



Consultation Response

Response to the Proposed Disabled Children and Young People (Transitions) (Scotland) Bill

The Scottish Commission for
Learning Disability
January 2020



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

The Scottish Commission for People with Learning Disabilities (SCLD) welcomes the opportunity to respond to the consultation on the Proposed Disabled Children and Young People (Scotland) Bill. SCLD is an independent charitable organisation and partner to the Scottish Government in the delivery of Scotland's learning disability strategy, *The Keys to life* (2013)¹ and *The keys to life* Implementation Framework (2019-2021)². The implementation framework defines a learning disability as follows:

"A learning disability is significant and lifelong. It starts before adulthood and affects a person's development. This means that a person with a learning disability will be likely to need help to understand information, learn skills and live a fulfilling life. Some people with learning disabilities will also have healthcare needs and require support to communicate."

(The Keys to life, 2019-2021, p.9)

SCLD is committed to creating an environment in Scotland in which systems and culture are changed to ensure people with learning disabilities have opportunities and are empowered to live the life they want in line with existing human rights conventions. SCLD believes that the discrimination and barriers faced by people with learning disabilities and other disabled people are not inevitable. These barriers stop people with learning disabilities and other disabled people being included in society and participating on an equal basis.

SCLD is focused on sharing innovation and good practice so that those providing services and interventions can learn from each other. SCLD also aims to be a knowledge hub and to build an evidence base, sharing how policy is being implemented and building on an understanding of what really works.

¹ [*The Keys to life* \(2013\)](#)

² [*The Keys to life* \(2019-2021\)](#)

In preparing this consultation response, SCLD held three focus groups. The make-up of these groups was:

1. Young people (10 recent school leavers, aged 18 – 28)
2. Parents of young people with complex needs (3 parents)
3. Professionals (range of local authority children and adult social care, teachers, health professionals, third sector children and adult services, Transitions workers – 9 in all)

In addition, SCLD led a discussion about this consultation at a meeting of the Social Work Scotland Learning Disability Sub-group.

Responses from these focus groups confirmed much of what has been evidenced previously in, for example, Scottish Transitions Forum's *Facing the Future Together*³ and the Alliance's *Experiences of Transitions to Adult Years and Adult Services*⁴

Some young people described feeling excited and happy to be leaving school, and indeed were now doing what they hoped they would do after leaving school, in particular being on the college course they wanted to get onto.

However, we heard about many challenges from other people for whom this had been a difficult time. Challenges included:

- Not being listened to
- No-one taking the lead in planning for transitions
- Not getting information about what is available
- Not having support in place from adult services in time. This had knock-on effects. For some it meant having to stay on at school for another year (not as a positive choice). For others it meant being unable to take up a college place they had been offered
- Even when things were put into place on time, it was often last-minute, causing considerable anxiety
- Finding out too late that services would no longer be available that they had access to as a child e.g. physiotherapy
- Not knowing about changes to income arising from benefits changes and/or a care charge being payable for adult social care
- Lack of choice e.g. being placed on a college course they had no interest in, because the course they wanted to do was unavailable
- Lack of support to do things other than reach a '*positive destination*' e.g. keeping up friendships, move into their own home

³ [ARC Scotland \(2017\)](#)

⁴ [Health and Social Care Alliance Scotland \(2017\)](#)

- Nothing being easy. Young people and their parents reported having to work very hard to get information that should be readily available, and to secure opportunities that should be straightforward to access.

Although some young people said they felt excited to leave school, others described feeling '*sad*', '*nervous*', '*scared*', '*terrified*', '*angry*' and '*confused*' about moving on.

The challenges identified can be grouped under two headings:

1. Planning difficulties. For example a lack of information, poor coordination between agencies, or lack of contribution to planning from individual agencies
2. Insufficient levels of provision. For example not meeting eligibility criteria for social care support, unavailability of physical therapies, and unavailability of college courses in the right subject or at the right level for the young person.

