

# **PROPOSED DISABLED CHILDREN AND YOUNG PEOPLE (TRANSITIONS) (SCOTLAND) BILL – JOHANN LAMONT MSP**

## **SUMMARY OF CONSULTATION RESPONSES**

This report summarises and analyses the responses to a consultation exercise carried out on the above proposal.

The summary and analysis of the consultation responses presented under Sections 2 and 3 of the report was undertaken and written by a team from the School of Education and Social Work, and School of Medicine, at the University of Dundee, led by Professor Divya Jindal-Snape. The team included Eilidh Ross (BA Hons Law) and Dr Lisi Gordon, with cross-check of analysis and interpretation by Dr Duncan Mercieca, Dr Elizabeth Hannah, Dr Daniela Mercieca and Dr Anna Robb.

The background to the proposal is set out in Section 1, while Section 2 gives an overview of the results. A detailed analysis of the responses to the consultation questions is given in Section 3. Section 4 includes Johann Lamont MSP's commentary on the results of the consultation.

Where respondents have requested that certain information in their response be treated as confidential, or that their response remains anonymous, these requests have been respected in this summary.

In some places, the summary includes quantitative data about responses, including numbers and proportions of respondents who have indicated support for, or opposition to, the proposal (or particular aspects of it). In interpreting this data, it should be borne in mind that respondents are self-selecting and it should not be assumed that their individual or collective views are representative of wider stakeholder or public opinion. The principal aim of the document is to identify the main points made by respondents, giving weight in particular to those supported by arguments and evidence and those from respondents with relevant experience and expertise. A consultation is not an opinion poll, and the best arguments may not be those that obtain majority support.

Copies of the individual responses are available on the following website <https://martinneill.wixsite.com/transitionsbill>.

A list of the respondents to the consultation can be found in the Annexe. These have been numbered, and where the report quotes from a consultation response the number of the consultation response will appear in brackets beside the respondent's name.

## SECTION 1: INTRODUCTION AND BACKGROUND

Johann Lamont MSP's draft proposal, lodged on 9 October 2019, is for a Bill to:

*Require the Scottish Ministers to introduce, and to implement, a National Transitions Strategy to improve outcomes for children and young people with a disability in the transition to adulthood, and to require local authorities to introduce a transitions plan to ensure each child and young person with a disability receives appropriate care and support before, and during, the transition to adulthood; and for connected purposes.*

The proposal was accompanied by a consultation document. This document was published on the Parliament's website, from where it remains accessible: <https://www.parliament.scot/parliamentarybusiness/Bills/113161.aspx>.

The consultation period initially ran from 9 October 2019 to 22 January 2020. Johann Lamont MSP extended the deadline to 31 January 2020 in response to requests from a small group of respondents for extensions. One response was received by email on 20 February 2020, and has been included in the analysis.

A total of 9 respondents requested that their responses should be considered on an anonymous basis. These are referred to in the Annexe to this report below as 'Anonymous'. A total of 5 respondents requested that their responses should be treated in confidence, and should not be published. These are referred to in the Annexe to this report below as 'Not Published – Confidential'.

One response was received, but did not provide answers to any of the questions in the consultation document. This response has, therefore, not been included in the analysis of responses.

The member hosted a launch event for her consultation on 9 October 2019 in the Scottish Parliament. Other speakers at this event included parents and a young person affected by issues around transitions. The member also hosted a consultation event in Glasgow on 11 November 2019.

The consultation exercise was run by Johann Lamont MSP's parliamentary office. Support in raising awareness about the consultation was also provided by Camphill Scotland and by Inclusion Scotland.

Other organisations arranged consultation events or meetings to discuss the Member's proposals, including those hosted by the Scottish Commission for Learning Disability (SCLD), and the Edinburgh Voluntary Organisations Council (EVOC). Meetings were also held with a group of East Renfrewshire Carers, and by a group of young people with learning disabilities and other support needs.

Updates about the consultation on the member's proposed Bill were provided by Johann Lamont MSP, or by Camphill Scotland or by Inclusion Scotland at meetings of the Cross Party Groups on Carers, on Children and Young People, on Disability and on Learning Disability.

The member has advised that a wide range of organisations, individuals and groups were sent details of the consultation. The consultation was also widely publicised through the media, including social media.

The consultation process is part of the procedure that MSPs must follow in order to obtain the right to introduce a Member's Bill. Further information about the procedure can be found in the Parliament's standing orders (see Rule 9.14) and in the *Guidance on Public Bills*, both of which are available on the Parliament's website:

- Standing orders (Chapter 9):  
<http://www.scottish.parliament.uk/parliamentarybusiness/26514.aspx>
- Guidance (Part 3):  
<http://www.scottish.parliament.uk/parliamentarybusiness/Bills/25690.aspx>

## SECTION 2: OVERVIEW OF RESPONSES

In total, 91 responses were received.

The responses can be categorised as follows:

- 11 responses (12.0%) from public sector organisations [e.g. Scottish Government body or agency, local authority, Health Board or Health Board body or organisation, or Non-Departmental Public Body]
- 12 responses (13.1%) from representative organisations [e.g. business association, trade union, third sector organisation, political party or other body with a role representing its members or supporters' views collectively]
- 39 responses (42.8%) from third sector organisations [e.g. charitable, campaigning, social enterprise, voluntary, not for profit organisation]
- 4 responses (4.3%) from others [e.g. clubs, local groups, groups of individuals, etc.]
- 25 responses (27.4%) from individuals; these can be categorised as follows:
  - 8 (9.6%) from professionals with experience in a relevant area
  - 3 (3.2%) from children or young persons with a disability
  - 13 (14.2%) from parents or other carers of a child or young person with a disability
  - 1 (1.0%) from members of the public
- 9 (9.8%) of respondents requested that their responses should be considered on an anonymous basis.
- 5 (5.4%) of respondents requested that their responses should be treated in confidence, and should not be published
- 1 (1.0%) late response was accepted.

Most respondents seemed supportive of the Bill. Respondents were asked for their views on the key components of the Bill – the need for statutory transitions plans, for a National Transitions Strategy and for a Scottish Government Minister to be appointed with specific responsibility for transitions. However, because respondents were not asked to (a) show their agreement/disagreement, (b) use a scale, or (c) use yes/no responses specifically about the Bill per se, we extracted this information from their replies to open-ended questions. Therefore, it is difficult to comment on who and how many supported the Bill unequivocally.

Those who appeared to support the Bill expressed dissatisfaction with the current treatment of children and young people with disabilities during their

transition to adulthood. Many were concerned about the low employment rates of these children and young people.

Those who did not seem to support the Bill said that existing legislation and frameworks should be focussed on and developed, rather than the creation and implementation of new legislation. Some of these respondents, similar to those who seemed to support the Bill, specifically indicated support for the Principles into Practice framework (a non-mandatory framework to support the practical implementation of the 'Principles of Good Transitions' across Scotland). Many respondents had concerns regarding funding and some were not convinced that new transitions planning could be met within existing resources available to them.

Most respondents seemed to support the proposal that children and young people with a disability should have a statutory right to a transitions plan, with some indicating conditional support.

Around a quarter of respondents stated that a National Transitions Strategy would assist young people with a disability to achieve independent living. A further quarter were of the opinion that a National Transitions Strategy would assist disabled young people to achieve independent living, but this was subject to conditions. Several respondents questioned what definition of 'independent living' was being adopted by the proposal, stating that this would have impact on its achievability. Some also questioned the contradiction between the definition of transitions presented in the Bill as an ongoing process and the single assessment point.

The majority of respondents said that it is necessary to have 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 transitions to adulthood. However, some stated that this responsibility should be embedded in an existing Minister's portfolio.

## **SECTION 3: RESPONSES TO CONSULTATION QUESTIONS**

This section sets out an overview of responses to each question in the consultation document.

### **Challenges faced during transition to adulthood**

Section 3 of the consultation document outlines some of the challenges faced by children and young people with a disability in the transition to adulthood. Respondents were asked:

<b>Question 1: What challenges do you think children with a disability face in the transition to adulthood?</b>
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Seventy four (81.3% of total respondents) respondents answered this question directly. Fifteen respondents (16.4%) did not answer the question directly, but an answer could be found within their broad response to the consultation. Three respondents (3.2%) did not answer the question.

The main challenges identified by the respondents were:

- 1.1 The transfer from children to adult services (n=39)
- 1.2 The transfer from children to adult healthcare (n=10)
- 1.3 Resources and funding (n=19)
- 1.4 Employment opportunities (n=26)
- 1.5 Limited options for the future (n=20) and lack of person centred approach (n=27)
- 1.6 Poor planning and a lack of information (n=20)
- 1.7 Voice and challenges communicating (n=14)
- 1.8 Financial challenges (n=11)
- 1.9 Social challenges and feelings of isolation (n=14)
- 1.10 Impact of transitions on mental wellbeing (n=11)

Please note that multiple challenges were reported by some respondents.

#### **1.1 The transfer from children to adult services**

A common challenge described by the respondents was transferring from children to adult services, with 39 (42.8%) respondents citing this. Sixteen (17.5%) respondents described a change or loss in support when transferring to adult services, in spite of no change in need. Many stated that the transition to adult services and consequential change/ loss in support was abrupt with many likening it to a 'cliff edge' or 'abyss'. For example, Inclusion Scotland (51) reported "*a feeling of 'falling off a cliff' when more rigid eligibility criteria for adult services lead to a sudden reduction in support*" previously received

by young disabled people. Eleven (12.0%) stated that a change/loss in support occurred due to different eligibility requirements and needs assessment tools used by adult services: There is also concern that many young people are missing out on support due to adult social care support being provided only where needs are considered critical. ARC Scotland (ARC) (19) stated that *“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.”* Independent Living Fund (ILF) Scotland (52) reported that *“Given the current financial climate and social work assessments use eligibility criteria of “critical” need, there is a risk of young disabled people not meeting the criteria to access adult services / support.”*

Many discussed the challenge of post-school transitions. Nick Burge (26), a professional with experience in a relevant area, described *“significant levels of support whilst at school and through the final stage of school”* but then a *“staggering”* change of support after leaving school. Glasgow Disability Alliance (45) reported that *“many young people with higher support needs, and especially those attending ASL schools have support and transport packages that end abruptly when they leave school, often unexpectedly as many parents/carers are not informed this support will cease when leaving school.”*

The Association of Directors in Education in Scotland (ADES) (21) discussed the challenge of *“moving from attending school five days a week, and the support and companionship which schools offer, to the adult world with its greater expectations for individuality and resilience”*. Inclusion Scotland (51) responded that *“some young disabled people who had received significant help with additional support needs at school, described finding at the age of 18 that they were no longer eligible to receive this help from the state and were simply unable to navigate systems of potential support without it.”* Several respondents commented on a lack of coordination between services post-school. Glasgow Disability Alliance (45) report that a *“lack of joined up services means that parents / carers often feel locked in a battle between education, health and social care services”* and ILF Scotland (52) reported a *“lack of a co-ordinated approach across different sectors and services with an absence of a clear lead agency and joined up planning for young people in transition.”*

Some respondents described a gap between children and adult services. An anonymous public sector respondent (7) reported that *“if there is any delay in handover to adult services, young people can be in limbo for some time or unable to progress planning.”* Inclusion Scotland (51) stated that *“many disabled young people in Scotland get lost in the no man’s land between*

*children's and adults' services, suddenly cut off from the support and services they received only a few weeks before."*

## **1.2 The transfer from children to adult healthcare**

Ten (10.9%) respondents stated the challenges of transitioning from children's to adults' healthcare. Respondents described how due to medical advancements more and more young people with life limiting conditions are making transitioning to adult health care where professionals are less familiar with such conditions. Together For Short Lives (88) stated "*for young people with life-limiting conditions, transition to adult services can be especially difficult as adult healthcare professionals may not be familiar with the range of often rare and complex health conditions*". Children's Health Scotland (30) reported that "*advances in medical treatment and care options through advanced technologies, have resulted in CYP surviving infancy, living longer and entering adulthood. CYP who often have co-morbidities and very complex health needs, would, in the past have not been seen in adult services. This is no longer the case and adult health services will need to adapt to meet the CYP's person-centred health needs.*"

Respondents also discussed the challenge of the transition from dealing with one paediatrician to having to deal with a range of specialist doctors. Children's Health Scotland (30) report that "*CYP are used to joined up holistic services in paediatrics but on transfer to adult services, the services are divided into specialities and therefore separate. Different specialities are also often located on different sites.*"

Respondents also reported that follow up appointments to manage conditions are less frequent in adult services. Heather Still (83), a young person with a disability, described her experience: "*I was seventeen when my cardiologist told me I would go from seeing them every six months to every two years, which I managed to change to yearly. I assumed I would be getting the same level of care throughout my life... nobody bothers explaining to you that adult services are different. I was terrified there (sic) were going to stop seeing me, that my pacemaker would run out and I would die because I was not being monitored.*"

## **1.3 Resources and funding**

Nineteen (20.8%) respondents cited scarcity of resources, lack of funding and/or insufficient budget allowances as a challenge. Action for Children (3) reported that "*large swathes of young people are missing out on opportunities that could make them thrive due to lack of appropriate resource and financial barriers... some Local Authorities have moved away from having specialist*



*teams specific to the field of disability. This can create a gap in knowledge of time scales, information and support that needs to be addressed with families.”* They also stated that demands of the statutory workloads conflict with the resources available. Values into Action Scotland (89) responded that *“all too often, adult services are not well enough resourced or accessible to meet the needs of those transitioning to adulthood with a disability.”*

Respondents also discussed a lack of professionals with relevant expertise and/or training. Children’s Hospices Across Scotland (CHAS) (31) described how *“many support providers do not have staff with the level of expertise required to meet care needs and support requirements of young people with complex health needs.”* Lily Hothersal (50), a parent of a young person with a disability, recounted how there had been a *“decrease in the level of provision of training”* and the Scottish Association of Social Work (75) reported that *“social workers often don’t have expertise regarding transitions into adulthood, or less complex disabilities.”*

Furthermore, many respondents reported a more general lack of support. Kiana Kalantar-Hormozi (55), a young person with a disability, described a *“lack of support hours given by social services due to funding”*. Sense Scotland (79) reported a lack of availability of support for those children and young people with learning disabilities, and no provision for parents with learning disabilities. National Deaf Children’s Society (62) identified an *“inconsistency of provision of specialist additional support within education, including school, college and university.”* One set of anonymous respondents (6), the parents of a young person with a disability, stated that *“service provision currently underestimates the length and variety of support needed for young people with disabilities”*. Kate Monahan (60), a parent of a young person with a disability, described a national incoherence and inconsistency of experience and service delivery, labelling the current situation as a *“postcode lottery”*.

