

‘10 lives in Brent’: A report on the impact of cuts in social care and public health to vulnerable groups in Brent.

4th February 2015

This report, commissioned through Healthwatch Brent as local ‘consumer champion’ for health and social care, is a review of evidence of the impact of cuts in Brent. It presents the national picture, the local view, and tells the stories of 10 Brent people, and how their lives have been affected by the cuts in social care and public health in the last 3 years.

At a national level there is a lack of evidence to demonstrate better outcomes for people on reduced budgets: In all of the literature reviewed, it has not been possible to find evidence to show that people have better outcomes with less money and less services. Every person in the UK has had to adapt to difficult times in a struggling economy. Despite some scarce instances of resilience, there is no evidence to show that this has led to any improvement in people’s lives.

This report starts with the **national picture**, (pages 2 – 9), understanding the legislation that has prompted services to change, and the view from national charities and organisations on how this has affected different groups and communities.

The **local picture** in Brent is then outlined (pages 9 – 13), with a summary of the proposed cuts. This is followed by views from Brent organisations and voluntary groups on the impact of the cuts on vulnerable groups within the borough.

The final part (pages 14 – end), tells the story of **10 Brent lives**, affected by the cuts. We hear people’s stories at first hand.

This report urges the council to consider the impact of the proposed budget cuts on these vulnerable groups, the cost of caring, carried by numerous Brent citizens, and the impact on those less able to find a voice.

Our 10 stories from Brent people tell of:

Carers at breaking point

'Feeling abandoned by social services'

Fear for the future

Fear of loneliness and isolation

Carers facing 'mounting debt'

Carers unable to continue their caring role

Council needing to provide (more costly) direct care as family situations break down

Distress, upset and upheaval for the cared –for

Severing of social ties

Threat of having to move, being 'priced out of the borough'

Impact on other services

Lowering of living standards and wellbeing

Reduction in hours of care provided affecting independence

'Tightened belts', less money and less time for other family members.

National Picture:

The legislation:

The Health and Social Care Act, (2012)ⁱ discussed new arrangements for more integrated health and social care services that were designed to make a simpler pathway through the maze of services and entitlements. There is encouragement for services to work more closely together with the introduction of Health and Wellbeing Boards, with Healthwatch as 'the patients' voice', and the co-writing of Joint Strategic Needs Assessments (JSNA) and Joint Health and Wellbeing Strategies. A number of pilot sites are introducing Whole System Integrated Care models. This system will be rolled out across the country in 2015. Under these arrangements, Public Health also transferred to the local authorities. The Better Care Fund was announced in June 2013, promising a pooled budget of £3.8bn, re-allocated from existing budgets, to support health and social care services to work together.

Significant and far-reaching changes to benefits and entitlements have seen the introduction of Universal Credit (2013)ⁱⁱ, Personal Independence Payment (PIP), will be replacing Disability Living Allowance (DLA), and Employment Support Allowance (ESA), replacing Incapacity Benefit. Council Tax benefit has been replaced by localised support, and the Social Fund is now a local assistance scheme.

The Care Act, (2014)ⁱⁱⁱ changes the role of local authorities to promote people's 'wellbeing', making sure that people:

- receive services that prevent, reduce and delay their care needs from becoming more serious
- can get the information they need to make good decisions about care and support
- have a good range of providers to choose from.

This duty to promote people's wellbeing applies not just to the direct users of services, but also to carers and is the driving force behind the new legislation.

Charging

The Care Act puts in place a system where people are charged for their care, where it is felt they are able to pay. From April 2016, the Care Act will introduce a cap (top limit) of £72,000 on care costs and will protect some of the savings of those with 'moderate wealth'. The cap means that people will be responsible to pay for their care costs up to the cap limit, if an assessment from the local authority shows that they can pay. This follows proposals made by the Dilnot Commission^{iv} to raise the top limit of people's 'assets' (e.g. if they own their own home) to £118,000 in April 2016. This will reduce the risk of people having to use most of their assets to pay for care. This cap will increase over time.

The financial situation:

Directors of Adult Social Services (ADASS) reported that Social Care services were 'unsustainable' in July 2014^v due to cuts of 26%. Cash being put into services has been reduced by 1.9% in 2014/5 equating to £266m. Spending on social care was down by 12%, whilst the number of people looking for support was up by 14%. Departments have been asked to make savings of 26%, which is equivalent to £3.53bn over the last 4 years. Social care services are also experiencing a substantial additional financial burden from introducing the Care Act. It is reported that 1 in 3 people rely on, or have a close relative who relies on, the care system.

"Gazing into the next 2 years, (2013/15), without additional investment, an already bleak outlook looks even bleaker."

ADASS President

News for 2015 suggests a 43% reduction in government grant. This will mean direct withdrawal of services (£104m) and reductions in the level of personal budgets. In the report, 19% of directors of Adult Social Care feel that the quality of life for those who use services will worsen.

