

The Forgotten Story of Social Care:

The case for improving outcomes for working
age and lifelong disabled adults

Part One: The evidence base for change

A County Councils Network and Newton Research Programme

LGA Conference, 23rd October 2024

Scope: What do we mean by 'working age and lifelong disabled adults'?



Anyone in receipt of support from Adult Social Care between the **ages of 18 and 64 years-old**, as well as some **lifelong disabled conditions**

- **Learning Disability**
- **Mental Health**
- **Physical Disability (18-64)**
- **Autism, Neurodiversity, and Sensory**
- **Substance use**
- and any combination of the above...

The changing history for how social care has supported these individuals shows change is possible

1800 – 1900s

Asylum based model

- *“Riveted alive in iron, & for many years confined, in that state, by chains 12 inches long to an upright massive bar in a cell...”*

1960 – 1970s

Hospital model (challenged)

- *1953 half of all NHS beds were for mental illness or mental defect*
- *Hospital scandals (Ely, Normansfield, South Ockendon)*

2000s

Community Model

- *2001 Valuing People; rights, independence, choice and inclusion*
- *2005 Mental Health Act*
- *2011 Winterbourne View scandal*

What next?

1900 - 1950s

Hospital model

- *Eugenics movement*
- *Involuntary sterilisation*
- *1944 Education Act ‘Ineducable’*

1980 – 1990s

Residential Model

- *1981 Education Act (mainstream schools)*
- *1990 NHS and Comm Care Act*

2010s - Now

- *2014 Care Act*
- *Supported Living, Direct Payments, Shared Lives,*
- *Life expectancy tripled for from 1960 to 2010*

Support for working age and lifelong disabled adults is now the largest area of adult social care spend across England

Working age and lifelong disabled adults make up

40%

of all adult social care service users.

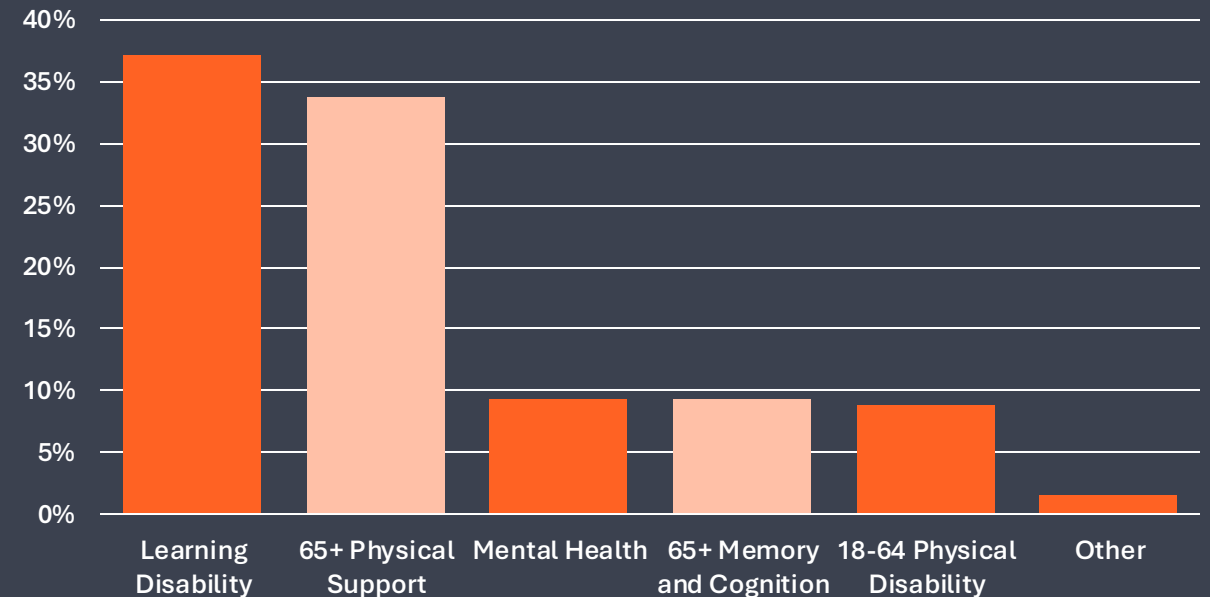
Spend on adult social care accounted for 39% of local authorities' total expenditure in 2023/24.

