

# The impact of cuts in services for people with learning disabilities in an inner city borough

A survey carried out by Haringey's learning disabilities partnership board revealed serious concern and distress about levels of service provision

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Since the May 2010 general election, the government has embraced an austerity agenda, aiming to curtail public expenditure, particularly in local government and welfare, with the goal of reducing the budget deficit (O'Hara, 2014). People with learning disabilities and their families and carers have experienced the combined effects of multiple cuts, caps and changes in benefits together with reductions in local services, which particularly affect communities already blighted by chronic joblessness, insecure, poorly paid work and stagnating living standards (Wood & Grant, 2010; Wood, 2013).

Though people with learning disabilities are highly vulnerable to policies of austerity, their voice has been little heard in relation to the developments of the past few years.

In response to expressions of concern from the learning disability community, local politicians and officials have claimed that people with learning disabilities have been relatively protected from austerity measures. In response, as members of the local learning disability partnership, including service users, carers and representatives of the voluntary sector, we conducted a survey of service users, family carers and care workers to discover the local experience of recent developments and the views of those affected by them. Though the

partnership board includes council officials and employees, they were not involved in this research.

### Methods

In early 2014 a questionnaire was drawn up and piloted with a small group of service users and carers at the Haringey Learning Disabilities Partnership Board. It was also piloted at the 'users and carers' forum at a local community centre providing a range of services to people with disabilities and their families.

Following modifications, and the preparation of an accessible version of the questionnaire, it was presented in April to a wider group, including service users provided by Mencap and the Markfield Centre and members of two local carers' networks. The questionnaire was also given to staff working in private and voluntary sector organisations (approached through the local service providers' forum), as well as local authority staff (approached via Unison). Respondents could give their name or reply anonymously. In total, 190 questionnaires were completed: 98 by service users, 26 by family or other carers and 66 by care support workers.

### Summary of findings

#### Service users' views

#### What difference do services make to people's lives?

Responses showed people value

services, such as day centres, social clubs, supported housing, highly. About half of service users said they were happy with the level of support they currently receive. The most commonly mentioned aspects of daily life that these services helped people with were: ■ Shopping and cooking ■ Making and attending health appointments, taking medication ■ Budgeting and paying bills ■ Socialising and going out.

"It meets all my needs and helps me to live an ordinary life. Going out for daily activities helps me to socialise within the community and have a sense of belonging," said one respondent.

#### How would service users feel if they did not have the services?

Responses showed that people with learning disabilities feel strongly that they would badly miss services. They said they would be "upset", "angry", "anxious", and "lonely" if services were withdrawn. Many said cuts to their services would have an impact on their health.

Service users said: "I cannot think of not having these services. I will have a breakdown. I will be at risk and may die."

"I would feel deprived of living a normal life. I would not feel valued."

"I think I would go back to my old ways. Not eating proper meals, getting into debt and have more health issues."

"I will be devastated because this will mean staying home and be isolated and cut off. It will really stress and stretch my family. It will affect my mental health and physical health badly."

"If I couldn't come here it would be bad. It would make me sad, it would make me swear. It would make me cry."

### **Carers' views**

Responses from carers echoed those of service users. Carers regard services as essential to their own wellbeing, as well as to that of the person they care for. A key point made was that cuts to services that enable carers to carry on supporting people at home would not actually save money because they would mean many carers could no longer fulfil this role, with the result that more expensive services, such as residential care, would be needed.

Carers said: "These services are absolutely crucial to help him to socialise get out of the house and learn new skills, exercise. His mental and physical wellbeing all depend on [going to the] day centre and being a part of society."

"I would simply not be able to care for him if he wasn't attending the day care. It gives me time to recoup my strength and carry on caring for him for the rest of the day and weekends."

"[If services were cut] He would need more expensive [residential] care. He would get depressed and challenging and need more drugs."

"My health would be worse – in fact I would have no life at all."

"All his support needs would fall on us, his parents. We would not be able to carry the full load of care which would have to pass to other care sectors such as supported living or residential [care]."

"I want to have a life outside of my caring role."

### **Impact of cuts**

Cuts that have already been made

to learning disability services were mentioned by several respondents, including: ■ Reduction in support staff hours ■ Closure of day centres, social clubs and respite centres ■ Cuts to/or inadequate personal budgets ■ Cuts in support staff pay leading to higher staff turnover and a lower quality service ■ Reduction in respite ■ Cuts to transport to day centres, clubs and activities ■ Ending of funding for day centre activities for people in residential care.

Responses included: "I have seen my daughter's behaviour regress because she does not have the activities and has been more difficult to handle when she comes home."

"Clubs I used to go to have closed down, like art club, art and music therapy. This helped me to express my feelings."

"At my centre some of the workers lost their positions. It was hard because they were there for years and it affects us and we miss them. It's not right [or] fair because it's hard for people with learning disabilities to find other jobs."

"The [day centre] where my daughter goes has far too many service users and staff in a small building. This is because of cuts – having to give buildings up."

### **Views on future cuts**

Everyone – service users, carers and staff – said that they did not believe that there should be cuts to services for people with learning disabilities: "These cuts are discriminating against the most vulnerable and at risk members of society and are unacceptable."

"I'm very frightened that yet more services will be cut."

"I feel like they no longer care about people with learning disabilities."

"My son has autism, ADHD, bi-polar and severe anxiety disorder and needs 24-hour supported living care. It takes him a tremendously long time to get used to a new support worker,

often months of severe tantrums and distress. However, once he is used to someone, he becomes very attached. His team has been entirely consistent since they began work with him and this has been essential to the progress he has since made. Future cuts that may get made to the support workers' pay will result in most of them leaving. They are quite clear about the fact that they cannot get by on less. The impact of starting again with what would likely be less educated and caring people is the stuff of my nightmares and I think would likely end up with my son back in a secure psychiatric provision, ultimately costing much more and ruining lives."

