

Response to the Education and Skills Committee's call for views on the Disabled Children and Young People (Transition to Adulthood) (Scotland) Bill

Children's Health Scotland (CHS), welcomes the proposal 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. We also welcome the requirement of local authorities to introduce a transition 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.

CHS is the leading children's health charity in Scotland. It is the only charity in Scotland dedicated to informing, promoting and campaigning on behalf of the needs of all children and young people within our healthcare system. How the organisation does this is informed by our Vision, which is "*for every child and young person in Scotland to realise their right to the best quality healthcare*" and our Purpose, which is, "*to make sure children and young people get the treatment they need*". The organisation works to inform children and young people, along with their parents and Carers of:

- Health rights and responsibilities.
- Where to access information and support.
- What they should expect from health service providers.

Ultimately, we want to empower children and young people to participate in decisions about their treatment and care. To achieve this, we work in partnership with: children and young people, the Scottish Government, NHS, the voluntary sector and health professionals. This is so that health services are planned in child-focused environments that are equipped with appropriate ratios of trained staff. We actively promote the use of evidence-based practice to provide high quality healthcare services at home, in hospital or in the community. All while working to obtain equality of services and access across Scotland.

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

- 1.1. CHS broadly agrees with the aims and objectives of the Bill, though considers it unlikely that these aims will be met without other actions being taken.
- 1.2. CHS is aware that there is currently a big gap for disabled children and young people once school finishes. With this awareness, ensuring clear Transition Plans would certainly help to allow those children to achieve their full potential.
- 1.3. CHS think that aims and objectives are only a start. Successful implementation in meeting these will require more than legislation to ensure that children and young people achieve successful transitions. They must also be seen

alongside the other barriers for disabled children and young people such as negotiating through the social security system and competing for work experience and on into employment. This is challenging enough for all young people and more so for those with a disability.

- 1.4. CHS is in regular contact with, and provides support to, many disabled CYP and their families. This makes our organisation very familiar with the issues that they face.

2. 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?

- 2.1. Having specific legislation sends out an important message that Scotland is serious about supporting disabled children and young people through transitions. It should provide an important base from which to build and make sure that there is accountability at the highest level and more continuity across the different local authorities in relation to the basic duties this will impose.
- 2.2. The Bill itself is just part of the solution. CHS would expect legislation to work alongside existing '*Getting it Right for Every Child*' (GIRFEC) and '*ARC*' transition guidance. There needs to be more sharing of good practice and increased support and training. Plans should involve professionals from various sectors. There is also a likely need to include improvements in basic training. It is worth bearing in mind that, as with GIRFEC which was introduced over 10 years ago, it is only now consistently being embraced since it came into legislation.
- 2.3. CHS does not feel that the existing *Child's Plan* and *Co-ordinated Support Plan (CSP)* are sufficient. Neither of these cover the correct age range and are limited in both cases. In the case of the former, it may be repealed. In the case of the latter, it is limited to young people in education to which very few CSPs are granted.
- 2.4. CHS believe that new legislation in the form of the Bill is necessary to emphasise the enormous importance of transition for disabled children and young people and underlines the priority being given by the Scottish Government to supporting them.
- 2.5. CHS is particularly concerned with the need to engage with adult health services, which are constructed in a different way to paediatric services. It is often the case that disabled children and young people have several medical conditions which may be seen by several different specialists in adult services, and even at different sites. This makes it more difficult for a Transition Plan to be effective unless the various adult services are engaged with the planning and implementation process. CHS hope that adult health services may begin to be more integrated in their approach when dealing with disabled children and young people and the Transition Plan could act as a focus for that change.

- 2.6. CHS would highly recommend that chronic diseases are to be specifically included in the definition of disability. Without this classification there is potentially an unforeseen consequence that a young person may compensate for their health condition and deny they have a disability whilst still very much requiring the additional support outlined in the Transition Plan.
- 2.7. CHS is also concerned if the reference to mental health is assumed to indicate a learning disability or mental illness or neurodiversity when possibly it could be a combination of them all.

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

- 3.1. CHS agrees with introducing a national strategy and having a Minister to oversee it. As with our response to question 2, this sends out an important public message and provides a real opportunity to indicate that effective transitions for disabled children and young people are of national importance.
- 3.2. This part of the Bill does identify the need for consultation, regular review, and scrutiny of the strategy. One of the main concerns of CHS is the consultation stage, to ensure that this is effective in including children and young people with a disability and their families. This will be more challenging for children and young people who have been in care. As listed, there are a number of organisations that can assist with this and CHS would recommend that adult health services are equally engaged. We already have GIRFEC and hope this extends so that we ensure that every person is included.
- 3.3. There are so many ways that consultation can be effective which should be adopted to ensure that it is more than the distribution of a paper document. Practical support for action will be needed as well as the strategy.

