

Education, Children and Young People Committee

4th Meeting, 2023 (Session 6), Wednesday 1 February 2023

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

Introduction

This morning, the Committee will hear evidence from two panels regarding [the Disabled Children and Young People \(Transitions to Adulthood\) \(Scotland\) Bill](#).

A [SPICe briefing](#) on the Bill is available online.

Panels

The first panel is comprised of representatives from disability and advocacy organisations.

Links to each organisation's submission to the Call for Views are provided below (additional submissions from two witnesses are also provided later in this paper)

- [LEAD Scotland](#)
- [The ALLIANCE](#)
- [Scottish Autism](#)
- [Scottish Commission for People with Learning Disabilities](#)

The second panel is comprised of health professionals.

Panel 2

- [Royal College of Occupational Therapists](#)
- [Royal College of Paediatrics and Child Health](#)
- [Royal College of Psychiatrists in Scotland](#)

Supporting information

A SPICe briefing, prepared for this session, is included in [Annexe A](#) of this paper.

Updated submissions have been received from the Royal College of Psychiatrists in Scotland and Scottish Autism. These are provided at [Annexe B.](#)

Education, Children and Young People Committee Clerking Team
26 January 2023

The logo for SPICe, featuring the letters 'SPICe' in a white, sans-serif font on a dark purple background.The text 'The Information Centre' and 'An t-Ionad Fiosrachaidh' in white, sans-serif font on a dark purple background.

Education, Children and Young People Committee

1 February 2023

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

Introduction

The Committee has been designated the lead committee at Stage 1 consideration of the [Disabled Children and Young People \(Transitions to Adulthood\) \(Scotland\) Bill](#).

This Bill seeks to improve opportunities for disabled children and young people as they grow up. SPICe's [Bill Briefing was published in December](#).

This week the Committee will take evidence from a range of children's rights and advocacy organisations, and then from representatives of health professionals.

This paper is organised around three themes.

- The issues faced by children and their families as they move into adult services;
- How effective current policy approaches are in improving this; and
- The proposals in the Bill.

The Committee will take evidence from two panels. The first will include—

- LEAD Scotland
- ALLIANCE
- Scottish Autism
- Scottish Commission for People with Learning Disabilities.

The second panel will comprise of—

- Royal College of Occupational Therapists
- Royal College of Paediatrics and Child Health and
- Royal College of Psychiatrists Scotland.

The paper largely draws on the submissions the Committee has received from the organisations that will be attending¹.

Transitions to adult services

The need to improve support for the transition from school and children's services to further and higher education, employment and the range of adult services is well-recognised in research and policy.

By their nature, transitions involve changes. The young person will be leaving school, perhaps accessing different services through social work, housing, education, and health. The frameworks, approaches and level of resource of these may differ to those in children's services. The young person themselves will change including their expectations and desires.

These issues were explored in a 2019 SPICe briefing, [Transitions of Young People With Service and Care Needs Between Child and Adult Services in Scotland](#). That briefing explored evidence that suggested that transitions can be a difficult process for young people and their families and that barriers to successful transitions include:

- lack of support from adult services
- poor co-ordination between services
- inadequate planning and confusion around who is responsible for planning
- lack of information on available options
- young people's voices not being heard.

Furthermore, support for transitions seemed to vary considerably among local areas.

Policy reviews and research studies offered various recommendations to improve the transition process for young people. Recurring themes include the following:

- co-ordination and collaboration between services
- person-centred focus, involving the young person and their parents in decision making

¹ Scottish Commission for People with Learning Disabilities and the Royal College of Paediatrics and Child Health had not provided a submission to this Committee's call for views but had to the Session 5 Committee. <https://archive2021.parliament.scot/parliamentarybusiness/CurrentCommittees/116502.aspx>

- starting the transitions planning process early
- young people and their parents having a single point of contact
- increased information about available options
- more support for families
- dedicated transitions staff
- appropriate training for staff.

A number of submissions to the Committee's call for views highlighted the difficulties that young people and their families face during this period. The Committee also sought views from parents/carers and young people directly through a shorter survey. One young person told the Committee—

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

Lead Scotland's submission stated—

“We see young disabled people being let down all the time when they try to move into post school learning, but social care support is not funded or the education provider does not meet their needs, and the placement falls through.”

ALLIANCE's submission said that it “has heard repeatedly that children and young people's experiences of transitions to adult services are inconsistent and can have a significant impact on the care and support that children and young people receive at a time of profound change and adjustment.”

The Royal College of Occupational Therapists said that its members “identified supporting young people at this pivotal life stage as a key concern because poor continuity of care risks disengagement from services, affecting people's long-term outcomes and quality of life.” RCOT highlighted the need for a holistic and “bio-social approach” to transitions support which includes “skill acquisition for independent living, move to further/higher education and the world of work, accessing benefits, health management, community mobility access to leisure and other community facilities etc.”

The Royal College of Psychiatrists in Scotland highlighted a number of reasons for a poor transitions process. These included: complexity of needs; lack of adaptiveness to needs; lack of expertise and/or knowledge in delivering transitions; lack of collaboration across teams/services; instability and variation in third sector support; and resources coming to a “cliff edge” when a young person turns 18 with a disparity in funding of children's and adult mental health services. It also said that “mental health services for children and young people with a learning disability are patchy

and unequal across Scotland and do not reflect the population need ... it is difficult to plan transitions adequately when mental health services in childhood and adolescence are not present or inadequate”

The Royal College of Psychiatrists in Scotland said, “underpinning all this is a lack of a clear understanding of what should be available as a baseline in transitions support and planning regardless of where a young person lives in Scotland.”

