

Response from the National Carer Organisations to the Proposed Disabled Children and Young People (Transitions)(Scotland) Bill

About the National Carer Organisations

The National Carer Organisations are brought together by a shared vision that all Scotland’s unpaid carers will be valued, included and supported as equal partners in the provision of care and will be able to enjoy a life outside of caring. They are Carers Trust Scotland, the Scottish Young Carers Services Alliance, Carers Scotland, the Coalition of Carers in Scotland, Shared Care Scotland, Minority Ethnic Carers of Older People Project (MECOPP and Crossroads Caring Scotland).

Questions

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

As the consultation paper sets out, the transition to adulthood is a key time for children with a disability, particularly in relation to their ongoing education, future employment and ability to live independently. Unless this time of transition is managed well, by putting the appropriate strategy, structures and resources in place, there can be long-term negative impacts for young people with a disability.

The evidence from the consultation paper is striking. Disabled young adults are less likely to be in employment and three times more likely to feel hopeless. Often poor transition planning is the root of many issues that emerge once disabled children become adults.

In addition, this time of transition also impacts on family carers. Parent carers commonly find the process of transition to be a very stressful and uncertain time. They worry about the right support being put in place and if the level of support reduces following transition they are frequently expected to provide the shortfall of care. This can have a negative impact on the carer’s health, wellbeing and employment prospects, as well as their ability to have a life alongside caring.

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

In terms of the uncertainty of future support, the *State of Caring report* found that 90% of carers don’t know what might happen to the practical support they receive in the future or worry that it might be reduced. One parent carer commented

*'I gave up a very well paid full time job to fulfil my caring role and the massive amount of paperwork it comes with. I was self-employed for a while, but have since had to give that up too, due to the volume of 'work' required by my role as a parent care'*¹

At the Carers Cross-Party Group in December 2019, Celia Sweeney, a parent carer put forward additional evidence on the some of the issues disabled children and carers face at the time of transition

She outlined the following statistics on transitions for disabled young people and young people with a visual impairment

- Disabled 16-24 year olds: have the second lowest employment rate (43.2%) of any age group and the highest unemployment rate (20.8%); and are more than twice as likely to be unemployed than non-disabled 16-24 year olds.
- 6% of pupils with an additional support need leave school with no NQ qualifications at Level 2 or better compared to 1.1% of pupils without an additional support need.
- 96% of pupils without ASN have a "initial positive destination" after school compared to 89.3% with additional support needs (87.8 of pupils with visual impairment).²

She also provided an insight from a Principle Teacher at a Special Needs School outlining the challenges of supporting disabled children through transition when there is often an inadequate patchwork of services.

'As budgets are getting squeezed and traditional building base centres such as xxxx are mainly full so the xxx team are looking at what can the young person can access in their community which fits their interests.

...Its all a bit of an unknown at the moment – a jigsaw puzzle in which you don't know which pieces to use and if they will even fit together to form a complete and supportive package which will meet the YP needs and not cause a complete headache and stress to the parents / carers!'

Other carers and organisations involved in supporting disabled children at the Carers Cross-Party Group raised several issues around transition which are also highlighted in the consultation documents after being raised at the Active Summit.

These included:

- Uncertainly and a lack of information about the process and timescales
- The stress of changes in routine for the disabled young person if not managed appropriately
- Lack of resources and gaps in services for some young adults, particularly those with specialised or intensive support needs
- A move from building based services to community services, where community services were felt to be inadequate due to recent cuts
- Concerns from carers about the impact on them from not meeting eligibility requirements and facing a reduction of support

¹ State of Caring 2019, Carers UK

² Our Vision for Equal Education, Royal Blind

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

Yes, we believe that this might go some way to addressing the issues outlined in Question one.

The key consideration should be ensuring transition planning is a positive experience for disabled young people and carers with an emphasis on young people having choice and control and achieving positive outcomes

We would like to highlight the Principles of Good Transition produced by the Scottish Transitions Forum, which provide a good starting point.

Principle 1.

