JOURNAL OF LONG-TERM CARE

Forrester-Jones, R, et al. 2021. The Impact of Austerity Measures on People with Intellectual Disabilities in England. *Journal of Long-Term Care*, (2021), pp. 241–255. DOI: https://doi.org/10.31389/jltc.59

RESEARCH

The Impact of Austerity Measures on People with Intellectual Disabilities in England

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Context: UK austerity measures following the 2008 financial crisis included budget reductions for health and social care. We aimed to investigate the extent to which austerity-measures had impacted the lives of people with intellectual disabilities in England, and whether their support costs were associated with their characteristics, needs and outcomes.
Objectives: We report on what services people with intellectual disabilities were using, whether they had lost care, the costs of their support, and what impact any loss of benefits and services had on individuals' lives.
Methods: 150 participants with intellectual disabilities across England were interviewed about their services and their well-being. Service and individual support costs were calculated. Statistical and thematic analyses were employed.
Results: The largest proportion (42%) of our sample had lost care. 14% had experienced changed care, and care had remained the same for 36%. Only 7% said their care had improved. No associations were found between costs and characteristics and needs except for whether the person had mild or severe intellectual disabilities. Those who had lost care engaged in fewer activities and had significantly lower self-esteem and quality-of-life scores compared with those who had not lost care. Loss of care impacted on individuals' independence and future aspirations.
Limitations: A comparative study of austerity impacts across the whole of England was not possible. Our costs data may be underestimated because full information on support from home, key, or support workers was unavailable.
Implications: In attempting to mitigate against COVID-19 impacts on people with intellectual disabilities, policy-decisions will need to consider the backlog of a decade of cuts.

Keywords: Austerity; intellectual disabilities; costs; adult social care; Care Act 2014

Introduction

> "Austerity is a form of voluntary deflation in which the economy adjusts through the reduction of wages, prices and public spending to restore competitiveness, which is (supposedly) best achieved by cutting the state's budget, debts and deficits." (Blyth, 2013: 2).

The UK National Health Service delivers free health care to those in need and is funded by central government. Adult social care (support with daily living tasks such as getting up in the morning, dressing, eating and budgeting), however, is delivered by a mixture of local authority, private and third sector providers, is funded by local councils via government grants, local tax, and, unlike health care, is means tested with access dependent upon eligibility. This model of funding social care has for decades been groaning under the weight of increased social care demand arising from increased longevity and concomitant complex personal and social needs. However, whilst England's gross expenditure on social care had increased in real terms by 53% during the Labour government's term of office (from 1997–10) (The King's Fund 2010) this, as well as other welfare spending was exposed to fragile tax revenues that plummeted following the 2008 Global Financial Crisis (see Chote, Crawford, Emmerson & Tetlow, 2010, p. 5; Diamond, 2015); the crash leaving national taxpayers bailing out the banks, and a huge hole in the welfare funding pot. Similar to other western economies (e.g. Sweden, the Netherlands, Canada, the USA) the UK Coalition's (Conservative-Liberal Democrat government 2010–15) response to the crisis was to adopt debt reduction or 'austerity' measures in the belief that reducing the public deficit would spark a private sector recovery (which also aligned with the neoliberal market-led growth model pursued by the previous Labour government [Clark, 2016; Malli et al., 2018, p. 1413]).

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Austerity actions included cuts to social care spending,[1] NHS Digital reporting that whilst[2] total expenditure on adult social care in England rose from £22.4 billion in 2009/10 to £22.6 billion in 2010/11 (under Labour) it reduced year on year to £20.6 billion by 2014/15 (under the Coalition). Whilst the Conservatives (2015–present) increased spending to £22.2 billion by 2018/19, this amounted to £0.4 billion below the 2010/11 spending level. Continuous annual spending data for intellectual disabilities is unavailable but annual data on long-term (residential, nursing and community) social care spending provide a similar picture on trends in expenditure. For example, in 2016/17 gross current expenditure on long term care for adults (aged 18–64 years) with intellectual disabilities was 4,733 million, rising only to 5 million in 2018/19 despite the steady increase in the number of people with intellectual disabilities needing support for a longer time period due to greater life expectancy (see Glasby, Zhang, Bennett & Hall, 2021) and concomitant complex care needs. Year-on-year budget reductions left local authorities (LAs) in England struggling to provide adult social care, exacerbated by a history of inconsistently applied assessments for eligibility across the country (Charles & Manthorpe 2007; Fernández & Snell 2012) with practitioners using their own professional judgement (rationing by discretion or what Lipsky [2010] termed 'street level bureaucracy') of client need and fairness (see Henwood 2015). Other factors that had begun before the 2008 crash included an expanded private care market (Laing, 2005), which cut care prices, thereby reducing care providers' ability to offer attractive wages (Hussein, 2017). Low pay resulted in lower recruitment and retention of care workers especially among those with uncertain 'zero hour' contracts (Ravalier, Fidalgo, Morton & Russell, 2017). An overstretched workforce capacity left some of the least qualified and/or trained staff (Cylus et al., 2012) attending the social care needs of the most vulnerable adults. It was hoped that the Care Act 2014, with its national eligibility threshold and legal duties on LAs to assess and provide support to maintain people's 'well-being', would alleviate some of the emerging social care deficits. Yet complaints of shoddy or non-implementation of the Care Act emerged and the Social Care Institute for Excellence (SCIE) (2016) reported how 'front line staff felt an obligation to make savings and cuts during assessments and review meetings' (p. 9). The triggering of Brexit in 2016 only compounded the problems, with many care staff returning to their country of origin (Read and Fenge 2019). This combination of impacts led the Association of Directors of Adult Social Services (ADASS) to warn the government that the quality of care they could provide was being compromised (ADASS Budget Survey, 2016). Whilst LAs tried to maintain their social care spending on adults with intellectual disabilities (while spending on older adults fell, including those with mild intellectual disabilities [see Glasby et al., 2021, p. 413]), the increased demand for social care specific to intellectual disability was such that injections of additional government funding (e.g., an extra £2bn for 2017/18–2019/20 incorporated within the Improved Better Care Fund [IBCF]) were not enough to keep pace with unmet need (see ADASS, 2018) leading to greater pressure on families to care for their loved ones (Glasby et al., 2021, p. 407). Set in this landscape, we aimed to talk directly to people with intellectual disabilities in receipt of services to find out what impact, if any, budget cuts and austerity measures had on their day-to-day lives. We also wanted to collect systematic data on how use of services had changed and whether this impacted on costs of services. Three research questions guided the study:

1. Have people with intellectual disabilities actually lost services (in particular social care services) as a result of austerity measures?
2. What services do people use and what are the costs of their care?
3. What impact if any has any loss of benefits and services had on individuals with intellectual disabilities?

