

HOW LEARNING DISABLED ADULTS LOST OUT UNDER HARINGEY'S NEW MODEL OF ADULT SOCIAL CARE

Save Autism Services Haringey (SASH) is a group of parents and carers of adults with autism in Haringey. SASH was formed in November 2014 in response to Haringey Council's plans to cut spending on adult social care by 40% resulting in the closure of residential and day care provisions, and cuts in care packages, for adults with autism and learning disabilities.

SASH has close links with Haringey Autism, the local branch of the National Autistic Society, with Haringey People First, which represents people with learning disabilities in the borough, the Haringey Carers Forum and the Social Care Alliance of Haringey. Some of us have professional experience of health and social care. Some are involved in voluntary organisations active in this field. All of us have personal experience of caring for adults with autism and, including some with learning disabilities, mental health problems, epilepsy and other complex needs.

Since the May 2018 local elections, the Council has established the Haringey Fairness Commission. This aims 'to develop practical recommendations on how the council - working with others - can tackle inequality and promote fairness in the borough.' We are submitting to the Commission this report, based on independent research carried out by SASH, revealing the full impact of Haringey council cuts in adult social care services. We believe that it provides the evidence for a fundamental change of policy in relation to adults with autism and learning disabilities and their families and carers, and the restoration of vital services, if we are 'to build a shared vision for a fairer borough'.

Abstract

Major cutbacks in spending on adult social care in Haringey since 2016 have severely reduced services to adults with autism and learning disabilities, resulting in blatant unfairness to users and carers.

Full-time attendance at day centres has been replaced by *part-time* day opportunities in the community, putting increased demands on family carers:

- Four in ten adults (40%) who formerly attended council-run day centres have experienced reductions in time they spend in day activities
- Adults whose day activity packages were changed (48%) were five times more likely to have their hours reduced rather than increased

- In 2016 the 144 adults attending day centres received full-time care five days a week. Now adults attending day activities get on average 3.4 days a week
- The 14 adults who joined day activities after the closure of day centres received on average only 2.1 days a week
- Carers with adults at home have 24 hour caring duties, interrupting nights as well as daily life. Yet only 3 families out of 51 with reduced packages received increased homecare. 48 families received reduced day opportunities but no additional home care to compensate for reduced packages.

Between 2016 and 2017 there was a significant reversal of opportunities for LD clients in supported living (SL) compared with those living with their families:

- In April 2016 the majority of clients using day centres were in SL (57%), with a smaller proportion living with families (43%)
- In August 2017 SL clients accounted for only 16% of the places at the Ermine Road day centre, while 48% were living with their families

There was also a significant reversal of opportunities for SL and family clients in accessing in-borough services.

- In April 2016 all 146 clients (including those in SL and with families) were attending day centres in-borough.
- In August 2017, 36 SL clients – compared with only two clients living with their families – were placed out of borough

This Council policy of excluding SL clients from in-borough day centres, on the basis of residential status rather than assessed need, is arbitrary, unfair and unlawful.

Introduction

Haringey Council claims that its new model of adult social care, introduced since 2016 in parallel with its programme of spending cuts and day centre closures, increases independence and choice. In fact it has replaced day centres that were popular with service users and their families with alternative 'day opportunities' that are of lesser duration and variable quality.

Haringey's new social care model is unfair to people with learning disabilities, who have been obliged to bear the heaviest burden of the Council's austerity policies. It is unfair to their families and carers who are obliged to bear a heavier burden of care, and it is particularly unfair to those in supported living schemes.

Haringey Council officials have hastily implemented their new social care model without due consideration for the impact on users and carers and without providing evidence to justify their proposals. This submission to the Fairness Commission is based on independent research conducted by SASH using data extracted from the Council through inquiries under Freedom of Information Act.

