

Stuck at home: the impact of day service cuts on people with a learning disability

Introduction

Although there has been a growing understanding of learning disability over the last few decades, and despite good intentions to improve the lives of people with disabilities, there has generally been inadequate social care support for people with a learning disability and their families. Mencap's report on the provision of respite services for family carers revealed that 8 out of 10 parents and carers have reached breaking point as a result of not getting the support they need.¹ Only 1 in 10 people with a learning disability are in paid employment, so they are generally more financially vulnerable, less able to purchase services themselves and more reliant on those provided by social services. There has never been sufficient investment in the social care system to deliver good quality services to all who need them, with too many people falling through the cracks and without adequate choice and control for service users. The recent central and local government cuts have made the situation even worse.

Over the past couple of years, Mencap has heard about many cuts being made to social care services for people with a learning disability. Cuts to services vary from one local authority to the next, but one common theme has been cuts to day services. Local authorities are cutting day services in a variety of ways; one way frequently experienced by the people who Mencap supports is the switch from traditional commissioned services to a personal budget that, in reality, covers a lower level of day support than was previously being received. The tightening of eligibility criteria by many local authorities has also led to lots of people with a learning disability losing all their services, including day services.

Mencap is very concerned about this trend, as we know the impact this has on the day-to-day lives of people with a learning disability, their families and carers. Day services are extremely important—they help people with a learning disability learn new skills, build confidence and interact with other people in their communities. They provide an environment where people with a learning disability can build and maintain friendships and support networks that many people take for granted. Day services also provide much-needed respite for parents and carers.

When people with a learning disability experience a reduction in their day services or lose them altogether, they can be left socially isolated, bored and lonely, and important friendships and support networks are lost. The knock-on effect for families can be severe, often with extra financial and emotional strain on already overworked family carers.

¹ <http://www.mencap.org.uk/campaigns/take-action/our-other-campaigns/breaking-point>

Mencap has undertaken this research to substantiate anecdotal evidence about day service cuts, and to establish the true extent of these changes and the impact on the lives of disabled people. This short report details Mencap's findings.

Data sources

Mencap conducted:

- a freedom of information request to the 152 local authorities in England that provide day services—we received responses from 151 of these local authorities
- an online survey of 280 people with a learning disability and family carers, asking about the changes to day services that they have experienced and the impacts of these changes
- an online survey of 194 professionals who work with people with a learning disability, asking for their opinion on the impacts of changes to day services on the people that they support.

Top-line findings

- In the past three years, almost 1 in 3 (32%) local authorities have closed day services. 1 in 5 (20%) of these did not say they have provided replacement services.
- Over half (57%) of people with a learning disability who are known to social services no longer receive any day service provision whatsoever (compared to 48% in 2009/10).
- 3 in 5 (60%) local authorities have increased charges for day service attendance and related services, such as transport, on average by 70%.
- 1 in 4 people with a learning disability who responded to Mencap's online survey now spends less than one hour outside of their home everyday.
- Over 1 in 3 admits to feeling 'scared about the future' (37%), 'isolated' (27%) or 'lonely' (28%).
- Almost one in four (23%) family carers state that their family is financially worse off due to the changes to day service provision.
- Almost three-quarters of carers (72%) fear that their child will not receive the support they need to live a full and independent life.

Freedom of information results

Mencap sent freedom of information (FOI) requests to each of the 152 local authorities that have responsibility for providing social care services, which include day services. The requests for information consisted of eight questions on day service provision over the last three financial years (2009/10, 2010/11 and 2011/12) and also asked for some 2012/13 predictions. In total, 151 local authorities responded, with some providing all the information requested. However, many local authorities did not have all or even most of the information centrally held and so were unable to provide a full response. This is worrying, as it means it is difficult for those local authorities to have a full picture of their day service provision, uptake or demand.

Cuts and closures

The data Mencap received showed that 32% of the 151 local authorities that responded to the information requests have closed day services since 2009/10. Of these, 20% did not say they had provided alternative services for the people who attended those services, or they simply cited the use of personal budgets as an

alternative. Of the remaining 80% that mentioned some kind of alternative provision, because responses were fairly limited, invariably there was not enough detail to ascertain the suitability of the alternative services or whether the change in service was a positive or negative one for service users.

