



Response from the National Carer Organisations to the Call for Views on the Disabled Children and Young People (Transitions to Adulthood)(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 and Minority Ethnic Carers of Older People Project (MECOPP)

### **Do you agree with the overall aims of the Bill? If so, do you think the Bill can meet these aims?**

The issue of transitions is regularly raised by carers at consultation events and was the focus of the Cross-Party Working Group on Carers in December 2019. In December 2020 the Coalition of Carers in Scotland on behalf of the National Carer Organisations developed a short survey for carers to ascertain their views on the proposals within the Transitions Bill. The survey was posted on Facebook and despite not being disseminated more widely it received 308 responses, which is an indication of the strength of feeling from carers on this issue.

The survey asked people if they supported the three main proposal in the Bill; for there to be a National Transitions Strategy, a Minister in the Scottish Government with responsibility for transitions and that local authorities should have to develop a transitions plan for every disabled child and young person. These proposals were supported by a clear majority of carers.

*"Implementing the three things you've asked about and implementing them well could make a huge difference, reduce anxiety and stress and provide predictability for so many young people and their families."* (all quotes in this submission are from respondents to our survey)

We also gave people the opportunity to post comments, again these reflected people's strength of opinion on the subject of transitions. The comments can be broadly categorised into the following themes:

- People's experience of transitions and failures in the current system
- The negative impact of Covid-19 on children and young people currently going through transition

- What needs to change and the elements required to improve the experience of disabled children and young people going through transition
- The key role of carers as equal and expert partners and the negative impact on transition planning when carers' views are not taken into account
- The need to also consider the impact on carers of the young person's transition to adult services, particularly when carers are expected to provide an increased level of support.

We have expanded on these themes within our submission to the Call for Views and have aimed to reflect the views of the carers who responded to our survey throughout.

**Is changing the law the only way to do what the Bill is trying to do? Would the Bill (as it is currently written) have any unexpected or unforeseen effects**

Carers strongly expressed the view that the system is currently failing the children and young people they care for. Their experiences of transitions were that there is a lack of information available about the process, meaning that families are either left in the dark or have to research and access information themselves. The process of transition does not start early enough and often carers' views aren't fully taken into account. Finally, many carers felt that there was little ambition from staff for the young people moving into adult services and often the packages of support after transition were inadequate and not tailored to their needs.

They expressed the view that this Bill is needed and is 'essential'

Here is a selection of comments from our survey:

- This is essential. Too many children and young people being failed
- The stress placed upon the families without "official diagnosis " as they leave the safe environment of school is palpable. The world is scary enough for those without additional support needs. The young people need a pathway to give them structure and understanding.
- This is necessary to give young people with disabilities their human rights. My daughter left school in June and suddenly there is nothing available for her.
- It is an extremely difficult time for parents and YP and there is a no mans land of what happens next! Unless you have a strong social worker or a spokesperson it is extremely difficult to access the services our YP need and deserve. Information on services can be a challenge to get with a point of contact or key person lacking within this. This is very much needed, as a foster carer I have transitioned YP from child services into adulthood and the lack of access to the service is so unsettling for all
- This is essential, especially for children in foster care. I have seen many children with disabilities end up in homeless accommodation which is so wrong.
- At the moment we are failing these children, they still need structure and support and something to do, if they are unable to work
- My son soon to be 18, has autism. He has been discharged from children's services and I was told they would not even refer him to adult services as 'adult services are

just for people so severely disabled they could never look after themselves'. This is in Moray so not surprised. So no further support at all. This needs to change

- At the moment it's not existent! Children transitioning are being badly let down. No support
- My son is due to finish school in June 2021 & so far nothing is in place. Any contact with college or outside agency has been made by myself! It's disgraceful!!!

The current pandemic has also magnified issues for children and young people transitioning to adult services. For many families transition planning has been put on hold, which has caused a great deal of stress. It may be necessary to extend the period of transition for affected families to compensate for this.