Current policies and approaches

There are a number of pieces of legislation and policies which relate to the transition of a disabled child or young person as they move from children to adult services.

Issues with transitions is a live and active area of policy development. The Scottish Transitions Forum has developed Principles of Good Transitions which includes [seven principles of good transitions](#). These are:

- Principle 1: Planning and decision making should be carried out in a person-centred way.
- Principle 2: Support should be co-ordinated across all services.
- Principle 3: Planning should start early and continue at least to age 25.
- Principle 4: Young people should get the support they need.
- Principle 5: Young people and their families must have access to the information they need.
- Principle 6: Families need support.
- Principle 7: A continued focus on transitions across Scotland.

Note that here transitions are intended to cover a wider range of children and young people than does the Bill. The Principles of Good Transitions says that these seven principles can be used by--

“professionals from all sectors, the Scottish Government and national bodies. This Includes those responsible for planning and delivering support for children and young people with additional support needs within:

- Paediatric and adult health
- Child and adult social work and social care
- Education – secondary, further and higher
- Employment and training
- Third sector

- Public sector services (such as housing and welfare)
- Scottish Government and Scottish Parliament.”

Following on from this, the STF developed a draft framework, Principles into Practice, to deliver improved transition planning and support. The Scottish Government is funding a Principles into Practice trial across ten local authorities in Scotland over a two-year period and is due to be completed in March 2023.

Transitions between health and social care services can pose particular difficulties for young people. Differences between child and adult services in the structure of services, eligibility criteria and specialised training of staff are among the factors that evidence suggests can negatively affect young people's experiences of these transitions.

In February 2016, the [National Institute for Health and Care Excellence \(NICE\)](#) published its guideline, [Transition from children's to adults' services for young people using health or social care services](#). The guideline is linked to English legislation and applies in England, Wales and Northern Ireland, but has been used to inform development of Scottish Government guidance, such as the mental health Transition Care Plan.

The [Transition Care Plan](#) was launched in August 2018. The purpose of the Transition Care Plan is to improve and streamline the transition process from CAMHS to adult mental health services across health boards. The Royal College of Psychiatrists in Scotland most recent submission to the Committee said—

“The reality is that these are not yet being followed. This is largely due to disconnects between CAMHS and adult mental health services. There is cultural difference between children and adult teams and more joined up working is a way to bridge this difference. Unless both services, as well as service users, value the transition document it is unlikely to be effective. The latter are unable to devote resources to transitions until the person specifically qualifies for adult services at 18.”

In terms of people with learning difficulties the Royal College of Psychiatrists in Scotland said—

“Transition plans for children and young people with a learning disability often need to involve a wide variety of health professionals in addition to CAMHS. Community Paediatrics, hospital specialist paediatrics and AHPs are frequently involved, along with social work, specialist education, third sector and others. Where community paediatrics is involved, they may have coordinated children's complex health care needs throughout childhood, with such children having limited contact with their GPs. As overall healthcare defaults to GPs in adulthood this can be a big change and some young adults may struggle with attending GP clinics. Families can be left trying to coordinate care between numerous medical specialties alone.”

Skills Development Scotland runs the Careers Information, Advice and Guidance service as well as administering Scottish apprenticeships. Its submission highlighted two elements of the recent [Career Review](#), which were:

- For all career services across the ecosystem to adopt the social model of disability and embed shared standards of accessibility; meaning that all services focus on removing barriers from their services rather than mitigating them so that disabled people are included.
- Career services across the ecosystem should understand and embed the Principles of Good Transitions for young people with additional support needs, considering that key transition points may happen at different times for some.

[The Independent Living Fund Scotland](#) disburses Scottish Government funding to support for disabled people in Scotland. The ILF includes a Transition Fund which provides grants to help young disabled people, between the ages of 16 and 25, with the transition after leaving school or children's services to be: more independent; more active and engaged in their community; and to build and maintain relationships with other people.

Legislative and implementation gap

The Bill proposes a statutory planning process potentially which could be in place for an individual from the age of 14 to the age of 25. There are a number of different statutory processes that may apply to a disabled child or young person in that period.

When a local authority is responsible for a disabled person's school education, there are duties under the [Education \(Additional Support for Learning\) Scotland Act 2004](#) on local authorities in relation to transitions. When the individual is finishing school, there is a duty to provide information regarding pupils with ASN to such agencies it "sees fit (if any)" (e.g. colleges); local authorities also are required to seek information from any agencies it "sees fit (if any)" to discover what support will be in place for the pupil after they leave school. These duties cover all pupils who have an ASN, but is limited by the words "sees fit (if any)"; ie the local authority may not see fit to exchange information with any agency about an individual child. More details on these duties are set out in the [Additional Support for Learning \(Changes in School Education\) \(Scotland\) Regulations 2005](#), again the duties in the regulations are caveated and apply to "only in relation to such children and young persons as the authority consider appropriate".

[Statutory guidance](#) on the operation of the 2004 act recognises that applying these duties to every pupil with ASN would be burdensome. However, it states—

"It will be for those working with the child to take into account the views of the parents and child, and the particular circumstances, to decide whether the duties described below apply; young people have the same rights as parents under the Act. Education authorities will wish to consider for each child or young person with additional support needs whether the transitional duties should apply. It is anticipated that the transitional duties will certainly apply to

all those children and young people with additional support needs where one, or more, of the following circumstances apply. They:

- have a co-ordinated support plan
- are in a specialist placement such as an enhanced provision, a special unit or a special school
- have additional support needs arising from a disability within the meaning of the Equality Act 2010
- are otherwise at risk of not making a successful transition such as looked after children and young carers.”

