



National Carer Organisations response to: Disabled Children and Young People Transitions to Adulthood) (Scotland) Bill

Response to Scottish Parliament: Education, Children and Young People Committee

Introduction

The National Carer Organisations welcome the opportunity to submit a response to the detailed call for views to the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill. The issue of transitions is regularly raised by unpaid carers at consultation events and through our research work. We welcome that the Scottish Parliament Education, Children and Young People Committee is seeking views to this important Bill.

The National Carer Organisations submitted a joint response in 2020-2021 to the initial call for views to the Bill. This response aims to reinforce and further highlight other key messages.

The National Carer Organisations are Carers Scotland, Carers Trust Scotland, the Coalition of Carers in Scotland, MECOPP, Shared Care Scotland, and the Scottish Young Carers Services Alliance.

Together we have a shared vision that all Scotland's unpaid carers will feel valued, included and supported as equal partners in the provision of care. The National Carer Organisations aim to achieve this through the representation of unpaid carers and giving them a voice at a national level.

We believe we can deliver more for unpaid carers by working together to share our knowledge and experience, and by focusing our collective efforts on achieving improvements in areas of policy and practice that are of greatest concern to unpaid carers.

Consultation questions and response

Question 1: The overall aims of the Bill and whether the Bill can meet these aims

The National Carer Organisations welcomes the three key objectives of this Bill and believe that these actions will deliver improved outcomes for disabled children and young people in the transition to adulthood.

Placing a statutory duty on Scottish Ministers to prepare, publish and implement a strategy in relation to improving outcomes for disabled children and young people in the transition to adulthood is a clear way to hold Scottish Government accountable to this work. A National Transitions Strategy, setting out aims, objectives and outcomes to be achieved, is welcome, however we do stress the importance of adopting a PANEL approach to this initiative.¹

The strategy will also set out the actions and arrangements which local authorities, Health Boards, Integration Joint Boards and other bodies or persons must take to meet these aims and objectives. In order for this approach to fully meet the aims of the Bill, the guidance must clearly set out who is responsible for undertaking, completing and implementing the transition plan. This should include local third sector organisations involved in direct service delivery. A National Transitions Strategy will only achieve positive outcomes for disabled children and young people if fully resourced.

We welcome the duty on Scottish Ministers, under section 2(1) of the Bill, to consult on the draft National Transitions Strategy and its review. Consultation with parents, legally appointed guardians or other unpaid carers of disabled children and young people is welcome, including young carers. Consultation is a crucial part in ensuring that transition planning for disabled children and young people is developed in a person-centred way. Consulting with parents and unpaid carers will also ensure a holistic, whole family approach to this initiative.

We believe that a Scottish Government Minister taking particular responsibility for this legislation will ensure that disabled children and young people have better outcomes in their transition to adulthood. A dedicated Minister who develops the strategy, monitors progress and develops initiatives is key to furthering this agenda. An annual report about the National Transitions Strategy also provides further scrutiny to this work.

Setting a duty on local authorities to prepare and implement a transitions plan for each disabled child and young person meets the aims of the Bill in theory. However, again, we stress the importance of resourcing this work fully to support local authorities' delivery of this initiative. It is important that within this legislation, Scottish Government monitor transition plans across all local authorities to ensure that all disabled children and young people are offered consistent support.

¹ National Carer Organisation response to Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill call for view 2020-2021 : [Response 551328244 to Support for Disabled Young People - Scottish Parliament - Citizen Space](#)

Section 7(5) outlines that when a child or young person lacks capacity to express a view, or to make a decision in relation to their transition plan, a local authority must regard the view of the child's or young persons' parents, legally appointed guardian or other unpaid carers. The role of sibling young carers must also be considered, and their views included in discussions.² All resources must therefore be accessible and inclusive to a broad age range.

We would suggest that the Bill also needs to take account of more recent developments on the National Care Service and how these will impact the experience of young people transitioning to adult services

Unpaid carers have broadly welcomed the Scottish Government's proposal to include children's services in the new structures and hope that this will lead to greater consistency and clarity in the level of support between the two services. However, some parent carers are not in agreement as they view children's services as superior to adult services and are concerned that this will lead to them levelling down rather than improving.

When we consulted carers on the inclusion of children's services, events, 84% of unpaid carers who attended our engagement events were in favour of this proposal, compared with 72% of unpaid carers who responded to our survey.

