

Education, Children and Young People Committee

Summary of the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill survey

The survey was published on 1 September 2022 and closed on 27 October 2022. It forms a part of the wider call for views on the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill. The survey was specifically aimed at providing young people and their parents and carers with an opportunity to voice their personal experiences.

The survey had a small number of respondents and as such cannot be considered an overview of the experiences of all disabled children and young people in Scotland who have experience of transition to adult services. It does, however, provide an insight into the personal experiences of the individual respondents.

Survey responses

There were 31 responses to the survey, 2 from young people and 29 from parents and carers. The two young people had both left school, while the responses from parents were evenly split between those whose children had already left (14 responses) and those who were still at school (15 responses).

Young People

Of the responses from the two young people, their experiences of planning for transition were mixed. One said that a teacher had helped them to look at college or university, but that they had not been asked what they would like to do or what extra help they might need. When asked if the plan had helped, they answered 'not at all'. The second young person said that 'someone else' had helped them to plan and that they were asked what they wanted to do. This respondent gave no additional details regarding the plan that was formed or if they found it helpful.

Both young people included comments about their experiences of transition which can be found in the Appendix.

Parents and carers

The majority of parents and carers whose children had already left school said that their children left school with no plan. Of the 14 responses in this category, only 4 children had a plan when they left, 1 of which was now considered to be out of date.

This experience is reflected by the parents and carers whose children have yet to transition. Of the 15 responses in this category, only 1 parent said their child had a plan, and 3 others said that they will have one before they leave school. The other 11 respondents have children with no expected plan for after they leave school.

The respondents whose children did, or will have, a plan represent 28% of the total survey respondents. They were asked further questions about their experiences of developing the plans.

All 8 of the parents and carers of children with plans reported that they had been involved in developing that plan for their children. Social workers (7 responses) and teachers (6 responses) were the professionals most likely to also be involved in the process.

The parents and carers stated that their children had limited involvement in forming the plans. Only half of the children had definitely been asked what they would like to do after leaving school, and only 3 out of 8 were certain that their children had been asked what support they would need.

All 4 parents and carers whose children had already left school noted that their plans contained information regarding the support they would receive from social workers. In addition, 3 said that the plans had information regarding expected support for their child from college or university. Only 1 plan contained information on the support expected from a medical professional. The 1 respondent whose child is still at school and has a plan said that it includes information on expected support from a college or university, social work and medical professionals.

When those with children who had left school were asked if the plans they had made had been helpful, 3 respondents felt that they had been 'a little' helpful, and 1 felt that the plan had been 'a lot' of help.

Each respondent was asked to include any comments they wanted to share with the Committee on their experiences of the transition process for their children. These comments are all included in the appendix.

**Laura Haley, Researcher, SPICe Research
18 December 2022**

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Appendix

Each respondent was asked at the end of the survey:

“What is the one thing that the Committee should know about your or your family's experience of moving on from school or other children's services?”

This appendix provides the responses to this question in full. They have been organised to show responses from young people and parents/carers separately. The parents/carers have also been divided by those who have children who already left school or children's services, and those whose children have yet to leave.

Aside from minor spelling corrections and amendments due to data protection, etc, the responses have not been edited or cut in any way.

Disabled young people who have left schooling

“I am visually impaired, so moving from school, to college was a difficult transition. Although communication was maintained with the school, it was never through me. So I wasn't aware of any plans in place until I started college. I then had to ask for orienteering support and alternative assessment arrangements. This took months of appointments and contact to be put into place. Even then, my file was wrong and I had to correct multiple times”

“I had absolutely no support from my high school which is one of the reasons I didn't stay into S6. I dropped out at the end of S5 and worked for a year before applying to the Open University to complete a degree part time. I have dyslexia so standard unis just don't work for me but no one ever told me this - I had to work it out for myself with no support”

Parents/carers of a disabled child or young person who has left schooling

“My son has never received any services other than pupil support assistant in school. Social work twice refused to complete an assessment of need, and therefore his Child Plan was focussed completely on supporting school. Therefore, there have been no other services to move on from. Receipt of support and disabled students funding at university has been a completely different world. Support for children with disabilities should follow this model.”

“The school and college recommended a supported education course for my son based upon his academic ability. It was a 3rd year course which wasn't explained to us, with the majority of students being in their 3rd year on Life Skills course. My son didn't cope and was moved to another course, this time a 2nd year course instead of a 1st year course. There was no plan and this resulted in my son not coping with college. There were also other issues that resulted in causing him severe anxiety. I put in a formal complaint which was upheld but it was too little too late!”

