, mobility issues and is non-verbal). Young person was in a special school however, due to Covid, they have missed 12 months of school. They left school in June, but cannot start their new placement until as late as next year because numbers on the course have been limited (due to Covid). Parent asked if the young person could return to school in the meantime, but this has been refused by the education authority. Parent told us they are at “breaking point” as young person needs to stay in the house and has no friends or siblings. Parent said they feel like the young person is basically “in prison here with me”. Parent is in contact with social work, who have been unable to provide any alternative.”

## About Enquire

Enquire provides advice and information about additional support for learning in Scotland, helping schools and families work together to ensure children get the right support. Enquire is also a partner in the My Rights, My Say support service, which is the national service that supports children aged 12-15 with additional support needs to exercise their rights to be involved in decisions about their support in school.

In the last year Enquire's helpline team has provided advice to over 1,550 parents, carers and professionals supporting children and young people about additional support for learning via our phone, webchat and email helpline services. Although the definition of additional support for learning is broader than disability, a significant proportion of our enquiries concern children who are disabled and therefore covered by this proposed Bill.<sup>1</sup>

### Case study

"Professional calling for advice about a parent they are supporting who has a young person (16) with epilepsy and is in the process of being assessed for autism. School had presumed young person would be leaving at end of S4, but they hadn't actually asked them. The school were then shocked the young person wanted to stay on. School have removed support - stating "they can't support pupils who have turned 16" - so the young person is struggling and feels the school don't want them there."

## What we hear from families about transitions to adulthood

20% of the enquirers we spoke to in the last year raised issues around transitions and 5% specifically raised issues about post-school transitions.<sup>2</sup> For those enquirers concerned about post-school transitions the top eight issues raised were:

- The impact of the pandemic on learning/support<sup>3</sup> (40%)

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<sup>1</sup> Between October 2020 and October 2021, the most frequent reasons given by helpline users for the child they were calling about needing additional support were: 48% Autism, 14% mental ill-health, 14% ADHD/ADD.

<sup>2</sup> 78 enquiries were specifically around post school transitions. We also record other types of transitions (transitions – nursery to primary and transitions primary to secondary). In total 327 of our enquiries cover transitions making up 20% of our calls. Although these do not specifically deal with this issue, they give our team further insight into the types of challenges transitions can lead to for disabled children and their families

<sup>3</sup> Recorded on our database as "Coronavirus."

- Post-16 options (23%)
- Communication from professionals (23%)
- Out of school education provision (22%)
- Support - level of support (21%)
- Support - lack of understanding of additional support needs (19%)
- Relationship difficulties with school/ education authority (19%)
- Deferral/ repeating a year (19%)

### Case study

“Parent calling about their young person who is due to leave school this year. There is nowhere for their young person to continue their education - as provision for life skills courses at college have been cut due to covid. Parent wondering if young person can repeat S6 in the mainstream base they are attending - this has been suggested by the school and other professionals “off the record”.

Within these issues we heard about:

- Lack of planning for transitions
- Communication difficulties and confusion over rights of young people and families
- Support that had been agreed not being delivered
- Lack of appropriate services for young people to move
- Families/ young people wanting an additional year at school

### Case study

“Young person (aged 16) was expecting to go to college this year, but transition was interrupted by coronavirus. The college felt they were not sufficiently prepared to attend college, but the school have said they will need to leave school now. If not allowed to return to school or go to college, parent fears young person will have no prospects.”

## Case study

“Parent of young person with Asperger’s Syndrome in S4 and attends a support base. Young person has a strong preference for staying on in school for S5. However, the school say that they are not sure whether it would be possible for them to stay, as they need to accommodate other pupils under 16 in the base. School suggested the young person speaks to a careers advisor about college or further training. Parent left feeling unclear whether pupils in bases are allowed to stay in school after 16. Young person is extremely stressed at the idea of having to leave school and go to college where the classes will be very large.”

## Conclusions

Our data from helpline enquiries and case studies show the range of issues around transitions parents and young people experience just within the education sector. As well as highlighting some of the key issues around planning, communication, lack of information stress caused to families and young people already evident in the current transition process, we can also see how the pandemic has exacerbated the challenges already faced.

## Case study

“A young person called the helpline asking for help as they do not feel like they are getting the support they need at school. Young person feels the school aren’t listening to them or their parent. They feel the school want them to go to college, but they want to stay on at school.”

**The stories we hear from the people who contact us evidence the need for changes to the system for our disabled young people and families.** With any changes to the system, we believe strongly the following must be considered:

- The vital input of children, young people, and families with lived experience of the current system to identify solutions.
- Learning from current legislation including The Education (Additional Support for Learning) (Scotland) Act (2004) and the legal duties it already places on local authorities
- Learning from the ASL review around the challenges of policy and legislation translating into practice (for example Co-ordinated Support Plan implementation)
- How ownership and responsibility of plans would be managed given the diverse group of children and young people who would be covered by such a plan.