

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

School for Social Care Research

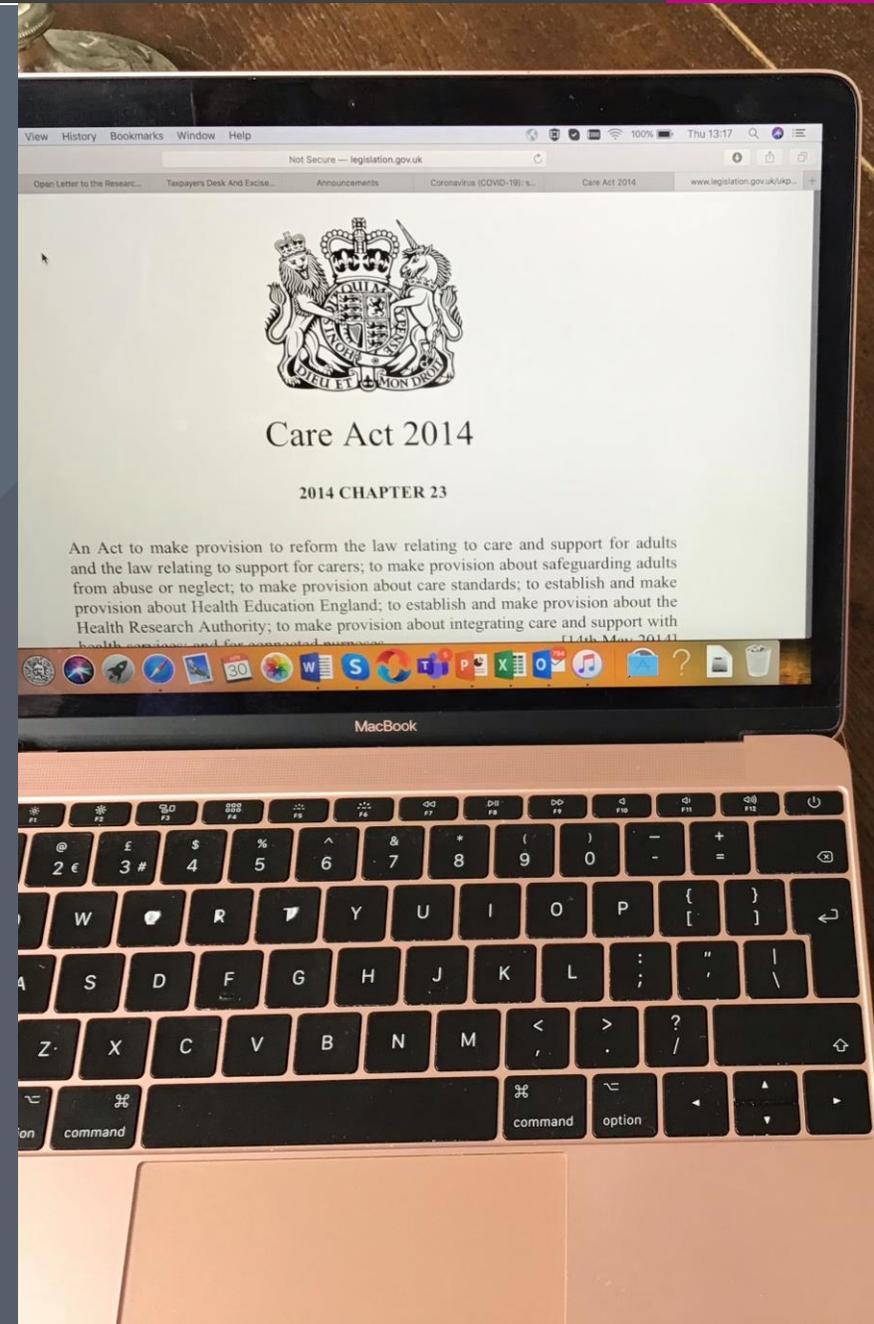
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Care Act 2014: Legal duties of local authorities to:

- assess people's needs
- develop care plans
- financial assessments
- provide care and support

ONE UNIVERSAL ELIGIBILITY CRITERIA

https://www.dropbox.com/s/tukukpc7ymm4rbf/mencap_care.mp4?dl=0



We **aimed** to find out: what impact austerity measures had on people with ID?

Research Team:

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A **systematic review** of the effects of recent austerity measures on the lives of people with intellectual disabilities (11 empirical studies found, 5 in the UK) showed austerity cuts may have led to poorer outcomes for people with intellectual disabilities.

Malli, M., 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*, doi.org/10.1080/09687599.2018.1497950

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.

