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

Session with Parents / Carers, ARC Scotland

January 2023

Sue Webber (Convener) – what worked well for your young person? What could have worked better?

Parent 2 – what worked well – a college course for young people with ASD and son was signed up to that – they told him it was the best thing for him – he didn't feel listened to – there wasn't a proper plan in place – it was over to me – just the college course and over to me. I was invited to a meeting with the head of the course a few weeks before it started and most of the parents/carers in that room were upset, concerned, because they were all saying "what do we do?" "who do we get to speak to about what concerns they may have?" but there was nothing, nothing at all. It was clear there would be no working partnership, we were there to be told about the coursework only. Even though I had guardianship, when things ran into trouble with people not fully understanding my son's disability and needs, I had to insist there was a meeting called where his stepdad and I were able to support him as his voice wasn't being listened to – and that was a course for young people with ASD. My son was not listened to and his mental health suffered as a result. His voice was not being heard.

Did anyone ask what your son wanted? – No. He was asking me and I couldn't answer anything. I had a fantastic relationship with the school – but they said we deal with the college, not you – and I reminded them I had a guardianship order in place and all I got then was an outline of what the course was, not an explanation for my son. The big thing about it was that he was transported to school because of his autism and sensory issues – our understanding was that as our son's disability hadn't changed, he would continue to receive this essential support. I found out the week before my son was due to start that this was not the case. I contacted social work, the school, no one cared. My son didn't want me to take him as he wanted the independence he had been used to at school through having this support in place. However no one took his ongoing needs into consideration, there was no planning for this young person who could not travel on public transport, was supervised 24/7 due to his disability and sensory issues, and also his lack of social skills which made him extremely vulnerable - at that time he could not even go out in the community unaccompanied. The responsibility for transport came back to me as a parent and this removed a huge part of his everyday independence. This was huge for my son, his mental health suffered and he also said on many occasions he felt he was a burden, he repeated this to health professionals.

Parent 4 – there are many transitions – not just when they leave secondary school – children are all different and transitions happen at different times. My son joined the SCOTS *[School-College Opportunities to Succeed]* Course at Forth Valley College – particularly aimed at helping people transition into college – and he was able to try lots of different courses. That worked well – but we found out about this ourselves. There's a wonderful person who does transitions in Falkirk – but she wasn't there then. My son left school at 16 – but because of that – I felt you slip through the system as people expect you to stay until S6. It fell apart when he got to college as he wasn't on a supported course – and some people on the course didn't understand neurodiversity – and he was assaulted by another student – and put into car park on his own to call me to collect him. It is indicative of the lack of support – and the building blocks required for transition. He then ended up leaving college - we couldn't put him back there. The employment training unit in Falkirk has been brilliant – I found him a job and he's been there a year.

Parent 1 – our situation was different. We moved back to the UK when my daughter was 11. We had no choice but to put our daughter into a private school as we didn't have a residential address in the UK. I had no knowledge of transitions plans – or transitioning – we had no contact with local council about my daughter having a disability. All the support came from the school – and from me – talking to the school to adapt things to her needs. I didn't find out about transitions plans until my daughter was at university. We had ongoing support from the paediatric audiology unit throughout school but in the final year(s) my daughter had her radio aid provision taken away because of a change in funding policy – and we had to have one lent to us by someone else – it's an essential piece of kit for any deaf student at school. The school supported her brilliantly and she got into university and that was the best thing that could have happened – and that was when the formal support happened – and she was picked up and supported for the whole time – from technology to mental health support. What's important is that often people see just a disability – but a lot of her needs have been around mental health needs. Young people's needs also change as you go through transitions – from school, to university to moving into employment. University went very well initially, but unfortunately, the last couple of years didn't go well – she continues to have mental health issues and has not worked since university. She is now 25 and all that support that would have been available before just doesn't exist. I spent my entire life going into schools and explaining what my daughter's deafness meant, what people needed to accommodate – and she did too. From the age of 7 or 8 years old, my daughter was advocating for her own needs and giving talks to classes on deafness. The informal support has been excellent – but if would have been useful to know there was formal support out there – but you spend your life being so busy putting out little fires – that you run out of time to look for the information and support that might be there to help you.

