

## 1. QUESTIONS

### 2. ABOUT YOU

**(Note: Information entered in the “About you” section may be published as part of your response except where indicated in bold.)**

1. Are you responding as:

- An individual – in which case go to Q2A
- X On behalf of an organisation? – in which case go to Q2B

2A. Which of the following best describes you? (If you are a professional or academic, but not in a subject relevant to the consultation, please choose “Member of the public”.)

- Politician (MSP/MP/Peer/MEP/Councillor)
- Professional with experience in a relevant subject
- Academic with expertise in a relevant subject
- Child or young person with a disability
- Parent or other carer of a child or young person with a disability
- Member of the public

2B. Please select the category which best describes your organisation:

- Public sector body (Scottish/UK Government or agency, Local Authority, NDPB)
- Commercial organisation (company, business)
- Representative organisation (trade union, professional association, membership organisation)
- X Third sector (charitable, campaigning, social enterprise, voluntary, not for profit organisation)
- Other (e.g. clubs, local groups, groups of individuals, etc.)

Please explain briefly below what the organisation does, its experience and expertise in the subject-matter of the consultation, and how the views expressed in its response were reached (e.g. whether it is the view of particular office-holders, or has been approved by the membership as a whole):

ARC Scotland is a charity that improves knowledge, policy and practice in health and social care by leading and facilitating networks that bring together hundreds of professionals, supported people and carers to generate new ideas and find solutions to the challenges they face. We are specialists in providing training and learning that improves knowledge and practice in Scotland’s social care sector.

Our vision is for people with learning disabilities or other support needs to be at the heart of their services and communities. We believe this can be achieved by enabling different organisations, supported people and carers to work together as equal partners.

3. Please choose one of the following:

- X I am content for this response to be published, and attributed to me or my organisation
- I would like this response to be published anonymously
- I would like this response to be considered, but not published (“Not for Publication”)

If you have requested anonymity, or asked for your response not to be published, please give a reason. (Please note your reason will not be published):

4. Please provide your name or the name of your organisation. (Please note that the name will not be published if you have asked for the response to be anonymous, or to be considered as "Not for Publication". Otherwise, this is the name which will be published with your response.)

Name: ARC Scotland

Please provide a way in which we can contact you if there are any queries regarding your response. (Email is preferred but you can also provide a postal address or phone number. Please note that we will not publish these details.)

Contact details: 

#### 5. Data protection declaration

X I confirm that I have read and understood the Privacy Notice attached to this consultation which explains how my personal data will be used.

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

The challenges faced by young disabled people and families during this period are already very well evidenced and documented in research, policy and consultations<sup>1</sup>. Briefly, young disabled people hope for the same things as other young people; to have a voice in what impacts them, a social life and to be involved as active, valued citizens<sup>2</sup>. Unfortunately, many young people don't get the support they need to achieve these basic human rights, and so their path post-school falls short of their aspirations.

As children, young people may have received substantial packages of support from children's services including social work and specialist health provision, in addition to universal services such as education. This support will often reduce or end abruptly when they are regarded as having become an adult. This risks losing the benefits of earlier investments, and leaving young people without the continued support they may need to reach their potential.

Too many young people and their family members describe their experiences of transitions as '*a black hole*' or like '*falling off a cliff*.' Due to austerity measures, in many local authorities adult social care support is only provided if people meet the eligibility criteria for 'critical' need and many young people miss out. One young person told us: '*I'm terrified of leaving school. No support- social work are already pulling away and I feel abandoned.*' (Facing the Future Together 2017)

Before proceeding, it is important to have an agreed definition by what we mean by the word 'transition.' Our publication 'Principles of Good Transitions 3' provides the following, which is widely accepted in planning, practice and policy:

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<sup>1</sup> The Transitions SPICe Briefing (2019) for Scottish Parliament provides a summary of these. See <https://digitalpublications.parliament.scot/ResearchBriefings/Report/2019/3/29/Transitions-of-young-people-with-service-and-care-needs-between-child-and-adult-services-in-Scotland#>

<sup>2</sup> NOP (2003) A survey of the views and experiences of young disabled people in Great Britain. Conducted by NOP on behalf of the Disability Rights Commission DRC; London; Morris (1999) Hurling into the void.

*'Transition is the period when young people develop from children to young adults. This is not a single event, such as leaving school, but a growing-up process that unfolds over several years and involves significant emotional, physical, intellectual and physiological changes. During this period young people progressively assume greater autonomy in many different areas of their lives and are required to adjust to different experiences, expectations, processes, places and routines. Transitions also impact on the family or on those who care for the child or young person.'* (Principles of Good Transitions; Introduction. P10.)