We interviewed **150 people** with intellectual disabilities about their:

- Quality of Life/Personal Outcomes (Claes et al., 2012)
- Social Networks and activities (Forrester-Jones, 2006)
- Self-esteem (Dagan & Sandhu, 1999)
- Anxiety (Mindham & Espie, 2003)
- Costs of their services (specially adapted Client Service Receipt Inventory (CSSRI, Beecham & Knapp, 2001))
- Space and time for people to tell us about their experiences

Location

- 58% South
- 19% North
- 10% Midlands
- 13% Greater London

Type of accommodation

50% on their own/with their family

29% supported living (with staff support)

13% group home with 24hr staff

6% shared lives placement

1% probation hostel



Average age = 42 (range 18-79)

Male 59%

Mild / moderate 87% **Severe** 13%

Ethnicity

94% White British

1% Black African

1% Black Caribbean

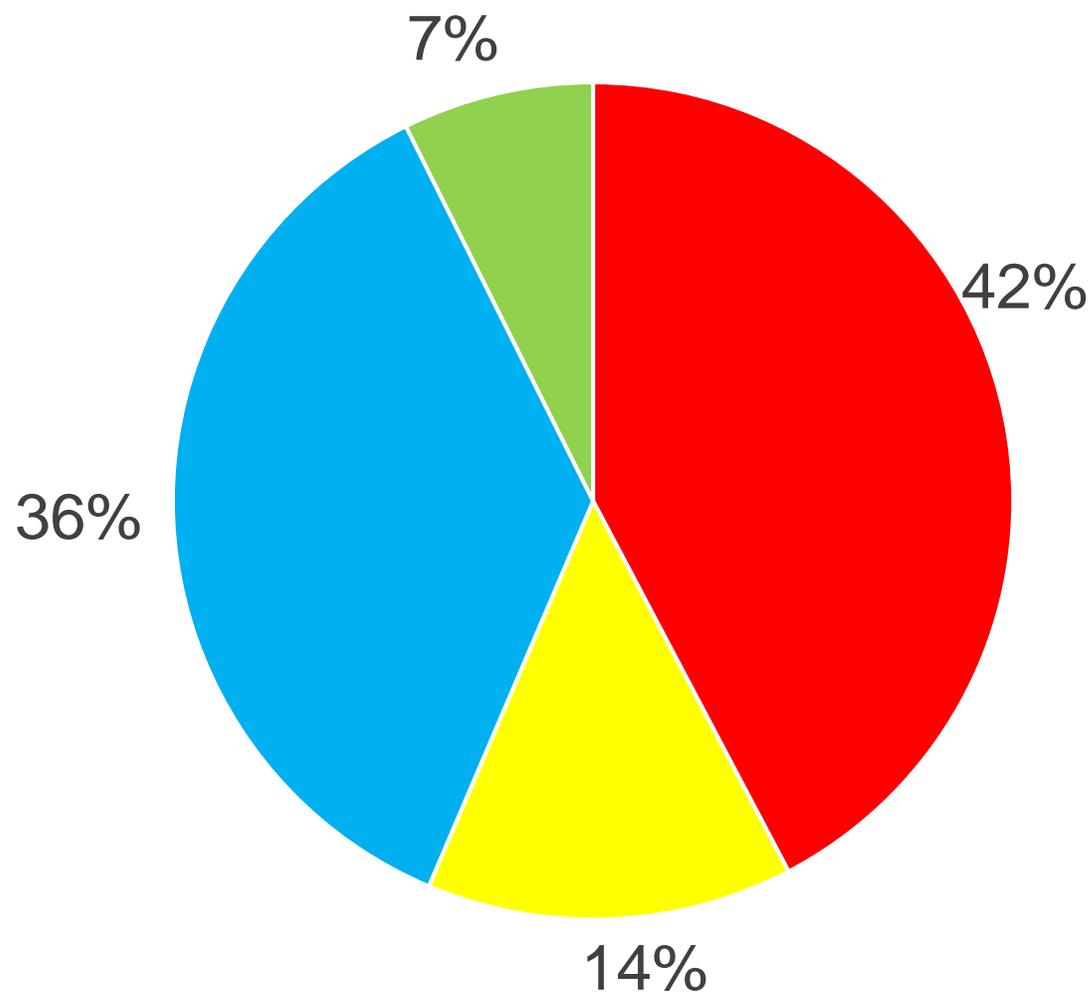
2% Asian

Marital/partner status

88% single



Care in the last 10 years (149 people)



■ Lost ■ Changed ■ Stayed the same ■ Improved

Costs

- Mean total costs – around £30,000 per annum (range from £5,000 to over £200,000)
- Mean costs were lowest for those whose care had remained the same (over half of whom lived with their families) where care costs are amongst the lowest anyway (mean £8,269)
- Most expensive - 24 hour staffed residential homes (around £73,000 a year) – about twice the costs for people in supported living.

