**Royal Blind response to the consultation on the proposed Disabled Children and Young People (Transitions) (Scotland) Bill**

A draft proposal for a Bill to improve the outcomes for children and young people with a disability in the transition to adulthood, by requiring the Scottish Government to implement a national strategy, and by requiring local authorities to prepare and deliver a transition plan for each disabled child.

**Introduction**

As Scotland’s largest visual impairment organisation, Royal Blind welcomes the proposal for a Transitions Bill. We believe too many young people with visual impairment do not have the support they need in the transition to adulthood, and this can have a lasting impact on their lives. This is why we support the proposal for an effective National Transitions Strategy.

We work with young people with visual impairment in a wide variety of settings and a range of individual needs.  We support young people with visual impairment through specialist education both at the Royal Blind School and through outreach support to pupils in mainstream schools. We provide 24-hour residential care and short breaks for adults with visual impairment and additional disabilities, based in Edinburgh.

Forward Vision is a transitional service for young adults between the ages of 17-25.

Allermuir provides a home for life with community-based supported living. Our adult services support young people with visual impairment and additional disabilities. There is a waiting list for these services as we are currently operating at capacity and we are aware too many young adults with complex needs are waiting too long or are unable to access the care support their need. We believe it is important the Bill recognises the needs of young people with complex needs so their inclusion and right to access appropriate care is achieved. We support the proposal for transition plans and it is important they are tailored to meet the individual needs of each young person.

**1. What challenges do you think children with a disability face in the transition to adulthood?**

Managing transitions is consistently one of the biggest challenges for the children and young people we work with. The issue has been a prominent theme in our campaigning, and effective transitions for blind and partially sighted young people was one of the four key asks of Our Vision for Equal Education campaign.

Part of the challenge is evident in the attainment gap for pupils with visual impairment. In 2017-18, 27.9% of pupils with a visual impairment progressed to higher education, compared to 45.6% of all leavers. In the same year, 22.6% of those with a visual impairment found employment, compared to 29% of pupils without any additional support needs. Scottish Funding Council College Leaver Data statistics for 2016-17 (the breakdown for the 2017-18 statistics is not available) show that just 11.3% of students with visual impairment progressed to work from college. Not only is this is substantially lower than the national figure of 20% of students progressing to work, it contributes to the situation where two thirds of working-age people who are registered as blind and partially sighted in Scotland are not in paid employment. This emphasises the importance of investing in the right specialist support for people with visual impairment during transitions from education into employment, and working with employers so they can better understand the support available for disabled people in the workplace. A person-centred approach to education and employment is crucial, rather than a one-size-fits-all offering for young people with disabilities. We welcome the focus on better access to apprenticeships and employment support, and believe that specific apprenticeship schemes should be developed for young people with visual impairment. Royal Blind commends the ASL vocational learning programme run by City Building, where every year, 35 pupils from ASL schools around Glasgow take part in vocational learning at Royal Strathclyde Blindcraft Industries. Pupils study vocational options alongside their other school subjects for one half-day per week over the academic year and all delivery takes place in a ‘real life’ factory environment. Similar apprenticeship opportunities for disabled pupils with public sector employers could make a positive contribution to supporting transitions for disabled pupils from education to employment.

It is also important to recognise that while for many young people with visual impairment attainment, employment and independent living skills will be important outcomes as part of a successful transition, many others have a range of disabilities and complex needs which mean that there will be other and sometimes different priorities for them in their transition between services. Young people with visual impairment are often not given clarity or confirmation of where they can go and which services they will receive when they leave education and care services for children. This is often accompanied by the loss or reduction in vital services that the young person received at school, such as speech and language therapy, physiotherapy and occupational therapy, and the loss of these supports can be particularly detrimental for young people with complex needs.

Young people with additional support needs, like all young people, benefit greatly from having friends, peers and a safe support network (whether in mainstream or specialist settings), and breaking from this environment without replacement coping strategies can be a lonely and unsettling experience.