We talk more about 'Principles of Good Transitions' in section 4.

The transition period is complex and non-linear. Young disabled people require support in different areas of their lives. There are multiple considerations associated with the move from school or college or the transfer from child to adult services. These may include identifying and achieving positive destinations in employment, education or training, managing welfare and housing changes, reviewing healthcare needs, providing information and advocacy, assessing capacity and working with risk. These processes should have the young person's personal outcomes, aspirations and wellbeing at the centre. When their wellbeing is fully supported, they will be better able to achieve their full potential and their Human Rights.

In 2017 we conducted a national survey to hear the voices of young people who require additional support and their parents and carers. 740 responses were received from people living in all 32 local authority areas, and published as *'Facing the Future Together'*

We learned that:

- Most young people are broadly optimistic about their transitions and their future
- There is a gap between their ambitions and reality
- Many carers do not share the optimism of their children and are challenged by their child's transition
- Many carers struggle to access the services they believe they need
- Support should be coordinated with a single point of contact
- All organisations should be more pro-active in engaging and providing information to young people and their carers.

We believe young people's sense of optimism for the future, desire to live independently and to contribute and progress is a precious resource largely overlooked within policy and planning frameworks. Young people who require additional support are too often perceived as a 'problem', which subsequent planning and assessment seeks to resolve through providing generic, risk-averse and often short-term solutions. Actions taken to improve transitions should recognise the optimism and potential of young disabled people by helping to increase their expectations for the future and equip their communities to embrace and welcome their contribution.

At this point we wish to take issue with some of the wording within the proposed Bill, which we feel does not always reflect the potential of all young people in Scotland. For example, Case Study A *'The young person's communication is very repetitive, and he seems incapable*

*of meaningful communication.* In our view, such statements and beliefs are not consistent with the stated intent of the Bill to 'empower and support young people' and careful consideration should be given to the wording of any future proposal.

Carers told us they struggle to get access to the information and services they believe their children need, and are often challenged by their child's transitions. In contrast, most young people tell us they are broadly optimistic about their transition and future, although there is a gap between their ambitions and reality. The improvements they ask for are generally modest and deliverable. These can be summarised as:

- Provision of the right information at the right time
- Early planning that is person-centred
- Coordinated support across professional sectors
- A single point of contact.

See: <https://scottishtransitions.org.uk/resources/>

Of particular concern, *'Facing the Future Together'* found that most carers were not getting the information they needed about the options available to their children once they left school. This included information concerning, health, social care, employability, further education and voluntary sector provision. Good work is happening in some local areas to address this that should be developed Nationally.

Professionals tell us that their biggest challenges are a lack of joined-up working across sectors and a lack of resources. Much good work is already happening and there is a clear willingness to 'do things better.' We are working hard to address these challenges through our facilitation of the Scottish Transitions Forum and engagement with other partners, including young people and carers. Many local authorities are using 'Principles' to inform a refreshed strategic approach and are now working with us to co-produce and test national standards and tools to improve transitions. More about this is set out in section 4.

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

We support the intention of the proposed statutory right and welcome its recognition of the importance of early planning during the transitions period which continues to at least the age of 25. However are unsure if the proposed Bill provides the most effective approach to achieving this.

Principle 3 of Principles of Good Transitions states:

'Planning should start early and continue to age 25. This means:

- Planning should be available from age 14 and proportionate to need
- Children's plans and assessments should be adopted by adult services
- Transitions planning and support should continue to age 25.'

Most young disabled people and their families either do not have a transitions plan, or do not know if they have one. In our survey 'Facing the Future Together' 76% (of 470 responses) of carers told us the young person they cared for did not have a written down plan to support their transition. We therefore welcome and encourage measures to widen the availability of effective transitions planning.

We understand and share the frustration about the unacceptably poor experiences of many young people during such an important and formative time in their lives. However, in its current form the proposed statutory right to a transitions plan requires further work if it is to:

- Address the most critical challenges faced by young people and those who care for them
- Align with and enhance an already complex policy framework and provide significant new entitlements for disabled young people
- Align with and enhance on-going innovation and practice initiatives
- Include all young people who may require a plan
- Consider any unintended consequences of shifting resources from service delivery to mandatory planning
- Make sure that plans become reality
- Be deliverable within existing resources.

We are concerned the time and resources dedicated to the work required to progress the Bill and its subsequent implementation will distract time, effort and resources from implementing more well developed non-mandatory solutions. Provided these are provided with necessary support nationally, they will deliver the intentions of the proposed Bill and should be allowed to progress before mandatory options are pursued further.

