Lead Scotland response to Scottish Government review of Autism Strategy Consultation

1. How can we ensure autistic people and their families enjoy healthier lives?

Autistic people and their families can enjoy healthier lives if they have access to earlier tailored interventions, support, information, advice and appropriate services at the right time and with suitable support.

We deliver a free national helpline service providing information and advice related to post-school education and disability. Evidence from the helpline suggests there are consistent issues in relation to post school transitions, post school destinations and appropriate support to learn for autistic people. Families have reported they did not receive timely and appropriate advice to support their autistic child with the transition planning process and consequently experienced a negative experience post school. We have heard incidences of autistic young people not being assessed for social care support early enough in the process which resulted in support not being in place in time for the start of college. Families have also been told their children's Self-directed Support packages cannot be used to support the young person to attend college or university and they have become embroiled in lengthy and distressing disputes with social work and education providers to try and find a solution that allows their children to attend appropriate post-school learning opportunities.

Families have told us their children have been left without support to take up learning opportunities or have not been offered a suitable place in post-school learning, which has had a significant impact on the health and wellbeing of both the young autistic person and their entire family.

Parents and carers have told us they have had to reduce their working hours or give up their jobs in order to provide care and support at home for young autistic people who have not been able to move into a post-school destination. This puts pressure on the family financially and we regularly hear reports of decreased mental wellbeing amongst the whole household. Families tell us they feel anxious, worried and distressed about ‘failing’ their children, who they fear will experience increased levels of isolation and a deterioration in the social, communication and life skills necessary to lead meaningful and independent lives.

Families have told us they needed access to appropriate information at the right time and support to understand and traverse the complex systems of health, care and education that feed into the whole transition process.

Autistic people need access to a wider range of post school destinations and to have more choice to use Self-directed Support in order to access these opportunities. This in turn can benefit their own health and wellbeing and that of their families, as we know the pillars of positive wellbeing include being active, learning new skills and having meaningful relationships with regular social interaction.

2. How can we ensure autistic people have proper choice and control over the services they use and in their lives more generally?

As discussed in the previous question, we are concerned about reports we receive from families about the difficulties that can arise in trying to use Self-directed Support to access learning opportunities. We regularly hear anecdotal evidence suggesting the approach to using SDS to access learning is dependent on the policy of an individual social work department. We have heard from social work staff that due to austerity measures and budget cuts, only people in need of urgent and/or critical care would likely receive an SDS budget. Additionally social work staff have told us that SDS should not be used to fund one to one support in the classroom unless the student has a physical impairment that requires this support, and if a student requires one to one support for behavioural or health and safety reasons, then they would question whether college was the correct environment for that person in the first place.

These approaches may feel necessary as a result of severe budget cuts, but the impact on autistic people could be disastrous and result in a lack of choice, dignity, respect, active citizenship and an independent life. This directly contradicts the principles of key national commitments and frameworks like ‘Opportunities for All’ and ‘A Fairer Scotland for Disabled People’. We would therefore like to see an update of the Partnership Matters document that embeds a rights based approach to support in post-school education and has clearer links to relevant legislation and national frameworks in order to give families and autistic people more power when trying to access services and influence the decision making process.

We also regularly hear that autistic people without additional learning disabilities are not assessed as requiring an SDS package, despite the significant barriers they may face in accessing and adjusting to post-school learning environments, especially in the transition phase. However evidence from our helpline suggests a small amount of funding to provide travel training and social support in the transition phase could make a positive difference to these young people’s completion rates and attainment outcomes in post-school education. We are encouraged by the new upcoming ILF transition fund and look forward to seeing how well it can address some of the gaps in funding and service provision for young autistic people in order to give them more choice and control when entering challenging transition phases of their lives.

3. What can we do to ensure autistic people can live independently?

We receive multiple calls on our helpline from autistic students in higher education and their families, voicing concern over access and appropriate support to learn on their courses. One of the key issues we hear about for autistic students, especially those at university, is the lack of access to appropriate advocacy, mediation and redress when in dispute with their institution. Currently their options are to try and resolve the dispute informally direct with the relevant department or to enter into what can frequently be long, drawn out, arduous and distressing complaint processes which can be extremely distracting from studying and have significant impact on the student’s wellbeing. Social interaction and communication can be difficult for some autistic people, so it is vital they have access to appropriate support and advocacy when trying to assert their rights, however there are extremely limited options for advocacy in these situations. Students can access support from their student unions/associations, but there can be capacity issues in doing this as they are often staffed by student volunteers and there may also be a lack of impairment specific knowledge and expertise. We signpost students to local advocates but service provision is patchy across Scotland, there can be long waiting lists and again there may be a lack of institution or subject specific knowledge necessary to try and understand the issues and to get the best possible outcome for the student. Parents and carers have told us they feel ill equipped to try and manage the complaint process themselves without appropriate support, as this quote from a parent who contacted the helpline shows,

“I must say I feel very overwhelmed by this process as it requires me to become an expert very quickly whilst also being so worried for my son both now and for his future.

I am determined to make sure my son gets the chance he deserves to fulfil his potential if that's what he wants but I can see why people give up and accept less/compromise because it's just so hard to explain to people. For my sons health and happiness there may come a point at which we have to give up and he comes home and does an OU course or something easier which would probably leave him feeling depressed and angry as he wants to do more and is capable if weren't for his ASD, although that is also a real strength as he works so hard and has a different perspective which brings new ideas.”