### **Views of staff**

We received a large number of responses from staff who support people with learning disabilities in a range of organisations, including council-run services and voluntary sector providers. The responses revealed widespread concern about the impact of cuts – both on service users and staff themselves. Recurrent themes were: restrictions on the capacity of service users to engage in activities in the community because of a lack of support staff and the detrimental impact of these restrictions on service users' mental and physical health and wellbeing.

Many staff members complained that pay had remained static or even fallen despite increasing workloads and rising living costs, particularly in inner London. Several staff mentioned that, as a result of high workloads and staff shortages, supervision and training were inadequate. Low morale was linked to high staff turnover. Many said that they did not feel appreciated by the local authority, and some were considering leaving.

Staff said: "I've seen service users becoming extremely distressed due to being confined to the home too long."

"Service users' health and safety are in jeopardy."

"Team meetings don't occur in my service. 'Monthly' supervisions occur six-monthly, due to not being able to leave the service [or] being needed in service. Health and safety is compromised – staff have too many service users to work with. Some minibuses drive service users without escorts. Staff stress levels and work satisfaction have been adversely affected."

A provider organisation said: "The quality of support provided to our clients has a direct correlation to two things: what we pay our frontline support staff and how well the staff are supported."

"A consultant from Haringey came to cut our funding using the Care Funding Calculator – the assumption used on the calculator is that we pay staff £7.07 per hour. Unfortunately, the myth is that you can pick someone from the Job Centre and give them two days training and [they] can be set to work without supervision managing very complex people. If this is the [council's] expectation, then there is another 'Winterbourne' waiting to happen!"

## Discussion

Our survey confirms the findings of a number of studies of the impact of recent public spending cuts on vulnerable groups. People with learning disabilities and their carers in Haringey are concerned about the current consequences of austerity on local services and even more apprehensive about the future.

A 2013 study found the basic needs of 40% of people with disabilities were not being met (Brawn *et al.*). Given the estimated £1.2 billion funding gap in social care support, they concluded that the system was "on the brink of collapse".

The third annual review by the Audit Commission (2013) of the impact of reduced central government funding for local government reported that, despite

a "high degree of resilience", some 29% of local authorities were experiencing "financial distress". To make savings many were forced to make staff cuts in social services, particularly in adult services.

The Joseph Rowntree Foundation observed that local government was "one of the foremost casualties" of public sector austerity, noting cuts in a range of services, especially in more deprived areas, despite an increase in demand for them (Hastings *et al.*, 2013). The authors acknowledged that even though authorities had taken "significant steps" to protect the vulnerable, cuts were still affecting crucial services.

At a time when more people are turning to the voluntary sector for support, journalist Mary O'Hara (2014) noted that "the impact of austerity on voluntary organisations was shattering".

Several respondents referred to the Winterbourne View scandal – the assessment and treatment unit where BBC *Panorama* exposed abuse of people with learning disabilities. Six workers were subsequently jailed, though the proprietors and inspectors escaped sanction (Flynn, 2012). In response, the government declared an action plan with the aim of returning people in such units to appropriate support in their local areas by June 1, 2014.

When this deadline passed, it was revealed that 3,250 people were still detained in such units (Challenging Behaviour Foundation & Mencap, 2014). Given the state of local services revealed by our survey, it is no surprise to us that the target was not met and the spectre of institutional abuse still haunts families of people with learning disabilities.

The experience of the learning disability community in Haringey reflects the nationwide impact of austerity policies. The lack of a concerted national response to these measures is also reflected locally. The survey was completed shortly

before council elections in May and we forwarded a summary of the results to all candidates, calling upon them to pledge to support services for vulnerable people. Only a small number responded and all the major parties ignored the concerns expressed. Even though some councillors recognised the predicament facing people with learning disabilities, they felt unable to make any commitment to resisting further austerity measures.

## Conclusion

Our survey revealed that, despite pledges to safeguard local services for people with learning disabilities, these services have been affected by austerity measures and there are high levels of anxiety about future trends. There is a consensus among service users, carers and support workers that it is a false economy to cut services that enable people with learning disabilities to have an 'ordinary life' and be included in society. They fear that they will become more isolated, their health will worsen and family carers will not be able to cope. ■

Audit Commission (2013) *Tough Times 2013: Councils' response to financial challenges from 2010/11 to 2013/14*. London: Audit Commission.

Brawn E, Bush M, Hawkings C & Trotter R (2013) *The Other Care Crisis: Making social care funding work for disabled adults in England*. London: National Autistic Society, Mencap, Leonard Cheshire Disability, Sense, Scope.

Challenging Behaviour Foundation & Mencap (2014) *Winterbourne View: The scandal continues*. Available at: <http://www.challengingbehaviour.org.uk/learning-disability-files/Winterbourne-View-the-Scandal-Continues.pdf>

Flynn M (2012) *Winterbourne View Hospital: A serious case review*. South Gloucestershire Safeguarding Adults Board. <http://hosted.southglos.gov.uk/wv/report.pdf>

Hastings A, Bailey N, Besemer K, Bramley G, Gannon M & Watkins D (2013) *Coping with the cuts? Local government and poorer communities, JRF Programme Paper: Austerity*.

O'Hara M (2014) *Austerity Bites: A Journey to the Sharp End of the Cuts in the UK*. Bristol: Policy.

Wood C & Grant E (2010) *Destination Unknown*. London: Demos.

Wood C (2013) *Destination Unknown: April 2013*. London: Demos.