Furthermore, the responses show that fewer people are accessing day services, or accessing them less often. In 2011/12, a shocking 57% of people with a learning disability (56,754 out of 100,245) who were known to social services received no day services from the local authority at all, up from 48% (61,299 out of 127,774) in 2009/10. Therefore in total, over half of people with a learning disability who are known to social services no longer receive any day service provision whatsoever. In addition, 25% of local authorities provided day services for only one day per week to more people (an increase of 52% on average) and 34% provided day services for four and five days per week to fewer people (a decrease of 20% on average) in 2011/12 compared to 2009/10. Also, 26% of local authorities provided day services to fewer than 1 in 3 adults with a learning disability in 2011/12.

Increased charging

As well as cutting day services, 60% of local authorities have increased charges for day service attendance or related services such as transport since 2009/10, on average by 70%. Of the local authorities that have increased charges, 23% have more than doubled them and nine local authorities said they now charge service users the full cost of the service. This puts further financial strain on people with a learning disability and their families, who generally have very little disposable income to cover these extra costs. Mencap is concerned that these increases will lead to people getting into debt to pay for services or stopping their use of services altogether, which will in turn lead to further isolation.

Adults with a learning disability known to local authorities

28% of local authorities cited a decrease in the number of adults with a learning disability known to social services in 2011/12 compared to 2009/10. This trend is contrary to a steady increase in the number of people with a learning disability in society in general, which suggests that local authorities could be failing to recognise learning disability and are therefore not providing services to people who need them. This means the actual number of people with a learning disability who do not receive any day services could in fact be much higher than this data shows.

Survey results: people with a learning disability and family carers

Mencap ran an online SurveyMonkey survey on its website, between February and April 2012. The survey asked people with a learning disability and their family carers to outline: their use of day services; what changes, if any, had taken place to the day services that they used; and what the impact of these changes had been both on individuals and families. A total of 280 people with a learning disability and their family carers responded.

Extent of cuts and changes to day services

The results of the survey reflect the findings of the FOI request, and again reinforce the idea that cuts and changes to day service provision for people with a learning disability have been extensive.

In total, two-thirds (67%) of respondents with a learning disability have experienced one or more change to their day services. This includes the closure of a day service (29%), shortened opening hours (16%) and increased charges for transportation or attendance at a day service (50%).

The survey asked people with a learning disability to state how many days per week they previously attended a day service, and then to state how many days per week they now attend following the changes to their day services. This highlighted that the number of people with a learning disability attending a day service on just one day per week has nearly doubled (from 12% to 20%), and those attending five days per week has decreased, from nearly half (47%) to under a third (29%).

Of those surveyed, two-fifths (41%) state that they no longer attend a day service anymore due to the changes at all.

Lack of consultation

People with a learning disability were asked to state to what extent they were asked for their views about changes to their day service. Shockingly, 88% of respondents did not feel that they had been adequately consulted, 64% of respondents stated that they were not in any way asked what they thought about the changes, and a further 24% felt that their views were not listened to. Only 12% of respondents felt that their views about changes to their day service were listened to. This is despite the fact that local authorities have a legal duty to hold a public consultation, and to engage service users in this, if they are closing or significantly changing a day service.

The impact of day service cuts

The impact of cuts to day services has been profound. 1 in 4 (25%) respondents to our survey now spends less than one hour outside of their home everyday. This has led to many people with a learning disability feeling 'isolated' (27%) and 'lonely' (28%). A further 37% admit to feeling 'scared about the future'. This is a very worrying and shamefully regressive trend. Indeed, the trend of reducing opportunities to participate in the community and increasing social isolation goes completely against both the Government's *Independent Living strategy*² and article 19 of the *UN Convention on the Rights of Persons with Disabilities*³. Both of these place emphasis on giving disabled people greater access to community life, supporting inclusion and preventing isolation. However, cuts to day services are leading to increased isolation and less inclusion.

The impact on families has been significant. Nearly 1 in 4 (23%) family carers state that their family is financially worse off due to the changes to day service provision. 14% have already been forced to give up paid employment, and almost 1 in 5 (19%) fear that they will be forced to give up work to look after their child or family member.

Concern about the future for people with a learning disability is high. Almost three-quarters of carers (72%) fear that their child will not receive the support they need to live a full and independent life.