“School reviews had everyone in the room - education, medical etc - adult social work was late to the table and slow in signing off proposals for education and support.”

“We don’t need another plan which will either be avoided by SW [social work] & schools, or will be completed and then nothing happens. Been seeking support for 5 yrs, child disengaged from school, ended up self medicating with drugs & alcohol, still had no Child's Plan because School DHT refused to do one for any pupil. Now started college and no plan to pass on to ASL service there so starting from scratch again.

SW assessed a need, but still haven't done SDS [self directed support] assessment. Our family should have had 4 different assessment/plans undertaken, only my Carers Assessment completed but none of the assessed services offered. How is adding a 5th assessment and plan to that going to help if there's no services/funding available to back it up.

Asked for respite and housing support/homecare support. Instead have had multiple referrals for support workers who just chat about things- Youngster's bedroom is still a tip, they still self harm, and I've worsened my own health condition being left to do everything on my own, because a free McDonalds and a chat doesn't mow the lawn or teach Youngster life skills/homecare skills!

This is a complete waste of time. Disabled children need a specialist whole family resource team to assist with children aged 12-25 if transitions are to be successful. That's a specialist team with single point of access in every locality. With OT, primary care, CAMHS, physio, SW, education, careers, welfare rights, and housing reps working together from the one team. Building individually tailored provision for disabled young people and offering training and support for their families. Real resources, not another form!

Also desperately need changes to how benefits work for 16-19yr olds. Whole family's income-based benefits rely on former school refusers turning up for college or training. Or young people for whom there is no suitable training provision due to their high levels of need. Those young people and their families need an extension of "dependent child" benefits to an older age regardless of education attendance (just as they had when under 16). They don't magically stop being disabled at 16 and suddenly have capacity to attend education/training. And having a teacher or social worker complete an assessment isn't going to put money in anyone's bank account.

We need a major change to the structure of benefits for 16-25yr olds affected by disability. More supported housing provision. Respite care which is more like a holiday for disabled young people. More CAMHS workers. Increased OT [occupational therapy] budgets. A specialist transition support service which works with young people to help them gain life and homecare skills. More ASL funding for college and training providers. Not more forms and dumping young people on already stretched 3rd sector provision and relying on unpaid family carers (whom the young person may want to become more independent from).”

“Looking for a placement for a disabled child who needs lots of care there is no where in Fife at all, 1 place in Perth has a waiting list just a joke really, he cannot walk the street he has to be at home with us as everything has been closed down, nobody cares but it is very hard work 7 days a week not having a break , Scotland needs to sort out places.”

“Terrible that there is no transport to take disabled people to services. All transport withdrawn during pandemic and has not been reinstated. Especially difficult for people in remote rural communities”

“Our children are treated like second class citizens and we have to fight for everything for our children and it’s a disgrace in this day and age and especially transport for our children going to abs from college”

“Lack of Training, transition from main land school to supported living on island not very good. New staff took a long time to get to know. Not much structure after coming from structured environment. Mind you school did not have much in place either. Still lack of training on autism for adults on island”

“Transition hasn’t existed for [the young person] and that is down to Glasgow City HSCP (GCHSCP). They are a crisis intervention/reactive service but hard to blame them as they are so under resourced for staffing - so appears the only way they can operate. [The young person] has complex needs and was at Hazelwood - complex needs school. Despite the best efforts of the senior management at Hazelwood it was impossible to get an adult social worker allocated to carry out an assessment before they left and their leaving date had to be extended from June to October. It has been up to us parents to get everything together and keep going. Feels like we are on our own since [the young person] left school. There are so few resources for adults with complex needs. [The young person] has become more dependent on me which was the last thing that was needed.

The lack of resources in social work and social care is the main problem. However, the response from the Chief Officer GCHSCP to our constituency MSP Humza Yousaf was not helpful at all. Before [the young person] left school, I asked if GCHSCP would be working within the Principles of Transitions framework. The Chief Officer had no trouble telling Humza Yousaf that they had no intention of doing that in fact were taking a contrary approach, ‘A year in a young person’s life is also a significant period for them to continue to develop their independent living and personal/social skills so it is important not to assess too early.’” [amended to remove the young person’s name for data protection reasons]

“The most stressful time as a parent carer, it was a total nightmare (redacted), social work adult transition said she had a plan moving from children with disability team, I’m her legal guardian via court of guardianship and I’ve still never seen or heard verbally what that plan is or if it even does exist, it's like some secret service. I do not feel empowered as a carer never mind legal guardian through the whole transition process. Guardianship was in place since October 2020 yet they just tell me a matter of weeks before her 18th the powers were not adequate to manage her SDS [self-directed support] budget as I have for years under children’s to keep employing our own PA [personal assistant] under option 1, they have known about the guardianship

all that time, it could have been back to court and the extra clauses to manage her SDS budget in place so our support was seamless. We lost our self-trained PA (huge loss due to the unique a-typical ASD type she has as I train my staff, school staff etc refuse to listen and so anywhere but home and PA support is traumatising for her, school failed her massively) as we couldn't guarantee hours ongoing, huge loss as had been employed and specially trained for 6 years.