Of this, spend on social care for working age and lifelong disabled adults now makes up

63%

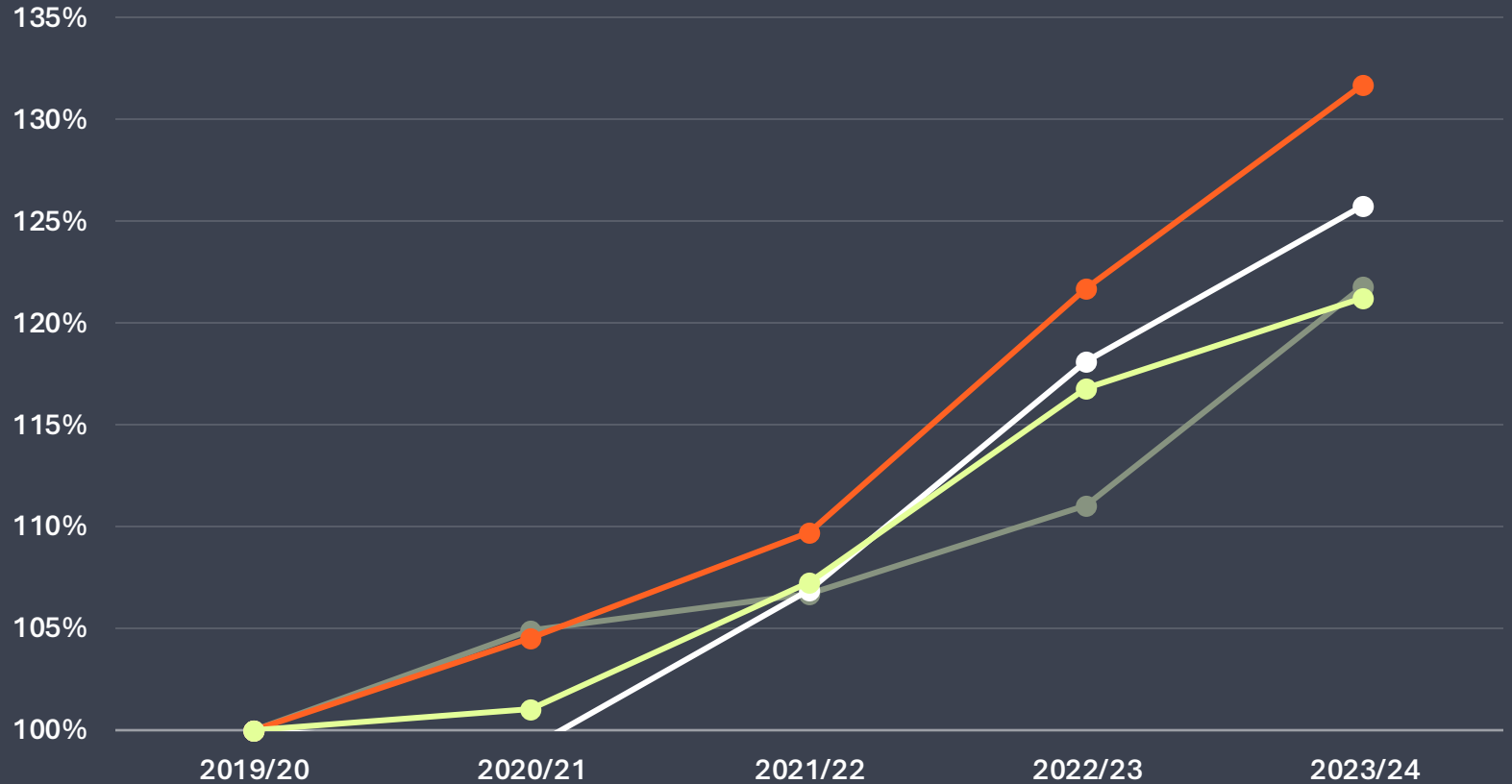
of all adult social care net commissioned spend nationally.