We support the further consideration of regulatory or legislative routes should the non-mandatory approaches we outline in our response not lead to the desired changes for young people and their families.

Significant work at a national level is already underway to co-produce 'bottom up' solutions to the complex challenges associated with planning and delivering joined up support for young disabled people. Providing 'joined up and consistent support' is the most important ask from families, and the biggest challenge faced by professionals.

The present Bill consultation directly coincides with the consultation for a comprehensive non-mandatory national framework to improve transitions called 'Principles into Practice.' Led by ARC Scotland through our facilitation of the Scottish Transitions Forum, this has been co-produced over the past 14 months with professionals from all relevant sectors, Scottish Government, national bodies (particularly Association of Directors of Education and Social Work Scotland), young people and carers. It is widely supported. This is the first time guidance and evaluation measures have been developed for local authorities and their

partners to enable them to work collectively to deliver the joined up, person-centred support that young people and carers have asked for. Gathering and collating feedback from young people and carers of their experiences of transition is central to its evaluation measures

Plans are in place to trial 'Principles into Practice' in a number of local authority areas later this year. The draft can be downloaded here::

<https://scottishtransitions.org.uk/principles-into-practice-draft-framework-consultation/>

Further information is set out in our response to question 4.

It is important to consider how this aspect of the proposed Bill aligns with the existing legislative, policy and practice framework related to planning and assessment and what additional rights it affords young disabled people. Current policy (Statutory Guidance on the Education (Additional Support for Learning) Scotland Act 2004 (as amended) Code of Practice (Third Edition) 2017) already makes provision for every child at school who has additional support needs arising from a disability within the meaning of the Equality Act 2010 to have access to transitions planning.

The existing Scottish Government legislative framework impacting on young disabled people who already provides an effective framework to improve their experiences of transitions. The problem is in its implementation. Many professionals, young people and carers perceive it to be over-complicated, with new initiatives sitting on top of older legislation without clarity as to how they interlink. As a result, there is already widespread confusion amongst professionals, young people and carers about what people are entitled to and who is responsible for providing it. Without further work the proposed Bill risks adding to this confusion. In particular more detail is needed to clarify how the new proposed statutory duty would fit with the existing policy framework for transition planning, assessment and support planning in the Education (Additional Support for Learning) (Scotland) Act 2004, the Social Care (Self Directed Support) (Scotland) Act 2013, and the Children and Young People (Scotland) Act 2014.

The significant challenges associated with coordinated approaches to planning, in particular information sharing, (e.g. as experienced under Part 4 & 5 of the Children and Young People (Scotland) Act 2014) are well known. To support practitioners to fulfill their statutory duties as proposed in this Bill there would be a need for comprehensive guidance around information sharing and potential implications in regard to the Data Protection Act and General Data Protection Regulation.

We are concerned this proposal implies the proposed Bill can be delivered broadly within current spending parameters. We feel this is unlikely and risks raising expectations unfairly among young people and their families.

We believe that the proposed Bill significantly under –estimates the number of young people who require a transitions plan, and believe it will be considerably more than “a few dozen” extra young people it anticipates in each local authority. A more rigorous estimate of numbers is required. This will greatly impact on the time and resources that required to be committed by local authorities towards the provision of mandatory planning and meeting the needs identified, to the possible detriment of existing non-mandatory provision.

Similarly, we are unclear about the proposed eligibility criteria for entitlement to a plan. The proposal uses multiple terms relating to the intended beneficiaries interchangeably – for example, “long term conditions”, “disability”, “learning disability”, “mental health and autism”, “deafness”, “blindness” and others. Planning should be available to all young people with identified additional support needs, as any young person in this category is by definition vulnerable and at risk to some extent of experiencing difficulties in making a smooth transition to adulthood and having a meaningful life post-school. We are concerned young people who may fall outwith the intended eligibility criteria will experience reduced support as funds are directed to mandatory provision.

In addition, the proposed Bill suggests (p11) *‘those assisted to achieve ongoing positive destinations will also cease to utilise this support’*. All the evidence shows young people need continual or extra support provision to maintain and progress through and beyond college or take up employment sustainably. Subsequent (post school leaving) transitions are reported by many to be the most challenging and distressing, particularly following the end of Further Education provision. There are also many further considerations that are important to young people and their carers at this stage in their lives beyond achieving a single ‘positive destination’.