The ASN Tribunal can hear references about failures to meet duties regarding post school transitions.

There are a number of social work duties that are applicable. For example, the Social Care (Self-Directed Support) Act 2013 seeks to ensure adults and children (including carers and young carers) are given more choice and control over how their social care needs are met. It also places a duty on local authorities to have regard to the general principles of involvement, informed choice, and collaboration when carrying out their social welfare responsibilities to both adults and children.

Evidence from various reviews would suggest that application of these duties is patchy. Respondents to the Committee’s call for views identified an implementation gap between policy and practice.

The Bill proposes a planning mechanism that spans the period from when a individual is in school to, potentially, the age of 25. This is beyond the scope of the transitions duties under the 2004 Act. Planning under SDS could cover this period, and beyond, albeit it may have a different focus.

Proposals of the Bill

The Bill seeks to improve the lives and outcomes for disabled children and young people. Its proposals have three strands:

- A statutory national strategy
- A minister to be specified as being responsible for the transitions of children and young people
- A duty on local authorities to plan for disabled children and young people’s transitions and a statutory process for this.

The overall aims of the Bill were welcomed by the witnesses in both panels. There were, however, some differing views on whether the specific proposals would achieve the aims of the Bill.

Lead Scotland’s submission stated—

“We agree with the overall aims of the bill, and would support initiatives that could lead to improved outcomes for disabled children and young people, as we mirror the concerns and frustrations around transitions expressed in the bill. However, we are not convinced the bill can meet these aims. We have concerns about the content of the bill, the financial implications and the impact it could have on an already cluttered policy landscape ... Despite the existing legislation and expectations on professionals, poor transition experiences are still regularly reported. This is a challenging, multi-faceted and multi-disciplinary area of policy, and we do not believe introducing a new law can be a silver bullet to overcome the layers of complexity transitions presents.”

Lead Scotland suggested instead that more focus and resource be put into existing policy. It placed the difficulties in improving outcomes not in inadequate legislation or intentions, but in the “the practical and logistical challenges of [implementation]”. SCLD agreed, cautioning that “legislation does not necessarily guarantee good outcomes for people” and “we believe that effective implementation is key to success.”

ALLIANCE supported a legislative approach. It said—

“The ALLIANCE believes that grounding these provisions in law is important to implement change and to place obligations on the Scottish Government and public bodies to deliver good quality, person centred care that meets the rights and needs of disabled children and young people, and their families as they navigate changes across interlocking systems. Changing the law will therefore support disabled children and young people to receive appropriate support to help them transition to adulthood.”

Royal College of Paediatrics and Child Health’s submission strongly supported the Bill. It said, “it is only by implementing the whole Bill as introduced, prior to any significant diluting amendment, that the anticipated aims may be achieved” and “non-legislative approach such as guidance would be more likely to be ignored than statutory duties”.

Scottish Autism’s submission welcomed the aims of the Bill to avoid a “cliff-edge” of support falling away as they leave full-time education. It said successful implementation would depend on “how the agencies responsible for delivering the legislation are held to account for those responsibilities”. ALLIANCE agreed and also argued that to achieve effective implementation the Bill should be “underpinned by human rights and a rights based approach.” It also called for “a culture shift at ground level to ensure disabled children and young people’s outcomes are at the heart of planning across services”.

The accompanying documents to the Bill say that this is a stand-alone Bill. It is insofar as it does not seek to amend any other legislation. However, in practice the additional duties proposed by the bill will interact with a range of duties and policies in education, health, social work and so on. The [SCLD’s submission](#) indicated that it supported the Bill introduced in Session 5 (which is very similar to the current Bill) and highlighted a number of measures that would be required for successful implementation, including work to:

“Align any new legislation with existing legislation which impacts on children’s and young people’s transitions planning. This must include clarification of the relationship between existing plans such as the Coordinated Support Plan and the proposed Transitions Plan.”

National Strategy

Part 1 of the Bill provides for a duty on Ministers to "prepare, publish and implement" a strategy "in relation to improving transitions to adulthood for children and young people with a disability" (section 1(1)). This strategy is to be called the National Transitions Strategy.

The Bill provides that a National Transitions Strategy (NTS) must set out:

- aims and objectives of the NTS
- the actions Scottish Ministers will take to meet these aims and objectives
- outcomes that will be achieved through the NTS
- actions that bodies or individuals must undertake to meet the aims and objectives of the NTS
- details on the support and assistance that will be available to children and young people.

The concept of having a NTS is well-supported and the Scottish Government is currently developing non-statutory national strategy.

ALLIANCE’s submission stated, “an underlying strategy is important to ensure the provisions and principles of the Bill are reflected at ground level and to outline core actions needed to achieve its core aims.”

The Royal College of Psychiatrists in Scotland said—

“A national strategy has the potential to house a clear understanding of what should, as a minimum, be expected by young people and their families/carers that local health boards, IJBs, and local authorities can be held accountable to. This can also include metrics to judge the success of these processes by, in order to build in performance improvement and outcomes-focused metrics. This currently only exists in some localities.

“A national approach to what metrics should be in place, their measurement and procedures to tackle underperformance should be prioritised as part of any strategy.”

The Bill provides for a duty to report annually on the progress made through the NTS (Section 16). The submission from the EHRC argued for better data on the long-term outcomes for disabled young people, e.g. understanding how employers and others had made reasonable adjustments. SCLD’s submission highlighted Article 31 of the UN’s Convention on the Rights of Persons with Disabilities which requires

states to “undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the [CRPD]”.