A global systematic review of the effects of austerity measures on the lives of people with intellectual disabilities (the first of its kind to our knowledge) formed the first phase of our research (Malli, Sams, Forrester-Jones, Murphy & Henwood, 2018). Just eleven empirical studies were found, five of which were based in the UK, confirming a scarcity of research on this topic (2018, p. 1412). Overall, the review found that during austerity, the funding made available to people with intellectual disabilities was increasingly poorly aligned to their care needs, possibly leading to poorer outcomes. Critical appraisal of the included studies, however, found a lack of clarity of methods used and broad and heterogeneous samples such that intellectual disabilities was not always the focus of study, nor was this specific population analysed separately from other groups (2018, p. 1423).

Current study

In seeking to add much-needed evidence of the impacts of austerity on the lives of people with intellectual disabilities, we interviewed individuals in receipt of services in England. This meant that we did not conduct a repeat-measures study – which was not possible in any case, because national routinely collected Adult Social Care Outcomes Framework (ASCOF) (2019) data pertaining to people's use of services in England was not available.

Before designing the study, we sought Patient and Public Involvement (PPI) (INVOLVE May 2010). We engaged 15 consultants (family carers, volunteers, service managers) with expert experience in discussions around the social acceptability of our study topic. We also presented the study to a Research Advisory Group (RAG) of paid consultants with intellectual disabilities. We incorporated all consultants' views into the theoretical design of the study.

Method

Ethical review

The study gained a favourable ethical opinion from the HRA Social Care Research Ethics Committee (SCREC) on 4 May 2017: REC 17/IEC08/0009; IRAS ID 216910. Research governance approval was also sought from every relevant National Health Service (NHS) Trust. Researchers then visited participating settings, and accessible information sheets and consent forms were provided to all potential

participants. For those without the capacity to consent an appointee was sought, as required by the Mental Capacity Act 2005.

Recruitment and sample

We recruited the sample through NHS Trusts and Social Services departments across England as well as local carer and service user organisations and independent service providers. The rest were recruited through snowballing (Griffiths, 2020); individuals with intellectual disabilities who had been interviewed told their colleagues about the research, some of whom then asked if they could be interviewed too. We recruited participants via 20 organisations including 11 charities, 5 NHS providers, 3 private care providers and 1 social service. Whilst we were unable to include equal numbers of participants across specific regions of England as planned, our target sample of 120 was exceeded by 30 individuals (so 150 in total and large enough for quantitative analysis), and they came from areas in the North, South, Midlands, and Greater London.

Measures

After collecting basic demographic data (i.e., age, ethnicity, current living situation), we asked participants whether they: had lost care (we defined this as a reduction in the number of hours people received from social care services); or gained more care hours; or had their care changed (e.g., they used to attend a day centre and now received 1:1 but the same number of hours); or had continued to have the same level of care, since austerity started.

A specially adapted *Client Service Receipt Inventory* (CSRI) was then used, on which we logged participants' contacts over the last year with social care services. The CSRI also allowed us to record contacts with hospital services and primary and community health care professionals, to provide an overall picture of service receipt (Beecham and Knapp, 2001). The costs of care were estimated at an individual level and then analysed according to accommodation type and in relation to those who had lost care or had experienced a change in care compared with those who had not lost care (Beecham, 2000; Curtis, 2013). Unit costs were sought for each service from publicly available sources such as the *Unit Costs of Health and Social Care* (Curtis & Burns, 2018) and the NHS Reference Costs. All costs are cited at 2017–2018 values. For further details of costs analysis, see Beecham & Forrester-Jones, 2019.

Using the *Social Network Guide* (Forrester-Jones et al., 2006; Bhardwaj, Forrester-Jones and Murphy, 2017; White and Forrester-Jones, 2019) we then asked participants to report on their lives in general, including their daily activities and their social networks. The *Glasgow Anxiety Scale* (GAS) (Mindham & Espie, 2003) was used to rate participants' general and more specific anxieties, and individuals also rated their satisfaction with their quality of life on Schalock and colleagues' *Personal Outcomes Scale* (Claes et al., 2012) and their self-esteem, using Dagan & Sandhu's (1999) adaptation of Rosenberg's *Self-esteem Inventory*.

All of the above quantitative measures had already been designed/adapted for people with intellectual disabilities, and previously tested for reliability and validity, and the researchers had experience of interviewing people with communication difficulties. In the main, most of the participants were able to answer the questions without additional support, but those with more moderate to severe intellectual disabilities had help from staff or family members.

Asking questions about the past

Understandably, for the participants who had experienced loss or changed care, most could not pinpoint dates when these changes occurred. But this was not our aim because cuts to services did not happen overnight in 2010 – rather they occurred over a period of time. Rather, we wanted to understand how loss of care services impacted on individuals' day-to-day lives. The majority of the sample were clear that their care and support had changed at some point over the period and could recount what the change meant to them. In order to capture individual's experiences and feelings about changes to their care, our package of measures included time and familiar safe spaces with appropriate noise levels and light to create a 'communication environment' (Bradshaw, 1998), which encouraged a conversational and prompting style of interviewing (Cambridge & Forrester-Jones, 2003) whereby participants were given the opportunity to share qualitative comments in response to open-ended questions such as:

- Please think about the kinds of help you used to get from [a service that had been cut].
- What kinds of help did you get?
- What did you like about that care?
- What didn't you like about that care?
- What is your life like now without that care?

Since some people with intellectual disabilities may find timeframe comparisons i.e., 'life before and after service changes' difficult to process or convey due to particular communication difficulties, alternative and augmentative communication styles (including graphic symbols, signs, and photographs) were used where appropriate, and the interviews were largely successful. Responses to questions were written down word-for-word to avoid interrupting the flow of individuals' stories or inhibiting spontaneity (Halcomb & Davidson, 2006). With consent, more extensive comments were recorded and transcribed. Interviews lasted between one and two hours, with breaks as and when participants requested or indicated they wanted them.

Analysis

Quantitative data analysis via SPSSv25 was used for the costs, quality of life, social network, self-esteem, and anxiety data. Qualitative comments were collated using NVivo12 to organise and manage the data which was then subjected to thematic analysis (Braun & Clarke, 2006).

Results

Sample characteristics

Our[3] sample included people living in the South (58%, n = 87), the North (19%, n = 31), Midlands (10%, n = 13), and Greater London (13%, n = 19). Almost all (92.6%, n = 139) said they lived in a city or town; only

10 (6.7%) lived in a rural area (one participant could not recall/describe the area in which they lived). Over half of the participants (59%) were male and 88% were single. Their average age was 42, with a range from 18 to 79. The majority had a diagnosis of mild or moderate intellectual disabilities (86.7%, n = 130), and 13.3% were described as having severe intellectual disabilities (n = 20). The majority were White British (94%, n = 141); 8 were Black, Asian, and Minority ethnic (BAME) (we had missing data on ethnic origin for one individual). Half of the participants said they lived on their own or with a family member (50%, n = 75), 29% (n = 44) lived in supported living accommodation, 13% (n = 20) in a group home with 24-hour staff, and 6% lived in a shared lives placement (n = 9). No government department collects comprehensive records of the numbers/details of people with intellectual disabilities in England, but, apart from numbers per area, our sample's characteristics generally align with reported national estimates (see Public Health England, 2016, 2020).