Breakdown of Adult Social Care Gross Commissioning Spend in England FY2022/23 by Primary Support Need



Source: Adult Social Care Finance Return (ASC-FR), Table 18: Gross Current Expenditure on long- and short-term care combined, by age band and primary support reason

Commissioned spend for this group is also growing faster than other areas of Adult Social Care



National commissioned spend on support for Learning Disability and Mental Health have both **risen by over a third between 2020 and 2023**, with forecasts for the recently closed financial year even higher.

This is double the growth we've seen in Physical Support, and significantly outstrips inflation and minimum wage increases.

Note: the total volume of individuals supported for Learning Disability has not risen over this timeline – but rather the level of support per person rising.

- National Minimum Wage
- Working Age and Lifelong Disabled Adults (England)
- Older Adults Physical and Dementia (England)
- CPI

The case for better outcomes for working age and lifelong disabled adults



There is no single, agreed definition of what **good outcomes** could or should look like for working age and lifelong disabled adults, but through the engagement carried out for this programme (including with those with lived experience), several key themes emerged consistently:

- Living a 'gloriously ordinary life'
- Living the lives of value they choose to lead
- Participation in local communities
- Keeping healthy and well
- Living as independently as possible
- Participation in education and employment
- Living a life, not a service
- Progressing throughout life
- Experiencing fairness and opportunity

“Everyone wants to live in a place they call home, surrounded by loved ones, in communities where people look out for one another, doing the things that matter to them.”

SOCIAL CARE FUTURE

Despite rising expenditure, outcomes for these individuals are still behind those of non-disabled peers

Although these outcomes are achieved (to a varying extent) for many individuals, this is not yet the case for all working age and lifelong disabled adults.

- Life expectancy for people with a learning disability tripled between 1960 and 2010, but it is still 20 years shorter than people without a disability.
- In 2022, 42% of deaths of people with a disability were found to have been avoidable, compared to 22% for the general population.
- There are still over 2000 people with a learning disability and/or autism currently in mental health hospitals in England, where people stay for five years on average.
- Working age disabled adults are 2.5 times more likely to leave education with no qualification, and one in two excluded from school are neurodiverse.
- Mencap have found that “people with a learning disability tend to have fewer friends, are less likely to be in a relationship, and have fewer opportunities for socialising than the general population.



About the Programme

The purpose of the first phase of this research programme is to:

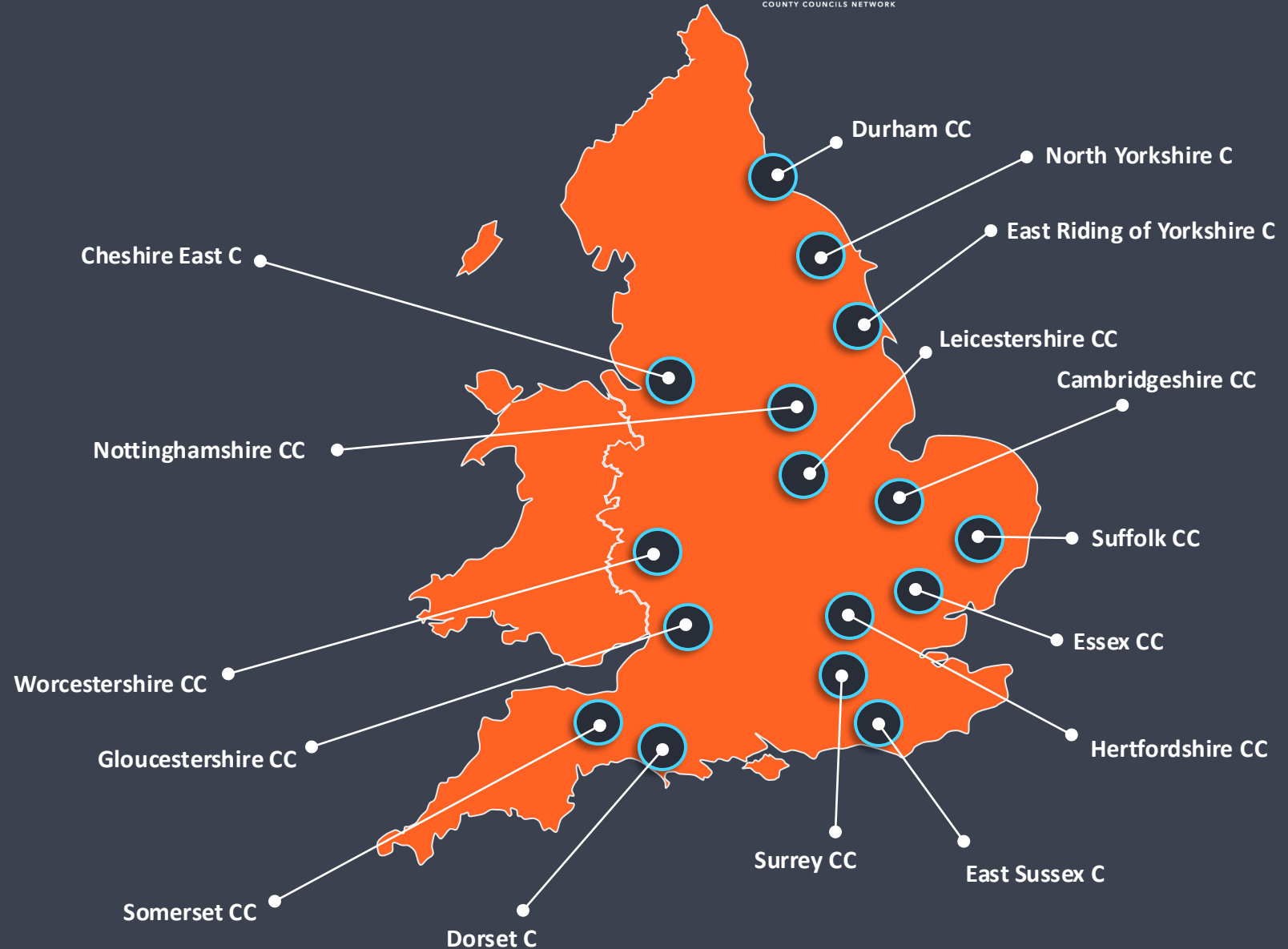
- Raise the profile of the key issues faced by working age and lifelong disabled adults, and the impact on outcomes being achieved. Understand if these outcomes are being achieved in the most effective way.
- Understand the likely changes to demand coming into the system.
- Analyse in detail the different cohorts of these adults receiving adult social care and identify recent trends such as age, deprivation, and changes in package costs.
- Recommend cohorts which might require initial focus of local intervention and national policy.
- Provide a series of recommendations and priorities for local action and national reform.

This programme aims to put **these individuals at the centre of the national conversation on social care** and help start a conversation about the key topics and issues that can make a **meaningful difference to people's lives**.

The programme involved county councils but the findings and recommendations are relevant to all authorities providing adult social care services.

16 local authorities have been involved in the data collection and analysis

Participating Local Authorities	
Cambridgeshire	Hertfordshire
Cheshire East	Leicestershire
Dorset	North Yorkshire
Durham	Nottinghamshire
East Riding of Yorkshire	Somerset
East Sussex	Suffolk
Essex	Surrey
Gloucestershire	Worcestershire



These 16 councils represent 21.6% of all of England's working age adults in receipt of Adult Social Care support

21.6%

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Phase 2 will be published in 2025 and will include:

- Case studies and operating models
- Employment, skills and training, and DWP link in
- 'Prevention' in working age