However, some parent carers of adults with autism expressed the view that they were more satisfied with the service they received from children's services and in general found the service they currently receive through adult services as challenging and inadequate. They also had concerns that as children's services and education work closely together at present, this relationship may be undermined if children's services became the responsibility of the National Care Service.

They were concerned that by integrating both services through the National Carer Service that children's services would level down, lose their specialism and be less responsive to the needs of children with autism. In particular they made the points that:

- There isn't an understanding of the needs of adults with autism in adult social care.
- Getting the views of people with autism requires specialism.
- Unpaid carers feel under-represented and not listened to.
- There needs to be better training of practitioners around autism.
- Decision makers don't recognise the specific needs of people with autism.

In contrast, respondents at other engagement events were hopeful that by including both services within the National Care Service would support transitions from child to adult services and lead to more consistent standards.

² Ask Me – I'm Here Too! A Research and Evaluation Project into the Lived Experiences of Young Carers Providing Care for Siblings with a Long Term Illness or Disability. University of Strathclyde and Edinburgh Young Carers, 2021: [Ask-Me-Im-Here-Too.pdf \(youngcarers.org.uk\)](https://www.youngcarers.org.uk/ask-me-im-here-too.pdf)

Question 2: If changing the law is the best way to do what the Bill is trying to do.

A change in the law will ensure that children and young people's rights are upheld, by placing statutory duties on local authorities to implement transition plans. A National Transitions Strategy and the ongoing monitoring and evaluation of this will also ensure that transitions are monitored closely.

However, this initiative must be fully resourced and we urge Scottish Government to work collaboratively with local authorities in the design and implementation of this approach.

Similar comparisons can be made to the Carers (Scotland) Act 2016³. This legislation sets out statutory duties on local authorities to provide support to carers, if they meet eligibility criteria set by the local authority. Freedom of Information requests, sent to all 32 local authorities in December 2018, showed that money for implementing this law was being spent inconsistently across councils. Whilst the Coronavirus Act 2020⁴ eased some assessment duties on local authorities, this evidence suggests inconsistent approaches continue to be adopted across Scotland. A change in the law can be the best way to achieve better outcomes for disabled children and young people, but only if fully resourced and effective monitoring put in place to ensure that statutory duties are translated into reality at local level.

Question 3: Any unexpected or unforeseen effects of the Bill (as it is currently written)

In conducting a review of mental health and incapacity legislation, the Scottish Mental Health Law Review (The Scott Review) consulted a number of parent/ unpaid carers, children, young people, statutory and non-statutory organisations across Scotland. The findings from these consultations and focus groups highlighted the poor nature of transitions experienced by many disabled children and young people.⁵

Any legislative changes made by Scottish Government have to take into account the United Nations Convention on the Rights of the Child (UNCRC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), both of which the Scottish Government have signed up to, with UNCRC further down implementation route. However, when we think about children and young people there can be clashes between UNCRC and UNCRPD.

The recent Scott Review stated that there could be implications for UNCRC in mental health law. The UNCRPD has major effects on how the UNCRC should be interpreted in this context.⁶ Both the UNHRC and UNCRPD state that children with disabilities, through their representative organisations, must be involved in developing all law, policy and practice which affects them.

³ Carers (Scotland) Act 2016: [Carers \(Scotland\) Act 2016 \(legislation.gov.uk\)](https://www.legislation.gov.uk)

⁴ Coronavirus Act 2020: [Coronavirus Act 2020 \(legislation.gov.uk\)](https://www.legislation.gov.uk)

⁵ Scottish Mental Health Law Review, 2022

⁶ As above

The UNCRPD has major effects on how the UNCRC should be interpreted in this context, so the Review has also considered that Convention in relation to children. The UNCRC and UNCRPD tell us that children with disabilities, through their representative organisations, must be involved in developing all law, policy and practice which affects them.

For children with mental or intellectual disabilities the UNCRC and UNCRPD require states to bring about equality for children with mental or intellectual disabilities:

- Law should focus on socially constructed barriers. Those barriers can be attitudinal, physical, environmental, social and economic. They interact with impairments and prevent children with disabilities from participating in life on an equal basis with their peers.
- Law should represent children as subjects of rights and agents of change, with evolving capacities. Children are not objects of charity or passive recipients of care, treatment or welfare.
- Law should require a human rights-based approach to designing, implementing, monitoring and evaluating all law, policy and practice. This approach respects children and enables them to affect these things to the full extent of their evolving capacities.