Further work is required to identify how is it proposed to make sure the plan becomes a reality, who will be responsible for delivering it and what resources (if any) will be attached. The role of families and parents in this proposal needs to be clarified, for example, around the choice of Lead Professional, ownership of data, and who decides when and how to involve parents and carers- recognising that the wishes and perspective of parents / carers often differ from those of the young person.

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

Where a young person has additional support needs, effective planning is required to ensure essential support will continue to be in place beyond school leaving age and into adulthood. We agree that the transitions plan should ‘belong to the young person’ and it should ‘consider all the relevant aspects of a child’s / young persons life’ (p6). However the further details set out in Section 2 points 10-11 (p39) do not demonstrate how the young person and their families, rather than professionals, will have ownership of the plan, or how it will extend beyond an assessment of their ‘critical’ needs.

We agree investments should be made to enable *all* young disabled people to have a meaningful transitions plan if they want one. Such investments will save the public purse through reduction in later crisis interventions, for example within health, social care and criminal justice, as well as averting the distressing personal impact of reaching crisis point for both the young person and their family. However further work is required to determine to what extent preventative spend in planning leads to improved individual outcomes and a decrease in longer-term spend.

We are concerned that within existing resources, the transition planning proposed will not be sufficiently far reaching to allow young people and families to identify what is most important and meaningful to them and to be aspirational about the future. Within the current challenging economic climate most local authorities are only providing funded packages of support to those who meet the criteria assessed as 'critical' level of need. Given the proposed statutory duty of the local authority to meet the needs identified in the transitions plan, we are unsure from the 'Contents of a Transitions Plan' (p38) how the transitions plan will differ significantly from any Social Work assessment of need, to which everyone is already entitled.

As it stands, the proposed Bill may unintentionally lead to cursory or inadequate 'needs assessment' (where decisions are ultimately made by professionals), which carries the risk of limiting rather than expanding the choices available, as the tendency is to populate existing services rather than explore how unique aspirations can be met and encouraged. We fully recognise the importance of meeting critical needs, however planning should move beyond 'need' towards outcomes (what matters to young people), mirroring the values that underpin other policy areas, such as the Self-directed Support Act (Scotland) 2013.

Approaches to effective and holistic transitions planning in which young people are supported to make their own decisions, are already well known and documented. Person-centred approaches (such as the 'Big Plan') provide a way to improve outcomes for young people in transition. They have been used successfully for many years, particularly by the voluntary sector, however are not routinely offered. Such approaches should be made more widely available and actively promoted to young people and their carers. We welcome the financial support recently made available to young people to access person-centred planning via the Independent Living Fund Scotland's 'Transition Fund'. We should be cautious about unintentionally replacing effective provision of non-mandatory person-centred planning- which we now have the opportunity to expand- with a less effective alternative.

Should the Bill progress, there needs to be a greater focus on the perspective of young people themselves their families and those who know them best, in defining what counts as a 'positive outcome' for them, how the planning should take place, what rights and entitlements they already hold under existing legislation, and what recourse they would have if they feel their transition plan does not reflect their requirements and aspirations.

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

A National Transitions Strategy would be helpful and much of the content required to populate it already exists. Principles of Good Transitions already provides the overarching and aspirational framework called for in the proposed Bill.

However we are concerned the consultation for a national strategy risks diverting time and attention from practical solutions towards re-visiting already well-known and documented issues and challenges.

Principles of Good Transitions 3 provides a framework to inform, structure and encourage the continual improvement of support for young people with additional needs between the ages of 14 and 25 who are making the transition to young adult life. It incorporates all relevant legislative duties that apply to young disabled people.

It is already widely used by many professionals and organisations to inform transitions planning and practice, and is referenced in many Scottish Government policies including 'Fairer Scotland for Disabled People', Scotland's United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) Delivery Plan: <https://www.gov.scot/publications/fairer-scotland-disabled-people-delivery-plan-2021-united-nations-convention/pages/1/>

The seven Principles are:

1. Planning and decision-making should be carried out in a person-centred way
2. Support should be coordinated across all services
3. Planning should start early and continue to age 25
4. All young people should get the support they need
5. Young people, parents and carers must have access to the information they need
6. Families and carers need support
7. A continued focus on transitions across Scotland.

Principles of Good Transitions was written in partnership with members of the Scottish Transitions Forum (STF) and other partners, including relevant Scottish Government policy teams. The STF is led and facilitated by ARC Scotland. With over 990 members from all relevant professional sectors, young people and carers, we work together to improve the experiences of young people (14-25) who require additional support who are making the transition to young adult life.