#### **1.4 Employment opportunities**

Twenty six (28.5%) respondents cited the struggle to find employment, work experience and/or further education as a challenge faced by children and young people with disabilities. A group of young people with learning disabilities and other support needs (9) highlighted the challenge of *“trying to get a job that suits them”*. Many reported low levels of employment among those with disabilities in comparison to their peers. The National Deaf Children’s Society (62) reported that *“deaf school leavers are less likely to be employed than their hearing peers”* and that *“young deaf people are under-represented in Higher Education and training and over-represented in Further Education”*. Fife Council Education and Children’s Services (42) stated that

*“despite effective planning or time at college disabled young people find it very difficult to access ‘real’, paid employment. Often voluntary work experiences become a default.”* Down’s Syndrome Scotland (36) reported that *“job opportunities are scarce with employment statistics for people with a learning disability (less than 7%) very much lower than for the general population (around 74%) or for other disabled groups (45%).”*

Many respondents described barriers to employment such as inaccessible training material and lack of awareness among employers of needs and requirements of young people with disabilities. Children’s Health Scotland (30) responded that *“many employers and higher and further education institutions may have a paucity of understanding of the health needs and access requirements (Equality Act 2010) of young people.”*

Respondents also reported an attainment gap. The National Deaf Children’s Society (62) stated that *“compared to their hearing peers deaf young people in Scotland are more likely to leave school with no qualifications (8.2% compared to 2.6% of hearing pupils) and less likely to qualify for entry into Higher Education (42.6% compared to 61.3% of hearing pupils)”* and The Royal National Institute of Blind People (RNIB) Scotland (71) reported that in 2017-18 *“71.3 per cent of pupils with no additional support needs achieved at least one Higher qualification. 40.2 per cent of pupils with a visual impairment achieved at least one Higher qualification. This is an attainment gap of 31.1.”*

Twelve (13.1%) respondents considered that young disabled people are faced with low societal expectations after school. The Usual Place (86) describes a *“poverty of expectation and ambition for young disabled people leaving school”*. Helen Bennett (25), a parent of a young person with a disability, describes young disabled people as facing *“the societal equivalent of an empty coke bottle, discarded as no longer useful or worthy”*.

### **1.5 Limited options for the future and lack of person-centred approach**

Twenty (21.9%) respondents reported that often the young person is not at the centre of their transition planning. Twenty seven (29.6%) respondents described limited options, choices, opportunities and positive destinations for young people with disabilities. For example, Glasgow Disability Alliance (45) reported that *“young disabled people tell us that they are offered very limited options and that they feel coerced into taking up places on college courses that are not vocational and not aligned to their interests or ambitions.”* This concern that many young people with disabilities are coerced into non-vocational, ‘life skills’ type courses featured in several responses.

For instance, The Usual Place (86) reported that, “*vocational courses for young people with additional support needs with a career pathway are virtually non-existent*” and that young people tell them that “*watching their school friends move on to work, further and higher education and apprenticeships whilst their options might be ‘whichever day centre has a space’ whatever their dreams and ambitions is truly crushing*”. Similarly, People First Scotland (66) reported that many members “*have described being offered limited options and when they have expressed their ambitions they have been told that certain jobs are not appropriate for them*” and that “*members have been guided onto general or ‘life skills’ courses for people with learning disabilities that do not offer the chance to develop skills for employment.*”

Partners in Advocacy (65) also reported on the limited options and its impact, “*substituted decision-making by many professionals rather than supported decision-making is a widely adopted model of choice... In situations like this, many children and young people may not feel they are able to express their own wishes or even know that they have an opportunity to do so. This limits personal choice and control which in turn limits opportunity.*”

Some respondents stated that transition planning can be resource-centred as opposed to person-centred. CHAS (31) reported that “*families’ feel that current practices are resource led, rather than tailored to individual person centred plans*”, and The Fostering Network (84) similarly reports that foster carers tell them that “*young people’s care plan pathways are not always being agreed on what is best for the young person, rather, they are resource led*”.

## **1.6 Poor planning and a lack of information**

Twenty (21.9%) respondents stated that transition planning is often inadequate. Several respondents described that transition planning would often begin too late. One anonymous public sector respondent (7) reported that “*even though the intention is for intervention to start at 14 sometimes parents don’t engage or child/adult services do not intervene until too late – this results in the young person not being supported early enough*”. Another anonymous respondent (10), a professional with experience in a relevant subject, stated that planning can come too late because young people with additional support needs are treated like “*eternal children*”. Action for Children (3) explained the effect delayed transition planning can have: “*delays in the early transition plan can have an impact on taking guardianship forward, benefits entitlements, finding appropriate work and college placements and general transition planning. Prolonged delays result in many children being placed in a state of limbo.*”

Several complained of poor planning and that planning is not person-centred. Partners In Advocacy (65) described how poor planning can lead to inappropriate college placements, attending community care services with older people and being expected to fit in with services rather than having personalised services to meet the needs and wishes of the young person. The Scottish Commission for Learning Disability (SCLD) (76) reported that *“lack of information, poor coordination and lack of contribution from individual agencies”* can contribute to poor planning. Lead Scotland (57) described how *“planning is sometimes a one-off meeting, rather than an on-going holistic learner-centred process.”*

Several respondents reported a lack of planning altogether. The National Autistic Society Scotland (61) reported that *“10% of parents and young people we come into contact with through our transition support service also tell us that they have been involved in no prior transition planning whatsoever, depriving them of the vital opportunity to meaningfully contribute to the planning of their own future”*.

Similarly, several respondents reported an inconsistent approach taken to transitions planning. ILF Scotland (52) states that *“there is no national standard for transition planning and there is a lack of a nationally recognised process / pathway available to all. Many young people and their families are not aware of their right to transitions planning and do not know if they have a plan or not.”*

Twenty four respondents (26.3%) reported a lack of information and advice about options, opportunities and rights which has a detrimental effect on young people’s ability to plan their future. Glasgow Disability Alliance (45) reported that the *“skills for independence”* type courses many young disabled people are encouraged into are missing *“key information, learning, and direct referrals/links with key agencies, particularly around social care, Independent Living Fund, Access to Work, all of which would make transitions planning post-college a more meaningful and smooth process.”* The National Deaf Children’s Society (62) articulated that transitional planning and arrangements are absent during most deaf young peoples’ post-school transitions, resulting in deaf young people being less likely to receive accessible information about their options and rights.

Several respondents noted that there is a knowledge and information gap with regard to guardianship. Children’s Health Scotland (30) reports that *“at the age of 16, where a CYP does not have capacity to give or refuse consent to treatment, a parent can no longer give consent on their behalf. The family must apply for legal guardianship.”* However, Action for Children (3) are aware of cases where family members didn’t recognise or fully understand the issue

of guardianship, and Laurence Alfred (4) reports that many parents are advised against becoming guardians giving them “*little or no voice*”.

### **1.7 Voice and challenges communicating**

Fourteen (15.3%) respondents discussed challenges in communicating, while ten (10.9%) respondents stated that young people with disabilities struggle to have their voices heard or feel that their concerns are ignored. Aberlour (2) noted that “*communication barriers for young people who have little to no verbal communication can be a particular issue during transitions*”. The Yard (87) explained that young people with disabilities “*face the same myriad of challenges in their transition to adulthood as all other young people*” however, in addition, “*a young person with a disability may find these challenges are compounded by the fact that they find it more challenging to articulate them and/or express how they feel.*”

The Royal College of Speech and Language Therapists (70) report that there is almost no availability of communication support services (including SALT) for young people living with communication disadvantage in order to facilitate access to health, information, education, training, housing, welfare, social care, social, sports and cultural opportunities.

Partners in Advocacy (65) reported that “*children and young people with a disability face a degree of personal discrimination in terms of their rights to be heard and listened to. They are often seen as more vulnerable and therefore more in need of a greater degree of substituted decision-making than non-disabled children by the professionals in their lives. This of course leads to difficulties for children and young people to be heard, listened to and fully respected.*” Befriending Networks (24) stated that “*children with additional support needs can often not be used to being heard or listened to and need support before this process to ensure they can participate.*” Some respondents noted a need for advocacy, to help young people voice their thoughts and concerns.

Autistic 'n' Awesome (A 'n' A) (22) reported that professionals often have a disrespect for young people’s ability to make their own choices and that it is a challenge for some young people with autism to have the confidence to “*speak up at the right time*”, before others have chosen for them.

### **1.8 Financial challenges**

Eleven (12.0%) respondents discussed financial challenges in their answer, with some stating that changes to the benefit system and the DLA to PIP transfer add to financial strain. COSLA (34) reported income inequality faced

by those with disabilities, and many respondents discuss a struggle to find employment. Glasgow Disability Alliance (45) noted that longer higher/further education journeys for young people with disabilities contribute to financial strain. Inclusion Scotland discussed the financial strain placed on families when a parent is required to leave work to become a full-time carer. The National Carer Organisations (Carers Trust Scotland, the Scottish Young Carers Services Alliance, Carers Scotland, the Coalition of Carers in Scotland, Shared Care Scotland, the Minority Ethnic Carers of Older People Project (MECOPP) and Crossroads Caring Scotland) (85) reported that, *“Carers UK recent State of Caring report (2019) found that 38% of carers had given up work to care and 18% reduced their working hours. For carers looking after a disabled child, the transition to adulthood is often a catalyst for them giving up work or reducing their working hours, which can push them into poverty”*.

### **1.9 Social challenges and feelings of isolation**

Fourteen respondents (15.3%) discussed feelings of isolation, exclusion and lack of a social life. Scotland Versus Arthritis (73) reported that many young people with disabilities miss large amounts of school and that going out with friends can be difficult, resulting *“in feelings of isolation, depression and over dependence on parents.”* One anonymous public sector respondent (7) discussed that the lack of options for young people with disabilities contributes to isolation experienced by young people with disabilities: *“The promotion of single tenancies with or without support worker presence is seen as the preferred option for young adults with a disability moving out of the family home. This denies them the option of a degree of communal living which is increasingly the norm for young adults who flat share for a period of time before pursuing a single tenancy/home ownership or moving in with a partner. In effect this policy isolates young people at a time when peer relationships are of prime importance.”* CHAS (31) reported a lack of resources allocated to reduce isolation.

The National Deaf Children’s Society (62) reported that *“as a result of social attitudes and communication barriers, deaf young people often experience bullying and social isolation.”* Eight respondents (8.7%) reported that young people with disabilities face discrimination. Kiana Kalantar-Hormozi (55), a young person with a disability, reported a *“prejudiced discriminatory attitude from people in authority (including school) about disabled people, their abilities and their rights.”*

Several respondents discussed that transitions are not just about education and employment and that there is a lack of focus on other important aspects of young people’s lives such as identity, sexual maturity, relationships and a

social life. The Scottish Association of Social Work (75) reported that, *“the transition into adulthood coincides with gaining sexual maturity. Women with a learning disability are often provided with insufficient information and advice regarding menstruation and pregnancy. Both men and women are also often given insufficient information on bodily changes, sex education and healthy relationships.”*

Several respondents reported accessibility barriers that affect their everyday life. Respondents stated that travel is a challenge, with one anonymous public sector respondent (7) reporting that appropriate public transport is *“non-existent”*.

### **1.10 Impact of transitions on mental wellbeing**

Eleven (12.0%) respondents reported feelings of uncertainty and ten (10.9%) described feelings of anxiety and stress amongst young adults. A group of young people with learning disabilities and other support needs (9) reported the *“stress”* they feel about, or have experienced during, transitions, and that the *“surprises and unexpected things”* arising can be *“hard and confusing”* and *“upsetting”*. The Yard (87) reported that the transition from children’s services to adult services can be abrupt and involve significant level of change and if not managed carefully this can create *“additional stress due to anxiety around the unknown”* for young people. They also reported that, *“it can be very stressful to suddenly have a whole new raft of services and relationships to negotiate, often without your friends made in children’s services”*.

Heather Still (83), a young person with a disability, described the effect of transitioning to adult health care services on her mental wellbeing: *“During a healthy person’s adolescence is where you are the most vulnerable to developing mental illness. This skyrockets when you have a congenital illness. It was during this period of my life where I truly became aware that I had a limited lifespan, that my heart was beaten (sic) by machine. I saw that my attempt of a transition was me being “dumped” and that nobody cared about me, why should I care about me when the people who are paid to care about me can’t even be bothered?”*

## **Need for a statutory right to a transitions plan**

Section 2 of the consultation document set out the aims of the Bill, and the need to introduce a statutory right to a transitions plan. Respondents were asked:

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

The respondents were asked whether they thought children and young people with a disability should have a statutory right to a transitions plan using an open question that collected qualitative data, rather than Yes/No answers. The categories of answers used in this report (supports, does not support, conditionally supports, not decided and not answered) were drawn from the qualitative responses and were chosen to best represent the responses. This classification is based on our interpretation of what respondents *seem* to be reporting. Most respondents used this opportunity to discuss their thoughts on a statutory right to a transitions plan and some used it as an opportunity to discuss their thoughts on the Bill as a whole. Many respondents also used this as an opportunity to discuss what they would like from new legislation.

- 66 (72.5%) respondents supported or seemed to support the proposal that children and young people with a disability should have a statutory right to a transitions plan.
- 18 (19.7%) respondents did not support or seemed not to support the proposal.
- 6 (6.5%) respondents seemed to conditionally support the proposal.
- 1 (1.0%) respondent stated that they were not decided on whether they supported the proposal.

If we break it down further according to sector, we get the following picture:

- Public sector respondents: 58.3%<sup>1</sup> (n=7) seemed either in support, or in conditional support of the statutory right; 41.7% (n=5) seemed not to be in support.
- Representative organisations: 58.3% (n=7) seemed either in support, or in conditional support; 33.3% (n=4) not in support, and 8% (n=1) not sure.
- Third Sector Respondents: 79.5% (n=31) seemed to be in support or conditional support; 20.5% (n=8) seemed not to be in support.
- Individual Respondents: 92.0% (n=23) seemed in support; 4.0% (n=1) not in support; and 4.0% (n=1) had not answered the question.
- Other: 100% (n=4) seemed to be in support.

