The effect of spending cuts on people with learning disabilities and their families: evidence gathered from the National Forum of People with Learning Disabilities and the National Valuing Families Forum

At the Learning Disability Board in February 2016, Sarah McClinton asked for evidence from people with learning disabilities and families on the effects of the Government’s spending cuts on people with learning disabilities and their families.

Both forums, the National Forum of People with Learning Disabilities and the National Valuing Families Forum have compiled this report collating evidence from people with learning disabilities, their families and allies throughout England. We asked the nine regions to tell us about

- Cuts in service, and
- Good practice/investment.

Evidence was received from 8 regions, with 24 local authorities directly referred to. Although these local authorities were directly referred to, we are not implying that they are any better or worse than others. Despite explicitly asking for evidence of good practice and investment, it is interesting that only one of the nine regions were able to provide evidence of good practice or investment in support and services for people with learning disabilities and families within their strategic approach to managing reduced budgets.

In order to protect individual families, we have kept this report as confidential. Some families are afraid of being identified, and others are involved in legal challenges which could be jeopardised if they were identified.

This report should be considered in the context of other reports with similar findings from a range of other stakeholders. These are briefly described at the end of the report.

How services are being cut – what people with learning disabilities and their families told us
Leeds
There was a consultation that ended in March on fairer charging. The council agreed to change their policy and so we have been informing people of their rights to a carer assessment and an assessment for people with a learning disability. We submitted an FOI to the council which found the amount of financial assessments is at least 5 times higher than the amount of other assessments. We are monitoring this.

Bradford
In Bradford they consulted on a huge change to fairer charging which proposed moving to 100% of disposable income after the minimum income guarantee and disability related expenditure. The consultation was done very poorly and no one including the major disability charities in the area knew about it. Complaints were made and the council agreed to re-run the consultation in an accessible format. We are working to challenge the council and assisting local groups (Keighley People First) and carers/parents on this, including seeking legal advice.

Bradford council has also cut their funding for hydrotherapy services leading them to close. People with learning disabilities in Bradford who access hydrotherapy services will no longer be able to do so.

Bradford council are also cutting their money for self-advocacy. Bradford and Keighley people first is looking at merging to try and keep some form of self advocacy available for people.

Rotherham
Rotherham council are cutting their money for self-advocacy. All services as generic advocacy is being commissioned under the Care Act. The advocacy services will be time limited crisis advocacy services. However, on a positive the council is looking at how they can co-produce a service for people with learning disabilities and or autism.

Cornwall
Cuts seem to be leading to disorganisation and a lack of communication from the council to self-advocacy and carer organisations.

In Cornwall support for self-advocacy has been cut by half with a complete cut planned for April 2017. This is because the council want to fund Care Act advocacy only. The increase in statutory obligations to provide independent advocacy and no increase in budgets seems to have led the council to cut funding for self-advocacy, prevention and well-being for people with learning disabilities.

People have been informing us that their assessments are leading to cuts in provisions. It seems as if the council are using assessments as a way of reducing services (costs) for people. We are being told about people who have always received a service who are now being assessed as not needing one. People who have never paid for a service are being asked now to pay for services. Nothing has changed for people in terms of increased independence from one assessment to the next but their assessments are leading to less provision and less personal budgets. We have not heard from anyone who has had an increase in their personal budget.
These cuts alongside cuts in self-advocacy mean that not only are people no longer receiving services, but they are no longer in a position to be heard about the impact the cuts are having for them.

In a very rural setting such as Cornwall this could mean people essentially disappearing completely until the point of serious negative incidents where people come into contact with the criminal justice system or have serious mental health problems. An outreach work at Cornwall People First has said:

“Cuts in funding have meant that people with Learning Disabilities and Autism have less opportunity to have their say and act as full citizens. In a recent event I attended, which was meant to engage with people with learning disabilities, only one self-advocate was supported to speak up, the rest were professionals speaking on people’s behalf. People are forced to going back to being passive recipients rather than active participants shaping our society”

Cornwall People First have also received information about the local health training service being cut.