The largest proportion of participants reported that they had lost care from 2008–2018 (42%, n = 63), 36% (n = 54) reported that their care had stayed the same, 14% said their care had changed (but not reduced), and the smallest proportion reported that their care had improved (7.3%, n = 11). These differences were found to be significant ($p < 0.05$ m 50.92 with 3 degrees of freedom) using a one-sample Chi-square test. One participant could not recall whether their care or support had changed.

Table 1 indicates little difference in the proportion of participants who had lost care between regions in England. No significant relationship was observed between whether participants had lost care and if they lived in an urban or rural environment or in relation to age or gender ($p < 0.010$).

Use of services

People's use of services was captured using the CSRI, which was at least partially completed by 149 participants, although most data were missing for six of these participants (n = 143). Data were collected for the year prior to the interview (see **Table 2** for a breakdown of services used). The first column of **Table 2** shows the wide range of supports used (people could report more than one service used).

Hospital-based services

In relation to hospital-based services, nearly one in five participants were admitted to hospital over the previous year, mainly for general health matters such as a broken leg of falling over. For a more detailed explanation and discussion on this aspect of the study, please see Beecham and Forrester-Jones (2019).

Use of community-based health services including primary care and specialists

As expected, general practice (GP) services together with dentists and opticians were the most commonly used in the previous year (over three-quarters had seen a GP; 50% had seen a GP nurse; 76% had seen a dentist; and 62% had contact with an optician). Around one in five had seen a physiotherapist in the previous year, but support from other allied health care professionals was less common (e.g., only 5% had used a speech and language therapist). Similarly, a small proportion of the sample had received support from specialist intellectual disabilities community services/teams (see **Table 2**, second row). This is interesting given the high prevalence of some form of communication difficulty experienced by people with intellectual disabilities (see Smith et al., 2020).

Twenty-eight people used mental health services (psychiatrist, psychologist, counsellor) and medication for mental health was most commonly prescribed (n = 31) (see **Table 3**). Ninety-six people had been prescribed medication in more than one of the categories shown in **Table 3**, 16 of whom were prescribed medication from four or more categories; suggesting that some people had multiple health problems.

Social care and criminal justice services (CJS)

Just over one in four participants had used advocacy services or self-help/support groups. A small proportion (13%) had received supported employment service in the previous year. It is of course, mainly social care organisations, including LAs, that provide key, home, and support workers as reported below.

Accommodation and social care staff

The highest proportion of participants (50% of the sample) were living on their own or with family members at the time of the interview. Fewer (30%), were in supported living, 13% were living in residential care homes, and 6% had a shared lives placement (**Table 4**). **Table 5** focuses on those people who had complete CSRI data, including contacts with professional social care workers – key and support workers. Contact rates over the last year are shown by the type of accommodation in which

Table 1: Care changes in each English Region.

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

Table 2: Service-use in the last year, n = 143.

Service	% using (n)	No. contacts	
		Mean (sd)	Range
Hospital			
Inpatient admission	19% (27)	1.7 days (1.6)	0–84
Outpatient clinic	31% (45)	3.5 (26.0)	0–300
A&E/MIU[1] unit	16% (23)	2.7 (25.6	0–300
Community specialist services			
Specialist doctor	22% (32)	0.5 (1.5)	0–10
Psychiatrist	10% (14)	0.3 (1.3)	0–52
Psychologist	8% (12)	0.6 (4.5)	0–52
Counsellor	8% (12)	0.7 (4.5)	0–52
Intellectual disabilities Team member	8% (11)	1.2 (6.9)	0–15
Primary care			
General practitioner	76% (110)	3.1 (5.4)	0–52
General practice nurse	50% (72)	1.9 (5.3)	0–52
Prescription	76% (110)		
Community health services			
Community nurse	5% (7)	0.19 (1.4)	0–52
Dentist	76% (109)	1.3 (1.4)	0–12
Podiatry	25% (36)	1.9 (5.9)	0–52
Optician	62% (89)	0.5 (0.8)	0–52
Physiotherapist	19% (27)	2.9 (0.9)	0–104
Occupational therapist	8% (12)	0.9 (6.1)	0–52
Speech and language therapist	5% (9)	1.0 (6.6)	0–52
Alternative therapist	6% (9)	1.3 (1.4)	0–64
Social care services			
Social worker	32% (46)	1.5 (6.5)	0–52
Supported employment	13% (18)	5.4 (26.4)	0–260
Advocacy	24% (34)	5.8 (14.7)	0–52
Self-help/support group	27% (39)	15.0 (43.4)	0–260
Other[2]	1% (2)[1]	0.44 (4.6)	0–52
Criminal justice services			
Police	15% (21)	0.2 (0.4)	0–1
Solicitor/lawyer	7% (10)	0.1 (0.6)	0–4
Probation officer	1% (2)	0.4 (4.5)	0–52
Other[2]	<1% (>1)		

Notes: 1. Accident and Emergency Department/Minor injuries Unit. 2. Carer support groups.

Table 3: Number of people with prescriptions for medications.

Broad area of health	N	Broad area of health	N	Broad area of health	N
Pain	25	Heart	5	Infection/antibiotic	10
Digestion	13	Blood pressure/cholesterol	25	Mental health	31
Chest or breathing	15	Diabetes	18	Other	59
Allergies	19	Arthritis/joints	12		

Table 4: Accommodation type, n = 149.

Accommodation type	No. (%) participants	Accommodation type	No. (%) participants
On own/with family	75 (50%)	Home with 24-hour staff	20 (13%)
High secure unit	0	Home with day-staff only	0
Low or medium secure unit	0	Supported living	44 (30%)
Probation hostel	1 (<1%)	Shared Lives placement	9 (6%)

Table 5: Accommodation and care staff contacts per annum, n = 143.