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<sup>1</sup> Please note these percentages are based on each category of respondent.



## **2.1 Reasons for supporting the proposed statutory right**

The main reasons given **in support** of a statutory right to a transitions plan were:

- 2.1.1 Current legislation/guidelines are not having the needed effect
- 2.1.2 Would ensure all young people have a right to their support needs being met in their transition to adulthood
- 2.1.3 Statutory right would bring clarity and consistency
- 2.1.4 Potential to increase awareness of the issue and to change understanding

### **2.1.1 Current legislation/ guidelines are not having the needed effect**

Many respondents in support of a statutory right to a transitions plan discussed legislation and guidelines designed to aid young people with disabilities in their transition to adulthood that are already in place. Six respondents (6.5%), all in favour of the right, reported that existing legislation is not implemented consistently. The National Deaf Children's Society (62) reported that although there is a statutory right to a transitions plan under The Education (Additional Support for Learning) (Scotland) Act 2004, *'it is uncommon for young people to have a plan in place'*. They also highlighted that, *"only four out of 30 young people who took part in the research" undertaken by the University of Edinburgh on the topic "had a transition plan in place, three of whom had additional complex needs and were educated in a special school"*.

This theme was echoed by the Children and Young People's Commissioner Scotland (29) and included in full here due to its comprehensive overview of existing legislation: *"The Education (Additional Support for Learning) (Scotland) Act 2004 (as amended) ("the ASL Act")<sup>2</sup> creates an obligation on education authorities to prepare and review a Co-ordinated Support Plan (CSP), where a child meets the criteria outlined in section 2 of the ASL Act. In the Additional support for learning: statutory guidance 2017, Chapter 6, the Scottish Government outlines its expectations of education authorities when planning for a disabled child's transition to adulthood, whether it be to further or higher education or to employment. However, it locates the planning process for this within the non-statutory Child's Plan rather than a CSP. It is our view that when a child's transition is being planned, they are likely to meet the criteria for a CSP set out in s2 of the ASL Act due to the number of agencies involved and the resultant complexity of support. However, the*

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<sup>2</sup> <http://www.legislation.gov.uk/asp/2004/4/contents>

*proportion of children with disabilities for whom a CSP is prepared is extremely low, amounting to only 1% of children with ASN<sup>3</sup>.*

*The provisions of the ASL Act relate only to children aged under 16, or aged 16 or over if the education authority is still responsible for their **school** education (our emphasis)<sup>4</sup> and the legal duties contained within it relate only to education authorities and not to other service providers (or even the local authority in its other roles) involved in disabled children's transition to adulthood. The ASL Act, as a result of its situation within education, does not address the social care (particularly if parents have been providing this care), employment support, or health supports required to ensure that disabled children and young people transition to adulthood in a way which enable them to fully realise the rights contained in the UNCRPD, for example in relation to independent living and freely chosen employment. There is limited scope for ongoing planning of transitions from further, higher or vocational education. In particular, the social care support required for young disabled people transitioning to studying or living away from home is often dislocated from educational transition planning. Eleven years ago, we documented the experiences of one young disabled person attempting to study at university<sup>5</sup>, but having to drop out due to a lack of social care support.*

*As a result, as the bill proposal identifies, disabled young people do not currently have a clearly defined right in domestic law to ongoing, multidisciplinary transition planning and support once they leave school, resulting in a failure to realise the human rights of many disabled children”.*

Some respondents reported that non-mandatory practices are not bringing about the required change. Kate Monahan (60), a parent of a young person, described her experience: *“The culture here is so toxic, non-mandatory ‘guidelines’ will have no impact. ‘Guidelines’ will simply be ignored.”* She stated that her Local Authority, *“tries to evade its existing legal duties, so they will certainly not consider themselves beholden by any non-mandatory guidance.”* Inclusion Scotland (51) reported that *“previous work to improve the position has focussed on ‘softer’ policy approaches – a range of work on the principles of good transitions, or attempts to carry over some of the principles of Getting It Right For Every Child (GIRFEC) into adult services for example. Whilst laudable this effort has simply not led to the pace of change or improvements in practise to the extent necessary to ensure transitions for young disabled people that consistently help them to access their rights, fulfil their ambitions and make the most of their lives.”*

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<sup>3</sup> <https://www.ed.ac.uk/education/rke/centres-groups/creid/projects/autonomy-rights-sen-asn-children/project-blogs/riddell-blog-csp>

<sup>4</sup> <http://www.legislation.gov.uk/asp/2004/4/section/2>

<sup>5</sup> Ritchie, L. (2008). *The Paper Hydra, My Transition Quest*. Edinburgh, Scotland's Commissioner for Children & Young People.

### **2.1.2 Would ensure all young people have a right to their support needs being met in their transition to adulthood**

Six (6.5%) respondents who supported the right, and one who did not support, stated that a statutory right to a transitions plan would ensure implementation of a transitions plan for those eligible, giving these children and young people the legal right to provision that meets their needs. The Scottish Association of Social Work (75) reported that *“a statutory right to a transitions plan would ensure that each young person with a disability has their individual needs recognised and would put support in place.”* Several respondents stated that a statutory right to a transition plan places a legal duty on relevant public sector organisations to ensure transitions plans are being made and that the right enables accountability. In addition, some stated that the statutory duty on Local Authorities and services would improve coordination and communication. CHAS (31) reported that *“a transitions plan would help local services and named professional to coordinate care in a timely manner and ensure that resources are in place to meet the young person’s holistic needs. There would also be a degree of accountability and measurable outcomes to achieve goals and objectives.”*

### **2.1.3 Statutory right would bring clarity and consistency**

Eleven (12.0%) respondents reported that a statutory right would bring clarity to young people and carers on their rights, timescales and on what to expect from their transition plan. Respondents also reported that it would bring consistency. Children in Scotland (32) stated that *“the benefits of a statutory plan are ensuring a level of consistency, clearly defined rights and entitlements and access to means of redress if required.”* Kate Monahan (60), a parent of a young person with a disability, stated that the Bill will, *“help eradicate the current postcode lottery and bring a national coherence and consistency of experience and service delivery that should be considered urgent and essential.”* A group of young people with learning disabilities and other support needs (9) reported that a statutory right to a transitions plan would help them *“understand what is going on”* and help to ensure they *“do not get confused or feel left out”*. Another young person (8) said *“from personal experience if the young person is not lawfully given this right it’s a lottery for how long it’ll take to actually start a transition plan”*.

### **2.1.4 Potential to shift understanding and bring awareness to the issue**

Four (4.3%) respondents, some in support of the right and some not in support, welcomed the raised awareness and attention the bill was bringing to the challenges faced by young people making a transition to adulthood. Scotland Versus Arthritis (73) stated that the right may unlock resources and

that it may create a sense of priority. The Family Fund (40), who were not in overall support of a statutory right to a transitions plan, stated that they welcomed, *“the fact that the proposal for a new Transitions (Scotland) Bill helps focus attention on making sure that young people have the right support and access to opportunities at this challenging and exciting time in their lives.”*

## **2.2 Reasons for conditional support**

Six (6.5%) respondents conditionally supported the proposal that children and young people with a disability should have a statutory right to a transitions plan. The conditions included children/young people and families being central and new legislation connecting with previous legislation and provision. More precisely, they were:

1. Person-centred: *“as long as the plan is person centred in nature with the individual at the centre, it should actively involve both the child/young person and their parents/carers.”* Befriending Networks (24)
2. In line with other legislation: Needs to be *“in line with other children’s legislation”, “resources would also need to be increased”, “should link in with ASL legislation”, “need to be clear about the definition of disability and who would be eligible”.* CPTM (Disability) City of Edinburgh Council (35)
3. In line with UNRC: *“the legislative and policy framework needs to take account of United Nations Convention on the Rights for the child, United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and its General Comment No. 4 on the Right to Inclusive Education.”* Socialist Educational Association Scotland (SEAS) (81)
4. Voice and accountability: *“Must include their voice, holds certain professionals and planning and milestones to account and is holistic.”* Anonymous public sector respondent (10)
5. Resourcing and in line with existing frameworks: *“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 - 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 (76)*

6. Meet gap: *“Where young people do not have a CSP we agree that a right to a transition plan would be helpful.” Connect (33)*

### **2.3 Reasons for opposition of the proposed statutory right and other concerns**

Respondents not in support, and even those in support, of a statutory right to a transitions plan discussed concerns with the right and the bill. The main reasons given for **opposing** a statutory right and the main **concerns** discussed, including from those in favour, were:

2.3.1 There is already legislation and guidelines in place

2.3.2 Uncertainty of eligibility criteria for entitlement to a plan

2.3.3 Resources

#### **2.3.1 There is already legislation and guidelines in place**

Ten (10.9%) respondents suggested that there is already legislation in place that locates a duty on social work and local authorities to ensure there is adequate transition planning. The Association of Directors of Education in Scotland (ADES) (21) took the view that, *“there is reasonable and appropriate legislation already in place which places responsibility on local authorities to ensure that transition planning takes place for those children and young people with Additional Support Needs. This includes Education (Additional Support for Learning (Scotland) Act 2004, amended 2009; Children and Young Peoples (Scotland) Act 2014, regulation 3(2) a).”*

Five (5.4%) respondents stated that additional legislation could lead to more confusion and two respondents suggested that additional legislation would lead to another layer of bureaucracy. Several respondents were concerned about the effect the proposed repeal of Section 5 (Child’s Plan) of the Children and Young People (Scotland) Act 2014 would have on the proposed Bill. For example, Down’s Syndrome Scotland (36) stated that this would, *“...complicate the process of introducing a transitions plan and raise questions regarding information sharing and maintaining consistency between the Child’s Plan and the transition plan.”* The Scottish Government’s Disabled Children and Young People Advisory Group (77) reported that *“proposing a Bill which is reliant upon legislation that is under review is a fragile approach”* and Children in Scotland (32) noted their concern that *“without the security of a Child’s Plan in statute to embed this within, the*

*experience of significant inconsistency across Scotland in the use of co-ordinated support plans and without clear alignment with the transition duties within the Education (Additional Support for Learning) (Scotland) Act 2004, as amended a new transitions plan would not have the intended impact.”*

Several respondents discussed the existence of non-mandatory guidelines. Down’s Syndrome Scotland (36) highlighted the Principles to Practice framework related to the Principles of Good Transitions, *“The current work of the Scottish Transitions Forum has developed a Principles to Practice framework which supports a bottom-up approach to embedding the Principles of Good Transitions. This work has been endorsed and supported by the Scottish Government and relevant bodies across the statutory sector and is due to start in early 2020.”* Six respondents suggested a focus on implementing their framework rather than dedicating time and resources to developing new legislation.

ARC Scotland (19), which facilitates the Scottish Transitions Forum, stated that they 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.”* Some respondents who supported the proposed statutory right also suggested in their response that the Principles of Good Transitions be used as a starting point for new legislation, and several highlighted the need to give existing legislation full consideration before implementing new legislation.

### **2.3.2 Uncertainty of eligibility criteria for entitlement to a plan**

Four (4.3%) respondents raised concerns about the eligibility criteria of the proposed statutory right. ARC Scotland (19) stated that they 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.”* Six (6.5%) respondents sought clarity on how the young people who may require a transitions plan were to be identified. Some respondents argued that the Bill leaves out some young people with comparable needs to those who would be entitled to a transitions plan under the current proposals. In the view of ARC Scotland (19), *“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.”*

### **2.3.3 Resources**

Five (5.4%) respondents discussed concerns about appropriate funding and resources. A further five respondents questioned the accuracy of the assertion in the proposal that new transition planning *“can largely be met within existing resources”*. ARC Scotland (19) were of the view that *“the proposed Bill significantly underestimates the number of young people who require a transitions plan”* and that 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 (sic) 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.”*

Eight (8.7%) respondents stated that for the proposed Bill to achieve its objectives it is necessary for appropriate funding to be put in place that facilitated the implementation of the statutory right. ILF Scotland (52) stated that if making transition planning a statutory requirement on authorities and health boards, *“there needs to be a resourcing package that goes alongside this, otherwise, if it is to be delivered within existing budgets, it is likely that other areas that need funding just as much get squeezed... There needs to be a statutory duty not just to plan but also to provide for the successful achievement of the plan outcomes.”*

### **2.4 Discussion of what respondents wanted from new legislation**

Several respondents discussed what they wanted from new legislation. As described above, six (6.5%) respondents sought clarity on who would be eligible to the statutory right to a transitions plan and the expected uptake. Eight (8.7%) respondents reported that appropriate resourcing was vital to the effectiveness of the proposed right and that it is essential that appropriate funding is put in place to support any added statutory duties. Some respondents stated that a commitment needs to be made to ensure agencies and professionals involved in transition planning are given appropriate training.

Eleven (12.0%) respondents, including some in support of the right and some not in support, highlighted the need for person-centred planning and a need for clarity on the role of the young person and their family in the planning process. The Royal National Institute of Blind People Scotland (71) stated that, *“all young people should have ownership over their plan, they should be aware of what is in it, when it is to be reviewed and the purpose of the plan.”*

The Scottish Independent Advocacy Alliance (78) said they would like to see *“a right to independent advocacy during the period of a Transitions Plan included in the Bill, this would support the young person’s views to be heard and their human rights to be upheld.”*

Several respondents stated the need for transition planning to be an on-going process of identifying and meeting changing needs. For example, Kiana Kalantar-Hormozi (55), a young person with a disability, supported the proposed statutory right to a transitions plan and suggested that *“the plan should extend beyond transition - there has to be full acknowledgment that impairments and health conditions are lifelong, and support to remove barriers will always be needed.”*

Five (5.4%) respondents stated the need for a holistic plan, one that focuses not just on health and education. The Royal National Institute of Blind People Scotland (71) suggested that legislation should *“approach transitions holistically, looking at how all individuals and organisations involved in a transition can be supported to achieve the best result for the child.”*



## **Advantages and disadvantages of a transitions plan**

Sections 2 and 3 of the consultation document set out the need for, and the advantages of, the proposed transitions plans. Respondents were asked:

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

Many respondents used this question as an opportunity to discuss the benefits and disadvantages of a transitions plan, some to discuss their concerns about the Bill as a whole and some to give an insight into what they would want from statutory transitions planning.

