

Becoming less eligible? Intellectual disability services in the age of austerity

RESEARCH FINDINGS



Of the 150 people interviewed, many (42%) had lost care, 14% had experienced changed care and care had remained the same for 36%. Only 7% said their care had improved.

Those who had lost care were engaged in fewer activities and experienced poorer self-esteem and quality of life than those who had not lost care.

For many losing support meant a loss of independence and an increased reliance on their families/ third sector for support. They were also anxious about their futures.

Mean total care costs were around £30,000 per annum. The most expensive was 24-hour residential care (mean = £73,000), while the cheapest was family care (mean = £8,269; although considerable family care was unrecorded).

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BACKGROUND

The 'financial crisis' of 2008 caused the UK to make cuts to health and social care funding. The commissioning of cheaper care, leading to less attractive wages, resulted in lower recruitment and retention of care workers. The influence of Brexit on an already overstretched workforce capacity has resulted in a fragile adult social care market.

The Care Act 2014 attempted to resolve what became known as the 'postcode lottery' in relation to access to care by reforming 'eligibility', with councils duty-bound to match 'eligible needs' to appropriate care so that individuals could remain independent and plan ahead for their future needs. Despite the aims of the Care Act, a new concern is the likelihood that a sizeable proportion of people with ID could fall through the net, suddenly becoming ineligible for care and support.

KEY QUESTIONS

The aim of this study was to gather empirical data concerning the wellbeing of individuals with ID by asking:

1. Have people with ID lost social care services as a result of austerity measures?
2. What services do people with ID use and what are the costs of their support?
3. What impact if any has any loss of benefits and services had on individuals with IDD?

Methods

The research team interviewed 150 people in England with ID about their experiences of austerity and changes in care since 2008.

The sample included people living in the South (58%), the North (19%), the Midlands (10%) and Greater London (13%). Over half (59%) were male and 88% were single. The average age was 42 (range 18 to 79). Most (94%, n=141) were White British; 8 were BAME (missing data on ethnic origin for one individual). The majority had a diagnosis of a mild or moderate ID (86.7%, n=130) and 13.3% (n=20) were described as having a severe ID. Half lived on their own or with a family member.

Measures included the Social Network Guide, the Client Service Receipt Inventory, the Glasgow Anxiety Scale and Self-esteem Inventory and the Personal Outcomes Scale.

FINDINGS

GLOBAL LITERATURE REVIEW

Research and guided data collection on how austerity has impacted the lives of people with ID is scarce. A systematic review, possibly the first on this topic, identified only 11 empirical studies: 5 in the UK, 4 in the Netherlands, 1 from Canada and 1 from the US published between 2008 and 2017.

The review showed that the funding available to support people with ID is increasingly poorly aligned to their care needs.

QUANTITATIVE INTERVIEW FINDINGS

As shown in Table 1, 42% reported that they had lost care (defined as reduction in hours received). 36% that their care had stayed the same and 14% that their care had changed (but not reduced). Only 7.3% said their care had improved. No significant difference was found between the regions of the UK.

Mean total costs for service provision was nearly £30,000 per year (ranging from £5,000 to over £200,000): 24-hour staffed residential homes were the most expensive (mean=£73,000 a year); living with one's family was the cheapest (mean=£8,269), although support from family members may be unrecorded.

Impact of losing care/support

The Care Act 2014 specifies that local authorities should promote wellbeing. The study examined how participants reported aspects of their wellbeing and the impact of reduced care support.

Activities (including employment and day-to-day activities): over half were not engaged in any

Table 1. How has the person's care changed since 2008, by region?

	Greater London	North	South	Mids	Total
Lost care	9	13	35	6	63
Changed care	2	8	10	1	21
Improved care	0	2	8	1	11
Care unchanged	8	8	33	5	54
Unknown	0	0	1	0	1
Total	19	31	87	13	150

FINDINGS

form of work (53.3%, n=80), and only one in ten were in paid work (10.7%, n=16). Under a third were engaged in voluntary work (27.3%, n=41) and three classed themselves as a student or engaged in vocational training/apprentice. Six (2.6%) attended college one or more days a week.

Those who had lost care reported engaging in significantly fewer social and independent activities than those who had not lost care. The quietest time was weekend evenings with an average of under one activity compared to an average of two activities on weekday evenings. A quarter of participants who answered this question (n=138) said they did not have enough things to do.

Social relationships: participants' total social network sizes varied widely from 4 to 157 people (mean=34; SD=28; n=105). No significant relationship was found between the total network sizes and whether or not an individual had indicated they had lost care.