I also have disabilities so the added stress is not good for me, I was basically left as per usual doing everything on my own, almost a year from starting transition still nothing is in place, school ended in May, she was denied a college place which was much needed post 18, as an adult who lacks capacity work paid or unpaid isn't an option so college for a few more years was very much needed. After the trauma of high school college was our hope to end education on a positive, they took that from her, she feels written off, there is now NOTHING for her but wasting away at home, neither of us wanted that and she cries saying she has no place in the world and would be better off dead!

It seems very dire for ASN adult transition for our guys. Sad state of affairs. I've tried complaining, you get fobbed off with lip service, I feel totally useless, helpless and like I've failed her when in reality we haven't got the support needed that should be there, yet I'm the 1 feeling I've failed!

Further education should be compulsory if a parent, carer or legal guardian thinks it's best for their young person, not all have co-ordinated support plans to fall back on, that was denied in our case too years ago, even though we moved from England with a then enhanced statement of special educational needs with 1 of the highest 1:1 support awards in our county for a child with her needs of over 22hrs per week, with specialist SSEN teacher, SALT [speech and language therapy] and outreach specialising in her a-typical ASD [autism spectrum disorder] type diagnosis. We came to Scotland 2012 and got zilch! Except PTSD [post-traumatic stress disorder], trauma and trichotillomania, supervised bullying was allowed too, to a supervised kid in a specialist base setting. As well as staff assault on her and the police investigation and pathetic outcome will forever haunt me. We are told by law to trust our kids to these so-called professionals! All she knows up to now is trauma and being failed from the people supposed to be professionally supporting her! The amount of times it's seen as a home issue when its clearly not is disgusting! Always the parents though, professionals can do no wrong. In our experience they do more harm than good. Something has to change."

"It seemed to be a very "reactive" service and required constant prompting by ourselves to get things progressed, planned and implemented. There also appeared to be varying degrees of support dependent on how hard you pushed for things to be done."

"No plans were made for my child leaving school at 16 and going to college. I had to organise everything and it was at a very high stressful time. This was 3 years ago. If it had not been for the amazing support from North Highland College tutor I don't know where my daughter would be now."

From Camhs to adult services it was goodbye straight away from Camhs psychological support one week and onto adult service the next week. As parents it immediately went from involvement to no involvement. Daughter spiralled downward for a long time.

Things could have been approached differently if more funding is put into Camhs. These professionals are amazing but have no time to give for transitions. The government needs to invest time and money to try and help these children go into the adult services in the highlands. It also needs tailored to ASD where changes are so difficult for the young person to adapt to.

Schools are stretched beyond what they can provide in the way of mental health support for ASD and young people are left on reduced timetables and unable to go to school due to no support in school buildings. This is not the schools' fault it is lack of teachers, funding and poor building layouts not catered to a person with ASD.

Scotland needs to invest and be inclusive towards disabilities because these very intelligent, creative young people are Scotland's future."

"Very difficult. Seemed to be no communication between child / adult services - especially NHS appalling my daughter was left in limbo. She is now 23 and after the failings she is a great deal of pain and being pushed from pillar to post"

"The yp [young person] I care for was a LAAC [looked after and accommodated child], and I felt that the disability SW team she was under didn't listen to my request for planning to be put in place and as a result she left school with no plans in place and due to COVID ended up with a year of no services in place and unable to get things started till earlier this year. A compulsory time frame needs to be put in place that SW needs to adhere to (school agreed with us and also tried to push the disability team involved)"

Parents/carers of a disabled child or young person who has yet to leave schooling

"My son is autistic. He attends an ASN secondary school and previously had a child's plan but LA removed his support package during the pandemic. I wasn't contacted or consulted by SW or LA for 2 years after I had previously managed his support package until 2019 and his SW left. I had previously asked for help managing his package as I'm a lone parent with no other support and a medical condition also at the time our neighbour was harassing us (an ASBO was put in place) so my mental health wasn't good. I repeatedly asked for support from SW but received none. My son is sixteen in 6 wks and will have had no support for the last 3 years."