Can you talk about your role in the transitions process – the Bill believes there are systemic and cultural problems in the process – and where it works well it is often down to individuals or organisations. Were you treated with respect or were you left feeling condescended/an adjunct to all this?

Parent 4 – it's a postcode lottery and we've become the CEOs of our children. A semi-professional psychologist, local councillor, semi-professional teacher…. – you have to be so socially aware – reading the room the whole time. You spend a lot of time going into school and teaching other people – how to work with your young person – *[the feeling was that people were]* making out it was your child that was the problem. Every time I spoke about it, though, I would always have someone come up to me afterwards and say “I know what that’s like. I’ve felt like that.” People often don’t know that they are not listening. You need to feel you are listened to – but you are not – sometimes you are coming up against a brick wall. I didn’t know what an educational psychologist was until I found one – and then we went to CAMHS and that wasn’t a good experience.

Parent 1 – one of the things I came up against again and again was pre-conceived ideas of what you were going to get with a child with hearing impairment – and every time I would have to explain that each child is different and the way that deafness affects them is very different. We were very lucky – we had people who listened to us – but yeah, fighting that every time is very tiring.

Parent 2 – from health, education, social care, higher education, doctors – it’s a continual battle. For my son, for example, when he was sitting 5th year exams, he was extremely stressed. He was asking “what do they expect of me?” because no one was telling us so we couldn't explain to him. I had to end up going and getting information from the National Autistic Society and taking it into the school. I had a great relationship with the school – but thought they knew best, and they didn’t. I told them you need to give him a timetable as this is different from doing English language on a day to day basis in school – this was exam preparation. As an autistic person learning new things he needed to know clearly what he was required to study, how his week and month would look, if staff weren't available as planned to work with him he needed a visual plan of when they would deliver the lesson. And if we hadn’t done that – he wouldn’t have been able to sit the exam, never mind pass it. His mental health had taken a beating. This isn’t just about my son, it’s about other young people. We had the same with college, they put him on an admin course as they thought he’d like repetitive tasks – but he hated it. Lecturer suggested that he drop part of the course – a module around finance as he struggled with numbers - but only found out later that would mean he would fail the whole course if he did. We worked with him – his stepdad and PA asked the college what our son had to learn, they broke it down in a way he would understand and left him to get on and he practised with past paper after past paper – and he passed the module. However, if my son had listened to the professionals and we hadn't stepped in to support him, he we would have wasted a year as dropping a compulsory unit meant failing the course.

Graeme Dey (Committee Member) – lack of evidence from organisations – or collective understanding of what young people might need. Any positive examples of where schools/orgs have learned from those experiences?

Parent 2 – my son wrote down his experiences at college as part of a project to write a magazine article showcasing why someone would like to study at the college, this was for his HNC in his 5th year in the college. At the time he was feeling discriminated against and not listened to. We asked to meet with the learning support department and our son handed over one piece of paper – and they said “this is great” – and he said “this is what it should be like” - and then he handed them another piece of paper – and he said “but this is the reality” - the learning support department manager immediately apologised to our son for everything he was going through and their part in letting him down and they said “what can we do to make this better?” They listened to him – and we all worked together to come up with a plan that was reviewed on a regular basis, they put proper plans in place to communicate with our son and us, we all worked together and focused on his needs, that's what helped him get through the course. Without the support of his parents/carers, no one was listening to his voice.

Parent 6 – because my son is one of the older young people – when he first started school they were just starting small *[additional support]* units in primary schools – but the parents there put in a petition saying they didn’t want their children mixing with children with additional support needs. The unit ended up being in a different place and the people there were very welcoming. We only had social work involved for pre-transition at 14 years old – but we didn’t have anyone else until later – at college. We had someone in learning disability unit – who really helped – I thought I had some understanding from my own *[professional]* role – but then I had to walk in those shoes myself. I am never “just a parent” – sometimes it made it worse having that insight. I set up parents’ group in my local Carer's Centre. You learn more from people going through things than from a room full of professionals. My son attends a day service outside of our local area – 2 days a week – we are fortunate in our local authority to have a dedicated transitions co-ordinator – and they are setting up a transitions team. As parents – we shouldn’t be the ones to share all the information – someone somewhere should have the responsibility for that – e.g. speech therapist says this, physiotherapist says this – they don’t speak to each other, so we have to do it. As a parent it is hard to go through. Occasionally they would ask my son’s views – but they would ask us as his parent guardians – hardly anyone asked for my daughter’s views as his sibling – it had an impact on her schooling and it affected her. He is still living with us and hopefully will be for a while – it’s hard to have that fight.