Anxiety, self-esteem and quality of life: no statistically significant difference in the anxiety score was observed but 74.8% (n=127) scored above 13 – indicating a clinically significant anxiety level. Those who had lost care had significantly lower self-esteem and quality of life scores compared with those who had not lost care.

QUALITATIVE FINDINGS

Lost care

Many participants said that they had lost care or support. This meant different things to different people. For some, it meant reduced support hours including one-to-one time with a support worker for activities such as going out for the day, assistance with paperwork, preparing food, cleaning, physical care or emotional support. Not having such support impacted on individuals' everyday lives:

The carer used to come in twice a week for one hour. Used to help me. But [I] was reassessed and they know I'm quite capable so hours were removed ... I still need support... I liked it when there was someone there for me when I had difficulties or something I need help with. With my letters and stuff, I don't know what to do with the letters I am getting.

Some participants had experienced multiple cuts in their support hours. For others, losing care meant a reduction in the number of days they could attend day services which meant ultimately, for some, doing very little or nothing on those days.

Some who lived in a group home setting said that the number of staff on duty at their home had been reduced and this impacted on their everyday lives in terms of personal, domestic and social needs:

I used to get support everyday. I've let myself go. Trying to get back on my feet but it doesn't work that way, why do we have to put up with it? Nobody not doing anything for us. Nobody is in our corner. We don't do anything, we only go to one club. We sit in here. It seems like we are waiting to die.

Not being provided with a clear reason for a reduction in support time added to participants' confusion, and cuts also impacted on their sense of empowerment – participants did not feel that they could complain about their loss of services:

But the social worker came and just took Tuesdays and Thursdays ... She didn't ask me, she just told me. I've been coming here for two years. My days got cut in January. Now I just do nothing on Tuesdays and Thursdays now, I just sit in my house.

For other participants, losing support meant a loss of benefits and financial support, ranging from a reduced amount to spend daily on what they wanted, to the complete loss of PIP (Personal Independence Payment).

Changed care

Participants talked about changes in how their care was being delivered due to restrictive staff regimes, limited access to transport, service closures and changes:

I have lived in the same residential care for 10 years. There is now less daytime activity and it is self-funded.

The drive to change the way day services are delivered – from congregate isolated day centres to more one-to-one bespoke support for individual activities – are rooted in positive notions of normalisation and person-centred care. However, for the participants in this study, day service erosion meant in reality, little or no alternatives to mitigate the impact.

Impact on people's lives

Three themes emerged about how losing care impacted on individuals' lives:

Loss of living normally – both physical and social events often represented some level of independence and achievement for individuals. Having these reduced impacted their sense of wellbeing with individuals reporting boredom and limited opportunities to vary their week. For many individuals, losing care also led to a sense of disempowerment – feeling that they were unable to complain about their situation:

We used to have arts and crafts, bingo. Now we have nothing. Now we're just a block of flats. Coz we're disabled nobody cares. Nobody explained to me when the

FINDINGS



hours were cut. We've been kept in the dark. The Warden used to live in, then they suddenly stopped. There's lots of things wrong but shouldn't be. But we can't say anything to get it sorted.

More long-term 'dreams' such as having 'more friends' or a romantic partner, a paid or voluntary job, moving into their own place to live and going to college to learn new skills or going on holiday were gradually being abandoned as cuts to services became more acute:

You can't go on holiday as a group now as it takes too many staff so (service) won't allow it. They cut it ... I can't do anything because of lack of transport. No point saying I want to do anything because you always have to think about transport. This is what the cutbacks mean. It feels like I have had my arms and legs cut off. If you can't get out, you can't do anything so you get depressed.

Family and the third sector take up the slack – participants commented on how their reliance on family members had increased following the loss of support or care hours:

My family support me. No care hours, my parents pay for all outgoings.

One participant explained they were told they were not eligible for support or care hours as they had family and friends who could support them:

No care. I have asked for support when I asked for direct payments. I was told I was a member of community groups and family and friends so I can get food from them so I can't get help ... I have asked people and get nothing

Another participant explained that he wanted to be more independent and had been waiting a long time to get a placement so he could move out of his family home. However due to cuts and loss of services he was in limbo:

I live with my parents. I would like to move out ... I have been waiting for a placement for 15 years on a waiting list. Now the council office I used to go to has closed down ... I don't know where to apply now. I want to be near my girlfriend. I used to have a social worker. Not anymore.

Apart from routine day-to-day domestic tasks and activities, family members were also relied upon to help participants applying for benefits:

I get full PIP [Personal Independence Payment]. I wasn't getting it but my sister sorted it out for me. I get bedroom tax I don't have to pay. I have to fill in a form every 6 months. My sister helps me.

