

May 2019

Disability assistance in Scotland: consultation

A submission from Together for Short Lives

Introduction

1. Together for Short Lives is the UK charity for children's palliative care. We are here to support and empower families caring for seriously ill children, and to build a strong and sustainable children's palliative care sector – so that no family is left behind.
2. We support all the professionals, children's palliative care services and children's hospices that deliver lifeline care. We have over 1,000 members, including Children's Hospices Across Scotland (CHAS), other voluntary sector organisations and statutory service providers. By working together, we provide a strong and unified voice for the sector, and help services deliver the best quality care and support tailored to each family's needs.
3. We support the response to this consultation made by CHAS.
4. Our submission focusses on the challenges and experiences faced by babies, children and young children with life-limiting and life-threatening conditions, and their families.
5. Thanks to changes in medicine and clinical support, children with life-limiting and life-threatening conditions are living longer. However, conditions are still unpredictable and can worsen suddenly and unexpectedly. Following diagnosis or recognition, the trajectory of a child's illness or condition is unpredictable. Irreversible but non-progressive conditions causing severe disabilities can put children at a high risk of an unpredictable life-threatening event or episode.

46. Do you agree or disagree with our approach to the eligibility rules for the different components of Disability Assistance for Children and Young People (DACYP)?

6. Disagree.

47. If you disagreed, please could you explain why.

7. Together for Short Lives calls on the Scottish Government to amend the criteria for the higher rate of the DACYP mobility component to include children under the age of three who are dependent upon bulky medical equipment, or need to be near their vehicle in case they need emergency medical treatment.
8. Children with life-limiting and life-threatening conditions often depend on ventilators, large equipment or other types of technology to stay alive. This equipment is big and heavy. Some babies and young children have permanent wheelchairs and are not able to use buggies suitable for well children of the same age. These wheelchairs are heavy because of the equipment and need to be fixed to a vehicle.
9. These children require specialist, adapted or broad base vehicles for transport which, without financial support, are often beyond the reach of their families. Without access to these vehicles, families can become trapped at home or in hospital, unable to go out to enjoy leisure activities, see friends and family and make memories together. Time is often short for these families; if they are unable to undertake these simple activities, it can have a profound impact on their long-term mental health.

10. Children who depend on life-sustaining equipment must be attached to it at all times. It is extremely difficult to lift children who depend on this equipment in and out of car seats and there is a significant risk that they can be accidentally disconnected. For example, a child with a complex condition who is on high level ventilation must have the following equipment at all times:
- A ventilator which is attached to them.
 - A spare ventilator nearby which includes a back-up battery.
 - A monitor to measure the child's oxygen saturation which provides alarms and vital monitoring.
 - An oxygen supply and mask in case the child suddenly collapses.
 - A tracheotomy emergency bag including spare tubes; this is vital in case one of the tubes in use becomes blocked, a scenario which can have catastrophic consequences for the child.
11. The current disability living allowance (DLA) is available to all families who incur extra costs as a result of meeting the additional care and/or mobility needs of a disabled child. However, children can only receive the higher rate mobility component of DLA from three years of age and the lower rate mobility component from five years of age. This is predicated on the views of medical advisors, [who advised the UK Department of Work and Pensions \(DWP\) that the majority of children could walk at the age of 2½ and so by the age of 3 it was realistically possible in the majority of cases to make an informed decision as to whether an inability to walk was the result of disability.](#)¹
12. A freedom of information (FOI) request made of all Scottish local authorities by Together for Short Lives in March 2017 showed that there were 255 children in Scotland under the age of three who depended upon bulky medical equipment, or needed to be near their vehicle in case they need emergency medical treatment who had a blue parking badge. If the DACYP higher rate mobility component is to be set at £58 per week as proposed, the Scottish Government would incur an additional cost of £769,080 per year in extending it to under threes.
13. Together for Short Lives welcomes the fact that if an individual is regarded as terminally ill, the Scottish Government has stated that their claim for Disability Assistance will be processed under 'special rules' for terminal illness as laid out in the Social Security (Scotland) Act 2018. We welcome the proposal that individuals regarded as terminally ill will be fast-tracked to both highest rate care and mobility components for Disability Assistance.
14. We also welcome the fact that, as a result of the act, in terminal illness cases a diagnosis by a registered medical practitioner, having regard to guidance that is produced by the Chief Medical Officer, will be sufficient evidence that a person qualifies for assistance. We do not regard the previous legal definition of being terminally ill as having six months left to live as being fit for purpose for children and young people.

¹ Written Question (13360) asked by Dr Sarah Wollaston MP on 26 October 2015. Answered by Justin Tomlinson MP. Available at: <http://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2015-10-26/13360/>

15. We call on the Scottish Government to commit to making sure that children who are diagnosed with terminal illness under three who need support should be automatically fast-tracked onto highest rate mobility components as soon as they are diagnosed.

Question 48. Do you agree or disagree with the proposal to make a £200 Winter Heating Assistance payment to families in receipt of the highest rate care component of Disability Assistance for Children and Young People?

16. Yes.

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