Support to make the transition from school varied, even within the one school. Most young people reported having had good support from the school, though that depended on the individual teacher. Parents often helped. One parent secured legal assistance. The college was sometimes helpful, but for some pupils this help felt very last-minute. Social workers were generally not seen as helpful.

More than anything, parents reported the difficulty of having to plan everything, from transport to physical therapies to finances. This was in contrast to when their child was at school and all provision was coordinated and delivered in a single location. Not knowing where to find information, and being given incomplete or contradictory information, were seen as enormous challenges.

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

SCLD believes young people with a learning disability have the right to the best possible childhood and the best possible support to make the transition into adult life, so that they might live fully as active citizens, with as much autonomy as possible to follow their own path and fulfil their potential.

These aspirations are laid out in the UN Convention on the Rights of Persons with Disabilities (CRPD). It asserts that disabled people have the right not only to good health, education and social care, but also the right to live independently, to take part in civic and cultural life, and to have the same chance to get a job and stay in work as anyone else.⁵

⁵ [United Nations Convention on the Rights of Persons with Disabilities \(2006\)](#)

General comments on the CRPD describes effective transitions like this:

Effective transitions: learners with disabilities receive support to ensure the effective transition from learning at school to vocational and tertiary education and, finally, to work. Learners' capacities and confidence are developed and learners receive reasonable accommodation, are treated with equality in assessments and examination procedures, and their capacities and attainments are certified on an equal basis with others⁶

Therefore, in order to ensure compliance with the UNCRPD, SCLD believes that young people with a learning disability should be fully involved in planning for their future. We also support the intention that a full range of agencies should be involved both in providing information that allows young people to make informed choices, and in providing the support needed to implement the plan.

SCLD agrees that careful planning at this stage is essential in ensuring a smooth positive transition into adult life, and that a lack of planning, information and support can negatively impact on young people to such an extent that it can be hard for them to realise their ambitions and goals.

Focus group members identified a number of benefits to having a transitions plan that was timely and well-coordinated:

- It might prevent the gap between leaving school and adult services kicking in
- It would give young people and their parents the information they need to make informed choices about their future
- It would act as a mechanism for a range of agencies to agree their individual roles in supporting the young person.

However, there was not unqualified approval for this proposal, on the basis that a statutory right on its own would not be effective. We explain this further in our response to the next question.

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

Given that young people have often experienced difficult and unsupported transitions to adulthood, SCLD understands the need to improve this situation. However, although supportive of the proposal to give a statutory right to a

⁶ [United Nations Convention on the Rights of Persons with Disabilities, General Comments \(2016\)](#)

transitions plan to every young person with a learning disability, this support is conditional on a number of factors.

Feedback from our focus groups identified a number of benefits to having a transitions plan that was timely and well-coordinated:

- It might prevent a gap between leaving school and accessing appropriate support in adult services
- It would give young people and their parents the information they need to make informed choices about their future
- It would act as a mechanism for a range of agencies to agree their individual roles in supporting the young person.

However, approval for this proposal from the focus groups was qualified, as some believed that a statutory right on its own would not be effective. Furthermore, participants repeatedly identified appropriate resources being made available as the main factor in the success or failure of the proposed statutory right to a transitions plan:

'The elephant in the room is resources. Without them, forget it.'

'To believe we could deliver the Bill within existing resources is naïve...fantastical.'

Without resources, the Bill proposal is *'a great plan that can't be executed.'*

SCLD disagrees with the statement on page 11 that the costs associated with this legislation are minimal, and could largely be met within existing resources. There are a number of reasons why we are sceptical about this claim:

- It underestimates the number of young people who would be entitled to transitions planning – it suggests around 1,450 disabled young people per year, whereas elsewhere in the report it suggests a figure of around 5,000 disabled young people leaving school each year
- It does not take into account the cost implications of a span of twelve years (ages 14 – 26) for planning and review
- It wrongly assumes that young people moving into employment or tertiary education will require no other support.
- It does not take into account the need to fund new advocacy services for disabled children and young people, while proposing that people should have access to advocacy support to develop and review their Transitions Plans (page 39)

SCLD would be concerned that allocating significant additional resources to Statutory Transitions Plans would mean disinvesting in other priorities. This point was made at the Social Work Scotland Learning Disability Sub-group.

