The forgotten story of social care

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

A County Councils Network and Newton Research Programme
Phase 1: The evidence base for change

Partners

CCN

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Foreword

Councillor Martin Tett

> "The findings in this report highlight some crucial learning for policy makers and professionals alike."

Given that many people think of their local authority's responsibilities as primarily collecting waste, repairing roads, or maintaining parks, it can often come as a surprise that it is actually social care which makes up the vast majority of upper-tier councils' activities. It also makes up the majority of upper tier councils' spending – figures published earlier this year by the County Councils Network showed that across its 37 member authorities, social care for adults and children accounted for 69% of their total budget on average, rising to over 75% for some county councils (where some services such as planning and housing are delivered across a parallel network of District Councils).[i]

The larger part of this social care budget is spent on support for adults, which is most often perceived as being services to support older people in their declining years of life. Indeed as the public discussion over reforming social care has increased in recent years, almost all of the debate has been concentrated on this cohort, with particular focus on what point, and how much, people should be expected to pay for their care.

Yet, again, many people are unaware that in reality, over half of the overall budget for adult social care services is actually spent on adults of working age and those with a lifelong disability. This includes those with a wide range of long-term physical disabilities, mental health conditions or learning disabilities. Despite this group containing some of the most vulnerable people in the country, minimal focus has been given to them in recent conversations about social care reform – an oversight compounded by the fact that charging reform will make hardly any difference to this cohort given that the vast majority do not have assets that would set them above any threshold for self-contributions to their care.

This report aims to start to rectify this oversight by shining a spotlight on this neglected area. Following previous successful collaborative reports including The Future of Social Care[ii], Preparing for Reform[iii], and Finding A Way Home[iv] – all of which have helped to shape national and local policy for social care – the County Councils Network has again partnered with Newton to explore the present situation on the ground.

The findings in this report highlight some crucial learning for policy makers and professionals alike. Whilst the size of the working age and lifelong disabled cohort has remained static in recent years, spending on many individual packages of care has continued to rise – partly driven by the recent period of inflation, but also by statutory increases to the minimum wage which the social care sector is particularly sensitive to given the rates paid to many of the workforce, and by increases in the average level of support provided per person.

There are also grounds for considering how far the number of working age and lifelong disabled individuals needing social care support may rise in the coming years. In particular the dramatic increase in need for children with Special Educational Needs and Disabilities (SEND) over the past decade[v], as well as the widely reported crisis in mental health among young people, suggests that there may potentially be a commensurate increase in demand for support for adult social care around the corner as these children move into adulthood.

In particular, better co-ordination and support for transition between children and adult services needs to be a priority for central and local government alike. Similarly, multi-agency working both within and across councils, and with the NHS, are crucial – the report argues for a more preventative approach to supporting these individuals from an early age. The needs of working age and lifelong disabled adults need to be as large a part of the agenda for Integrated Care Systems as for local authority cabinet meetings.

The findings contained in this document are designed to start debate on how future reform of the social care system can properly address the needs of the diverse range of individuals up and down the country who rely on the support of these vital services to 'live their best life' and push the limits of their potential. The work represents only the start of a journey which CCN and Newton intend to continue into 2025, looking more deeply into specific areas of this wide-ranging collection of services.

That this report has come at a particularly propitious time was unexpected when this work was commissioned – at that time councils were still focused on preparing for previous proposals for social care reform that had been due to come into effect in 2025. Now that these have been abandoned and the new Government is embarking on its own review before determining ways forward for the social care system, we sincerely hope that this timely study can feed in and help to inform next steps in the development of this crucial area touching the lives of so many of our most vulnerable in society.

Councillor Martin Tett
County Councils Network Spokesperson for Adult Social Care and Leader of Buckinghamshire Council

01: Executive summary

Context

40% of people receiving adult social care support in England are working age individuals aged 18–64 with a disabled condition (a learning disability, a physical disability or a mental health condition) who make up the working age adult population, or individuals aged 65+ with a lifelong disabled condition (a learning disability or long-term mental health condition).

Yet historically, there has been less of a national focus on these younger individuals and those with a lifelong disabled condition who require adult social care support to maximise their independence, compared to older adults with declining physical health, frailty, or dementia.

Meanwhile, national expenditure on social care support for working age and lifelong disabled adults has risen by over a third between 2020 and 2023 in England, with forecasts for the 2024 financial year even higher, despite the total volume of individuals in this population supported not having risen over this period.

Most importantly, outcomes for these adults do not appear to be improving in line with this increased expenditure, in terms of health, education, employment, and social interactions and relationships. In addition to improved outcomes, if working age and lifelong disabled adults are enabled to have better and more equitable access to the right education, employment and housing opportunities, they would also be supported to develop the skills to more actively participate and contribute to their local community through work, volunteering, and education, as they make clear is important to them and just as for their non-disabled peers.

It is therefore these two cohorts of individuals (working age and lifelong disabled adults) which this programme of work explores in further detail.

Programme overview

The research programme was commissioned by the County Councils Network (CCN) and delivered in partnership with representative groups from across the health and social care sector, including an advisory group. It has been supported by Newton, who gathered the evidence and insight presented. This involved bringing together analysis from several sources, including national data sets, bespoke data requests provided by a sample group of 16 participating local authorities, and change programmes undertaken by Newton. This was overlaid with the rich insight from many conversations, and the report aims to reflect the breadth and depth of the views, opinions, and examples of good practice shared. Colleagues from across CCN's network of 20 county councils and 17 unitary authorities were invited to contribute.

The purpose of the programme of work has been to:

- Raise the profile of the key issues faced by individuals aged 18–64 with a disabled condition (known as working age adults) and individuals aged 65+ with lifelong disabilities.
- Understand the impact on outcomes being achieved, and 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 in package type, age, deprivation, gender, ethnicity, region, or 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.

In short, this report – the first output from this programme of work – 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**. This is particularly timely given the new Government and the potential Royal Commission on social care, and as a result this report seeks to inform both.

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. However, as Social Care Future defines, "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"[vi].

> "Being independent means having my own life and my mum having her own life. My mum hasn't had a chance just to have her own time, she's always worrying about me."
> **Dan, 27**

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. The report highlights several of the outcome inequalities that disabled people experience, across health, education and employment, and social interactions and relationships, demonstrating the scale of what remains to be achieved.

For example, working age disabled adults are 2.5 times more likely to leave education with no qualification[vii], and while 86% of unemployed people with a learning disability want a paid job (estimated to be approximately 950,000 people in England aged over 18-years-old), only 5.1% of adults with a learning disability known to their local authority are in paid employment[viii].

However, through sector engagement carried out for this programme, all those engaged raised several issues in the current system which they believe to be impeding the delivery of improved outcomes. These are key barriers which stakeholders engaged believe will need to be overcome by local and national government in the coming years, and which will be explored further in the second phase of this programme in 2025.

Model of care: Many of those engaged shared the view that the delivery model for working age and lifelong disabled adults is out of date and needs redesigning.

> "I wish they'd involve me more in planning my care. The social worker often just talks to the carer, not me. It makes me feel invisible."
> **John, 32**

Housing: Inappropriate and insufficient housing was highlighted repeatedly through this programme as a key issue preventing optimal outcomes being achieved for working age and lifelong disabled adults. In particular, the lack of suitable local authority housing was cited as leading to a greater use of supported living, reducing independence and driving up cost.

> "If I had my own house I'd have my own independence. I'm still living at home and we've been trying for years but we keep being told there is no way."
> **Salman, 34**

Whole-system working: Stakeholders agreed that a whole-system and multi-agency approach is essential to both improving outcomes and improving financial sustainability. The interfaces with housing and health were highlighted as being particularly important.

Commissioning and market management: Several authorities engaged said that they are grappling with feeling somewhat 'at the mercy' of local and national chains of care providers who they believe to be resistant to changing packages of support and who are seen to prioritise the more financially lucrative older adult self-funder market.

Many stakeholders also raised issues relating to requirements for high levels of bespoke support (e.g. 1:1 or 2:1 support) being specified as a minimum requirement by providers.

> “I asked for a cleaner as I have trouble with physical things but they won’t give me one, they’re too rigid. It needs to be more centred around the person. You can have some things like entertainment or travel, but if you want something else they seem reluctant, especially if it doesn’t fit in with them.”
>
> **Amy, 46**

Drivers of cost of support

The report explores the key drivers of cost of support for working age and lifelong disabled adults. In doing so it demonstrates that, perhaps surprisingly:

1. Support for working age and lifelong disabled adults has become the largest area of expenditure in adult social care. It made up 63% of the net adult social care commissioned spend in England in the financial year 2022/23 – £10.1bn[ix].
2. This area of expenditure has also been growing faster than any other part of adult social care. Expenditure on support grew by 32% between 2019/20 and 2023/24, which is a faster rate than the growth rate of inflation and the minimum wage, and faster than the growth rate of expenditure on support for older adults.
3. Expenditure is increasing due to the type of care which working age and lifelong disabled adults are receiving. The report demonstrates all areas of adult social care are seeing rising costs due to factors such as inflation and the minimum wage. However, the increase in average level of support per person is higher for working age and lifelong disabled adults than for older adults, and is due particular attention.

The financial analysis undertaken for this report calculates the direct costs of councils' commissioning of care and support, such as residential and home-based care. This makes up the majority of adult social care spend and excludes costs of council staffing and back-office functions.

Increasing demand from transitions to adulthood

In the context of already rising expenditure, understanding further changes to demand coming into the system is particularly important. With the increase in the number of individuals in receipt of local authority support for Special Educational Needs and Disabilities (SEND), many authorities have expressed a need to better understand the likely long-term impact this will have on adult social care services, as they ‘transition’ from childhood to adulthood.

The report explores the expected volume, timing, and potential cost of increasing transitions of younger adults from children’s services over the next 10 years.

There are six key findings:

- **Finding 1:** There will be a temporary 20% increase in the number of all 18-year-olds, peaking in 2030.
- **Finding 2:** The proportion of young people with Education, Health and Care Plans (EHCPs) has increased by 140% and is still increasing. Whilst it is expected that most of this group will not meet the eligibility for ongoing adult social care support, it will nonetheless be likely to lead to an increase in demand.
- **Finding 3:** Combining the above factors, the forecasting carried out for this programme shows that the number of transitions per year is expected to increase, resulting in at least 25% more people a year by 2030.
- **Finding 4:** The number of individuals who will not transition to adult services but who will likely need additional support from the local authority and wider place system is also set to increase.
- **Finding 5:** The forecast net increase in expenditure for support for 18–24-year-olds for adult social care is expected to be at least 40% more by 2030.
- **Finding 6:** The differences in the needs and support for young people transitioning from SEND support to adult social care are wider than most other age categories.

This insight can be used by local authorities to help inform the planning and design of support for working age and lifelong disabled adults.

Improving outcomes for the working age and lifelong disabled adults' population

To better understand the working age and lifelong disabled adults population receiving adult social care in a meaningful and non-anecdotal way, and to help provide an evidence base for targeted improvement activity, this programme conducted detailed analysis into the similarities and differences between different individuals and the ways in which they are supported. This provided a rich and data-led articulation of **12 different groups or cohorts of people** who receive support beyond one reason or individual factor.

Of the 12 main cohorts into which working age and lifelong disabled adults can be categorised, there are **six key cohorts** which – based on the data analysed for this programme – warrant particular attention for authorities seeking to improve both outcomes and the financial sustainability of the support provided. These were identified due to average package costs being typically high, and where significant escalations in cost are evident. These are shown below in order of relative total cohort spend.

1. **LD Cohort Two:** 40+-year-olds with high needs and whose care packages are increasing slightly in cost
2. **LD Cohort Three:** 18–39-year-olds with high needs and whose care packages are increasing slightly in cost
3. **LD Cohort Six:** Individuals with high needs and whose packages of care are increasing significantly
4. **LD Cohort Four:** Individuals with low levels of need and whose packages of care are escalating in cost
5. **MH Cohort Three:** Individuals with average levels of need whose packages of care are increasing significantly in cost
6. **PD Cohort Two:** 40–65-year-olds with average levels of need and whose packages of care are increasing in cost

The report looks in detail at why these cohorts should be a priority, and how outcomes can be improved for them.

Interim recommendations

This programme has identified that, in addition to the imperative to improve outcomes for working-age and lifelong disabled adults, there is a financial necessity to improve the current model of support. Unmitigated without system reform, and with a continuation of current adult social care support trends, analysis indicates that forecast overall expenditure on support for working age and lifelong disabled adults will be 50% more per year – or £6bn more – for England by 2030.

Analysis also indicates that 18–24-year-olds currently account for £1.4bn a year in adult social care support (13% of expenditure on working age and lifelong disabled adults). Although the majority of the increased number of young people with Education, Health and Care Plans (EHCPs) will not be eligible for adult social care support, it is expected that expenditure on support for 18–24-year-olds will grow by at least 40% by 2030 as a consequence of increases in SEND and population growth.

In this context, and based on the engagement undertaken for this programme, there is consensus across the system that there is potential for the scale of system progress to be achieved in the next 5–10 years that has historically taken nearer 30 years to achieve.

To achieve a substantial improvement in outcomes and the financial sustainability of these services, a greater national focus on working age and lifelong disabled adults is vital, involving a more prominent and more transparent debate as to how this can be achieved.

This greater focus also needs to be supported by significant reform at both a local and national level. There is no doubt that reform on this scale will be challenging – local authorities engaged through this programme reported having grappled with the issues identified in this report for many years with varying degrees of success.

The interim recommendations set out below will form the basis of the next phase of this programme, to be delivered in 2025. This second phase will build on the case for change demonstrated in this report and will **look in more detail at what the evidence indicates are the practical changes that should be made** at a local and national level to deliver better outcomes for working age and lifelong disabled adults.

Priorities for national decision-makers

1. **Delivering better outcomes for working age and lifelong disabled adults needs to receive more focus in the national conversation on social care:** Working age and lifelong disabled adults require a greater level of priority from political leaders and central government departments. Support is also required from national bodies essential for sector-led improvement, including research bodies, advocacy groups, charities, and professional bodies. A new policy framework could also be beneficial, for example by refreshing the 2001 Valuing People white paper. Improving outcomes for working age and lifelong disabled adults should be a key focus of the Government's proposed national care service, to support this greater national focus and priority.

2. **Defining a common ambition for exceptional outcomes for and with working age and lifelong disabled adults, with promoting independence and preventing escalation of need at its core:** To know whether optimal outcomes are being achieved with the most appropriate use of resources, it is important to be able to define what this looks like, centred on what working age and lifelong disabled adults say is important to them. If there can be agreement on the aspiration, the most cost-effective means of achieving those outcomes can be identified, and there can be confidence that outcomes and cost are being measured on that basis.

3. **New housing solutions for disabled adults, to help move away from both a reliance on 24-hour residential and nursing placements, and also away from supported living being used due to a lack of alternative housing options:** New housing solutions are required for a wide range of working age and lifelong disabled individuals. Stakeholders engaged for this programme reported that 24-hour residential and nursing placements are often used due a lack of alternative housing options to enable the provision of low-level background support, subsequently significantly reducing individuals' independence and also increasing costs. Additional suitable housing provision is also required to support individuals with moderate levels of need who reportedly rely more heavily on sometimes inappropriate supported living accommodation, due to a lack of suitable local authority housing.

4. **Improved approach to recording and collection of key data relating to care for working age and lifelong disabled adults at a national level, to enable improved understanding and insight:** Although much insight is available already through national returns, the analysis conducted for this programme was constrained by limitations and gaps in the data available nationally. Greater guidance and clarity to improve data collection and recording for local authorities would be likely to significantly improve data quality and the resulting understanding of this population.

5. **A review of national funding for working age and lifelong disabled adults:** There was a widespread view amongst stakeholders engaged that the current means of funding support for working age and lifelong disabled adults is not fit for purpose. An improved national model for working age and lifelong disabled adults is required to ensure that funding comes from the right source and gets to the right place. Furthermore, the analysis for this programme shows that the quantum of funding for working age and lifelong disabled adults also needs to be reviewed. This report demonstrates that the expected unmitigated level of growth in expenditure, even with inflation at low levels, is expected to reach 46% more by 2030 in comparison to current expenditure. This equates to an additional cost of £6bn per year for local authorities and would require significantly more funding to ensure quality and safety of support is maintained.

Priorities for change at a local level

1. **Whole system change for working age and lifelong disabled adults based on their specific needs, not based on an older adults' model.** Stakeholders engaged through this research programme argued that the current delivery model for working age and lifelong disabled adults is out of date and needs redesigning, in close conjunction with people with lived experience and with a wide range of system partners. They agreed that this must continue to be a social model of care and support, not a medical model, and be more strengths-based. The role of local partners should be prioritised, for example maximising the role of education partners. Nationally, the Department for Work and Pensions (DWP) is an example of a partner who could play a different role by supporting better employment outcomes for working age and lifelong disabled adults. Clarifying shared and measurable objectives across partners will help to improve alignment and reduce current fragmentation.
2. **A more effective approach to influencing and managing the market, ensuring that commissioning best practice is implemented, and working with providers to develop a jointly beneficial arrangement.** Several authorities engaged in this programme reported needing to increase their use of more expensive out of area placements to meet local needs or feeling 'at the mercy' of the provider market. There were also reports of 'handbacks' from providers happening more frequently, negatively affecting individuals and often increasing package costs. More widespread use of commissioning best practice could help to address this issue. For example, through more long-term, strategic planning; more rigorous use of local population data to inform commissioning decisions; working with and responding to variation in local provider set-ups; and a more rigorous and consistent approach to managing local markets. In addition, there is potential for commissioning best practice to be shared and implemented more widely across adult social care nationally, so that local authorities are managing their local providers and markets to best effect.

3. **An approach which places maximising individuals' independence at its heart, including long-term planning with providers and with families, to ensure that over-provision of support is minimised**. Innovation and investment is needed to take a more forward-looking, preventative approach and improve longer-term outcomes. Such an approach requires more effective transition planning from an earlier stage, as well as more joined up working with a wider range of partners, in particular schools. An in-depth understanding of different cohorts' needs (as illustrated in this report) will also be important for effective targeting of appropriate preventative interventions, for example identifying key points in people's life journeys where timely and appropriate support can prevent needs from escalating.

4. **A specific focus and investment on the 18–25 transitions cohort to ensure a proactive and joined up approach to meeting the needs of young people, both those who transition to adult services, and those previously in receipt of an EHCP who are not eligible for adult social care but still have needs.** Modelling for this report estimates that there will be at least 25% more 18–19-year-olds transitioning to adult social care by 2030, and the support for 18–24-year-olds will cost at least 40% more for adult social care services by the same year. There will also be increasing demand from individuals who previously had an EHCP but will not be eligible for adult social care. All these individuals are likely to require support from, if not adult social care, other local authority departments and a new approach will be needed to ensure that increased future need is managed and prevented. Specifically, a review may be required of the ongoing model of support from local authorities and partners for individuals with autism only, or social, emotional and mental health difficulties.

Support for working age and lifelong disabled adults made up

63%

of the net adult social care commissioned spend in England in the financial year 2022/23. Expenditure is increasing due to the type of care which working age and lifelong disabled adults are receiving.

Forecast overall expenditure on support for working age and lifelong disabled adults will be

50%

more per year – or £6bn more – for England by 2030.

It is expected that expenditure on support for 18–24-year-olds will grow by at least

40%

by 2030 as a consequence of increases in SEND and population growth.

If we enable working age and lifelong disabled adults to have better and more equitable access to the right education, employment and housing opportunities, **they can lead 'gloriously ordinary' lives.**

In addition to better outcomes, this would also enable them to develop the skills to **more actively participate and contribute to their local community** through work, volunteering, and education.

Working age and lifelong disabled adults make up

40%

of all adult social care service users.

In 2023/24,

63%

of the **net adult social care commissioned support budget** was on working age and lifelong disabled adults.

Expenditure on adult social care support for working age and lifelong disabled adults has **increased by**

32%

between 2019 and 2024. This makes support for working age and lifelong disabled adults the **largest and fastest growing area of expenditure** in adult social care[1]

Increased spending is driven primarily by the **complexity** and **type of care** that individuals are receiving.

The average level of weekly expenditure per individual has **increased by**

31%

between 2019 and 2024.

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(1) Support for working age and lifelong disabled adults makes up 63% of the net adult social care budget in England in the financial year 2022/23 – £10.1bn. This area of expenditure has also been growing faster than any other part of adult social care. Expenditure grew by 32% between 2019/20 and 2023/24, a faster rate than of growth than inflation and the minimum wage, and faster than the growth rate of expenditure on support for older adults.

Outcomes for these adults do not appear to be improving in line with this increased expenditure, in terms of health, education, employment, and social interactions and relationships.

For example:

Life expectancy is **20 years shorter** than people without a disability

Working age disabled adults are **2.5 times more likely** to leave education with no qualification

While **86%** of unemployed people with a learning disability want a paid job, only **5.1%** of adults with a learning disability known to their local authority are in paid employment

Without reform, total council spending on working age and lifelong disabled adults will need to **increase by**

50%

by 2030.

There is an **opportunity to reform the system**, with central government support and local delivery.

This requires a shift to a model of support which **genuinely maximises the independence of each individual**, by developing a care system which is more **aspirational** and **less risk-averse**, and which as a result reduces institutionalisation and over-provision of care.

There are several **key enablers** to making this shift happen:

More focus in the national conversation on social care

Defining a common ambition for exceptional outcomes

New housing solutions for disabled adults

A review of national funding

A combination of crucial local enablers

02: Introduction

Context

40% of people receiving adult social care support in England are individuals aged 18–64 with a disabled condition (a learning disability, a physical disability or a mental health condition) who make up the working age adult population, or individuals aged 65+ with a lifelong disabled condition (a learning disability or long-term mental health condition).

On the one hand, there have been radical shifts in how social care services have supported people with physical and learning disabilities or mental health conditions over the last few hundred years, for example from the use of asylums in the nineteenth century to the community model of today. There has been a step change in attitudes, in the efficacy of support, and in the associated outcomes achieved for these individuals. However, evidence also suggests that there is a strong case for doing more – or doing things differently.

Historically, there has been less focus on younger individuals with a disabled condition and older adults with a lifelong disabled condition who require adult social care support to maximise their independence. Older adults with needs associated with frailty, declining health, or memory issues tend to receive the primary focus of the national narrative. When asked about social care people will often talk about older adults; when searching for social care on news sites, results will nearly all be about older adults; at national health and social care events, the focus is often on older adults; and in a similar way, much of the historical national policy agenda has focused on older adults. There has been no national policy development specifically aimed at improving outcomes for people with a learning disability since the 'Valuing People' white paper in 2001.