**Plymouth and Devon**

Plymouth has got a complete cut in self-advocacy from Sep 2016, and Devon has had an 80% cut in self-advocacy.

What self advocacy is still being provided has experienced a drop off in attendance. We are being told by council run day provision that there is no longer the ‘staff’ to support people to come. Although we haven’t been told directly of funding cuts it seems implied.

We have also been informed by providers that they are increasingly squeezed and feel at some point their delivery will be effected. There has been no cut but hourly rates have been frozen or are not increasing in line with increasing costs. Many providers were paying minimum wage and with the recent increase in outgoings has not been matched by the council so that the ‘books are no longer balancing.’

Overall we see a very worrying picture that will start to have a very negative impact on people real lives in the near future if something is not done to prevent this.

The combination of cuts to people provision and effective silencing of their voices means that we will not know what is happening to people until it is too late.

**West Sussex**
'Building provision review', the council is claiming buildings are unfit for purpose but are at the same time reducing capacity to save costs. Campaign advice given and offer of workshop to get the campaign to prevent the closures organised.

The council are trying to enforce a blanket policy county-wide for people with a learning disability for whom the council manages their money. Currently they get an ATM card to withdraw funds, however the LA's financial safeguarding team are implementing a blanket policy forcing people or their carers to visit county hall to access their cash. This may be a misguided venture to save money, it is however obviously not appropriate for many people in the county who cannot travel well over an hour each time they need money. Campaign advice given and offer of direct contact and advice should they want it.

**Hampshire**

£19million of cuts are planned from the Learning Disability budget by 2017. Moves from residential care to supported living; sharing support with others. Increased use of telephone support. Reduced support with transport. People are worried about the effect of these cuts. A major concern is less access to transport; it is likely people will be stuck at home more. People living in rural areas are a major concern. We expect less face-to-face support too – telephone support is much less effective. The council appears to be planning to rely more on family and friends to provide informal support with travel and respite, but this support will vary greatly for people, and risks less access to communities and services.

**Kent**

Access to advocacy is still a good commitment from the local authority, but may be cut when recommissioned in April 2017 – we are monitoring this. Self-advocacy groups don’t get the funding support they need. One self-advocacy group had to close in 2015, but advocacy for parents with learning disabilities is protected. There are still good networks and access to support through the Partnership Board and regional groups, but there is reduced opportunity to develop self-advocacy skills and confidence.

Supported living budgets will be cut by approximately 20% later this year. We expect reduced quality of support for independent living. Kent’s commitment is a good model for other local authorities. Although supported living budgets will be cut, they were healthy compared to other authorities.

**Surrey**

Five advocacy services consolidated to one in the last few years, which subcontracted to other services to provide for different support needs. There are now several good, targeted services, but not enough capacity to meet demand. With so many people moving to supported living, it is hard for people to get to groups. Sometimes we have had to use day centres, although we did not want to. People do not know about the help they can get or cannot get in to a group to get the support they need. People have not got enough support to access what they are entitled to. Services are overrun.
Berkshire
The council has turned to technology to offset the problem of having less staff with less time and resources to travel. Face-to-face support has reduced. Some people find it hard to engage with staff over the phone. The internet is not always accessible for people. Face-to-face support is always more effective, but has reduced. People feel there is too much reliance on technology, especially the internet.

Isle of Wight
The local authority has pulled funding from services that are not their priority. Self-advocacy is one of these. It is harder for people to access support to be self-advocates and get advice. We expect people to be less independent over time.

Oxfordshire
Self-advocacy is still well-funded and the main charity doing this, My Life My Choice, has grown from 300 to 500 members. Oxfordshire is another example of protecting services that really matter to people, despite the pressures of austerity.

London:

Sutton Council is threatening to cut the supported employment service for 50+ people with a learning disability in October 2016. The outcome of their review is due at the end of June 2016. We are challenging this in meetings with the council, providing case studies, informing local MPs of the potential closure and securing coverage in local media.

Enfield Council has switched to using a new online portal called 'Access' for assessing all eligibility for social care. This will affect thousands of people with a learning disability and autism by forcing them to complete a form online and denying access to an in-person assessment. We are working with the National Autistic Society and a lawyer from Irwin Mitchell to work with an individual to bring a case.

