

# Education, Children and Young People Committee

## Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill

Note of Session with young people (Divergent Influencers) hosted and supported by ARC Scotland

Part one

### **What worked well for you when leaving school?**

Young Person 1:

I was helped by a charity called [Thistle](#), which brought their '[big plan](#)' project into schools and helped young people to plan for their future – to establish what they want to do and what they want to achieve, and to set out a plan to achieve that. The focus was on what you wanted to achieve, not what labels or conditions you have.

Young Person 2:

The best part of my journey leaving school was meeting other Divergent Influencers (DIs) and working with Thistle on the Big Plan project, which ensure that people with ASD or any other ASN have a voice and a sense of direction. To have a good transition, you have to know where you are going, but it is important that you aren't being taken in a direction where you don't know where you are going or that doesn't fit your future ambitions. When developing our big plan, we are talking to someone who is truly supportive rather than someone who wants us to fit their vision. Good transition is when you are being treated as a human being, and that you feel that your views and ambitions matter.

Young Person 3:

I didn't have a transition between secondary school and college. The school abandoned me. We contacted the college who helped with the transition, they helped me to adjust to the college, to literally feel my way around the buildings but I had to fight for everything.

Young Person 4:

I agree, finding classes in college is always a pain especially when temporary changes happen.

Young Person 5:

It was difficult for me to plan for the future because I had no idea of what life would look like long term, to envision the future and what job I wanted. So more immediate, express needs

were what mattered most to me. I was interested in going to art school, but my parents weren't that interested in art, or knew what living in Glasgow would be like. My teacher took me to an independent cinema, to libraries etc to see how what it was like and give me an idea of how I could live in a different city. This was valuable. They took the time to show me ways of life.

Young Person 6:

At my high school, I felt that I didn't have support in general from teachers but there was one teacher who helped me get to where I wanted to go. My mum knew someone at the university that I wanted to go to, who helped to look at other ways to join university, through summer school, which is something that I hadn't known about. Different contacts, not just through schools was really helpful.

Young Person 4:

What works well? Having a place on a college course before case was really helpful as it meant that there was a degree of transition, from the school. It was good enough but not good.

## **What could have been better about leaving school?**

Young Person 2:

Some of the staff were fully aware and knew how to support young people with different needs, but not all. Autism is seen as a challenge and of course it is but treat us as human beings and do not infantilise or condescend us. We don't want to be treated differently from our peers. When you are 16 in Scotland, you have adult rights, but we can often be treated as children. We aren't oblivious to things; we see us being treated differently. It varies in different aspects.

How autism is represented, as a difficulty, rather than as a unique way of going through life, is common to lots of different ASN and is something that can be improved.

Young Person 1:

School wasn't planned the way I wanted it to be planned, I felt that there was no compassion and that you were out of the loop to a lot of what happened in school. Leaving school was great, as there was no enthusiasm when I was there.

Young Person 4:

It would be good if there hadn't been as many barriers when transitioning. There was no support from college for transitions, for instance with a lack of transport measures in place – there had been talk about pre-arranged taxis but that never happened. My needs were not understood. During the five or six years you are at school you build relationships and people understand your needs, but the college did not try to understand those needs

beforehand. The lack of support led to mental health issues, and they have stuck with me ever since, maybe not always as bad as they were, but they are still there.

Young Person 3:

I tend to need a lot of support. I had a very good transition from primary to secondary, but in the last year of school, to transition to college, there was no communication with me, or with my parents. I had to advocate for myself with the college [which I didn't know how to do], to set out what I needed when I was there. The college were great in helping me but there was this gap in communication and support. I shouldn't have to advocate solely on my own, I am a young adult with opinions and ambitions and capabilities, but I still need support. I am still a vulnerable adult, so the support needs to be there.

Young Person 4:

I get that, College staff didn't speak to either my parents or school teachers and staff who worked closely with me prior to the end of my final year in secondary school. Well, they didn't communicate with them as much as they should have, which would have helped massively when fleshing out a transitional plan.

Young Person 5:

In thinking about my own transitions, as well as other peoples (after university I worked in mental health transitions projects), no one has ever asked me, and I have never seen anyone else asked, what do I like to do? What do I want from life, what kind of person want to be? Practitioners are not given the time or the resources to find out these things – they have to focus on absolute needs. They are only focused on positive destinations in the most cynical way because they are under so much pressure to ensure that people are seen to have a “positive destination” regardless of whether it is right for them.