Work carried out with children, young people, parents and unpaid carers as part of the Scott Review highlighted that children and young people experiencing mental or intellectual disabilities can spend a lot of time waiting to be assessed in CAMHS. Parent/unpaid carers reported often feeling excluded, not supported or empowered. There was also evidence that transitions from childhood to adolescence, and adolescence into adulthood, are often poorly managed.⁷

One area raised in the Bill is the definition of child. Section 19 defines a child as a person under 18 years of age and a young person as a person between 18 and 26 years of age. The Bill however has not taken into account that once a child reaches 16 years of age, they are considered an adult under Adults with Incapacity (Scotland) Act (2000). Full account needs to be taken of this.

The bill needs to be clearer about how the voices of children and young people, including young carers, will be heard and will be at the centre of transition planning.

Question 4: If the Bill adds to or duplicates any existing legislation

Supporting Children's Learning: Statutory Guidance on the Education (Additional Support for Learning) Scotland Act 2004 (as amended)⁸

In Chapter six, it states that education authorities must plan for a disabled child's transition into adulthood.

⁷ Ref Scott Review

⁸ <https://www.gov.scot/publications/supporting-childrens-learning-statutory-guidance-education-additional-support-learning-scotland/>

“It is anticipated that education authorities will carry out their duties to plan the post-school transitions of those leaving school who:

- have a co-ordinated support plan*
- are in a specialist placement such as a specialist unit or a special school*
- have additional support needs arising from a disability within the meaning of the Equality Act 2010*
- are otherwise at risk of not making a successful transition such as looked after children and young carers.”*

The Act places a duty on the education authority to request information from an appropriate agency or agencies, which include NHS Boards, other Local Authorities, Skills Development Scotland, Further and Higher Education.

The Act also makes reference to Child’s Plans and Co-ordinated Support Plans as part of the transitions process. A transitions strategy should work in tandem with the current forms or should seek to replace these. Therefore reducing the need for information to be continually repeated by children and young people, their parents, unpaid carers and other agencies involved.

Question 5: The financial impact of the Bill on the Scottish Government, local authorities or other bodies

We welcome that further and clearer financial resource has been allocated in the Financial Memorandum for local authority costs for preparing, implementing and reviewing transitions plans from when the Bill was previously introduced in 2020-2021.

It is important to recognise that the actual cost of successful transitions is the cost of delivery support and as previously stated in our joint response, planning alone will not deliver good outcomes for disabled young people, their families and their unpaid carers. Some individuals and unpaid carers may not want local authorities to prepare and oversee transitions plans. Further detail is needed on how the individual needs of children, their families and unpaid carers will be met in these situations.

Many unpaid parent carers have told us that when their child transfers from child to adult services that they can often experiences a significant reduction to the support and services available. This can be for many reasons, including pressure on local services or lack of required services available in their locality. We hope that if a National Care Service is introduced that this will help to combat some of these postcode lotteries to quality service provision that currently exists. It is important to closely monitor on whether inclusion of children’s services will also form the proposed National Care Service and how this will impact transitions from child to adult services.

Appropriate investment will be needed to ensure communications, consultations and information resources around the Bill are accessible and inclusive to the needs of those with lived experience and their unpaid carers. Investment in inclusive and accessible information around transition planning processes is also paramount.

For the policy intent of the Bill to be fully delivered, it is imperative that transition planning is as seamless and robust as possible. This will ensure disabled young people get the support that they require to fulfil their full potential and reach positive destinations in their lives.

The National Carer Organisations believes that it is vital to invest in the future of disabled children and we must allocate sufficient financial resource to ensure these children and young people get the support that they need and experience a positive transition to adult services. As we noted in our previous joint response, the more disabled people that can be adequately supported to achieve independent living will result in less costs to public funding overall. It is also likely that improved support for disabled young people in transitions will reduce health and social care costs further by improving their overall health and wellbeing. The same principle also applies to unpaid carers where adequate and some preventative support can also avoid unpaid carers reaching crisis and result in an expensive intervention being required at a later stage.

Question 6: How the Bill will affect (for better or worse) the rights and the quality of life of the people covered by the Bill

In Section 7 (5) there is a statement of a child “lacking capacity to express a view”. Article 2 of United Nations Convention on Rights of the Child states that no child should be treated unfairly on any basis and Article 12 states children have the right to state their opinion. By stating that a child “lacks capacity to express a view” appears to us to be treating that child unfairly compared to a child who can express a view. We suggest that wording be changed to “be unable to express a view.” UNCRPD requires that every support should be made possible to help someone express a view, and the past wishes, present wishes, will and preferences of the person should be considered. The obligation to form a best interpretation of the child, young person’s will and preference should also be included in this section.

