

Save Haringey autism and learning disability services

The National Autistic Society (NAS) is the UK's leading charity for people affected by autism. We have 20,000 members and over 100 branches, who are at the heart of what we do. We provide a wide range of advice, information, support and specialist services to 100,000 people each year. A local charity with a national presence, we campaign for lasting positive change for people affected by autism, and empower local people to influence change they will experience at a local level.

1. Autism spectrum disorders and the need for expert support

Autism, including Asperger syndrome, is a serious, lifelong disabling condition that affects the way a person communicates with, and relates to, other people. More than 1 in 100 people have autism. It is a spectrum disorder which affects each individual in different ways. Some people with autism are able to live independent lives with support, whilst others need specialist support throughout their lives.

Historically, people with autism have been poorly served and poorly supported by both the social care and welfare system. As a result, outcomes are often poor. In NAS surveys:

- 65% of adults with autism told us they need prompting to wash, dress or prepare a meal¹
- 86% of adults who need prompting have not washed, 70% have missed meals and 69% have not got dressed because they didn't get this help²
- A third of adults with autism have experienced severe mental health problems because of a lack of support³

Recent research by the National Autistic Society revealed that abuse of adults with autism is common and often very serious. Autism makes it hard for people to recognise the intention of others or to understand when they are being manipulated or abused. This makes people with autism very vulnerable. People with autism are also particularly vulnerable to social isolation, and this has a huge impact on both their mental and physical health.

Autism is a condition which is still less well understood than other disabilities by professionals across health and social care, which means that many people with autism do not get the support they need. This leads to higher levels of mental ill health and many people with autism hitting crisis.

The care packages and day centres that Haringey currently provide for people with autism and learning disabilities are therefore an essential lifeline. Those who currently receive care and support through Haringey care packages or services, are lucky in the sense that their needs have been picked up and assessed as eligible and are currently being met. Any cut to these will have a devastating impact on the lives of people with autism and their families and carers.

2. The National Autistic Society's concerns regarding Haringey's budget proposals for transforming adult social care

- Closure of 3 of 4 remaining day centres for adults with autism/ learning disabilities

¹ The National Autistic Society (2014). *NAS survey for Careless campaign*

² The National Autistic Society (2014). *NAS survey for Careless campaign*

³ Rosenblatt, M. (2008). *I Exist: the message from adults with autism* London: The National Autistic Society

- Proposed cuts to care packages of almost £10 million which will undoubtedly impact adults with learning disabilities and autism who make up a large proportion of those with comprehensive care packages because of their 'substantial' and 'critical' needs
- The legality of a cost saving figure of £10 million being attached to care packages. Adults assessed to have eligible needs must have those needs met by law. Those with learning disabilities and autism have complex, lifelong conditions which mean that their needs are unlikely to decrease over time.
- Cuts of 25% to social work staff
- Lack of evidence-based alternatives for how day and residential services would be delivered if current services are closed down
- Loss of providers who are autism-specialists if Haringey move to 'block contracts' to drive down care package costs. Good autism providers have well-trained and experienced staff who will not be able to provide the same service for substantially lower costs/wages. There is a danger that if this happens adults with these complex conditions will not be supported properly which could lead to safeguarding issues and longer-term costs in crisis care.
- Impact on people with complex autism and learning disabilities currently in receipt of care packages once they are 'reassessed' and offered alternatives to current provision such as reablement or lower support packages in order to make care package savings
- Use of reablement and enablement as alternatives to traditional care provision

3. Short-term savings at the cost of long-term savings

The proposals to cut all buildings-based day services and to bring down the cost of care packages by almost £10 million are extremely short-sighted and, we believe will lead to higher costs in the longer-term. As outlined above, NAS surveys indicate that a third of adults with autism have developed a severe mental health problem due to lack of support. A report by the National Audit Office from 2009 states: *"Beside the negative impact of such crises on a person's life, acute services are also expensive, with inpatient mental health care costing between £200 and £300 per day."*⁴

This report also looked at other cost-benefits of investing in services and found that if local services identified and supported just 4% of adults with high functioning autism and Asperger Syndrome the outlay would become cost neutral over time. Furthermore, they found that if they did the same for just 8% they could save the Government £67 million per year.

Economic Modelling by Deloitte on social care funding and longer term savings that could be made by properly investing in support for people with disabilities, including people with autism found that for every £1 spent on support for people with 'moderate' level needs, an average £1.30 will go back to the NHS, local and central government, and individuals.⁵

In light of this, Haringey's proposals to cut the care packages of disabled people deemed to have 'substantial' and 'critical' needs seem counter-intuitive. If these people are not supported by comprehensive care packages and are instead reassessed to have fewer needs or are moved from existing placements and providers to those offering a cheaper service, the outcome is likely to be a rise in mental ill health, rise in challenging behaviours, and a rise in more safeguarding cases, and potential admittance to the very residential institutions that Haringey is trying to move away from.