People should be less fussed on what a positive destination looks like for the government, or the tick box, but what it looks like for the individual.

Young Person 4:

If people don't ask you what you'd like to do, then how will you know what you want to do.

The theme of positive destinations should include your long-term goals.

Young Person 6:

I left high school in 2012. I was the only wheelchair user. I don't think that they knew how to listen to me, how to understand what I needed and wanted.

I felt that they were pushing me towards college, and were negative about my desire to go to university. They said that 'I would get tired, I wouldn't be able to handle it'. They didn't give me information about universities, about open days. I didn't get the support that I needed. I did go to open days, but only because my parents got that information.

I still feel like I am going through social work transitions, but they need to look at the bigger picture. They also didn't listen to my aspirations.

They wanted everyone to fit into a box, and talk about the college course intro to learning, as opposed to going to university. We need a vehicle to help people hear our aspirations, what we want to do and achieve.

I graduated in the four years I attended university, proving them wrong.

Young Person 5:

Instead of 'how do you cope with the long days, do you sleep well?' and their assumptions on what they believe 'wheelchair users can or can't do'.

Support worker 1:

One participant and their sibling are at university, but the participant's school never thought they would make it to university. Their parents had to advocate for them and get private tuition as the school didn't provide it.

Credit to their parents for doing this, not everyone's parents would be able to.

Young Person 2:

It is important that individuals are at the centre of the process.

Young Person 3:

Disabled people sadly get ignored in this transition and either the individual or parents have to advocate for them.

Young Person 4:

The admin course that I did in my 3rd year at college sticks with me as the prime moment when my needs were not being considered. The college only put me on it because they thought that my autistic brain could handle repetitive tasks when in reality that is actually quite draining. Essentially stripping away the strength of my mental health.

## Part two

### **What kind of plans did you have when leaving school, if any?**

Young Person 3:

My plan was always to go to university to study politics but the school wasn't very good at explaining the realities of how that would work so my plan changed to going to college. Your goals can change when you are better informed as part of the transition process. Schools should negotiate alternatives [to university] but my school was focused on closing the attainment gap and those students achieving the high grades needed for university.

I felt that there was a gap between school and university and that it would be too big a gap for me to jump at that point.

College was right for me in the end as I am able to negotiate my way from home to college but it was interesting how I had planned my next 5 years and then very quickly the reality of going to University may not have been possible based on friends' and sisters' experiences.

It is stressful when plans don't always go right.

Young Person 2:

I planned to learn to drive, which I have done and to do a course in science or the arts – possibly film making or journalism – I am doing biochemistry. I would like to work in medical research or in film making. [Media Education](#) is an outstanding organisation. I worked on a play which was set 100 years in the future. This allowed me to be creative and problem solve, this was really useful. Unfortunately this project ended as the staff member left and was not replaced.

Thistle Big Plan – allows you to get creative and explore those skills to help

Since leaving school I have found some things challenging. I wasn't sure if it was normal to be treated as a child even when you were 16 and 17, or if it something that I experienced because I have additional needs.

Young Person 4:

In terms of the plan - little to nothing, it was like walking over a river without a bridge, just random stepping stones. No one talked about where I wanted to go or what I wanted to do next.

Difficult and insensitive course application processes for people with ASD.

I had a comprehensive Disabled Student Support form filled in, but lecturers clearly didn't look at it which meant that there were not things in place for me, as indicated in that form, eg not having scribes for classes or assessments. I felt excluded from classroom situations. It was a really poor system.

The college wanted me to write a piece on why they were great and inclusive to be used on their website and other places. I did this, but my experience was the polar opposite to what I wrote. My experience of college was completely disjointed and lacking in support.

Not to mention when selling tickets for event organisation project in college, I was tasked to stand about with a megaphone and try to sell remaining tickets. Didn't even have a proper stall set up and it made feel really stupid. Like why would a lecturer ask someone with autism and anxiety to stand in the busiest part of the building at lunchtime of all periods, on my own with nobody else from my team to support me? If they had read my disabled student support prior, they'd have known this was the equivalent of nightmare fuel for me.

Young Person 1:

When I left school I wanted to travel more, and that is something that I do now. The only good thing that I got from college was meeting my partner.