Planning and decision making should be carried out in a person-centred way

Principle 2.

Support should be co-ordinated across all services

Principle 3.

Planning should start early and continue up to age 25

Principle 4.

Young people should get the support they need

Principle 5.

Young people, parents and carers must have access to the information they need

Principle 6.

Families and carers need support

Principle 7.

A continued focus on transitions across Scotland³

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

As mentioned in Q2, we believe transition planning should go some way to addressing the issues in Q1, provided there is a rights-based approach to transition planning and the Principles outlined in Q2 are adhered to.

We believe that in order to ensure the transitions plan produces positive outcome for disabled young people and carers, the legislation and guidance needs to clearly outline:

- Who is responsible for undertaking, completing and implementing the transition plan. We believe there is a role for third sector organisations, provided there are clear lines of

³ Principles of Good Transition, Scottish Transitions Forum, updated 2019

responsibility and additional resources are made available to the third sector to increase their capacity to respond to this additional demand

- This initiative is fully resourced and there is appropriate monitoring and evaluation to ensure full implementation
 - The process is not too prescriptive, or overly bureaucratic and resources are not re-directed from frontline services for transition planning
 - Local areas have an adequate range of services to enable plans to be implemented
4. Will a National Transitions Strategy assist disabled young people to achieve independent living?

This needs to be one of the key principles of the Strategy.

We also suggest that the Strategy adopts the PANEL approach:

Participation: Everyone has the right to participate in decisions, which affect their human rights. Participation must be active, free, and meaningful and give attention to issues of accessibility, including access to information in a form and a language that can be understood.

Accountability: Accountability requires effective monitoring of human rights standards. For accountability to be effective there must be appropriate laws, policies, administrative procedures and mechanisms of redress to secure human rights.

Non-Discrimination: Human rights based approaches means that all forms of discrimination must be prohibited, prevented and eliminated. It also requires the prioritisation of those in the most vulnerable situations who face the biggest barriers to realising their rights.

Empowerment: People should understand their rights, and be fully supported to participate in the development of policy and practices, which affect their lives. People should be able to claim their rights where necessary.

Legality: Human rights based approaches require the recognition of rights as legally enforceable entitlements, and is linked to national and international human rights

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

It is essential that disabled young people, disabled adults and carers are involved in co-producing the National Transitions Strategy.

The Strategy must also set out how it intends to support carers of disabled children and young adults to ensure they are consulted and involved in transition planning and are involved in supporting the person they care for to achieve independent living.

We suggest the Strategy has a wide scope, looking at transition planning for individuals and setting out a national strategy for ensuring there is adequate support available for young disabled people, as well as initiatives to support them in relation to further education employment.

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?

Yes – In order to further this agenda 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. As well as ensuring there is appropriate social care support for them to achieve independent living.

7. Do you have any other comments?

The Bill should include clear timescales for transition plans to commence, be completed and be implemented, The Draft Bill says transition plans must be in place 3 months before a person's 16 birthday. But it is important this process starts well in advance and that disabled young people and carers are informed of the process and timescales. Also, the completion of the transition plan is not the end of the process, there needs to be a separate timescale for support to be put in place.

There needs to be engagement with disabled young people and their carers to determine appropriate timescales

As mentioned previously there may be a role for the third sector in developing transition plans for disabled young people, where they are the organisation who provides them with support and who knows them best. For example, many local Carers Centres have been contracted by their local authority to undertake Adult Carer Support Plans. (ACSPs)

However, if the third sector is involved in undertaking transition plans, they must receive adequate resources to ensure they have sufficient capacity, so that resources are not taken away from frontline services. A recent survey of local carers centres found that 50% indicated they had less capacity to deliver preventative support services due to the additional resources needed to undertake ACSPs who.

Finally, it is important that this legislation links to other relevant legislation, including The Carers Act, SDS Act, Additional Support for Learning Act and the Public Bodies Joint Working Act. For example, carers who are involved in transition planning for the person they care for, should be made aware of their rights under the Carers (Scotland) Act 2016 and offered an Adult Carer Support Plan.

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