Background

In 2015 Haringey Council, in accordance with its endorsement of a three-year budget imposing cuts of 40% (£25m) in spending on adult social care, adopted a new model. This involved closing the two remaining day centres for people with learning disabilities (Always and Birkbeck) and the borough's only dedicated autism day centre (Roundway). Following a campaign supplemented by legal action by two families affected by the Roundway closure, the Council agreed to retain places for 15 people with autism at the Ermine Road centre (half the number who previously attended Roundway). (According to the Council's own estimates, there are around 2000 adults with autism in the borough, half of these with an associated learning disability.)

The Council claims that its abandonment of 'buildings-based' services in favour of 'day opportunities in the community' reflects the wishes of people with learning disabilities and their aspirations for greater independence and choice. But the Council has produced no evidence to support these claims and research carried out by Mary Langan and Sarah Miller in 2014 confirmed a high level of support for day centres among service users and their families, many of whom continued to resist closure and supported the legal action taken by Roundway families.* Though the Council claims that its new policy was the outcome of a process of 'co-design', families and carers represented on the Council's Learning Disability and Autism Partnership Boards consistently opposed the new model from the outset.

In the course of the May 2018 Council election campaign, Save Autism Services Haringey drew attention to the damaging impact of the day centre closures. A SASH briefing noted that, as a result, people with learning disabilities and autism lose contact with networks of family and friends. More people have to go out of borough for daytime activities, resulting in higher transport costs and longer time spent in travelling. Closures make it more difficult for family carers – and the Council – to keep in contact with service users so that neglect and abuse are less likely to be detected.

Many incoming councillors pledged support for the establishment of a base in Haringey for day activities for people with learning disabilities, which could provide a safe space in which people could meet friends and an information hub for parents and carers. It could also help autistic people to engage with local services for health, training, employment, housing and leisure. Yet, so far, the incoming Council leadership has not changed the direction of policy in adult social care.

When Roundway day centre closed, Grace's 48-year old daughter, who has autism and severe learning disabilities, was transferred to a day centre in Walthamstow. But earlier this year, she was excluded from this centre because the staff could not cope with her autism. She has transferred to a supported living scheme where Grace says 'we have to rely on staff who don't have proper training or the skills to organise special activities for her'.

Cuts in hours – and care packages

Our review of data provided by Haringey Council reveals the impact of the day centre closures on affected families. In August 2016, some 144 people with autism and learning disabilities were attending a day centre for between 5.5 hours a day, five days a week. Of these 144 clients, data were available on 130 who remained within the Haringey system: 51 (40%) had experienced a reduction in their care packages; 11 (8%) had had an increase; and, in 68 (52%) of cases, it had remained unchanged. For clients whose hours were reduced, these reductions varied between one and four days. Whereas in 2016, on average clients spent 5 days a week at day centres, by 2017, they were engaged in 'day opportunities' for an average of 3.4 days a week.

Whereas in 2016, clients spent an average of 27.5 hours a week in day centres, a year later 'day opportunities' took up only 18.7 hours a week. In addition to covering evenings, nights, weekends and holidays, family carers now have to provide care for an additional 9 hours every week. Data on new arrivals, who had not been attending day centres in 2016, show that their day opportunities packages covered, on average, only 2.1 days a week, in practice, a mere 10.5 hours.

In addition to a loss of continuity of care, contact with familiar peers and experienced staff for service users, the new model has resulted in a substantial increase in the burden on families and a further restriction on the scope for recreation – or employment – for family carers. Of the 51 clients with reduced packages, only three received additional hours of home care to support their family carers whilst clients spent additional days at home due to cuts in day care. The family carers of 48 adults with reduced day care received no additional home care.

Catherine's 25-year old son, who lives in the family home, was sent to an out-of-borough centre but after a few weeks she was phoned to come and pick him up: 'they said that they couldn't cope with his challenging behaviour and that he couldn't come back'. He is now back at home all day and relies on visiting carers. Catherine says 'he needs a local day centre – and so do I'.