SCLD is further concerned about the risk of unintended consequences of placing statutory duties without providing the required level of funding to meet these responsibilities. Focus group participants identified three main areas of risk:

- That transitions plans would be superficial and tokenistic
- That resources for planning would inevitably be prioritised towards those defined in this statutory duty, at the expense of others who might need just as much transitions support (e.g. some pupils with Additional Support Needs who do not have a disability)
- That staffing resources would have to be diverted away from service provision in order to meet the statutory requirement for transitions planning.

SCLD does agree that good transitions planning is central to preventing crises occurring at a later stage, and can reduce the level of support that people might need over time. However, SCLD is not convinced that it has been evidenced that the savings made would outweigh the level of investment required both to plan transitions effectively and to meet the support needs identified within these transitions plans. It would also be argued that any savings would accrue over time, not immediately.

It therefore appears likely that significant new and additional funding would need to accompany a statutory duty to deliver individual transitions plans.

In contrast, a number of focus group participants argued that the proposed statutory duty would help bring about a greater level of consistency in transitions planning than currently exists. For example, staff from the Royal Blind School, whose pupils come from across Scotland, stated that they see a wide variation in transitions planning practice from one local authority area to another. Most participants agreed that not only is practice inconsistent, it is largely poor quality. They argued that given the current low success rate in transitions planning, placing a statutory duty on this could only help.

However, it is worth examining two questions before supporting this view. The first question is: does legislation always help achieve desired outcomes? Secondly, is legislation already in place?

Would new legislation improve practice?

SCLD is aware of examples of new legislation changing practice in Scotland, e.g. raising levels of tax on cigarettes helped reduce the number of smokers and raising a 5p levy on plastic bags reduced their usage. However, we are concerned that where legislating complex, interconnecting systems, as per transitions planning, there are also examples where the introduction of new legislation has been less effective. For example, the recent review of The Implementation of Part 12 of the Children and Young People (Scotland) Act 2014 found that services for families (where children are at risk of being removed from parental care) had not significantly improved since the legislation came into force. The review concluded that:

*'in isolation legislation does not bring about culture change' (page 26)*⁷; instead, the key drivers for change are *'culture change, relationships and skillsets, and resources'* (page 27).

In addition, despite the Self-Directed Support (Scotland) Act coming into force in 2014, various reviews, including Audit Scotland's Review of progress in 2017, have concluded that comprehensive implementation of the legislation is still a work in progress, with significant issues remaining around consistency of delivery, communicating information and workforce development.⁸

SCLD would therefore urge caution about assuming that legislation will be a more useful instrument than other courses of action. It is also important to be aware of unintended consequences of passing legislation.

Is sufficient legislation already in place?

The second question is whether legislation already exists to give a statutory right to transitions planning. The consultation paper states that current legislation falls short of what the Bill proposes. This is true. However, legislation and policy does already exist: the Education (Additional Support for Learning) (Scotland) Act 2004⁹, the Social Care (Self Directed Support) (Scotland) Act 2013¹⁰, and the Children and Young People (Scotland) Act 2014¹¹ all place various duties for care and support planning for children and young people. Statutory Guidance on the Education (Additional

⁷ [CELCIS \(2019\)](#)

⁸ [Audit Scotland \(2017\)](#)

⁹ [Scottish Government \(2004\)](#)

¹⁰ [Scottish Government \(2013\)](#)

¹¹ [Scottish Government \(2014\)](#)

Support for Learning) (Scotland) Act 2004 (as amended) Code of Practice (Third Edition (2017) gives a right to access transitions planning.¹²

Given the scale of negative experiences of transitions to date, SCLD believes this demonstrates that legislation does not necessarily guarantee good outcomes for people. Instead, we believe that effective implementation is key to success. Furthermore, there is a risk that this proposed Bill would constitute another layer of legislation on top of these existing Acts, duplicating in part what already exists in law.