“...even where councils have tried to protect the most vulnerable from cuts, the cumulative effect of all cuts will still fall hardest on the poor, who cannot buy replacement services.” Audit Commission Report

The Audit Commission Report confirms councils serving the most deprived areas have seen the largest reductions in funding relative to spend. This is mostly due to grants being stopped that were specifically to help tackle deprivation. The difference in spend between ‘deprived’ and ‘affluent’ areas is about £100 per head in England and Scotland. The difference between those living in the north and

south of the country is £69 per head.

Simon Duffy, writing for The Centre for Welfare Reform (CWR) in a paper ‘A Fair Society?’^{vi} talks of an overall cut in public expenditure by the government of £63.4bn by 2015. It measures that 50% of cuts will fall on benefits and local government. The extreme unfairness of the cuts is even clearer if the effect is compared between different groups.

People in poverty will lose an average of **£2,195** per person, per year - this is **5 times** more than the burden placed on most other citizens.

Disabled people will lose an average of **£4,410** per person - this is **9 times** more than the burden placed on most other citizens.

The combination of cuts in benefits and services means that people with severe disabilities will lose an average of **£8,832** per person - this is **19 times** more than the burden placed on most other citizens.

“In other words, the cuts are not fair but targeted, and they target people in poverty, disabled people and their families.

The government seems to have made no effort to understand the cumulative impact of its cuts on minority groups, especially those with the greatest needs.” Simon Duffy: A Fair Society?

The report estimates that the combined impact of the cuts will have the following effect on different groups:

- people in poverty (21% of the population), will bear 39% of all cuts
- Disabled people (8% of the population) will bear 29% of the cuts
- People with severe disabilities (2% of the population) will bear 15% of the cuts.

60% of all spending over which local authorities have control, is spent on social care for children and adults. Social care will have been cut by £8 bn in 2015. The CWR report also states that cutting back on social care will create ‘more crises’, ‘more institutional, abusive and inefficient services’ and will increase the pressure on the

NHS and other public services. It will lead to more family breakdowns and reduce the ability of citizens and families to participate in their communities and in the economy.

A recent article in The Observer^{vii} from representatives from the Local Government Association, (LGA), Royal College of Nursing (RCN), British Medical Association (BMA) and Care Support Alliance (CSA) clearly states that health and social care are 'chronically underfunded.' There is a strong view that putting extra money into the NHS without easing the pressure on council budgets is not the solution. As services and support are further stretched in social care, there is the inevitable risk that people deteriorate and end up needing NHS, and perhaps even emergency care. Once in hospital, it is likely that people will not be able to return home with ease, because the support available will only be patchy and underfunded. The report's authors state: 'the system is in crisis now; we cannot wait any longer for it to be fixed.'

Impact on vulnerable groups in society:

"...the English public has given a vote of 'no confidence' in the care system." YouGov poll 2014

A lack of confidence in care: A YouGov poll commissioned by the Care and Support Alliance (CSA)^{viii}, which is supported by 75 leading charities, in September 2014 found that 60% of people were not confident they will receive the care they might need. This figure increases to 70% for those over 60. An increase in government expenditure was their top priority along with health services.

Councils struggle to maintain services: The Learning Disability Coalition (LDC), formed in 2007, represents 15 Learning Disability organisations. It published a survey in 2012 looking at cuts in care^{ix}. One of the main findings was that despite the best intentions of councils to manage the situation by making savings, the consistent message is that of a struggle to maintain services. This challenges the way that people with learning disabilities want to lead their lives. 46% of local councils responded to the survey. Of those, 77% were facing difficulties in funding services, 13% had tightened their eligibility criteria, making it more difficult to qualify for help and 50% had increased the charge that they make for services. Of the 312 people with learning disabilities and their carers who took part in the survey, 17% had seen a reduction in their support hours, 13% had less money to spend on support, 18% had seen an increase in charges for services and 2% had lost the support that they used to receive.

..."spiralling costs of caring, coupled with devastating cuts to support are leaving families caring for loved ones in serious hardship."

Risk of breakdown of health and ability to cope: Specific issues exist for other vulnerable groups, highlighted through the mental health charity MIND, in a paper designed as response to the Care Act^x. Chief Executive, Paul Farmer states: "social

.. a low level of inexpensive support can enable someone to stay on their feet and manage their mental health- take it away and people descend into illness."

Paul Farmer, C.E. MIND

care is not just for older people or those with physical disability, it can play a vital role in keeping people with mental health problems well and able to cope."

The paper suggests that a lack of funding and change in eligibility criteria will deny access to much needed care and support. There is a concern that removing this care can lead to deterioration in the person's condition and necessitate the need for higher level intervention. Other organisations talk of the 'revolving door' situation, where people are

passed from one service to another, at a cost to the tax payer, and not necessarily of benefit to themselves.

Less people are qualifying for help and support: Similar issues exist for people with visual impairment, outlined by an RNIB paper: "When the system doesn't care"^{xi}. In this, the message is that blind and partially sighted people are increasingly being failed by assessment processes and are no longer qualifying for care or support services. This situation is thought to get worse until no blind or partially sighted person will qualify for help, within ten years. Adult social care data for England (March 2014)^{xii} show the numbers of people receiving social care decrease for all groups, but in proportion, most of all for people with visual impairment. The number of people receiving care has almost halved since 2005/6.