Entry to learning skills course, it was crap. Then I did a mainstream course but I didn't feel like the support was there. I don't want to go back to college ever again.

Young Person 6:

When I was at school, my parents supported me with all the personal care that I needed. After school I then went through the process to hire people to assist me with the support that I needed when I was leaving school. It was a really difficult process. Social work said that they had never dealt with someone like me. Because my needs were complex but because I also knew what I wanted to do and had ambitions that I shared.

I had to, and still have to, advocate for myself a lot.

Going to university was a great help as SAAS was a great support because they provided some of the money for the care I needed during the day. Social work only had to support some of my care.

I am still transitioning as I have complex social work and health needs, e.g. when I moved into my own house, and organising the 24 hour social care that I needed.

It was difficult. People tried to work together but communication was not always the best and we always had to advocate for what I needed. It has been a long journey.

Young Person 3:

I agree, that absolutely highlighted that there is a transition in everything from school and medical things. Disabled people get transitioned from child to adult services and i guess for me I was disadvantaged because i turned 16 during the height of COVID and that's when people begin your transition. I was in a sense "forgotten" about.

Young Person 5:

I am training to be a teacher and I have worked in colleges and schools. In terms of my plan when leaving school - person centred plan - the chat is dominated by education but there are so many other needs. Transition is an ongoing process; we never stop coming of age.

I didn't particularly have a plan as life isn't framed that way. I worked 12 hour shifts every day in the summer between school and university so I could have enough money to go. I was always told university is free in Scotland but when I arrived at university I met properly wealthy people for the first time. I had no idea how to manage money or sustain a lifestyle in that context. No one ever spoke to me about it. It would have been good to have support to learn how to manage money etc.

I really want to highlight that of course the transitions Bill includes people with mental health diagnoses as per the equality act. A lot of today's chat is super relevant to planning for life with mental health challenges.

In mental health we already talk about living a holistic life e.g. 5 Ways to Wellbeing or SHANAARI, how is this embedded in transitions with a focus on ACTIVE LISTENING?

Young Person 2:

You shouldn't force support on people with ASN – you need to give people the choice of having the support or not.

## **What should this plan look and feel like?**

Young Person 1:

I would have hoped that it would have been easier to access, a smoother process, regardless of whether you left a SEN school or a mainstream school.

Young Person 4:

Not to mention, public transport at rush hour was a constant sensory overload. I was given some support and independence with funding from SAAS for transport. Didn't have to feel like a kid who needed his mother to constantly pick me up from college like my nursery and primary school days.

Many didn't bother asking me what I wanted or what I needed, not just for college but for life outside of education. Things like access to social situations. I bring up social situations because others around the same age as me didn't need to rely on their parents to take them to social situations. So why should I just because of my disability?

Young Person 3:

Its challenging when everyone just assumes that you can come out and i think teaching young disabled students how to work on their independence might also help with the transition. I was promised throughout my school career that i would be taught how to handle

stress and how plans cannot always go my way, this didn't happen and i think that sometimes that schools promise certain things but do not follow through on this.

Young Person 4:

What was needed to look after my mental health encompasses proper planning + implementation of a plan that would have avoided me getting referred to psychological services when I hit breaking point due to that feeling of abandonment by the services that could have and should have been listening and working with me.

Its why I'm glad that my parents have a guardianship, they could help me out in areas where I couldn't help myself. Though it shouldn't feel like a fight to get even a snippet of support from services, but instead a coordinated effort with a united team behind you with everybody's listening and working together to help build your success.

That guardianship was the one thing that helped keep things from falling apart completely. In college, more often than not, I had to bring my parents into discussions because you felt I wasn't being listened to and it makes me glad we had a guardianship for that reason.

Young Person 6:

Every plan should be person centred and based on the needs and aspirations of the individual – they need to look at who can support you. I felt more supported when I was being supported for my physical disabilities rather than the learning disabilities too.

Young Person 3:

My transition was during the Covid pandemic so there were additional challenges. I would have liked to have conversations about the wider world, about moving from child to adult services, it was a big jump from someone who had rarely left the house. I would have like to talk about what they wanted to do / achieve. I think that would help other young people going through the process now.