Accommodation type	Mean No. key worker contacts (range)	Mean No. home care worker contacts (range)	Mean No. support worker contacts (range)
On own (n = 19)	25 (0–365)	69 (0–703)	66 (0–365)
With family (n = 52)	35 (0–365)	8 (0–365)	28 (0–365)
Multi-units; low staffing (n = 6)[1]	52 (0–260)	43 (0–164)	104 (0–365)
24-hour staffed home (n = 19)	4 (0–52)	3 (0–50)	3 (0–52)
Supported Living (n = 39)	79 (0–365)	<1 (0–7)	170 (0–365)
Shared Lives (n = 8)	7 (0–52)	0	7 (0–52)
Mean (range) all accommodation types	**40 (0–365)**	**14 (0–730)**	**70 (0–365)**

Note: 1. Sheltered Housing (n = 5) and Probation Hostel (n = 1) are grouped and costs estimated as the same for both. These establishments incorporate separate accommodation for residents with usually only one member of staff on duty.

people lived. The highest mean number of contacts are recorded for people in supported living arrangements. Care staff contacts appear lowest for people in 24-hour staffed care homes but the figures in **Table 5** do not separately record on-site staff as the accommodation-related costs already include the costs of staff attached to those facilities. Six people living on their own and 23 living with their families reported no contacts with care workers.

The costs of care services

One of our research aims was to investigate any differences in costs of these services under austerity cuts. We therefore needed to establish the overall costs of services, and then look at any differences in costs between those who had lost care, and those who had not lost care. Using the broad categories of services shown in **Tables 4** and **5**, we present the costs of support received for accommodation and care staff costs and also costs of hospital- or community-based services in **Table 6**.

Accommodation and direct care staff support comprised the largest proportion (86%) or over four-fifths of the total costs of care (see **Table 6**). Living in 24-hour staffed accommodation was the most costly at around £73,000 per annum, about twice the costs for people who lived in supported living arrangements. Those living with their families were the least costly to the public purse. There are two cost-related caveats. First, our care staff costs for participants who do not live in 24-hour staffed accommodation may be underestimated as we made conservative assumptions about the *duration* of contacts. Second, we have not included any costs that accrue for the support provided by informal carers (family, friends, neighbours). Further, these cost figures do not take into account any associations between needs and costs. We would expect people with higher needs to be living in more costly settings where higher support is provided.

Community-based services (i.e., services based away from the place of residence) account for 14% of the total cost of support. Within this category, hospital based-care accounts for over half the costs. Notably, the highest cost for hospital services (£128,100) reflects support for one person – the member of staff helping this individual complete the questionnaire stating that they had to go to Accident and Emergency 'most nights' and outpatient visits about once a week for self-harming behaviour. This accounts for a third of all hospital costs. At just over £800 per day, the three long inpatient admissions (84, 42, and 35 days) for general health conditions are also strong drivers of the high hospital-related costs. Although they are the most commonly used, primary care services (general practitioner and GP nurse) account for only a small proportion of total service costs.

Social care costs

At less than a quarter, social care costs accounted for the second highest proportion of the total service costs. However, when considering the funding position for social care services, they are also likely to be the largest funders of key workers, home care workers and support workers, which are included in the upper half of **Table 6**, as well as many of the (fees for) 24-hour staffed care homes.

Table 6: Costs of supports per annum, n = 143.

Supports	Mean £ (SD)	Range £	% total costs
Accommodation & care staff			
On own (n = 19)	£10,995 (3,037)	£8,276–£17,330	
With family (n = 52)	£8,269 (2,481)	£4,627–£16,169	
Multiple units; low staffing (n = 6)[1]	£9,794 (–)	–	
24-hour staffed home (n = 19)	£72,903 (563)	£72,714–£75106	
Supported Living (n = 39)	£34,027 (4,609)	£27,149–£44,476	
Shared Lives (n = 8)	£26,173 (497)	£25,896–£27,092	
Total cost of accommodation & care staff (n = 143)	**£25,649 (21,799)**	**£4,627–£75,106**	**86%**
Community-based services			
Hospital	£2,596 (12,838)	£0–128,100	
Community specialist services	£143 (464)	£0–£2,826	
Primary care[2]	£113 (182)	£0–£1,612	
Community health services	£299 (709)	£0–£4,131	
Social care services	£939 (2109)	£0–£19205	
Criminal justice services	£21 (112)	£0–£1,199	
Other services	£6 (53)	£0–£450	
Total cost of community-based services	**£4,118 (13,191)**	**£0–£129,876**	**14%**
Total cost of accommodation & care staff, and services	**£29,767 (28,417)**	**£5,197–£202,636**	**100%**

Notes: 1. Sheltered Housing (n = 5) and Probation Hostel (n = 1) are grouped and costs estimated as the same for both. These establishments have separate accommodation for 20–90 residents with very low staffing levels (usually only one person).
2. Includes only the costs for general practitioner and general practice nurse contacts. Data were insufficient to estimate costs for prescribed medications.

Mean total costs for the sample were almost £30,000 with a range from around £5,000 to over £200,000 per year. **Figure 1** shows the distribution of costs with the three most expensive care packages removed from the sample (each of the three were living in 24-hour staffed residential care, and each made high use of hospital services). Most people reported using relatively few services – 70 people had costs of less than £20,000 – with costs for fewer than 20 people accounting for the right-hand skew of the normal curve on the histogram below.

Cost variations in relation to loss of care

Given[4] the data distribution and sample size,[5] analysis of cost variations was challenging, and we advise cautious interpretation. Nevertheless, a sizeable proportion (44%) of those responding to the CSRI questions (n = 143) said they had lost care hours over the period of austerity in health and social care services. Mean costs as shown in **Figure 2** (which links reported changes in care to total services) were lowest for those whose care had remained the same, half of whom lived with their families where care costs were among the lowest anyway. People living with their families are most likely to use the highest level of informal care hours (care provided by families and friends), and we do not know how much of this type of support had been provided or the extent to which these support hours had increased when formal support hours were lost.

People living on their own (63%) and people in 24-hour staffed residential care (58%) were particularly likely to report losses in care hours, as well as 45% of those in supported living arrangements. Comparing the total support costs between those individuals who had lost care and those who had changed/improved/same care produced similar means (**Table 7**), each with large standard deviations. No significant differences in support costs between those who had lost care and those who had not were found, using either an independent samples simple t-test (means; $p = 0.275$), or a non-parametric comparison of medians ($p = 0.681$). This implies a leavening down of higher costs of care – for example, a high proportion of people living in 24-hour staffed residential care had lost care. That loss of care still appeared to result in a tendency to higher mean costs in **Table 7** (a difference of around £5K), may indicate that changed care might have equated with cheaper care, such as a range of specialist day centre activities being replaced with one cheaper activity in the community, even though the care hours had not changed.

These analyses have been undertaken without adjusting for people's characteristics and needs. Using ANOVA, we explored the associations between total costs and seven continuous variables; age; self-esteem and Glasgow Anxiety total scores; the well-being, independence and quality-of-life scores from the Personal Outcomes Scale; and the number of medications each person was prescribed.