Several respondents to our survey specifically mentioned issues arising from Covid-19:

- My son was diagnosed aged 15. All support was withdrawn as soon as he turned 16. Due to covid he hadn't had his CHAD assessment. So apart from being told he had ASD and severe oppositional behaviours we received no help or direction to help.
- Help and guidance through the transition is needed. Covid has possibly impacted but we have had a horrendous year and are currently without a social worker yet again. It is imperative to have a plan for children who will need to transition
- Yes because of Covid it has not been fair on them and if their anxiety is high we should be allowed to keep them back one year and make sure we get it right

A recurring theme was the need for more specialised support, including specific support for children and young people who are non-verbal and for people in hard to reach communities, such as BAME and rural and island communities. The development of a National Transitions Strategy to address the need for more dedicated and specialised support, overseen by a Scottish Government Minister, would help to address these deficits in the current system.

Comments from carers included:

- Despite recommendations adult services refused to even see my son. Also the GP referred him to the Mental Health Team who say they cannot assess him if he won't talk to them - he is non-verbal over the phone and may take hours to speak to someone in person. This is unacceptable. There are ways to assess without words. Why is he being ignored.
- There is a severe lack of support and opportunity and inclusion in rural areas. Disabled people and children living in remote or rural areas are isolated and unsupported

Finally, we believe the Bill has the potential to have a very positive impact on the lives of children and young people with disabilities and their carers. However, it does require a careful balancing act. While the introduction of the strategy and individual transition plans should result in more consistency, higher standards and better outcomes, it is also important to ensure that the system and process remains flexible enough to be person-centred and ambitious in approach.

As one carer put it *“There should be a standardised approach but an appreciation that there may need to be flexibility based on individual needs.”*

**The Bill would require the Scottish Government to introduce a National Transitions Strategy (sections 1 to 6 of the Bill). Do you agree with introducing a strategy, and a Scottish minister to be in charge of it?**

We asked carers “Should there be a national transitions strategy to support disabled children and young people transitioning to adult services?”

From the 308 responses we received 98% replied ‘Yes’

We also asked them “Should there be a Minister in the Scottish Government with responsibility for transitions?” 93% replied ‘Yes’

There is clear support from carers for both of these proposals. The National Carer Organisations are also of the view that both of these proposals would contribute to better outcomes for disabled children/young people and their carers and would provide welcome focus and accountability in relation to transitions

**The Bill places a duty on local councils to prepare and implement transition plans for each disabled child and young person within their local authority area (sections 7 to 13 of the Bill). They would also have to explain:**

- **how plans were going to be prepared and managed.**
- **what would happen if there was a disagreement about what was in a plan or how it was working.**

**Do you agree with these proposals?**

We asked carers “Should local authorities have to develop a transitions plan for every disabled child and young person to improve their experience and outcomes in their transition to adulthood?”

Of the 308 people who responded 97% responded ‘Yes’ showing clear support for this proposal.

Many of the comments we received were suggestions from carers on how improvements could be made to the current system. These included:

**1. The need to involve carers in the process of transition to a greater extent**

- Yes. If LAs are to be enforced to have transitional plans, it has to have full parent involvement. I ensured that my son had one and one that met his needs and not one that would have been easier for social work, schools and college.
- Listen to parents, they are the voice of their children & know them better than anyone. Sadly most of us have had to fight for everything our children need...even the most basic of things like being supplied a continence product that actually fits. Things like this are a basic necessity not a luxury.

- Parents are very involved throughout their child's life, it is very difficult for both the parent and child when they are separated in their ongoing care and needs, and this can be very upsetting and scary for both. Children need to be listened to with the support of everyone and parents need to be included. My sons experience left him unsure and scared on his own with very big decisions in a world of strangers.

## **2. The need for transition plans to be both person-centred and ambitious**

- Society is often not ambitious enough for these young people. Just because they have a disability it does not automatically follow that they will never be able to work. Investing in their learning and supporting them better on leaving school could ultimately lead to them becoming both contributing members of society and financially independent. They have dreams and ambitions like everyone else, and they are achievable. They just need better support.
- I would love to see supported College places with real specialist education & fully geared for those who are learning disabled.
- I would love to see young people who have left school or just leaving school still have loads of opportunities to be kept active , I worry for my son who doesn't have a lot of friends (only ones in a school) that when he leaves he will become isolated as he will do nothing
- There is hardly any exposure of disabled young adults in mainstream society who have successfully transitioned from special needs education to employment in wider mainstream organisations. A poor reflection of what we assume lives will be like for our disabled children. How can they use their equal rights to achieve and establish successful lives for themselves?