Meanwhile, national expenditure on support for working age and lifelong disabled adults has risen by over a third between 2020 and 2023 in England with forecasts for the 2024 financial year even higher. Support for working age and lifelong disabled adults has now become the largest area of expenditure in adult social care, making up 63% of the net adult social care commissioned spend in England in the financial year 2022/23 – £10.1bn[x]. This is despite the total volume of individuals with a learning disability supported not having risen over this period. At the same time, and most importantly, outcomes for these adults do not appear to be improving in line with this increased expenditure, in terms of health, education, employment, or social interactions and relationships.

It is therefore these two cohorts of individuals (working age and lifelong disabled adults) which this programme of work is most interested in exploring in further detail. In doing so, it has sought to put **them 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**. It has also sought to put forward **a series of local and national interim recommendations** for how these individuals can be better supported in a way which improves their life outcomes, while also maximising the use of limited resources.

The interim recommendations put forward in this report will form the basis of the next phase of this programme, to be delivered in 2025. This second phase will build on the case for change demonstrated in this report and will **look in more detail at what the evidence indicates are the practical changes that should be made** at a local and national level to deliver better outcomes for working age and lifelong disabled adults.

Who do we mean by working age and lifelong disabled adults receiving adult social care?

How do adult social care services support people with disabilities?

There has always been a proportion of adults in society who have additional needs or who are vulnerable.

Nearly everyone will at some point in their lives experience a physical or mental health condition that reduces their ability to carry out day-to-day activities (such as a broken limb, a cold or flu, or a period of lower mental health). However, a smaller proportion will experience a physical or mental health condition through which they will experience such an impact for 12 months or more. In 2021, the Office for National Statistics identified that 17.8% of the population of England and Wales were disabled (as defined by the Equality Act and able to be medically diagnosed), equating to over 10 million people[xi]. This group of people includes those with a disability and entering older age, where frailty and declining health is met with a different lifestyle and an increasing need for support, but also includes those with different needs at younger ages.

Some individuals with disabilities will require support from social care services. This is typically offered to those with a higher level of need – less than 10% of the total 10 million people reported to have disabilities in England and Wales[xii]. Whilst these individuals may additionally receive support from the NHS for any medical factors relating to their condition, adult social care's goal is to ensure individuals live a fulfilling life, where they are able to realise their potential to contribute to their local community[xiii] (rather than treating their condition).

Adult social care does this by providing support to help adults of all ages with physical or learning disabilities and autism, mental illnesses, or substance misuse. This can either come from helping them directly or by supporting their carers and networks.

Adult social care and public health services also support many people with alcohol, drug and other substance use issues – these issues can also be a significant factor alongside other presenting issues, and although not the focus of this study, do have an impact on individuals' needs, risks, and associated costs.

Who do we mean by working age and lifelong disabled adults?

A significant proportion (over 60%) of individuals supported by adult social care services are older adults above the age of 65 whose needs have increased, often from declining physical health and frailty, and increasingly from conditions such as dementia. There is a crucial interdependency between adult social care and the National Health Service in supporting this population. This has and will always be a significant group within the health and social care system, and continued innovation and reform is required to ensure that the system is adapting to the changing needs of the people requiring support.

However, almost half (40%) of people receiving adult social care support are either:

- individuals aged 18–64 with a disabled condition (a learning disability, a physical disability or a mental health condition) who make up the working age adult population, or
- individuals aged 65+ with a lifelong disabled condition (a learning disability or long-term mental health condition).

These individuals (who will be termed 'working age and lifelong disabled adults') are the focus of this report.

Purpose of this report

The programme of work was commissioned by the County Councils Network (CCN) and delivered in partnership with representative groups from across the health and social care sector. It has been supported by Newton, who has gathered the evidence and insight presented.

The purpose of the programme of work has been to:

- Raise the profile of the key issues faced by individuals aged 18–64 with a disabled condition (known as working age adults) and individuals aged 65+ with lifelong disabilities.
- Understand the impact on outcomes being achieved, and 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.

In short, this report – the first output from this programme of work – 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**.

It has also sought to put forward a **series of local and national recommendations** for how these individuals can be better supported in a way which improves their life outcomes, while also maximising the use of limited resources. This is particularly timely given the new Government and the proposed Royal Commission on social care, and as a result this report seeks to inform both.

This report begins by describing the historical background to how public services have supported working age and lifelong disabled adults. In this context, Section 4 offers an evidence base which makes the case for opportunities to achieve better outcomes for these individuals.

The report then considers the system supporting working age and lifelong disabled adults, with Section 5 exploring the key drivers of cost for support for working age and lifelong disabled adults, while Section 6 analyses the likely changes to demand coming into the system, specifically from transitions to adulthood for 18–25-year-olds.

Section 7 of the report then looks in detail at the different cohorts of working age and lifelong disabled adults receiving adult social care support. In doing so, it identifies the most significant recent trends in terms of age, ethnicity, deprivation, support type, and package cost. It suggests specific groups of individuals who require the greatest local and national focus when it comes to opportunities to improve outcomes and reduce cost.

Section 8 provides a consolidated summary of the key findings from this analysis, and the report concludes with Section 9 which offers a set of recommendations and priorities for local action and national reform.

03: Methodology

This report is the result of a programme of work which involved bringing together analysis from several sources, including national data sets, bespoke data requests provided by a sample group of 16 participating local authorities, and change programmes undertaken by Newton.

This was overlaid with the rich insight from many conversations; the report is designed to reflect the breadth and depth of the views, opinions, and examples of good practice that have been shared. Colleagues from across CCN's network of 20 county councils and 17 unitary authorities were invited to contribute.

To provide a balance of perspectives, national representatives and colleagues from non-county unitary, metropolitan, and London boroughs also engaged with the research, with a view to developing conclusions that should be relevant to the whole sector.

Engagement

In the summer of 2024, six roundtables and numerous one-to-one conversations were undertaken with leaders from local government. Chief Executives, Directors of Adult Social Services, Directors of Children's Services, and Directors of Finance contributed to the discussions, as well as representatives from the Local Government Association (LGA). Two dedicated engagement sessions were also held with individuals with lived experience, to ensure that their perspective was represented in the research. In total, over 60 individuals contributed.

Advisory group

This work programme was overseen by a cross-sector advisory group. The advisory group's objectives were to:

- set the direction for the work, and ensure a high-quality output
- build cross-sector alignment and broad agreement of the high-level recommendations
- facilitate engagement with wider groups of individuals to input into the research, for example by chairing roundtable discussions
- identify good practice to be included in the analysis and this report.

The advisory group members were:

- James Barber, Head of Adult Social Care Strategy & Briefing, Department for Health and Social Care
- Anna Earnshaw, Chief Executive, West Northamptonshire Council and ACCE Joint Social Care Lead
- Mark Fitton, Director of Adult Social Services, Worcestershire County Council
- Patrick Flaherty, Chief Executive, Staffordshire Council and ACCE Joint Social Care Lead
- Anjan Ghosh, Director of Public Health, Kent County Council
- Jess McGregor, Director of Adult Social Services, London Borough of Camden
- Jackie O'Sullivan, Executive Director of Strategy and Influence, Mencap
- Phil Rook, Chief Financial Officer, Worcestershire County Council and representing the Society of County Treasurers
- Rachael Wardell, Director of Children's Services, Surrey County Council
- Richard Webb, Director of Adult Social Services, North Yorkshire Council, and County Health and Social Care Forum Joint Chair
- Simon Williams, Director of Adult Social Care Improvement, Partners in Care and Health (PCH), Local Government Association

CCN and Newton would like to extend their thanks to all those involved in this programme of work for being so generous with their time, expertise, and support.

Data analysis

This programme of work involved completing in-depth analysis to better understand the working age and lifelong disabled population.

National level insight into the historic and current trends was produced, alongside the forecasting of potential future impact. This included understanding the current and potential future impact on demand for adult services from individuals aged over 18 as a result of growth in SEND provision since legislative changes in 2016.

16 local authorities volunteered to take part in the programme's local analysis, providing detailed data on the working age and lifelong disabled adults they support, their demographics, and the packages of support they received over the last four years (2020/21–2023/24 inclusive). Data from participating authorities received by August 2024 was used for the analysis, which will be updated as required with the participating authorities to support their local analysis. This enabled an evidence-based analysis of:

- their reasons for requiring social care support
- the volumes of individuals receiving different types of social care support
- the costs associated
- other factors which may contribute to need and outcomes, such as age, gender, and levels of deprivation in the local area
- the extent to which any of these factors are staying constant or are changing.

The method used to analyse this information was a popular machine learning algorithm: k-means clustering. This type of artificial intelligence is able to analyse vast numbers of individual cases, and analyse what they have in common, or what links them. The output is then a prioritisation of various factors and a grouping of appropriate features (such as demographic features, costs, and the way costs are changing over time for an individual). This has enabled a rich and data-led articulation of **the different groups or cohorts of people** who receive support beyond one reason or individual factor.

This data was used to build on and enhance local level insight to identify the main characteristic groups most authorities are likely to have, as well as any trends which are unique to particular authorities and regions. This analysis was provided to the 16 participating local authorities.

The 16 participating local authorities represent 21.6% of all of England's working age and lifelong disabled adults in receipt of adult social care support. As much as possible, statistically reliable data sources have been used. However, in some cases, where data is difficult to obtain, small samples have been gathered manually and analysed. In the analysis of national datasets, the data does not always allow for a perfect comparison. While best efforts have been made to navigate this, it inevitably leads to some degree of assumption and approximation. Where this is the case, the data is clearly highlighted.

The financial analysis undertaken for this report calculates the direct costs of councils' commissioning of care and support, such as residential and home-based care. This makes up the majority of adult social care spend and excludes costs of council staffing and back-office functions.

An introduction to disabilities

This report focuses on individuals aged 18–64 with a disabled condition (a learning disability, a physical disability or a mental health condition), and individuals aged 65+ with a lifelong disabled condition (a learning disability or a long-term mental health condition).

The **Equality Act (2010)** shows the variety and breadth of impairments that can lead to a disability, such as:

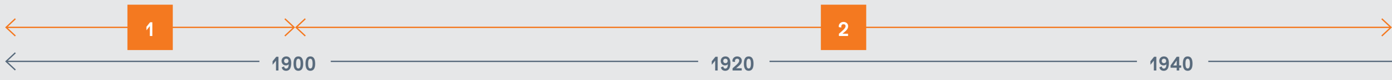
- **sensory conditions** (e.g. visual and hearing impairments)
- **those with fluctuating or recurring effects** (e.g. chronic fatigue syndrome and epilepsy)
- **progressive conditions** (e.g. motor neurone disease)
- **organ specific** (e.g. respiratory conditions such as asthma, and cardiovascular conditions such as heart disease)
- **developmental conditions** (e.g. autism spectrum disorder, dyslexia, and dyspraxia – often recognised under the neurodiversity term)
- **learning disabilities**
- **mental health conditions** (e.g. anxiety, eating disorders, post-traumatic stress disorder and bipolar)
- **mental illnesses** (e.g. depression and schizophrenia)
- and **those caused by injury to the body** (e.g. loss of a limb, or brain damage).

The extent to which these disabilities may impact an individual in their everyday life will vary. Naturally, the severity of the impairment if it is a constant condition makes a difference (e.g. partial or total sight loss), but it is also important to recognise other reasons that will affect the extent of the impact of the condition on an individual's life, including:

- **What the activity is:** few impairments will make every activity equally challenging.
- **How experienced the individual is and what their routine involves:** few people complete an activity for the first time with the same level of assurance and expertise as when they've completed it for the hundredth time.
- **The nature of an individual's environment:** there is often difficulty in replicating something you can do in your own home (often with your own equipment or possessions, on your own, or with familiar company and surroundings) in an alien environment.
- **How adaptable aspects of society are:** much of society is designed for 'average', despite this not typically reflecting how society operates. If important aspects of life are not sufficiently adaptable to different needs, the extent to which someone's condition may affect their ability to interact with that aspect of life may vary.
- **Societal expectations and stigma:** Societal stigma has a very real impact on limiting how someone can complete aspects of day-to-day life. This might include, for example, people with a learning disability being talked to or considered like children into their adulthood.

All of these, similarly as they do for non-disabled individuals, have an impact on individual's ease in completing day-to-day activities, and therefore the type or level of support they may need around them. In addition, these needs are not static – what someone needs in terms of support or adaptations will change throughout their life, for different areas.

Improving social care models for disabled people and people with a learning disability in the UK



1 The Asylum Model – 19th Century

Disabled people called "lunatics" or "idiots".

Those with higher level needs were supported in asylums, prison-like institutions with high walls to prevent escapes, with little to no likelihood of leaving once admitted.

1886 Idiots Act – separated out the distinctions of "lunatics" (those largely with mental illness) and "idiots" (those with a learning disability)[xiv].

There were 120 new asylums in England and Wales by the end of the century housing more than 100,000 people[xv].

2 The Eugenics Movement and National Health Service – 1900–1950

Disabled people called "Moral Defective", "Moral Imbecile", or "Feeble Minded"[xvi].

Eugenics movement prevalent, and in 1934, the Brock Report (a British parliamentary report) advocated for the involuntary sterilisation of disabled people.

Eugenics largely discredited after World War II, but eugenicist agenda still evident in local and national policies[xvii].

Two million newly disabled British servicemen returned from the First World War which led to advancements in prosthetics, employment protection, accommodation, and recognition of some mental illness[xviii].

1944 Education Act determined many disabled young people 'ineducable', and to remain under hospital stays. In parallel, there was a rise in special schools and some amalgamation into mainstream school provisions[xix].

3 The Medical and Hospital Model – 1950–1980

Disabled people called "Subnormal" or "Backward" or "Retard"[xx].

NHS took responsibility for hospital services in 1948, and the model of care became long-stay hospitals, which were often physically isolated institutions managing disability as an illness. There tended to be a poor quality of life for those being cared for, separate and isolated from communities[xxi].

By 1953, nearly half the National Health Service's hospital beds were for 'mental illness or mental defect'[xxii].

1958 Professor Jack Tizard's 'Brooklands Experiment' showed that disabled children living in small houses in the community developed better than those who lived in hospitals[xxiii].

1959 Mental Health Act cemented the move from Victorian asylums to conventional hospital wards[xxiv].

In 1976, the first UK ruling was made that involuntary sterilisation would 'deprive [a woman] of a fundamental right to reproduce'[xxv].

There were eight major hospital inquiries between 1969–79 in England into overcrowding, isolated and impoverished environments of care, poor staffing levels, and a lack of meaningful activity for patients[xxvi].

The last few hundred years have seen radical shifts in how social care services have supported disabled people and people with a learning disability. This shows the different ways in which the same type of conditions can be supported, and the resulting impact on outcomes. With each of these generations, reflections on the progression of models of care and the societal relationship with supporting those with disabilities are possible.

4 The Residential Care Model – 1980–2000

People called "mentally handicapped" or "people with a learning disability"[xxvii].

Increasing numbers of individuals supported in residential care homes in the community. Disability is seen through less of a medical lens, but often still institutional. These homes offered limited tailoring to an individual's needs and tended to be separate from the main community[xxviii].

The King's Fund launched their 'An Ordinary Life' campaign in 1980 – "Our goal is to see mentally handicapped people in the mainstream of life, living in ordinary streets, with the same range of choices as any citizen, and mixing as equals with the other, and mostly not handicapped members of their community."[xxix]

1981 Education Act included that children should be educated in mainstream schools or classes wherever possible[xxx].

1983 Mental Health Act revised, and issue of consent introduced[xxxi].

1990 National Health Service and Community Care Act placed the principal responsibility for community-based care on local authorities. Care was to include a range of services and individual packages of care needed for people. Introduction of direct payments for disabled people to choose the services they wanted[xxxii].

In the late 1990s, the idea of community care for those with a learning disability or mental health illness provoked some anxiety among the public after a small number of incidents involving psychiatric patients were picked up by a largely unsympathetic press[xxxiii].

5 The Community Model – 2000–now

Introduction of Supported Living model *("At the centre of the model is the notion that people with a learning disability should be able to live in their own homes, as tenants or owners, with the support they receive tailored to their own circumstances and needs. Typically, somebody receiving a supported living service will live in their own house or flat, maybe sharing with one or two other people they have chosen to live with.")*[xxxiv].

2001 'Valuing People' was published. It was the first white paper about learning disabilities in 30 years. It was based on four key principles: rights, independence, choice, and inclusion[xxxv].

2005 Mental Capacity Act: Vulnerable people have the right to make their own decisions if they have the capacity to do so[xxxvi].

2010 Equality Act to provide law to tackle discrimination, including disability based[xxxvii].

2011 Winterbourne View Hospital scandal: BBC Panorama programme in May revealed widespread abuse by staff [xxxviii].

2014 Care Act: aims to give greater control and influence to those in need of support [xxxix].

Transforming Care Programme – Homes not Hospitals – to reduce the number of people with a learning disability and autistic people in a mental health inpatient setting and to develop community alternatives to inpatient care[xl].

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

When discussing the evolution in models and in quality of care for working age and lifelong disabled adults during the engagement phase of this programme of work, it typically resulted in both a sense of encouragement and challenge. Encouragement in the scale of progress made in attitudes, efficacy of support, and associated outcomes, but also challenge in terms of how much more progress could be made in a relatively short time frame. It frequently resulted in those providing social care to working age and lifelong disabled adults to look at the current models of care in operation, and to raise questions including:

- Are we achieving the best possible outcomes for the people we are supporting?
- Are we achieving these outcomes in the most effective way?

To start to answer these questions, this section looks at the outcomes being achieved for working age and lifelong disabled adults, and the key barriers identified by sector stakeholders engaged through this programme as impeding improved outcomes.

What do good outcomes look like 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 have emerged consistently.

'Good outcomes' include:

- **Living a 'gloriously ordinary life':** working age and lifelong disabled adults should be able to enjoy a life that feels normal and fulfilling, just like anyone else.
- **Living the lives of value they choose to lead:** individuals should have the freedom to lead fulfilling lives that they find meaningful and valuable, tailored to their personal needs and aspirations.
- **Participation in local communities:** active involvement in the community is essential, ensuring that individuals are not isolated but are integral members of their local communities.
- **Keeping healthy and well:** maintaining health and wellbeing is crucial, in environments that are safe, stable, and protected from harm.
- **Living as independently as possible:** individuals should be empowered to live independently, with support that enhances their autonomy rather than creating dependency. Individuals should have the power to make choices and control their lives, with flexibility and autonomy.
- **Participation in education and employment:** individuals should be able to receive the education opportunities they wish and be employed in jobs they find fulfilling.
- **Living a life, not a service:** the focus should be on enabling individuals to live their lives fully, rather than being merely "service users".
- **Progressing throughout life:** recognising that life involves progression, change, and occasional challenges for anyone – disabled or not. Support should be adaptable to these changes, rather than seeing them as 'complex'. There should be ample opportunities for learning and employment, tailored to individual needs.
- **Experiencing fairness and opportunity:** individuals should experience fairness of opportunities, ensuring that those with disabilities have the same chances as those without. Social care should act as a springboard for equal opportunities, providing more than just a safety net.

Ultimately, as Social Care Future defines, “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”[xli].

> “Being independent means having my own life and my mum having her own life. My mum hasn’t had a chance just to have her own time, she’s always worrying about me.”
>
> **Dan, 27**

There is potential to further improve outcomes for working age and lifelong disabled adults

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. Below are examples of just a few of the outcome inequalities that disabled people experience, highlighting the scale of what remains to be achieved.

Health

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[xlii]. People with a learning disability from Black, Asian and minority ethnic backgrounds are dying even younger. Recent data analysed by Mencap suggests that their average age of death is 34 compared to their white counterparts at 62[xliii].

In 2022, 42% of deaths of people with a disability were found to have been avoidable, compared to 22% for the general population[xliv]. People with a learning disability are twice as likely to die avoidably and four times more likely to die avoidably from causes considered treatable with good quality healthcare than the general population[xlv]. There has been a significant decrease in the use of hospitals as long-term placements for individuals with disabilities. However, there are still over 2,000 people with a learning disability and/or autism currently in mental health hospitals in England, where people stay for five years on average[xlvi].

Only 26% of local areas have no more than 30 adult inpatients with a learning disability and/or autism per million adults in the population, and 33% of local areas now actually have a higher adult inpatient rate compared to the earliest available data[xlvii]. Internationally, some organisations, such as the United Nations, have even begun to argue this practice could be viewed as tantamount to “cruel and inhumane treatment”, or potentially “torture”[xlviii].

> “Too many people with disabilities die, and it’s got worse – doctors don’t listen to us.”
> **Julie, 57**

Education and employment

Working age disabled adults are 2.5 times more likely to leave education with no qualification[xlix], and one in two excluded from school are neurodiverse[l].

There is an inequality of employment outcomes and financial stability between individuals with a disability and those without. Approximately a third of disabled people live in poverty[li] compared to 19% of the non-disabled population[lii], and disabled households require an additional £1,000 per month to have the same standard of living as households without someone with a disability[liii]. 86% of unemployed people with a learning disability want a paid job (estimated to be approximately 950,000 people in England aged over 18-years-old), whilst only 5.1% of adults with a learning disability known to their local authority are in paid employment[liv].

On average, between 2014 and 2022, disabled workers moved out of work at nearly twice the rate (8.9%) of non-disabled workers (5.0%). Workless disabled people moved into work at nearly one-third of the rate (10.0%) of workless non-disabled people (27.3%)[lv].

> “When I was younger I applied for a job and when they found I had a disability they wouldn’t take me on. They didn’t even want to meet me.”
> **Julie, 57**

Social interaction and relationships

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”[lvi].

One in three 18–35-year-olds with a learning disability spend less than one hour outside their home on a typical Saturday[lvii]. They are three times more likely to report feeling lonely than people in the same age group without a learning disability.

People with a learning disability are twice as likely to experience online bullying as those without[lviii], and people with a disability are significantly less likely to develop and maintain loving relationships, particularly sexual and romantic ones, than non-disabled people[lix].

> “I feel lucky because social care helps me, it helps me live in my own home.”
> **Amy, 46**

Barriers to improved outcomes

This section has sought to make the case for improving outcomes for working age and lifelong disabled adults. Through sector engagement carried out for this programme, all those engaged agreed that this group of individuals requires a greater focus and greater priority. However, they also raised several issues in the current system which they believe to be impeding the delivery of improved outcomes.

These are key barriers which stakeholders engaged believe will need to be overcome by local and national government in the coming years, and which will be explored further in the second phase of this programme in 2025.

Model of care

Many of those engaged agreed that the delivery model for working age and lifelong disabled adults is out of date and needs redesigning. New housing solutions was a key priority identified, as well as suitable provision to support individuals with moderate levels of need. Increasingly complex needs are also driving the requirement to question approaches. Stakeholders were keen to explore how in-house provision could be used in new ways to support changing needs, for example by having more flexible, neighbourhood-level background support to enable a wider range of options for individuals when planning their support. This would be likely to improve independence as well as potentially reduce the need for some out of area placements.