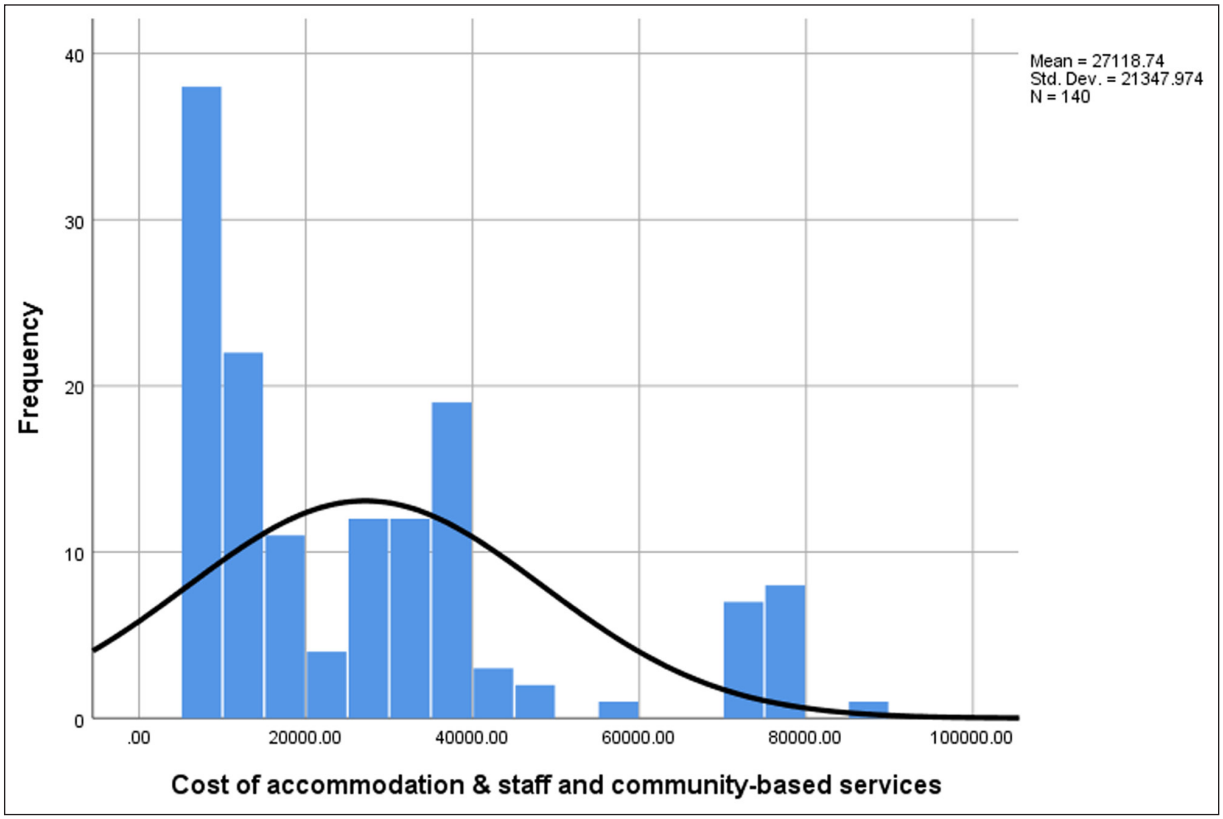

Figure 1: Total costs of accommodation, care staff and community-based services, n = 140.

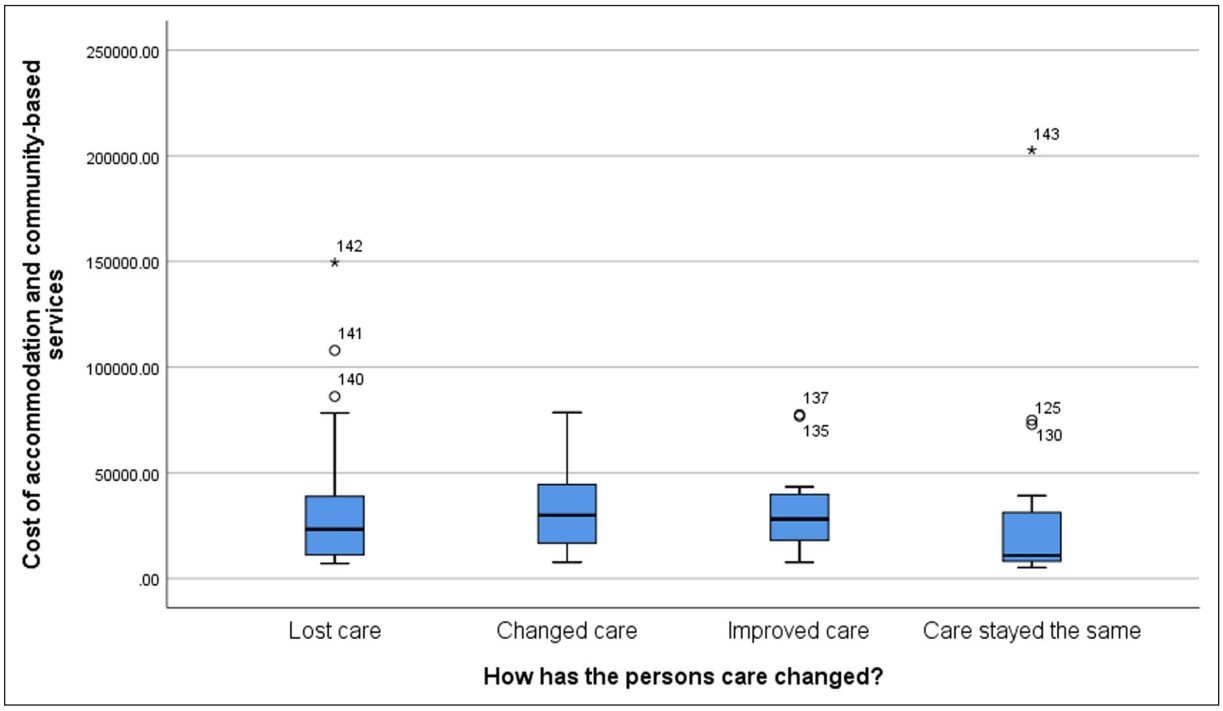

Figure 2: Cost of accommodation & staff by changes in care.

Table 7: Total cost variations between those who had lost care hours and those who had not (n = 143).

		N	Mean	Std. Deviation	Std. Error Mean
Cost of accommodation & staff and community-based services	0 (lost care hours)	63	£32,709.32	28,672.37	3612.38
	1 (care changed, improved or the same)	80	£27,450.63	28,177.53	3150.34

None of the continuous variables were found to be associated with total costs ($p > 0.010$).

A t-test comparing means found no differences in total costs between males and females ($p = 0.397$) nor between those with or without symptoms of anxiety (cut off <13, $p = 0.109$). We did, however, find a significant difference for level of intellectual disabilities ($p = 0.001$) showing these varied in the expected direction, that is, mean total costs were higher for people with severe intellectual disabilities (n = 19, mean cost = £49,210) than for those with mild intellectual disabilities (n = 124, mean cost = £26,788). The non-parametric comparison also suggests median costs are not similar ($p = 0.045$). Looking at the accommodation people lived in, 31% of the people with severe intellectual disabilities lived in the more expensive 24-hour staffed residential homes (and tend to have the highest cost care packages) compared to just 10% of those with mild intellectual disabilities.