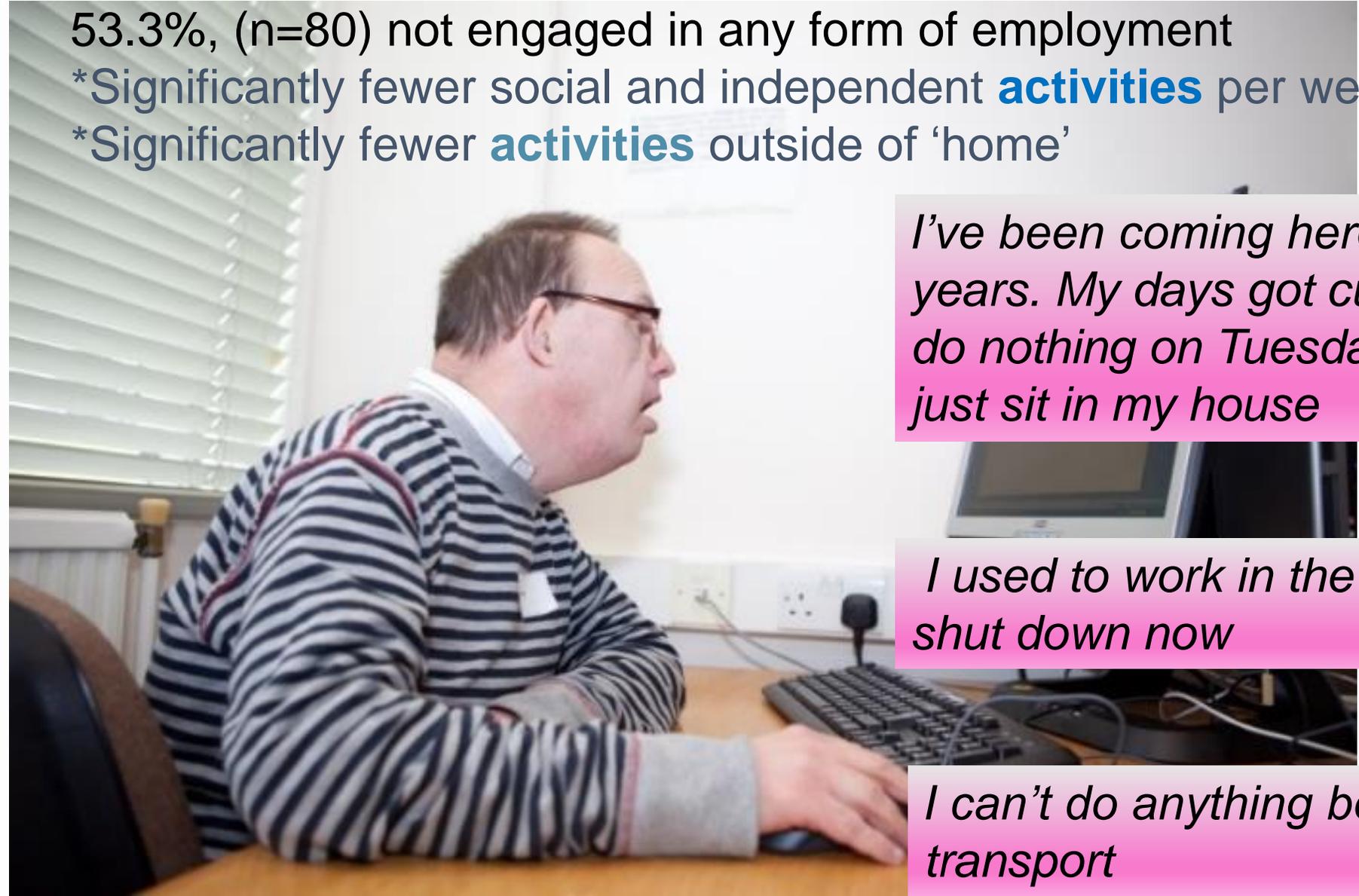
What life looks like for those who have lost care

53.3%, (n=80) not engaged in any form of employment

*Significantly fewer social and independent **activities** per week

*Significantly fewer **activities** outside of 'home'

*P<0.01



I've been coming here [day centre] 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

I used to work in the resource centre, this has shut down now

I can't do anything because of lack of transport

Quality of life, self-esteem, social networks, anxiety

- Those who had lost care had significantly lower scores on the Quality of Life index (including social participation and wellbeing) and lower self-esteem compared with those who had not lost care ($p < 0.01$)
- No difference in network size (mean 34; range 4 to 157) ($n=105$)
- 46% said they had no one to support them to meet new people or spend time with friends
- Three quarters (74.8%, $n=95$) scored highly for having clinically significant anxiety

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

Reliance on third sector and family support

Some had been referred to charities by the council or social services if they had lost care. Others relied on their families.

I live with my parents. I would like to move out. I want to do things myself, wash my own clothes. I could cook if a staff member was there to make sure I didn't burn anything. I have been waiting for a placement for 15 years. Now the council office 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.

Key messages

- **The pressure on LAs to make social care savings is irreconcilable with rising needs of people with Intellectual Disabilities as they get older.**
- **Austerity measures have impacted negatively on the lives of people with Intellectual Disabilities who themselves are aware of their own loss of support – they attribute this to austerity measures**
- **We are starting from after 10 years of reductions in local services, with additional challenges from the impact of COVID-19. These will need to be addressed to support LAs to fulfil their legal duties under the Care Act 2014.**
- **Vast amounts of resources are needed - and the scale of the challenge cannot be under-estimated.**

Thankyou to all the participants