The role of local partners was also raised as a priority, for example taking a stronger community strengths-based approach to support and maximising the role of education partners. Nationally, the Department for Work and Pensions (DWP) was used as an example of a partner who could help support better employment outcomes for working age and lifelong disabled adults.

There was a recognition that despite the progress made in models of care in recent history, the new model required for the future will inevitably be more multi-faceted.

> “I wish they’d involve me more in planning my care. Everyone just talks to my support worker, and not me. My doctor, my social worker, shop staff... It makes me feel invisible.”
>
> **John, 32**

Housing

Inappropriate and insufficient housing was highlighted repeatedly through this programme as a key issue preventing optimal outcomes being achieved for working age and lifelong disabled adults.

Due to a lack of local authority housing, many authorities engaged in this programme reported having to use supported living to provide accommodation to individuals with low support needs. Some supported living placements come with a ‘minimum’ amount of support from the provider to warrant a placement (e.g. a set number of 1:1 hours). This limits these individuals’ independence, costs more to the state than local authority housing would, and further places individuals away from the same experiences as their non-disabled peers.

Changing needs also require different housing solutions. For example, with more individuals with a learning disability now being cared for by relatives in their 80s and 90s, there is an increasing risk of care breakdown as carers’ health declines. Supported housing for family units could be an effective way of maintaining family relationships alongside maximising independence, were the provision available.

Whole system working

Stakeholders agreed that a whole system and multi-agency approach is essential to both improving outcomes and financial sustainability. The interfaces with housing and health were highlighted as being particularly important.

There was also agreement that the relationship with the NHS is critical for improvement, with a widespread view that the gap between Care Act and Continuing Healthcare (CHC) eligibility (whereby an individual may be eligible for support from one source but not from the other) is leading to a greater cost impact for local authorities and for the NHS. Several colleagues reported having seen a significant 'cost shunt' from the NHS to the local authority in recent years. This has reportedly occurred through programmes such as Transforming Care and is exacerbated by the premium reported by some to be placed on NHS CHC cases by providers.

Stakeholders engaged through this programme also raised the impact of the lack of availability of NHS specialist services to support people in the community and to enable them to live well. Secondary mental health and learning disability health services reportedly tend to be limited to shorter-term interventions, rather than supporting longer term care and support needs.

Commissioning and market management

Several authorities engaged said that they are grappling with feeling somewhat 'at the mercy' of local providers who they believe to be resistant to changing packages of support and who are seen to prioritise the more financially lucrative older adult self-funder market. There were also reports of 'handbacks' from providers happening more frequently, negatively affecting individuals and often increasing package costs.

There was an appreciation of why providers would not see working with working age individuals of complex needs as an attractive commercial offer – due to the large potential reputational risk and lower profit margins. They also felt that coming to a position where local systems can achieve "a happy individual, a happy provider, and a happy local authority" felt almost impossible.

> “I asked for a cleaner as I have trouble with physical things but they won't give me one, they're too rigid. It needs to be more centred around the person. You can have some things like entertainment or travel, but if you want something else they seem reluctant, especially if it doesn't fit in with them.”
>
> **Amy, 46**

National enablers to support local improvement

Through the engagement there was a widespread view that even though there is much that can be done at a local level to improve outcomes, there are several key national enablers which could facilitate improvement and help overcome key barriers.

For example, some stakeholders questioned whether a new policy framework could be beneficial, such as by refreshing the 2001 Valuing People white paper.

There was also consensus that the current means of funding support for working age and lifelong disabled adults is not fit for purpose, and that the quantum of funding available is insufficient to meet the needs of this group.

Potential national enablers of improved outcomes are explored further in Section 9.

05: Drivers of cost of support

The following section explores the key drivers of cost of support for working age and lifelong disabled adults. In doing so it demonstrates that, perhaps surprisingly:

1. **Support for working age and lifelong disabled adults has become the largest area of expenditure in adult social care.**
2. **This area of expenditure has also been growing faster than any other part of adult social care.**
3. **Expenditure is increasing due to the type of care which working age adults and lifelong disabled adults are receiving.**

1. Support for working age and lifelong disabled adults has become the largest area of expenditure for adult social care and for local authorities

As of 2022/2023, there were 516,000 people over the age of 65 who had received support from adult social care for their physical needs or for dementia support, equating to 60.4% of all people who interacted with adult social care that year[lx].

As demonstrated in Figure 1, whilst working age adults and those with a lifelong disabled condition make up a smaller proportion of the number of people interacting with adult social care (337,910 people in 2022/23, so 40% of the total), they represent the majority of the financial expenditure on support. Support for working age and lifelong disabled adults made up 63% of the net adult social care commissioned spend in England in the financial year 2022/23 – £10.1bn[lxi].

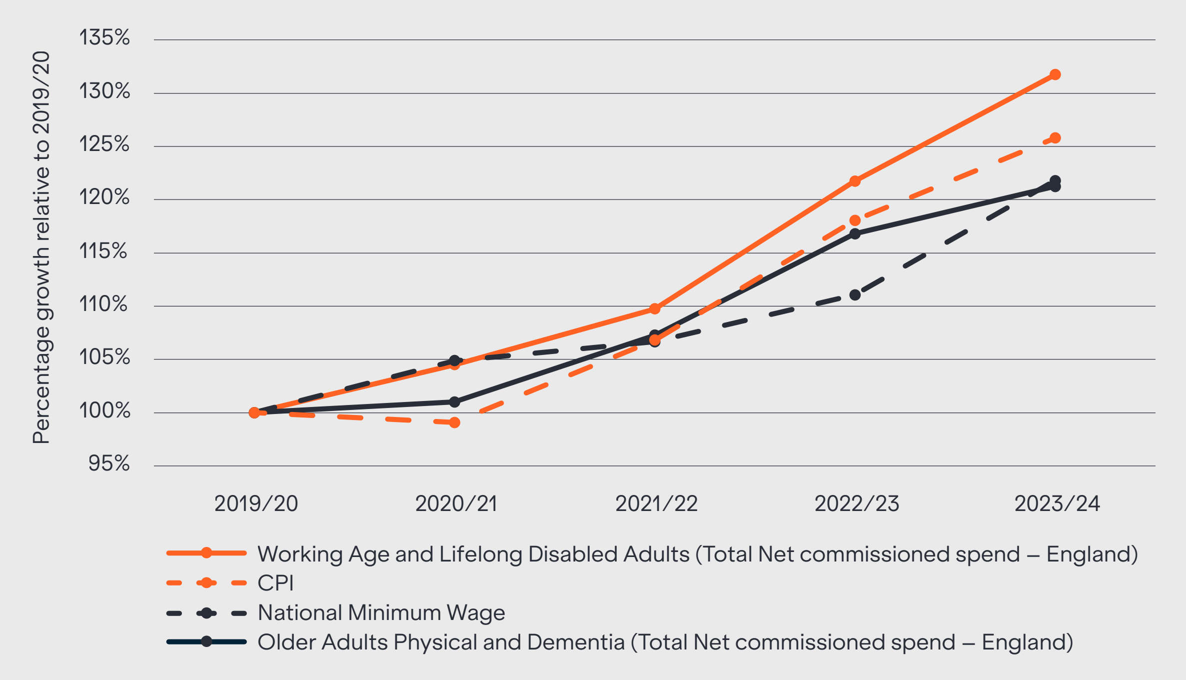
Support for working age adults and those with a lifelong disabled condition is now the largest area of adult social care spend, which itself is the largest budget area in local government. The spend on this cohort alone is equal to the total spend on all children's social care by local authorities[lxii].

Figure 1: Summary of volumes and expenditure 2022/23[lxiii]

2. This area of expenditure has also been growing faster than any other part of adult social care

Alongside being the largest area of spend in adult social care for at least the last five years, it has also been the fastest growing. As shown in Figure 2 below, net expenditure on adult social care support for working age and lifelong disabled adults looks to have increased by 32% from 2019/20 to 2023/24 (from £8.3bn to £10.9bn). This is compared to an increase of 25% for older adults and dementia, and to a 21% rise in inflation over the same time period.

Figure 2: Expenditure on support trends per cohort, 2019 – 2024[lxiv]



3. Expenditure is increasing due to the type of care which working age adults and lifelong disabled adults are receiving

This programme of work has sought to examine various potential factors which may be driving this increase in expenditure. It has found that volumes of people supported and levels of health contributions have less of an impact on expenditure for this cohort than level of support provided.

Expenditure is increasing due to the type of care which working age and lifelong disabled adults are receiving. All areas of adult social care are seeing rising costs due to factors such as inflation and the minimum wage. However, the increase in average level of support per person is higher for working age and lifelong disabled adults than for older adults, and is due particular attention. This is summarised in Figure 3.

Figure 3: Growth in commissioned spend for working age and lifelong disabled adults 2019/20 to 2023/24

Impact on spend growth 2019/20 to 2023/34	Working age and lifelong disabled adults	Older adults physical and dementia
Spend Growth	**132%**	**126%**
Volume changes	1%	0%
Inflation changes (CPI)	21%	21%
Decreases in net contributions as % of spend	0%	7%
Increase in average level of support per person	**10%**	**-2%**

1. Impact of change in the absolute number of people on expenditure

As shown in Figure 4, evidence suggests that the total number of individuals has increased by only 0.7% since 2019/20, and even reduced over the period 2020–2022. The largest and highest areas of expenditure (learning disability, mental health, and physical support) have seen the smallest changes in volume of individuals receiving support. Due to the nature of their underlying condition, the turnover of individuals with a learning disability over a five-year period was only 2.8%, highlighting the very stable and predictable nature of this group of individuals.

Volume may well become more of a factor influencing upward or downward trends in expenditure in the future. For example, there is likely to be an increase in the number of individuals who transition from disabled children's services to adult services due to the increasing volume of, and average expenditure on, new 18-year-olds entering the system (see Section 5 – deep dive on 18–25 and SEND). Conversely, birth rates for the most common high need disabilities have reduced in the last 10 years with the introduction of non-invasive prenatal testing (NIPT) to the UK and which may therefore lead to a reduction in number of individuals and expenditure. For example, Down's Syndrome births are estimated to have decreased by half in the UK[lxv]. The positive change in increasing life expectancy may also translate to some longer-term shifts in trends, but this has not impacted the growth of the last four years.

Figure 4: Number of people accessing long term support from adult social care in England at the end of the year, by age band and primary support reason[lxvi]

	2019/20	2020/21	2021/22	2022/23
Learning Disability Support (18–64)	126,775	125,480	124,635	125,795
Learning Disability Support (65+)	16,070	15,865	16,805	16,690
Mental Health Support (18–64)	44,485	45,120	43,505	45,470
Mental Health Support (65+)	26,980	25,035	25,495	26,790
Physical Support (18–64)	69,950	71,595	71,290	72,775
Sensory Support (18–64)	3,175	3,205	3,250	3,260
Sensory Support (65+)	5,590	5,055	4,775	4,480
Support with Memory and Cognition (18–64)	3,970	4,375	4,435	4,590
Social Support (18–64)	6,120	6,435	6,600	7,045
Social Support (65+)	7,205	6,260	6,470	5,595
	310,320	**308,425**	**307,260**	**312,490**
	100%	**99%**	**99%**	**101%**

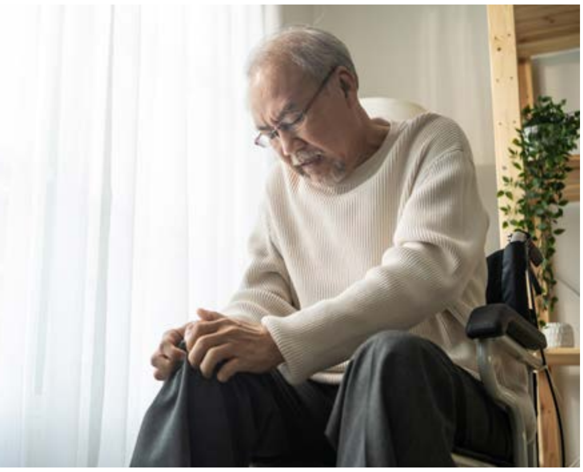
2. Impact of the level of contributions or health funding on expenditure

Evidence suggests that, at a national level, the amount of additional funding contributions towards individual support packages has only changed to a minor extent over the last four years. As illustrated in Figure 5, the overall relationship between gross and net expenditure has stayed close to an average of 91.2%, and the scale of Continuing Healthcare (CHC) and Section 117 contributions (NHS funded care after a hospital discharge for support or services linked to an individual's mental health condition) as a proportion of expenditure have stayed at approximately 6%.

From the data shared by the 16 local authorities who participated in this research programme, the number of individuals in receipt of Section 117 aftercare services has changed minimally, with the proportion of individuals in receipt of support in 2022/23 (6.43% of packages) being the same as 2019/20 (6.44% of packages).

Similarly, at a national level, data from NHS England indicates that the proportion of individuals eligible for NHS CHC has not changed substantially, as illustrated in Figure 5.

There is, however, significant variation in how healthcare contributions are applied regionally. The BBC highlighted earlier in 2024 that "NHS data shows that in some parts of England more than 50% of adults who apply get support. In other areas, it's fewer than 10%, according to data obtained from 33 of 42 NHS Integrated Care Boards (ICBs), who run the schemes"[lxvii].



With the increasing strain on budgets for ICBs – NHS Confederation's 2024 survey found that 90% of ICBs are planning to reduce non-clinical staff costs and redesign their services to meet cost pressure[lxviii] – it is expected that this will feature more as a national pressure on adult social care budgets, if health partners seek to adjust this balance nationally. The ADASS Spring Survey 2024 showed that almost 74% of Directors of Adult Social Care reported an increase in disputes on CHC fundings escalated to local resolution, an increase from 64% in 2023[lxix]. Through the engagement carried out for this programme, many Directors of Adult Social Care raised this issue directly, and described how they are seeing NHS partners 'pulling back' as their budgets tighten, resulting in increased financial pressure on local authorities. Unmitigated, this would likely apply additional increases on expenditure for working age and lifelong disabled adults by adult social care.

Figure 5: CHC and S117 contributions as a proportion of expenditure[lxx]

	2019/20	2020/21	2021/22	2022/23
Net spend as a proportion of gross commissioned spend for working age adults (England)	90.90%	91.40%	91.20%	91.40%
Size of CHC and S117 contributions as a proportion of gross commissioned spend for working age adults (England)	6.30%	6.30%	5.90%	5.80%
Growth in percentage of packages with S117 contributions	100%	103%	103%	100%

3. Impact of changes in inflation or by minimum wage on expenditure

Analysis for this programme indicates that both these factors have had a substantial impact on increasing costs for support for working age adults and individuals with lifelong disabled conditions. As shown in Figure 2, the Consumer Price Index increased by 21.25% from March 2020 to March 2024[lxxi], and the minimum wage in the UK increased at a similar rate of 21.79%[lxxii]. This growth rate has been mirrored in the increasing respective cost of older adults and dementia support.

Whilst inflation over this period has been significant, the increase in costs to support working age adults and individuals with lifelong disabilities has remained above inflation. Figure 2 shows that growth in spend has always been above inflation – an average of 4.7% greater. This would mean that even in a zero-inflation forecast, or a stable 2% every year level, growth in weekly cost would still be expected.

4. Impact of increase in average level of support per person on expenditure

Based on the analysis conducted for this programme, this appears to be the largest unique factor driving expenditure increases for working age adults and individuals with a lifelong disabled condition. The level of weekly expenditure has increased by 31% for working age and lifelong disabled adults since 2019 (as illustrated in Figure 6)[lxxiii].

This is due to more individuals (as a proportion of the total volume, which has not changed) receiving higher cost and higher support-level packages. This is the opposite of the trend seen in older adults' frailty and dementia support, where the average level of support (excluding the level of inflation and changes in levels of net contributions) has seen a slight decrease[lxxiv].

Figure 6: Working age and lifelong disabled adult weekly spend[lxxv]

	2019/20	2020/21	2021/22	2022/23	2023/24
Gross weekly spend	£565.21	£591.59	£624.86	£679.67	£735.40
% growth gross	100%	105%	111%	120%	130%
Net weekly spend	£514.03	£540.50	£569.68	£621.50	£672.45
% growth net	100%	105%	111%	121%	131%

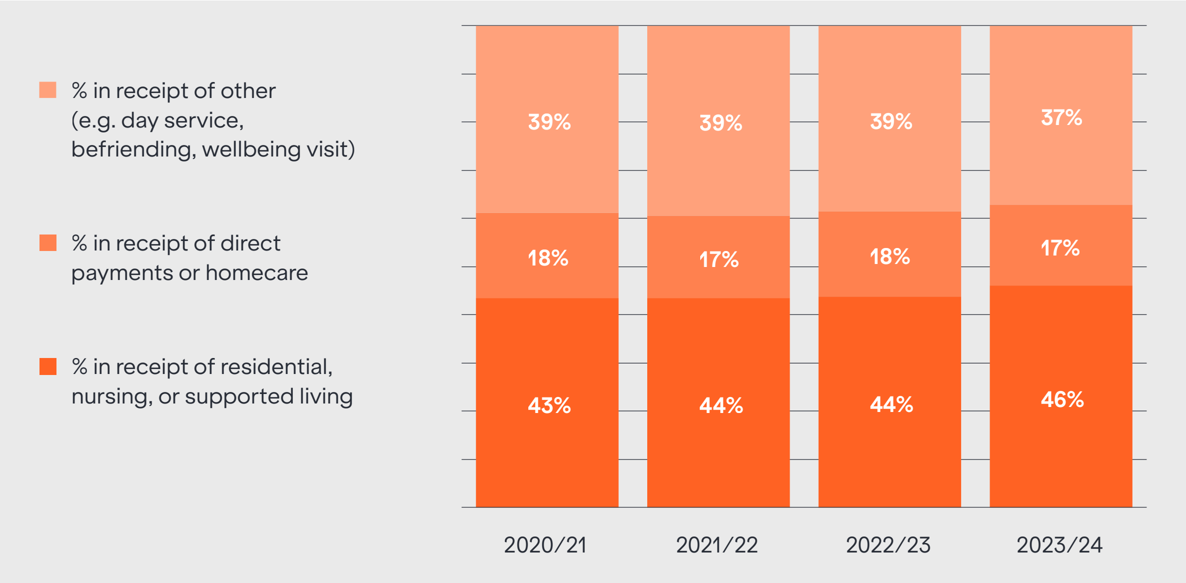
The data analysed for this programme from the 16 participating authorities shows that the proportion of individuals with a learning disability living in residential, nursing, or supported living has increased 3% since 2020/21 (as shown in Figure 7), equating to 9,400 more people. Whilst there has been a slight reduction in overall residential and nursing numbers, this is equivalent to only half of the growth in supported living placements.

Analysis suggests that the average cost of these setting types has increased – for the authorities participating in this programme, residential placements for people with a learning disability have increased 18% since 2020, and supported living by 25%. A greater number of people in higher need settings, with each of these being higher cost, has led to the significant increases in commissioning budget for this cohort. Meanwhile, the proportion of individuals who are in receipt of support that might be described as 'prevention' such as befriending, wellbeing visits, and day services has reduced by 2%, equating to 6,300 fewer people.

One contributor to these various increases in support per person will be the increasing complexity of need – indeed 74% of Directors of Adult Social Care Services reported this in 2024 compared to 67% in 2023[lxxvi]. The life expectancy of disabled adults is increasing, so for example, Alzheimer's is now beginning to present in people with Down's Syndrome more often. This is likely to lead to more substantial differences in support needs in 10–20 years' time given the gradual rate of change.

As outlined above, analysis indicates that the average cost per person supported is increasing, and that there is a higher proportion of working age and lifelong disabled adults in accommodated support settings (supported living, residential, and nursing care). It is possible that the increase in cost per person could be driven, at least partially, by people with less complex needs no longer being deemed eligible for care. The effect of this change would be an increase in the average cost of care per person supported, however, the underlying driver would be an increase in volume as opposed to a change in the type of care provided. However, given that the data available shows that there is a low level of turnover of this population, this therefore suggests that increasing complexity is driving the increase in costs.

Figure 7: Types of support for individuals with a learning disability



Summary

The data outlined above suggests that expenditure is increasing due to the type of care which working age and lifelong disabled adults are receiving. There is a risk that people are receiving more intensive packages of care than they need, which not only reduces independence but also increases cost. Engagement with participating authorities suggests that this is likely to be due to a combination of factors such as changing societal attitudes to risk, increasing expectations from families, and pressure from providers to maintain certain levels of provision.

The next section of this report looks in detail at the specific needs of different cohorts of working age and lifelong disabled adults, how their needs vary by cohort, and potential opportunities to improve outcomes while reducing cost.

06: Increasing demand from transitions to adulthood for 18–25-year-olds

Introduction

In the context of the disparity in outcomes for working age and lifelong disabled adults, and in the context of rising expenditure outlined in the previous section, there are opportunities to optimise the current system of support for these individuals.

Achieving this requires an understanding of:

- The likely changes to demand coming into the system.
- The key characteristics and needs of working age and lifelong disabled adults currently receiving adult social care support.
- The improvement approaches that are likely to improve outcomes and financial sustainability on this basis.

The following section explores the likely changes to demand coming into the system, specifically from 18–25-year-olds transitioning to adulthood.

Section 7 then explores the key characteristics and needs of working age and lifelong disabled adults receiving adult social care support and provides suggestions for the improvement approaches that are likely to improve outcomes and financial sustainability on this basis.

Increasing demand from 18–25-year-olds transitioning to adulthood

Individuals transitioning from support with SEND to adult social care account for a significant proportion of new people requiring adult social care support each year. As a result, it is important to consider how the volume and needs of these people are likely to change in the coming years, to help inform the planning and design of support for working age and lifelong disabled adults.

Engagement carried out for this programme also highlighted the sector's concern about the future impact of transitions on adult social care, and the challenges with modelling potential increases in volume and cost. There was also widespread recognition of the potential impact of current parental expectations of support, and how this can be managed to maximise independence.

With the increase in EHCPs and high needs block expenditure since legislative changes 10 years ago, several Directors of Adult Social Services raised a concern regarding how this growth in size, spend, and need may translate to adulthood, and may therefore create additional pressures on adult services.

About transitions[lxxvii]

Young people transitioning to adulthood require a specific focus and a lifelong approach to managing disability and mental ill health.

Transitioning to adulthood can represent a period of significant change for a young person with care needs, particularly across their wider support network, including their education (they will stop attending school), their relationship with their family, and possibly their accommodation (they may be moving out of the family home). At the same time, this is typically the point where the management of the individual's care and support 'transitions' from children's services into adult social care.

By the time a young person reaches their teenage years, it is often possible to predict whether they are likely to have long-term care needs, as well as what support they will need to continue to prepare them for their adult life, to maximise their chance of living as independently as possible in their community. These young people may need help with the basic skills of day-to-day living, or they may require more complex help such as with managing challenging behaviour or emotional support.