A number of professionals in our focus groups also reported confusion about responsibilities for provision of transitions planning and about young people's entitlements. This confusion may also play a part in the failure of implementation, and there is a risk of this being exacerbated by yet another layer of legislation. In order to prevent this, clarity is required about how these laws align with each other.

What kind of plan is being proposed?

The proposal describes young people's transitions plans as a means by which they 'fulfil their dreams and ... make the most of their lives' (page 5). This suggests an aspirational, outcomes-based, whole-life plan. SCLD is aware of the person-centred planning approaches. These are life planning processes, used regularly by third sector organisations. There are different person-centred planning approaches, sometimes using specific planning tools such as MAPs or PATHs¹³. These flexible approaches encourage people to think about their futures as a whole, and enable a range of individuals and agencies to consider what support each of them can make. Planning is regularly reviewed to assess progress, which gives people the chance to set new goals and revise old ones.

This would appear to be very similar to what is envisaged in the proposed Bill:

The Plan should... consider all the relevant aspects of a ...young person's life, including, but not limited to ...education, employment, training, health, financial affairs, housing, leisure, citizenship and independent living'. (Page 6)

However, the proposal also refers to a '*transitions assessment*' (page 6), and refers to the aim of the planning process as achieving '*a positive destination*' (page 7). It refers to a duty on the local authority to '*meet the needs*' identified in the plan (page 16). This needs-based, assessment-based process would appear to suggest a different kind of plan, which is measurable but possibly less ambitious.

¹² [Scottish Government \(2017\)](#)

¹³ <http://helensandersonassociates.co.uk/person-centred-practice/care-support-planning/>

It is important to provide clarity about the kind of plan being proposed. More focus group participants supported a holistic, aspirational plan than one based on a needs assessment.

It is also important to provide clarity on where responsibility will lie for the delivery of the plan. The proposal is clear that the local authority will have responsibility for undertaking, delivering and reviewing the transitions plan. However, if the plan does consider all the relevant aspects of a person's life, as stated above, then the duty to deliver those services should fall on the range of delivery agencies involved, including supported employment agencies, colleges and Health and Social Care Partnerships.

A non-statutory approach

We are aware that ARC Scotland has produced *Principles into Practice*¹⁴. This is a national transitions framework that aims to provide practical guidance on how to embed the Principles of Good Transition¹⁵. ARC Scotland has worked collaboratively with professionals from all relevant sectors and with the Scottish Transitions Forum, which ARC Scotland facilitates, to produce this framework. ARC is now planning to trial the implementation of *Principles into Practice* in a number of local authorities across Scotland.

This is another major transitions initiative, and it is important to take account of it when considering the possibility of passing a Bill that places statutory duties around transitions planning. *Principles into Practice* is a non-mandatory approach, which relies on local areas voluntarily committing to implementing the seven Principles of Good Transition. An evaluation framework is being developed to assess the impact of this implementation.

SCLD proposes taking the evaluation of the *Principles into Practice* trials into consideration when deciding whether to pursue a legislative course of action. If these trials result in significantly improved outcomes for disabled young people, it may be decided that further legislation is not required. If, on the other hand, it is decided that further legislation is required, it seems likely that the evaluation of the trials will usefully inform accompanying guidance.

¹⁴ [ARC Scotland \(2019\)](#)

¹⁵ [ARC Scotland \(2019\)](#)

Eligibility

It is important to clarify who would receive a right to support for transitions planning under this proposed legislation. The proposal states that any child 'with an impairment or long term health condition' would be eligible (page 5). It would be helpful to confirm that this means any child or young person who meets the definition of disability under the Equality Act (2010).¹⁶

It should also be recognised that this is a different and smaller population from those children and young people designated as having Additional Support Needs (ASN). Such a definition may also cause an additional unintended consequence to arise, if transition planning resources are directed towards disabled children and young people and away from those children and young people with ASN, who could be argued to be equally vulnerable and requiring support to navigate their progress into adulthood despite not being disabled.

