

JOINT RESPONSE TO THE CABINET OFFICE REPORT
‘IMPROVING THE LIFE CHANCES OF DISABLED PEOPLE’
FROM ACT¹ AND THE ACH²

GENERAL COMMENTS

Firstly ACT and the ACH wish to congratulate the Strategy Unity on the production of this report. Much of the content is absolutely in line with what ACT and the ACH have been campaigning for over many years. This is particularly the case in relation to the need for keyworkers and more timely and appropriate access to personal and communication aids and adaptations in the home.

There are however a few general suggestions that we would like to make on how the report could have been improved:

- The term ‘disability’ is defined in the report as including all those with impairments or ill health who experience disadvantage due to barriers to life opportunities. We assume therefore that this includes children and young people with life-limiting health conditions who have highly complex needs. However it is not explicit that these children and their families are included in the scope of the report. In general the report does not adequately address the needs of those most vulnerable to disability - those with highly complex needs who are unable to access mainstream services.
- Given the scope of the document it is disappointing that no bilateral discussions took place with ACT or ACH. This does highlight that there remains a gap in awareness of the close relationship of disability with life-limiting conditions.
- It may have been useful to have included in the references some of the research that has been published by ACT, in particular the following documents which can be found on ACT’s website:

Report on Palliative Care for Young People, 13-24

<http://www.act.org.uk/documentation/pdfdocuments/youngpeople.pdf>

Voices for Change: Current Perception of Services for Children with Palliative Care Needs and their Families

<http://www.act.org.uk/documentation/pdfdocuments/voicesforchange.pdf>

Framework for the Development of Multi-agency Care Pathways for Life-limited Children

http://www.act.org.uk/documentation/pdfdocuments/act_pathway.pdf

¹ ACT is the Association for Children with Life-threatening or Terminal Conditions and their Families

² ACH is the Association of Children’s Hospices

We also have a number of specific points to make in relation to the report:

- In chapter 5 (p105) it could be stated that not all parents wish to return to work and hand over the care of their child, particularly if that child faces a shortened life expectancy. The term childcare seems inappropriate for families of life-limited children. However parents do need access to short breaks to ensure that they continue to achieve as normal a life as possible for their family. Children also benefit from spending time with carers other than their parent and, if the break is away from home, from being in a different and stimulating environment.
- In chapter 5 (p108), it could usefully allude to the barriers that face children with a disability who are also highly technology dependent. Often this requires negotiation between education providers and specialist children's nurses so that a child can be supported in school and have safe medical interventions where required. Often there is a requirement for a child's support worker to be trained by these specialist children's nurses. In PCT areas where there is a lack of specialist community children's nurses this process can be severely hampered, reducing the opportunity that a young child has to access mainstream school.
- In chapter 5 (p116-8) some families have even reported to ACT that their child has died before they received the equipment that they needed!
- In chapter 5 (p119) it is acknowledged that there are shortages of professionals such as social workers and Speech and Language Therapists. We would also like to highlight the lack of specialist children's nurses and Occupational Therapists.
- Chapter 5 (p120) could also mention that the lack of joined up working in the provision of home respite care causes enormous problems. Support in the home is often withdrawn by social services when a child is in need of medical support and often there is no nursing service to replace it.
- Chapter 6 (p134) could mention the lack of services for young people with, for eg, Duchenne Muscular Dystrophy who reach their most fragile and vulnerable state of health in early adulthood. Many children's hospice services cater for these young people beyond the scope of their referral criteria because there is nowhere else for them to go.
- Chapter 6 (139) for many young people who are unable to attend school or further education or enter employment, it is vital that they have access to specialist services such as children's hospices which provide support and leisure activities and the opportunity to mix with peers.

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