Southwark Council informed parents and users of the Fast Forward youth service in January 2016 that the service was being reviewed and a consultation was taking place to determine if it would stay open. The consultation was not publicised externally and no parents or young people were able to feed into it. The parents campaigned with support of Mencap and received news that Fast Forward would stay open in February 2016.

Barnet Council withdrew Freedom Passes without consultation for over 2000 disabled and older people in the borough in the past year. Barnet Mencap is challenging the council’s claim that these people were no longer eligible for a Freedom Pass with support from Royal Mencap Society. Issue is ongoing.

Redbridge Council have announced they are 'piloting' a cut to the transport for severely disabled children this Autumn, changing their door to door minibus service to a coach which will pick children up from fixed meeting spots or laybys, regardless
**Worcestershire County Council** has cut supported employment contracts that help people with learning disabilities to find and keep paid employment. There is now only one operational worker for nearly 2,000 people with a learning disability. People will find it even harder to find paid work. Most people will not be able to get a job.

They have also closed Malvern day centre moving the day service to one room in a community centre with fewer staff. The plan to connect people with community activities has failed because there are too few staff to give people individual support. People’s days are spent in large groups going for walks or minibus trips.

**Walsall Council** has closed their Links to Work supported employment service. There is now no employment support for people. People who use the service are trying to look for other ways to get work but are very worried about their future.

They have also closed 7 community day service bases and there are now just 2 large day centres. People have to travel further for a less personalised service which is not connected to their local community.

**Birmingham City Council** cut funding to Birmingham People First. This led to the city’s only user-led organisation of people with learning disabilities closing. There is now no self-advocacy group for anyone with a learning disability in Birmingham.

People have no safe place to speak up about bad things that happen to them. They have no support to speak up. They are more isolated and vulnerable. They are at greater risk of abuse and even more powerless to do anything about.

Birmingham City Council have introduced a new cap on hours for each child of 100 hours a year. Resources for Autism outlined that this would mean if a child attended every date of their club this would come to 104.5 hours of the allocated 100 hours meaning children and families would be unable to access holiday play schemes, Reach Out Service or other Birmingham funded services without self-funding. They offered new service users alternate weeks at club to free up more hours so they could access both term time and holiday provisions without going over the 100 hour cap. The cuts mean that children loose out due to funding hours impacting on both the children and families as this may be there only Respite.

**Weymouth** training budgets are being cut substantially for staff in the Tricuro day services. In the longer-term, is bound to have an effect on skills, staff morale and quality of activities. Restructuring and the removal of talented managers will also have a negative effect.

**Cambridgeshire County Council** have made cuts to their continence service. This led to people and families having to use their benefit money to buy continence.
products, and further financial hardship. Families report there being no notice, no consultation, just a cut.

**Doncaster Council** have increased the cost of day service transport following cuts to their budget. People with learning disabilities will have to find additional money out of their own budgets to be able to pay for transport to attend the day service of their choice.

Personal stories from the **North East**:

**Why self-advocacy groups matter**, Skills for People:

*Heidi’s story*

Heidi had her ESA stopped following a medical with ATOS at which she scored zero points (a person needs to score a minimum of 15 points at assessment to be awarded ESA). We (eventually!) were successful in contesting the decision, which was finally overturned after two tribunals. The first tribunal had to be stood down to due to lack of medical evidence. I accompanied Heidi to a subsequent tribunal which eventually overturned the original decision.

Although the CAB had helped Heidi to prepare her appeal ‘on paper’ they informed her that they were no longer able to support people to attend tribunals. The tribunal in recording the reason for their change of decision cited the verbal evidence given by myself at the hearing – hence the written appeal would have been insufficient to alter the decision.

I don’t recall the score that they later gave to Heidi – but it must have increased from zero at the medical assessment to *at least* 15 following the second tribunal. Heidi has never accessed any support from statutory learning disability services, as she has not needed social work support in her own right and appeared unlikely to meet FACS criteria – so was not known to the learning disability social work team. Heidi required subsequent support from us to attend various appointments with the job centre and to understand the outcome of the tribunal.

