

17 February 2017

Department for Work and Pensions and Department of Health: Work, health and disability consultation

A submission from Together for Short Lives

About us

Together for Short Lives is the leading UK charity that, together with our members, speaks out for children and young people who are expected to have short lives. We are here to help these children and their families have as fulfilling lives as possible and the very best care at the end of life. We can't change the diagnosis, but we can help children and families make the most of their time together.

Together for Short Lives has established a Transition Taskforce (http://www.togetherforshortlives.org.uk/professionals/projects/transition_taskforce/about_the_taskforce) to lead the development of a co-ordinated strategic approach to providing care and support to young people with life-shortening conditions. The Transition Taskforce is chaired by David Strudley, Chief Executive at Acorns Children's Hospice and led by Lizzie Chambers at Together for Short Lives. The Taskforce is informed by a stakeholder group which includes representatives from key partner organisations including Hospice UK, National Council for Palliative Care, Marie Curie Cancer Care, SCOPE and the Preparing for Adulthood Programme.

4.1 Should we offer targeted health and employment support to individuals in the Employment Support Allowance Support Group, and Universal Credit equivalent, where appropriate? How might the voluntary sector and local partners be able to help this group?

Voluntary sector organisations which work closely with young people who need palliative care understand the barriers which stop them from entering the workplace. They are often best placed to support young people by giving them the skills, knowledge and confidence to successfully apply for jobs. We note that DWP has run the Innovation Fund which has focussed on disadvantaged young people aged 14 – 24.

We support the Transition Taskforce calls for DWP to support voluntary sector organisations by:

- building capacity through a grant funding programme
- provide a standardised form to enable voluntary sector providers to express their interest in DWP tenders more easily.

4.2 What type of support might be most effective and who should provide this?

Every Disabled Child Matters (EDCM) reports that people with severe disabilities find it very hard to access employment support; young disabled people face significant barriers to get a

job and are often unable to break the cycle of poverty. Young people with a learning disability are three times more likely not to be in education, employment and training (NEET) by the age of 19 than young people without a learning disability.

EDCM reports (<https://www.rnib.org.uk/sites/default/files/EDCM%20report.pdf>) that people with severe disabilities find it very hard to access employment support. We also note the findings and recommendations of Action on Hearing Loss, Mencap, Mind, RNIB and Scope (https://www.rnib.org.uk/sites/default/files/Work_in_Progress_DCC_report_JuL_13.pdf).

We support the Transition Taskforce calls for the Department for Work and Pensions (DWP) to support young people by:

- supporting locally commissioned employment support services through payment for outcomes
- making sure that contracted services reflect available evidence
- making sure that knowledge about what works is retained by the department
- making sure that initiatives do not duplicate each other - for example the specialist employment support (SES) and Work Choice
- improving the Access to Work programme
- providing an update on the progress of the Disability and Health Employment Strategy.

7.2 Building on our plans to exempt people with the most severe health conditions and disabilities from reassessment, how can we further improve the process for assessing financial support for this group?

The DWP should simplify the application process for disabled people to access the benefits system.

Benefits can help disabled young people and their families redress the financial inequalities they face compared non-disabled young people. The Every Disabled Child Matters (EDCM) campaign reports that personal independent payments (PIP) cause anxiety for young disabled people over the age of 16 as they try to claim it in place of Disability Living Allowance (DLA).

EDCM go on to report that a recent survey which it, CLIC Sargent and Contact a Family has conducted has found that (<https://www.rnib.org.uk/sites/default/files/EDCM%20report.pdf>):

- 73% of young people 'disagreed' or 'strongly disagreed' that the PIP application process was straightforward
- 82% found the application process stressful
- 55% said that applying for PIP has had a negative impact on their wellbeing.

Contact a Family's Counting the Costs 2014 survey has found that 63% of people surveyed are worried about the introduction of PIP
(http://www.cafamily.org.uk/media/805120/counting_the_costs_2014_uk_report.pdf).

We support the EDCM in calling for disabled young people and their families to be given adequate financial support to help them meet the additional costs associated with their disability. This support should enable disabled young people with life-limiting conditions - and their families - to lead dignified lives.