While the statistical disparities facing young people during transitions are troubling, transitions are not just about educational or vocational milestones and “positive destinations”, important though these are. There are different points of transition - as the consultation document states, “Transition is not an event but “an ongoing process that involves moving from one context and set of interpersonal relationships to another to another”. The ages between 14 and 26 are important formative years in any person’s life, and it is vital that young people are given help to become well-rounded, confident people, with positive relationships. It is therefore welcome that the Bill’s consultation document views transitions in a broad sense, encompassing the young person’s health, financial affairs, housing, leisure, citizenship and independent living.

**2. Do you think that children and young people with a disability should have a statutory right to a transitions plan?**

We agree it is vitally important for there to be equal access to a transition plan which focuses on and meets the individual needs of each child and young person. Although every child is currently entitled to a Child’s Plan (under the Children and Young People’s Act 2014), there is no statutory requirement to implement ongoing and fully supported transition plans, nor do disabled young people have a right to ongoing support after they have left school. We are aware of one instance where a parent was told the local authority had a transitions policy, but when challenged to provide was subsequently informed that it did not exist. Without this statutory requirement and effective transitions policies many children and young people with visual impairment are left isolated, often leading to poorer outcomes for them. The current system also puts young people at the risk of losing out from a “postcode lottery”, with transition planning varying greatly from one local authority to another. Some local authorities employ social workers with specific responsibility for transition, but this still does not always in itself result in a good flow of information to parents and carers on transition or a successful transition process. That is why it is crucial that either on the face of the Bill or through guidance there is a clear process for how parents, carers and young people themselves will be properly consulted and included on the development and implementation of their transitions plan, and that it is tailored to their individual needs. These should form important elements of the statutory right to a transitions plan.

**3. Why do you think that a transitions plan would be helpful or unhelpful?**

A transitions plan would put in place clear, agreed objectives and timescales. It would help to manage expectations and better prepare the young person for moving into adulthood. Vesting responsibility in the local authority, and in turn a Lead Professional, would help ensure crucial accountability for every individual young person, ensuring they were not forgotten or passed between different authorities. If implemented effectively, the co-production of the plan would help to protect the child or young person’s agency and autonomy. It is also welcome that the Bill would give Scottish Ministers powers to introduce provisions about dispute resolution under the legislation. For some young people who have attended a specialist school outwith their home local authority for many years it may be that more than one local authority may be involved in transition arrangements, and a transitions plan could help facilitate communication between local authorities and health and social care partnerships where there needs to be collaboration and discussion on a disabled young person’s transition arrangements.

Successful transitions planning would also ease the stress on both the young person and their family or guardians. It is common for the parents or carers of young people with disabilities to face lengthy and demanding campaigns just to secure fundamental rights for their children, often at a considerable emotional, mental and financial cost. Moreover, some parents or carers may lack the health, resources, self-confidence or expertise to navigate the multiple statutory bodies and associated bureaucracy when advocating for their child. A transitions plan would provide a basic guarantee for disabled children and young people and ensure their future is not dependent on whether they have parents or carers with the means to fight their corner.

It would also be beneficial if transitions plans linked disabled students at college or university to further information on where they can access support and advice, whether from student services or associations.

It is not just the young person that stands to benefit from a smoother passage into adulthood. Society also has a lot to gain from their contribution and misses out when young people are unable to live up to their full potential. Too often spending on additional support needs education or adaptations for people with disabilities is viewed in terms of short-term financial cost, rather than long-term gain. If young people with an impairment or long-term health condition are not given the necessary support due to funding concerns then the economic and social effects will likely be felt in the future, whether in increased demand for mental health services, issues with unemployment or underemployment or pressure on the social care sector.