It is essential that children's services and adult social care are communicating throughout the young person's teenage years to ensure that they are achieving the best possible outcomes. This is a common area where authorities feel there is opportunity for improvement.

What do we mean by transitioning to adulthood?

Young people with care and support needs, including physical and learning disabilities and mental ill health, are typically supported by children's services until the age of 18 under the Children and Families Act (although in some cases EHCPs remain in place up to age 25 under individual circumstances to allow additional time for the transition into adulthood). At this point, if they have ongoing care and support needs, they will 'transition' to being supported by adult social care teams. These teams will typically support adults from the age of 18 until the end of their life under the Care Act. There may also be a further 'transition' point later in life from a 'working age' service into an 'older age' service, usually when an individual reaches 65.

'Transitions' often refers to planning for and managing this process. Some services set up dedicated teams and structures to work with young people through this period of their lives. For example, some county authorities have a dedicated transitions team, often supporting children between the age of 16–25, which may sit as part of their children's or adults' service. Others have also constructed whole-life disability directorates – where disabled children and adult teams sit within the same organisational leadership.

Often, young people with physical and learning disabilities and mental ill health, and their families, receive significant care and support. This might include specialist educational support, such as a placement in a specialist residential school; 1:1 (or higher) ratios of care and support at home or in the community; and significant respite support for the family and carers. When transitioning to adulthood the nature of this support will typically change and this can present a challenge for services to ensure the best outcomes can be achieved for the young person and their family.

The future of transitions

What do we expect to happen to future transitions to adulthood?

With the increase in the number of individuals in receipt of local authority support for Special Educational Needs and Disabilities (SEND), many authorities have expressed a need to better understand the likely long-term impact this will have on adult social care services, as they 'transition' from childhood to adulthood.

With the already demonstrated recent increases in cost pressures for supporting working age adults, and the subsequent challenges for authorities in the supply and management of high-quality local placements, understanding any additional demand from transitions is important to deliver a high performing service.

This section explores the expected volume, timing, and potential cost of increasing transitions of younger adults from children's services over the next 10 years.

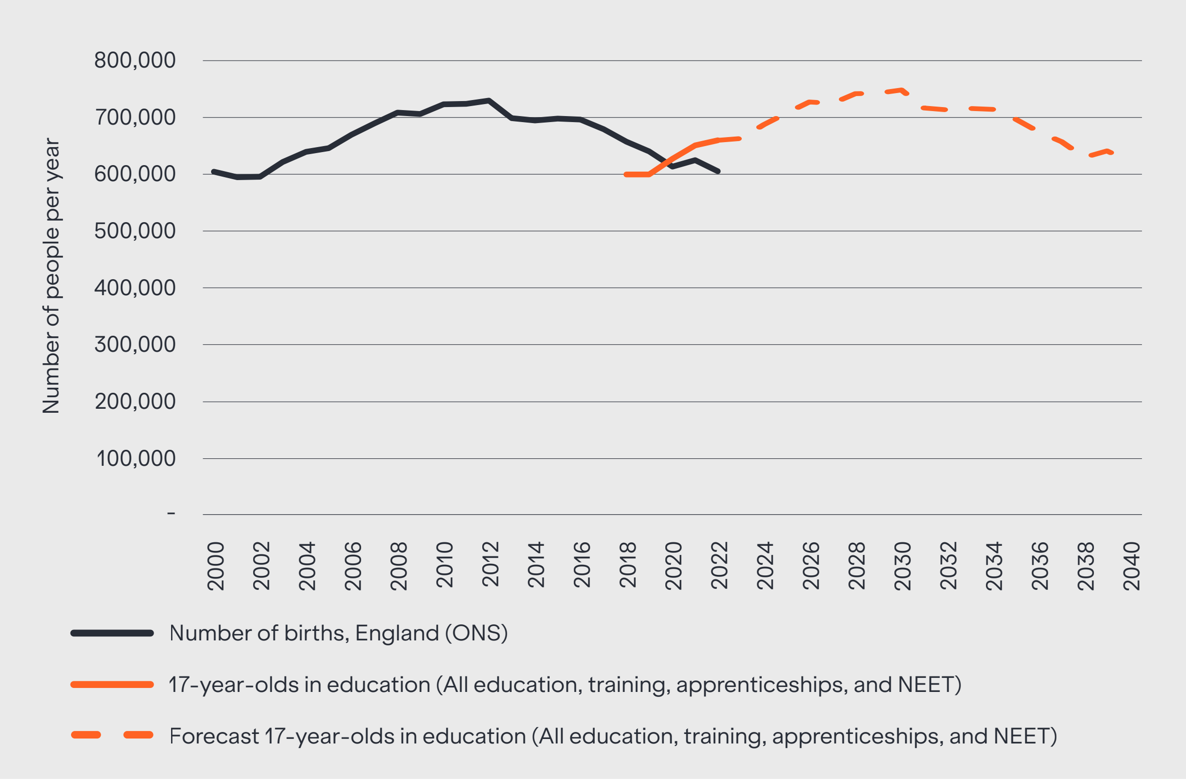
Finding 1: There will be a temporary 20% increase in the number of all 18-year-olds, peaking in 2030.

Across the UK population, there was an increase in the rate of children being born from 2001 (570,000 births in England), reaching its peak in 2012 (695,000 births)[lxxviii]. The number of births at this peak was 22% more than at the start of the century (see Figure 8). This high volume of births has since steadily declined, and the early 2020s saw similar birth rates to the early 2000s.

This group of children born around 2007–2016 (i.e. in the years preceding or following the 2012 peak) has aged through the education system, requiring increasing amounts of resources as a whole group as a response to their greater numbers. For example, there was a record number of Year One school placements (5–6-year-olds) in 2018 (five to six years after the birth peak).

This means there will be an increase in the number of young adults turning 18, regardless of changes in the national SEND system, building up to 2030, at which point the number will start to decline. The below figure shows the forecasted number of 17-year-olds in education, training, apprenticeships, and NEET in 2030 will reach 748,000, 13% more than the 659,000 in 2022/23[lxxix].

Figure 8: Growth in birth rates versus growth in 17-year-olds in education, training, apprenticeships, or NEET



Finding 2: The number of young people in receipt of an EHCP has increased by 140% and is still increasing.

Whilst it is expected that most of this group will not meet the eligibility for ongoing adult social care support, it will nonetheless be likely to lead to an increase in demand.

Individuals with disabilities and higher levels of need are most likely to be those requiring adult social care. As such, a helpful indicator of demand (in addition to volume of total young people) is the proportion of those young people receiving support for Special Educational Needs and Disabilities. Those in receipt of Education, Health and Care Plans (EHCPs) – available for those who require more individualised or intensive support than SEN support can provide – represent those with complex needs and thereby higher provision.

The number of pupils with an EHCP increased by 140% from the school year 2015/16 to 2023/24 (240,183 plans and statements to 575,963[lxxx]), whilst the total number of pupils has only increased by 7% over the same period[lxxxi].

This growth rate in EHCPs nationally is expected to continue. However, it is reasonable to assume that it will not grow exponentially forever (or that 100% of pupils will have an EHCP). One assumption proposed by the Department for Education is that authorities could use a future planning limit – this has been suggested at 6% of the total pupil population[lxxxii]. Despite ongoing growth in EHCPs issued, 6% is being suggested because gov.uk data suggests that fewer than 7% of local authorities have more than 6% of pupils in schools with an EHCP (albeit this has grown by 1.35% in the last year). In comparison, the national rate was 4.7% of pupils in 2023, and 2.8% of pupils in 2015. At the current growth rate in EHCPs, this 6% cap would be reached in late 2029. Uncapped, this would reach 14% by 2036.

However, not everyone with an EHCP will transition to adult services. The threshold of eligibility for an EHCP, informed by the Children & Young People's Act 2008, is not the same as those in adult social care (as set out by the Care Act 2014). Consequently, not all individuals who have an EHCP will meet the threshold for ongoing care and support from adult services.

From the data provided by participating councils, currently 21% of individuals with an EHCP in Year 13 transition onto an adult social care package by their 20th birthday. However, only five of the authorities participating in this programme were able to easily reproduce this data (where those in receipt of adult packages can be linked to whether they were historically or currently (if under 25-years-old) in receipt of an EHCP). This was recognised as challenging by many authorities (or not tracked at all) largely due to children's and adult services often working on separate systems and databases (and within children's, sometime social care and education both being on separate systems).

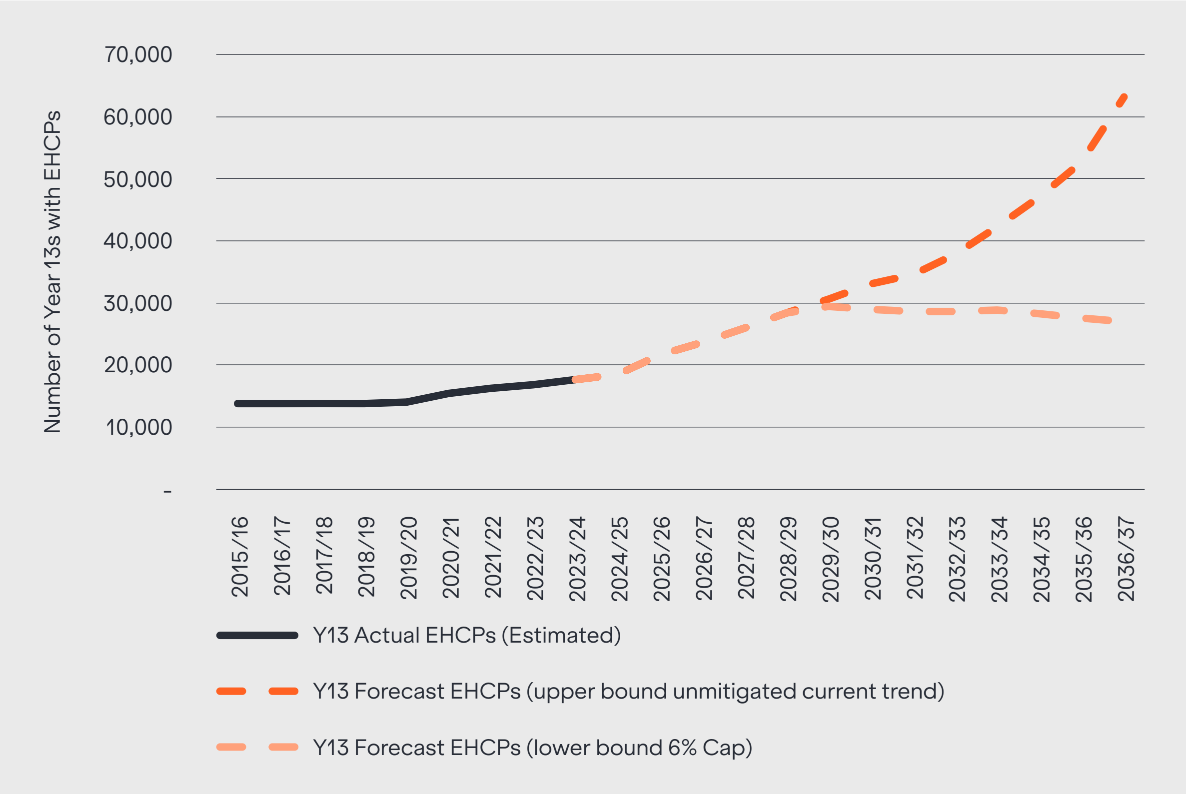
As an EHCP can last until age 25, an individual may potentially transition to adult social care during their early-20s. From the same data, it appears that those who are going to transition are likely to do so before 25. On average, 64% of individuals will commence their adult social care support by their 20th birthday, whilst 36% will start between 20 and 25-years-old. It cannot be deduced from the data what proportion of the 36% had an EHCP.

It also appears that as the proportion of Year 13s with an EHCP increases, the proportion of that cohort who transition to adults' packages decreases. This suggests that the scale of the increase in SEND, or the situational conditions requiring additional EHCPs, does not translate directly to meeting adult social care eligibility. However, this isn't a fully mirrored relationship – i.e. the proportion of individuals transitioning from the SEND system to adult social care is not staying the same.

As an example, in 2021 there were 16,287 Year 13s with an EHCP, and the data from the participating authorities shows that an estimated 21% of these young people started an adult social care commissioned package before their 20th birthday. If this trend continues, then the estimated number of EHCPs for Year 13s will hit 28,000 by 2029, but it would be expected that only 17% of these young people would transition to adult service by age 20. If the EHCP rate continues to as many as 63,000 Year 13s by 2027 with an EHCP, it would be expected that 12% transition.

There is also a proportion of individuals that start adult social care packages aged 18–20 who did not have an EHCP. Based on the data from the participating authorities, this was 20% of all 18–20-year-olds with support.

Figure 9: Current and forecast EHCPs at Year 13



Finding 3: Combining the above factors, the forecasting carried out for this programme shows that the number of transitions per year is expected to increase, resulting in at least 25% more people a year by 2030.

When the above factors are combined (the 20% peak increase in all young person population and the 140% increase in EHCPs, with a declining rate of those who require adult social care support) a forecast number of transitions by year has been developed for this programme.

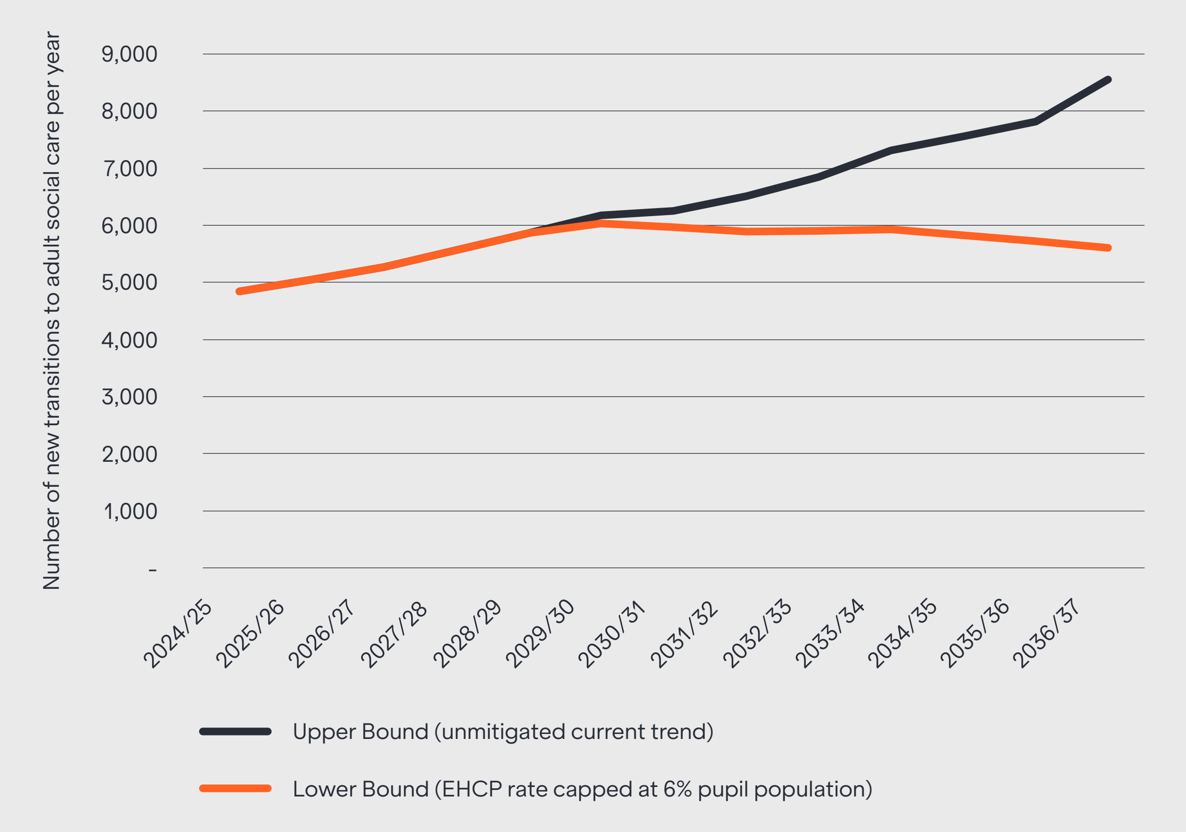
Two versions of the forecast have been developed: a lower bound (more conservative estimate), and an upper bound (a less conservative estimate). For the lower bound forecast, the proportion of pupils with EHCPs was capped at 6% of the total pupil population. For the upper bound forecast, the proportion of EHCPs was not capped and is assumed to continue to grow at its current rate (although the larger the proportion of the pupils with an EHCP grows, the smaller the proportion of that cohort is then forecasted to meet adult social care eligibility).

The lower bound forecast indicates that the number of 18–19-year-olds transitioning from children's services to adult social care each year will increase by 25%. This will mean an increase from 4,800 a year at present to just over 6,000 in 2030 (in line with the population peak described above). This will then gradually decrease to an ongoing rate of 5,500 a year.

This is driven **equally** by the increase in total population (with the anticipated volume of 18-year-olds expected to be 12.5% greater in 2030 than in 2024) and by the increase in EHCP volume – this will predominately be young people turning 18 in 2030 who have already received their EHCP by 2024.

In comparison, the upper bound forecast sees the expected 6% EHCP cap point being exceeded in 2029, reaching 8,500 in 2037, equating to 77% more individuals transitioning to adult social care than at present. This is predominately driven by the rate of EHCP provision continuing as it has done for the past eight years, although the proportion of those transitioning would reduce by half under this forecast (from 24% to 12%).

Figure 10: Forecast number of 18-and-19-year-olds transitioning to adult services annually



Finding 4: The number of individuals who will not transition to adult services but who will likely need additional support from the local authority and wider place system is also set to increase.

As important as the number of individuals expected to transition to adult services is the group of individuals who are not expected to meet the threshold for adult social care. The lower bound forecast indicates that the number of 18-year-olds with an EHCP who will not transition to adult social care will increase by 67% from the current 14,574 to 24,344 by 2030.

Whilst they may not be ‘transitioning to adult social care’, these young people will still be ‘transitioning to adulthood’. These individuals will have had a different level of support and experience during their teenage years than the current generation of adults – they will have experienced less of a mainstream education environment, greater support with everyday activities, and will potentially have had different conversations regarding future expectations for adulthood or what could be achieved for them. This is likely to therefore create a different set of challenges for how local authorities and their partners can best support these individuals.

This cohort will likely have the following impact on local authorities and their local system partners:

- **Assessment volume:** From the data available for this programme, it is only possible to see which individuals are in receipt of packages of support, and not the additional number who had an assessment. However, from engagement with participating authorities, it is clear that more individuals are assessed than those who receive support, with some either not meeting eligibility or having their needs met through different means. For example, if 33% of 18-year-olds with EHCPs are assessed, this would equate to 75% more assessments being carried out by 2030 compared to now.

- **Expectation of outcome:** The change in EHCP legislation has also resulted in a significant national increase in the number of SEND tribunals, whereby parents are taking the local authority to an appeal to contest the decision relating to an EHC assessment or EHCP. There are now nearly four times the number of registered appeals than in 2012, with 98% of these decided in favour of the parents or family[lxxxiii]. Whilst the same tribunal process does not apply in adult social care, this change in attitude and relationship with the local authority could potentially translate to either longer, more complex, and/or more confrontational Care Act assessments. There is likely to be a need for adult social care services to provide more staff and support to manage the greater numbers of assessments needed and the potentially more challenging relationships between parties involved. This was a concern raised by several senior stakeholders in the engagement carried out for this programme. Good practice may also become even more important to ensure good outcomes.
- **Alternative provision outside adult social care:** Even if individuals in this cohort do not meet the threshold for receiving adult social care, they may still need some additional support to ensure they have the best opportunities to prepare for adulthood. There is likely to be a greater demand for other services such as housing, employment, and benefits. This is still an important responsibility for cross-departmental cooperation across the local authority, as well as working more closely with local partners. Central government departments, particularly the Department for Work and Pensions, may see this change in volume create different needs and challenges for their resources.
- **Remaining on an EHCP till 25-years-old:** At present, an EHCP can remain in place until a young person reaches 25 years of age, whether or not that individual is in receipt of adult social care. For those who do not meet the threshold for adult social care, it may be that they will keep drawing on support through SEND for longer. This in turn would put more demand onto the already strained SEND system and create additional financial pressures for the local authority.

Figure 11: Forecast of transitions into adult social care

	Forecast of all transitions into adult social care		Forecast of Y13s with an EHCP not transitioning	
Year	Upper Bound	Lower Bound (capped EHCP @6%)	Upper Bound	Lower Bound (capped EHCP @6%)
2024/25	4,843	4,843	14,574	14,574
2025/26	5,057	5,057	17,581	17,581
2026/27	5,273	5,273	19,310	19,310
2027/28	5,567	5,567	21,397	21,397
2028/29	5,863	5,863	23,524	23,524
2029/30	6,172	6,033	25,339	24,344
2030/31	6,256	5,963	27,356	24,006
2031/32	6,507	5,890	28,652	23,656
2032/33	6,842	5,905	31,369	23,727
2033/34	7,310	5,929	34,995	23,845
2034/35	7,555	5,832	38,943	23,376
2035/36	7,821	5,724	43,633	22,859
2036/37	8,549	5,613	52,293	22,323

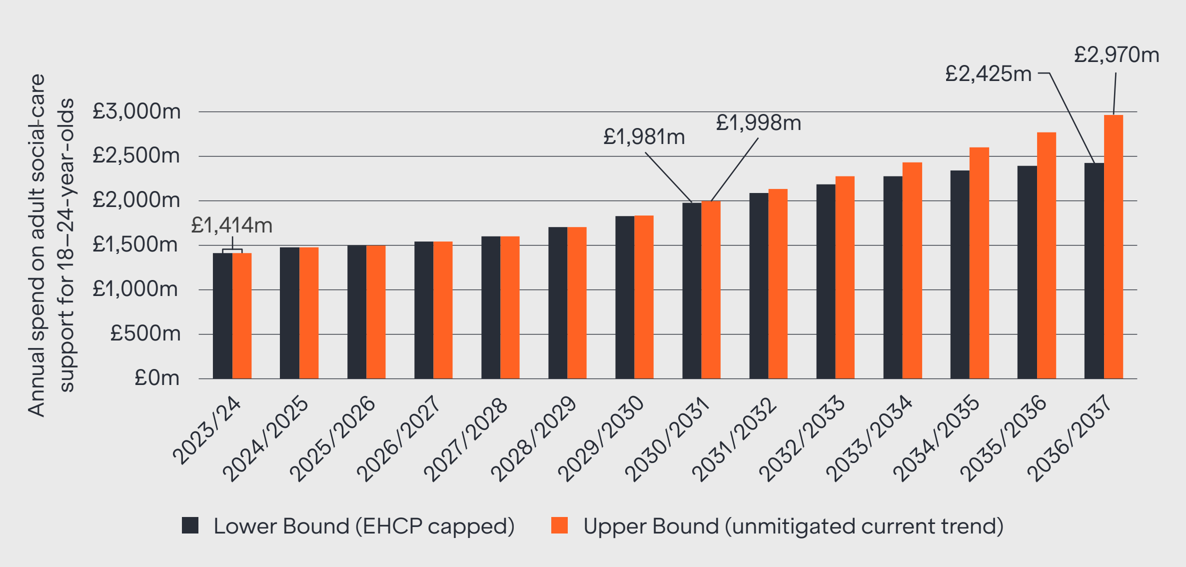
Finding 5: The forecast net increase in expenditure for support for 18–24-year-olds for adult social care is expected to be at least 40% more by 2030.