Cost of communication needs not being met: An Action on Hearing Loss, (formerly RNID) survey in 2012^{xiii} found that 50% of local authorities did not have a sensory loss strategy and 10% of services do not gather feedback from this group. 20% reported cuts to services for people with hearing loss in June 2012. Information about the support offered to those who do not 'qualify' for services, found people being offered information and advice or signposted on to other services, but most people being unlikely to have the costs of their communication needs met.

Inclusion London, an organisation promoting equality for London's deaf and disabled people, talks of disabled people's experience under welfare reform between 2010 and 2014.^{xiv} This states that disabled people will lose £28.3bn of support by 2018.

Disabled people experience huge problems with PIP assessments and payments: People with disabilities have found themselves in extreme financial hardship as a result of the delays in PIP assessment. They have become isolated and unable to access the support they need, like transport to hospital appointments, or help around the home. "Not having an answer on PIP makes it much harder to claim other important benefits like carers' allowance, the blue badge and working tax credit," the Guardian newspaper reports on 28.1.15^{xv}

Families experience 'unmanageable debt': Carers UK, a national charity, talk of families moving towards a situation of 'unmanageable debt', unable to cope due to a

loss of income, savings and benefits and an increase of fuel, food and care related costs. The organisation reports that this is 'pushing families to the brink'^{xvi} Carers UK calls for an end to cuts to carers' benefits and support, urgent reform of financial help for carers and for the government to commit to future policy that will not leave carers worse off.

Widespread underfunding of care for disabled adults: 'The Other Care Crisis'^{xvii}, 2013, a report funded by SCOPE, Mencap, National Autistic Society (NAS), SENSE and the Leonard Cheshire Foundation estimates social care for disabled adults is underfunded by at least £1.2bn and that 105,000 working age disabled people could lose out on social care and support as a result of local authority funding cuts.

Low income families to pay more council tax: Joseph Rowntree Foundation (JRF) writes widely on the impact of these changes to the most vulnerable in our society, particularly those on low incomes. In an article about council tax benefits changes^{xviii}, it was estimated that 2.34m low-income families will pay on average £149 more council tax per year. 70,000 will have their support cut for the first time, 580,000 will see a second cut and levels of arrears (unpaid taxes) will rise.

Care provided does not meet needs: Age UK, a charity championing the needs of older people produced a document in November 2014^{xix} showing that 160,000 people received 'inadequate care'. While 2.3m older people received some form of care at home, 6.9% felt that it 'sometimes or hardly ever, met their needs.' In the 2011 census, 458,010 people were providing more than 50 hours a week care. 80,000 people received local authority support, meaning that 380,000 people went without that support.

... "policy makers owe it to the public, older people especially, to confront the crisis in social care, and its consequences."

'Chronic underfunding' means preventative services are disappearing: On 20th January 2015, Age UK produced a social care 'scorecard'^{xx} that outlined 'calamitous' cuts to older people's care. In this they looked at social care spending and the numbers of people receiving care, using 22 different sets of data.

They found the following:

- Between 2010 and 2014 a reduction of funding of £1.1bn
- The number of older people receiving home care down by 32% since 2010
- The number of day care places down by 67%.

In response to the report, the Local Government Agency's community wellbeing board described the system as 'chronically underfunded.' This lack of funding is in the context of growing demand, escalating costs and a 40% cut to local government budgets. The report concludes that despite councils' best efforts, they are having to make tough decisions. There are concerns that the more preventative services like

meals on wheels and day care are especially hard hit, storing up bigger problems for the future and further demand on crisis, emergency services and acute hospital care.

Joseph Rowntree Foundation comments on the autumn statement 2014^{xxi} saying that despite 'near record-high expenditure, there are now fewer escape routes for the majority of people in poverty.'

Households are £489 per year worse off, on average: The Institute of Fiscal Studies (IFS) produced a document looking at the effect of tax and benefit changes on household incomes and work incentives in January 2015.^{xxii} This study found the average loss to households of £489 per year. This is calculated from an average gain of £321 from cuts to direct taxes, minus a loss of £333 a year from increasing indirect taxes and a loss of £477 from benefit cuts. Some households have lost out more than others. Low income working age households are reported to have lost out the most, mainly as a result of benefit cuts. A press release on 23.1.15^{xxiii}, reported that combined with benefit changes, the incomes of poorer working age households decreased as did the incomes of most families with children. Middle to higher income working age households have escaped remarkably 'unscathed' from these changes, whereas those in this group without children have actually gained. This is clear evidence to show the impact of the cuts falling hardest on low income families.

Change from DLA to PIP represents a 28% cut in benefits: From the outset, this reform has had a 'savings first, support second' approach with an upfront commitment to reduce spend on disability benefits by 20 per cent, says a report from the Citizens Advice Bureau (CAB)^{xxiv}. The Government has now estimated that over 600,000 fewer people will qualify for PIP by May 2018 than would have qualified for DLA. This is a cut of 28 per cent – and as a result will strip away the very support that enables many disabled people to be independent and in work. This, and the lack of support for carers, is likely to lead to increased pressure on already over-stretched social care budgets and the NHS.