**4. Will a National Transitions Strategy assist disabled young people to achieve independent living?**

Assisting disabled young people achieve independent living should be a key objective of a National Transitions Strategy. Disabled young people are just as likely as their non-disabled peers to want to live away from the family home. However, their disability often means they are dependent on other family. Student support and promoting attainment of disabled students is vital to widen access, but it is also crucial during their school education that pupils are provided with the habilitation and independent living skills they need to thrive at work, university and college. If this is not provided in a mainstream setting, then the Transitions Strategy must stipulate alternative arrangements for the pupil to ensure can acquire these essential skills.

Too often visually impaired children in mainstream schools, even if they have performed well academically, are not supported to develop the life skills they need to move on to tertiary education or employment. One pupil recently attended Royal Blind School for a year before going on to university just to attain these vital skills which were not provided throughout his mainstream experience. This approach to preparing pupils for an independent life is wholly inadequate and can only scratch the surface of their needs. Early intervention and timely ongoing support to be an independent person is critical.

**5. What do you think the advantages and disadvantages would be of a National Transitions Strategy?**

A National Transitions Strategy would help ensure accountability and place transition planning on a statutory footing. It would also provide the opportunity for joint-working through an overarching framework giving agency to local authorities, NHS Health Boards, the Integration Joint Boards and other bodies. This strategy would afford a clear reference point to these agencies in terms of aims and objectives, and outcomes to improve transitions for disabled children and young people.

The strategy should include fundamental commitments to supporting disabled young people in their move to adulthood and subject to appropriate parliamentary scrutiny so that commitments are not watered-down or under-resourced. We believe the strategy should set out national standards in key areas of policy around transitions. For example, concerns have been expressed in the past over young people with complex needs not receiving care in age appropriate settings. We believe the national strategy should set out that all young people should receive care in age appropriate settings.

We welcome the proposal for an annual report and believe there should also be evidence sessions with Ministers at committee at appropriate intervals so MSPs can be reassured satisfactory progress is being made through the strategy and that it is being adequately resourced. A national strategy has the potential to improve transitions for disabled children and young people, but it must be understood that a strategy on its own without a different approach to resourcing provision at a national and local level will not result in the step change which is required. We welcome the proposal that statutory instruments with regard to the legislation should be subject to the affirmative procedure.

**6. Do you think it is necessary for there to be a Minister in the Scottish Government with special responsibility for ensuring that children and young people with a disability receive appropriate levels of care and support in the transition to adulthood?**

We agree it is essential to have a Minister to lead and take responsibility for the transition strategy. Their oversight would help give direction, create a clear strategy and ensure accountability through the publication of an annual report.

**7. Do you have any other comments?**

As the Royal Blind School and Royal Blind’s adult services support a number of children and young people with multiple and complex disabilities in addition to their visual impairment, we wish to stress that transitions planning must ensure these young people continue to receive an excellent level of care and are assisted to fulfil their potential beyond leaving school. For some young people, maximising their independence and ensuring all their care needs are met through a transition plan will be the priority. It is important the Bill and subsequently the National Transitions Strategy recognises the needs of these young people along with those of young people with visual impairment for whom effective transition planning means better educational outcomes and improved employment opportunities.

We really appreciate the case studies presented in the Bill’s consultation document. Please see below a case study of our own, which provides an example of the challenges during transitions faced by the families of young people with complex needs who use our services.

**TRANSITION CASE STUDY**

After beginning the transition process for my child at age 14, I was told that nothing of any significance would or could be agreed until they were at least in their final year of school. I was very proactive in looking at the various post school options that were available and at all our school reviews stated what my preference would be and what backup options I would consider if this were not available. In the transition review at the beginning of the final year, I discussed that I would like my child to remain at school as there was currently no appropriate provision to move onto. I stated that my preferred provision was the right option and best met my child’s needs, but as no places were available, we could only be on their waiting list. It therefore made sense for them to remain at school, in an environment where staff knew them well and all their needs were catered for. Other options were raised by social work but would not have been appropriate on any level. I also advised that I had investigated a possible plan B, but no places are available there either and we were also placed on their waiting list.