Based on analysis of the 16 participating local authorities in this programme, in 2024 the average weekly cost of packages of adult social care support for 18–24-year-olds was £597.02 per week. This has increased by 7% since 2021. This is below inflation and is less than the average cost increase for the rest of the working age adults population by nearly a third over the same time period. It has been assumed in the forecasting for this programme that this will continue to increase at the same rate.

As shown in Figure 12, based upon all the factors presented above, the combined forecast indicates that the total net expenditure for support for 18–24-year-olds will reach £1.98bn for England by 2030 in the lower bound scenario. This is in comparison to a forecast of £1.63bn based solely on inflation of 2% each year, and 40% more than current expenditure. By 2036, forecast expenditure is expected to reach 71% more in the lower bound scenario, and 110% more in the upper bound scenario.

The total gross expenditure on adult support for 18–64-year-olds in 2022/23 was £9.4bn, and for all ages and support reasons was £19.4bn. This increase of £584m by 2030 therefore represents an additional pressure equal to 3% of the current total adult social care spend.

Figure 12: Forecast total support expenditure on 18–24-year-olds (inflation assumed at 2% pa)



Finding 6: The differences in the needs and support for this cohort are wider than most other age categories.

As part of this programme of work's cohorting analysis (detailed in Section 7), it was identified that individuals in the 18–25 age range showed such substantial variety in their different features (such as their setting type, package cost, change in cost, and primary support need) that there is little similarity between the young adults in this group. In fact, the differences in their needs and support are wider than most other age categories (many of which are identified in Appendix 1).

This is a notable finding for social care, as it is a group that is often considered together in processes and services. Most local authorities have dedicated Learning Disability or Mental Health specialist teams or workers, as a response to the differences in type of support and features outlined in the next section. Additionally, many councils will have a dedicated 'transitions team' focussed on supporting individuals before their 18th birthday as they look to leave children's services and understand their potential eligibility and plans for adult social care. The analysis for this programme suggests that these teams would see a greater level of variety of individuals than other parts of working age and lifelong disabled adults' operational services.

Summary

Phase 2 of this programme will explore in more detail what the evidence indicates are the practical changes that should be made at a local and national level to deliver the improvements required for working age and lifelong disabled adults.

Nonetheless, there is already strong evidence emerging from within the sector about how targeted, evidence-led improvement can help to offset the forecast rise in demand and expenditure.

For example, in one London Borough, a new service has been created between the council's children's and adults' directorates to support over 200 young people to seamlessly transition from one to the other. As a result, the council has seen a reduction in ongoing support at transition by 21% for those going through this new service, with greater involvement and satisfaction from the young person and their family.

The forecast net increase in expenditure for support for 18–24-year-olds for adult social care is expected to be at least

40%

more by 2030

By 2036, forecast expenditure is expected to reach

71%

more than current expenditure

The number of transitions per year is expected to increase, resulting in at least

25%

more people a year by 2030

07: Understanding the working age and lifelong disabled adult population

Introduction

This report has so far:

- Made the case for why a greater focus on improving outcomes for working age and lifelong disabled adults is important (Section 4)
- Covered the key drivers behind rising costs of support (Section 5)
- Looked at how demand from transitions into the system is likely to change in coming years (Section 6)

The following section now uses both national and local data to highlight the key groups and trends within the current working age and lifelong disabled adults cohorts, to enable insight-led prioritisation and outcomes-focussed improvement.

To better understand the working age and lifelong disabled adults receiving adult social care in a meaningful and non-anecdotal way, this programme conducted detailed analysis into the similarities and differences between different individuals and the ways in which they are supported. This provided a rich and data-led articulation of the **different groups or cohorts of people** who receive support beyond one reason or individual factor.

The following section of the report provides a **summary of the key findings from this cohort analysis** and **highlights the priorities for action and improvement for local system leaders** to address the disparity in outcomes and cost identified.

Opportunities for improving outcomes will be explored more fully in the second phase of this programme (taking place in 2025).

Methodology

Using data provided by the 16 participating local authorities on the working age and lifelong disabled adults they support, their demographics, and the packages of support they received over the last four years (2020/21–2023/24 inclusive), an evidence-based analysis was conducted of:

- their reasons for requiring social care support
- the volumes of individuals receiving different types of social care support
- the costs associated
- other factors which may contribute to need and outcomes, such as age, gender, and levels of deprivation in the local area
- the extent to which any of these factors are staying constant or are changing

The method used to analyse this information was a popular machine learning algorithm: k-means clustering. This type of artificial intelligence is able to analyse vast numbers of individual cases, and analyse what they have in common, or what links them. The output is then a prioritisation of various factors and a grouping of appropriate features (such as demographic features, costs, and the way costs are changing over time for an individual). This has enabled a rich and data-led articulation of **the different groups or cohorts of people** who receive support beyond one reason or individual factor.

The cohorts identified reflect the total population of the working age and lifelong disabled individuals in receipt of adult social care, excluding a small proportion (approximately 3%) who do not meet the characteristics of these cohorts.

Regardless of the focus – whether on age, package type, or other factors – the results of the algorithm consistently showed that the most significant trends emerged based on primary support reasons. Consequently, primary support reason features significantly in the definitions of the cohorts described in this section and in Appendix 1.

There are some challenges using this data field: whilst they are consistent categories used for national returns for all authorities, they are not always applied in the same way by each. Some will have further breakdowns under categories (e.g. 'Physical Support-Access and Mobility' vs 'Physical Support – Personal Care'), some will categorise the same condition differently (e.g. whether alcohol related brain impairment is under mental health or physical support), and some will capture 'secondary support reason' to allow recognition of comorbidities in individuals.

However, primary support reason has been used throughout the cohorts given:

- this is still largely how local authority operational teams are grouped into respective specialisms and therefore how an individual's support is managed (i.e. LD specialists supporting those with an LD primary support reason, even with mental health needs)
- the analysis consistently grouped these individuals into the same cohorts based on their statistical significance

Cohorts of working age and lifelong disabled individuals

Through the analysis the following cohorts were identified (these are shown below in order of the proportion they account for of the total volume of working age and lifelong disabled individuals in receipt of adult social care):

Individuals with a learning disability:

- **LD Cohort One:** Individuals with a very low level of need whose packages of care are not changing in cost
- **LD Cohort Two:** 40+-year-olds with high needs and whose care packages are increasing slightly in cost
- **LD Cohort Three:** 18–39-year-olds with high needs and whose care packages are increasing slightly in cost
- **LD Cohort Four:** Individuals with low levels of need and whose package of care is escalating in cost
- **LD Cohort Five:** Individuals with low levels of need and whose packages of care are not changing in cost
- **LD Cohort Six:** Individuals with high needs and whose packages of care are increasing significantly

Individuals with a mental health condition:

- **MH Cohort One:** Individuals with low levels of need whose package of care is not changing in cost
- **MH Cohort Two:** Individuals with high levels of need whose packages of care are increasing slightly in cost
- **MH Cohort Three:** Individuals with average levels of need whose packages of care are increasing significantly in cost

Individuals with a physical disability:

- **PD Cohort One:** 40–65-year-olds with average levels of need and whose packages of care are not changing in cost
- **PD Cohort Two:** 40–65-year-olds with average levels of need and whose packages of care are increasing in cost
- **PD Cohort Three:** 26–39-year-olds with higher levels of need and whose packages of care are increasing slightly in cost

The proportion that each cohort makes up the total working age and lifelong disabled population receiving adult social care is illustrated in Figure 13.

These cohorts can be of particular interest to those seeking to improve outcomes and the financial sustainability of support for these individuals because of the characteristics they share and the trends that are evident, particularly in relation to recent package costs.

Figure 13: Breakdown of working age & lifelong disabled volume and spend by cohort

Cohort	% of working age & lifelong disabled volume	% of working age & lifelong disabled expenditure	% of total package cost increases accounted for by cohort
LD Cohort One: Individuals with a very low level of need whose package of care is not changing in cost	11.00%	1.90%	0.61%
LD Cohort Two: 40+-year-olds with high needs and whose care package is increasing slightly in cost	11.00%	23.90%	10.82%
LD Cohort Three: 18–39-year-olds with high needs and whose care package is increasing slightly in cost	7.20%	19.70%	8.26%
LD Cohort Four: Individuals with low levels of need and whose package of care is escalating in cost	6.60%	6.10%	13.58%
LD Cohort Five: Individuals with low levels of need and whose package of care is not changing in cost	6.50%	4.03%	2.00%
LD Cohort Six: individuals with high needs and whose packages of care are increasing significantly	2.60%	11.30%	41.11%
MH Cohort One: Individuals with low levels of need whose package of care is not changing in cost	10.70%	6.60%	0.36%
MH Cohort Two: Individuals with high levels of need whose packages of care are increasing slightly in cost	3.40%	4.60%	3.18%
MH Cohort Three: Individuals with average levels of need whose packages of care are increasing significantly in cost	2.20%	1.60%	4.06%
PD Cohort One: 40–65-year-olds with average levels of need and whose packages of care are not changing in cost	14.00%	8.80%	3.70%
PD Cohort Two: 40–65-year-olds with average levels of need and whose packages of care are increasing in cost	3.40%	2.50%	5.86%
PD Cohort Three: 26–39-year-olds with higher levels of need and whose packages of care are increasing slightly in cost	2.80%	2.70%	2.66%
Other support reasons	18.60%	6.1 %	3.79%

Priorities for improvement

Figure 14 shows the relative average weekly package cost and the average yearly cost increase for each cohort, with the ‘bubbles’ indicating the relative size of total spend attributed to that cohort. LD Cohort Six has been excluded from the figure due to its substantial outlying package cost and growth, which reduces the visibility of the other cohorts.

Based on this data, of the 12 main cohorts into which working age and lifelong disabled adults have been categorised, there are six key cohorts (shown in orange and white in Figure 14) which appear to warrant particular attention for authorities seeking to improve outcomes and the financial sustainability of the support provided. These were prioritised due to the average package cost being greater than £1,500 per week and/or the rate of cost escalation being greater than £100 per year.

Figure 14: Average weekly package cost versus average weekly cost increase per year, bubbles indicate relative total cohort spend (LD, PD & MH cohorts, excl. LD6)

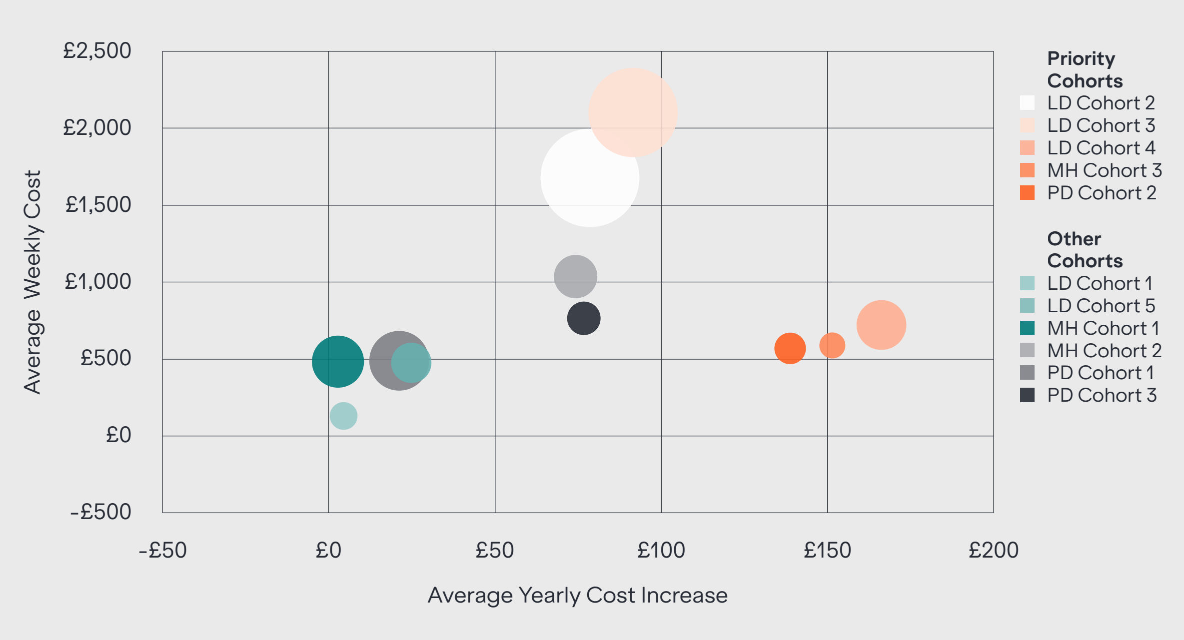
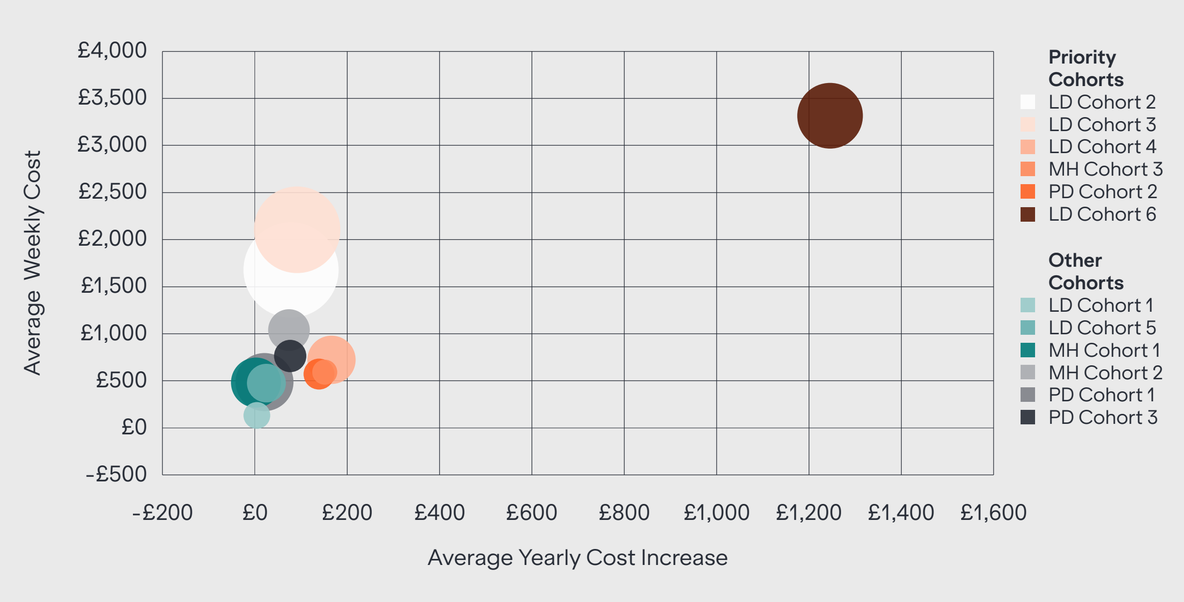


Figure 15: Average weekly package cost versus average weekly cost increase per year, bubbles indicate relative total cohort spend (LD, PD & MH cohorts, including LD6)



These six priority cohorts are described below, along with suggestions of action that can be taken to improve outcomes and reduce costs. Additional cohorts identified are described in Appendix 1.

LD Cohort Two: 40+-year-olds with high needs and whose care package is increasing slightly in cost

Dawn is 52 years old and loves dancing and music. Her CD collection has grown over the years, and she always prefers the physical nature of picking an album over using a computer. Dawn has Down's Syndrome and lives in a residential home, where she has lived for the last 25 years.

She receives support in the residential home for most of her day-to-day activities – helping her to dress each day and prepare her meals. She received extra support to go into town a couple times a week as a group.

As she has got older, Dawn has found herself feeling less physically mobile. As a result, she now receives some extra support in helping her to use the shower safely each day.

Why is this cohort a priority for improvement?

In this cohort, average packages of care are typically high and some variations in cost are evident between authorities. As a result, this cohort appears to be a high priority for potential improvement activity.

Individuals in this cohort typically receive a care package with an average weekly cost of £1,417 per person. This has increased £90 per week per year from 2021 to 2024. The cost ranges from £1,214 per week in one participating authority to £1,935 in another participating authority.

What are the characteristics of individuals in this cohort?

Based on the data analysed for this programme from the participating authorities, this cohort makes up 24% of all individuals with a learning disability, and accounts for 34% of learning disability expenditure.

81% of individuals in this cohort are aged between 40 and 64. On average, they are slightly more likely to be female compared to individuals with a learning disability as a whole. 48% of individuals in this cohort receive residential care and 36% live in supported living accommodation.

How can improved outcomes be delivered for this cohort?

This cohort is made up of individuals who have been in some form of adult service accommodated setting for several years, particularly residential accommodation. For many in this cohort, whilst residential care was likely the most common independent setting type available when they were younger, they would be highly unlikely to be placed there now if they presented to adult services at the same age.

To deliver optimum outcomes for individuals in this cohort, evidence from more than 30 authorities suggests that approximately 30–50% of individuals would have significantly more autonomous and independent outcomes in a lower need setting than in residential accommodation. This is often supported living but can also include use of local authority social housing with additional support from homecare or a direct payment. It could also include Shared Lives (a national scheme that helps to match an individual with an approved host with whom they live with and share family and community life, whilst the host provides some care and support).

Transitioning suitable individuals out of residential care is a complex process. This is primarily due to challenges identifying people who are interested in the move (individuals may have resided in these settings for decades and will often have little awareness of the alternatives available); having a stock of quality and appropriate placements available; and preparing and matching the individuals to these properties. This would be a significant change to the individual's life and routine, and a large operation for an adult social care service to do at scale.

As such, authorities who deliver this most successfully often do so with a dedicated joint team of social work staff, commissioners, and transformation and change specialists. Whilst navigating the available housing may look different between unitary and two-tier authorities (the former generally having greater control and access to housing), there are examples of two-tier authorities successfully employing this approach and reducing their residential placements in learning disability and mental health. One authority achieved a reduction of over 38% in three years. This was achieved through not only looking at how existing shared houses for supported living were being used, but also through working creatively with commissioning colleagues to buy, rent, or even build new schemes.

LD Cohort Three: 18–39-year-olds with high needs and whose care package is increasing slightly in cost

Abbas is 29 years old. He has been living in a flat within a supported living block for the last few years, ever since he moved out of his childhood home. Abbas originally found the move hard, but now enjoys having his family come to visit him in his flat which he has decorated exactly how he wants.

Abbas has autism and a learning disability. He was diagnosed with Fragile X syndrome as a child, which impacts his ability to communicate in the same way as many other people do.

Whilst he overall really likes the 1:1 support staff that he has in the flat, he finds night times harder as different people don't always understand his routine. This can cause him to feel frustrated and upset with staff. This has resulted in his social workers reviewing the placement more regularly than once a year, and each time has resulted in a slight increase in 1:1 support he receives.

Why is this cohort a priority for improvement?

In this cohort, average packages of care are typically high, and large variations in cost are evident between authorities. As a result, this cohort appears to be a high priority for potential improvement activity.

Individuals in this cohort typically receive a care package with an average weekly cost of £1,815 per person. This has increased £103 per week per year from 2021 to 2024. The cost ranges from £1,717 per week in one participating authority to £2,353 in another participating authority.

In addition, the data from participating local authorities shows that there is a significant difference in how supported living is being used for this cohort. Within this cohort, the cost of a weekly package varies from below £1,000 a week on average for three of the 16 authorities, to above £2,000 a week for four out of the 16.

What are the characteristics of individuals in this cohort?

Based on the data analysed for this programme from the participating authorities, this cohort makes up 16% of all individuals with a learning disability, and accounts for 28% of learning disability expenditure.

84% of individuals in this cohort are aged 26–39-years-old, and 16% are 18–24-year-olds. 66% of individuals in this cohort are male, compared to the national average of 51%. 39% of individuals in this cohort live in supported living, 38% live in residential care, and 12% receive a direct payment.

How can improved outcomes be delivered for this cohort?

Individuals in this cohort have largely similar needs to ‘LD cohort two’ but were born 10–20 years later. This means that they are more likely to have their needs met in supported living than in residential accommodation. Whilst the move towards a more community-based setting has the potential to improve outcomes for individuals, in practice not all these placements will provide more independence than their residential alternative.

Delivering optimum outcomes for individuals in this cohort involves ensuring that an authority’s supported living model is maximising the autonomy of its residents – this may involve increased flexibility (such as exploring the ratio of support for the individual or sharing support across a number of people); redesigning support to focus more on the individual’s control of their own life (even where individuals cannot complete an activity themselves unsupported – such as meal preparation for example – them being involved in choosing the meal or assisting in the tasks involved); and balancing risk with the individual having greater space and freedom from support (often common in the proportionality of whether waking overnight support is required).

Despite the gradual move away from residential accommodation and towards supported living in recent years, several models of supported living are beginning to look increasingly less flexible in relation to support options (e.g. requiring a minimum number of hours that are similar or greater to what the individual requires), or are increasingly intense (e.g. 3:1 or more constantly across the week in a small property).

Whilst there will likely be a difference in the local market costs (although there are no clear trends such as a north/south or rural/urban divide in the data), supported living certainly looks different across the country. There are differences relating to whether authorities use shared houses, blocks of flats, or individual flats in the community as their primary supported living delivery. Evidence from within the sector suggests that there is three-fold variation in the use of overnight support for similar need levels between authorities in the same region alone.

This significant degree of variation in models of provision appears to be an important factor in growth of spend and is therefore a priority area for review. This is made more difficult by the absence of supported living in national data collection returns, despite being the most common support type for learning disability (the largest primary commissioned spend reason for adult social care).

The second phase of this programme in 2025 will look to focus on bridging this gap in knowledge and good practice, by showing the different operational and commissioning frameworks authorities are using to deliver quality and cost-effective supported living around the country.

LD Cohort Six: Individuals with high needs and whose packages of care are increasing significantly

Liam is 27 years old and has a moderate learning disability and autism. He loves going to the swimming pool at the local leisure centre and playing games on his tablet.

Five years ago, Liam's family were finding it hard to support him as he became older, and after a particularly challenging summer for Liam he was briefly sectioned and admitted to a mental health unit. This was very difficult for Liam, but he was able to leave after nine months and move into supported living where he received 1:1 support through most of the day.