Impact of Losing care/support on people's day-to-day lives

The following results demonstrate quantitatively how participants reported aspects of their well-being and the impact of reduced care. To test the association between losing care and activities, social network size, self-esteem, anxiety, and quality-of-life index we formulated analysis sets as follows: Set 1 allowed comparison between individuals who indicated they had lost care with those who indicated they had not lost care (i.e., their care had stayed the same, improved or changed); Set 2 compared only those who indicated they had lost care with those who said their care had stayed the same; and Set 3 compared only those who reported that they had lost care with those who said the care they received had stayed the same or improved.

Activities (including employment and day-to-day activities)

The psychological and social benefits of meaningful activities for individuals with intellectual disabilities have been well reported in the literature (see Forrester-Jones, Heason, and Di'Terlizzi, 2004). They have also long been important policy and practice outcomes (Valuing People Now, 2009). However, we found that for those who answered the question (n = 143), over half were not engaged in any form of voluntary or paid work (53.3%, n = 80); 10.7%, n = 16 were in paid work. Under a third were engaged in voluntary work (27.3%, n = 41), three were engaged in vocational training/apprentice, and three said they were unable to work due to their long-term illness. Six participants indicated that they attended college (2.6%). The number of out-of-home activities participants engaged in a week varied widely (range 0–73 activities; mean = 12) (n = 144). Those who had lost care reported engaging in significantly fewer activities than those who had not lost care[6] and in significantly less social[7] and independent[8] activities a week than those who had not lost care. The majority of activities took place during the day on weekdays with an average of six activities during the week (mean = 6.48, sd = 4.12, r = 0–40, n = 144) compared to just two during the day at weekends (mean = 2.23, sd = 1.38, r = 0–8, n = 144). The quietest time was weekend evenings with an average of under one activity (mean = 0.55, sd = 0.93, r = 0–4, n = 144) compared to an average of two activities per week on weekday evenings (mean = 2.84, sd = 2.98, r = 0–22, n = 144). A quarter of participants who answered this question (n = 138) said they thought they did not have enough things to do (25%, n = 35).

Social networks

Similar to activities, the importance of belonging to a wide and varied social network for individual's wellbeing has been reported (see Forrester-Jones et al., 2002; Forrester-Jones et al., 2006). For our sample, no significant relationship was found between the total network size and lost care. However, individual's social networks were generally small in size (mean = 34; sd = 28; n = 105) these varying widely from 4 to 157 people.

The highest proportion of all participants social network members were from a day centre or supported work setting (29%), followed by a club or church (16%), and family members they did not live with (15%). Visiting and residential staff members made up 11% of all participants social network contacts. A smaller number of participants social contacts were members of their household (7%), public services such as a pub or café (7%), other friends (7%), social acquaintances (4%), or neighbours (4%).

On average, participants reported seeing 17 (sd = 16.82) social contacts with an intellectual disability weekly, 2 (sd = 2) family members and 4 (sd = 20.12) people without an intellectual disability. A large proportion of participants who answered this question (n = 135) said that there was no one to support them to meet new people or spend time with friends (45.9%, n = 62).

Anxiety, Self-Esteem and Quality-of-Life Index

No statistically significant difference in the anxiety score between Sets was observed, but three quarters of participants (74.8%, n = 95 of a total of 127 participants who answered this question) received a score which indicated a clinically significant anxiety level (above 13). Participants who had lost care had significantly lower self-esteem[9] and lower scores on the quality-of-life index (including the domains 'social participation' and 'wellbeing') compared with those who had not lost care.[10]

Experiences of lost care

The statistics reported above indicated that a large proportion of the sample had lost care hours during the period of austerity cuts. The following three themes delineated from the qualitative data demonstrate how losing care impacted on individuals' day-to-day lives. Each theme is exemplified by quotes using pseudonyms.

Theme 1: Loss of 'living normally'

For many participants, loss of 1:1 care support hours resulted in difficulties with everyday tasks, including for example discriminating between 'junk' mail and 'real mail':

> *The Carer used to come in twice a week for one hour... to help me. But* [I] *was reassessed and they know I'm quite capable so the hours were removed...I still need support, I have letters I don't understand. I liked it*

when there was someone there for me when I had difficulties or something I need help with…I don't know what to do with the letters I am getting. I get a lot of them. Need help knowing what-is-what. (Keith)

Reduced care also meant that some participants inadvertently may have lost benefits they were eligible for:

My disability living allowance was stopped in 2016 as I did not file in time…I was in a bad place and I couldn't work out where to go. (Julian)

Social activities and opportunities that represent some level of independence and achievement for individuals were also squeezed due to reduced care. One-to-one bespoke support for individual activities, rooted in positive notions of person-centred care have generally out-performed congregate settings. However, for our study participants, day service erosion – 1 in 3 LAs have closed their day services (Unison Report 2019) – resulted in few if any alternatives:

They are closing the centre where I see my counsellor every month. I will not have one anymore. (Andrew)

I come to [day service] *3 days a week, Monday, Wednesday, and Friday all day…I used to come 5 days per week, 2 days were stopped. This happened this year.* (Mary)

This loss impacted their sense of wellbeing with individuals reporting boredom and frustration:

Not doing anything, I get bored then agitated then annoyed then I get irritable with other people. (Margaret)

Margaret's quote also demonstrates how for many individuals, losing care also led to a sense of worthlessness and disempowerment – feeling that no one cared and/or that they were unable to complain about their situation. Others reported an emotional response to reduced staffing:

… it's very poor the amount of staff, y'know, …erm… staff are leaving, it's upsetting. (Christine)

If losing days and hours of support was felt to be injurious to participants, not being provided with a clear reason for the reduction added to their confusion and perceived powerlessness:

But the social worker came and just took Tuesdays and Thursdays. I'm a bit sort of annoyed really. 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. (Andrew)

I have a support worker… but this has been reduced to 5 hours a week now. There was no review. They just did it…I now have to go shopping on my own. They used to come with me. (Kim)

We used to have arts, and crafts, bingo, now we have nothing…we're just a block of flats. Cos we're disabled nobody cares. Nobody explained to me when hours were cut. We're kept in the dark. (Kate)

Theme 2: Loss of independence as 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:

[I want] *more activities but there's not enough money. They have cut my money and my activities I get money from my mum now which helps.* (Margaret)

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

Others explained how they were told they were not eligible for support or care hours as they have family and friends who could support them (even though under the Care Act they have a legal 'right' to support):

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. (Sasha)

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.* (Tim)

For those who had limited or no family support, seeking help from local charities and public services was their only option.