For others, who had limited or no family support, help from third sector organisations was their only option:

I don't get any benefits now they stopped my PIP. A charity is helping me reapply for PIP.

In the absence of any support, some participants inadvertently may have lost support that they were eligible for:

My disability living allowance was stopped in 2016 as I did not file in time... My DLA was stopped last year. I was in a bad place and I couldn't work out where to go. No one helps me with letters.

Some participants reported being referred to charities by local authority

or social service representatives if they had not been awarded care hours or had lost care:

Anxiety about the future – many participants reported stress and anxiety about what the future held for them. This often related to the assessment of their eligibility for benefits and support:

I phoned social security daily as I was so anxious following all the rules ... I am worried about the cuts the government has made. It feels like they have a 'hearing' for PIP. They don't understand what it is like. You feel bullied and they are wrong. They don't understand people's conditions. They are targeting the wrong people. Everyone says 'stop worrying' but that is really hard.

Fears about future cuts to benefits and services made some individuals question the purpose of becoming more independent:

You know they want you to be independent but I'm scared because if you get more independent it feels like you are going to get less hours

Participants' views about austerity

Finally, some participants gave their views about austerity (i.e. cuts to services) in general. The research team found that individuals regarded government austerity measures as the root cause of their impoverished care – and they were able to articulate this in no uncertain terms:

I don't feel protected by the government. I am just a number. The government doesn't value me. You are very vulnerable and there's nothing you can do.

CONCLUSIONS & IMPLICATIONS

- The last decade has been characterised by social care budget cuts leaving local authorities (LAs) in England struggling to provide adult social care. The commissioning of cheaper care leading to less attractive wages has resulted in lower recruitment and retention of care workers especially among those with uncertain “zero hours” contracts. The influence of Brexit on an already overstretched workforce capacity has resulted in a fragile adult social care market.
- Set in this landscape, austerity measures have placed pressure on local authorities to make social care savings that are irreconcilable with the rising needs of people with ID as they get older. The mean age of the study sample was 42 (range 18–79 years), reflecting increased longevity. This also means that there is an additional imperative for local authorities to enact the Care Act 2014 aims of improving and maintaining people’s independence and wellbeing.
- It is not difficult to see from the evidence that austerity measures which have directly hit social care services have impacted negatively on the lives of people with ID who themselves are aware of their own loss of support and who attribute these to service cuts.
- Current social care practice could inadvertently leave people with ID to fall into a trap of being less eligible for the support that they need to remain independent. Higher dependency can lead to more demands on (often older) family members. When they are no longer able to support their loved ones, the only option is often for people with ID to enter 24-hour staffed residential care – at around £73,000 per year – the most costly form of support for health and local authorities. This trajectory conflicts with the spirit of the Care Act 2014.
- Policy decisions need to consider the significant negative impact that austerity measures have had. Responsibility for people with ID needs to be properly ‘shared’ between health and social care to avoid people falling between them.
- Further research would be useful on how social services are interpreting eligibility.

COMMENT

“Because of austerity, it is very much a funding based [system] and it is dehumanising. It is so valuable, you know, to actually now have the quantitative evidence. So people doing research – people like yourselves who can go to the commissioning agencies and can advocate for people like us, who are the hidden carers. I found the research really useful both from a professional but also from a carer point of view as well. It’s really valuable.”

Professional working in adult social care and an informal carer for their daughter with intellectual disabilities and autism

“What needs to change is the value base from the government down really, because if we were all working to the same value base it would eradicate some of these problems [in the research report]. The message to the local authority and government is that the Care Act is the legal framework and the assessments need to be done based upon that framework and not on budget needs. Also, the turnover of staff, you know, social workers need to be personally committed to those people for a long period of time so they have relationships with the individuals. Newly qualified social workers need good training about learning disabilities – that should be in their continual professional development. I’ve been doing this job for a long time but coming and listening to all of this today... I thought at first ‘ok I understand that’, but actually – do I really? Do I really think about all of this? Am I stuck in this statutory sector? So...re-thinking about these kinds of things is really important.”

Social Worker

FURTHER READING

Malli MA, Sams L, Forrester-Jones R, Murphy G, Henwood M (2018) Austerity and the lives of people with learning disabilities. A thematic synthesis of current literature, *Disability & Society*, 33, 9, 1412–1435.

The School for Social Care Research was set up by the National Institute for Health Research (NIHR) to develop and improve the evidence base for adult social care practice in England in 2009. It conducts and commissions high-quality research.

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