### 3.1 Reasons for the benefits of a transitions plan

- 3.1.1 Person-centred approach
- 3.1.2 The ability of a transitions plan to coordinate different agencies and services
- 3.1.3 A transitions plan facilitates accountability
- 3.1.4 Provides clarity on the process of transitions
- 3.1.5 Enables monitoring of progress
- 3.1.6 Facilitates early planning
- 3.1.7 Helps reduce feelings of stress and anxiety
- 3.1.8 Facilitates a smoother transition and better outcomes
- 3.1.9 Facilitates dispute resolution and rights of redress
- 3.1.10 Society gains from smooth transitions
- 3.1.11 Will help ensure consistency

#### **3.1.1 Person-centred approach**

Twenty-one (23.0%) respondents discussed the benefit of a person-centred transitions plan. Camphill Scotland (27) highlighted the approach in the proposed Bill, which would ensure that the transitions plans were person-centred: *“We also welcome the person centred approach taken in the Bill. In this respect, Section 10 and 11 will ensure that the views of children and young people will be at the centre of the processes for preparing, and managing, their own transitions plans. We feel that this statutory right will help rebalance some of the power towards children and young people at this crucial time in their lives”.*

The Yard (87) stated that *“a transitions plan would be helpful in so far as it was focused on the individual. An effective transitions plan would support the individualised nature of each young person’s needs, and what assistance and consideration could be required to ensure their input is represented. This*

*requires a nuanced and collaborative approach, involving those who understand each situation best, such as family members and support providers (not only educators)."* Partners in Advocacy (65) discussed the benefits of a person-centred transition plan: *"a transition plan with its associated professional responsibilities would allow children and young people to have a greater emphasis placed on their personal rights, thoughts, feelings and wishes at times when major life-decisions require to be made. It would seem reasonable to argue that the development of a personal transitions plan would offer the individual greater choice and control over those decisions thereby enhancing their life experiences and assisting the individual to feel confident that their views matter to others and are being listened to and acted upon."* Autistic 'n' Awesome (22) highlighted the importance of independent advocacy in being able to contribute to a transitions plan that is focussed on the desires and thoughts of the individual: *"A transitions plan will be helpful if we have appropriate support to make it meaningful. Again we believe that independent advocacy is an essential part of that process, as it will provide us with the support to develop a meaningful understanding and participation in making that plan and therefore having better outcomes."*

### **3.1.2 The ability of a transitions plan to coordinate different agencies and services**

Seventeen (18.6%) respondents reported that a transitions plan would be helpful due to its ability to coordinate the different aspects of the individual's life and its ability to coordinate the different agencies and services involved. CHAS (31) suggested that a transitions plan would *"enable the addressing of all areas of the young person's needs including the right to social inclusion, mental health and wellbeing, education and employment services."* Partners in Advocacy (65) stated that good transition planning should be *"co-ordinated between education and all other services to be involved in the child or young person's life, such as social work, health, support providers, further and higher education and careers guidance (Skills Development Scotland). In order that all agencies co-ordinate efforts to achieve positive destinations and person-centred planning takes place at an early stage, we believe that a statutory transitions plan is required."*

### **3.1.3 A transitions plan facilitates accountability**

Six (6.5%) respondents stated that a transitions plan would be helpful as it would facilitate accountability. For example, the Children and Young People's Commissioner Scotland (29) welcomed the proposal's focus on *"improving individual transition planning and in particular the potential introduction of legal duties upon the full range of public sector organisations involved in*

*the health (including mental health) care, social care, support and education of disabled children and young people, together with a dispute resolution process where duties are not met. This represents a substantial opportunity to improve both delivery of transition support and the accountability for that support and thus improve the lives of disabled young people as they transition to adulthood.*

*“We welcome the provisions in this bill proposal which aim to strengthen strategic planning for young people’s transition to adulthood, in particular the potential to develop links between the different children’s and adult services which support disabled people. Young people often report experiencing abrupt loss of support at the point they leave school or formal education, a concern which has been raised with our office by young people and their parents and was also highlighted by young disabled attendees of the Activate summit held by Inclusion Scotland<sup>6</sup>. The fragmentation of current planning processes negatively impacts disabled children’s rights”.*

### **3.1.4 Provide clarity on the process of transitions**

Fourteen (15.3%) respondents reported that a transition plan would provide a clear pathway, identifying the different stages of transition, the timescales and the roles and responsibilities of the different individuals involved. Ochil Tower School (64) stated that the introduction of statutory transitions plans would *“lead to a clearer understanding, and demarcation, of when social workers from adult services and transition workers will become involved in providing support for children and young people with a disability.”* A group of young people with learning disabilities and other support needs (9) highlighted that a transitions plan *“would help you to understand choices”,* and *“help you know where you are, and what the plan is”.* Social Work Scotland (82) reported that *“transitions plans, when needed, should help clarify (with a young person and those most significant to them) purpose, steps, responsibilities and timescales for action and review.”*

Inclusion Scotland (51) highlighted that the draft proposals locate responsibility for transitions plan on the Local Authority and that the Local Authority would be responsible *“for identifying a Lead Professional, in line with GIRFEC, and would work in partnership with the child/young person/family to assist the young person in carrying out an assessment; formulating the Transitions Plan; keeping the Plan on track and organising reviews of progress. This provides clear lines of responsibility and much needed clarity for young disabled people and their families.”*

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<sup>6</sup> <https://inclusionScotland.org/activate/>

### **3.1.5 Enable monitoring of progress**

Six (6.5%) respondents discussed that a transition plan would be helpful as it would facilitate monitoring of progress with transitions and allow opportunities for review. Independent Living Fund Scotland (52) stated that *“authorities can regularly review and reassess plans as young people embarks on different transitions in their lives. This should also assist local authorities to plan resources and budgets.”* Health and Social Care, North Lanarkshire (47) reported that, *“for many young people, the continued opportunity to be involved in person centred planning and to have their plans reviewed and further supported as they approach further transitions, such as leaving college, may be very helpful, and to have their progress and post school destinations tracked.”*

### **3.1.6 Facilitate early planning**

Seven (7.6%) respondents stated that a transitions plan would facilitate early planning. Partners in Advocacy (65) reported that a statutory transitions plan is required in order that person-centred planning takes place at an early stage. Action for Children (3) outlined the benefits of early transitions planning: *“there is an issue around the length of time it can take young people to settle into any change not only with the environment but with new staff and support workers and changes to routine and familiar settings. Having a plan in place at an early stage can overcome and mitigate many of these issues, it gives young people and their family time to digest and comprehend the proposed changes.”*

### **3.1.7 Help reduce feelings of stress and anxiety**

Five (5.4%) respondents reported that having a transition plan in place would reduce a lot of anxiety and stress felt by young people and their family. Colette Walker (90), parent of a young person with a disability, stated that successful transitions planning would ease the stress on both the young person and their family or guardians. Fibrous Dysplasia Support Society UK (41) reported that in the experience of a psychologist who is on their Medical Advisory Board, a well-developed transitions plan *“will reduce a lot of anxiety (in the young person and their family) about the transition and the young person’s future. Even though the future of the young person will still hold many uncertainties, the plan will ensure the young person and the family have a plan to cope with these uncertainties.”* This was echoed by a young person (8) who said about the plan *“it’ll reduce the amount of stress a disabled young person would face which would be only beneficial for them”.*

### **3.1.8 Facilitate a smoother transition and better outcomes**

Nine (9.8%) respondents stated that a transitions plan would mitigate the challenges and poor transitions currently faced by young disabled people and would improve the outcomes of transitions. Several respondents stated that a transitions plan would help address some of the challenges faced by young people with disabilities that are outlined in the proposal and in answers to Question 1. Action for Children (3) said that, *“having such legislation in place regarding planning would end the poor examples of transition planning that they have come across.”* Inclusion Scotland (51) reported that the *“proposed new legal duties are a proportionate and necessary response to the current evidence in relation to poor outcomes for young disabled people in Scotland and will make a positive difference to the lives of disabled children and young people in Scotland.”*

Four (4.3%) respondents stated that a transitions plan would encourage professionals to aim higher for young people with disabilities and to ensure that their potential is maximised. Several respondents stated that a transitions plan would increase the choice and opportunities available to young people with disabilities. Children in Scotland (32) stated that a transitions plan would help *“ensure that the opportunities available to disabled children and young people to access, for example, employment, training and educational opportunities are significantly increased.”*

Some respondents stated that a transitions plan would facilitate the availability of information about rights and opportunities. For example, The Scottish Commission for Learning Disability (76) stated that a timely and well-coordinated transitions plan would *“give young people and their parents the information they need to make informed choices about their future”*.

Some respondents highlighted that a successful transitions plan will have a positive impact on the rest of their life. For instance, Camphill Scotland (27) stated that, *“getting the transitions planning right earlier, and before the children and young people reach adulthood, will increase the chances that disabled children and young people will be able to secure positive outcomes throughout this transition, and into their adult lives.”* Partners in Advocacy (65) stated that, *“the development of a personal transitions plan would offer the individual greater choice and control over those decisions thereby enhancing their life experiences.”*

### **3.1.9 Facilitate dispute resolution and rights of redress**

Five (5.4%) respondents highlighted that a statutory transition plan would facilitate dispute resolution and would give young people rights of redress. For example, Kate Monahan (60), a parent of a young person with a disability,

stated that where a council has deviated from its obligations the statutory transitions plan would give families who can afford legal representation the hope of redress. Royal Blind (68) stated that, *“the Bill would give Scottish Ministers powers to introduce provisions about dispute resolution under the legislation.”*

### **3.1.10 Society gains from smooth transitions**

Three (3.2%) respondents stated that a transitions plan would be helpful as society would benefit from the smooth transitions of young people with disabilities into adulthood. This is exemplified by Royal Blind (68) here, *“it is not just the young person that stands to benefit from a smoother passage into adulthood. Society also has a lot to gain from their contribution and misses out when young people are unable to live up to their full potential. Too often spending on additional support needs education or adaptations for people with disabilities is viewed in terms of short-term financial cost, rather than long-term gain. If young people with an impairment or long-term health condition are not given the necessary support due to funding concerns then the economic and social effects will likely be felt in the future, whether in increased demand for mental health services, issues with unemployment or underemployment or pressure on the social care sector.”* Similarly, ARC Scotland (19) stated that, *“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.”*

### **3.1.11 Will help ensure consistency**

Seven (7.6%) respondents stated that a statutory transitions plan would allow for consistency across the country. Kate Monahan (60), parent of a young person with a disability, said that a statutory transitions plan will *“help eradicate the current postcode lottery and bring a national coherence and consistency of experience and service delivery that should be considered urgent and essential.”*

## **3.2 The main reasons why a transitions plan would not be helpful**

Although the following points are given by those who responded that a transitions plan would not be helpful, their comments provide insights into the key aspects that could help improve and enhance transitions plans and their

implementation, for example, by using research and evidence-based conceptualisations of transitions.

3.2.1 Impact of conceptualisation of transition as an event

3.2.2 Existing legislation and frameworks

3.2.3 Resources

3.2.4 Planning starts too late

### **3.2.1 Impact on conceptualisation of transition as an event**

Six (6.5%) respondents stated that a transitions plan would not be helpful if transition is viewed as an event, rather than an ongoing process. Scotland Versus Arthritis (73) stated that transition, *“can sometimes be misunderstood as an event, i.e. the transfer from paediatric to adult care. Service planning and design then become focused on the point of transfer and neglect the multiple aspects of transition facing young people.”* Lead Scotland (57) contested that, *“the Bill refers to support ceasing once a young person has moved into a positive destination. This contradicts the proposal’s earlier definition of transitions as not being an event but “an ongoing process that involves moving from one context and set of interpersonal relationships to another to another”<sup>7</sup>. Even if a young person does move into a successful ongoing positive destination, the proposal already acknowledges that transitions are life-wide, so on-going support may well still be required to achieve positive outcomes within other areas such as health, social care and housing.”* The Scottish Government’s Disabled Children and Young People Advisory Group (77) also noted this and said that, *“the suggested Bill adds an assessment at a single point that is unhelpful as it creates an inequitable approach”* and that *“planning for the target group within the proposed Bill creates inequity and does not take into account the benefits that could be gained by taking a life-course approach, such as the ability to project need across the life course.”*

### **3.2.2 There is already existing legislation and frameworks**

Like the response to Q2, several respondents were concerned a statutory transitions plan would not be helpful as there are existing legislation and frameworks in place. SCLD (76) stated that, *“legislation and policy does already exist: the Education (Additional Support for Learning) (Scotland) Act 2004, the Social Care (Self Directed Support) (Scotland) Act 2013, and the*

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<sup>7</sup> Jindal-Snape, D. (2016). *A-Z of transitions*. Palgrave Macmillan.

Jindal-Snape, D. (2018). Transitions from Early Years to Primary and Primary to Secondary Schools in Scotland. In T. Bryce, W. Humes, D. Gillies, & A. Kennedy (Eds.), *Scottish Education* (5 ed.). Edinburgh University Press.