During the first year, the support provider raised concerns to the local authority and requested that his support be increased to 2:1 for certain periods. In the second year, the nighttime support increased to waking night support after an additional request. With challenges around personal space in the flat due to the level of extra support staff, Liam recently moved into a larger property with more space for the extra staff.

Why is this cohort a priority for improvement?

In this cohort, average packages of care are typically very high, and package costs have been escalating significantly. As a result, this cohort appears to be a high priority for potential improvement activity.

Individuals in this cohort typically receive a care package with an average weekly cost of £3,316 per person. This has increased £1,299 per week per year from 2021 to 2024. Costs range from £2,266 per week in one participating authority to £5,224 in another participating authority.

What are the characteristics of individuals in this cohort?

Based on the data analysed for this programme from the participating authorities, this cohort accounts for 6% of all individuals with a learning disability, and 19% of learning disability expenditure.

35% of individuals in this group are aged 26–39, 25% are aged 40–55, 18% are aged 18–25, 16% are aged 56–65, and 6% are aged 65+. 41% of individuals in this group live in supported living accommodation, 26% receive residential care, and 19% are in receipt of direct payments. People aged 56+ are twice as likely to be in residential placements as people aged 18–39.

How can improved outcomes be delivered for this cohort?

Individuals in this cohort tend to have the highest level of support needs. This is often both in terms of the severity of their disability (for example, being non-verbal), but also their experience and response towards support (such as a history of exhibiting aggression towards support staff). They are also likely to experience comorbidities, such as a learning disability with autism, a mental health condition, or physical disabilities. A significant proportion of individuals in this cohort will have experienced a long-term stay in a hospital unit, and this would have been the main support model for this cohort 20+ years ago. As a reflection of advancements in medical care, this cohort's life expectancy will be significantly longer than it used to be. This positive change, however, does create a new role for adult social care in terms of how it supports these individuals.

Delivering optimum outcomes for individuals in this cohort in general requires finding a balance between the relatively high levels of support required for ensuring safety, with ensuring that disproportionate levels of 2:1, 3:1 or more support that could severely limit the individual's personal space and autonomy are avoided. This was referred to by some stakeholders during engagement for this programme as "accidentally recreating hospitals in the community". This will often require working across social work and commissioning teams to identify appropriate housing options with local providers to ensure consistent and quality support staff options, and with health partners to ensure their specialist input is involved in support and any potential joint funding.

LD Cohort Four: Individuals with low levels of need and whose package of care is escalating in cost

Joe is 32 years old and lives in a shared supported living house with three other men. Whilst he enjoys time to himself, the housemates enjoy playing video games together and going on days out. They eat together every night and share the house jobs.

Joe receives some 1:1 support for managing his finances, but most of his support is shared across the housemates for cooking, food shopping, and keeping the house clean.

When Joe first moved into the house, it allowed him to feel like his own boss and he has loved the freedom it has given him. However, over the last couple of years he has been feeling a bit low and bored, which has resulted in him falling out with staff and with his housemates. His social worker has increased his support to attend a local day service three days a week to help him explore new activities.

Why is this cohort a priority for improvement?

In this cohort, the average cost of care for individuals is similar without much variation, but with significant levels of escalation in cost each year. As a result, this cohort appears to be a high priority for potential improvement activity.

The average weekly care package cost is £722. The cost of care packages has risen annually, increasing by £167 per week on average over the period from 2020/21 to 2023/24.

For 80% of authorities, the average cost of packages of care for individuals in this cohort was close to £722 per week, but the remaining few authorities showed a range of £445 to £862 per week.

What are the characteristics of individuals in this cohort?

Based on the data analysed for this programme from the participating authorities, this cohort makes up 14% of all individuals with a learning disability, and accounts for 10% of learning disability expenditure. The proportion of working age and lifelong disabled individuals in this cohort ranged from 2.7% in one participating authority to 15.3% in another.

The most represented age group is individuals aged 26–39 who account for 34% of the cohort, followed by individuals aged 40–55 who account for 22% of the cohort. The most common support that individuals in this cohort receive is community supported living (30%), followed by direct payments (27%), and day support (18%).

How can improved outcomes be delivered for this cohort?

Delivering optimum outcomes for this cohort can be achieved with help from two types of enablers from adult social care services.

Firstly, through working with the individual to develop a long-term plan centred around their ambitions for life, building on opportunities to navigate key life moments that all individuals experience. This involves social care staff working together with the individual and any support providers to set meaningful and aspirational goals that are relevant to their period of life. For example, those in this cohort will potentially see their 20s involve a change in setting, maybe moving away from the family home into often shared environments with other younger adults where they develop and learn independent living skills.

However, this will then likely change again in their 30s. Services can enable this through regular application of the Care Act assessment and review process to ensure the individual's voice and wishes are heard, and not expecting a person's ambitions and life to necessarily look the same every 10–20 years.

Secondly, authorities can ensure that their review process, particularly for 'unplanned reviews' (those taking place from a request or change in circumstances, not an annual review), does not automatically respond to a situational change with the provision of long-term support. Evidence from within the sector has shown that the typical unplanned review results in an average increase in support of £100–150 per week, for similar reasons as to Joe's example.

The ideal response would focus on understanding the underlying concerns, such as life challenges or lack of stimulation, and seeking to connect individuals to a tailored response (often resulting in a change of what existing support is used for or making greater use of community resources and charities). An increase in support for many individuals often offers only temporary management of these needs, as it does not support the underlying cause, and can lead to a similar further request in the following years. Several years of this often results in levels of care cumulatively building up, and inadvertently reducing the level of autonomy and independence of the individual.

Through successful delivery of this alternative response to unplanned reviews, evidence from the sector suggests that some local authorities have seen a 65% average reduction in increases in long-term support levels.

MH Cohort Three: Individuals with average levels of need whose packages of care are increasing significantly in cost

Lydia is 66 years old and has had periods of poor mental health for a few years. As her depression deteriorated, she began hoarding at home, not eating for days at a time, and developed agoraphobia.

When she initially became known to adult services, a small homecare package was put in place to help her with food shopping and meal preparation. This was increased the following year to support with the hoarding and to help Lydia maintain a safe and habitable home.

After a recent visit, where Lydia became distressed and had an altercation with the homecare staff, her social worker is exploring whether they will need to change provider or increase the calls to have two staff present. Alternatively, if another appropriate homecare provider willing to support Lydia's needs in her own home can't be found, she may need to explore a move to a supported living placement.

Why is this cohort a priority for improvement?

In this cohort, typical packages of care do not vary significantly at a national level, but some variations in cost are evident between authorities. The average package cost is also increasing significantly per year. As a result, this cohort appears to be a high priority for potential improvement activity.

The average weekly package is £530 per person, and this cost has been escalating since 2021, with an average weekly cost increase of £154 each year. Significant variation in cost is evident for individuals in this cohort. The average cost of packages of care for individuals in this cohort ranged from £413 per week in one participating authority to £701 in another.

What are the characteristics of individuals in this cohort?

Based on the data analysed for this programme from the participating authorities, this cohort represents 13% of all individuals with a mental health condition, and 12% of total mental health expenditure. The proportion of working age and lifelong disabled individuals in this cohort ranged from 1% in one participating authority to 4.8% in another.

The majority of individuals in this cohort are aged 66–79 (accounting for 24%), with an equal distribution across remaining age groups.

The two most common support types for these individuals are homecare (26%) and community supported living (26%).

How can improved outcomes be delivered for this cohort?

Individuals in this cohort tend to see sporadic fluctuations in the intensity and type of care support required during periods of particularly poor mental health. As a result, delivering optimum outcomes often involves adult social care supporting two areas.

Firstly, working with the individual to develop a long-term plan that allows for response mechanisms if another period of poor health returns in the future.

Secondly, similarly to individuals in cohort four with a learning disability, developing strong processes related to 'unplanned reviews' is key – where the ideal approach is driven by understanding and managing the reason for the request being raised, rather than using an increase in long-term commissioned support as the main response. Evidence from the sector suggests that the most effective approaches for achieving this have been where either experienced team managers or approved mental health professionals have been involved in the triage and allocation process of 'unplanned' reviews – particularly where there can be more complex eligibility areas for social care (such as substance dependency and misuse).

PD Cohort Two: 40–65-year-olds with average levels of need and whose packages of care are increasing in cost

Martha is a 59-year-old with multiple sclerosis. She has had a homecare package with the local authority for the past 10 years to support her weekly food shop.

Her condition has declined in recent years, and this has impacted her ability to swallow, to move around her home safely, and to carry out personal care. This has resulted in an increase in support twice over the last four years for Martha, as well as input from the council's Occupational Therapy team.

Why is this cohort a priority for improvement?

In this cohort, the average cost of care for individuals is similar without much variation, but with significant levels of escalation in cost each year. As a result, this cohort appears to be a high priority for potential improvement activity.

The average weekly package cost is currently £511 per person, and this has increased by an average of £138 per week each year between 2020/21 and 2023/24. For 80% of authorities, the average cost of packages of care for individuals in this cohort was close to £511 per week, but the remaining few authorities showed a ranged from £445 to £788 per week.

What are the characteristics of individuals in this cohort?

Based on the data analysed for this programme from the participating authorities, this cohort accounts for 16% of individuals aged 18–64 with a physical disability, and accounts for 16% of total working age physical disability expenditure. The proportion of working age and lifelong disabled individuals in this cohort ranged from 0.7% in one participating authority to 7.2% in another.

Individuals in this cohort are significantly more likely to be female than male, but there is no defined trend in the ethnicity of individuals in this cohort nor in their levels of deprivation. 50% of individuals in this cohort are aged 56–65, and 34% are aged 40–55.

In terms of social care support provided, 50% of individuals in this cohort are supported through home support and 34% are supported through direct payments.

How can improved outcomes be delivered for this cohort?

Delivering optimum outcomes for this cohort typically involves maximising independence wherever possible, and ensuring that increases in support are proportionate and support the individual to remain in their own home where safe to do so. This often involves utilising support with multi-disciplinary input from occupational therapists and physiotherapists, to ensure that the individual's physical and mobility needs are best accounted for.

08: Summary of analysis

In summary, this analysis indicates that:

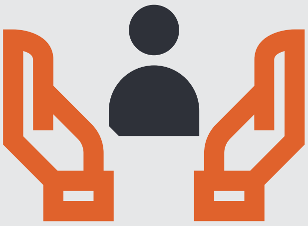
1

There is still **disparity between the health, employment, and social outcomes** achieved by disabled adults in comparison to their non-disabled peers.

2

This is **not due to expenditure on support reducing**. Support for working age and lifelong disabled adults has become the largest area of expenditure in adult social care, and this area of expenditure has also been growing faster than any other part of adult social care.

3



Expenditure appears to be increasing due to the **type of care** which working age adults and lifelong disabled adults are receiving.

4

The report has also shown in relation to the **volume**, **timing**, and **potential cost** of increasing transitions of younger adults from children's services over the next 10 years:

There will be a temporary **20% increase** in the number of all 18-year-olds, peaking in 2030.

The proportion of young people with EHCPs has **increased by 140%** and is still increasing. Whilst this will likely lead to an increase in demand, it is expected that most of this group will not meet the eligibility for ongoing adult social care support.

Combining the above factors, the forecasting carried out for this programme shows that the number of transitions per year is expected to increase, resulting in at least **25% more** people a year by 2030.

The number of individuals who will not transition to adult services but who will likely need additional support from the local authority and wider place system is also **set to increase.**

The forecast net increase in expenditure for support for 18–24-year-olds for adult social care is expected to be at least **40% more** by 2030.

Differences in the needs and support for this cohort are **wider** than most other age categories.

Improvement activity between children's and adults' services can **help to offset** the forecast rise in demand and expenditure.

5

Finally, and perhaps most importantly, to enable insight-led prioritisation and outcomes-focussed improvement of outcomes, an **in-depth understanding** of the key groups and trends within the current working age and lifelong disabled adults' cohorts is necessary.

6

Of the 12 main cohorts into which working age and lifelong disabled adults have been categorised, there are **six key cohorts** which appear to warrant particular attention for authorities seeking to improve outcomes and the financial sustainability of the support provided. These were prioritised due to the average package cost being greater than £1,500 per week and/or the rate of cost escalation being greater than £100 per year.

7

These **priority cohorts** are:

LD Cohort Two:
40+-year-olds with high needs and whose care package is increasing slightly in cost

LD Cohort Three:
18–39-year-olds with high needs and whose care package is increasing slightly in cost

LD Cohort Six:
Individuals with high needs and whose packages of care are increasing significantly

LD Cohort Four:
Individuals with low levels of need and whose package of care is escalating in cost

MH Cohort Three:
Individuals with average levels of need whose packages of care are increasing significantly in cost

PD Cohort Two:
40–65-year-olds with average levels of need and whose packages of care are increasing in cost

09: The future for working age and lifelong adults

This report has outlined the case for why outcomes need to and can be improved for working age and lifelong disabled adults. Based on the engagement undertaken for this programme, there is broad consensus across the system that there is potential for a scale of progress to be achieved in the next 5–10 years that has historically taken nearer 30 years to achieve.

Forecast cost pressures for adult social care

Although this report has focused on making the case for improving outcomes, there is also a financial imperative for change.

With the significant rise in support expenditure for this cohort now above inflation and minimum wage, if this trend continues (without national reform) it will likely result in an escalating cost pressure on adult social care services.

If the current trend for spend growth in adult social care support continues, including the additional forecast pressures from transitions, **this will lead to a total increased cost to local authorities of at least 50% more – or £6bn more per year – for England by 2030**, as shown in Figure 16.

This forecast has been developed by taking the increase in expenditure over the last five years and using the average rate of above-inflationary growth.

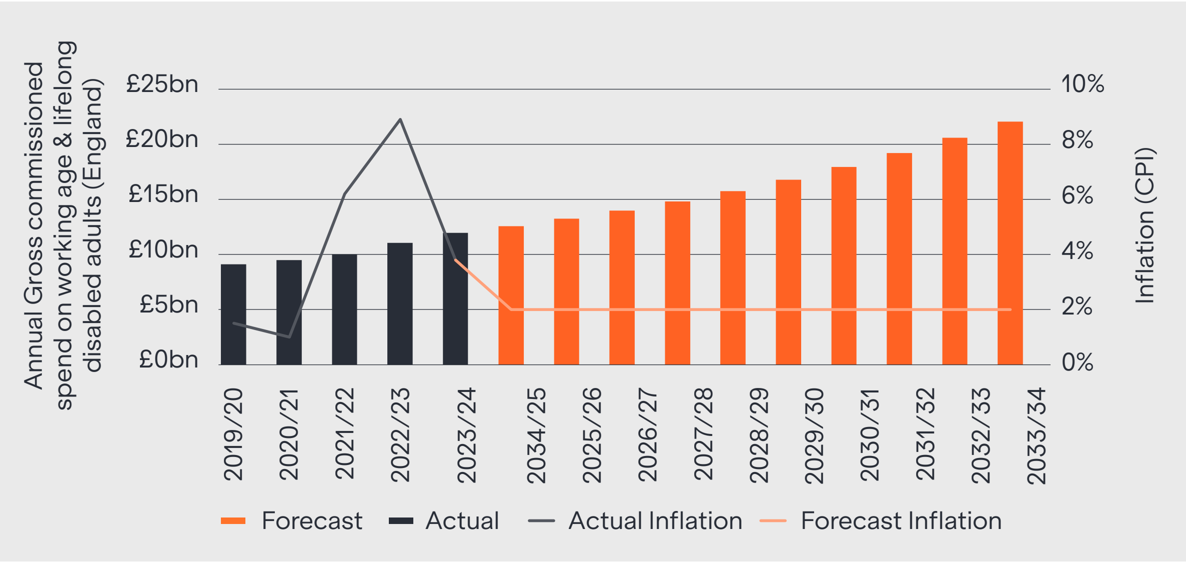
The model assumes a conservative flat rate of inflation of 2% CPI every year for the future forecast horizon. This provides an average growth of 6.8% each year. This also excludes any additional cost pressure that may arise from potential changes in joint funding with health partners, particularly Continuing Healthcare. As shown in Section 4, any increase in the minimum wage above inflation is expected to create further growth in expenditure, and this too would need to be factored into further pressures, for example if the proposed wage increase to social care workers by the new Government were to be enacted.

Interim recommendations

To achieve a substantial improvement in outcomes and the financial sustainability of these services, a greater focus on working age and lifelong disabled adults is vital, involving a more prominent and transparent national debate as to how to optimise outcomes and improve financial sustainability.

This greater focus also needs to be supported by significant reform at both a local and national level. There is no doubt that reform on this scale will be challenging – local authorities engaged through this programme described having grappled with the issues identified in this report for many years with varying degrees of success. Nonetheless, based on the analysis conducted for this programme, several priorities exist at both a local and a national level.

Figure 16: Current and forecast annual gross commissioned spend on working age and lifelong disabled adults



The interim recommendations set out below will form the basis of the next phase of this programme, to be delivered in 2025. This second phase will build on the case for change demonstrated in this report and will **look in more detail at what the evidence indicates are the practical changes that should be made** at a local and national level to deliver for working age and lifelong disabled adults.

Priorities for national decision-makers

1. **Delivering better outcomes for working age and lifelong disabled adults needs to receive more focus in the national conversation on social care**

To enable the scale of reform required in this area, greater local and national attention, focus, and support is required.

Within local systems, authorities (including all departments of adults' social care, children's social care, education, housing, and corporate services), local partners (health bodies, local employers, providers, and schools), and residents (those who draw on support, families, and carers) will need to invest time and resources into understanding their current position and ambitions together.

Nationally, working age and lifelong disabled adults require a greater level of priority from political leaders and central government departments.

Support is also required from national bodies essential for sector-led improvement – including research bodies, advocacy groups, charities, and professional bodies. Improving outcomes for working age and lifelong disabled adults should be a key focus of the Government's proposed national care service, to support this greater national focus and priority.

A greater focus on outcomes and support for working age and lifelong disabled adults in the media would help to improve the public's awareness of the lives, aspirations, and challenges of this community. This could help bridge the gap in making disabled people feel more included and contribute towards improved outcomes.

A new policy framework could also be beneficial, for example by refreshing the 2001 Valuing People white paper which set out the then Government's proposals for improving the life chances of people with learning disabilities.

2. **Defining a common ambition for exceptional outcomes for and with working age and lifelong disabled adults, with promoting independence and preventing escalation of need at its core**

At present there is little available in terms of guidance and definition of what good outcomes look like for working age and lifelong disabled adults in relation to adult social care support. There is even less in terms of vision or aspiration for what best in class support looks like.

To know whether optimal outcomes are being achieved with the most appropriate use of resources, it is important to be able to define what this looks like – if there can be agreement on the aspiration, the most cost-effective means of achieving those outcomes can be identified, and there can be confidence that outcomes and cost are being measured on that basis. Although of course the ideal outcome for each person will vary from individual to individual, having several core principles defined will help to support improvement and progress tracking.

In addition to understanding the differences in need between working age and lifelong disabled adults in comparison to the needs of older adults, a better understanding is required of how the needs of people with whole life conditions vary from those who come into the system for a shorter period – a different response and model of care is needed for both cohorts to achieve optimal outcomes for each.

3. **New housing solutions for disabled adults, to help move away from both a reliance on 24-hour residential and nursing placements, and also away from supported living being used due to a lack of alternative housing options**

The extent to which local areas' housing provision effectively meets the needs of its working age adults was queried by many individuals engaged in this programme.

Stakeholders engaged for this programme reported that 24-hour residential and nursing placements are often used due a lack of alternative housing options to enable the provision of low-level background support, subsequently significantly reducing individuals' independence and also increasing costs.

Additional suitable housing provision is also required to support individuals with moderate levels of need who reportedly rely more heavily on sometimes inappropriate supported living accommodation, due to a lack of suitable local authority housing.

Housing is crucial for delivering good outcomes for working age and lifelong disabled adults, but there are particular complexities of managing this inter-dependency in a two-tier environment which also need to be managed.

There is also a requirement to ensure the inclusion of supported housing options in new housing and planning reforms and local planning targets.

4. **Improved approach to recording and collection of key data relating to care for working age and lifelong disabled adults at a national level, to enable improved understanding and insight**

Although much insight is available already through national returns, the analysis conducted for this programme was constrained by limitations and gaps in the data available nationally. Greater guidance and clarity to improve data collection and recording for local authorities would be likely to significantly improve data quality and the resulting understanding of this population.

In addition, further extending categories would also be beneficial on completion of national data returns for working age and lifelong disabled adults, as some key package types do not currently translate into current SALT or ASC-FR reporting (e.g. direct payment, supported living, day services), which limits analysis and comparison at a national and regional level.

5. **A review of national funding for working age and lifelong disabled adults**

There was a widespread view amongst stakeholders engaged that the current means of funding support for working age and lifelong disabled adults is not fit for purpose. An improved national model is required to ensure that funding comes from the right source and gets to the right place. This may require exploring alternatives to funding support through means other than through council tax.

The relationship between local authorities and the NHS, for example, is critical for improvement, with gaps between Care Act and Continuing Healthcare eligibility leading to a greater cost impact for local authorities. Many authorities engaged reported having seen significant 'cost shunts' from the NHS to the local authority in recent years through programmes such as Transforming Care, which is having a significant impact on local authority budgets.

Furthermore, in addition to the model of funding, the analysis for this programme shows that the quantum of funding for working age and lifelong disabled adults also needs to be reviewed. This report demonstrates that the expected unmitigated level of growth in expenditure, even with inflation at low levels, is expected to reach 46% more by 2030 in comparison to current expenditure. This equates to an additional cost of £6bn per year for local authorities and would require significantly more funding to ensure quality and safety of support is maintained.

Priorities for change at a local level

1. **Whole system change for working age and lifelong disabled adults based on their specific needs, not based on an older adults' model**

Unlike many other areas within health and social care, working age and lifelong disabled adults are typically less described and perceived as a whole-system responsibility. Attention is often focussed on very specific individual needs, and whilst this is vital at a personalisation and support level, this can miss the opportunity to recognise themes for system roles and reform. The cohorting analysis undertaken for this programme shows clear common themes in different groups across the country.

Stakeholders engaged through this programme argued that the current delivery model for working age and lifelong disabled adults is out of date and needs redesigning, in close conjunction with individuals with lived experience and with a wide range of system partners. They agreed that this must continue to be a social model of care and support, not a medical model, and be more strengths-based.

Despite the progress made in models of care over the last 100 years, the new model required for the future will inevitably be more multi-faceted and will require government support to help embed it nationally.

The fragmentation of current referral routes, eligibility criteria, and funding streams creates issues for individuals and their families trying to navigate a very complex system, whilst also forcing additional strain and conflict between organisations with no benefit to the individual. Clarifying shared and measurable objectives across partners will help to improve alignment and reduce fragmentation.