At the next transition review in January our educational psychologist gaveverbal confirmation that we could have another year at school. It was confirmed this would be put in writing after the review (this was never received but I was advised it was not necessary). It was deemed essential that we had a provision which would offer a consistent team of staff as this was important for feeding regimes, hydrotherapy and other 1-2-1 care needs. The SALT shared her concerns that a consistent group of trained eating and drinking staff was imperative due to silent aspiration, and the need to maintain oral feeding. At this point Outreach at home was raised as a possible option but this would be a last resort due to its unsustainability.Due to both the level of care needs and the stimulation gained from being in a group environment, it was again stated that the proposed provision would be the only option that could offer the level of care and expertise required within our own community, particularly around visual impairment.

At the beginning of April, I was advised that a place had unexpectedly become available at the placement and I confirmed that I wished to take up this place. I advised our social worker and they stated we should get all the required information to them as soon as possible so the application could be processed. I met with the placement to discuss assessments, detailed care needs, a proposed weekly timetable and costings which were then submitted. I was advised that Social Work would also need to submit cost comparisons for alternative placements with the application.

At our next transition review in May, I advised that if the placement was not funded my preference would still be for my child to remain at school, as no suitable alternative was available. It was also agreed that the placement was the best option in terms of continuity and if agreed, transition could take place over the summer holidays.

By then end of May I had received no contact from Social Work and was becoming concerned as the place could not be held open indefinitely. I continued to chase for contact and advised that any delay in submitting the application may result in the loss of the place. I finally received a call from our social worker in the second week of June to say they were was still working on the application. I asked for the offer of an extra year at school to be reconfirmed if we had no positive decision by the start of the new term. In the third week of June I received an email to say that the educational psychologist now felt a return to school was not the best idea as a suitable adult placement was available. At this point I stated that I would not accept being left with nothing and my child should return to school if no decision was made, to ensure a continuing suitable placement and a proper transition. The social worker scheduled a meeting at the end of June to discuss the transition arrangements with the placement. At this meeting they stated that the application was just a paper exercise and only needed to be rubber stamped. They agreed for everything to be processed by 1 August and told the placement to go ahead with the transition. This involved staff visiting my child in respite during the summer holidays. I was pleased but surprised as from experience I knew things were not normally committed to in this way. I therefore emailed Social Work to state that I would await confirmation in writing before feeling relaxed that the application process was complete and authorised.

Despite trying to get in touch on numerous occasions I had no further contact with the social worker until the end of July when I was advised that the application had still not been finished but had been submitted anyway. I emailed back to ask if we should now consider setting a new deadline date for processing and should we also consider an interim plan if we had no decision by the time school restarted. Again, I stated that I would not accept being left with nothing and was disappointed as the delay had created further issues and uncertainty for us.Because we were unable to gauge how long it would take to get a decision, I felt it would be prudent to contact the educational psychologist to advise that we may need to return to school. I was happy to do this myself but believed that Social Work could give a better picture of where things stood.

By the second week in August I had still had no contact, so spoke to the Social Work Manager. They advised the Locality were not prepared to look at the application based on the costs (which I believed were incorrect). The Locality had asked for costs to be clarified and for comparisons for other possible placements. I was under the assumption this had already been done and advised it was not what had been agreed at the meeting in June. After a couple of days Social Work advised that the correct and much lower cost had been clarified, but the Locality were still saying they would not consider the application. Social Work had been asked to look for costings for 5 alternative placements, 4 of which were out of area but that this would take time and the Locality process must be followed. I was told not to contact them myself as it was an internal matter. Social Work stated that under no circumstances was a return to school possible. They suggested we look at other options even though they were not suitable or available and again suggested Homecare as the last resort. I stated how difficult it would be to put in place (find and train appropriate people) and would not be suitable respite for me, or indeed suitable for my child and their level of needs.