*Children and Young People (Scotland) Act 2014 all place various duties for care and support planning for children and young people. Statutory Guidance on the Education (Additional Support for Learning) (Scotland) Act 2004 (as amended) Code of Practice (Third Edition (2017) gives a right to access transitions planning. Given the scale of negative experiences of transitions to date, SCLD (76) believes this demonstrates that legislation does not necessarily guarantee good outcomes for people. Instead, we believe that effective implementation is key to success.”*

Six (6.5%) respondents expressed concern that another layer of legislation could result in duplication of planning. The National Deaf Children’s Society (62) questioned how duplication will be avoided between CSPs, IEPs and the Child’s Plan under the Children and Young People (Scotland) Act 2014 (CYP Act). COSLA (34) also raised concerns about duplication: *“Firstly, it can be upsetting and confusing for service users to repeat similar processes without clear reason or gain. Secondly, it could add to the workload of those staff who would have responsibility for transition plans.”* Some respondents stated that additional legislation would just add further confusion to the already confusing legislative landscape and would add another layer of bureaucracy. Social Work Scotland (82) stated that this extra legislation *“could be confusing, bureaucratic and unhelpful if this forms one of multiple strands of parallel planning processes with overlapping intent.”* SCLD (76) raised further concerns that new legislation will not have the desired effect, using the Children and Young People (Scotland) Act 2014 as an example of legislation that has not improved what it sought to. SCLD report that *“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); instead, the key drivers for change are ‘culture change, relationships and skillsets, and resources’ (page 27).”*

Some respondents worried about the effect of the proposed repeal of Section 5 (Child’s Plan) of the Children and Young People (Scotland) Act 2014 on the Bill. The Scottish Government’s Disabled Children and Young People Advisory Group (77) report that, *“the proposed Bill in itself is inequitable as it doesn’t take into account the current political context or amendments, for example when re-visiting the Child’s Plan. This could result in a narrowing of the help available with some young people missing out.”*

Some respondents were concerned that new legislation would detract focus and resources away from existing, well-developed frameworks. Glasgow Disability Alliance (45) said that, *“existing transitions mechanisms, including*



*the Framework for the Children and Young People's Act, GIRFEC and the 7 Principles of Transitions, are under-utilised, and require more significant political support to make them fully effective. It is our opinion that a drive towards another Bill and/or Strategy may delay implementation and support for these frameworks that were developed over many years and involved the active participation of many young people, their parents and the organisations that support them."*

### **3.2.3 Resources**

Sixteen (17.5%) respondents expressed a concern for lack of resources. One anonymous public sector respondent (7) stated that, *"a Bill does not prevent the problem of waiting lists; it also does not help the issue of resources", "a statutory document does not facilitate access to resources" and "a transition plan could increase expectation of resources".* SCLD (76) reported that some participants of focus groups they organised stated that a statutory right on its own would not be effective and that 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."* SCLD (76) were also concerned that, *"allocating significant additional resources to Statutory Transitions Plans would mean disinvesting in other priorities"*. Their focus group participants worried about unintended consequences of placing statutory duties without providing the required level of funding to meet these responsibilities. Their main reasons for this were *"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)" and "that staffing resources would have to be diverted away from service provision in order to meet the statutory requirement for transitions planning."*

Some respondents were not convinced by the proposed Bill's suggestion that a *"few dozen [young people] per local authority"* would seek additional support with their transition to adulthood. Some respondents, including the National Autistic Society (61), believed that to be a crucial underestimate *"that could lead to local authorities being vastly under-resourced and under-prepared to deal with, what we would expect to be, significantly higher numbers."* Lead Scotland (57) challenged the proposal's view that costs would be minimal and could largely be met within current resources. Their view was that if all young disabled people aged 14-26 are entitled to a mandatory plan, *"where before many would not have been eligible to access support, this will inevitably cost more money and it would be very unlikely this could be met within current resources. Given that transition planning is already a legal requirement, not*

*always upheld, we would urge caution around creating new legislation that will unavoidably cost more but not necessarily lead to improved outcomes, as it could distract attention and divert vital resources away from where it is needed most.*" Other respondents also reported that there is a lack of resources and funding to meet the gap between expectations that will be raised by a statutory right to a transitions plan and the reality of available resources for each eligible young person and their family.

### **3.2.4 Planning starts too late**

Three (3.2%) respondents stated that a transition plan would be unhelpful if planning started late. The proposed bill states that a plan must be agreed by the local authority and the child or young person, with it being put in place no later than three months before the child's 16<sup>th</sup> birthday. Some respondents believe this to be too late. For example, the National Autistic Society Scotland (61) said that, *"this may be too late for some young people as there are those who are able to leave school prior to their 16<sup>th</sup> birthday and, therefore, the proposed timescale could lead to plans being prepared too late to support early school-leavers."* ILF Scotland (52) suggested that it would be preferential to start working on a plan according to individual circumstances as opposed to age. The National Deaf Children's Society (62) also said that, *"co-ordinated early intervention is critical and it is possible unintended consequences could include a lessened focus on earlier critical milestones in disabled children's lives."*

### **3.3 What respondents want from statutory transition planning**

Four (4.3%) respondents placed emphasis on the need for person-centred planning. Values Into Action Scotland (89) stated that a transitions plan would be helpful if planning was done with *"the full involvement and agreement of the young person and their carer/family and not one prepared or delivered just by professionals."*

Some respondents suggested a holistic approach to transitions planning. Partners In Advocacy (65) stated that, *"transitions planning should be co-ordinated between education and all other services to be involved in the child or young person's life, such as social work, health, support providers, further and higher education and careers guidance."* Kiana Kalantar-Hormozi (55), a young person with a disability, highlighted that a transitions plan should take into account *"everything required for that child/young person to live a full life, and one person responsible for making sure that happens for real -not passing on the blame to different departments"*. Similarly, other respondents also stated a desire for there to be one person to take the lead responsibility for a transitions plan, e.g., Magdalen MacInnes (58), a young person with a

disability, said that, *“a lead professional with an overview of all the opportunities and possibilities would be able to help the young person and their family in making decisions, and, after review, assist them in changing course when this is beneficial.”*

Some respondents shared a desire for a transitions plan that is outcome focussed, not needs focussed. Some respondents were concerned that lack of resources would result in planning being service-focussed as opposed to outcome-focussed. The National Carer Organisations (85) stated that in order to ensure the transitions plan produces positive outcomes for disabled young people and carers, the initiative must be fully resourced and appropriately monitored and evaluated.

## **Potential impact of a National Transitions Strategy**

Sections 2 and 3 of the consultation document set out the need for a National Transitions Strategy, and how this would benefit children and young people with a disability. Respondents were asked:

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

### **Advantages and disadvantages of a National Transitions Strategy**

The following responses were received:

- 26 (28.5%) respondents stated that a National Transitions Strategy would assist young people with a disability to achieve independent living.
- 29 (31.8%) respondents answered that they think that a National Transitions Strategy would assist disabled young people to achieve independent living, subject to conditions.
- 4 (4.3%) respondents answered no, a National Transitions Strategy would not assist young people with a disability to achieve independent living.
- 32 (35.1%) respondents did not answer the question.

#### **4.1 Reasons for answering 'yes':**

The main reasons given for answering 'yes' to Question 4 were that, a National Transitions Strategy would:

- 4.1.1 provide a consistent framework and would engage services
- 4.1.2 support education to build on independence skills
- 4.1.3 bring increased focus and attention to the area
- 4.1.4 encourage more meaningful opportunities

##### **4.1.1 Provide a consistent framework and would engage services**

Six (6.6%) respondents who agreed stated that National Transitions Strategy would provide a consistent framework and a clear plan and would facilitate the engagement of services and agencies. This is exemplified by this response from The Usual Place (86) who stated that, "*a National Transitions Strategy with an accountable Minister will provide the framework required for national and local action to improve the transitional civic and economic outcomes for children and young people.*" The issue of accountability was also highlighted by a young person (8) who stated: "*it would be a step in the right direction as a Government Minister could be held accountable if no change was happening. The whole issue would have to be investigated and discussed*

*with disabled young people and groups who represent them parents, teachers social work departments hopefully these discussions would help make transition to adult services and further education less stressful". Camphill Scotland (27) also stated it can "provide a framework that will help agencies to work together to maximise the life opportunities for disabled children and young people, and to help greater numbers of disabled young people to achieve independent living."*

#### **4.1.2 Support education to build on independence skills**

Two (2.1%) respondents who agreed stated that a National Transitions Strategy could support the development of independence skills of children and young people with disabilities. For instance, Enable Scotland (38) argued that an early focus on employability support provided by a transitions plans would, *"expose young people to more support with soft skills and skills for living, including independent travel, which is so important to empowering young people with the confidence and ambition to broaden their employment options."* A group of young people with learning disabilities and other support needs (9) agreed, and stated that they would then be prepared and *"learn how to budget, use the bus, cook, use the bank and take care of our home"*.

#### **4.1.3 Bring increased focus and attention to the area**

Three (3.2%) respondents stated that the increased awareness and focus on the issue that a National Transitions Strategy would bring would assist young people with disabilities to achieve independent living. One anonymous individual (11), a professional with experience in a relevant subject, stated that a national strategy would *"ensure the rights of disabled people are at the forefront of everyone's minds"*. Lead Scotland (57) reported that a National Transitions Strategy could *"assist disabled young people to achieve independent living as it will bring increased focus, attention and responsibility on such an important policy area."*

#### **4.1.4 Encourage more meaningful opportunities**

Two (2.1%) respondents stated that a National Transitions strategy would make more opportunities available for young people with disabilities, assisting them to achieve independent living. Claire Edwards (37), a professional with experience in a relevant subject, stated that a National Transitions Strategy would *"foster and encourage meaningful opportunities"* and Ochil Tower School (64) states that *"the National Transitions Strategy would increase opportunities for young people to fulfil their potential, and to achieve greater independence in their adult lives"*.

### **4.2 Reasons for answering 'conditionally, yes'**

There were several reasons given for answering that a National Transitions Strategy will, subject to conditions, assist disabled young people to achieve independent living. Respondents stated that it would only help if:

- 4.2.1 Suitable resources are in place
- 4.2.2 The plan is person-centred
- 4.2.3 'Independent living' is clarified
- 4.2.4 It is accompanied by a significant societal shift
- 4.2.5 It is developed from existing frameworks

#### **4.2.1 Suitable resources are in place**

Thirteen (14.2%) respondents whose answers have been classified as 'conditionally, yes' stated that a National Transitions Strategy would assist disabled young people to achieve independent living if suitable resources are in place. This is echoed by an anonymous public sector body (7) which stated that it will only assist if "*suitable resources are in place during their transition to adulthood: e.g. Only if suitable college course/accommodation is available at the time of transition and matched to the young person's aspirations for living solo or with peers; within easy accessible travelling distance of college/work/activities/family/health care; in a safe community known to the young person.*" Children in Scotland (32) highlighted that a "*strategy alone will not assist young people to live independently. There must be enough availability of support and resources to enact this strategy in a meaningful way.*" Similarly, Kiana Kalantar-Hormozi (55), a young person with a disability, stated that whether it could help achieve independent living was dependent on "*who is in charge, how it's executed and what funding will be allocated to truly allow this plan to work*". Values into Action Scotland (89) stated that it "*depends very much on whether there are sufficient resources behind it, those resources are allocated in the right way to the right places and are not diverted for political benefit to the those who shout the loudest or have the highest profile.*"

#### **4.2.2 The plan is person-centred**

Four (4.4%) respondents stated that a National Transitions Strategy would assist disabled young people to achieve independent living if the strategy allows for involvement of the young person and their family in the planning for their future. ILF Scotland (52) stated that "*a National Transition Strategy, which requires each young person to be involved in the creation of a thorough planning process for their future, has the potential to provide a solid basis from which the young person can develop their skills and abilities and work toward achieving the level of independent living they wish.*"

### 4.2.3 If 'independent living' is clarified

Three (3.2%) of respondents who answered 'conditionally, yes' stated that whether 'independent living' is achievable for some young people with disabilities depends on what is meant by independent living'. An anonymous public sector body (7) stated that, "*there needs to be further clarity about the term 'independent living' Some young people will always require services for personal care, dressing, etc. Does the term mean independent of services or out with parental home? Independent living may not be a priority for all young people.*" This can be seen from the comments of some respondents stating that independent living is neither a priority, nor achievable, for many young people with a disability. Fibrous Dysplasia Support Society UK (41) reported that, "*even with the bill, this is likely still going to be a difficult path for many young people and their families, but we anticipate the bill to greatly facilitate independent living compared to the current situation.*" This was further clarified by ILF Scotland (52) who stated that, "*the Strategy should make clear that the aim of effective transition is not necessarily for a young person to live independently by moving into his or her own accommodation. By setting this as a single outcome, the Bill could lead people into thinking that Transitions is all about this when transition from children's to adult services is seldom, at that stage of life, about living independently. It might be better express the outcome by focussing on the young person having the skills, confidence, communication and support networks to lead as independent a life as possible.*"

### 4.2.4 It is accompanied by a significant societal shift

Two (2.1%) respondents stated that a National Transition Strategy would only assist disabled young people to achieve independent living if it is accompanied by a significant societal shift. People First Scotland (66) said that, "*it's positive that the suggested strategy supports and describes how young people should achieve independent living*" however there are barriers that exist that need to be addressed. They noted that there is not the same societal expectation for young people with a learning disability to move out of the family home as there is for other young people once they leave school. Similar to previous research<sup>8</sup>, People First Scotland (66) reported that young people talked about wanting their own space and their own flat but not being provided with support to explore this as an option. They also highlighted that,

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<sup>8</sup> Jindal-Snape, D., Johnston, B., Pringle, J., Kelly, T., Scott, R., Gold, L., & Dempsey, R. (2019). Multiple and Multidimensional life transitions in the context of life-limiting health conditions: Longitudinal study focussing on perspectives of Young Adults, Families and Professionals. *BMC Palliative Care*, 18, 1-12. [30]. <https://doi.org/10.1186/s12904-019-0414-9>

*“people with a learning disability are often placed in care homes or shared accommodation because it is cheaper to provide support to a group of people than an individual. This is very far removed from the idea of support to live an independent life.”* Similarly, one anonymous respondent (10), a professional with experience in a relevant subject, stated that whether a National Transitions Strategy would assist disabled young people to achieve independent living is dependent on people’s perception of ‘independence’ and ‘living’. Further, The Royal College of Speech and Language Therapists (70) stated that to succeed the focus of policy must change to *“consider the holistic needs of young people with disability (and not solely focus on health, education and employment)”*. However, one respondent was not sure that independence is necessarily the best outcome as this can often lead to loneliness and a low quality of life.