A climate of fear, and fear for the future, but some resilience too: The Young Foundation report in July 2012, looking at the impact of cuts in the lives of vulnerable people in Camden^{xxv}. In this study, the researchers talked to 88 people to understand how their lives had been affected by national cuts and changes to local services. The study found that young people felt helpless, angry and victimised by the cuts. Families were under pressure and people with disabilities and their families had fears of isolation and loneliness. Everyone was fearful of further cuts. In the midst of this grim picture there was resilience however. It seemed that neighbourhoods and communities had set up support networks and clubs, faith communities had provided support and people were adapting and adjusting, finding their own coping strategies.

Short term money to help social care manage delayed discharges: The government has provided £25m in emergency aid to 65 councils (20.1.15) to help

them tackle delayed discharges and reduce pressures on hospitals over the winter. The money will go to 65 councils in areas most afflicted by delayed discharges, will be distributed straight away and must be spent by the end of March. There are concerns that this is seen to 'reward' those areas where people have been delayed in returning home from hospital (delayed discharges).

A lack of evidence to demonstrate better outcomes for people on reduced budgets: In all of the literature reviewed, it has not been possible to find evidence to show that people have better outcomes with less money and less services. Apart from a very few stories of resilience in communities, there is no evidence to show that this austerity has led to any improvement in people's lives.

Locally, in Brent:

Poverty: The London Poverty Profile^{xxvi}, 2013 shows Brent scoring a change to 'worse' (i.e. up to 4th worst affected boroughs in London), in relation to other London Boroughs in the following areas:

- Low pay
- Overcrowding
- People in temporary accommodation
- Local Housing Allowance claims

The profile also shows that Brent scores 'slightly worse' (from 4th- 12th worst affected boroughs in London) in:

- Child poverty
- Unemployment
- Benefit polarization- where there is a big difference between those living in the most and least deprived areas of Brent
- Inequalities in life expectancy
- Repossession
- Limiting life long illness
- Schools at above average capacity
- GCSE achievement
- Out of work benefits
- Council tax support cut

This gives an overall picture of a borough where many people face an unequal struggle on a daily basis in many aspects of their and their families' lives.

Local impact of cuts: The report, 'Hard Times, New Directions?'^{xxvii} looks specifically at the impact of local government spending cuts in three deprived neighbourhoods of London, including Brent. This is as part of a larger study entitled;

'Social policy in a cold climate.' The report looks at a neighbourhood level at people's experience of 'hard times', the effect of the spending cuts since 2010. The report concentrates on the following groups: older people, young people aged 16-24 and those with children under 5.

The report found that front line changes, i.e. staffing and direct help and support was most evident in older people's services. In each ward studied, a day centre was lost, there was an increase in lunch club charges, fewer activities or an increase in activity charges and changes to discretionary (paid or part paid), transport. Residents were left with a reduced level of community-based provision and needed to pay for services that they used more often. This had led to greater boredom for older people, and an increase in people's isolation, with social ties being severed through services closing.

Services were expected to use volunteers to cope with staff reduction. Where this can work well, there can also be issues of reliability. The majority of front line staff said that their work had increased substantially, but they felt that in most cases, quality had not been compromised. It was felt that because staff teams were dedicated, the extra work was absorbed. This is probably sustainable in the short term as people apply extra effort to maintain standards but there is a question of whether this can continue to be sustained, particularly in the face of future cuts.

All councils report greater targeting of services towards those most disadvantaged, or those at risk. The report found no evidence of this in Older People's services.

The report found evidence that councils have obviously not found it easy to make cuts and in some cases had then re-instated services, but it is clear that future cuts are on the horizon.

The report also looked at voluntary and charitable organisations in the three areas and found here too, an increase in financial pressure in recent years. They reported having to do more for less or the same money, in the context of rising costs. Those that received council funding had seen a reduction, or no increase in this funding. The report paints a picture of these services 'under strain'. There is no indication that these services would be able to take on an increased load as a response to local council cuts in provision, without further funding.

Carers in Brent: In Brent, there are 1,312 carers providing unpaid care of 50 or more hours a week. 26,600 provide care of an hour or more a week. A high proportion of adult carers in Brent face social isolation. 39% of adult social care users in Brent experience social isolation.

Carers in Brent report difficulties with taking up Direct Payments, as being 'too complicated'; they are reluctant to become 'employers' and deal with even more paperwork in already busy lives. They report difficulties in finding suitable carers with the necessary skills to support them with complex issues of caring. There is also a

concern that they are being asked to fund care at a rate lower than that paid to council workers for the same care. It has proved difficult for carers struggling with finance and tax issues to receive targeted help from social services; they experience being passed around from one department to another. All of this takes precious time away from their caring.

Individuals ‘weighed down’ by the system: Some people do not challenge because they do not have the means or the process to do this. Some carers are so worn down by the energy needed to keep their loved one at home, safe and in optimum health, that they may not be fully informed about their own entitlements.

