

Hospice UK response to proposed Disabled Children and Young People (Transitions) (Scotland) Bill, January 2020

About Hospice UK

Hospice UK is the national charity for hospice and palliative care, supporting over 200 hospices across the UK. We work to ensure all adults and children living with a terminal or life-shortening illness receive the care and support they need, when they need it. Our mission is to transform the way society cares for the dying and those around them.

Hospice UK supports the breadth, dynamism and flexibility of modern hospice care by influencing national and local policy, improving quality of care through the sharing of good practice, and providing resources, education and training, and grant programmes. In Scotland, hospice care providers support over 20,000 people every year, through inpatient, outpatient, day hospice and hospice at home services, and bereavement support.

We welcome the proposals outlined in the draft Disabled Children and Young People (Transitions) (Scotland) Bill and the opportunity to provide comments on these. Our response focuses specifically on the needs of children and young people with life-shortening conditions, their families and carers.

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

Children and young people living with a life-shortening condition can have particularly complex health and care needs, and the challenges they face in the transition period to adulthood can be acute. It is important that the proposals in the draft Transitions Bill recognise and respond to their needs, so that individuals with complex palliative conditions have the same opportunities as their peers, as far as this is possible.

The number of young people with life-shortening conditions living into adulthood is increasing in Scotland¹. This means more young people will need specialist support as they transition into adulthood.

Children and young people with life-shortening conditions can experience a range of challenges during the transition period. They may experience changes to the health or social care support they receive, because the availability or criteria for adult services are different to children's services. As a result care can become disjointed. Young adults with progressive, degenerative conditions will also be experiencing health and support needs that are becoming

¹ Fraser et al (2015) Children in Scotland requiring palliative care: identifying numbers and needs (The CHiSP Study) https://www.york.ac.uk/media/spru/projectfiles/ProjectOutput_ChispReport.pdf

increasingly complex as they get older. During this period individuals and their families/carers may be making difficult decisions around end of life care. Transitioning to adult services can add another layer of uncertainty to living with a life-shortening condition, which can impact on an individual's emotional and mental wellbeing, and feelings of social isolation.

To support young adults with life-shortening conditions to live as independently as possible, services need to be co-ordinated and to focus on their needs as a whole, with clinical, psychosocial and educational support for them and their family².

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

Yes

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

A statutory right to a transitions plan is a positive step in helping young adults with a disability, including those with a life-shortening condition, to get the support they need as they transition into adulthood.

We support the Scottish Transitions Forum's Principles of Good Transitions³ and the supplementary work developed by Children's Hospices Across Scotland⁴ to support people with life-shortening conditions in the transition period. The proposal for having a transitions plan aligns with these principles of early planning, co-ordinating support across services and planning in a person-centred way. We support that the proposals recognise that the transition period continues into adulthood and that plans intend to support people until the age of 25. This is especially pertinent when referring to young people with palliative conditions, who previously may not have expected to reach adulthood but are now in their twenties.

We have some suggestions/comments to support more detailed development of proposals around the Transitions Plan:

- **Co-ordination with the Child's Plan:** Individuals who will have a Transitions Plan may well also have a Child's Plan, under the Children and Young People (Scotland) Act 2014. The consultation document states that where there is an existing Child's Plan, this will be incorporated into the Transitions Plan. However the draft Bill does not make this explicit. There will need to be clarity over how the two will be co-ordinated and managed in practice. A principle of good transitions is that there should be a single plan³. It will also need to be clear what needs to happen to the plan if an individual moves from one local authority area to another.
- **Lead professional:** We support the proposal that there will be a lead professional within the transition period. This is important, particularly for young adults with life-shortening

² Jindal-Snape et al (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* 18:30

³ <https://scottishtransitions.org.uk/summary-download/>

⁴ <https://scottishtransitions.org.uk/blank/wp-content/uploads/2018/01/Principles-of-Good-Transition-CHAS-2017-supplement-Final.pdf>

conditions who greatly value the support of a trusted professional to talk about issues such as end of life planning. While reference to a lead professional is in the consultation document, this does not appear to be included explicitly in the draft Bill. The legislation will need to be clear on the role and responsibilities of the lead professional in the transition period, in particular around developing and reviewing the transitions plan. In addition there will need to be clarity on how this will be co-ordinated with any lead professional already appointed in relation to the Child's Plan, to avoid there being multiple leads. The consultation document states that it will be the local authority's responsibility to appoint a lead professional. For individuals with complex health needs, for example those with palliative conditions, it may be that the most appropriate lead professional is a health professional who is not employed by the local authority. The Bill will need to be clear over the responsibility of health boards/integration authorities in these cases.

- **Involvement and responsibilities of health and social care:** Young people with complex health needs will have many professionals involved in their care and treatment. Health and social care colleagues will be integral to the successful implementation of the transitions plan and allowing young people to access the opportunities that their transitions plan is aiming to achieve. Young adults with life-shortening conditions may also require specific involvement with hospice care providers. The Bill needs to be clear how these professionals will be involved in the development and implementation of the transitions plan, and the responsibilities of health boards and integration authorities, as well as those of local authorities.
- **Support for professionals:** There should be guidance and support/training for professionals responsible for developing the transitions plan.
- **Early planning:** The earlier transition plans are developed the better the outcomes will be for the young person. The Scottish Transitions Forum states that transition planning should be available from the age of 14. People with life shortening conditions can spend considerable periods of time off school or in hospital or hospice care, which can mean the planning process takes longer.
- **Review:** Transition is an on-going process and it is important that transition planning and preparation is on-going, with provisions for when and how there will be regular reviews.
- **Person-centred planning:** The young person must be placed at the centre of the planning process, with their holistic needs taken into account. People with life-shortening conditions may require support to make decisions or have access to advocacy services. They may have particular communications needs, which will need to be taken into account to allow them to engage effectively in the planning process.

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

Having a National Transitions Strategy for Scotland is important in making sure there is strategic leadership around supporting young people with disabilities, including those with life-shortening conditions, during their transition to adulthood. A national strategy will also help

address some of the wider issues that will impact the successful implementation of a transitions plan, and help avoid it being a tick-box exercise.

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

For a National Transitions Strategy to be successful, there will need to be robust engagement and co-production to develop the strategy, support for implementation, and clear accountability for delivery and progress against the strategy's aims.

The co-ordination and integration of care and support is vital during the transition period, and the National Transitions Strategy will need to be clear of the different agencies involved, their responsibilities and how they will work together to support young people and their carers/families.

Some of the issues that a National Transitions Strategy will need to consider include:

- Tools, training and support for professionals developing and implementing transitions plans
- Developmentally appropriate services and resources
- How to bridge the gap between 'higher intensity' care and support for children, and the 'lower intensity' (and limited availability) of care and support for adults
- The opportunity to explore future wishes and aspirations, including with individuals who are severely cognitively impaired
- Suitable accommodation
- Access to benefits
- Access to short planned breaks/respite
- Engagement with businesses/employers/voluntary employers to open up opportunities for those with disabilities and complex needs
- Education and support around relationships and intimacy
- Issues around privacy and dignity

It is also important a National Transitions Strategy and transition plans recognise that family members and carers have their own transition needs and will require support during the transition period². This could be linked in with requirements for carers' assessments.

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?

Having a Minister in the Scottish Government with specific responsibility for transitions would help with strategic leadership and accountability around transitions for young people.

7. Do you have any other comments?

N/A

Contact

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