[Charity name] *is really important to me. It means someone to help and support you….The staff at* [charity] *know I am struggling for money. They will give me things- food as they know I can't afford things. I have been having to go to food banks on a weekly basis.* (Elaine)

In accordance with this, some participants, as represented by Victoria reported being referred to charities by social service representatives if they had lost care:

They couldn't decide what to do with me as I only have a mild learning disability but I have mental health problems – [I was] *told to go to MIND.* (Victoria)

Loss of future aspirations

Hopes of having 'more friends' or a romantic partner, a paid or voluntary job, attending college, or going on holiday were gradually being abandoned as cuts to services became more acute:

I used to work in the resource centre, this has shut down now. (Kathy)

I want to see outside people a bit more often and go on holiday. 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.* (Mark)

Matthew explained how he wanted to move from his family home into more independent accommodation, but this aspiration had been stymied due to a loss of support:

I live with my parents. I would like to move out. I have been waiting for a placement for 15 years. Now the council office I use to go to has closed down. They didn't send me a letter or anything. They have let me down. They can't even be bothered to let me know. I don't know where to apply now. I want to be near my girlfriend. I used to have a social worker. Not anymore. (Matthew)

Many participants who had already lost care, reported stress and anxiety about what the future held for them. This often related to re-assessments of their eligibility for benefits and support:

I have just had a PIP assessment. I am worried they will say I need to lose care. I have just what I need at the moment. I do worry about what will happen in the future. You hear about all those people losing care. My support workers are really important to me. I can't do a lot of things safely on my own. I can't cook on my own because of my dyspraxia. I worry a lot about the future because I have just had to have a PIP assessment. They tell you in 6–8 weeks. My disability is invisible. So people don't always know that I need support. If you saw me in the street you wouldn't know. (Roger)

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. (Suzie)

Finally, some participants gave their views about austerity (i.e., cuts to services) in general. They regarded government austerity measures as the root cause of their inadequate support – 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. (Melanie)

Why should we have to suffer for the government? We can't say anything, it's all cutbacks, everything is cutbacks. We haven't got no rights, everything's taken away from us. (Kate)

Discussion

Our findings prompt serious concerns about how people with intellectual disabilities are faring after a decade of austerity. The largest proportion (42%) of our sample reported that they had lost care. They themselves were aware of their loss and they attributed lost opportunities for support to enable independence to service cuts. Taken as a whole, perhaps we should be encouraged that care for more than half the sample had not deteriorated. However, the fact that only 7% have experienced any improvement in their care does not instil confidence that government policies (e.g., Valuing People, 2001; Valuing People Now, 2009) aimed at improving people's quality of life, are having any lasting effect. This is especially so when we consider that over half of our participants were not engaged in any form of employment (with only 13% receiving supported employment input) and those who had lost care were engaged in significantly fewer independent and social activities compared to those who had not lost care. Three quarters (74.8%) of our sample scored highly for having clinically significant anxiety. Our more qualitative findings indicated that fears about pending cuts to services and benefits could fuel individuals' anxiety. Those who had lost care also had significantly lower self-esteem and quality of life scores including the 'social participation' and 'well-being' domains than those who had not lost care. The social networks of the sample were also impoverished (average network size = 34; and mainly consisted of other people with intellectual disability) compared to mainstream populations estimated to be around 125 (Hill & Dunbar, 2003).

These findings indicate that despite considerable research and practice interventions in the interim decades, the reality is that people with intellectual disabilities remain disadvantaged in terms of health, (McVilly et al., 2006), employment; (Forrester-Jones, Gore & Melling, 2010) and romantic and platonic relationships (Bates et al., 2020). Emerging research also reports how needs assessments fail to translate into outcomes for people with intellectual disabilities and their carers Forrester-Jones (2021). This all weakens our trust that the theoretically laudable Care Act 2014 – premised on promoting a person's 'well-being' and enabling individuals to realise 'normal' life goals (e.g., employment; living in a home of one's own choosing; friendships; and intimate relationships) has had any tangible impact on the lives of people with intellectual disabilities due to poor implementation (see Forrester-Jones, 2021; Glasby et al., 2021). The fact that there has been no government national intellectual disability strategy since Valuing People Now finished in 2012 adds weight to Glasby et al.'s lament that we have experienced a 'lost decade' of adult social care in the UK (Glasby et al., 2021, p. 406).

Our sample included individuals with multiple health problems including age associated illnesses. A significant number (n = 96) were taking prescribed medication and there was a high rate of hospital admissions. At the

same time, the highest proportion of the study participants were living on their own or with family members. National data similarly reports that around two-thirds of adults with intellectual disability in England now live with their families, mainly parents (Cairns et al., 2013; NICE, 2017). This may be regarded largely as a result of consistent government policy that has emphasised community and family-based support (Gant & Bates, 2019). Our study found this type of care arrangement to be the least costly.

Whilst an attractive option for LAs, this low cost masks the likelihood of considerable amounts of unrecorded family care (the economic value of which is estimated to be worth on average £9,000 per carer per annum [Carers UK, 2015]). Yet reliance on family can also lead to feelings of reduced self-sufficiency and independence, fewer opportunities for friendships, and tensions between family members (Forrester-Jones 2021). As people with intellectual disabilities get older, it is sensible to expect that some may want to do older-age-appropriate activities (Wilson et al., 2010). Yet the 'generation gap' between the adult with intellectual disabilities and their parents can also raise tensions since interests, hobbies, and social needs of the family carer may not necessarily coalesce with those of the person with intellectual disabilities (see Forrester-Jones, 2021).

Given the reduction of day-service provision, it is little wonder that many of our participants reported being bored and frustrated. High levels of support can also put a physical and psychological strain on family carers – especially for those who are ageing and in need of social care themselves (Forrester-Jones, 2021). We were not able to gather data for informal carer support or granular level data for key or support workers (e.g., the number of minutes a support worker actually spent with an individual) and thus support received and costs per person may well have been an underestimate. This may also help explain the lack of association found between costs and well-being and social outcomes data. Yet at an individual level, we know that some of the sample (and their carers) had rising needs which would imply a greater requirement for more funded support which, theoretically, is irreconcilable with the pressure on LAs to make social care savings. Further detailed work in relation to how to adequately cost care is needed. In addition, a growing inequality between those who have family members they can rely on and those who do not is also concerning and warrants further investigation.

People living on their own (63%) and people in 24-hour staffed residential care (58%) were particularly likely to report losses in care hours, as well as 45% of those in supported living arrangements. Yet the mean total costs were lowest for those whose care has remained the same over the last decade. Current social care practice, therefore, appears to be in danger of doing more harm than good by inadvertently 'allowing' people with intellectual disabilities to fall into a trap of being less eligible for support to become and/or remain as independent as possible in the community. Squeezing support to the extent that an individual's family/supported living fails can lead to higher costs for 24-hour residential care, the potential loss of skills and well-being of the individual, and thus to higher costs to social services/NHS in the long run.