Voluntary organisations advocating for individual’s rights in the face of cuts: Voluntary organisations have supported a number of people and their families to understand their rights in terms of social care assessments and the local authority’s duty to meet unmet needs.

In all these cases the individual has ended up with an adequate and appropriate level of support. However, this has only been the case because the voluntary organisation knows what people’s rights are and has insisted on these rights being met. There have been many barriers and it has often been a long and difficult process to ensure that these processes have been conducted properly. There is concern for those people who cannot access advocacy or support to navigate these processes and overcome the barriers that they will not receive the level of support that they need. This will inevitably reduce the council’s costs but not provide for those most at need.

Brent, the finances:

In 2011/13, savings of £2.412m were made. Of these, £1.09m were cut from residential and nursing care placements due to a reported reduction in demand and 4.38% from the budget from domiciliary care, again due to reported less demand and the introduction of the Re-ablement service. There was an increase of 4.48% in all client groups’ expenditure. The key area for improvement noted by the council was for carers. There were low levels of satisfaction with the support received, with carers wanting more and better information and advice and more involvement in planning the care for their family member. The Quality of Life survey for Adult Social Care service users scores carers in Brent as 17.5, with the national average for England at 18.8.

The Borough Plan consultation (2012-2016) shows a reduction in budget of over £80m. It is expected that the council budget will be almost halved by 2018.

The Brent Cabinet Budget Report, 15.12.14^{xxviii} provides an update on the financial position for the next two financial years and sets out the draft savings proposals.

The report states that ‘savings of at least £53.9m will need to be agreed, most of which will fall in 2015/16.’ In the medium-term, to 2018/19, it is anticipated that total

savings of £100m will be required. This will force the council to reduce its net revenue budget by between one third and a half of the current level. This is on top of savings of £89m that have already been delivered since 2010.

The council has looked hard at how these savings can be made in the fairest way and with the least impact on direct care and support, but the position is very difficult indeed.

The cuts have been proposed using a 'hierarchy' (showing what's most important to protect) to try and protect services that directly support people.

£34.9m is proposed to be saved by more efficient services- running things differently. £14.3m by building independent and community resilience, which means transferring some services to other groups, like the voluntary sector, and asking people to make 'modest changes' to their lives.

£3.4m in 'leveraging in resources and income'. This will mean increasing charges for some services.

£9.1m in stopping services completely.

These cuts are described in Table 1. Page 13.

Table 1. Cuts proposed in Adult Social Care (see full document for detail)

2015/2016 (£000s)	2016/17 (£000s)	Future years (£000s)	Description
-410	-420		Ensuring 'value for money' in residential and nursing care
-80			Reduce funding to Brent Community Transport
-120			Reduce community and user engagement
-187			Reduce voluntary grants
-50			New model for West London Alliance Adult Social Care programme with reduced budget
-582	-323		Close New Millennium Day centre and Kingsbury Resource Day Centre (subject to consultation) and re-provide in independent sector
-120	-187		Doubling the number of Direct payments
-610			10% saving on home care by working together with health
-2,297			managing increased demand with the same money
-776			Not providing inflation for providers of services
-1,155			Reducing provision for bad debt
-500	-250		Redesign the way mental health social care is provided
-450	-450		Reducing front line social work staff by 20% over 2 years
-500			New model for commissioning services
-125			Stopping learning and development for non-essential training
-370	-4,110	2,800	Reducing focus on residential and nursing care towards extra care/ supported living
-400			Supporting people to access continuing health care funding

The following are direct service cuts.

2015/16	2016/17	Description
-450		Reduce cost of respite care
-520	-520	Reduce day care by up to 40%
-600	-620	Reduce home care. Re-introduce 15 minute home care calls 'where appropriate'
-60		Review future of appointeeship service

10 lives in Brent- the case studies:

We now look at the implications of the past 3 years of cuts in social care and public health and how they affect 10 people from vulnerable groups, living in Brent. These are their stories:

*Dominik is a 30 year old man from the EU, living in Brent, with **mental health** problems including depression, social anxiety and several admissions to hospital for suicide attempts. He has had a troubled past, being bullied at school and work. His **housing situation** has been **unstable**, with a period living in hostels, and emergency accommodation. He is currently housed with a private landlord, but is having **trouble claiming housing benefit**, has been **evicted** once and receives weekly contact from a floating support worker. He had some **difficulty in accessing benefits** and needed the help of the support worker to prove his eligibility for ESA. This is contribution- based and will run out. He is not currently in work, but has worked in the past two years in a short term capacity. A previous job finished due to his mental health issues. He has had a few admissions to hospital for mental health treatment. He currently uses drop- in and other services from a local mental health charity, but does not appear to have contact with statutory services*

This is a clear case where **reduction/problems with benefits**, affecting housing, can **impact** on other areas of a person's life, such as **mental health**. An intermittent and low level of social care support can help an individual to manage and 'keep afloat' and maintain reasonable mental health. Voluntary sector organisations can also help bridge that gap and provide **meaningful support**.