The role of local partners should be prioritised, for example taking a stronger community strengths-based approach to support and maximising the role of education partners. Nationally, DWP is an example of a partner who could play a different role by supporting better employment outcomes for working age and lifelong disabled adults.

Stakeholders were also strongly of the view that this new model needs to be more imaginative and ambitious in what support is provided. It should look at wider constraints, such as opportunities for more diverse work experience, recruitment, and employment. It should also consider how people can be better supported flexibly in their communities, day to day, without setting them up with inflexible levels of support based on their largest need area.

2. **A more effective approach to influencing and managing the market, ensuring that commissioning best practice is implemented and working with providers to develop a jointly beneficial arrangement**

Providers play a crucial role in delivering quality support to individuals and are an important part of any future reform.

Amongst stakeholders engaged for this programme, there was a recognition that support providers will often find working with working age and lifelong disabled adults with complex needs less commercially attractive. There are greater potential reputational risks if they struggle with managing quality with complexity, and different profit opportunities compared to largely self-funded older adult provision.

This is resulting in several authorities needing to increase their use of more expensive out of area placements to meet local needs or feeling 'at the mercy' of the provider market.

In addition, there is potential for commissioning best practice to be shared and implemented more widely across adult social care nationally, so that local authorities are managing their local providers and markets to best effect. For example, through more long-term, strategic planning; more rigorous use of local population data to inform commissioning decisions; working with and responding to variation in local provider set-ups; and a more rigorous and consistent approach to managing local markets.

3. **An approach which places maximising individuals' independence at its heart, including long-term planning with providers and with families, to ensure that over-provision of support is minimised**

Stakeholders engaged through this programme emphasised that further innovation and investment is needed to take a more forward-looking, preventative approach and improve longer-term outcomes. For example, many young people are reaching adult services without the 'life skills' to get into employment, and intervention from social care earlier to influence an individuals' later life would be beneficial.

> “When they showed me how to cook, it was amazing! Being allowed to cook for myself after that made such a difference, I felt like I was really independent at last.”
> **Keisha, 27**

Such an approach requires more effective transition planning from an earlier stage, as well as more joined up working with a wider range of partners, in particular schools. An in-depth understanding of different cohorts' needs (as illustrated in this report) will also be important for effective targeting of appropriate preventative interventions, for example identifying key points in people's life journeys where timely and appropriate support can prevent needs from escalating. The involvement of individuals with lived experience will be crucial in this analysis and identification.

This opportunity for more preventative thinking applies both to support staff in local authorities and in provider organisations (e.g. thinking for every individual – how can we help maximise their independence?) as well as for parents (e.g. helping them understand the likely journey for their disabled child and make decisions early that will maximise their later independence, such as location of the family home).

Working age and lifelong disabled adults should be enabled to have better and more equitable access to the right education, employment, and housing opportunities from the earliest opportunity. In addition, they should be supported to develop the skills to more actively participate and contribute to their local community at every stage of their lives, through work, volunteering, and education. This is something that individuals with lived experience consistently highlighted as important to them, as it is for their non-disabled peers.

4. **A specific focus on, and investment in, the 18–25 transitions cohort to ensure a proactive and joined up approach to meeting the needs of young people, both those who transition to adult services, and those previously in receipt of an EHCP who are not eligible for adult social care but still have needs**

The population of young people turning 18 and transitioning into adult social care is perceived by many to be shifting. The analysis in Section 6 shows that modelling for the lower case is likely to correspond to 25% more 18–19-year-olds transitioning to adult social care by 2030, and the support for 18–24-year-olds will cost 40% more for adult social care services by the same year.

Whilst some individuals have high levels of needs and require adult social care support, others with different needs who previously had an EHCP will not be eligible for adult social care. All these individuals are likely to require support from, if not adult social care, other local authority departments (e.g. housing) or other public sector areas (e.g. benefits or health), and a new approach will be needed to ensure that increased future need is managed and prevented.

Specifically, a review may be required of the ongoing model of support from local authorities and partners for individuals with autism only, or social, emotional and mental health difficulties. These are large growing groups in the EHCP space, but early findings indicate they will generally not meet Care Act eligibility. This needs to be seen as an extension of any SEND reform.

Exploring these potential solutions in the programme’s next phase

This report has made clear the need for – and the potential for – improved outcomes for working age and lifelong disabled adults. Several suggestions have been made for how the needs identified in this report can be met more effectively to improve outcomes for the different individuals in need of support, and these potential solutions will be explored in more detail in the next phase of this research programme.

That will be published in 2025 and will include detailed case studies of how authorities across the country are tackling the issues identified in this report to enhance outcomes for working age and lifelong disabled adults.

10: Appendix 1: Cohort analysis

To better understand the working age and lifelong disabled adults receiving adult social care in a meaningful and non-anecdotal way, this programme conducted detailed analysis into the similarities and differences between different individuals and the ways in which they are supported. This provided a rich and data-led articulation of the **different groups or cohorts of people** who receive support beyond one reason or individual factor.

Through the analysis the following cohorts were identified (these are shown below in order of the proportion they account for of the total volume of working age and lifelong disabled individuals in receipt of adult social care):

Individuals with a learning disability:

- **LD Cohort One:** Individuals with a very low level of need whose package of care is not changing in cost
- **LD Cohort Two:** 40+-year-olds with high needs and whose care package is increasing slightly in cost
- **LD Cohort Three**: 18–39-year-olds with high needs and whose care package is increasing slightly in cost
- **LD Cohort Four:** Individuals with low levels of need and whose package of care is escalating in cost
- **LD Cohort Five:** Individuals with low levels of need and whose package of care is not changing in cost
- **LD Cohort Six:** individuals with high needs and whose packages of care are increasing significantly

Individuals with a mental health condition:

- **MH Cohort One:** Individuals with low levels of need whose package of care is not changing in cost
- **MH Cohort Two:** Individuals with high levels of need whose packages of care are increasing slightly in cost
- **MH Cohort Three:** Individuals with average levels of need whose packages of care are increasing significantly in cost

Individuals with a physical disability:

- **PD Cohort One**: 40–65-year-olds with average levels of need and whose packages of care are not changing in cost
- **PD Cohort Two:** 40–65-year-olds with average levels of need and whose packages of care are increasing in cost
- **PD Cohort Three:** 26–39-year-olds with higher levels of need and whose packages of care are increasing slightly in cost

Section 7 of the report provided a **summary of the key findings from this cohort analysis** and **highlighted the priorities for action and improvement for local system leaders** to address the disparity in outcomes and cost identified.

This Appendix provides further information on the characteristics of individuals with a learning disability, and then explores in further detail the six additional **cohorts of individuals (beyond those prioritised in Section 7).** It then follows the same approach for individuals with long-term mental health conditions and individuals aged 18–64 with a physical disability. For each cohort it also makes suggestions for how this information can be used by local authorities to improve outcomes (largely based on experience from previous improvement programmes).

Individuals with a learning disability

What is known about this group, based on data from the 16 participating local authorities:	
Volumes	• This is the largest cohort in the working age and lifelong disabled adult group, accounting for 48% of the working age and lifelong disabled individuals receiving adult social care support.
Demographics	• 40% of this group are female and 60% are male. This does not reflect the national UK ratio of 51% female:49% male[lxxxiv], which suggests that men with a learning disability are more likely than women to be in receipt of a package of support from adult social care. • 92% of this group are white, 3% are Asian/Asian British, 1% are Black/African/Caribbean/Black British and 2% come from multiple ethnic groups – this mirrors the demographics for the participating authorities. • The population of adults with a learning disability is much younger, on average, than the UK population. For example, Figure 17 shows there are 60% more 18–39-year-olds in this cohort compared to the UK population and that those with a learning disability receiving support are more likely to be under 40 years old than over 55 years old.
Expenditure	• Support for individuals with a learning disability accounts for 67% of all expenditure on support for people in the working age and lifelong disabled adult group. • 92% of the total expenditure on support for people with a learning disability is for those aged 18–64, with the remaining support provided to those 65+ years old. • The average weekly cost of support is £941, nearly three times larger than the average cost for older adults with physical needs. However, the distribution of costs is spread more widely, with 20% of people receiving a package costing between £100–300 per week, 20% receiving a package costing £300–700,17% receiving a package costing £701–1,200, and 17% receiving a package costing £1,201–2,000. This is illustrated in Figure 18. • Total net expenditure increased 28% between 2019/20 and 2023/24, which is at a greater rate of growth than minimum wage, inflation, and older adults' expenditure (as outlined in Section 4). • Over the course of the four years from 2020/21 to 2023/24 inclusive, package costs increased for 61% of individuals. 37% of packages increased by less than a hundred pounds per week each year, 17% increased by an average of £167 each year, and 8% increased in weekly cost by an average of £1,202 (see Figure 19).
Support types	• The most common type of support provided is supported living, with 30% of individuals with a learning disability living in this setting at an average weekly cost of £1,155 (illustrated in Figure 20 below). Interestingly, supported living is not captured in national returns as a sub-category but is one of the largest support types in the country, and is the support type that is used in the largest variety of ways by different authorities. Along with 19% of individuals in residential care (at an average weekly cost of £1,916), this means that 49% of all individuals with a learning disability are supported in an accommodation-based setting rather than in local authority social housing, their own private tenancy, home ownership, or living with family/carers.

Figure 17: Distribution of age groups of individuals with a learning disability (April 2024)

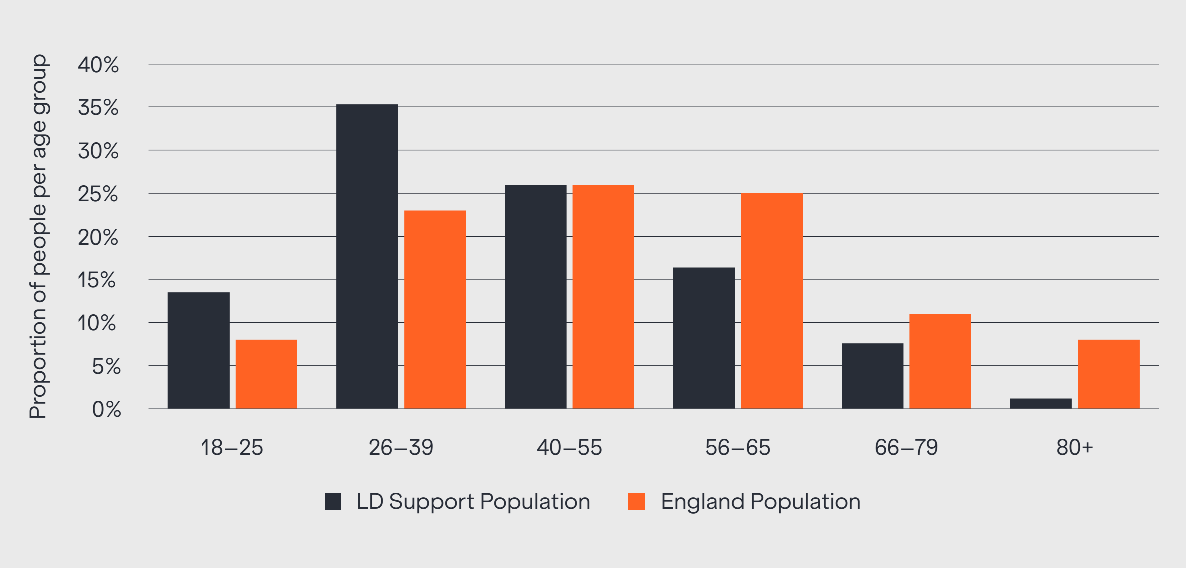


Figure 18: Distribution of weekly package costs

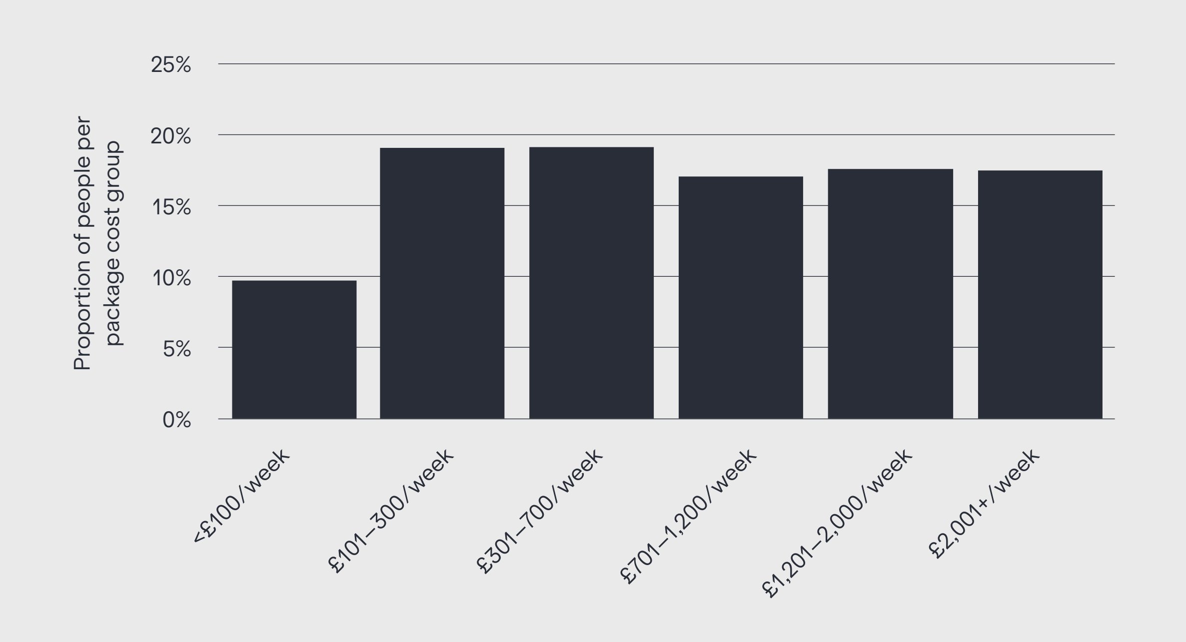


Figure 19: Distribution of average package change per year

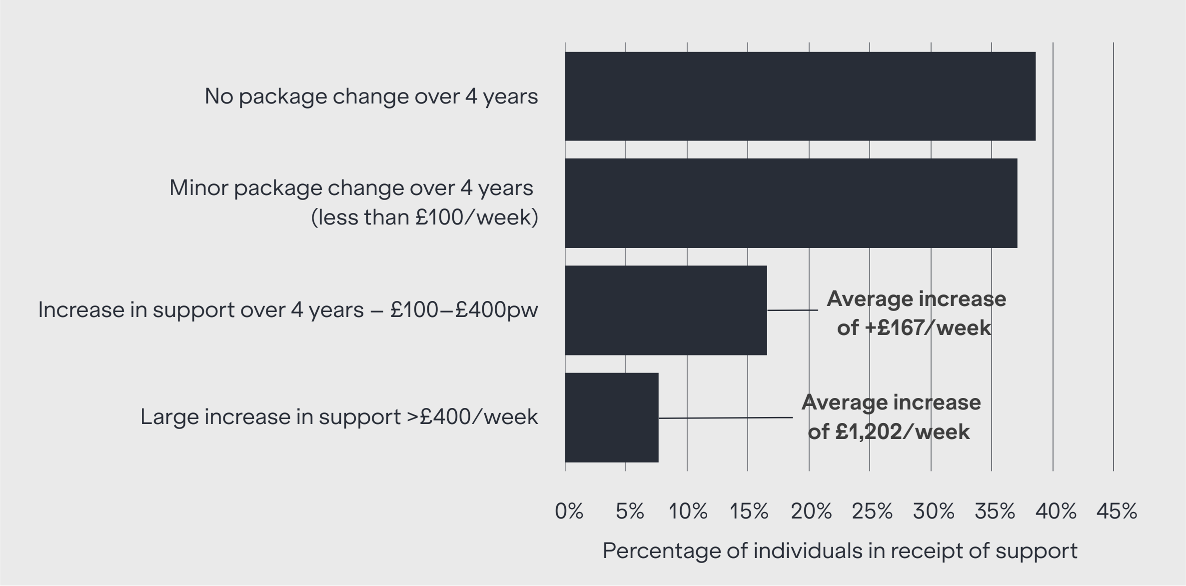
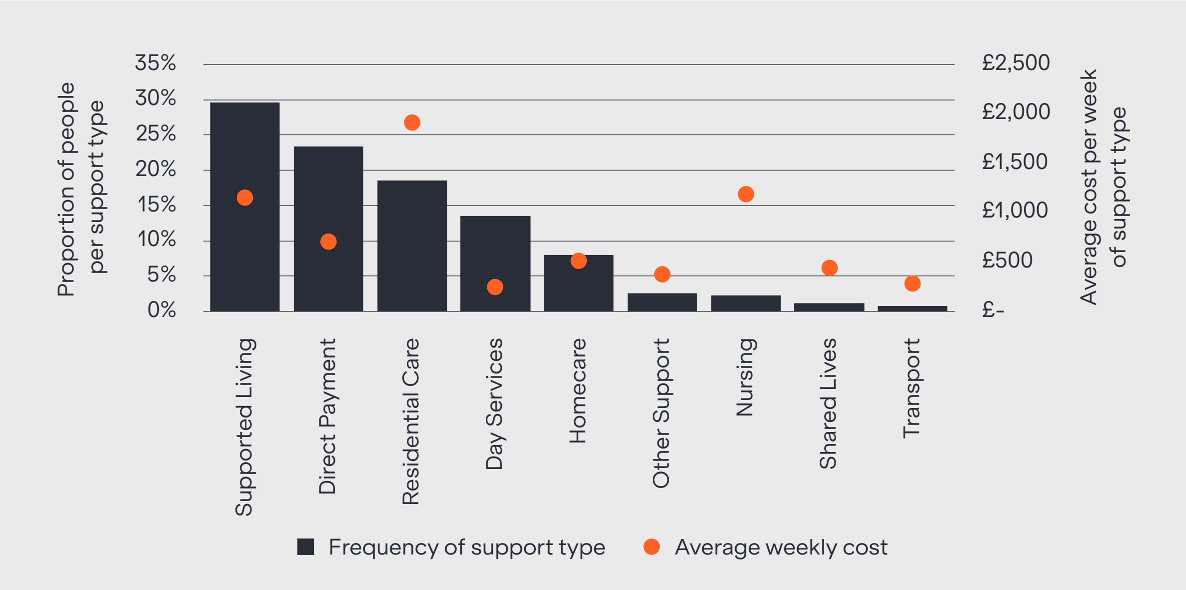


Figure 20: Distribution frequency and average weekly cost of support types



The following section breaks down individuals with a learning disability into six specific cohorts who share similar characteristics (as identified by the cohorting analysis), namely:

- **LD Cohort One**: Individuals with a very low level of need whose package of care is not changing in cost
- **LD Cohort Two:** 40+-year-olds with high needs and whose care package is increasing slightly in cost
- **LD Cohort Three:** 18–39-year-olds with high needs and whose care package is increasing slightly in cost
- **LD Cohort Four:** Individuals with low levels of need and whose package of care is escalating in cost
- **LD Cohort Five:** Individuals with low levels of need and whose package of care is not changing in cost
- **LD Cohort Six:** individuals with high needs and whose packages of care are increasing significantly

To inform improvement activity and the prioritisation of effort, evidence is provided about the reasons why these different groups require social care support, the volumes of individuals receiving different types of social care support, and the costs associated, in addition to other factors such as age, gender, and levels of deprivation in the local area which may contribute to need and outcomes. Insight into the extent to which any of these factors are staying constant or changing is also provided.

Figure 21 shows the way in which the overall group of individuals with a learning disability is broken down into the specific cohorts. Individuals with a very low level of need whose package of care is not changing in cost (cohort one) and 40+-year-olds with high needs and whose care package is increasing slightly in cost (cohort two) are the largest sub-groups.

In comparison, Figure 22 shows that cohort one only accounts for 3% of expenditure whereas cohort two accounts for 33%.

Figure 21: Learning disabled cohorts broken down by volume

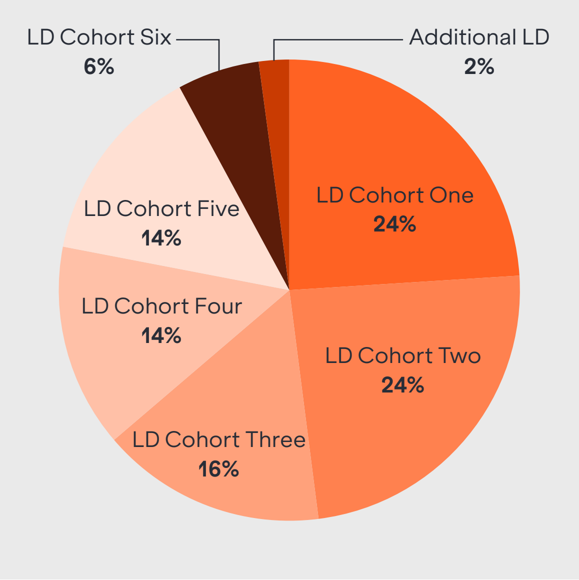
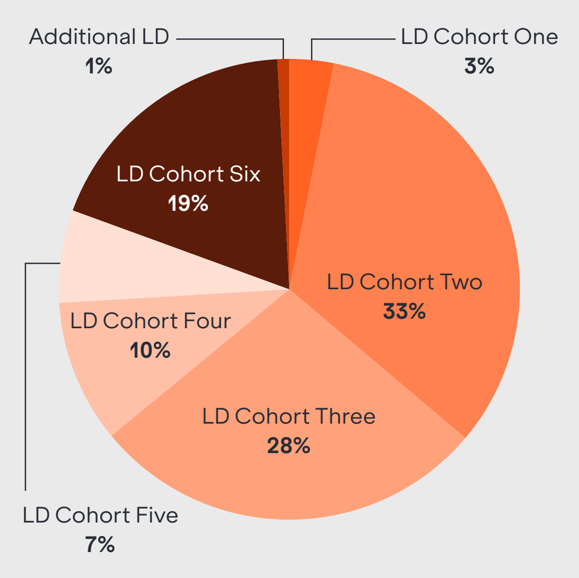


Figure 22: Learning disabled cohorts broken down by spend



LD Cohort One: Individuals with a very low level of need whose package of care is not changing in cost

Sarah is 34 years old and has a moderate learning disability. She lives with her sister and their two rabbits. She has been volunteering at a local charity shop twice a week for the last 10 years and enjoys catching up with her colleagues and the routine it provides. She has a direct payment of £130 per week which she uses for a PA who supports her to manage her finances and correspondence, as well as access the community.

Since her routine has been the same for the last few years, Sarah hasn't reached out to her social worker/local authority learning disability service. She hasn't received a review for the last two years. Sarah would like to have more money for socialising and would love to explore paid employment at some point (such as with animals or in a café). However, she doesn't know how to find a job as it was a social worker she had 10 years ago that helped her get a volunteering role at the charity shop.