SCLD is also unclear whether a young person would need to have a formal diagnosis of a learning disability by an educational psychologist or health professional, to be entitled to this new statutory right. SCLD is aware that there has been, and remains, a reluctance by some to give a diagnosis of learning disability to a child in order to avoid any stigmatisation. However, SCLD is aware that the recognised drawback to this is that a diagnosis is needed to access some adult services. To SCLD, this appears at odds with the social model of disability and would urge a different approach towards eligibility for transitions planning. We would support a process based on the social model of disability and existing equalities legislation which promotes self-identification.

In fact, SCLD is concerned that there is very little recognition of the specific needs of children and young people with learning disabilities in the proposal. We would argue that it must be recognised that the experience of transition may be quite different for these young people. For example, the proposal states that 44% of disabled (working age) people are in employment. This compares to 4% of working age people with learning disabilities in employment¹⁷. Many young people with learning disabilities both want to work and are able to learn the skills needed for work. However, the type of support needed to achieve this is often different from that needed to support young people with physical impairments into work. This needs to be explicitly acknowledged in the paper, because it has implications for the

¹⁶ [UK Government \(2010\)](#)

¹⁷ [SCLD \(2019\)](#)

kind of agencies that need to be engaged in the planning process, and for the nature of the collaborative working they undertake.

There is also a significant population of young people with profound learning disabilities for whom paid employment is unlikely to be an option. For them, the emphasis in the proposal on transitioning to employment is problematic. One parent explained that some professionals assume that the move from secondary school marks the end of 'learning' for many people with profound learning disabilities. The emphasis from some professionals at this point is on assessing their care and support needs, rather than considering what would be a 'positive destination' for them. Her own experience was two years of (ultimately successful) struggle to secure a positive destination for her son, who can now continue to learn at a level and pace appropriate to him.

SCLD considers it essential that suitable planning, and resources to implement such plans, are made equally available young people with profound disabilities as to any other disabled young people.

The proposal also emphasises that the young person should co-produce their own transitions plan, along with a lead professional. To do this effectively requires the lead professional both to know the young person well, and in some cases to be skilled and experienced in alternative and augmentative communication techniques to ensure a meaningful and ongoing dialogue with the young person. Good practice guidance in supported decision-making should be used in all cases¹⁸, and communication tools such as Talking Mats should be considered.

It should also be recognised that what the young person wants for their future may be different from what their parents want. The weight that is given to parents' views in the proposal needs to be clarified. It was also suggested that a number of disabled young people would not want a transitions plan. It should be made clear that any statutory right to support is just that – an entitlement rather than a mandatory requirement to go through an unasked for process.

¹⁸ [Mental Welfare Commission Scotland \(2016\)](#)

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

SCLD supports the proposal for a National Transitions Strategy. Focus group participants agreed that this would be helpful in terms of raising the profile and giving focus to the issue.

However, there were a number of provisos in relation to this proposal.

It was acknowledged that local differences have led to different approaches, all potentially effective, and that any national strategy had to be flexible enough to take account of these local differences.

Equally, the strategy would have to be '*aspirational, detailed and well-resourced*', in the words of one participant.

Some participants found the language of the question confusing as they believed that there would be other outcomes to a national strategy in addition to independent living, in the same way as independent living might be one outcome of several in an individual young person's transitions plan.

There was also no clear understanding of the term 'independent living' shared by focus group participants. Any proposed legislation should include a definition of 'independent living', in line with Article 19 of the UN Convention on the Rights of Persons with Disabilities¹⁹

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

Overall, members of the focus groups agreed that a national strategy could give focus to and raise the profile of an important and problematic issue.

It was believed that this could be an effective mechanism for helping young people get the support they need and beneficial to the young person, and their families.

There was also general agreement that a national strategy could give clarity and transparency to what is often an obscure process. It could explain clearly what rights young people and their families have and give clarity to professionals about their duties and responsibilities.