#### **4.2.5 It is developed from existing frameworks**

Six (6.5%) respondents stated that a National Transition Strategy would only assist disabled young people to achieve independent living if such a strategy is based upon existing, well-developed frameworks. Down’s Syndrome Scotland (36) stated that, *“a National Transitions Strategy should be based in the Scottish Transitions Forum Principles of Good Transition and Principles to Practice Framework. This already has considerable buy-in from Government, statutory and other agencies and from parents and young people. With the more robust implementation of these principles, young people are more likely to be able to achieve their full potential and live the life they choose.”* Likewise, ADES (21) stated that a National Transitions Strategy would not necessarily assist disabled young people to achieve independent living without *“aligning ‘Keys to Life’ with GIRFEC and ASL planning to ensure that provision and support for children and young people from a very early age is aimed at promoting and valuing their independent living skills.”* This is echoed by ILF Scotland (52) who said that, *“such a strategy should assist disabled young people to achieve independent living if a framework similar to GIRFEC and wellbeing resources (SHANARRI) is developed.”*

#### **4.3 Reasons for answering ‘no’:**

The main reasons given for answering ‘no’ to Question 4 were in some cases the same as those who had responded ‘yes but with conditions’ (see 4.2):

- 4.3.1 The meaning of ‘independent living’
- 4.3.2 Achieving ‘independent living’ goes far wider than any transitions strategy
- 4.3.3 Independent living is neither a priority nor an achievable outcome for all



4.3.4 A National Transitions Strategy would not be more helpful than the current approach

#### **4.3.1 The meaning of 'independent living'**

Glasgow Disability Alliance (45) discussed the meaning of 'independent living' in their answer to this question. GDA stated, "*the definition of independent living, as defined by the disabled people's movement is not fully understood, nor embedded in health, social care or education services*". GDA's (45) view was that many 'Skills for Life' courses misinterpret 'independent living' as "*doing for oneself, fending for oneself, independent of others*". In contrast, the disabled people's independent living movement defines independent living differently as '*...disabled people of all ages have the same freedom, choice, dignity and control as other citizens at home, at work and in the community. It does not mean living by yourself or fending for yourself. It means having rights to practical assistance and support to participate in society and live an ordinary life.*' GDA (45) stated that "*until this definition is an integral part of transitions planning, then any strategy cannot ever assist young disabled people to achieve independent living.*"

#### **4.3.2 Achieving 'independent living' goes far wider than any transitions strategy**

Glasgow Disability Alliance (45) noted that independent living for those with disabilities relies on access to a range of support, including housing, employment, education, leisure activities, legal protection, etc. Therefore, GDA (45) reported that they believe achieving 'independent living' is far wider than any transitions strategy and that the "*wider context must be addressed to remove the barriers faced by young disabled people to achieve their ambitions and enjoy the same life chances as their non-disabled peers.*"

#### **4.3.3 Independent living is neither a priority nor an achievable outcome for all**

Social Work Scotland (82) answered that, "*independent living may not be a priority objective for all; or realistic for some with profound and complex needs.*" Ann Maxwell of the Muir Maxwell Trust (59) responded that a National Transitions Plan will "*only help a few to achieve independent living*". She goes on to state that she disapproves of the ambition for independent living for the majority as "*one shoe does not fit all*" and that it will "*lead to greater problems in the future as mental health issues result from social isolation, even with visiting carers, which is simply not enough.*"

#### **4.3.4 A National Transitions Strategy would not be more helpful than the current approach**

Glasgow Health and Social Care Partnership (46) answered 'No' to question 4 and stated that a National Transitions Strategy would not be more helpful in assisting young disabled people's independent living than the existing process. It states that, "*Glasgow City provides assessment of needs with the intention of "getting it right for every" young person requiring Social Care support. For disabled young people, they are each supported on an individual basis to maximise their opportunities and independence. This will include work, training, independent living or any other measure appropriate to their ability, circumstances and choice. It is not envisaged that any National Transitions Strategy, in placing further responsibility on Local Authorities, would alter this process or the support offered to children and young people.*"

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

## **5.1 Advantages**

The main advantages of a National Transitions Strategy given by the respondents were:

- 5.1.1 Greater consistency of delivery
- 5.1.2 Greater coordination
- 5.1.3 Allows monitoring and learning
- 5.1.4 Would result in better outcomes for the children and young people
- 5.1.5 Would facilitate greater respect for the rights of the children and young people
- 5.1.6 Could be correlated with other strategies
- 5.1.7 Would give greater clarity
- 5.1.8 Would facilitate accountability
- 5.1.9 Would raise the profile of the issue
- 5.1.10 Will result in higher expectations and aspirations

### **5.1.1. Greater consistency of delivery**

Fifteen (16.4%) respondents stated a National Transitions Strategy would allow for greater national consistency. For instance, Kate Monahan (60), parent of a young person with a disability, reported that a National Transitions Strategy “*will help eradicate the current postcode lottery and bring a national coherence and consistency of experience and service delivery that should be considered urgent and essential.*” Similarly, Connect (33) stated that a national strategy could “*provide an opportunity to join the dots between national government, local authorities, health boards, and other agencies, and improve the consistency of support for young people with a disability making the transition to adulthood across the country.*” A group of young people with learning disabilities and other support needs (9) reported that an advantage of the National Transitions Strategy “*will be that help is there for you*”.

### **5.1.2 Greater coordination**

Thirteen (14.2%) respondents stated that a National Transitions Strategy would facilitate a coordinated approach to transition planning. Royal Blind (68) reported that a National Transitions Strategy would “*provide the opportunity*

*for joint-working through an overarching framework giving agency to local authorities, NHS Health Boards, the Integration Joint Boards and other bodies.” The National Autistic Society (61) stated that a “statutory plan for transition along with a national strategy in which health, social work, education and other providers can work together could greatly improve the chances for many young people to have a successful transition to meet their potential.”*

### **5.1.3 Allow monitoring and learning**

Ten (10.9%) respondents stated that a National Transitions Strategy would afford the opportunity for the Scottish Government and Local Authorities to share practise and learning and to monitor the success of transitions planning and to make changes accordingly. The Scottish Commission for Learning Disability (76) reported that a National Strategy 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.*” Shetland Islands Council (80) stated that a National Strategy will “*promote the opportunity to share practice and learning across local authority areas*” and Glasgow Centre for Inclusive Living (44) stated that the Strategy would “*help share examples of good practice with localities which are performing least well.*”

### **5.1.4 Would result in better outcomes for the children and young people**

Eight (8.7%) respondents stated that a National Transitions Strategy would result in better opportunities and outcomes for young people with disabilities. Ochil Tower School (64) stated that the strategy will “*provide a framework that could help to significantly improve outcomes for children and young people with a disability in the transition to adulthood.*” The National Autistic Society Scotland (61) concurred that a National Strategy can “*greatly improve the chances for many young people to have a successful transition to meet their potential.*” Inclusion Scotland (51) reported that a National Strategy would provide a framework that will help statutory and voluntary agencies to “*work together to maximise the life opportunities for disabled children and young people across Scotland.*”

### **5.1.5 Would facilitate greater respect for the rights of the children and young people**

Six (6.5%) respondents stated that an advantage of a National Transitions Strategy would be its ability to encourage better protection of the rights of young people with disabilities. The Law Society of Scotland (56) reported that a National Strategy would “*contribute to achieving all of the rights accorded by*

*the UN Convention on the Rights of Persons with Disabilities by ensuring that all relevant policies and planning- as well as individual planning- achieves that purpose.”* Kiana Kalantar-Hormozi (55), a young person with a disability, agreed that a National Strategy could bring a well overdue end to the violating of the rights of young disabled people.

#### **5.1.6 Could be correlated with other strategies**

Six (6.5%) respondents stated that an advantage of a National Transitions Strategy would be the opportunity to embed other well-developed frameworks into the National Strategy. For instance, Aberdeen City Council (1) reported that *“a National Transitions Strategy would offer a more robust legislative framework to embed the vision, priorities and culture created by the Principles of Good Transition.”* COSLA (34) concurred that it could build on *“the good, cross sector work undertaken by ARC Scotland on The Principles of Good Transitions.”*

#### **5.1.7 Would give greater clarity**

Five (5.4%) respondents stated that a National Transitions Strategy would provide clarity to Local Authorities, agencies, services, and young people and their families on the transitions process, aims, rights and opportunities. The SCLD (76) stated 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.”* SCLD (76) also stated 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.”*

Seven (7.6%) respondents stated that a National Strategy would provide clear national aims, objectives and outcomes. Colette Walker (90), parent of a young person with a disability, reported that a National Strategy would *“afford a clear reference point to these agencies in terms of aims and objectives, and outcomes to improve transitions for disabled children and young people.”* An observation that echoes The Usual Place’s view (86) that *“a National Strategy will provide clear national aims, objectives and outcomes which can be used to develop local strategy and inform best practice and multiagency working.”*

#### **5.1.8 Would place transitions planning on a statutory footing and would facilitate accountability**

Five (5.4%) respondents stated that a National Transitions Strategy would facilitate accountability and three (3.2%) stated that it would place transitions

planning on a statutory footing. For instance, Aberlour (2) stated that a National Strategy would ensure “*greater accountability for those responsible for planning and coordination*” and SCLD (76) reported that the strategy would “*give young people and their families recourse if they do not receive the planning support that they are entitled to.*” Colette Walker (90), parent of a young person with a disability, also reported that “*a National Transitions Strategy would help ensure accountability and place transition planning on a statutory footing.*”

### **5.1.9 Would raise the profile of the issue**

Four (4.3%) respondents stated that a National Strategy will raise the profile and bring a newfound importance to the relevant issues. SCLD (76) reported that members of their focus group agreed that, “*a national strategy could give focus to and raise the profile of an important and problematic issue.*” One young person (8) said that the strategy “*would also bring this issue into the public eye if it was being discussed in the Scottish Parliament and, therefore, in the media.*”

### **5.1.10 Will result in higher expectations and aspirations**

Three (3.2%) respondents stated that an advantage of a National Transitions Strategy would be that it would result in higher expectations being set for young people with disabilities. Fife Council’s Education and Children’s Services (42) reported that a National Strategy would set “*higher aspirations and expectations*” which would enhance practise and outcomes. The Usual Place (86) stated that, “*a National Strategy will clearly demonstrate the value The Scottish Government has for all young people. This is very important in changing the prevailing culture of low expectation and the poverty of expectation disabled young people experience.*”

## **5.2 Disadvantages**

The main disadvantages of a National Transitions Strategy given by the respondents were:

- 5.2.1 Resources
- 5.2.2 Workload
- 5.2.3 Lack of flexibility in line with a young person’s changing needs
- 5.2.4 Lack of independent advocacy
- 5.2.5 Existing legislation and frameworks
- 5.2.6 One size fits all approach

### **5.2.1 Resources**

Twenty-three (25.2%) respondents cited financial implications as a disadvantage of a National Transitions Strategy. Six (6.6%) stated an insufficient level of resources to deliver successful transitions. Aberlour (2) reported that they did not believe *“the aims of the bill can realistically be achieved within existing resource and capacity”*. The Royal College of Paediatrics and Child Health Scotland (69) reported that, *“a National strategy would not be cost neutral and additional funding to health and social care partnerships would be required to allow the strategy to be delivered.”*

Some respondents stated that a Strategy will not in itself bring with it any increased funding. For example, Colette Walker (90), parent of a young person with a disability, stated that, *“a strategy on its own without a different approach to resourcing provision at a national and local level will not result in the step change which is required.”*

Six (6.5%) respondents stated that a National Strategy would not necessarily take account of local differences in resource and need, risking discrepancies of support between local authority areas. The Scottish Association of Social Work’s view (75) was that a National Strategy brings with it a *“risk of provision of support becoming a postcode lottery because of discrepancies between different local authority areas.”*

Two (2.1%) respondents reported a lack of resources and funding to meet the gap between raised expectations and reality. The Usual Place (86) reported that, *“a high expectation National Strategy in place without appropriate resources to deliver the outcomes could lead to increased despair and no measurable improvements.”*

### **5.2.2 Workload**

The view of five (5.4%) respondents was that a disadvantage of a National Strategy would be the consequential increased workload. One anonymous public sector body (7) suggested that a National Strategy would *“require restructure of current policies and processes with cost implications and work load for local authorities and other professionals”* and *“may add further pressure to agencies who are working within a context of reduced resources.”* ADES (21) also questioned how *“authorities (and especially smaller authorities) – in a time of financial restraint - respond to an increase in demand on services and service development.”*

### **5.2.3 Lack of flexibility in line with a young person’s changing needs**

Three (3.2%) respondents stated that a National Transitions Strategy would be disadvantageous if it promoted a single point of assessment as opposed to a continually evolving plan. The Scottish Government's Disabled Children and Young People's Advisory Group (77) stated that, "*the suggested Bill adds an assessment at a single point that is unhelpful as it creates an inequitable approach. We would argue that availability of planning (rather than assessment) is particularly required through the transition period.*" Children's Health Scotland (30) concurred that "*the approach may be fixed and not responsive to changing needs and potentially leave the [young person] stuck without support or doing something they do not enjoy, to meet a local authority need to be seen to demonstrate this statutory duty.*"

#### **5.2.4 Lack of independent advocacy**

Three (3.2%) respondents noted a need for advocacy, such as Autistic 'n' Awesome (22), who stated that a "*disadvantage will come if there is not adequate independent advocacy support to make our involvement in such a strategy meaningful.*"

#### **5.2.5 Existing legislation and frameworks**

As noted under previous questions, several respondents stated there are existing relevant legislations and frameworks in place and questioned the advantage of dedicating time and resources to a new legislation. Health and Social Care, North Lanarkshire (47) discussed the work currently being taken forward by the Scottish Transitions Forum and questioned "*whether it may be that with further Scottish Government recognition and support of this current work, providing it with the status of a National Strategy, the objectives can be achieved without the need to develop a further strategic approach. It would seem preferable to support the development of one cohesive approach which involves key stakeholders nationally than to develop another strategy which runs the risk of duplicated effort.*" CHAS (31) also noted that there is already national guidance, and Connect (33) warned against the disadvantage of replicating existing work.

#### **5.2.6 One size fits all approach**

Three (3.2%) respondents discussed the disadvantages of a 'one size fits all approach'. Enable Scotland (38) mentioned that "*the risk of the imposition of a "one size fits all" approach which does not take into account differing issues and challenges in different locations, and in particular, the impact of rurality and connectivity for Scotland's rural and island communities.*" Befriending Networks (24) also reported "*a danger that young people will not be treated individually and their plans not relevant if the strategy is not flexible.*"



**Question 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?**

The following responses were received:

- Fifty Four (59.3%) of the respondents answered that yes, they think that 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
  - Eight of the respondents who answered yes stated that they think ministerial oversight is necessary but that the responsibility should be embedded in an existing minister's portfolio
- Six (6.5%) of the respondents answered yes but subject to conditions
- 14.2% (n=13) respondents answered no
- 19.7% (n=18) respondents did not answer

In terms of a further analysis of the responses based on the sector, there were interesting differences across and within sectors. Five (41.7% of the 12) public sector respondents answered either yes, or conditionally yes, that a Minister is necessary. Whereas the same number of public sector respondents answered no. Seven (58.3% of the 12) representative organisations answered yes or conditionally yes, with two (16.7%) answering no. Twenty-eight (71.8% of the 39) of third sector respondents answered yes or conditionally yes, while five (12.8%) answered no. Whereas, sixteen (64.0% of the 25) of individual respondents answered yes or conditionally yes, while only one (4%) answered no. The rest of the respondents in every sector category did not answer.