"We are in the process of starting school. The nursery intake was the worst start for my daughter. There was no one to guide us on the correct placement or nursery setting to meet her needs. The nursery she attended promised the earth, every support but left her alone, excluded, nervous and anxious. They didn't have time for

her or willing to take time. Every day was a negative impact and broke our hearts let alone hers. We fought and fought but failed promise after promise.

The system is broken for kids with Additional needs from the get go.

I dread for the future”

“It has been a very haphazard approach so far and the over-riding impression has been that, rather than working in tandem, the agencies instead seem to try and push back the responsibilities and workload to each other, without anything much being decided or actioned.”

“My daughter has just started her 6th year. She attends a mainstream school which I fought for. Because of this she has missed out on some opportunities/information that seems to be provided to those in special needs schools but doesn’t seem to make it to those in mainstream. Different assumptions are also made because she is in mainstream. There needs to be equity of opportunity and information irrespective of which school system you are in. We have only just been allocated a social worker with a TAC meeting in two weeks so we are at the early stages of planning.”

“My son is 6 weeks away from turning 16 and has complex learning disabilities and associated health issues. I'm petrified over what I'm going to have to try and do to get some sort of transition and future plan in place. I'm aware of his peers being told they won't get an adult social worker till they are 18. If our kids are valued citizens, respected and equal to others then how on earth can they be treated in this manner? Why, as parents, are we treated in this manner- all the stress is undoubtedly reducing our life expectancy .. things have to change- we can't allow future generations of young people, their families and their siblings too- to continue to be ignored and let down.”

“There is absolutely no communication about where or when this needs to start so will definitely be nothing in place”

“Lack of understanding of what the equality act provisions should be.”

“Unless you fight for support and continually are chasing this up it feels you’re on your own and that nothing will happen to help”

“My son has not attended school since December 2021 and there appears to be little provision for his education. He has ASD and ADHD and is pathologically demand avoidant. His demand avoidance means he cannot be home schooled and cannot cope in mainstream school. He is academically capable but there is nothing that can fit his needs.”

“I have had to do everything by myself with no help from social work.”

“The sheer and utter lack of information being shared is a disgrace. Departments blaming each other for a lack of information and expecting families to deal with this.

Having to find out about transition from a Facebook parents' group and not having this information available from the disability social worker or the school? You ever wonder why so many of our young people 'slip through the net' 'the cracks' my child and my family will not be another statistic due to failure. The other pathetic excuse which is wearing extremely thin is Covid.

Hate to point out the obvious, services were in a dreadful state prior to Covid. Time for another excuse for the failings for our young people."

"My son leaves school next year and there is no plan, no support and no adult social worker appointed. As parents we have to do all the work ourselves and can't get any support from social services. It is very difficult and stressful."

"My child is almost 17 and is in S6. She has no plan. Never had a plan. Should have a plan. She is disabled, but it is invisible and a long term illness. There is nothing for her. She has no options. She couldn't work more than a few hours a week so can't get an apprenticeship. She has no highers so can't go to college. She is very bright and articulate and mature. Yes the local authority guidance says there should be a plan. But there isn't. No I don't know why. It will be same reason there has been no proper assessment of learning support needs, no proper learning support, bad attitudes, discriminatory language, and a whole system designed to erode any confidence or hope from a young person. They now just want her out of the door, they just need a box to be ticked saying she has a destination. The idea of a meaningful realistic plan is completely absurd. But that's in keeping with the way high school has responded to someone with an invisible condition that has no medical cure."

"I feel as though there is a minefield facing us as a family both in terms of funding for my son when he leaves school in 2023 but also in terms of giving him valuable activities to engage in which do not impact on us having to give up our current roles. These children and young people have engaged in school since the age of 5 attending Mon - Fri for 30 weeks of the year only to be faced with prospects of a college course which may last 3 days at most per week. Grappling around to try to fill in the remaining days has been exhausting for friends of ours in a very similar situation resulting in one parent having to reduce their days to part time working only.

We currently have no social worker as we didn't feel the need for one before however, as my son moves on into adulthood, a request was made for one in May and it still has not been delivered. The current system of planning is being driven by his school but there is only so much they can do."

"Trying to even get a plan in place is proving difficult. My son is in S5 and still no formal planning has started. Because he doesn't have a learning disability, he doesn't qualify to use the dedicated transitions team although he has complex needs, is a full time power wheelchair user, already has SDS option 1 in place for carers and has 1:1 support at school. Frustrating!!"