¹⁹ [UN Convention on the Rights of Persons with Disabilities \(2014\)](#)

Transitions planning felt to some like a ‘postcode lottery’ at the moment whereas a national strategy could give a degree of consistency throughout the country.

It was also acknowledged that there is currently no agreed timeline for a young person’s transition planning. A strategy could provide this, and it would be beneficial to have clarity about when certain actions on the timeline could be triggered.

Another possible advantage identified by participants was that a National Transitions Strategy accompanied by a robust delivery framework would enable the Scottish Government to review progress made and make changes accordingly. A detailed reporting mechanism would also enable good practice to be shared and highlighted. It would also give young people and their families recourse if they do not receive the planning support that they are entitled to.

However, in contrast, some participants questioned the value of a National Transitions Strategy, which appeared to be based on a general scepticism about the impact that national strategies can make. SCLD’s publication ‘Developing a Learning Disability Strategy’²⁰ discussed the advantages and risks of strategy development. Risks include:

- Not involving the intended beneficiaries of a strategy in its development
- Not communicating the contents of a strategy to the people it is for
- Not ensuring that a strategy is implemented
- The process of developing a strategy which can be both time-consuming and distracting from delivery.

Some focus group members made a similar point: one possible drawback to strategies is that they can distract people away from delivery and into strategy development, but are then forgotten about until it is time to renew/refresh. In this case, this risk would be exacerbated without a sufficient level of resources to deliver successful transitions and sustain improvements.

In order to address these risks, SCLD would propose:

- Using the Scottish Transitions Forum as the basis of any National Strategy
- Working with a diverse group of disabled young people and their families (possibly the Disabled Children and Young People’s Forum) to co-create the strategy

²⁰ [SCLD \(2019\)](#)

- Building a clear and measurable outcomes-based reporting framework, and a robust monitoring and scrutiny process with clear lines of accountability
- Resourcing the strategy appropriately.

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?

SCLD supports the idea of a Minister in the Scottish Government with special responsibility for disabled children's transitions given the critical nature of the transitions period for most disabled young people. This could usefully be part of the robust system of accountability that SCLD believes needs to be in place for the proposed National Strategy to be as effective as possible.

It must be borne in mind that 'Transition' is a process that impacts on a number of Scottish Government policy areas including health, education, equalities and human rights and children and families. Currently no one minister has responsibility for this and the advantage of giving this responsibility to a single minister is that the line of accountability is clarified and sustained.

SCLD accepts that there is a risk in doing this in effectively removing responsibility for Transitions from all but one policy area. Any minister given responsibility for Transitions would have to be enabled to influence the practice of support for young disabled people during transition across all relevant policy areas.

7. Do you have any other comments?

Having considered all of the preceding information and the many, often competing and contradictory, points made through our consultation work on this issue, SCLD is supportive of the proposal that every young person with a learning disability and other disabled young people should be offered a transitions plan. Furthermore, we would support this becoming a statutory duty if:

- Appropriate levels of new and additional funding is provided to fund both the planning and implementation of the resultant plans
- Work is done 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

- There is clarification regarding who should lead the planning process
- There is clarification about the scope of the proposed Transitions Plan
- Any move to legislate takes full account of the evaluation of the Principles into Practice trials currently being developed
- There is clarification of the need for all young people with a learning disability to be eligible for this proposed planning process, regardless of a formal diagnosis being in place
- Good practice guidance in supported decision making should be used to ensure that young people contribute as fully as possible to their own plan.

SCLD is also supportive of the proposal for a duty to prepare, publish and implement a National Transitions Strategy where:

- Disabled young people are directly involved at all stages of the development of the strategy
- The proposed Strategy includes a communications plan to inform disabled young people and their families of their entitlements in formats that take account of their various communication needs
- The proposed Strategy is accompanied by a robust, outcomes-based implementation plan and review process.
- Strategy development and strategy delivery is properly resourced.

SCLD supports the proposal that the Scottish Government should give special responsibility for Transitions to a Minister.

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