² <http://odi.dwp.gov.uk/docs/wor/ind/ilr-executive-report.pdf>

³ <http://www.un.org/disabilities/convention/conventionfull.shtml>

Survey results: professionals working with people with a learning disability

Through the same online survey, Mencap also questioned 194 professionals about the extent of social care cuts to the services that they provide, and their views of the impact of cuts on the quality of services and the lives of people with a learning disability and their carers.

83% of professionals stated that they have already experienced funding cuts to the services that provide. Just 4% of respondents feel that this had not had an impact on the quality or level of the service, while 61% believe that cuts have already had a negative impact, and a further 34% fear that it will have a negative impact on the quality and level of services they receive in the future.

Regarding the potential impacts of cuts to services on people with a learning disability and their families, the biggest worry appeared to be the financial and emotional stress that this would place on carers (70%). Worryingly, 62% feared that cuts may lead to a higher risk of neglect or abuse of people with a learning disability.

Case studies

Reassessed and no longer eligible: Susie's story

Susie is a 41-year-old woman with Down's syndrome from south England. She used to attend a day centre five days per week, but this has been cut to one afternoon in her local library. Susie also used to have 12 hours of one-to-one care support from a social care worker, but last December this support was cut to just one two-hour session per week – barely enough to help with her shopping, let alone sort her finances and day to day care needs.

Susie now spends much of her time either indoors and inactive or in cafes in town trying to find someone to talk to. As a result, she has put on over 2 stone in weight. Her mother Kate says: "Susie's care needs have not changed since she was last assessed 12 years ago. What has changed is the council's agenda, and I believe they are leaving her very vulnerable."

Increased charging: Claire's story

Claire is a 37-year-old woman with a learning disability and autistic characteristics who lives with her parents in the Midlands. Claire attends a day service five days per week, providing essential respite for both Claire and her parents.

They have recently been informed that, due to fairer charging guidelines, they will now be forced to pay £41 per week towards Claire's day services, as well as £20 per week for transport that had previously been free.

Both of Claire's parents are in their 60s, and they do struggle with the burden of care. They feel this added expense could push them to breaking point, and they feel in despair and disregarded.

Personal budgets leading to a reduction in day activities: Jane's story

Jane is a 40-year-old woman in south England. Jane attended a day centre five days per week until she was reassessed in July 2011. As a result, she will be offered a

personal budget to the value of £74 per week but will no longer be entitled to attend the day centre.

Working with brokers to get the best they can for Jane, her parents have only been able to make her budget stretch to three half-days a week of activity. In real terms this means Jane will go from 5 full days to 1.5 days of activity per week.

Jane's mother says: "A lot of us are now over 70. We're tired, we're weary, we've been fighting a long time and we still have to fight."

What Mencap wants to see

Mencap's findings show that cuts to day services for people with a learning disability have been extensive. As a result, many people with a learning disability are finding themselves stuck at home with nothing to do, isolated and scared about the future. Although everyone is feeling the effects of central and local government spending cuts at the moment, there are few, if any, groups in society who are being as adversely affected as people with a learning disability. Mencap does not think it is fair that the most vulnerable in our society bear the brunt of cuts and lose the social care services they need to live happy, safe and independent lives.

In recent years, government policy has encouraged local authorities to modernise day services, to make them more 'person-centred'. Mencap welcomes this, as there are still too many day services that are outdated and fail to provide meaningful activities. However, Mencap believes that often modernisation of day services has been driven by a desire to save money and, as such, has failed to improve day services as was originally intended. Changes to day services are often justified as giving people more choice and the opportunity to access services in the community, but these can be empty words used to disguise a cut. Day services should only be changed with the full involvement of the people who use them, and if this will genuinely increase choice and improve quality for service users. If not, local authorities are undermining the principles set out in the Government's *Valuing People Now* strategy⁴, principles that are often cited as a driving force behind modernisation.

Mencap wants local authorities and the Government to acknowledge that cuts to day services are letting down people with a learning disability, and undermining Government strategies around inclusion, control and choice. Often the politicians' response to concerns about cuts is a political blame game: local authorities blame the Government for cutting their funding and the Government blames local authorities for cutting frontline services. Mencap urges all politicians – at both local and national levels – to put the needs of people with a learning disability first, and to stop cuts to services now.

The Government must take strong action in its forthcoming Social Care White Paper and the draft Bill that will follow, and ensure greater funding is available for these vital services. Local authorities must find other ways to make savings that do not involve taking much-needed services away from society's most vulnerable people.

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http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093377