A safeguarder could be appointed to help ascertain the wishes of the child in so far as is ascertainable. We also suggest that, as well as a duty on local authorities to ascertain the views of any parents, legal guardians or other unpaid carers, the Bill should also place a duty to take into account views of the Power of Attorney, in the rare situations where these differ from those already listed.

If the Bill is clearer around definition of child, respects the past, present wishes of the child or young person and support a child or young person who may need help to express such views then there could be a positive impact on the rights and quality of life for the individual. Taking the views of any young carer or sibling carer into account will also be in line with Carers (Scotland) Act 2016 and provide a mechanism for their rights to be observed.

Question 7: Do you agree with introducing a strategy, and that a Scottish Minister should be in charge of it?

Yes the National Carer Organisations agree with introducing a National Transitions Strategy and that there should be a Scottish Minister with responsibility and accountability for transitions. From our consultation work with unpaid carers there is strong support to both of these.

When the National Carer Organisations last consulted on the Bill, we asked unpaid carers, “Should there be a national transitions strategy to support disabled children and young people transitioning to adult services?” From the 308 responses received 98% replied ‘Yes’.

We would also want to ensure detailed accessible and inclusive consultation with people with lived experience and the third sector, including unpaid carers and local and national unpaid carer organisations, is undertaken in the development of the National Transitions Strategy.

The National Carer Organisations also asked unpaid carers, when we last consulted on the Bill, “Should there be a Minister in the Scottish Government with responsibility for transitions?” 93% replied ‘Yes’.

We would hope that these proposals would contribute to improved outcomes for disabled children and young people and their unpaid carers. Both the strategy and having a Scottish Minister that would be in charge of this would help to ensure transitions remain at the fore when policy decisions are made that could impact disabled children and young people and their unpaid carers.

Question 8: Do you agree with the proposals relating to transition plans?

The National Carer Organisations welcome the proposals in the Bill which should implement transition plans for all disabled child and young people within their local authority area. We think this would help to contribute to positive outcomes and further highlighting rights for all children and young people.

Bill proposals do include views from the child or young person, parents, unpaid carers and other agencies involved, we believe that this should be taken a step further and include any support needed from social care and additionally the impact on unpaid carers should also be included. There should also be enough resources available to support the proposals in the Bill.

Some young people and their families will require more tailored information on transition due to a wide range of additional support needs, including young people with mental health problems, with English as a second language or with emotional and behavioural issues. There is a need for the information available about transition planning to be accessible and relevant to all of these young people, and for the transition pathways to be clear, joined up and understood by all involved. Currently, there is potential for confusion about Pathway Plans, Transition Plans, Co-ordinated Support Plans, the Child's Plan and Support Plans. The Transition Pathway should be streamlined, and relevant to all young people with an additional support need. All young people with an additional support need should have a clear plan which sets

out how they are to be supported to achieve their hopes and dreams, and they should have the information they need upon leaving school to share with others involved in their lives.

Question 9: Who do you think should coordinate the transitions plan?

Once the National Care Service is established and full responsibilities detailed, there could be considerations that coordination of transition plans would form part of this remit. Regardless of which provider becomes responsible for coordinating transition plans, it is vital that the views of children and young people and their unpaid carers are at the heart of this.

It is essential that young people approaching transition are identified and have access to support and coordination through a single point, such as a Transition Planning Team and that other staff and agencies working with young people have access to their support and expertise. They can play a crucial role in:

- Attending transition meetings from S4 for young people identified as having a disability and/ or sensory impairment.
- Spending time in the schools getting to know the young people to highlight the young people who will require post school support and who require allocation for an assessment of their needs.
- Ensuring that young people are linked into an appropriate level of support post school to pursue their ambitions and to meet outcomes.
- Working closely with school staff, Skills Development Scotland, social workers and health staff to ensure that every young person has a positive destination.
- Ensuring that social work localities are aware of the young people leaving school who require support.
- Providing support to social workers with transition planning.

For those young people who have periods of absence or who are home schooled, it is important that they do not fall through the net when it comes to transition. There should be robust systems to ensure that these young people are known to localities and to the transition team.

Guardianship is an area where there is scope for confusion about whether or not it is needed. Families can hear from lawyers that it's needed; school staff can feel unsure about whether it is needed for children who receive support with health needs in schools; and children and families staff are often unfamiliar with this area. Good information targeted towards school leavers would be helpful.

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