*Mr. A is an 85 year old Brent man with dementia who is cared for by his 80 year old wife and son. He is non-verbal, has some violent behaviour due to his dementia, but has charm and a sense of humour, and a real presence in a room. He attends **day centres** five times a week which is seen as valuable time by his wife and son as they have precious little time to themselves. They use this time for **rest and respite** for themselves. Mr. A attends a voluntary sector day centre 3 days a week and a council run day centre two days a week. The family are extremely worried that if the council run day centre closes, or the hours are reduced, Mr. A will not be referred to another day centre and will have a further two days at home.*

*Mrs. A's health has been deteriorating over the past two years and she now has to go out in a wheelchair. At 80 years of age, she is exhausted with looking after her husband who was diagnosed with dementia 14 years ago. She has said that she really does not know how she will cope if her husband loses two days of day care. She is also aware that one of the **Council's budget proposals** is to **cut day care by 40%** over 2 years, and this has made her **very fearful for the future** of her husband and the health of herself and her family.*

She would like to ensure her husband stays at home in familiar and loving surroundings, and is scared by the thought that the family may reach a time when they are unable to look after him anymore and he would have to go into nursing or residential care. She has said that this would destroy her. Mr. A's son has expressed that he finds the situation increasingly stressful as he

This is a story of a family **stretched to the limit** by their caring responsibilities. Their efforts to keep their family member within a loving family home are costing them dearly in terms of their own **health and wellbeing**. Any reduction to the current level of respite offered through day care is likely to seriously endanger their ability to continue to manage at home. They live in **constant fear** for the future.

*Sidney is a man in his mid sixties, living in a private rented –sector accommodation in the borough. The flat is both cold and damp and he has no bed and no phone. Due to **benefit changes**, he has **insufficient money to live on**, having just £57 a week after various charges are taken from his benefits. He is being pursued for **energy debts**. His current living standards are well below an acceptable level and his future looks grim. Social services have stated that they will be doing **telephone assessments**. While this may be a more cost effective approach for the council, Sidney has no telephone and will be **unable to have an assessment in this way**. It is unclear*

The impact of changes in **service delivery**, probably cost -saving for the council, can affect how people access the service they need or may prevent them from doing so.

*A carer was concerned as she had started to receive a **charge** for her son's day care place - for which he had not been previously charged. There had been **no change** to her son's income or circumstance. She is a **pensioner**, living in Brent, and has **multiple health problems** herself. She is a **full time carer** for her adult son who has a severe learning disability and gets Income Support and the highest rate of Disability Living Allowance. They live together and her son's time at the Day Centre gave her valuable time to herself to have some rest and to get out of the house. The carer and her son found it difficult to find the extra money to pay for the day care – but felt that they **could not cope** without it, so eventually gave in and **accepted the cost**. They could not however pay any more for the service if charges were to increase and this is a **constant worry** for the carer. It is no doubt that any reduction in day care services in the future would have a huge impact on not only the carer, but the son who has some hyper-active behaviours and would get very frustrated if he were not at the day centre. The day centre provides invaluable activities and social interaction. Any **cuts** in service would mean that the carer would be unable to have time to herself to de-stress and look after herself – potentially leading to isolation*

Here we see a mother, a **pensioner** with her own health issues, providing care for her son, with all the challenges that he can present. Her finely balanced and already **stretched budget** is seriously affected when the day centre begins to **charge** for care. The son's needs have not reduced in any way, but the mother feels that she has no option but to accept the charges as she cannot manage without the respite offered by the day centre. Any further cuts or increase in charging would leave her in an **intolerable** situation, with potential **debt**, and deteriorating health.

*A Brent resident in her 30's, who has three disabled children, had her **care hours reduced** having a devastating impact on her and the children. Her eldest child has renal failure and kidney disease, her two younger children both have neurological and physical disabilities and all three children have **high care needs**. The younger children had their hours of **care cut** and this in turn meant that the mother had less time for the eldest child and his **health** began to **deteriorate**. The carer was under **enormous stress** and she was **very anxious** about how the family would **cope** with the **reduced hours** offered. This family are **very vulnerable** and **totally reliant on services** provided. The impact of future cuts would be **catastrophic** for the **whole family's health and wellbeing**. The family are also in accommodation that is **unsuitable** for their needs and this is also having an impact on the family's health. They are totally reliant on means-tested benefits and the children receive DLA.*

Cuts to services and support have put **unbearable strain** on this Brent family. The impact of less care provided has meant **deterioration** in the health of one already seriously ill child, and **increased pressure** on the whole family.