Young Person 2:

I agree with those comments. Without properly speaking and listening to the people, you can't hold them up / support them to live the life that they want to live, not the life you presume that they want / need. By not listening to them properly, it affects people. Hearing our voices and respecting our choices.

Listening to people and not making assumptions is really important.

Young Person 5:

Many staff in mainstream schools do not consider people with mental health diagnoses within the ASN / disabilities stream of planning.



Young Person 4:

My plan should have had me at the centre, where I am right now, where I want to go and what I need to get there. We need to know there is a bridge strong enough to hold the weight of us crossing the river, not just stepping stones.

Young Person 5:

Active listening, person centred and holisticness are all well known concepts. I'm not confident everyone has the skills to listen meaningfully. People who are very experienced and maybe aren't able to suspend their knowledge in order to fully hear today's challenges. Things move so quick these days! A lot of people put their own information in first. Transitions can be more complicated for people with ASN, there are common experiences for all young people – so listening to young people and their ambitions is really importance. Person centred planning training is amazing.

## **What one thing?**

Young Person 3:

There is a lack of proper disability awareness when handling and supporting these transitions, there is a disconnect between what people should know and what they actually know. Some teachers are coming into classrooms without any training awareness so I have regularly had to teach teachers or to reinforce what they should know. My school was “disability aware” but I had to teach my teachers how to handle my disability. I have since learned from teachers that they had no training in this area.

Young Person 2:

We are reliant on teachers. and teachers can be fearful of making mistakes, but trying their best and even failing with good intentions is better than not caring. Obviously, it is better not to make mistakes.

People need to follow through with what they promise you.

## **Did you feel respected when you were formulating your plan?**

Young Person 3:

I attended a disabled unit within a mainstream school and I was treated like I was a child and spoken to like I was a child. They acted as if they knew more about my disability than I did and I think that they were quite dismissive of what I was saying.

They would then treat me differently around my parents when I would raise an issue and be like "well we're not doing what she's saying" making my issues feel smaller and I ended up just not going to them for support.

Young Person 1:

Students were not allowed to come to parents' evening. At parents' evening, teachers suggested that I wasn't doing their work properly because I used the spell check and other aids that I needed. But I did get positive feedback from other teachers in other subjects, recognising the work that I was doing. Some teachers did respect me and one recognised that I achieved something that they thought would not be possible.

Young Person 6:

I am still regularly spoken over, to my parents, carers or whoever I am with. When doing my plan, I would say what I wanted. Social workers would say "it isn't what you want, it is what you need." My aspirations were not listened to. I was disrespected in meetings.

Young Person 2:

It is difficult because parents should know their children well and be able to advocate for them, however, when a child is getting older the parents may not know everything about the young person, so it is vital to listen to the young person.

Young Person 4:

There are lots of time when I have felt that I wasn't respected. And I felt that some of the college lecturers treated me as more disposable. I struggled with one unit towards the end of my course and the college suggested I should just drop out, rather than support me.

Me and mum wrestled for two years for access to support through social work. Mother also brought in advocacy agency to fight my corner as well. I should not have been like that when we brought in advocacy people in senior positions that listened.

I also had a good lecturer with an erratic teaching style so I asked if they could adjust their style to be more accommodating to my needs. I just want to even the playing field.

## **How important is advocacy?**

Young Person 1:

Never make assumptions about someone's needs.

Young Person 3:

It is important to learn to self-advocate.

I had a teacher who understood the additional needs that I have, they were reasonable with accommodations that I needed which included extra time at points etc. That was really helpful. But more people – across the teaching staff and the student body – having awareness of the needs and accommodations that maybe are needed.

Young Person 6:

I have been told in the past that there wasn't anyone able to advocate for people because I had physical disabilities rather than a learning disability, but it is exhausting so more advocates for people with physical disabilities and that it is important that we can choose our own advocates, someone that we feel understands us and can give their additional voice to what we want, not what they think we want or need.

Young Person 4:

You have to have a co-ordinated effort from all those in the plan. And think about what is needed at each step on the journey.

I had the right to be listened to, as did my mum through my guardianship. Shouldn't take an agency saying the same as us to get appropriate course of action we'd been asking for and were entitled to.

Having a Bill is all well and good, it is the funding and infrastructure in place that's key

Young Person 3:

The one thing I would definitely stress if you're focusing on education, **DISABILITY AWARENESS IS KEY.**