One of the more contested elements of the proposed NTS is that bodies would have a duty to comply with actions set out therein. In other words, duties could be created on a range of bodies through the publication of the NTS, rather than being approved by Parliament. COSLA has expressed concerns about this power. However, the Royal College of Paediatrics and Child Health’s submission stated—

“We particularly welcome the proposed requirement that; Ministers, local authorities, Health Boards and Integration Joint Boards must comply with the aims and objectives of the National Transitions Strategy in exercising their functions as this would not only enhance consistency in service delivery but will also bind these stakeholders to aim to provide the highest standard of transition planning and delivery.”

Who should the Bill cover and how should young people be identified?

The Bill defines a child as a person under the age of 18, and a young person as being under the age of 26, i.e. between the ages of 18 and 25.

The Bill proposes that the duties under the Bill would apply to individuals who fall under the definition of disability in Section 6 of the Equality 2010 Act. This says—

“A person (P) has a disability if—

- (a) P has a physical or mental impairment, and
- (b) the impairment has a substantial and long-term adverse effect on P’s ability to carry out normal day-to-day activities.”

This is a legal test and [statutory guidance on this definition](#) noted that “in the vast majority of cases there is unlikely to be any doubt whether or not a person has or has had a disability” but in some cases it will not necessarily be clear. Iain Nisbet, a lawyer who specialises in education law, said in his submission—

“The definition of disability by reference to Section 6 of the Equality Act 2010 is the correct approach, but it is not a clear dividing line. Using this definition does invite disputes as to whether a particular pupil is, in fact, disabled and therefore entitled to a plan. Any dispute resolution mechanism needs to be equipped to give a quick and definitive answer to this (complex) question. The Tribunal already deals with questions under the Equality Act 2010 and would be well placed to do so.”

Local authorities have a duty to identify pupils’ additional support needs. This is a different definition to that in the Equality Act and applies only to those pupils for whose education the local authority is responsible. It is not clear how local authorities could identify every child or young person meeting the Equality Act definition of disability.

The EHRC's submission argued that the Bill should "clarify the process for identifying children and young people eligible for a plan" to ensure consistency. The National Autism Society Scotland's submission welcomed the use of an "Equality Act compliant definition of disability" but asked for references to "diagnosis" in the Bill to be removed and "clear and concise guidelines are provided on who exactly would qualify for a transition plan".

The submission from the ILF supported the use of the definition in the Equality Act 2010, but argued that it would cover a greater number of people than is envisaged in the Financial Memorandum as it would include, "young people with autism, mental health challenges, visual and hearing impairments, and long-term health conditions, as well as physical and learning disabilities and others." The ILF also questioned how disabled children and young people who have little or no interaction with statutory services would be identified.

The Royal College of Psychiatrists in Scotland suggested that the 2010 Act definition would limit "the Bill's scope and, in the case of mental ill health conditions, fails to recognise those:

- with mild to moderate mental ill health
- those going through a mental health crisis
- those with fluctuating support needs."

The duty to prepare and implement a transitions plan under section 7 of the Bill applies to all disabled children and young people in the local authority area up to and including 25 year olds. This duty does not rely on a request being made for a plan, nor is it qualified by considerations of reasonable practicality. It appears that the intention is that the plans would be initially prepared for individuals under the age of 18, indeed subsections 7(2) and 7(3) suggest this, but the drafting is not clear in respect to disabled persons who are 18 and over and who do not have a transitions plan. The Bill does not explicitly allow a child or young person to refuse to have the plan prepared in the first instance.

Proposed planning process

Part 2 of the Bill provides for a duty on local authorities to "prepare and implement a transitions plan for each child and young person with a disability within the local area" (section 7(1)).

The intention is that the local authority will be the body responsible for developing, reviewing and delivering the plan.

Section 10 of the Bill provides for the content of the plan to include both a "statement of needs" and "details of the care and support which shall be put in place to address these needs". One of the criticisms (e.g. from Lead Scotland) of the plans is that Section 10 has a focus on needs, rather than outcomes (i.e. what the child or young person wants to do/achieve.) Outcomes are referenced in Section 12 which is concerned with the ongoing management and review of the plans.

Section 12(2) would require local authorities to keep under review the needs of the individual, the support to meet these needs and whether the outcomes of the transitions plan are being achieved.

During both the initial preparation of a plan and the review process, the Bill provides that the local authority must consult with the child or young person, their parent/carers and potentially others. In doing so the local authority must have regard to the importance of communicating in an inclusive way.

Under section 7, local authorities are expected to implement transitions plans. Further, section 9 says:

“A local authority must ensure each disabled child or young person within the local authority area receives the care and support necessary to meet the needs identified in the child’s or young person’s transitions plan.”

Exactly what this would mean in practice is unclear, particularly if the plan relies on, for example, a college or specialist medical support to support the young person to achieve their goals. The Financial Memorandum envisages on average around 1 hour after every meeting in relation to Transition Plans would be required for follow-up action.

The plans will be managed by an officer of the local authority. While the individual is at school, the intention is that a teacher would develop the transition plans and then a social worker would take on the duty to manage plans thereafter.

ALLIANCE’s submission noted that having a central plan could reduce the need to provide the same information across several services. Its submission stated—

“ALLIANCE members have repeatedly highlighted the importance of holistic and coordinated support, and would welcome a central contact to support families through transitions. It is important that the person responsible for coordinating the plan has good knowledge of several services, and is able to share information with others.”

Sharing information must be done in line with overarching legislation. The ICO’s submission noted that the provisions of the Bill would require information sharing of “[special category data](#)” which is personal data that needs more protection because it is sensitive, e.g. data concerning health. This means that organisations sharing data will need to have both a lawful basis for processing under both [Article 6](#) and [Article 9](#) of UK GDPR.