(Please note this response has been prepared by ARC Scotland. While we have sought to accurately reflect our learning from leading the STF, it does not necessarily represent the views of all members)

Working with the Association of Directors of Education (ADES) and Social Work Scotland (SWS) we have formed a network of 80 senior statutory sector and Scottish Government leaders drawn from sectors including education, health, employability, child and adult social work, and social care. Young people, parents and carers are also part of the network.

They have worked with us to co-produce the first draft of *Principles into Practice*, a national non-mandatory transitions framework setting out practical steps to coordinate planning and practice across all relevant practice areas, deliver better outcomes, and measure the difference they are making.

*Principles into Practice* asks all relevant stakeholders in local authority areas to review and improve the service(s) they are directly responsible for, and to work in a coordinated way with other partners. This includes:

- Paediatric and adult health (including mental health services)

- 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)
- Youth Justice
- Advocacy and self-advocacy
- Local Government
- Scottish Government
- Young people
- Parents and carers.

See <https://scottishtransitions.org.uk/principles-into-practice-draft-framework-consultation/>

This is the first time practical guidance of this nature has been produced to enable diverse partners to work together to address the complex challenges associated with coordinating support for young people. Twelve local authorities have indicated interest in trialling *Principles into Practice*, with a view to this beginning in April 2020.

We would be happy to discuss *Principles Into Practice* with you.

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

As stated above we believe a national strategy would be helpful to coordinate transitions planning and practice across all relevant practice areas. We would also welcome the additional attention that a national strategy would bring to the complex issues surrounding transitions.

We believe ‘Principles of Good Transitions’ should form the basis of a national transitions strategy which should”:

- Enhance already well developed successful and supported work in this area while avoiding lengthy and costly consultation processes that will cover old ground and potentially confuse an already cluttered policy landscape
- Provide a clear national narrative for combined policy intent as it applies to young disabled people (as opposed to children or adults)
- Provide an overview of legislative duties that apply to young disabled people
- Enable focussed work to establish the cost-benefit of early planning and interventions
- Re-direct resources from crisis to prevention models
- Provide a shared framework (*Principles into Practice*) that professionals from *all relevant sectors* and Scottish Government can use to work collaboratively in the best interests of young disabled people

- Coordinate provision of accessible information to young people and carers
- Standardise the terminology used in Scottish Government publications
- Provide a framework whereby progress can be monitored and improved through routinely gathering the experiences of young people and their carers
- Oversee the provision of National funds and embed project learning into longer-term strategies.

We propose that young people and carers are closely involved in making the national strategy meaningful and accessible to them, so they are clear about what they can expect as they move on from school, their statutory rights and how to exercise them.

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

Yes, we believe it is necessary for there to be a minister, or ministers who have special responsibility for transitions. However, we are unsure this requires the appointment of a new ministerial post, rather than incorporating into the portfolio of existing minister(s).

Our hesitation in fully supporting a new ministerial position should not be confused with any lack of support for the intent of the proposed Bill: There is a clear need to better coordinate and monitor the impact of the multiple policy areas that impact on young disabled people, to advocate on their behalf nationally and to have a clearer national narrative for combined policy intentions related to this group.

As we have stressed throughout our response, holistic support for young people in transitions is multi-faceted and links with multiple policy areas, in both children and adult services, such as education; further education, higher education; social care; health; mental health; justice; finance; communities and local government; transport; social security, housing; business, fair work and skills; and equalities. Each of these policy areas should already take regard of the needs of potentially excluded groups, including young disabled people.

The development of a new ministerial portfolio would therefore require combining elements from a particularly wide range of existing ministerial disciplines. For this reason, we feel careful consideration is needed to ensure any minister for transitions has the appropriate reach to be able to speak to all of these policy areas as they impact on young people who begin their transitions journey as children but complete it as adults.

An alternative would be to allocate special responsibility for transitions to relevant portfolios of existing ministers who, along with their policy teams, can bridge the gap between different policy areas, particularly those between children and adults.

A small transitions team or lead within the Scottish Government could coordinate the actions proposed above (5). The approach adopted by *'Fairer Scotland for Disabled People'* may provide a useful model to inform thinking.

However this is structured, it is important that any new policy initiative is built on the practical delivery of the changes we know are required to improve the lives of young people and their carers, rather than further research, consultation or analysis of the underlying issues or where improvements are needed.

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

We welcome the increased focus this Bill has brought to the complex and challenging issue of transition to adult life for young disabled people. We are committed to contribute to, lead and support all work that helps to improve lives and futures for young disabled people in Scotland.