If autistic people are not able to access appropriate and timely advocacy to assert their rights in education, then they may be prevented from obtaining the appropriate support and reasonable adjustments they require in order to complete their course or achieve a qualification representative of their talent and capabilities. As the parent in the above quote explains, this could lead to a loss of independence if autistic people do not have the same access to services, education and work as their peers. In school education children, young people and their families/carers have a right by law to appropriate mediation, advocacy and a tribunal process when disputing an issue related to additional support for learning. This same system and right needs to be extended to post-school education to ensure autistic people have a voice and a right of redress in order to maintain their place at college/university and consequently their independence. Previously the Disability Rights Commission (DRC) referred cases to the Disability Conciliation Service, which provided professional mediation for disabled students in dispute with their education providers. However, this service no longer exists under the Equality and Human Rights Commission following the implementation of the new Equality Act legislation. We would therefore encourage policy makers to consider making funding available for disabled students to access mediation, or implement a contractual service level agreement between institutions and a mediation service.

Another concerning trend we are starting to pick up on our helpline and when talking to colleagues, is the potential lack of choice and thus independence autistic people have when selecting educational support workers funded through the Disabled Student's Allowance (DSA). Evidence from the Equality Challenge Unit's annual 'Equality in Higher Education' report shows Scotland has the lowest take up rate of DSA amongst the disabled student population in the UK, with only 28% of Scottish disabled students claiming it in 2015/16 in comparison to their counterparts in the other UK nations, which averaged 42%. We shared this report with SAAS and Scottish Government Higher Education division colleagues, but they could not provide an obvious answer why there was such a low take up rate. The report also shows there is an attainment gap for students claiming DSA, with disabled students more likely to achieve a 1st/2:1 if they claimed the funding. Additionally, the report showed that autistic students were less likely to achieve a 1st/2:1 than non-disabled students as well as disabled students with another impairment type.

Autistic students may be assessed by the college or university as requiring mentoring support to help organise their study, access all of the institutions' services and facilities and generally integrate into and manage student life. This element of DSA is known as the 'non-medical personal help allowance (NMPH)' and students have the option to allow their institution to arrange the support workers, ask a specialist agency to provide the support workers or they can select and recruit their own support workers. However, the latter option is not encouraged by the Student Awards Agency for Scotland (SAAS) who fund DSA, or the students' institutions, due to concerns about the extra responsibilities this will impose on the student as an employer. SAAS have also voiced concerns about the student selecting their own support workers as they have no guarantees that the individual will be reliable or qualified and experienced enough to carry out the role. If students do want to choose their own support worker, then SAAS look to the student's disability service for approval of the individual's CV, however we are aware of incidences where the university will refuse to endorse or approve any workers not directly employed by them. This leaves the student trapped in a situation where they have no choice but to use an agency or use the institution's own support workers. However we have heard multiple reports recently that some large autism specific services are inundated with requests, and do not have sufficient staff to meet the demands of the DSA funded student mentoring service.

To further add to this issue, the DSA application process can take up to three months, as students have to go through multiple steps and have their needs assessed by a validated assessment centre – normally their own institution. Students calling our helpline regularly report delays in obtaining DSA, and can be faced with a minimal choice when selecting support workers due to the lack of availability of mentors so late into the academic term. We have raised the issue of delays with SAAS and government colleagues recently and would be happy to discuss this further to try and find a solution.

We would advocate for an intermediary service to be made available for disabled students looking to recruit their own support workers with DSA funding in a similar way independent living centres across Scotland support people to employ their own personal assistants using SDS. This would allow autistic students to have choice and control over the workers they select to provide them with the support they require to access higher education and maintain their independence, and it would alleviate SAAS' concerns about the reliability of staff being recruited and the extra responsibility it would impose on students.

We would also suggest Scottish Government look into wider use of the 'Brain in Hand' application, a new piece of software technology that institutions can pay a license fee for and then provide to students for free via an app on their smartphones, as cross sector professionals have reported positive outcomes through its use. The app allows students to manage their timetable and study requirements, can provide personalised coping strategies as well as allowing them to contact a member of the student support team to let them know they require extra help. The stigma and anxiety of speaking up and asking for help is routinely reported on our helpline by autistic students, so removing this barrier by allowing students a simple way of alerting a staff member would help to alleviate this and provide students with more control and independence.

4. How can we ensure autistic people are active citizens, fully integrated and able participate in their communities and society?

We would advocate for an increase in summer transition programmes for autistic students ahead of starting college and university to familiarise them with the campus, accommodation, facilities, services, associations, clubs and general student life. Autistic students and their families contacting the helpline often tell us it is the social aspect of moving away from home, living in a new city and having to make new friends that creates the most challenges for them when starting college or university. Glasgow Caledonian University offers a programme like this for autistic students over the summer, and report that bringing a student cohort together in this way can create new friendships, bonds and peer support ahead of the start of term.

We are also aware of an autistic student led peer group at Inverness College, supported by a local autism charity, that offers autistic students a forum and source of support from their peers when coping with everything student life can bring. Ensuring autistic students and local services have the capacity and are equipped to create similar student peer groups like this across Scotland would help more autistic people feel integrated into student life and part of the local student community.

5. What one single thing could the Scottish Government do to improve autistic people's lives?

Through discussions with cross sector professionals, it is apparent there is not enough comparable data available on the school attainment of autistic pupils and subsequent post school destinations, successful completion rates, attainment and post graduate employment of autistic people in Scotland. Some reports suggest there may be an under representation of autistic students studying at university level and there may be an attainment gap between them and their peers. We would suggest further research and evidence is required to ascertain what the barriers and enablers are in supporting autistic students to reach their full potential.

We would be happy to discuss this and other issues further as part of this consultation.