Section 12 of the Bill allows for the Transition Plan to be “transferred to another relevant authority” during a review. The Explanatory Notes give the example of an individual moving to another local authority area. Although not wholly clear, this could also be read as being transferred to another type of service, which may be desirable if the young person’s needs are largely health related. Section 12(7) provides for Ministers to make regulations on this matter. The Royal College of Occupational Therapists said that “Occupational therapists have the skills and expertise to take on the role of named worker to work with a young person and their family to coordinate plans and services during the period of transition.”

The Royal College of Psychiatrists in Scotland said—

“Local authorities taking the lead on this ignores the new landscape of health and social care. IJBs and Health and Social Care Partnerships are bodies focused on the multi-disciplinary work required to fulfil transition plans in a mental health setting, and ideally these bodies should lead on developing these plans with local authority input.

“We would suggest the Bill be amended to better reflect the current health and social care landscape, and for this duty to be placed on IJBs and/or Health and Social Care Partnerships.”

In relation to the proposed plans, the SCLD called for clarification in a number of areas. These were:

- who should lead the planning process
- the scope of the proposed Transitions Plan; and
- whether all young people with a learning disability will be eligible for this proposed planning process, regardless of a formal diagnosis being in place

The SCLD also questioned whether a statutory planning process would divert attention and resources away from service delivery.

The financial memorandum suggests that Transitions planning would be either not required or be minimal for over half of the people that it considered would be eligible for a transition plan (para 18 of the FM). This is because those people would enter employment or higher education. This is similar to the modelling in the FM for the previous Bill and the SCLD suggested that this was “misconceived”. It said—

“The Bill will require local authorities to have responsibility for reviewing young people’s transitions plans to the age of 26. In our view it is extremely likely that those who do move from school to a positive destination will still need support with their transition before this age. For example, all those who graduate from college and university are likely to require a review/update of their action plan at this point. As are those who move into temporary or short-term training or employment, including apprenticeships where the young person does not move seamlessly into permanent employment. As are those who decide in their early 20’s that they would like to move out of their parents’ house.”

The SCLD also suggested that the average time to develop and manage the plans (c4 hours a year) is likely to be an underestimate as it does not take account of:

- the logistical challenges involved in co-ordinating a meeting with so many people from a range of agencies
- the time it takes to liaise with the young people and their families and to ensure they are prepared for the meeting

- the time it takes to prepare accessible notes in at one or more formats
- extra time demands arising from a key player failing to attend a meeting
- any allowance for travel time particularly in rural areas

Available support and services

In the Committee's call for views, one of the critiques the Bill has been that planning in itself will not create the opportunities and support required for disabled young people to flourish. A National Strategy could be a policy vehicle that improves those opportunities and support, but there would be likely be an additional resource requirement as well.

Scottish Autism's submission said that plans could only be meaningful if there are "opportunities to transition to - whether in education, training, employment, or support services that are accessible to people with a range of needs." Lead Scotland's submission said—

"We accept the intention of the Bill is not to provide new provision or fund provision. However, it is only logical that if more young disabled people are getting proper transition planning than before, and have a plan that requires support, where previously these young people wouldn't have had a plan or support on leaving school, then there is going to be a higher demand for services and provision. It is the funding of this provision that is raising concerns for us."

Ned Sharratt, Senior Researcher (Education, Culture), SPICe Research

26 January 2023

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Annexe B

Disabled Children and Young People (Transitions to Adulthood) (Scotland Bill) - Submission from Royal College of Psychiatrists in Scotland

24 January 2023

Who we are:

- **Who we are** – The Royal College of Psychiatrists is the professional medical body responsible for supporting the psychiatry profession to develop standards and act collectively to improve clinical care and treatment for people with mental ill health. This support extends throughout their careers, from training through to retirement, and in setting and raising standards of psychiatry in Scotland and the United Kingdom.
- **What we do** – The College aims to improve the outcomes, not just of people with mental ill health, but to also positively address the mental health of all individuals, their families and communities. To achieve this, the College sets standards and promotes excellence in psychiatry; leads, represents and supports psychiatrists; improves the scientific understanding of mental illness; works with and advocates for patients, carers and their organisations. Nationally and internationally, the College has a vital role in representing the expertise of the psychiatric profession to governments and other agencies.

Current Experiences

What are the key issues that disabled young people face as they move out of children's services and into adult services?

In 2022, to gain a greater insight into this area, we engaged with our members on the subject of transitioning between child and adult services. This can be a critical moment in the lives of children and young people.

Our members reported that children and young people are more likely to experience a positive transitions process when they are supported by a multidisciplinary team. They are then able to adapt more successfully and see their chances of recovery and/or maximised living increase.

When transitions processes fail, children and young people suffer. This can be a result of:

- The complexity of a young person's needs
- The lack of adaptiveness by their local area and service/care providers to said needs
- The lack of expertise and knowledge in delivering transitions
- The lack of joined up thinking and co-working across multi-disciplinary teams

- The instability and variation in available local third sector and community provision
- Resourcing provision within services, and the inability for resources to transfer gradually over the transition period rather than the cliff edge that currently exists once a young person turns 18.

Underpinning all of this is a lack of a clear understanding of what should be available as a baseline in transitions support and planning, regardless of where a young person lives in Scotland.

Many of the difficulties young people face with the transitions process happen over time once they are in adult services, after the immediate transition. Targeting funding at children's services alone therefore exacerbates a cliff edge for young people and the level of support they can expect in adult settings.

