

newlife

foundation for disabled children

L314

ILF Consultation Team
Ground Floor
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LONDON
SW1H 9NA

9 October 2012

Dear Sir/Madam,

The Future of the Independent Living Fund

I write on behalf of Newlife Foundation for Disabled Children, a charity which helps children with disabilities and life-limiting conditions and their families across the UK by providing equipment to help individual children, by providing nurse led support services, by funding pioneering medical research and by raising awareness and campaigning. We welcome the opportunity to take part in this consultation and make our submission specifically on behalf of disabled and terminally-ill children and their families.

For this reason, we do not intend to answer the specific questions posed in the consultation document as most applicants to the ILF since 1993 have had to be at least 16 years old and, with the closure of the fund to new applicants from June 2010, the youngest recipients are now at least 17 years old. We would, however, like to make general comments about this fund and eligibility to assistance from it in the future for children across the whole age range.

You will be aware that, in the context of NHS Reform, the Department of Health set up the Children's & Young People's Outcomes Forum because of the specific concerns initially raised that children and young people did not figure prominently enough in the original proposals. This is even more the case for disabled children and we are constantly lobbying both national and local statutory bodies on behalf of them

Action to help disabled and terminally ill children in the UK.

Providing equipment to help individual children, nurse led support services, pioneering medical research, awareness and campaigning.

THE UK'S LEADING DISABLED CHILDREN'S CHARITY

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Registered Charity No. 1001817 Formerly known as Birth Defects Foundation/BDF Newlife.



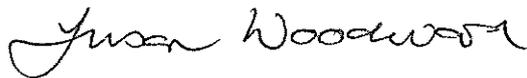
and their families to ensure that their needs are acknowledged and addressed.

The Fund originally had no age restrictions. We believe that the age restrictions imposed in 1993 and, since June 2010, the closure of the Fund to new applicants has, in effect, relatively disadvantaged disabled children by excluding them from access to a significant funding source. We welcome the Government's commitment to a more streamlined and cohesive care and support system administered by local authorities and devolved administrations and to the further development of personal budgets, as reflected in this consultation document. However, we want to ensure that this applies across the whole age range, not just for adults.

We cite, in particular here, disabled teenagers who are about to move into transition. Without appropriate long-term planning, the life-chances of such a child may well be restricted as they move from school, to college or into work. Delays in the provision of the support needed could limit their options at this crucial time in their life and we therefore feel that ILF resources, devolved to local authorities or the Scottish and Welsh administrations, should be accessible across the whole age range.

While we are aware of the growing numbers of older and disabled people in higher age groups, we also make a plea on behalf of the growing numbers of disabled children that their access to every possible source of funding for the care and support they need is not restricted.

Yours faithfully,



Susan Woodward
Parliamentary Officer