⁴ National Audit Office (2009). *Supporting people with autism through adulthood*. London: The Stationery Office

⁵ Deloitte (2013) *Economic Impact of Social Care Services: Assessment of the Outcomes for Disabled Adults with Moderate Care Needs*: <http://tiny.cc/othercarecrisis>

4. Use of reablement and 'enablement' for people with lifelong and complex disabilities

In their proposals for Care Purchasing Packages, Haringey Council have stated that they aim 'to review the appropriateness of packages through a reablement approach'. Following this they state that this may mean 'providing a period of intensive reablement (up to six weeks) with a view to promoting full independence or reducing on-going high cost care packages'.

Reablement is an approach which has been used mainly in the treatment of elderly disabled people or those suffering a physical health condition usually on discharge from hospital following something such as stroke or fracture. The emphasis is on restoring physical abilities and re-learning skills. Reablement programmes are typically short-term (approx. 6 weeks) and intensive in nature. People with autism and learning disabilities on the other hand, have lifelong, complex conditions which require a lifetime of specialist, expert support. While some may develop the ability to manage aspects of their disability, such as improving verbal communication, or overcoming inability to travel by learning a specific route, such positive change only happens as the result of ongoing support from experienced and consistent support staff. Haringey Council officers have also referred to an 'enablement' approach. This is an approach for which we have found no research evidence and our concern is that this is an untested and unknown approach which seems to have arisen alongside the 'reablement' proposals.

The inadequacy and inappropriateness of the reablement approach for adults with autism and learning disabilities should therefore become immediately obvious. The adults attending Haringey day centres and receiving social care packages are those who have already been assessed as having 'substantial' or 'critical' needs under the Fair Access to Care criteria. It is impossible to see how a 6-week reablement programme will enable this group of disabled people to live independent, fulfilling lives, let alone support them to carry out everyday tasks such as washing, eating and engaging with the community.

Lack of evidence for a reablement approach

Haringey Council have previously referred to a study on reablement conducted by Professor Emerita of Social Policy, Caroline Glendinning of the Social Policy Research Unit at the University of York, along with Professor Gerald Pilkington.

We contacted Professor Glendinning and explained Haringey Council's proposal to cut care packages by focussing on a reablement approach. We also informed her that Haringey have quoted her study as evidence for the successfulness of this approach. In response, she commented:

'The evidence base relating to the effectiveness of reablement approaches other than older people is virtually non-existent. We originally intended our study to focus just on older people, but due to difficulties in recruitment we lowered the age threshold to 18+ (and able to give informed consent). Nevertheless 93% of the reablement sample were over 65 and 97% were retired. Numbers were too small at the follow-up stage to any analysis of outcomes for subgroups (eg older vs younger people).'

She followed this by saying:

'I don't think there's any evidence from our research that justifies Haringey cutting services for adults with autism.'

5. Impact on carers and families

The proposals for Care Purchasing Packages state that the Council proposes to 'make more use of personal, community, family and voluntary sector resources rather than professional help'. As mentioned previously, those adults currently receiving social care packages are the ones deemed to have the highest needs of all those assessed for social care support in the borough. A report by the NAS, Mencap, Leonard Cheshire Disability, Sense and Scope called 'Ending the other care crisis' revealed that in May 2013 two in five disabled people were already failing to have their basic social care needs met – this amounted to a £1.2billion gap in social care spending.

In this context, the adults in Haringey who are currently receiving social care packages are already those at the very highest end of social care need. These care packages are an absolute necessity and are provided precisely because they have lifelong, complex needs which cannot be met by parents/ carers or the voluntary sector alone. The suggestion that care packages for this group of adults can be reduced by making further use of carers and personal or community connections, is unrealistic at best. The NAS receives thousands of calls from parents/carers of adults with autism every year – many of whom are seeking to get social care support because they are unable to provide for adult children with extremely complex and challenging needs.

Locally, Haringey carers of adults with autism and complex needs have already described reaching breaking point, despite their adult children receiving social care support. Many have said that their own physical and mental health has deteriorated – their caring duties meaning that they have been unable to adequately look after themselves.

6. Summary of what we are asking

Our concerns centre on Haringey's Priority 2 document, which details every area of social care and the projected savings within each that these proposals will achieve.

We ask that within Corporate Priority 2, the following proposals are not accepted:

- Reference 12 New Pathways for People with Learning Disabilities (Accommodation)
- Reference 13 New Pathways for people with learning disabilities – Day Opportunities
- Reference 16 New model for social work and care management
- Reference 17 Care purchasing residential care
- Reference 18 Care purchasing packages

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