To avoid these impasses, the funding of care needs to be much more adaptive, switching gradually over time between child and adult services and 'going with the patient,' rather than the current overnight switchover that can take place. This would require a greater level of planning and adaptiveness across the services involved in delivery. A gradual move of resources between child and adult mental health services was seen as a potential means to address this.

The pandemic had a significant effect on young people too, impacting upon their ability to access education and properly socialise. We have already seen evidence that this has consequently affected children and young people's mental health. [An NHS study conducted during lockdown](#) estimated rates of probable mental ill health increased during the pandemic from one in nine children and young people to one in six.

We know that children and young people with a learning disability have much higher rates of mental ill-health, even before the pandemic.

An international review (Munir, 2016) concluded that the prevalence of learning disability in children and young people is around 1-3%, with prevalence of co-occurring mental ill-health being around 40%, and persistent mental ill-health around 30%.

We know that mental health services for children and young people with a learning disability are patchy and unequal across Scotland and do not reflect the population need. Their services have not increased in line with improvements in CAMHS as a whole. Thus, in relative terms, access for children and young people with a learning disability is reducing compared with their peers. Any transitions bill cannot ignore this inequality in services based on disability. It is difficult to plan transitions adequately when mental health services in childhood and adolescence are not present or inadequate.

How effective are health-focused transition plans, e.g. CAMHS Transition Care Plans?

Transition care plans were introduced in 2018. The reality is that these are not yet being followed. This is largely due to disconnects between CAMHS and adult mental health services. There is cultural difference between children and adult teams and more joined up working is a way to bridge this difference. Unless both services, as well as service users, value the transition document it is unlikely to be effective. The latter are unable to devote resources to transitions until the person specifically qualifies for adult services at 18.

Transitions for children and young people from CAMHS to adult services is made more complex by the great variation between local services. For example, children and young people with a learning disability may be seen by specialist LD CAMHS services or within 'mainstream' CAMHS (where there may not be the required experience). In adulthood, most of those with LD would usually be seen by LD services, rather than adult mental health. CAMHS transition plans need to take account of the local service arrangements and ensure that these complexities of service provision are accounted for.

Transition plans for children and young people with a learning disability often need to involve a wide variety of health professionals in addition to CAMHS. Community Paediatrics, hospital specialist paediatrics and AHPs are frequently involved, along with social work, specialist education, third sector and others. Where community paediatrics is involved, they may have coordinated children's complex health care needs throughout childhood, with such children having limited contact with their GPs. As overall healthcare defaults to GPs in adulthood this can be a big change and some young adults may struggle with attending GP clinics. Families can be left trying to coordinate care between numerous medical specialties alone.

How are young people and (where appropriate) their families views' taken account during the transitions process?

Currently, many families are forced to advocate for their child to receive the right transitions support for them. This disenfranchises some families and carers who do not have the resources (including time and knowledge) to be able to advocate as strongly. This is particularly challenging for single parents.

Transitions champions are needed to ensure, no matter how able a parent or carer is to advocate, every child is able to get the transitions plan they need.

It is essential going forward that the needs and rights of parents and carers are also recognised in transition planning. While the plans should be centred around the young person, parents and carers are also critical and, in the case of a young person with complex mental ill health, may be providing 24/7 care with little to no respite.

Making sure their needs are catered to and that they are enabled to create as positive an environment as possible for the young person is therefore critical.

Young people with a learning disability also require additional communication support to ensure that their views are adequately sought and heard. Specialist advocacy may be required, along with support from those who know the young person best, with use of communication systems like signing, PECS and talking mats, as appropriate SLT may need to be involved to support.

How well do health services collaborate and co-ordinate with other services (e.g. education, social work) to support holistic approaches? How does this differ in children's services, adult services and the transition between the two?

Coordination between services could be improved.

Our members felt that expanding the number of bodies responsible for transitions would be a positive step. By ensuring it was 'everyone's business' to work to deliver the aims of a transitional strategy, it would create the drive needed to bring the multidisciplinary voices required for successful transitions planning together. Too often, it was suggested different parts of the system felt the transitions process was 'someone else's problem.'

Making transitions a key responsibility for relevant bodies was seen as a means of addressing a lack of willingness in some services to play their part, though this needed to come alongside additional steps such as more flexible resourcing.

Any expansion of transitions planning would also need to be accompanied by additional training for staff, with the resulting impact on resources needing to be considered. The training could ensure everyone involved understood the expectations for this process and how they can contribute. By delivering it jointly for different professions, it would also build in cross-disciplinary working.

How successful has the work of the Scottish Transitions Forum been in improving transitions processes?

The Scottish Transitions Forum have played an important role through their analysis of children and young people's experience of transitions.

[A 2020 report from the Scottish Transitions Forum](#), during the height of the pandemic, surveyed carers and parents of young people with additional support needs. It found that 70% hadn't had a transitions meeting and nearly nine in ten families didn't have or know about a transition plan.

The above demonstrates that the pandemic and its subsequent impacts have fallen hard on children and young people transitioning in their care. Therefore, the importance of a national strategy and accompanying statutory duties has only grown.

In 2021, the forum published their [Divergent Influencers report](#), bringing together the views gathered from a survey conducted by young people, with young people. It found that:

- The path towards young adult life for young people with additional support needs fluctuated widely between periods of happiness and unhappiness. This transitions journey was impacted with a significant lowering in happiness ratings between the ages of 18 and 19.
- Transition has an impact on young people's mental health and wellbeing. For many this had developed into stress and more severe anxiety as they grow into young adults.
- Young people are not generally asked simple questions (for example, what is your dream/goal? What is it you love to do?) and person-centred planning wasn't available to provide them with encouragement and inspiration to do what they would like to do.
- Self-awareness and self-management of diagnosis and health conditions help young people to become more independent.
- Taking more responsibility and control was rated highly by young people to help them become more independent. They indicated their experience of independence was related to their ability to manage social and personal barriers to inclusion, needing more confidence in social and everyday situations.
- And availability of support was the most important thing to help young people become more independent. Support could be provided by a family member, professional or other person.