Parents 3 – we are at a different stage – my son is in 5th year – has autism and a learning disability. I am a home educator for our younger son who has severe mental impairment and complex needs. I am on a more positive note tonight – and it is great to hear from others who have been through it and are still surviving. We have had a really good experience – the transitions co-ordinator at our Local Authority is amazing, but it is a post-code lottery. We have had our first transitions meeting for our son – and we were very nervous – we didn’t know what we were going into – we had all these questions, but the majority of the questions got answered that day for us. They gave us an e-mail for any further questions. We asked about independent travel – he has never been out of the house without me or his dad – so he is going to work with a transport co-ordinator and other young people – to explore different routes. The first transition meeting was really positive and they did listen to our views and at the end of the meeting – they got our son in – and asked him his views – and they included him and that was really nice. I think the big part of the meeting for me was that it was very respectful. I had heard all these horror stories and I was dreading it – but it was very good. It was a small group of people who knew our son – and they knew his needs, but they also knew his strengths. They also talked about a possible work placement – with a small group of people – at the hospital. We were at the right place, at the right time, with the right people. Every authority should have these people *[transitions co-ordinator].* The only thing I would say is that there will only be two big formal meetings *[around my son’s transition]* – maybe an extra meeting might be better – to try and get all the information in one go *[is challenging]*. Our younger son is home educated – he is 14 years old – we’ve just started a transition process for him (there is no formal process for children who are home-educated) – but we’ve been reassured that he won’t go under the radar.

Parent 4 – Project SEARCH *[an internship programme, supporting young people with additional needs in gaining skills and experience to move into employment]* runs out of Forth Valley Royal Hospital – SERCO supports it – my son ended up on that – got an interview half way through and got another job – but was allowed to graduate. You need people who do good practice – if we did GIRFEC (Getting It Right For Every Child) we wouldn’t need this Bill. We need to see the people who are working well – and grow what they are doing. The school has done an incredible job. Find the people who know what they are doing – and get them to do them more.

Parent 2 – Our son did his Duke of Edinburgh Bronze award at school and thought never again – After completing his HNC my son couldn't continue with his higher education journey due to barriers and mounting challenges in college. It had affected his mental health terribly. During Covid he saw an advert and, with the right support from us, was able to meet with the DofE leader and enter the Gold Duke of Edinburgh programme. His support worker came with him on the expeditions – and he successfully passed his Gold DoE. It built his confidence back up – organisations like that are vital.

Stephen Kerr (Committee Member) – you’ve mentioned the Transitions Co-ordinator at your Local Authority and that everyone needs someone like her – can you expand on what it is she does to make you say that?

Parent 4 – with my parent hat on, I didn’t know she existed. With my school hat on, I discovered her and now all of our kids have transitions plans. Her enthusiasm, dedication – if she has to work until 10pm, she will, she will track down the right person – it’s her passion. But she was on a yearly contract – so it’s hard to attract someone to a role [*if it could be temporary*] where you can’t get a mortgage etc. - so it’s a worry.

Parent 5 – *[the Transitions Co-ordinator is]* working across children’s and adult services – the fact she can go across those two areas – and cross that boundary – that’s absolutely crucial.

Parent 6 – there’s only one Transitions Co-ordinator [*in Scotland in a role like this*] – the local authority I know of may have someone in the children with disabilities team who may help – but when they come into adult services – transitions records will be sent across – but whenever they come into the Learning Disability Team – funding restrictions mean that they want confirmation the person has a Learning Disability. They then go into the generic teams in adult services. Nurses may not work with a young person if they don’t have a confirmed diagnosis; social work may not work with them for another reason. The Transitions Co-ordinator has a background in Learning Disability nursing and is very approachable – and she takes on questions and finds out answers. She is attending *[transitions meetings]* from age 14 all the way through and following it through – then they go onto a different worker. Sharing information *[is an issue]* - children and families, GP records, social work records, someone from education – and even the systems don’t speak to each other to share information. Or it can't be recorded or it gets lost in translation…it's hard as a parent and the young people themselves. They find people that work with them – and approaches that work well – but then the worker changes.

