



PRESS RELEASE: Embargoed until 00.01GMT 15 December 2010

Autism charities warn that families will be left without support

Respite care and leisure services for children and adults with autism are under threat because of cuts to funding. A new report finds that nearly 40% of autism charities are expecting to cut frontline services next year. Many charities are also concerned that the implementation of the new autism strategy, which aims to improve services for adults, is at risk. The report comes out as the government is due to publish its final guidance on the strategy this week.

Changing Lives, a report by charity think tank and consultancy New Philanthropy Capital, reviewed the situation facing autism charities following the introduction of the Autism Act in 2009 and the national autism strategy.

'Autism charities are facing tough times, especially as many of them rely on local government contracts,' says report author, Sarah Hedley. 'Funding cuts are forcing charities to rethink what services they provide and in some cases work will have to be scaled back or stopped altogether. Services such as leisure and respite care are often a lifeline for people with autism and their families, but are likely to be the hardest hit.'

Liza Dresner, director of Resources for Autism, adds, *'There is still appalling neglect of people with autism, and families are constantly struggling, often going from one crisis to another. People tell me that the sessions we run are the highlight of their week. Many parents have had very little support and simply can't carry on. I think we could see more parents of children with autism having mental health breakdowns and more children going into care as a result of the loss of services.'*

Charities are concerned that if the guidance on the autism strategy is not strong enough, local authorities will not take the action needed to improve services for people with autism. This, coupled with the lack of additional funds for implementation, means the strategy could move down local government's list of priorities.

Mark Lever, chief executive of The National Autistic Society, says: *'As local authorities set their budgets, they need to take account of the new legal duties coming into force under the Autism Act, and not allow people with autism to continue to fall between the gaps in services. Now more than ever, they and their families need support. One third of adults with autism are without a job or benefits, potentially living well below the poverty line, and families tell us that they are often left struggling to cope.'*

The report also raises charities' concerns about education for children with autism. Over a third of charities that responded to NPC's survey believe the government's plans for more Academies will have a negative effect on education for children with autism. Charities claim that some children will not get the specialist support they need and will be at greater risk of exclusion.

Jolanta Lasota, chief executive of TreeHouse, outlines the risks posed by the changes: *'The danger is that the budget for providing special educational needs will be squeezed or even disappear as central government shifts towards funding Academies directly and not via local authorities. If local authorities aren't able to prioritise SEN [special educational needs] provision, all the good work is at risk of being lost and we will see a rise in exclusions and tribunals.'*

This is a situation all too familiar to Jan Greenman, whose son Luke was diagnosed with autism when he was ten years old. Jan found it very difficult to get any help and believes that families deserve more support. *'I've received no help with Luke and have had to fight all along the way. The new Autism Act does set out what help families should receive, but it is frustrating because while we wait to see what happens, many families are struggling to cope. There is a gap between what people are saying and what's actually happening on the ground.'*

NPC's report highlights the good work of charities in the autism sector and the successful partnerships between charities but warns that these achievements may be put at risk by funding cuts.

- ENDS -

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

Notes to Editors

1. Case studies:

Jan and Luke

Luke was diagnosed with ADHD when he was five years old, but his mum, Jan, always felt that something else was causing Luke's impulsive and sometimes aggressive behaviour. It was only when he was ten that Luke was finally diagnosed with autism. Jan says: *'The picture had never been put together for us up until that diagnosis. It had always been there but we had to fight to get it recognised. Before that, Luke had always been labelled as naughty and disruptive.'*

Another year passed before Jan managed to get a statement of special educational needs for Luke, just days before he started secondary school. The teaching assistant who was assigned to Luke was not trained in helping someone with autism, and even with Jan's help, secondary school did not go well for Luke. Jan received almost daily calls about his behaviour and on a few occasions, Luke was excluded from school. In Luke's words: *'School was a horrible place for me. I didn't understand what was going on, I didn't understand the sarcasm or the jokes and I couldn't get involved in the usual banter so I got left out.'* Luke was bullied and after one incident, when he reacted badly, he was expelled from school. Jan says it was an awful time. *'Luke got very depressed after he was expelled and spent weeks in his bedroom not talking to anyone. Everything he'd tried to do, the friends he'd tried to make, it had all gone wrong.'*