**6.1 Main reasons given as to why a Minister is necessary:**

- 6.1.1 Ensures there is someone responsible for overseeing the effective implementation of a National Transitions Strategy
- 6.1.2 Someone to be held accountable
- 6.1.3 To be an advocate for the children and young people
- 6.1.4 Will bring an increased focus to the area
- 6.1.5 To provide a point of contact for young people and their family

**6.1.1 Ensures there is someone responsible for overseeing and monitor the effective implementation of a National Transitions Strategy**

Twelve (13.1%) respondents stated that a minister with a special responsibility will help ensure the transitions strategy is implemented in practice and will ensure that children and young people are receiving sufficient support. A group of young people with learning disabilities and other support needs (9) highlighted that a Scottish Government Minister with specific responsibility for transitions *“would be someone to stand up for your rights, and get the job done”*. This was also highlighted by another young person (8) in his response to the consultation: *“it is important so that someone in representing disabled young people in the Scottish Parliament. I feel that the matter is more likely to be taken seriously also by social workers, local authorities Colleges and Universities. The young people themselves will have a point of contact to be able to highlight the issues they face”*. Fibrous Dysplasia Support Society UK (41) state that ministerial responsibility is *“necessary to ensure the proposed bill and associated actions are implemented as intended as well as evaluated on a regular basis to ensure it keeps meeting the needs of the young people with a disability and their families.”*

Five (5.4%) respondents stated that a minister would be able to hold decision makers to account for the implementation of the legislation. Kate Monahan (60), parent of a young person with a disability, stated that, *“a minister should hopefully be someone whom might act in applying scrutiny and securing accountability from errant, hostile, unwilling, non-compliant councils.”*

Four (4.3%) respondents reported that a minister would be able to coordinate services and policies. Association of Directors in Education (21) discusses the advantage of a minister being able to join up the strategy between Government departments *“to ensure that there is a ‘pull’ from adult health and social care.”* The National Deaf Children’s Society (62) states that there is a *“clear need to coordinate and monitor the impact of multiple policy areas that will affect disabled young people’s lives”*.

Six (6.5%) respondents stated that a Minister would be able to monitor the implementation and progress of the Transitions Strategy. The National Carer Organisations (85) report that *“it is key there is a Minister responsible for developing the National Transitions Strategy, monitoring progress through annual reporting and developing initiatives in relation to supporting young disabled people in education and into employment”*.

### **6.1.2 Someone to be held accountable**

Twelve (13.1%) respondents stated that it is necessary that there be ministerial responsibility as it will provide accountability. Marcus Sangster (72) stated that, *“unless there is accountability that is tied to an individual there will be no change in behaviour. Accountability MUST NOT be vested simply in a process.”* Enable Scotland (38) states that *“assigning special responsibility for*

*transitions to a specific Minister would also help improve accountability in this policy area, with that Minister responsible for implementing the policy, answering questions in Parliament, and reporting on progress against targets".* Three (3.2%) respondents state that as this area crosscuts portfolios, there is a need for a minister to ensure coordinated accountability.

### **6.1.3 To be an advocate for the children and young people**

Nine (9.8%) respondents stated that there is a need for a Minister in order to advocate for the children and young people. The Scottish Association of Social Work's view (75) was that *"given the unique set of needs for young people with a disability, and the lack of equal opportunities for them, a Minister with such a responsibility would highlight the need for improvements and advocate appropriately for change where required."*

### **6.1.4 Will bring an increased focus to the area**

Four (4.3%) respondents said that a benefit of a Minister with special responsibility for transitions planning would be the increased focus that it would bring to the area. CPTM (Disability) City of Edinburgh Council (35) commented that it would *"raise awareness of disability"*, Lead Scotland (57) reported that *"assigning a Minister with specific duties around transitions would bring important increased focus on this area of work"* and one anonymous respondent stated that the matter is more likely to be taken seriously by social workers, local authorities, colleges and universities if there is a Minister in the Scottish government with a special responsibility for transition planning.

### **6.1.5 To provide a point of contact for young people and their family**

Four (4.3%) respondents stated that a Minister in the Scottish Government with a special responsibility for transition planning would provide a route for appeals and would be a point of contact for young people and their families. ILF Scotland (52) also commented that a Minister would act as *"a public champion and appeals route if things were not working as expected"* and one anonymous respondent stated that a Minister will provide the young people with *"a point of contact to be able to highlight the issues they face."*

## **6.2 Yes, but subject to conditions**

Six (6.5%) respondents provided the following conditions:

6.2.1 More than a coordinator: *"If the role of a Minister is just to coordinate the plans becoming statutory, then it would not be beneficial. However*

*if such a role ensured that the needs of this group of young people are highlighted, represented and protected, then this would be very beneficial. It would also demonstrate that there is a need for transitioning young people to be seen as a group in their own right and would hopefully highlight the need for transition workers in all fields to ensure good planning and support for a sustained period of time rather than the arbitrary cessation of child services at 18. This would also require the provision of appropriate resources.” Anonymous public sector body (7)*

- 6.2.2. Improve life chances: If a minister “*is what it takes to improve the life chances/opportunities of greater independence for young people with disabilities, then yes*”, a minister is necessary. Anonymous professional with experience in a relevant area (11)
- 6.2.3 Understands disabled people: There should be a Minister – “*but a Minister who actually has a clue about what disabled people need and who actually wants to take positive action. There should be checks in place for the Minister.*” Kiana Kalantar-Hormozi (55), a young person with a disability
- 6.2.4 Enhances resourcing: “*Yes, if this means that the legislation has a positive impact on resourcing and funding for young people with a disability.*” ASN Teacher (13)
- 6.2.5 Hold local authorities accountable: “*there is an accountability gap between the Scottish Government and the local authorities tasked with providing the relevant support. In order for a Minister to be able to address this crucial factor specific duties would need to be proposed, including the ability to effectively hold local authorities to account and ensure that high-quality services and transition plans are provided where required.*” National Autistic Society Scotland (61)

### **6.3 Main reasons for why a Minister is not necessary:**

The main reasons respondents gave for a Minister no being necessary were:

- 6.3.1 There may be other ways of overseeing the implementation of a National Transitions Strategy
- 6.3.2 Transitions should be embedded within the remit of several Ministers
- 6.3.3 Resource implications

#### **6.3.1 There may be other ways of overseeing the implementation of a National Transitions Strategy**

Four (4.3%) respondents suggested alternative methods of ensuring young people with disabilities making a transition to adulthood receive appropriate

levels of care. Scotland Versus Arthritis (73) were of the view that, *“holding resource holders and decision makers to account for the implementation of the legislation is implicit to its success. Having a dedicated ministerial post to oversee its roll out is one option”*. They went on to state however that *“it may be worth looking at more participative methods of holding power to account, which are built around the input of disabled young people and families and are fully resourced and supported.”* Jim Arnott (20), parent or other carer of a young person with a disability, stated that, *“if the strategy is accepted and incorporated into departmental obligations, it does not need a Minister. It can be covered alongside other Social Services.”* Shetland Island Council (80) was *“unsure whether there needs to be a minister with special responsibility for disability when we work within Getting it Right for Every Child. A transition strategy could sit within this and be monitored alongside all children.”*

### **6.3.2 Transitions should be embedded within the remit of several Ministers**

Three (3.2%) respondents stated that the responsibility for transitions should be embedded within the remit of several Ministers’ portfolios. One professional with relevant experience, working at a health body (15) focusing on transformational change, pointed out that *“dimensions of transition are multi-faceted and should be included in all ministers’ portfolios e.g. Minister for Young people, Employment, Housing and Health.”* Down’s Syndrome Scotland (36) stated that *“although we believe that there should be responsibility for transitions within the Scottish Government, this may not have to be through a new ministerial post. We think it is important that this oversight represents different policy areas, in particular children and adults and could perhaps be best served by a team approach and could be shared amongst the portfolios of relevant existing ministers.”*

Three (3.2%) respondents noted that a Minister with special responsibility for transitions is unnecessary as there are already Ministers with relevant responsibilities. Glasgow City Health and Social Care Partnership (46) stated that, *“it is the opinion of the Glasgow HSCP that a Ministerial responsibility for Disabled Children and Young People’s transitions as part of the Scottish Government is unnecessary. The responsibility to ensure children and young people with disabilities receive appropriate levels of care and support at all points in their lives already fall within the remits of the Equalities Minister and Minister for Children and Young People. Particular responsibility for transitions to further education, training and work falls within the remit of the Education Minister. Otherwise, it is unclear with the role would be for such a position, with the current level of expertise in place of existing Ministers to consider the issues.”* CHAS (31) emphasised that they *“consider that this responsibility*

*already sits within the portfolio of the Scottish Government's Minister for Children and Young People. The Minister supported the Good Principles for Transitions Three, and we would see this role as the lead role, while acknowledging the importance of transitions being recognised across multiple portfolios".*

### **6.3.3 Resource implications**

Two (2.1%) respondents questioned the resource implications of such specific ministerial responsibility, for example The ADES (21) queried "*the longer-term, sustainable impact and outcomes of such a move*" and CPTM (Disability) City of Edinburgh Council (35) noted that a Minister may "*raise expectations that cannot be met and would have resource implications*".

## **Any other comments**

Respondents were asked:

<b>Question 7: Do you have any other comments?</b>
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When asked whether they had any further comments, 64 (70.3%) of respondents did give additional comments. They were, in the main, ones that have been previously captured in the report. The most frequently raised points were:

- 7.1 Resources
- 7.2 Support for the Bill
- 7.3 Existence of other legislation, frameworks and models
- 7.4 Who is involved in the shaping of a National Strategy
- 7.5 The scope of the Bill
- 7.6 Concern around a focus on a single point of transition
- 7.7 Independent advocacy
- 7.8 Accessibility
- 7.9 Outcome focussed planning
- 7.10 'Age and maturity'
- 7.11 Disempowering language
- 7.12 Employment
- 7.13 Timescale for implementation
- 7.14 Definition of child
- 7.15 Training needs
- 7.16 Further and Higher Education

### **7.1 Resources**

Fourteen (15.3%) respondents raised points concerning resources. Several respondents called for appropriate funding. The Scottish Commission for Learning Disability (76) supports a statutory duty to a transitions plan for young people with disabilities *if “appropriate levels of new and additional funding is provided to fund both the planning and implementation of the resultant plans.”* COSLA (34) stated that, *“if the Bill is to offer provisions above and beyond what is currently offered under existing legislation, this cannot and should not be met within existing Local Authority budgets. A robust Financial Memorandum, which consults with all professionals, including Local Government Directors of Finance, is required and any additional cost identified would require to be fully funded as per the new burdens rules.”* The view of Laurence Alfred (4), a professional with experience in a relevant subject, was that, *“the Scottish Government is very*

*good at producing useful, positive legislation, but very poor in providing the training and resources to see things through at all levels. Unless this is rectified this proposed legislation will raise expectations but the reality will remain the same- that generally there is not the quality provision available as needed.”*

Some respondents were concerned about a lack of services and trained professionals. Fibrous Dysplasia Support Society UK (41) expressed concerns about *“how successful a Transitions Strategy will be given the uncertain financial climate and the closures of projects which have played a role in helping young people with impairments or health conditions, such as the Engine Shed in Edinburgh.”* Garvald West Linton (43) reported that, *“we are currently operating in a period of austerity with major cuts in Council and Third Sector Services. Standstill budgets have put enormous pressure on the Third Sector organisations’ ability to continue to offer high standards of service and resources.”* A group of carers (18) highlighted a lack of support workers. Three respondents stated a need for education and training of those involved in transitions. Kiana Kalantar-Hormozi (55), a young person with a disability, states a need for the education of MSPs and others in charge *“to change the attitude that currently pervades our societies.”*

Some respondents discussed investing in young people with disabilities. The Law Society of Scotland (56) stated that, *“the consultation document takes into account the wider cost of inaction, in comparison to the costs of implementation. A narrow view of the costs of a proposal can be inappropriate where there would be overall benefit to the public purse.”* Claire Edwards (37), a professional with experience in a relevant subject, said that funding a National Transitions Strategy should be viewed as an ‘investment’ and that young people with disabilities should be recognised as bringing value to society, not just viewed as *“objects for expression of compassion and care.”*

## **7.2 Support for the Bill**

Fourteen (15.3%) respondents stated their support for the proposed bill in response to question 7. The Usual Place (86) stated that, *“should this legislative reform be enacted it will have a transformational effect on the life chances of disabled children and young people contributing to making Scotland a very much fairer and much more equal society for us all to live, work and play in.”* The Glasgow Centre for Inclusive Living (44) believed the Bill could *“play a significant role in ensuring that disabled people are able to face the future with confidence, have the opportunity to reach their full potential as adults, and ultimately assert their rights as equal citizens.”*

## **7.3 Existence of other legislation, frameworks and models**



Thirteen (14.2%) respondents discussed further the existence of other relevant legislation, frameworks and models. Some questioned the need for new legislation given existing relevant legislation and frameworks. COSLA (34) stated that it does not support the call for a new Bill due to there already being legislation in place: *“many of the actions in the proposed Bill are already covered by the Education (Additional Support for Learning) (Scotland) Act 2004. COSLA would not support the introduction of new legislation where existing legislation is already in place, it is far better to work in partnership to implement existing legislation and though not referenced in the consultation document, that partnership work is taking place.”* One anonymous public sector body (7) stated that, *“there are many example of good practice and good plans – focus should be placed on following these models rather than putting in place a new Act.”* ADES (21) questioned the need for a Transitions Bill, *“as a wide range of appropriate legislation already exists covering transition support and planning”* and whether *“additional legislation would add value to what already exists - additional legislation runs the real risk that it may serve to further complicate planning frameworks.”*

Some respondents stated that any new legislation must align with and take account of existing legislation and frameworks. The Scottish Commission for Learning Disability (76) supported the proposals if *“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.”* Some respondents discussed the work currently being undertaken by the Scottish Government to improve transitions and the development of the ‘Principles of Good Transition’. Children’s Health Scotland (30) recommended that these principles guide the Bill.

Iain Nisbet (63) explained that *“section 12 gives powers to the Scottish Ministers to put in place dispute resolution mechanisms. The Health and Education Chamber of the First-tier Tribunal for Scotland already has a jurisdiction in relation to post-school transitions.”* He then stated that *“rather than creating a new mechanism, it would make sense to have these matters handled by the same body.”* Children in Scotland (32), also in discussion of The Health and Education Chamber of the First-tier Tribunal, suggested that *“this route to redress could be supported as part of any new legislation”*.