## **3. The need for clear and timely information**

- Parents and young people should be given the information (instead of having to search for it or find out it's needed at last minute) so that they can plan for it!
- Parents need information up front and a clear pathway to understand how to best support their child through transition. This needs to be discussed years before it is due to happen in order to give sufficient time and support to the child and parent navigating this journey.
- This needs to be a transparent service with ALL steps needed to transition to adult services documented and available to parents in one place - medical, educational, allowances, housing - I am so fed up going from one NHS and government website to another; this service needs to be about enabling the user!

## **4. The need for the process of transition to start early**

- Transition is not a one off event, it's a process that starts (should start) a long way back. If earlier supports and transitions worked better, then it wouldn't be such a cliff edge when leaving school.
- These transitions need to be planned well in advance. If a youngster is to transition at 18, planning should start at the latest at 15

- Needs to start in S1 , planning for opportunities throughout the 4.5 years in Secondary that are real experiences in real community settings , building relationships as well as in school learning .
- Daughter currently in last year of school, it seems like they think transition is for the 9 months before leaving school. The low aspirations of 'special schools' seem to be embraced by others. The inequalities between people leaving these institutions and those leaving mainstream is huge. This is a cliff edge and totally unacceptable

**5. The need for clear systems and a transparent process which is easy for families to navigate, including a designated contact**

- There should be access to a named social worker, you should not have to wait months to speak to them there should be time limits within which contact is made, more than 1 social worker within each council. It must work better than present system
- Please also look at some local authorities policies where a 16 year old is no longer considered a child but cannot access adult services till 18.
- Communication between child and adult services is essential. The ability to appeal against decisions should also be available as should advocacy support be available if required. Sadly all too often budget constraints will affect outcomes for the young person
- It needs to be enforceable, or this will be a big waste of time. Otherwise each local authority will keep doing their own thing and letting young people down.
- I think all families of young people transitioning from school to adulthood services should have a link worker who provides families with step by step info about services available, benefits available and general support during the worrying next steps

Another clear theme that came across from our survey was the need to ensure the role of unpaid carers and family members was also considered within transition planning.

Many carers find themselves in a position of having to provide a much greater level of care following the move to adult services. Often they are not consulted about this change and are expected to pick up the shortfall. This can have an impact on carers health and wellbeing, finances and ability to combine caring with employment as well as have a life alongside caring.

The transition process must incorporate a recognition of the support needs of carers and family members and must include the question ' How much care is the carer or other family members **willing** and **able** to provide. Assumptions must not be made about the level of care available from unpaid carers

Some of the comments we received from carers on this issue were:

- Respite for care givers is essential, after all these unpaid carers save the government thousands of pounds every year. Respite should not just happen at crisis. The transition from child services to adult services is traumatic enough for the person and the parent never mind the huge differences in resourcing and joined up care.

- I was told there would be no increase in budget after transition. Things are financially difficult now, am I expected to give up work to pay for the care costs. What is in place to encourage and keep parents of disabled young people in work? Most parents are unable to work and are thus disadvantaged.
- This is about the wider family too. Parents suddenly not having resources or support following their disabled child leaving school.

**What financial impact do you think the Bill may have, either on the Scottish Government, local councils, or other bodies?**

The costs set out in the Financial Memorandum for the development of a National Transitions Plan are relatively low.

The cost of undertaking individual transition plans and reviews has been estimated at £783,200 per annum for local authorities. However, this is only the cost of the planning aspect. The real cost of good transitions is the cost of delivering the support. Planning alone will not deliver good outcomes for families.

As can be seen from our survey many families find that once their child moves into adult services the support they receive is drastically reduced in real terms. Both because of the pressure on local services, resulting in rationing via eligibility criteria and because of a lack of any suitable support available in their local area.

These costs are not related to the additional duties within the Bill, but with the ongoing failure to provide families with the support they need.