Limitations and strengths

We were unable to include equal numbers of participants across regions of England as planned, making it difficult to provide a comparative study of austerity impacts. The COVID-19 pandemic has shown how different LAs react to a crisis; six LAs[11] triggered the Coronavirus Act 2020 easements to the Care Act to relax their duties to carry out needs assessments or provide care.[12] Such measures are likely to affect those who have already been impacted by austerity cuts. Given that the Care Act was supposed to eradicate the 'post-code lottery' of care, it would be useful to compare the experiences of individuals under different LAs. Full information on support from home, key, or support workers was not available and therefore our costs data may be underestimated. Costs data were also collected at one time point, so although we know that almost half of the sample had lost care hours during the period of austerity, we do not have any quantitative data around the costs of that reduction and when this occurred. It is also possible that a proportion of our sample (14%) may have lost some support as a result of transitioning from either child health and social care services/education to adult social care (which in the UK generally happens around age[13] 18) or from adult to older care services (at age 66) rather than austerity per se. Despite these limitations, our sample (n = 150 people with intellectual disability) was considerably higher than those of previous studies (Malli et al., 2018) and we were able to provide a detailed picture of how austerity has played out in the lives of people with intellectual disabilities in different areas of England.

Conclusion

Our study has contributed to the hitherto scarce empirical evidence on how austerity measures in the UK have affected the lives of people with intellectual disabilities in England. Similar to services for other groups at risk (e.g., older people), whilst basic needs are often met, 'higher-order' needs (e.g., social, day activities/occupations) are less likely to be actualised and there is a risk that, in the wake of COVID-19 and a pending recession, these latter needs may become secondary. An 'invest to save' approach to services that enable people with mild-to-moderate intellectual disabilities to maintain their well-being would prevent such scenarios. Quality Impact Assessments would also enable LAs to continually consider how their policies or decisions affect people with intellectual disabilities under the Equality Act 2010 s149 (1), which places a duty on the public sector to ensure that its services do not discriminate against those with a disability. By providing a more granular understanding of austerity's impacts, we also found a growing mistrust between recipients and social care providers; we would urge LAs to find ways to sensitively communicate pending service cuts or changes to pre-empt anxiety and fear. This is especially important where staff and service-users have no control over changes. Similarly, it is imperative that social services meaningfully consult with people with intellectual disabilities and

their families about what they have lost and what can be done to improve what social care offers. One recent positive example is documented elsewhere (Forrester-Jones, 2019). We also recommend a closer alignment between health and social care where the responsibility for people with intellectual disabilities is properly 'shared' between the two to avoid people falling between the cracks. Finally, it is baffling to think that a person with intellectual disabilities who needs support to do everyday tasks to maintain their independence is not eligible for support under the Care Act 2014 and we recommend that how social services are interpreting eligibility should be investigated. In 2016, the United Nations stated that reduced budget allocations for social welfare, in addition to health care, employment, and education, have impacted adversely on the human rights agenda (UN Committee on the Rights of Persons with Disabilities, 2016). Policy attempts to mitigate the additional problems COVID-19 has brought to people with intellectual disabilities will also need to take into account the backlog of a decade of cuts.

Notes

[1] NHS Digital In Social care 360: expenditure|The King's Fund (kingsfund.org.uk).

[2] 'Total expenditure' on social care includes spending that derives from three main sources – money which councils allocate to social care from their central budget (including money they raise from the additional 'social care precept' on council tax), income from social care service users (through fees and charges) and income from the NHS.

[3] Parts of these results have been summarised by the project funder the Nationl Institute for Health Research, School of Social Care Research under Forrester-Jones, R, Beecham, J, Randall, A, Harrison, R, Malli, M, Sams, L, Murphy G. 2019. Becoming less eligible? Intellectual disability services in the age of austerity. https://www/sscr.nihr.ac.uk/SSCR-research-findings_RF100.pdf.

[4] These analyses have been undertaken without adjusting for people's characteristics and needs.

[5] A more technical discussion specific to costs is provided by [redacted].

[6] Mann-Whitney U test: **Set 1** U = 1,704,500, P-value: 0.002 n = 143; **Set 2** U = 1,002.000, P-value: 0.003, n = 109 **Set 3** U = 1,152.500, P-value: 0.001, n = 119.

[7] Mann-Whitney U test: **Set 1** U = 1,949.000, P-value: 0.044 n = 143; **Set 3** U = 1,383.500, P-value: 0.042, n = 119.

[8] Mann-Whitney U test: **Set 2** U = 1,148.500, P-value: 0.038 n = 109; **Set 3** U = 1,339.000, P-value: 0.021, n = 119.

[9] Mann-Whitney U test: **Set 1** U = 1,537.500, P-value: 0.027 n = 128; **Set 3** U = 1,124.000, P-value: 0.038, n = 108.

[10] Mann-Whitney U test: **Set 2** U = 530.000, P-value: 0.016 n = 79; **Set 3** U = 694.500, P-value: 0.033, n = 87.

[11] https://www.lawgazette.co.uk/news/councils-move-to-ditch-adult-social-care-duties/5104011.article [Accessed 30/06/20].

[12] https://www.cqc.org.uk/guidance-providers/adult-social-care/care-act-easements-it [Accessed 09/08/21].

[13] Moving from children's social care to adult's social care – NHS (www.nhs.uk).

Acknowledgements

We thank all the participants in this project for their time and willingness to share their experiences of austerity. We also thank our advisory team, including David Oliver and Melanie Henwood. Thanks also go to David Raper and Theodoros Papadopoulos. Particular thanks to Jane Millar, for her constructive comments on the manuscript.

Funding Information

The research was funded by the National Institute for Health Research (NHIR) School of Social Care Research (SSCR) (Grant C088/CM/UKJF-P100). The Tizard research team included Rachel Forrester-Jones (PI) and Glynis Murphy (Co-I), Jennifer Beecham (costs analyst), three part-time RAs (Amy Randall, Melina Malli and Lara Sams) and a PhD student (Rachel Harrison).

The views expressed in this publication are those of the author(s) and not necessarily those of the NIHR SSCR, NHS, the National Institute for Health Research or the Department of Health and Social Care.

Competing Interests

The authors have no competing interests to declare.

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How to cite this article: Forrester-Jones, R, Beecham, J, Randall, A, Harrison, R, Malli, M, Sams, L and Murphy, G. 2021. The Impact of Austerity Measures on People with Intellectual Disabilities in England. *Journal of Long-Term Care*, (2021), pp. 241–255. DOI: https://doi.org/10.31389/jltc.59

Submitted: 17 October 2020 **Accepted:** 09 July 2021 **Published:** 20 August 2021

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