When the Transition Team Manager called me the following week, I told them I was very angry as I was now in exactly the situation I had been trying to proactively avoid since April. I could not access respite unless my child was still at school, so I was left with nothing. I was told our SDS budget would continue, but what good was it to me if I have nowhere to spend it. Overnight respite is vital to sustain my ability to care because of my own increasing health issues and exhaustion. I also advised that I had reluctantly given up employment the previous year because of the transition process and my child’s health deterioration. Our financial situation was therefore not as secure as it had previously been, and this was an increasing concern if I was going to be unable to return to work in some capacity.

When Social Work called again things were no further forward, but the cost comparisons had now been submitted. A respite facility had been contacted and could accommodate my child for 24 nights out of the 42 we had in our budget, but I again stated I did not feel this would be appropriate due to feeding issues and familiarity. I told them that although this was very challenging for me, it was my child that was suffering as they were getting no peer interaction, physiotherapy or hydrotherapy. This is particularly important due to issues with their legs, feet, and pain and muscle spasms.

When Social Work next called, we were no further forward. They had chased the Locality, who ‘hadn’t had time’ to look at the application. They agreed to update me the following week.

Frustrated by the lack of progress, I sent an email to theSenior Manager for Children with Additional Support Needs asking for urgent support due to the abject failure on the part of the system and appealed to them to facilitate a meeting to address the situation. They responded to say they were sorry to hear of the difficulties I had been facing but stated that following a reorganisation of health and social care all adult funding decisions are made by the Locality Teams, so they had no influence over the decision making. They advised using the formal complaints system to highlight the situation and ask for a resolution.

The next day I had a call from the Transition Team Manager to say that funding had been agreed (but would be reviewed annually) and apologised for what had happened during the process. The Senior Manager for Children with Additional Support Needs also emailed to ask about progress and when advised of the positive outcome were sorry for the stress that had been caused. A planning meeting was arranged, and a start date agreed. The placement could now not be progressing any more smoothly. My child is happy and seems boosted by a change of environment and increased interaction as they can access all the things that they not only enjoy but are essential for their wellbeing.

As you can see, I was proactive in continually contacting the Transition Team to prepare and plan for the move into adult services. I fully articulated my child’s needs, how those needs could be best met by a specific provider and how this provision would deliver on their assessed and agreed outcomes. Despite my efforts my child left school and was at home without a service, no access to respite and no plan. The cost of the provision was cited as 'too high' and out with authority settings (which were utterly unsuitable) were looked at as comparisons. The initial error which took place meant that we were no longer felt to be entitled to an additional year at school because a suitable place was available in our choice of adult provision and this was further compounded by failures in the system.

My own health has suffered in part because of the enormous caring responsibilities I have had as a carer, providing 24-hour support for the last 18 years to my child who has profound disabilities. I have had limited respite and have been continually on alert as they can become unwell very quickly. Last year I had to give up paid work, which I did specifically to plan for this essential transition and because of the number of meetings and appointments I was having to attend. This put our family in a more challenging financial situation but would have happened in any case immediately following school when we were left with nothing. I want the best for my child and that includes ensuring they are well cared for in a setting that can provide the stimulation and opportunities they need as an adult, independent of their family and that I recognise I can no longer fully provide for them. It was also vitally important to me to secure a future for when I am no longer around as it would have been extremely difficult to find a placement for my child in the event of a crisis and would also have been extremely difficult for them to cope with.

Whilst the Transition Team Manager acknowledged this failure to some degree there was no real sense of urgency to move the case forward. I had to push constantly for information, commitments were made then not followed up on and both myself and my child were sorely let down and were essentially abandoned as a family. I was told I could make a formal complaint but from previous experience know this is time consuming, hugely stressful, wasteful and ultimately there is no guarantee that anything changes. I am not aware of anyone who has had a smooth and stress-free transition. This has either been due to the lack of choice, lack of place or lack of funding. Everyone I know has had very similar and frustrating experiences, with some still not being resolved. Even though I have knowledge of the system I have found it to be one of the most challenging times I have ever experienced and one which I am still in the process of recovering from.