*Ruth’s story*

Ruth lives in a 2 bed housing company flat in a tower block in central Gateshead. She moved there voluntarily three years ago – giving up a three bedroom bungalow in what many people might consider a more ‘desirable’ area - at the suggestion of the
housing company after her husband and son both died suddenly and she could not bear to remain in the property on her own.

Ruth has learning disabilities and mental health problems – including anxiety and depression - but her mental health had gradually improved as she came to feel safe in the flat, where she has supportive neighbours and family very close by. She had begun to help out as a volunteer at a local brownies, attended the local church and was accessing other social activities.

Ruth has never had any involvement from social services, as she has been able to cope using the informal support networks where she lives, along with the support of learning disability community health services – her psychiatrist and community nurse. Recently Ruth was informed that she would now have to begin contributing to her council tax, while her housing benefit would be greatly reduced due to her now being considered to have a ‘spare’ bedroom. Gateshead housing company suggested to her that she may prefer to move rather than cover the additional cost.

Ruth has been incredibly anxious both about the prospect of moving and about the prospect of finding additional moneys to pay the rent/council tax. Consequently she has become more isolated, as she feels unable to meet the costs of her social activities and travel to brownies where she volunteered. Ruth is still able to attend church each week as a member of the congregation provides transport; however she cannot afford to put money in the collection plate as she had always done in the past, which she feels embarrassed about and which makes her consider whether she should stop attending church as well. Her community nurse made a referral to us due to the concerns that health professionals were having about Ruth’s isolation and mental health.

Ruth is assisted by the housing company to ‘bid’ on other properties each week but states that so far the only properties suggested to her have been in areas such as Chopwell and Springwell Village; a long way from her support networks. She is in any case highly anxious at the prospect of moving and has no desire to leave her flat – which she has carpeted and decorated - although she would reluctantly consider a move within the immediate area. We have so far been able to assist Ruth to apply for – and be granted – a discretionary payment from the local authority to assist her with some of the impact of the changes. We are trying to help further by finding other ways that she can save money – such as sharing transport with other volunteers when she attends brownies and looking at her outgoing costs, such as what food she buys, how much housing insurance she pays, her phone line – in the hope that she can afford to remain in her current flat.

The Green family’s story
We received a call very recently from a family member regarding four middle-aged siblings, all of whom live together in a housing company property in Chopwell. The four brothers and sisters are all described by their family – and by their GP - as having learning difficulties or learning disabilities from birth; all attended special school as youngsters but had had never received any support from statutory services, as they have managed – albeit with significant difficulty - to support one another. The eldest of the siblings appears to have learning difficulties himself but is essentially the main ‘carer’ to the others and takes main responsibility for managing the household. None of the siblings can read or write and have difficulty managing their correspondence.

Recently one of the family, who is aged in her 50s, was reassessed for ESA and required to attend a medical with ATOS. Despite a letter from her GP suggesting that she had mental health problems including depression and anxiety, along with lifelong learning difficulties, the ATOS assessor concluded that she there was ‘no evidence of cognitive impairment’. She subsequently received a letter informing her that she had scored zero points and that her ESA payments would be stopped. Her response to this was to attempt suicide and she was taken to hospital following an overdose and cutting her wrists.

When I carried out an initial visit to meet the family recently, I found her crying, shaking and rocking backwards and forwards in her chair and stating that she remained intent on taking her own life. Her brother, meanwhile, the ‘head of the household’ informed me that this was the final straw in his efforts to care for his siblings and said that he could no longer cope in his role as carer and wished his brothers and sisters and himself to each be re-housed separately with support. We are now therefore supporting one sister with an appeal against the decision to stop her ESA; we are supporting another of the siblings to complete the paperwork ahead of their own claim; and we must assist all four with securing appropriate assessments both to diagnose learning disability and then – depending on eligibility – will request social care assessments and carers’ assessments from Gateshead’s learning disability social work team either with a view to providing support to maintain the family in their current home; or possibly to assist with re-accommodating each of them.