How would you measure success of a transition at an individual level? How might you measure the success of outcomes for disabled young people at a national level?

Any Bill should include metrics to judge the success of these processes, in order to build in performance improvement and outcomes-focused metrics. This currently only exists in some localities.

A national approach to what metrics should be in place, their measurement and procedures to tackle underperformance should be prioritised as part of any strategy.

In this regard, ministerial responsibility for overall national performance should also drive performance improvement and ensure the government of the day is held accountable for the transitions our most vulnerable young people have in mental health settings. This ideally could be accompanied by regularly updated performance metrics with breakdowns by locality.

The Bill

Would a national transitions strategy support more consistent approaches and better outcomes? If so, how?

Many of the difficulties in delivering transitions in a mental health setting stem from a lack of understanding as to what constitutes best or even baseline practice in localities, leading to significant variations and resulting geographic inequalities.

A national strategy has the potential to house a clear understanding of what should, as a minimum, be expected by young people and their families and carers. Local health boards, IJBs, and local authorities can then be held accountable to this.

Should local authorities take the lead on planning transitions? In all cases?

Local authorities taking the lead on this ignores the new landscape of health and social care. IJBs and Health and Social Care Partnerships are bodies focused on the multi-disciplinary work required to fulfil transition plans in a mental health setting, and ideally these bodies should lead on developing these plans with local authority input.

We would suggest the Bill be amended to better reflect the current health and social care landscape, and for this duty to be placed on IJBs and/or Health and Social Care Partnerships.

Shifting the burden of proposing a transition plan from the families to an authority, whether it be IJBs or local authorities, was a significantly better approach. The current approach in many cases, of families and carers having to navigate the system to be able to identify what is available only for those plans to be rejected, is inadequate.

Increasing the role of local authorities and IJBs to lead on these processes should also be accompanied by a clear understanding of what options should be available. Without a sufficient variety of options, there will always be real failings in meeting the needs of a young person.

A greater understanding of the baseline for delivering transitions support could be delivered through the process of establishing what should be provided through transition plans within the national strategy.

How should/can local authorities identify children and young people eligible for a transitions plan?

We would recommend following the principle of starting early, focusing on complexity and anticipation of needs. Children and young people should be at the heart of planning, as should their parents and carers.

Sometimes starting at a transitions plan at the age of 14 is too late, while other times it may be too early. Asking children, young people, their parents and carers about when to start is helpful. Often, it needs buy-in from all services to participate in transition plans. It is better to leave this with team around the child as a task to initiate using the GIRFEC principles.

All children and young people need to be kept in mind when it comes to transitions. Prioritising young people with more complex like in OOA placement, LAAC, Pt with complex health and social care need.

To what degree (and how) would a statutory planning process support better outcomes for disabled children and young people?

On its own, a statutory process is unlikely to make a huge impact on improving outcomes for disabled children and young people. The current services for disabled children and young people can often be a postcode lottery, with only four boards having CAMHS LD clinicians.

Alongside legislation, there needs to be investment in a managed service network for CAMHS LD/ID that has regional, national and local service components. This should be able to improve connections with Paediatrics as well as adult LD, working to decrease unhelpful variability in practice across Scotland. This would complement pathways for the new national LD CAMHS beds. It may be worth considering life span disability services for mental and physical health for smaller boards, investing in workforce and pathways to achieve this cultural shift.

In addition to this, there should also be a statutory need for children and young people with a learning disability to have equal access to mental health services. This should be the case under Equalities and Human Rights Legislation. Getting things right for children and young people with a learning disability in childhood would provide a much firmer foundation for delineating and then providing for their needs into adulthood.

Disabled Children and Young People (Transitions to Adulthood) (Scotland Bill) - Submission from Scottish Autism

New Struan School

New Struan School is an independent special school providing education and residential care services to autistic children and young people aged between 4 and 18. Our services are commissioned by local authorities across Scotland and we currently have young people from 11 local authorities. The average age of our population on admission to the school is 14 years and 3 months. Our cohort are those with the highest level of need and most challenging presentations of autism within Scotland and as such all will need carefully planned, managed, and supported transitions into adulthood to secure positive outcomes.

Current experiences

What are the key issues that disabled young people face as they move out of school/children's services and access adult services?

- Young people and their families face losing a network of people (school staff, social workers and key health professionals) who know them well and understand the support they may require. This coincides often with a significant change to routine as school finishes and requires many to leave their homes (in residential care) or their respite places.
- Transition planning starts too late. In the current guidance 16 is good practice but 6 months prior to transition is the requirement. This is simply not enough time to put together a package of support and plan an effective transition particularly for those with a more complex profile of needs.
- Arbitrary point of transition for many – could be sooner or later if the right systems existed and could be at the right time for young people
- Transitions are at the mercy of the system in terms of the capacity of social work teams, budgets and the availability of placements or services
- Assessment processes differ across local authorities and this leads to inconsistent experiences and an equity gap.
- We have young people who despite accessing the most specialised kind of education placement are assessed as not being eligible for ongoing support when they leave schools as they do not meet a threshold.
- For those who will require care and support throughout the rest of their lives there is a lack of available placements.
- The social care crisis and recruitment challenges impact on the timescales for transitions as even if there is a placement identified then there is a delay whilst recruitment takes place. This leads to young people either being without a service and families having to step in to fill the gap or young people remaining in placements that are no longer suitable.
- Young people and their families are left stuck waiting for the next stage of their lives to begin because there is nothing available at the time they need it