The exclusion of clients in supported living schemes

Adults living in supported living (SL) schemes, who often have high levels of need and lack mental capacity, have been particularly affected by the closure of day centres. Council policy has given clients no alternative but to rely on their supported living providers to seek access to 'day opportunities' in the community. Data from adult services reveal a dramatic shift in the proportions of clients from SL schemes and those living in their own homes who attend a day centre. In 2016, 90/159 (57%) of those attending Haringey day centres came from SL schemes and 69/159 (43%) from their own homes. By June 2017, these proportions had become reversed: 10/63 (16%) from SL, 53/63 (84%) from family homes. Looking specifically at Ermine Road, in April 2016, 42 (61%) of service users came from SL and 21 (39%) from families; by March 2018, only 2 came from SL and 11 from home. By contrast, at Roundway before closure, 19 attenders came from SL, only 12 from families.

Where have the clients from SL schemes who formerly attended Ermine Road day centre now gone? The data are not clear. Many are presumably being supported by their SL staff to attend day activities 'signposted' by Haringey adult services. Some, estimated at around a dozen, are attending out-of-borough day centres such as Acorn in Walthamstow. Most, between 50 and 74, are pursuing out-of-borough day opportunities.

Questions arising

The wide scope and rapid implementation of Haringey's cuts programme raises questions over its compliance with the statutory requirements of the 2014 Care Act and the Council's responsibility to achieve equitable outcomes.

Have changes to care plans been adequately justified by formal needs assessments under the Care Act? It appears that case reviews have been undertaken hastily by relatively inexperienced staff under the shadow of impending closures.

Have care plans been adjusted on arbitrary grounds unrelated to individual needs? (see Care Act Statutory Guidance, para 13.33) For example, are 'day opportunities' in the community recommended simply because a day centre is being closed, rather than because of assessed need? Are clients treated differently according to whether they are in SL rather than in their family home, i.e. because of residential status, not assessed needs?

Have the needs of parent carers as well as those of service users been adequately considered (Care Act, s10)? Have carers of each of the 51 clients whose care packages have been reduced been formally asked whether they were able and willing to undertake additional caring duties arising from the loss of day care (s10(5)(a&b)? What extra provisions have been made to support these carers during the hours in which their adult children are no longer attending day care?

Has the Council ensured that 'the method used for calculating the personal budget produces equitable outcomes to ensure fairness in care and support packages' (Statutory Guidance, para 11.22)?

Have care packages been adjusted in an arbitrary manner in response to closures rather than in pursuit of fair outcomes?

Has the Council complied with the core Care Act principle of providing continuity of care for users when the Council commissions services from new providers ("recommissioning") (Statutory Guidance, para 4.94)?

Given the large number of SL providers how can continuity of care and an equitable quality of care and support be guaranteed?

Conclusion

Cuts in the care packages of four in ten former in-house day centre clients have resulted in a substantial loss of hours spent in day activities for many adults with autism and learning disabilities in Haringey and the further exclusion of those in SL schemes from in-borough provisions. This deterioration in care contradicts the assurances given by Council officers to clients, carers and the public regarding the new model for adult social care. They claimed that the new day opportunities programme would:

- *Provide a more diverse range of community-based provision..*
The new scheme provides shorter hours and a narrower range of activities
- *Reduce reliance on council-run day centres..*
This was achieved, not by reducing reliance, but by closing the day centres.
- *Offer service users greater independence and choice of activities..*
Closing day centres denies diversity and choice and removes the support necessary for the independence of some service users (see Care Act, s5)
- *Follow co-design with service users, active participation with stakeholders..*
Family carers who participated in discussions with council officers were not 'broadly in agreement' with the new policy, but broadly and consistently opposed to it.

Rhetoric about promoting choice, independence, diversity and co-design provides an ideological cover for policies of retrenchment. Haringey Council has failed to provide evidence to support its new model of adult social care. Meanwhile the burden of these policies is borne by vulnerable individuals and their families.

*Mary Langan, Sarah Miller, The impact of cuts in services for people with learning disabilities in an inner city borough, *Learning Disability Today*, November/December 2014, p 22-24.