Again, this is a family who up until recently had not felt that they needed any support from statutory services and were not known to the social work team but who have been so worried by the implications of welfare reform that they now feel in ‘crisis’.

*Paul’s story*
Paul is a single father with a ‘mild’ learning disability and mental health problems. He and his partner lived in a two bedroom housing company flat in Bensham with their two young children.

The couple separated and the children’s mother left, leaving Paul as sole carer for the children. Social services had concerns regarding his ability to meet the children’s needs and they were later removed from the family home on the basis of neglect because it was felt that Paul may be unable to meet their needs. The children were placed in foster care while a fuller assessment was carried out regarding Paul’s parenting ability. The local authority have not yet decided on their long term plan for the children, while Paul is seeking their return to his care. Social services have indicated that the court case is likely to take around 6-8 months to conclude.

I visited Paul recently and he had, on the same day, received one letter informing him that he must start contributing to his council tax; another letter requesting him to attend a medical interview regarding his eligibility for ESA; a letter from a utilities company regarding debts; and a fourth letter telling him that as he was now under-occupying the property (the children’s shared bedroom now considered to be ‘spare’ under housing benefit rules, even though their long term future is undecided) his housing benefit is to be reduced and he will be required to pay rent on the second bedroom.

Paul was extremely worried at not being able to afford this increase – but also recognized that he could not move to a one bedroom property, as he would then not have room to accommodate the children. He considered the possibility of a friend moving in and renting the second bedroom but again worried greatly about how this would be perceived by social workers and court visitors when in the middle of a legal battle to have the children returned to his care.

As well as financial difficulties, this disadvantaged Paul in terms of his legal case and contributed to his already worsening anxiety and depression – and the need for further support from agencies such as ourselves.

Mr B’s story

Mr B is an older gentleman with a learning disability and physical disability. He lives in his own flat in a supported living complex and has support provided to promote his independence.

Mr B had a review / reassessment with a social worker. Following this, the social worker then reduced Mr B’s support package, from 58 hours down to 42 hours, leaving most of the hours for 2:1 support and very little for social inclusion.
Mr B was very worried and upset by this as it meant he could be left on his own for long periods of time during the day, which he and his support providers felt would not be safe. Mr B was particularly upset as he has his own motability vehicle which he used at the weekends but this now meant that he had less support time to enable him to do social activities using his vehicle.

**With the support of his Independent Advocate**, Mr B challenged the reduction in his support hours. The Independent Advocate wrote a complaint about how Mr B felt the review and reassessment was unfair and did not meet Mr B’s wellbeing as he was at risk of social isolation. The social worker changed and met with Mr B again and he was reassessed. The weekend hours were reinstated and also it was recognised that Mr B would benefit from a lunch time call so this extra support was put in.

**The fear of cuts**

**Michael’s story**

I had my benefits taken from me in 2010. This was the result of an inadequately explored assessment by a doctor in Sheffield, who I feel didn’t probe enough into my support needs which consequently resulted in my benefits being stopped. This left me with a gap of 3 months with no income, having to pay rent and bills without any benefits to fund them. I applied for a crisis loan with the support of Speakup, but was rejected. I appealed and eventually got my benefits back. But Speakup had to help me out with money and buy me food until then. I worry that with the current cuts, inadequate assessments will be taking place regularly and more people will lose their benefits. It is not a position I want to be in again.

**The real difference the right preventative support makes.**

**Philip’s experience**

I finished college at 25 and luckily there was a local Learn Direct Centre where I could go until I was 27. No-one would give me a job because of my disabilities and I got no help from the Job Centre. I had to sit at home I got bored and fed up, I also got stressed because of pressure from the job Centre. There was no-one to help me with all this and me health got worse and I kept going to hospital. Two years ago I started coming to People First, so now I get Support and got out of the home.
Evidence from other organisations

The UN Committee on economic, social and cultural rights expressed “serious concern” about the impact of regressive policies on the enjoyment of economic and social rights in the UK.

The Committee concluded that austerity measures and social security reform breach the UK’s international human rights obligations.