To be successful, the Bill needs to come with a higher resource to ensure transition planning translates into young people receiving the support they need to achieve their independence and their full potential. This is the only way to avoid the cliff edge of adulthood and the stress both young people and their carers experience during the transition period and also long term as a result of the consequences of inadequate support.

We hope that the current Independent Review of Adult Social Care which is also looking at transitions will make recommendations which will complement and enhance this Bill and address the issue of the chronic underfunding of social care, including support for carers.

Finally, as illustrated in the financial memorandum, the costs of doing nothing are far greater than the cost of investing in the future of disabled children and young people. The more disabled people that can be supported to achieve independent living, the less cost to the public purse. The same argument applies to supporting carers of disabled children and young people, where a small amount of preventative support can avoid costly crisis intervention further down the line.

The comments we received from carers on this issue included:

- Funding issues should not take priority over identified need

- A transition plan is useless without the resources to back it up. I have two disabled children leaving school in May and neither have a plan in place. One gets no support outside school, and the other they can't find any resources for.
- What should happen and what actually does happen are often miles apart (as seen with GIRFEC.) If this bill comes to pass there has to be adequate funding and actual accountability for not meeting targets, otherwise it just becomes another meaningless soundbite.

**Is there anything else you'd like the Committee to know about the Bill? Do you have any comments on how the Bill will affect (for better or worse) the rights and quality of life of the people covered by the Bill?**

*"Transition isn't just about transitioning to adult services but to adult life!"*

Overall the Bill has been welcomed by carers. It is clear from the comments we have received that the current arrangements for transitions are inadequate. The process and transition period are stressful and outcomes are often poor. In addition, the views and support requirements of carers are often overlooked.

Provided the Bill is fully implemented with adequate resources we believe it has the potential to make a real difference to people's lives. However, we believe the Bill needs to be strengthened in the following areas:

1. Carer involvement in transitions needs to be strengthened and in particular the needs of carers following transition should be considered alongside the needs of the disabled children and young people they care for. Specifically in undertaking transitions planning, local authorities should have to take account of the care that unpaid carers are **willing** and **able** to provide and should not make assumptions about their availability to make up any shortfall of care resulting from the move from children's services. We also believe the language in relation to carer involvement should be strengthened. In Section 12 of the Bill relating to the review of transition plans it sets out that local authorities must 'consult' with carers, whereas in Section 11 the duty is set out that local authorities must 'have regard to the views of' We believe this position is stronger and should be consistent throughout the Bill
2. We welcome the move to set specific timescales for the transition period and the proposal in the Bill to have the transition plan agreed, no later than 3 months before the child's 16<sup>th</sup> birthday. We believe that it would be beneficial to also set a timescale for when the process should begin and when the transition plan must be enacted and services to support the young person should commence. We have heard from many carers that the process started too late and was therefore not comprehensive enough. We also know of carers who have had to give up employment due to services not being put in place in time, leaving them without any form of support for a period of time. This situation is not acceptable.

3. The Bill would benefit from a specific duty in relation to the provision of information. Part 2 (7) of the Bill sets out a duty on the local authority to 'take action to raise awareness' of their duties under the Bill in relation to undertaking transition plans. We believe this proposal would be strengthened by making it a duty on local authorities to provide disabled children and young people and their families with information on their rights in relation to transition, alongside clear and transparent information on the process, on complex issues such as legal and welfare guardianship, as well as pathway and timescales involved.
4. We also welcome that the Bill includes a proposal on dispute resolution. This is strongly welcomed by carers who often find that they are not treated as equal and expert partners in this process, despite typically being the primary carers and knowing the disabled child or young person better than anyone. While the Bill does not provide any details of the dispute resolution we believe it must be a robust and independent process and that carers must be involved in its development. We also believe that there may be a role for advocacy organisations to play in ensuring that disabled children and adults and their carers are supported in this process
5. Finally, it is important that this legislation links to other relevant legislation, including The Carers (Scotland) Act, the Social Care (Self-directed Support) (Scotland) Act, the Education (Additional Support for Learning) (Scotland) Act and the Public Bodies (Joint Working) (Scotland) 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 Act and offered an Adult Carer Support Plan.

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