Parent 2 – why can't we have a Transitions Co-ordinator in all Local Authorities? Principles into Practice – the framework is there – do we need to rewrite this? We know what is working well, so why not share good practice? For me, if you have evidence there – then follow that up and look at how to make that work across Local Authorities across Scotland. Every young person is entitled to have that kind of support. It is about people and it is clearly about people working together – why not have that happen?

Ruth – Bill proposals re plan in the Bill – what are your thoughts on the timing of the plan and the suggestion it should last until young people are 26 years old?

Parent 1 – most of us have young people in their mid-20s – so the "when does it end?" is a big question – for me that transition from child to adult services has got to be captured and carried through for that entire time. Their needs from education, college, university, jobs, should be carried forward and shared – so that people are not starting from scratch each time. For us, transitioning from paediatric audiology services to adult audiology services has been a complete failure - despite the good intentions. The transition from paediatric audiology started from 16/17 years old. At the meeting, there was a big table of people there so that meant my daughter couldn't follow what was going on. A very clear transitions plan was created by paediatric audiology – but none of what was in the plan happened beyond the first year. There is a lack of knowledge of Deaf young people in adult services – The young people have grown up with audio tech and they know it like the back of their hands – but the young audiologist *[my daughter met with]* didn't know how to set up the tech – so my daughter had to tell them how to do it. The audiologist then had to refer back to paediatric audiology to ask how to programme my daughter's hearing aids. Information in the transition plan was passed on from paediatric audiology, it just wasn't followed.

Parent 2 – the proposals for change – thank you for listening to us as parent carers and wanting to hear our voices and our experiences. What concerns me greatly is I can't see where we are mentioned in the proposed changes, yet we are the people who are supporting our young people continually. My son continues to need support – we are trying to give him more and more skills. I won't be here forever and we have to make sure we help him to learn things about day to day life – so he can learn how to use a washing machine, for example. I am deeply disappointed that we are not mentioned anywhere in there. There are services across the board who are trying *[to support transitions]* – and the resources are not there.

Parent 5 – we tend to look at transitions at the moment and assume young people are going to go through it in a particular way and meet certain targets – it's a conveyor belt. *[In reality]* young people develop at different stages and what someone might be able to do at 16/17, may not be right for another young person until 22 yrs old. One of the things that is a challenge is recognising that because of my daughter's mental health issues – she wasn't able to complete school – and a lot of things because of that, meant she wasn't able to engage with certain services - but when she was ready *[to engage]*, she was too old for some of those services. She seemed to fall through the cracks, and there wasn't a way back. You feel a bit on your own – but beyond school, if you haven't got a social worker involved, then falling through the cracks in your early 20s is scary – as that's when you really start to realise as a parent you are on your own – you don't know where to go for help.

Parent 4 – my son's mental health – every day is a challenge – what has worked really well, the ILF *[Independent Living Fund]* Scotland Transition Fund allowed him to access Kung Fu – they listened to him – he's now an ILF ambassador – he has a voice - and the fund for me was vital. There are a lot of parent/carers out there *[accessing the fund]* themselves – but getting the fund into schools is vital – and that needs resources to do that. It is life-changing for so many people – it helped my son to evidence his Duke of Edinburgh award. Another initiative *[redacted to avoid identifying the young person]* has given young people the chance to be heard – listening to young people's voices is essential.

Parent 4 – ILF – I found it by accident – can be used for driving lessons/motability. Siblings/families need to be involved. I am not going to be here forever. I had to go to GP to say it was me who was cracking up, not my young person, before we got support.

Parent 1 – I think ILF finishes at 25.

Parents 3 – we've not applied to ILF yet as our son is just 16. Information is key – you shouldn't have to go to one place for this info, another place for that – it should all be pulled together under one umbrella. You want that knowledge asap as you want to try and plan for the future as much as you can – even if you know things will change along the way. The Transitions Co-ordinator was great for us – she was one person who gave us so much information. It's the not knowing that's scarier than knowing the worst scenario. ILF sounds absolutely fantastic – we're looking at the forms for our son. It should be extended beyond 25. There should be something beyond 25.