4. 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?

- 4.1. CHS has several points to raise in relation to this part of the proposed legislation. Firstly, of critical importance is that it should be made clear from the outset that the Transition Plan belongs to the child/young person. It is after all their plan. The Bill, places the duty with the local authority irrespective of the wishes of the child or young person. This raises a potential conflict of interest if the child or young person is also in the care of the local authority. The Bill,

further suggests the involvement of a guidance teacher and a social worker - neither of whom may be the first choice of the child or young person. For some children and young people this may not be an appropriate point of contact. For others it may even mean that they remove themselves from the idea of having a plan rather than face the problem of finding an appropriate person.

- 4.2. Transition is a process not an event. As such, it involves many services, agencies, and people. It is vital that the process is managed through the application of robust and coordinated plans to ensure that all children and young people covered by the Bill get the personal support, information, and resources they require. This will ensure equality of access and better outcomes for all, not just for those children and young people who have parents or carers to advocate for them.
- 4.3. The Bill simply asks the local authority to 'have regard' to the views of the children and young people, (11.1). This is unlikely to give confidence to a child or young person with a disability that their views are really being taken seriously.
- 4.4. CHS is concerned that it is possible for the plan to be agreed as late as three months before the child's 16 birthday. We feel this is far too late and while this is proposed as a latest date, it may act as a marker that leads to rushed last minute plans. The existing Principles of Good Transitions 3 talks more realistically of planning starting once the child or young person is 14 years old. It will be just as important that the reviewing is carefully carried out, as responsibility may need to transfer as the child or young person gets older or their circumstances change.
- 4.5. Consultation around the plan should be based around GIRFEC and is likely to need to include the involvement of adult health and housing.
- 4.6. CHS is aware that a disabled child or young person may well be involved with several plans. Therefore, care needs to be taken that these are viewed as one plan for every child or young person and not a series of unrelated plans. It would help if this is referred to within the Bill.
- 4.7. The Bill does expect that the plan will be monitored, and its achievements noted by the local authority. While the Bill talks of consulting with the children and young people, CHS would like to highlight that it is the responsibility of the child or young person to decide if the plan has been successful rather than the local authority.
- 4.8. The Bill does allow for dispute resolution. CHS would recommend that careful planning and consultation would keep any disputes to a minimum. CHS feels that this section does not appear to be sufficiently robust and simply says: 'may by regulations make provision...'. This is inadequate and CHS refer policy makers to similar situations where redress in the event of dispute is vital. For

example, the Additional Support Tribunals when a child's rights have not been upheld within ASL legislation. It is vital that such recourse to dispute resolution is available to CYP and their families. It is necessary for children and young people and families to be supported in any dispute and for appropriate advocacy to be available.

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

- 5.1. CHS is aware of the expectation that this will largely be delivered within existing resources. This is possible, but will immediately limit the scope of what can be achieved and certainly limits future plans for how the outcomes of Transition Planning can be improved.
- 5.2. CHS has already identified the need for extensive and effective consultation for various parts of the Bill in relation to the national strategy, individual plans, and making the public aware of the existence of the right to a plan. These can be basically completed, or effectively completed, dependent on the resources available. CHS is concerned that without reasonable resources they will simply become basic exercises that fail to get to the heart of good Transition Planning which could save money in the longer term. We can also learn from other experiences, such as the hospice movement, which had similar challenges of transitions between children and adult services. In all cases higher and further education needs to be involved.
- 5.3. Appropriate resources will help achieve equitable access to human rights. The simple term, disabled children and young people, does hide a very wide range of needs - with access for some being more costly. This should not create a barrier. It is the experience of CHS that, even with the existence of Integrated Joint Boards, many still often operate as separate branches which reduces any cost saving of joint Transition Planning. There is still often disagreement about what should be provided by the NHS as opposed to the local authority. At the early stage, with new legislation, adequate resources will help develop better ways of joint working.

6. 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?

- 6.1. CHS campaign on issues of transitions in healthcare and work in partnership with several organisations including National Services Division, NHS Ayrshire and Arran and the Prince and Princess of Wales Hospice in Glasgow. Recommendations made following this campaign work include:
 - Clear transition policies or pathways in each Health Board led by an overarching Scottish Government Policy.

