



## Disabled teenagers left isolated by lack of support

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Many disabled teenagers and their families feel isolated and unsupported in the move from child to adult services, and say the process makes them feel like they are on a 'cliff edge'. A new report exploring the issue finds that help for disabled youngsters varies widely across the country, and that charities are plugging the gaps in government services.

*Rights of passage*, a report by charity think tank and consultancy New Philanthropy Capital, finds that many disabled young people who could lead independent lives are being held back.

*'Things that most teenagers take for granted, such as going to college or university, getting a job or simply moving away from the family home, are not happening for disabled young people because they are not getting the support they need,'* says report author Clare Yeowart. *'We found that charities like Mencap, Scope and Leonard Cheshire Disability are providing crucial support for families and young people when other services have failed.'*

Christine Lenehan, Director of the Council for Disabled Children, adds, *'Families tell us that instead of seeing their child's 18th birthday as a time of celebration and excitement, they see it as a challenge and are fearful, thinking, "What are we going to have to fight for now?"'*

This lack of support affects young people throughout their lives. One problem highlighted in the report is the low levels of employment for people with disabilities. For example, only 17% of adults with learning disabilities are in paid employment, and this figure falls to 10% for adults with autism. NPC's research found that it is charities that are leading the way in developing innovative schemes to support young people into higher education and employment.

Moving away from home is another point where disabled youngsters face challenges, as many families struggle to find the right kind of support. Andy Lusk, Executive Director of Services at disability charity Scope, believes the situation is reaching a critical point.

*'There is a severe shortage of suitable services available to young disabled people when they make the transition to adulthood. We even know of cases where families, as a last and often desperate measure, are forced to place their son or daughter in*

*residential care homes intended for the elderly because there is no other placement available.'*

Despite there being over 600,000 disabled young people aged 14-25 in the UK, a survey by the government's Transition Support Programme found that only half of all local areas in England had a transition plan in place for disabled young people. The survey, highlighted in NPC's report, also discovered that in only a third of all areas did young people get access to a key worker.

Helen Wheatley, the programme's Director, agrees that more needs to be done. *'For many years support for disabled young people moving into adulthood has been inconsistent and often of a poor quality. We have an excellent opportunity to shine the spotlight on the current support available in local areas and to work with disabled young people, families, and staff from all agencies to ensure services improve.'*

Miro, is 20, and has a neuromuscular condition. Although social services started talking to him about the transition process when he was 14, he feels they didn't really listen to what he wanted: *'I didn't really know what was going on and how it was going to work. There was very little communication between the different departments and I felt like a passive observer. I just wanted the usual things that any teenager wants but they kept talking about residential care.'*

The report warns that unless transition is taken more seriously and co-ordination between child and adult services improves, then the investment in disabled children made early on in their lives, will be lost.

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For further information, or to arrange an interview with one of the researchers or families mentioned below, please contact Gemma Davidson (PR Manager) on [gdavidson@philanthropycapital.org](mailto:gdavidson@philanthropycapital.org), or Esther Paterson (PR Executive) on [epaterson@philanthropycapital.org](mailto:epaterson@philanthropycapital.org) or +44 (0)207 785 6300/6310. [www.philanthropycapital.org](http://www.philanthropycapital.org).

## **Notes to Editors**

### **1. Case studies:**

#### **Miro**

Miro is 20 years old and has a neuromuscular condition, which means he uses a power-wheelchair and has muscle weakness from the neck down. He has been in the social services transition process since the age of 14. He says the process failed to take account of what he wanted. *'I didn't really know what was going on and how it was going to work. There was very little communication between the different departments and I felt like a passive observer. I just wanted the usual things that any teenager wants but they kept talking about residential care.'*

With the support of his family, Miro went to his local college to do his A-levels. It was when he got a place at university that the problems with transition became serious. No-one told him that the arrangements for his personal assistant (PA) were going to change, and following a disastrous transition meeting, he found himself at university with no money to pay for help with his personal care. In the end Miro used his student loan to pay for the care he needed until the delay with his Independent Living Fund was sorted out. *'The move from children's services to adult services felt like being "thrown over the fence" from one service to the other. Going to university should have been a new and exciting experience, not one of anxiety and worry about PA provisions. I'm sure many disabled students might find these barriers too difficult and just pack in the course.'* Miro is now in the last year of his degree course and is planning to leave home next year and study in Leeds for his Masters' degree.