- There is no clear, coherent pathway to identify and assess need. Who holds the knowledge of the young person?
- The funding change from Children and Education to Adults is a source of tension within local authorities and impacts the effective planning. From the perspective of a commissioned service this appears to be around budgets and resource allocation criteria being different
- Young people often fall between the gaps in legislation
- Where there is no suitable placement the option of last resort can result in the liberties of young people being removed when, for example, they are detained in hospitals or in environments unable to meet their needs. This is catastrophic for young people and devastating for their families.
- Young people have no voice in many of the decisions about what they can access. There is not a suite of options as there are for other young people (higher education, apprenticeships etc) decisions based on funding and availability not the best level of service to meet the needs and preferences of young people.

How are young people and (where appropriate) their families views taken account during the transitions process?

- This should be happening during either education-based reviews, transition planning or statutory reviews such as Looked After Children's Reviews.
- There is a lack of independent support for parents to understand the process and their rights and obligations within this (e.g. Guardianship) which enables active participation.
- Parents describe facing a 'cliff edge' when the young person is leaving school. There are often networks of support and key relationships will end.
- Guardianship takes a long time to secure and there is a lack of clear and accessible information available to parents about benefits for young people as this is all happening at the same time as transition is (or should be) being planned it causes frustration.

Is there a lack of services or opportunities for some disabled young people when they leave school? If so, what are the gaps?

- There is lack of specialist provision that can meet the needs of autistic young people and particularly provision developed to meet the sensory, communication and environmental needs into adulthood.
- There is also a lack of developmentally appropriate opportunities for many of the young people that we work with.
- Often specialist services are offered by the third sector who are trying to plug the gaps. This means that is a further equity gap based on location as these services are often not national in scope.
- Conversely, there may be no services within a local authority area meaning that young people are moved away from family in order to receive the support that best meets their needs which impacts on family relationships.
- For other young people the challenge is that they do not meet the criteria of being disabled enough to access support. For those with hidden disabilities

such as autism this can result in increased vulnerability and poor outcomes due to isolation. The result of this has a huge impact on the mental health and wellbeing of young adults.

- The current social care and recruitment crisis is having a very real impact on the availability of placements and the staff to deliver services. This in turn creates bottlenecks in residential special school provision and availability of placements.

How well do services collaborate and co-ordinate to support individuals? How does this differ in children's services, adult services and the transition between the two?

- For a number of the young people we support there is a real lack of collaboration between children's and adult's services both in Social Services and in Health. CAHMS is an example. There is then the issue of collaboration between Social Services and Health. Prior to 18 this is buffered by the pastoral role of the school and is well coordinated in special schools
- Where young people are placed in a service such as New Struan (an independent special school) this adds another partnership dynamic into the transition

How successful has the work of the Scottish Transitions Forum been in improving transitions processes?

- Clackmannanshire is not one of the areas in the trial however we do have young people from three of these areas.
- For those who are in out of authority placements we have not seen the principles filter through to practice

How would you measure success of a transition at an individual level? How might you measure the success of outcomes for disabled young people at a national level?

- At an individual level successful transition can be measured in terms of how well the destination service is matched to need and allows the person to thrive. Living a meaningful and fulfilling life.
- Also how well the transition supported the young person's wishes and aspirations is an equitable way of measuring individual success
- Outcomes in work, further/higher education should already be tracked and so could be used
- A way of asking disabled people throughout the transition and into their adult lives also offers the opportunity to keep improving the system
- Measures around wellbeing are useful although these are subjective

The Bill

Would a national transitions strategy support more consistent approaches and better outcomes? If so, how?

- Yes – accountability and a holistic overview – this bill needs to have teeth
- Strategic overview must also include a funding strategy so it isn't creating a hierarchy of need and a race to the bottom
- The Bill offers the opportunity to recognise and plan for the fact that people are adults for a much longer time than they are children and that there must be planning for beyond statutory education as early as possible

To what degree does part two of the Bill replicate duties under ASL or social work or Skills Development Scotland legislation? What are the reasons for the gap between implementation of policy and duties and experiences?

There are inevitable overlaps within these pieces of legislation and what is being proposed within the Bill. In my view this is not an issue as the legislation should be considered as a suite and ensure that fewer young people's rights are not upheld or their individual circumstances mean they fall through the gaps.

- The pressures of funding placements and opportunities post compulsory education mean impact on the implementation of these policies in the fullest form
- There is a capacity issue within Social Services meaning that there is a delay in allocating a young person to a worker or that there are multiple workers throughout transition which leads to delays and frustration

Should local authorities take the lead on planning transitions? In all cases?

- Yes but there must be accountability and involvement from health services too.

How should/can local authorities identify children and young people eligible for a transitions plan?

- Local authorities should know exactly who these young people are through their data and tracking from both education and health care.
- Statutory processes such as Co-ordinated Support Plans or those within the Children's Hearing system also provide this information
- A statutory obligation to identify and report on those who may need transition support might be a way to ensure equity as the mechanisms to do this already exist through the Pupil Census, Education tracking etc already exist

To what degree (and how) would a statutory planning process support better outcomes for disabled children and young people?

- Accountability and independent oversight of the process would hopefully enable better strategic planning for disabled young people so there are services available
- A requirement to track and report on outcomes at key points during transitions would allow issues to be flagged earlier giving a chance to course correct.