Follow-up information

We welcome the interest of the ECYP Committee in our views and experiences as parents and carers of young people with Additional Support Needs.

Following the evening session on Monday 30 January, we felt the constraints of time meant we did not explore some points as fully as we would have liked. We have therefore set these out briefly below, and would ask they be shared with the members of the Committee as part of our evidence from the session.

Thank you.

What good practice looks like

The biggest difficulty is not that we don't know what good practice looks like, but that it isn't happening. Good practice:

- **Should recognise and support ALL disabilities and additional support needs.** There are many young people with additional needs, but without a learning disability, who nevertheless need support to make a smooth transition to adulthood.
- **Should apply to ALL education settings.** There should be consistent information and support, whether the young person is in mainstream; special school; private school; or home educated.
- **Should be flexible.** Systems and processes are often rigid and don't fit real life. We need flexibility around funding, access to support, and availability of support so it fits the young person, not the other way round. One size does not fit all.
- **Should be consistent**. There should not be a "postcode lottery" where some young people receive a good service and others don't. If the needs are the same, the support should be the same.
- **Is about equal rights for our young people.** Legislation already exists that is not being applied properly or consistently. This does not adequately support equal rights.
- **Ensures young people and families have the information they need**. Checking awareness of benefits and finance (including self directed support); guardianship; other entitlements such as bus, rail and cinema passes; practical advice; listening: these cost nothing, but can make a huge difference to young people and families.
- **Listens to young people and families**. They will tell you what works and what doesn't, and what they need. Requests for help are too often not being heard.
- **Should support parents and carers.** Parents should be entitled to support and helped to access it so they can better support their young person, especially when they are expected to "pick up the pieces" or plug essential gaps in support.
- **Gets the simple things right**. Take a holistic approach: transitions involve more than just leaving school. It's about building a life that works.

Our views on the Transitions Bill

- **Feels like another "one size fits all" approach**. No mention of different education settings, flexible approaches, or provision for all additional support needs.
- **What happens if the Bill's provisions are not met?** Services already fall short of their legislative duties. Reporting annually to Parliament will not automatically help families ensure they actually receive the services they are entitled to.
- **Does not mention parents and carers.** We hold a huge amount of knowledge about our young people and their needs, and have to pick up the pieces if things go wrong. The Bill offers nothing to support the role of

parents and carers, help us carry out our role, or address our stresses and concerns.

- **Transitions in health care do not feature in the Bill**. These will be crucial for many young people, not only those with complex needs.
- **Will not address the shortage of services/resources.** Vital services proven to work, such as advocacy, continue to be underfunded or cut. If we can't develop what is already working well and implement it more widely, more legislation is unlikely to achieve this.
- **Could absorb valuable time and resource**. Will the Bill become a useful excuse to pause or halt progress? Will the money spent on its implementation be tracked, and if so, how? We believe knowledge mapping, funding and resourcing should be worked out before legislation, because if not there is no point in passing a law.

We would like to see:

- **Good practice developed consistently across all areas that impact transitions**. This includes local authorities, colleges, universities, employability services, health care and all other settings that prepare young people for adult life. Follow the things that are already working well.
- **More equitable access to funding and services**. Universities and colleges can access funding, e.g. for learning aids, counselling and travel, but similar support is not there for young people studying at a lower level or entering employment. This level of support also usually ends very abruptly at the end of the course, even though the need may not have changed and a young person requires help to take their next steps.
- **Funding and resources directed to developing what is proven to work**. This is a more efficient use of resources in the short term, and more likely to reduce the chance of a crisis further down the line.
- **More information events aimed at parents and carers**. This could include workshops, transitions "fairs", and more opportunities to network with other parents to tackle isolation and increase awareness.
- **The flexibility to spread transitions out over time**. It doesn't serve young people or families well when everything has to happen at the same time. For example, being able to remain in some childrens' services to age 21 would be beneficial for some young people.
- **Better training for professionals**. Skills, knowledge and understanding needed.
- **Services that work together and an ongoing commitment to making things better**. From senior management to frontline services, we would like to see buy-in to new ways of communicating and working together.