*The G family has been badly affected by the '**bedroom tax**' and the **additional council tax** which has pushed residents in social housing over the edge from a finely managed budget into not being able to cope. This has put the family under **additional stress**. Continued stress, self disconnection at the gas and electricity meters (in order to save money) all contributes to long term lowering of **living standards** and **wellbeing**. For this family, the future is a stark contrast of options - either to **move** to a smaller property, often outside the borough and further away from their social, family and friends **support network**.*

*Mrs P. is a full time carer for her 20+ year old daughter who has learning disabilities. Her daughter needs care with every aspect of her life and cannot be left alone. She was accessing a Brent day centre 5 days a week. This has worked well for Mrs P, giving her some time for her own life and a break from the **24 hour care** that she provides at home. Her daughter was re-assessed and the **day centre attendance cut** by 2 days, with 6 hours to be provided through Direct Payments. Mrs P. was also told that she would need to **pay for transport** costs to the day centre, using her Disabled Living Allowance. Unfortunately the money for this was over £50 a week short and **debts** have been mounting up as she is unable to find the extra money needed. Mrs P. describes a feeling of **helplessness**, running around to different services trying to get help and **increased stress and tiredness**, in the midst of an already stressful caring situation. She is extremely concerned to be in a position of **mounting debt**. She has been able, with the support of a voluntary organisation, to appoint a lawyer to challenge this situation and this has prompted a review of her daughter's case. The outcome of this is not yet known.*

In this story, a service is **reduced** and **charges** are made for an existing transport service. The amount received in benefit specifically for this purpose is £50 a week less than the charge made. This vulnerable family now has **mounting debts**, on top of the **stress** of **caring** responsibilities, less **respite** and an as yet, unknown outcome about whether the council will continue to provide a service for the daughter's **assessed need**.

*Lizzie, a woman with Asperger's syndrome living independently in the borough, received '**floating support**' on a weekly basis. This support fills the gaps in an individual's skills to manage living on their own, for example, reading and responding to bills and mail, shopping and cooking, GP appointments, benefits. Following a change in service provider, Lizzie now only received 1 ½ hours of support a week- a **reduction in care** from the 6 hours a week she had received previously. This is despite assurances having been given that care would not be reduced, when service providers changed. Family members expressed concern about a gradual **deterioration** in her **health** and **appearance** and were concerned that she was not receiving the regular support that was needed for her to maintain an independent lifestyle. Following a visit to **A&E**, the family remained extremely concerned about Lizzie's health and wellbeing. The position deteriorated still further when a fault within the house meant that Lizzie had been living in a room that was seriously **water damaged**, sleeping in wet bedding and wearing wet clothes. There was also **no lighting** on the stairs due to the water damage. At this point she **moved** from the accommodation to stay*

Fundamental to the values of care and support are **enabling** people to do things as **independently** as possible. This is an example of a woman, able to live within her community, travel independently and function as a member of society, with a **low level of flexible support**. Cuts to the level of this service, led to a **gradual deterioration** in her health and wellbeing, necessitating hospital attendance, and also having to be moved from unsafe accommodation by her family.

*A young woman in her 20's who uses a wheelchair and is hearing impaired. Her first language is **British Sign Language (BSL)** and she lives in the borough with her father who **does not sign** and has paid carers to support her again who are **not able to sign** except for a few key words such as "toilet", "go out" etc. The care package that she receives does not supply carers who can communicate in her first language, BSL. Her carer asked the group facilitator at the deaf support group to support her to explain about boundaries as the lady being supported did not understand that carers are not her friends. The group facilitator was able to explain this issue to using signing to help explain the difference between being a paid carer and a friend. Support given in the care package is currently **not meeting her communication needs** and in her home situation, where she is **potentially isolated** through lack of a shared language deaf support*

Mr and Mrs H, both Brent pensioners, had approached a voluntary organisation for help and support with finding suitable and affordable housing.

*They had been affected by the **benefit cap, low income and high rent** increase. The couple had sought all other possibilities to find a lower level of affordable rent, but were unable to find any. They were advised to sign up for **sheltered housing** as a cheaper and affordable way of making ends meet each month.*

*Assistance was also given with the **food bank** on a twice monthly basis but the couple felt that their life had spiralled deeply out of control. Both people were affected by **ill health**, and having an advanced stage of cognitive impairment.*

Mr and Mrs H are now happily settled in sheltered accommodation with

This last example is the only one that at present, happily, has a positive ending. The initial effects of the benefit cap on this couple caused extreme stress and deterioration of their health and skills, and a feeling of loss of control of their lives. A new accommodation situation has been successful for them, at present, but as receivers of benefits, any future cuts may also have an impact.

Our 10 stories tell of:

Carers at breaking point: carers with deteriorating health, full time carers in their 80's, carers facing cuts in respite.

'Feeling abandoned by social services'.

Fear for the future: both service users, and carers are living in fear of future cuts and what this might mean for them and their families. Where carers have had to absorb increases in charges, there is real fear that this is not sustainable.

Fear of loneliness and isolation: as day centres are closed or attendance reduced or cut, carers are losing their access to the outside world. Where caring commitments mean staying at home with a family member, day centres provide an opportunity to leave the house, to socialise and maintain social networks, and to carry out vital household tasks such as shopping. Any cut in respite will reduce this access and lead to loneliness and social isolation.

Carers facing 'mounting debt': as benefits reduce and there is no other family income, or the ability to get an income due to caring commitments.

Carers unable to continue their caring role.

Council needing to provide (more costly) direct care as family situations break down.

Distress, upset and upheaval for the cared –for: as family caring situations break down, the individual faces a possible move out of the family home, and even in some cases out of their familiar community.