Under pressure from Jan, the local education authority eventually found a new school for Luke. It wasn't a specialist school for young people with autism, but instead helped children with emotional and behavioural problems. Jan was not convinced it was the right place for Luke until she met the headmaster. *'He just understood straight away. He knew what Luke needed and I knew I could trust him to do the best for Luke.'* At first, Luke found it hard at his new school, but he soon got used to the clear rules and reward system. He found that staff were able to help him because they understood his condition. *'With autism, the social education is almost more important than the academic. I needed those social skills to be able to learn and survive and it gave me a real sense of self-confidence.'*

After just one year at the school, Luke passed eight GCSEs and started acting as an ambassador for the school, giving speeches about autism. At 18, Luke is now a mentor to other children at the school and has won an award for his public speaking. *'Every day is still very tiring—certain things do not come naturally to me. I have to think about keeping eye contact with people, when I sit down I have to think about where to put my arms so that it looks okay, it's all the things other people take for granted. But I have good friends now and a good outlook on life. I still have slip ups and do stupid things like any other normal teenager, but the good thing is that now I learn from those mistakes.'*

Dorothy and Michael (names have been changed)

Michael was diagnosed with autism in 2003 when he was 38 years old. His mum Dorothy says that Michael had been suffering for a long time and was constantly in trouble, first at school and then later on when he went to work. *'I wasn't surprised when I found out he had autism as I knew something was wrong. Michael was always very upset, he would smash things up and get very hyperactive. It made sense when they told me.'*

Michael says he was shocked when he found out. *'I didn't realise I had Aspergers. I just knew I had always felt like this and found meeting people and being in a group very hard. I was like this when I was very young and always had trouble concentrating at school.'*

Michael is now unemployed, having lost his job four years ago. He has recently started going to sessions run by the charity, Resources for Autism. He hopes it will help him gain more confidence. *'The first time I was in a group with new people I found it very intimidating and scary. I hope I will get more help now because I really lack confidence and my self-esteem is very low. I'm hoping to go back to work but it's difficult to find anything at the moment because of all the job losses.'*

Apart from the sessions provided by the charity, the family have received no help since Michael's diagnosis. Dorothy is very worried about what will happen to him as she is now 77 years old and has diabetes. *'Sometimes he gets very hyper and I don't know what to do. In the past I've had to call the police as I can't control him. I have no help and I'm very scared but I try my very best. Sometimes I have a cry because no one is coming here and I am very worried about Michael. I know he doesn't like it when I get upset. I worry all the time about what will happen to Michael. He often goes out and I don't know where he is or if he will come home.'*

2. As part of this research, **New Philanthropy Capital** conducted an **online survey** of 155 autism organisations in England. The majority were identified using the Charity Commission's register of charities. The remainder, including some autism rights organisations, were identified through consultation with various charities and experts in the sector. Of the 155 organisations invited to take part in the survey, 39 completed it—a response rate of 25%. A further 14 charities produced partially completed responses.

3. The **autism strategy** was launched in March 2010. Draft guidance for local authorities and NHS bodies setting out how the strategy should be implemented was put out to consultation in July 2010. The final version of the guidance is due to be published on 17 December 2010.

4. **New Philanthropy Capital (NPC)** is a charity consultancy and think tank dedicated to helping funders and charities to achieve a greater impact. We provide independent research, tools and advice for 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

5. **Changing lives** has been funded by **The Clothworkers' Foundation**. The Foundation is the independent charitable arm of The Clothworkers' Company, which was originally established to promote and control the craft of clothworking within the City of London, including providing financial assistance to its members in times of need. The charitable function of the Company has grown over the centuries and its major function now lies in supporting a broad range of charitable causes from education to poverty relief, the majority of which is carried out through the Foundation. For further information, see www.clothworkers.co.uk.