## Anna and Jamie

Anna's son Jamie was born with a life-limiting metabolic condition and she was told he would not live beyond the age of 12. As a result there was very little in the way of transition planning for Jamie. Anna says the question of transition was finally raised when Jamie was 17. *'We discovered that there are very few options for people who need a lot of care. No-one in social services knew what to do with him and the best they could offer was a nursing home with elderly people.'* She felt that all the support they had for Jamie throughout his childhood simply disappeared and they were left facing a nightmare. *'Despite Jamie's disabilities he knew that he wanted to leave school at 17 and that he wanted to leave home at 18. But no-one knew what his options were, it was like he was too complicated for the system. I said "What's going to happen?" and they all looked blank.'* Through friends, Anna found out about a house run by the charity Scope, where Jamie could live and get support with transition. Anna says, *'The greatest offer of hope and opportunity for Jamie has been through the Third Sector. Jamie is now with his peers and enjoying his life but I have had to fight all the way. Trying to get child and adult services talking to each other has left me frustrated, angry and upset.'* Anna has since set-up parent forums to give families a voice and to help change the system.

## Robin

Robin is 17 years old and is on the autistic spectrum. His mum Joanne says their experience of transition has been very negative. *'We have battled everything over the years. We fought to get him into a mainstream secondary school, only to find that in the first few weeks Robin kept getting excluded because they didn't understand his needs. In the end everything worked out well, but when he was 16 we were told he couldn't stay on for the sixth form as he hadn't got the right GCSE grades. He's now at college but we're facing another battle as we've just heard that he won't get his one-to-one support next year.'*

Joanne has also been very disappointed with the Connexions service, and feels that they have failed to offer any options for Robin's future, despite many meetings. *'Connexions haven't helped at all. It took so long for them to get to know Robin. I found out recently that we should have had someone from social services present during the meetings but Connexions didn't seem to know about that.'* Robin is interested in working in the media and has been on courses at Channel 4 and worked for a couple of weeks at a national magazine. Joanne feels that without support, all the great things he has achieved will come to nothing, and she is worried about what will happen in the future.

**2. New Philanthropy Capital (NPC)** is a consultancy and think tank dedicated to helping funders and charities to achieve a greater impact. We provide independent research, tools and advice for both charities and funders in the UK and internationally. We have an ambitious vision: to create a world in which charities and their funders are as effective as possible in changing people's lives and in tackling social problems. For charities, this means measuring the results of their work and using evidence to learn and improve, as well as to attract support. For funders, it means using evidence of charities' results to make funding decisions and to measure their own impact. For further information, see [www.philanthropycapital.org](http://www.philanthropycapital.org).

**3. The Transition Support Programme** is a joint initiative of the Department of Health and the Department for Children, Schools and Families. It is running from 2008 to 2011 and being managed by the Council for Disabled Children, which has for a number of years hosted the Transition Information Network, an alliance of organisations and individuals supporting the transition of disabled young people. The programme forms part of the government's Aiming High for Disabled Children strategy (2007), which identified, among other things, the need to improve services to help disabled young people with the transition to adult life. For further information, see [www.transitionsupportprogramme.org.uk](http://www.transitionsupportprogramme.org.uk).

**4. Connexions** is a government-funded information and advice service for young people in England. It is designed for 13-19 year olds, although it provides support up to the age of 25 for young people who have learning difficulties or disabilities (or both). For further information, see [www.connexions-direct.com](http://www.connexions-direct.com).