Severing of social ties: for carers, whose reduced respite means being restricted to a life at home, and individuals who are isolated as services change, reduce or close.

Threat of having to move, being 'priced out of the borough' : change in benefits situations mean some families may be unable to stay in their communities, having to uproot and move out of area to cheaper, more affordable accommodation.

Impact on other services e.g. accident and emergency services, acute hospital admission, long term hospital admission, probation services, long term housing and residential care.

Lowering of living standards and wellbeing: in already fragile, vulnerable households, leading to a higher risk of situation breakdown, deterioration of health and mental health.

Reduction in hours of care provided affecting independence: making the difference between being able to maintain someone as independently as possible in their local community, to more expensive options of full time or registered care.

‘Tightened belts’, less money and less time for other family members.

The 10 lives glimpsed, present a picture of what is some people’s everyday reality in Brent. Each story has its own circumstances and difficulties, but there are clear themes running through them. These are mostly the result of cuts that have already happened, but there is evidence to suggest that this situation can only get worse, if further cuts are made. Those who have found resilience so far, or who have escaped the worst of the cuts, are likely to be trapped by the cumulative effect of further cuts. National evidence shows that further cuts will create more crises, increase pressure on the NHS and other public services and lead to family breakdown. Continued chronic underfunding is challenging the way that people want to live their lives.

This report urges the council to consider the impact of the proposed budget cuts on these vulnerable groups, the cost of caring, carried by numerous Brent citizens, and the impact on those less able to find a voice.

Cathy Lenton

On behalf of Healthwatch Brent

For this report, the following organisations were approached for information and case studies: Age UK Brent, Ashford Place, Asian People’s Disability Alliance, (APDA), Brent Carers, Brent Irish Advisory Service (BIAS), Brent Mencap, Brent MIND, Elders’ Voice, Energy Solutions, Iraqi Welfare Association, Middlesex Association for the Blind, PLIAS, Royal Association for Deaf People, (RADP), The Asian Health Agency.

For the purposes of this report, all names have been changed to protect people’s identity. The case studies represent people from different communities, backgrounds, abilities and disabilities.

ⁱ Health and Social Care Act 2012

ⁱⁱ The Universal Credit Regulations 2013

ⁱⁱⁱ The Care Act 2014

^{iv} Fairer Care Funding : The Report of the Commission on Funding of Care and Support ;July 2011

^v Social Care services ‘unsustainable’ 2.7.14, ADASS

^{vi} A Fair Society? How the cuts target disabled people. Simon Duffy (2013), Centre for Welfare Reform.

^{vii} ‘Spending cuts have left the NHS and social care in crisis.’ 25.1.14 The Observer

^{viii} YouGov poll, Sept 2014

^{ix} Learning Disability Coalition Annual Survey 2012

^x MIND response to Care Act, 23.10.14

^{xi} ‘When the system doesn’t care’; Coyle, N: RNIB; 2015

^{xii} Adult Social Care data yearly March 2014

^{xiii} Life support: a survey of Hearing loss , May/June 2012; Action on Hearing Loss

^{xiv} ‘From cuts to resistance’, disabled people’s experiences under welfare reform 2010-2014; Inclusion London

^{xv} Delays and disarray shatter lives of new disability claimants; gentleman, A; The Guardian 28.1.15

^{xvi} Caring and family finances legacy: carers struggling with alarming levels of hardship, 4.2.14 Carers UK

^{xvii} ‘The Other Care Crisis’ 2013, SCOPE, Mencap, NAS, SENSE, Leonard Cheshire Foundation

^{xviii} How have low income families been affected by changes to the council tax system? Burke et al 2014: JRF

^{xix} 70,000 older people in significant need go without paid or unpaid care, finds study; Age UK ; M.Samuel, 27.11.14

^{xx} Charity’s social care scorecard outlines ‘calamitous’ cuts to older people’s care. Age UK; Community Care online. R. Schraer, 21.1.15

^{xxi} ‘Autumn statement: last chance to ensure recovery does not bypass worst-off people and places’ Unwin, JRF 2014

^{xxii} ‘The effect of the coalition’s tax and benefit changes on household incomes and work incentives.’; Browne, J; Elming, W 23.1.15 IFS

^{xxiii} ‘Low income households with children and the very rich have lost the most from the coalition’s tax and benefit changes.’ 23.1.15 Browne, J and Elming, W. IFS.

^{xxiv} ‘PIP: is it fit for purpose?’ 8.4.2013; Pearlman, V; CAB

^{xxv} An insight into the impact of the cuts on some of the most vulnerable in Camden, July 2012;

Mhairi Aylott, Will Norman, Catherine Russell and Vicki Sellick

^{xxvi} London Poverty Profile, Trust for London 2013

^{xxvii} ‘Hard Times, New Directions? The impact of local government spending cuts in three deprived neighbourhoods of London.’ Oct 2014; Fitzgerald, A; Lupton, R and Brady, A.M. Centre for the Analysis of Social Exclusion, LSE

^{xxviii} Brent Cabinet Budget report, 15.12.14 Brent Council