In a wide ranging assessment, the Committee sets out the following findings:

- Tax policies, including VAT increases and reductions in inheritance and corporation tax, have diminished the UK’s ability “to address persistent social inequality and to collect sufficient resources to achieve the full realization of economic, social and cultural rights”. The Committee recommends the UK adopt a “socially equitable” tax policy and the adoption of strict measures to tackle tax abuse, in particular by corporations and high-net-worth individuals.
- Austerity measures introduced since 2010 are having a disproportionate adverse impact on the most marginalised and disadvantaged citizens including women, children, persons with disabilities, low-income families and those with two or more children. The Committee recommends that the UK reverse the cuts in social security benefits and reviews the use of sanctions.
- Concerns about how often the UK government used benefit sanctions, and the absence of “due process and access to justice” for those who have been sanctioned, and called for a review of their use.

- Equality and Human Rights Commission’s submission in April 2016 on Socio-economic rights in the UK highlighted that a range of the Government’s recent social security reforms have had a disproportionate impact on disabled people, women and children. They say the UK Government should improve its planning and monitoring of these changes, reviewing policies and identifying mitigating actions where adverse impacts are identified. They highlighted that not all groups have equal access to the labour market citing disabled people as one of the groups that have disproportionately high unemployment rates. They also raised concerns about the restrictions in the scope of legal aid in England and Wales which will have a significant impact on the ability of people to access justice when their rights under the International Covenant on Economic, Social and Cultural Rights (ICESCR) have been breached. The submission says that the way in which legal aid is administered also impedes access to justice and that the UK Government should monitor the actual impact of these changes, including on potentially vulnerable groups. They also raised concerns about the mental
healthcare of adults stating that the Government has yet to realise its commitment to give equal priority to mental and physical health. Both inpatient and outpatient mental health services vary widely in England. Suicide rates have increased, police detention under the Mental Health Act 1983 continues and non-natural deaths in detention could be prevented.

Just Fair Consortium updated submission to the UN, in May 2016 made a new submission to the UN body that monitors compliance with the International Covenant on Economic, Social and Cultural Rights. The submission sets out evidence that the UK is failing to comply with its obligations under the Covenant in respect of, among others, the right to social security and the right to an adequate standard of living, including food and housing. Just Fair also highlights multiple concerns about the economic and social rights of disabled people.

Conclusion
The cuts that we have highlighted and that are being made across the country are having an impact that we can see now in the lives of people with learning disabilities and their families, but which will also yield further long-term devastating effects on people’s lives.

We view the cuts evidence against a backdrop of fear and uncertainty which includes pressures on early intervention and issues around implementation of The Care Act. As one family carer said ‘we are all scared!’:

“My son’s funding has not been cut but it presumes the sustainability of several third sector projects which he engages in during the day. They are now under serious threat and if they go, the notion of building ‘community presence’ and ‘participation’ disappears”

People’s lives are being diminished, their options and opportunities reduced, their access and visibility in their own communities becoming more limited, reliance on family increasing and voices lost. Fear is causing people to stay silent about the support they have (and any issues they may have with it) for the worry of losing it.
“I have lost count of the number of people who have said they dare not ask for more support – which they need – in case it all goes wrong and they end up with less”

The report highlights cuts to support to get into employment, to access services in the community, to get the most basic needs in terms of hygiene and personal dignity, and perhaps most crucially to have a voice.

Self-advocacy, the independent voice of people with learning disabilities, is being lost to generic advocacy time-limited contracts across the country. When central and local Government look to hear the voices of people with learning disabilities about the services and support they are receiving where will they go to? How will the voices of people not known to services or supported by providers be heard? Where will the voices of people with the most complex needs be? A generation of children and young people with learning disabilities and families will face an uncertain future as they move into adulthood.

We are clear that self-advocacy is crucially important for people with learning disabilities. Without it they are more isolated, and more vulnerable.

The National Learning Disability Board has a critical role to play in looking forward and we want to help and support you in that role. We need to build confidence and co production – they have to be our way ahead. Community and inclusion can be achieved without much money and we can help and support you to do this.

“If people are shut into their rooms at home at weekends, nobody sees and knows them. We have to tell the stories”