#### **7.4 Young people with disabilities at the centre**

Seven (7.6%) respondents discussed the importance of young people with disabilities and their families being central to the shaping of a National Transitions Strategy. Aberlour (2) stated that, *“if the proposed bill is to be*

*taken forward it will be vital to ensure that disabled children and young people and their families are involved in shaping it and that it is informed directly by their experiences.” Glasgow Disability Alliance (45) stated that action must be led by “disabled people themselves, along with their organisations, and that young disabled people’s voices are heard, not only in the development of policy, but in the resultant mechanisms set up to support them at all points of transition in their life.” Lead Scotland (57) encouraged “close liaison and consultation with ARC Scotland, as well as disabled people’s organisations, disabled young people and parents, should the Bill progress.”*

## **7.5 The scope of the Bill**

Five (5.4%) respondents sought clarity about the scope of the Bill. Aberlour (2) stated that there is *“no specific reference in the proposals to children and young people with Autism and it is therefore not clear whether it is intended they would fall within the scope of any national strategy.”* Several others questioned how disability is to be defined in the Act. Children’s Health Scotland (30) reported that the definition used by the Bill *“needs to be much clearer and include sections for learning disability, physical disability, sensory disability and long-term conditions; without this, the scope of the Bill is unclear.”* The Scottish Commission for Learning Disability (76) asked for *“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.”* Some respondents asked that the scope of the Bill be extended beyond only those with disabilities. ADES (21) questioned, *“why the focus for transition planning is only on those with a disability. Young people who are, for example, care leavers or are known to the justice system and have risks, are equally in need of effective transition.”*

## **7.6 Concern around a focus on a single point of transition**

Four (4.3%) respondents discussed concerns over a transitions plan that features a single point of assessment and that ends once the individual reaches a ‘positive destination’. Glasgow Disability Alliance (45) are concerned that, *“a well-intentioned effort to assist young disabled people to achieve independent living could be undermined and risk losing credibility with young people if the reporting of progress of the National Transitions Strategy is fixated upon a single point of transition e.g. measured in terms of the first post-school positive destination. A successful transition is not and never will be an ‘end point’.”* GDA (45) stated that, *“the Transitions Bill does not seem to appreciate the requirement for long-term ongoing and intermittent support for young disabled people.”* COSLA (34) reported that, *“disabled young people may go through multiple phases of transition up until age 26 and beyond. Disabled young people who initially go on to positive destinations may find*

*that these are not sustained for various reasons. The young people themselves may wish to change direction and need support to consider options. Therefore, we would question whether uptake would be as low as suggested if the service was well designed. If the aim is to give this as a legal right to all disabled young people, there needs to be realistic consideration of the broad scope of young people this may include so that the offer is not limited in any way."*

### **7.7 Independent advocacy**

Four (4.3%) respondents discussed a need for independent advocacy. National Carer organisations (85) (see detailed information above) stated that, *"a right to independent advocacy should be enshrined within a future bill in order to uphold their UNCRC Article 12 right to have their views heard in any decisions affecting them."* Children in Scotland (32) reported that, *"access to independent information and advice, advocacy and independent support to help children and young people to share their views is critically important to ensure a person-focused and rights-based approach is taken."* Fibrous Dysplasia Support Society UK (41) is concerned however that *"there does not appear to be the capacity in advocacy services to meet the needs of everyone with an impairment who may benefit from it."*

### **7.8 Need for accessibility**

Three (3.2%) respondents were concerned about accessibility of the Bill and of transitions plans. Children in Scotland (32) stated that consideration should be given to *"the accessibility of the Bill itself as well as all related guidance and information."* People First Scotland (66) stated that, *"it would have been useful to have different formats of this consultation available, including Easy Read"* and that *"any document or paperwork associated with the transitions plan must be in an accessible format which reflects the communication needs of the child or young person. This will allow the person to be more involved in the process."* The Yard (87) stated that it must be acknowledged that *"there is a requirement to consider alternative communication methods when involving young people in creating their own transitions plans."*

### **7.9 Outcome focussed planning**

Three (3.2%) respondents stated that transitions plan must be outcome focussed as opposed to needs focussed. Iain Nisbet (63), a professional with experience in a relevant subject, noted that, *"Section 9 of the Bill sets out the required contents of the plan, which are needs-led. While a plan clearly needs to reflect the needs of the child or young person in question, this structure*

*would inevitably tend towards deficit led discussions. A better model is to begin with the transition objectives: where does the young person want to end up?"*

### **7.10 'Age and maturity'**

Two (2.1%) respondents took issue with sections 10.2 and 11.4 of the proposal. These sections state that when having regard to the views of the child, the local authority preparing the transitions plan must take account of the child's age and maturity. The Yard (87) stated that, "*the communication involved in engaging a young person with their own transitions plan should be young person led, individualised, and dependent on or tailored to the young person's needs and/or the needs of their family. This would be our preferred way of explaining the 'age and maturity' concept.*" The Law Society of Scotland (56) suggested that these sub-sections are contrary to human rights requirements and obligations and should be deleted. The Society's view was that "*there should be attributable obligations to ascertain the views of the child/young person in every case, if necessary by any means of communication, and if necessary with all appropriate support. Where that is demonstrated to be impossible, there should be an attributable obligation to determine the best interpretation of the views of the child/young person.*"

### **7.11 Disempowering language of the document**

Two (2.1%) respondents reported disappointment with language used in the consultation. Glasgow Disability Alliance (45) stated that they found the language of the case studies "*extremely disempowering*" and "*contrary to a social model approach*", for example "*someone being deemed 'incapable of communication' which is extremely disappointing in a Bill paper aimed at improving the life chances of young disabled people. Similarly, defining potential entitlement around impairments, e.g. blindness, deafness, learning disability, instead of around 'needs'.*" GDA (45) "*strongly feel that the language used in the Bill and all related communications should embrace the Scottish Government's commitment to the Social Model of Disability and Human Rights Based Approach.*" Fibrous Dysplasia Support Society UK (41) reported that they were "*put off by the language of the bill, which mainly uses the term 'disabled children', which to us is not the right way to refer to this group of vulnerable young people.*"

### **7.12 Employment**

Eight (8.7%) respondents discussed employment. Fibrous Dysplasia Support Society UK (41) reported that "*the employment rate of people with disabilities is significantly below those without disabilities. It is important that*

*employability support is excellent for young people with impairments and health conditions and that the Scottish Government learn from best practice in terms of employer engagement and increasing the employment rate of people with disabilities.”* Children’s Health Scotland (30) however noted that throughout the draft Bill there is considerable mention of young people’s aspirations to future work and employment yet *“there should be no assumption made that all disabled CYP will automatically be seeking or in a position to pursue active working lives.”* Glasgow City Health and Social Care Partnership (46) stated that it currently *“operates from a position that every young person will be supported on a “needs-led” basis and therefore will be supported into work wherever appropriate, but will not be encouraged to work when their circumstances would be detrimentally affected by doing so.”*

### **7.13 Timescale for implementation**

Two (2.1%) respondents, Social Work Scotland (82) and an anonymous public sector respondent (7), were concerned that the timescale for implementation of the Bill, within one year of Royal Assent, is tight. Social Work Scotland notes that, *“implementation of any change in a system, requiring humans to work differently, requires careful planning and consideration, and then time and meaningful support (such as training, coaching, peer feedback, etc.) to make it real.”*

### **7.14 Definition of child**

Two (2.1%) respondents questioned the definition of child adopted in the Bill. Iain Nisbet (63), a professional with experience in a relevant subject, highlighted that Section 16 *“defines “child” as a person under 18, when in all other educational contexts it is 16. I realise that other legislation adopts 18 as an age limit, but 16 makes much more sense in this context.”* He also stated that defining a child as under 18 raises capacity issues. The Law Society of Scotland (56) also raised concerns about the definition of child in section 16: *“it is inappropriate to include persons who are adults under both the Age of Legal Capacity (Scotland) Act 1991<sup>9</sup> and the 2000 Act within the definition of “child”. “Child” should mean a person under 16 years of age.”*

### **7.15 Training needs**

Social Work Scotland (82) highlighted a training need and in their view there is *“scope for a pre-qualifying and cross-service training module covering effective support for transition, for example in social work, nursing and housing. The Scottish Government and other partners should consider the feasibility of developing such a resource.”*

## **7.16 Further and Higher Education**

One young person (8) raised the issue of the difficulties which disabled young people can face in applying for courses in Further and Higher Education, including getting accessible accommodation, unfair accommodation costs and the need for greater flexibility in relation to entrance requirements: *“It is all well and good passing a law to put a plan in place to ensure that local authorities help disabled students in transition to adult life but that is only scratching the surface of the problems disabled students face trying to enter Further Education”.*

## **SECTION 4: MEMBER'S COMMENTARY**

I would like to thank Camphill Scotland and Inclusion Scotland for their help in developing my proposal for the Disabled Children and Young People (Transitions) Scotland Bill.

I would also like to thank Professor Divya Jindal-Snape, Eilidh Ross, Dr Lisi Gordon, Dr Duncan Mercieca, Dr Elizabeth Hannah, Dr Daniela Mercieca and Dr Anna Robb from Dundee University for their excellent work in analysing the responses received to the consultation on the proposed Bill and in drafting Section 2 and 3 of this Report. The consultation analysis is very helpful and the support of everyone who contributed to drafting the summary has been invaluable.

Special thanks goes to all the individuals and organisations who took the time to share their views, particularly to those who shared personal stories and experiences. The wide-ranging responses helped ensure the consultation exercise was wide in scope.

My Bill is intended to give young people with a disability a proper and fair system of support as they make the transition to adulthood.

The transition to adulthood is crucial in determining their future. My proposed Transitions Bill would give additional rights and support by placing a statutory duty on local councils to prepare and introduce a transitions plan for each young person with a disability to improve outcomes in their transition to adulthood. Many of the families who responded to the consultation highlighted the difficulties they face on a daily basis and I welcome their overwhelming support for the aims and objectives of the Bill. These challenging testimonies should be the spur for change.

I am clear legislation is needed and indeed necessary to bridge the gap for young people with a disability making the transition to adulthood. This Bill presents an opportunity to give young people with a disability the chance to fulfil their potential and to make the most of their lives. I believe it can make a real and lasting difference for young people with a disability and their families.

I have lodged a final proposal to seek cross-party support to introduce the Disabled Children and Young People (Transitions) (Scotland) Bill. Due to the impact of Covid-19 the 1 June deadline for introducing a Member's Bill has now passed, and I will be applying to the Parliamentary Bureau to extend this deadline.

Given the impact of Covid-19 upon business in the Scottish Parliament, and on the work of MSPs of all parties, I am hoping that the Parliamentary Bureau will look favourably upon my request, particularly as a draft of my Bill has already been completed, and was included in the consultation document.

I look forward to working with everyone who contributed to the consultation and with families striving to improve the lives of all young people with a disability.

**Johann Lamont MSP**

**June 2020**



## ANNEXE - RESPONDENTS

A total of 91 submissions were received, and are listed below. Copies of these submissions are available on this website:

<https://martinneill.wixsite.com/transitionsbill> - except for the submissions of those respondents who requested confidentiality.

Response Number	Name of Organisation/Individual
1.	Aberdeen City Council
2.	Aberlour
3.	Action for Children
4.	Alfred, L
5.	Not Published – Confidential
6.	Anonymous
7.	Anonymous
8.	Anonymous
9.	Anonymous
10.	Anonymous
11.	Anonymous
12.	Not Published – Confidential
13.	Anonymous
14.	Not Published – Confidential
15.	Anonymous
16.	Not Published – Confidential
17.	Not Published - Confidential
18.	Anonymous
19.	ARC Scotland
20.	Arnott, J
21.	Association of Directors in Education (ADES)
22.	Autistic 'n' Awesome
23.	Ballantine, J
24.	Befriending Networks
25.	Bennett, H
26.	Burge, N
27.	Camphill Scotland
28.	Carlson, J
29.	Children and Young People's Commissioner Scotland
30.	Children's Health Scotland
31.	Children's Hospices Across Scotland (CHAS)
32.	Children in Scotland
33.	Connect
34.	COSLA
35.	CPTM (Disability) City of Edinburgh Council
36.	Down's Syndrome Scotland
37.	Edwards, C
38.	Enable Scotland
39.	Enquire
40.	Family Fund
41.	Fibrous Dysplasia Support Society UK
42.	Fife Council Education and Children's Services
43.	Garvald West Linton

44.	Glasgow Centre for Inclusive Living (GCIL)
45.	Glasgow Disability Alliance (GDA)
46.	Glasgow Health and Social Care Partnership
47.	Health and Social Care, North Lanarkshire
48.	Hewitt, P
49.	Hospice UK
50.	Hothersall, L
51.	Inclusion Scotland
52.	Independent Living Fund Scotland
53.	Ingram, J
54.	Interest Link Borders
55.	Kalantar-Hormozi, K
56.	Law Society of Scotland
57.	Lead Scotland
58.	MacInnes, M
59.	Maxwell OBE, A, Muir Maxwell Trust
60.	Monahan, K
61.	National Autistic Society Scotland
62.	National Deaf Children's Society
63.	Nisbet, I
64.	Ochil Tower School
65.	Partners in Advocacy
66.	People First (Scotland)
67.	Perth & Kinross Council
68.	Royal Blind
69.	Royal College of Paediatrics and Child Health Scotland
70.	Royal College of Speech and Language Therapists
71.	Royal National Institute of Blind People (RNIB) Scotland (RNIB)
72.	Sangster, M
73.	Scotland Versus Arthritis
74.	Scottish Accessible Transport Alliance (SATA)
75.	Scottish Association of Social Work
76.	Scottish Commission for Learning Disability (SCLD)
77.	Scottish Government's Disabled Children and Young People Advisory Group
78.	Scottish Independence Advocacy Alliance (SIAA)
79.	Sense Scotland
80.	Shetland Islands Council
81.	Socialist Educational Association Scotland (SEAS)
82.	Social Work Scotland
83.	Still, H
84.	The Fostering Network
85.	The National Carer Organisations
86.	The Usual Place
87.	The Yard
88.	Together for Short Lives
89.	Values into Action Scotland
90.	Walker, C
91.	YouthLink Scotland