- A transition champion within each Health Board with a clear remit to oversee policy and practice across paediatric and adult services.
 - That Age-Appropriate Care for children and young people should be provided, regardless of whether they are in adult or paediatric provision. The European Association for Children in Hospital (EACH) Charter (<https://www.each-for-sick-children.org/each-charter>) should be adhered to in adult focused wards admitting children and young people.
 - Education should not be available only in paediatric settings and that the educational needs of young people should be supported in adult wards.
- 6.2. CHS agrees that all children and young people with a disability - in the widest sense of this definition - should have control of a Transition Plan. A national strategy with a Minister leading will set the scene for local planning. CHS expect, on top of this, that there is a firm commitment to existing robust guidance and comprehensive accessible consultation.
- 6.3. The Bill should improve rights and quality of life. It should allow families to have a view of a positive, fulfilling future that has aspiration and is unique to the child or young person. This process must be person centred, with plans allowing the child or young person to flourish.
- 6.4. From CHS' work with families facing transition, CHS know that there should be a free legal service for all families to support their path through transition. This includes the application for guardianship ahead of the creation of a Transition Plan. This can currently be beyond the resources of many families.
- 6.5. CHS welcomes the approach taken in the Bill for the age range to span the years from 16-26, as this encompasses all the different legislative ages and is aligned with the Children and Young People (Scotland) Act 2014. This is especially relevant from the point of view of care-experienced children and young people for continuity of care up to 21 year and aftercare up to the age of 26.
- 6.6. Coordination among the agencies approaching families for Transition Planning is made more stressful by differing ages for the steps involved - e.g.
- 16 years in health,
 - 18 years in education and Community Child Health,
 - Below 18 years for children and young leaving school early or attending FE College or apprenticeships,
 - Later ages for care-experienced young people in Social Work.
 - Care leavers moving from Child and Adolescent Mental Health Services (CAMHS) to adult mental health services.

- 6.7. For career choice advice, there should be a national specialist service that incorporates occupational health considerations for those with chronic disease that may place them at risk in some work situations, or who are excluded by reason of their diagnosis.
- 6.8. The young person should have a say in the allocation of their key person for continuity through transition. This person should have responsibility to inform and involve the young person in the coordination of the GIRFEC triad of services. For young people with communication and/or learning disabilities the key person must have the additional skills to support their communication needs.
- 6.9. The multiple or triad of services – health, education and social work really need to come together for effective Transition Planning. CHS calls for a model in adult services which mirrors/replicates that of GIRFEC in children’s services.
- 6.10. Throughout the documents accompanying the Bill, there is considerable mention made of young people’s aspirations to future work and employment. While this may be true for very many disabled children and young people (as set out in the figures and percentages given in the draft proposal for the Bill), some may be affected by long-term health conditions. This may mean that they are unable to engage in employment, or that their health conditions are life shortening where they may be in or approaching the end-of-life phase. There should be no assumption made that all disabled children and young people will automatically be seeking, or in a position to pursue, active working lives.
- 6.11. The Bill would benefit from a distinct section on health transitions. NICE/SIGN Transition guidelines are in place to adhere to. Existing good practices are in place. For example, local Looked After Children Area Coordinators, Teenage Cancer Trust, certain health specialists and Managed Clinical networks already have good transition processes.
- 6.12. The ‘Principles of Good Transition’ should be referred to and guide the Bill.
- 6.13. The proposed Key Worker role was recommended in the Royal College of Physicians of Edinburgh (RCPE) Think Transition publication in relation to the care of young people with a chronic health condition. It is important to recognise the demands of this role and the need to define what are the intended criteria for the allocation of this role. It is possible that existing specialist community children or adult nurses could take this role for young people with an identified chronic disease diagnosis or with severe learning difficulties. However, there are many individuals whose condition does not fit a diagnosis defined allocation or who are not receiving specialist healthcare yet fall within the risk groups for sub-optimal healthcare and reduced life expectancy. In these cases, the expectation may lie with Primary Care with a predictable need for trained Community/District Nurses adding young people to their workload. Many

of the demands for this group of disabled young people are like those of adults identified for specialist rehabilitation assessment and management.

- 6.14. CHS supports the introduction of a Transitions Bill to ensure that a child's right to the best possible health is not undermined in the change from child to adult services. A transitions plan will help to focus on the needs of the CYP rather than be determined by the needs and resources of our public authorities. A child's health rights should also transition into person centred care with joined up services.

Further information

If you would like to discuss any of the topics raised within this response, or to request any further information, please contact:

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