What is known about this cohort:	
Volumes	Based on the data analysed for this programme from the participating authorities, this cohort on average makes up **24% of all individuals** with a learning disability, but accounts for only **3% of total expenditure** on support for individuals with a learning disability.
Demographics	On average, individuals in this cohort are slightly **more likely to be under 50 years old** than individuals with a learning disability as a whole, but there are no defined age trends within this cohort.
Expenditure	The **average weekly** expenditure is **£133 per person**, and this cost has **not increased** over the last four years.
Support types	33% of individuals in this cohort have a **direct payment** as their main support type, 31% use **day services** as their main support type, and 15% receive a small homecare package as their main support type. The remainder of individuals receive a range of other low support types.
Variation between authorities	The proportion of working age and lifelong disabled individuals in this cohort ranged from **6.1%** in one participating authority to **24.6%** in another. Significant variation in cost of packages was evident for this cohort. The average cost of packages of care for individuals in this cohort ranged from **£71 per week** in one participating authority to **£175** in another.

How can improved outcomes be delivered for this cohort?

Individuals in this cohort are likely to have a low-need learning disability (on the cusp of eligibility), or high levels of met needs (such as those living with their parents who provide the majority of their day to day support).

From a sample analysis of five participating authorities' data, the average rate of annual Care Act reviews being completed was approximately 35% for individuals with a learning disability, likely due to lack of capacity. Individuals in this cohort are likely to be in the 'infrequently reviewed' group as it is uncommon to see an unplanned request for support or safeguarding arise.

Thematically, delivering optimum outcomes for individuals in this cohort involve navigating barriers related to employment, volunteering, and wider use of public services.

Local authorities who tend to deliver the most independent outcomes for individuals in this cohort often use short-term interventions in order to help navigate additional initial barriers for those with mild disabilities. This might involve a progression or enablement service (similar to reablement in older adults) which focusses on 3–6 months support from a support worker helping the individual, or a specialist service such as employment, adult learning and volunteering support. Without this type of intervention, some services may resort to using a long-term package of care to provide activities in substitute of volunteering, employment or community activities.

This long-term package of care tends to most commonly be access to day services, which is likely to further differentiate the independence of the individual compared to others in their non-disabled peer group.

LD Cohort Five: Individuals with low levels of need and whose package of care is not changing in cost

Sade is a 35-year-old woman with Williams Syndrome who lives with her parents and two young sisters. She enjoys cooking with her mum and spending time in the garden.

Sade receives support from a PA through a direct payment for three hours a day. She predominately uses this for personal care support and accessing the community. Her family provide her with support in all other areas.

This has been a stable routine which has largely looked the same for the last 5–10 years. Her parents are worried about what will happen to Sade as they get older and find it harder to provide the same level of support to her.

What is known about this cohort:	
Volumes	Based on the data analysed for this programme from the participating authorities, this cohort makes up **14% of all individuals** with a learning disability, and accounts for **7% of learning disability expenditure**.
Demographics	On average, individuals in this cohort are slightly more likely to be **aged 26–39 years old** than individuals with a learning disability as a whole, and overall are more likely to be less than 55 years old.
Expenditure	The average package cost of **£475 per week** per person has **not increased** over the last four years.
Support types	46% of individuals in this cohort are in receipt of **direct payment** or homecare, 25% are supported through **low cost supported living** or extra care, and 14% receive **day services**.
Variation between authorities	The proportion of working age and lifelong disabled individuals in this cohort ranged from **1.8%** in one participating authority to **9.8%** in another. Minimal variation between package costs was found for this cohort. The average cost of packages of care for individuals in this cohort ranged from **£445 per week** in one participating authority to **£534** in another, indicating minimal variation nationally.

How can improved outcomes be delivered for this cohort?

Delivering optimum outcomes for this cohort centres around continuous forward planning, similar to cohort four above. However, in contrast, individuals in this cohort are less likely to be prioritised for review if an authority is delayed on their annual Care Act review cycle. This is most commonly due to individuals in this cohort having a long-term routine with the same support, without a change in needs. Whilst it is positive that this cohort has a stable routine, there may well be a missed opportunity for authorities to help these individuals to better plan for their future.

With the age group of this cohort being largely under 40-years-old, many individuals will be living with or having additional support from their family, most commonly their parents. As these individuals increase in age above 40–50-years-old, their parents are more likely to suffer from frailty and decreasing health, and therefore may be less able to provide the same level of support as they did previously.

This can then result in the individual experiencing a significant increase in their level of social care support, so joining a different cohort (likely cohort two), and undergoing a change in their routine and level of autonomy as they often need to move setting (to residential or supported living) with a higher level of support.

In order to ensure the optimum long-term outcomes, stronger performing social care services tend to focus on progression, enablement and future planning with this cohort. This may involve a progression or enablement service (e.g. supporting learning to use public transport, meal preparation, or other independent living skills without the same reliance on parents), or through focussed goal setting and regular reviews through existing support plan providers (e.g. direct payment or homecare).

Individuals with mental health conditions

What is known about this group, based on data from the 16 participating local authorities:	
Volumes	- This is the joint second largest cohort in the working age and lifelong disabled adult group, accounting for 24% of these individuals receiving adult social care support. - Support for individuals with mental health conditions as the primary support reason accounts for 16% of all expenditure on support for people in the working age and lifelong disabled adult group, the second largest subgroup. As shown in Figure 23, two thirds of this support is specifically for individuals aged 18–64-years-old, the remainder is support for those aged 65+ with mental health conditions (excluding dementia).
Demographics	- There is no defined trend in the data regarding the ethnicity or gender of individuals in this cohort – these both mirror the total population trends. - There is a relationship between the greater the level of deprivation of the individual's postcode and the likelihood of them having a higher level of support. This may suggest that an individual's level of mental health need is exacerbated by the level of deprivation and poverty in which they live. In turn, this could mean that adult social care services within an individual authority will see greater levels of demand for mental health support in its most deprived areas. It could also mean that authorities with higher levels of deprivation at a whole may have additional demand and cost pressures for mental health support than those with lower levels of deprivation.
Expenditure	- The average weekly cost of support is £607, but similarly to individuals with a learning disability, the range of costs is significant, as shown by the even distribution of cost groups in Figure 24. - Mental health support appears to be the fastest growing area of expenditure for working age and lifelong disabled adults, with national total net expenditure having increased 46% from 2019/20 to 2023/24 in England[lxxxv].
Support types	- 28% of individuals with mental health as their primary support need are supported through a residential care placement, at an average cost of £998 per week. Supported living is the second largest support type, accounting for 23% of individuals at an average cost of £642 a week. Homecare is the third largest support type accounting for 21% of people with an average weekly cost of £268.

Figure 23: Distribution of age groups for individuals with mental health conditions

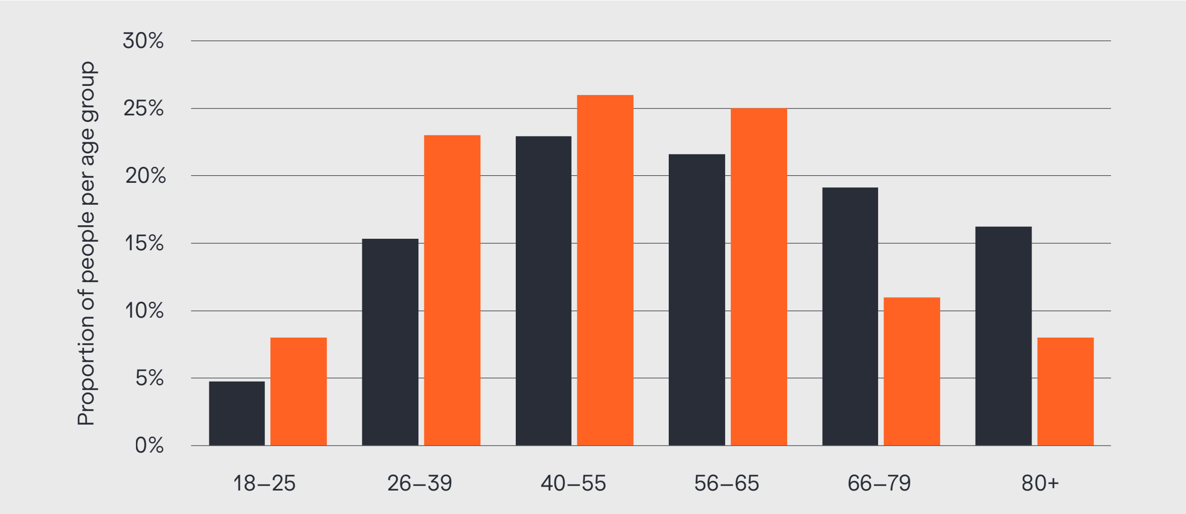


Figure 24: Distribution of weekly package costs for individuals with mental health conditions (April 2024)

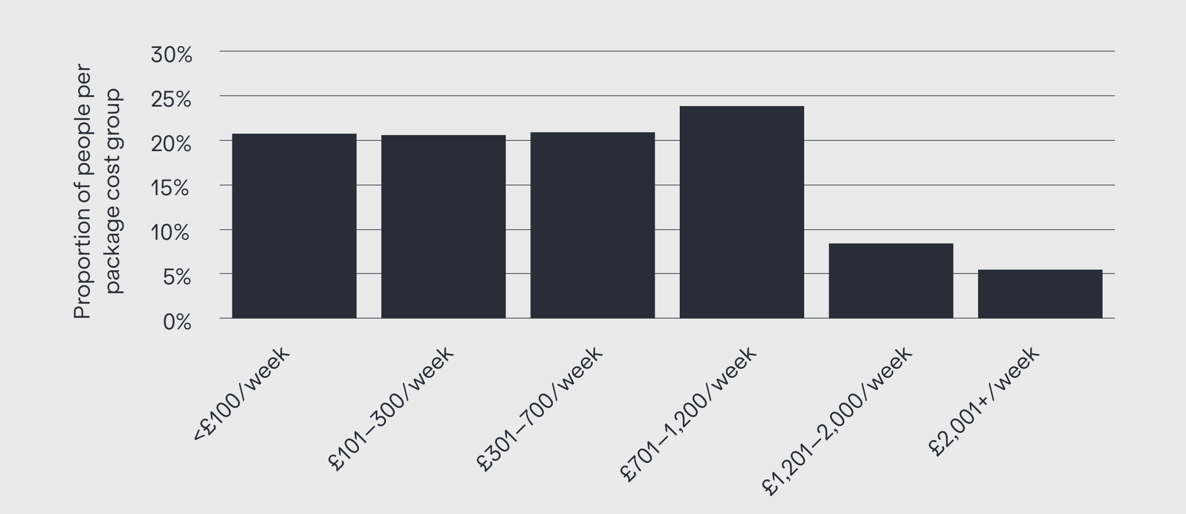
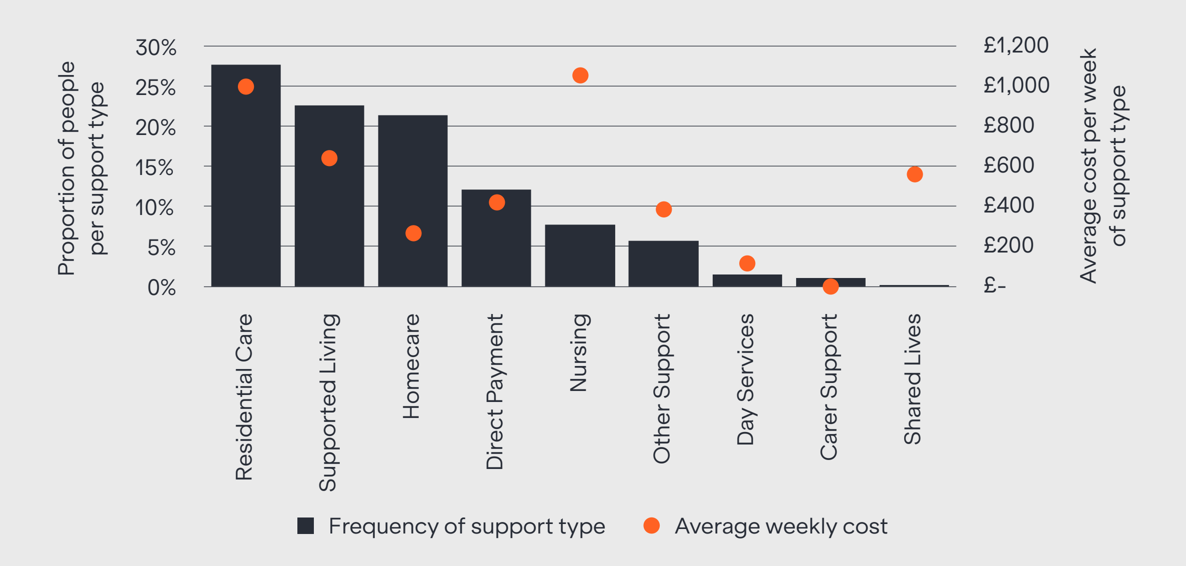


Figure 25: Distribution frequency and average weekly support costs for individuals with mental health conditions



The following section breaks down individuals with mental health conditions into three specific cohorts who share similar characteristics, namely:

- **MH Cohort One:** Individuals with low levels of need whose package of care is not changing in cost
- **MH Cohort Two:** Individuals with high levels of need whose packages of care are increasing slightly in cost
- **MH Cohort Three:** Individuals with average levels of need whose packages of care are increasing significantly in cost

To inform improvement activity and the prioritisation of effort, evidence is provided about the reasons why these different groups require social care support, the volumes of individuals receiving different types of social care support, and the costs associated, in addition to other factors such as age, gender, and levels of deprivation in the local area which may contribute to need and outcomes. Insight into the extent to which any of these factors are staying constant or changing is also provided.

Figure 26 shows the way in which the overall group of individuals with mental health conditions is broken down into various specific cohorts, with individuals with smaller packages of care that are not changing in cost (cohort one) being the largest sub-group by far (64%). Figure 27 shows that this cohort accounts for 50% of expenditure.

Figure 26: Mental health cohort broken down by volume

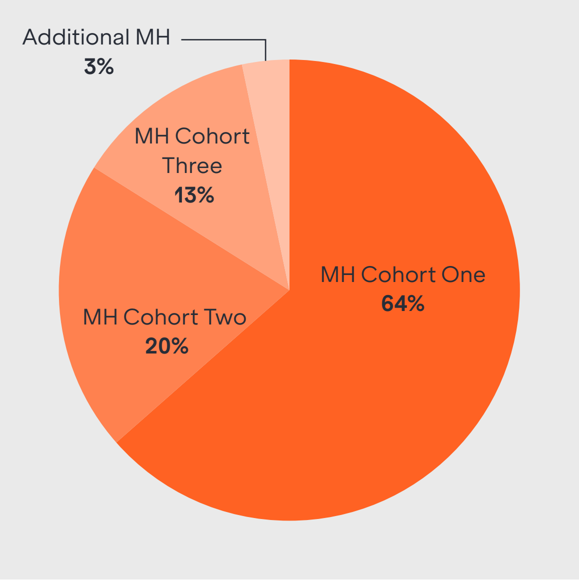
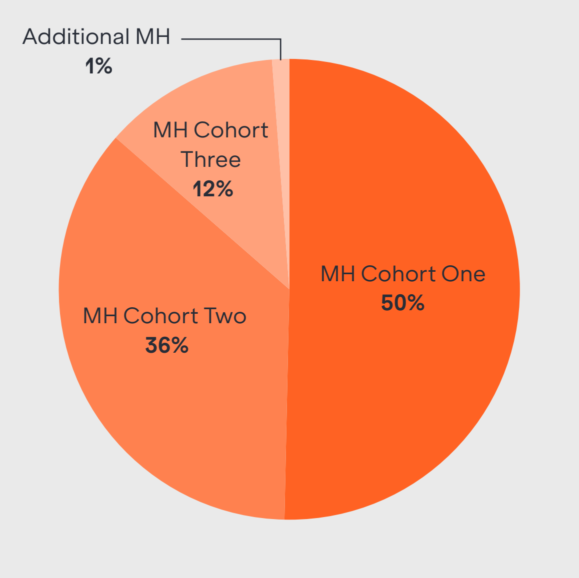


Figure 27: Mental health cohort broken down by spend



MH Cohort One: Individuals with smaller packages of care that are not changing in cost

Kirsten is 42 years old, and has a history of anorexia, self-harm, OCD, and depression. She has been unwell since she was 11 and through her teenage years had several acute admissions. Despite her complex needs, Kirsten has a clear plan and is determined to build a positive future for herself.

Kirsten has lived in supported living for the last three years with a low level of background shared support. She has built good relationships with the staff and other residents who she mentions are "helping [her] move on and manage [her] anxieties". She would like to work towards independent living through a recovery plan with her social worker.

What is known about this cohort:	
Volumes	Based on the data analysed for this programme from the participating authorities, this cohort makes up the majority of individuals with a mental health condition, accounting for **64% of individuals** and **50%** of total mental health expenditure.
Demographics	Individuals **aged 40–55** represent 24% of this group (the largest age group in this cohort) with a range across the remaining age groups. Although 18–25-year-olds are the smallest age group in this cohort, accounting for only 6%, they represent nearly twice as much of the total spend – 12% of expenditure on support for individuals with a mental health condition.
Expenditure	The average weekly package cost of **£434 per person** has **not changed** over the past four years from 2020/21 to 2023/24 inclusive. 57% of individuals in this cohort have a weekly package cost **under £300**.
Support types	The two most common support types for individuals in this cohort are **homecare** (26%) and **supported living** (25%).
Variation between authorities	The proportion of working age and lifelong disabled individuals in this cohort ranged from **4.3%** in one participating authority to **25.6%** in another. Significant variation in cost is evident for individuals in this cohort. The average cost of packages of care for individuals in this cohort ranged from **£317 per week** in one participating authority to **£1,382** in another.

How can improved outcomes be delivered for this cohort?

Individuals in this cohort have a more stable package of care in comparison to a more variable care journey for other cohorts with a mental health condition. Evidence from within the sector suggests that this tends to be because individuals in this cohort – although they have poor mental health – do not experience a significantly increasing level of needs and therefore do not require an increase in support.

This does not necessarily mean however, that their level of need has decreased to a level below the adult social care support they receive. It has been found on average that 25-40% of individuals in this cohort would have more independent and sustainable outcomes if their needs were met through other services not unique to mental health provision, for example living in private or local authority housing instead of in supported living, or having support through a network of friends and family, local community groups, and/or charities rather than by a paid care staff worker.

However, this is often made challenging to achieve based largely on stigma and social barriers to accessing this support with the individuals' diagnosis and potentially their history.

Delivering optimum outcomes for this cohort often requires adult services to help individuals in this group work towards recovery planning, which is sometimes supported by an intervention from a mental health social worker or mental health reablement-style service. Using this approach to set meaningful goals to the individual (for example, how they best manage their health and wellbeing if they have a relapse), alongside the process of reviewing can ensure that all parties share clear aspirations and expectations, and can support the individual to have the best opportunity to achieve their recovery outcomes.

MH Cohort Two: Individuals with high levels of need whose packages of care are increasing slightly in cost

Duncan is a 52-year-old man with bipolar disorder and psychosis. Having spent periods of time being homeless in his 20s and 30s as various tenancies broke down due to poor mental health, he moved into a residential placement with adult social care.

Duncan has moved between different residential homes over the last 20 years, but he is largely supported through shared support from staff across the home rather than having any 1:1 needs. He goes out during the day on his own. With the property being shared with several vulnerable residents, including a number of people who have suffered from substance misuse, it is often targeted by local dealers.

Duncan would be interested in moving out but would need to explore local authority housing through the district council. He is aware that his history of poor tenancies, although over a decade ago, will impact his chances at finding a property.

What is known about this cohort:	
Volumes	Based on the data analysed for this programme from the participating authorities, this cohort represents **20% of all individuals** with a mental health condition, and **36%** of total mental health expenditure.
Demographics	The majority of individuals in this cohort are **over 40 years old** and are spread across the older age groups, with 25% of individuals in this cohort being aged **80+**. Only 2% of individuals in this cohort are aged 18–25, and 11% of are aged 26–39. Similar trends are seen for the distribution of expenditure.
Expenditure	The average weekly package of **£968 per person** has **increased by £67** a week on average per year of the package duration.
Support types	In terms of support types for these individuals, half of the individuals in this cohort are supported through **residential care**, with an average weekly cost of £1,033.
Variation between authorities	The proportion of working age and lifelong disabled individuals in this cohort ranged from **1.1%** in one participating authority to **7.7%** in another. Significant variation in cost is evident for individuals in this cohort. The average cost of packages of care for individuals in this cohort ranged from **£715 per week** in one participating authority to **£1,582** in another.

How can improved outcomes be delivered for this cohort?

Individuals in this cohort are likely to be living in long-term residential care. Evidence from within the sector suggests that, for approximately 25–40% of this cohort, this is not due to their level of needs requiring this high level of support, but rather is often driven by their inability to obtain an alternative tenancy, for example due to past behaviour or incidents. This then often leads to adult social care needing to provide accommodation at an average cost of £1,000+ per week.

Delivering optimum outcomes for individuals in this group often involves exploring alternative long-term accommodation options for these individuals, working towards a stable long-term community placement (similar to the accommodation moves approach outlined for individuals in cohort two). This often requires mental health social work teams to work closely with housing colleagues (at district level or within the authority if unitary), or with commissioning teams to ensure that creative housing options are being explored (e.g. renting, buying, or building).

Individuals with a physical disability aged 18–64 years old

What is known about this group, based on data from the 16 participating local authorities:	
Volumes	• This is the joint second largest cohort in the working age and lifelong disabled adult group, accounting for 24% individuals receiving adult social care support.
Demographics	• Compared to the national average, there is no difference in trends when it comes to the ethnicity of individuals or the level of deprivation of the local area. However, individuals in this group are more likely to be female (57% for this group, compared to 51% for UK population). • As illustrated in Figure 28, individuals in this group are much more likely to be aged 56–65 than the average national distribution of individuals aged 18–64 in the UK. This suggests that a number of this cohort may not have had a level of need that has required constant support from adult social care since a young age, but that their level of disability has either increased or developed as they reach middle-age.
Expenditure	• The average weekly cost of support is £529, with a more normal distribution than the previous two support reasons (individuals with a learning disability or mental health condition) (as shown in Figure 29 and Figure 30). This means that most of the data is clustered around the mean average value, rather than being spread out across a wider range of costs.
Support types	• In comparison to the other support areas, the main provision types for individuals with a physical disability are homecare (provided to 41% of individuals in this group) and direct payment (35%), with very low amounts of accommodated support types (residential, nursing, supported living).

Figure 28: Distribution of age groups

Figure 29: Distribution of weekly package costs

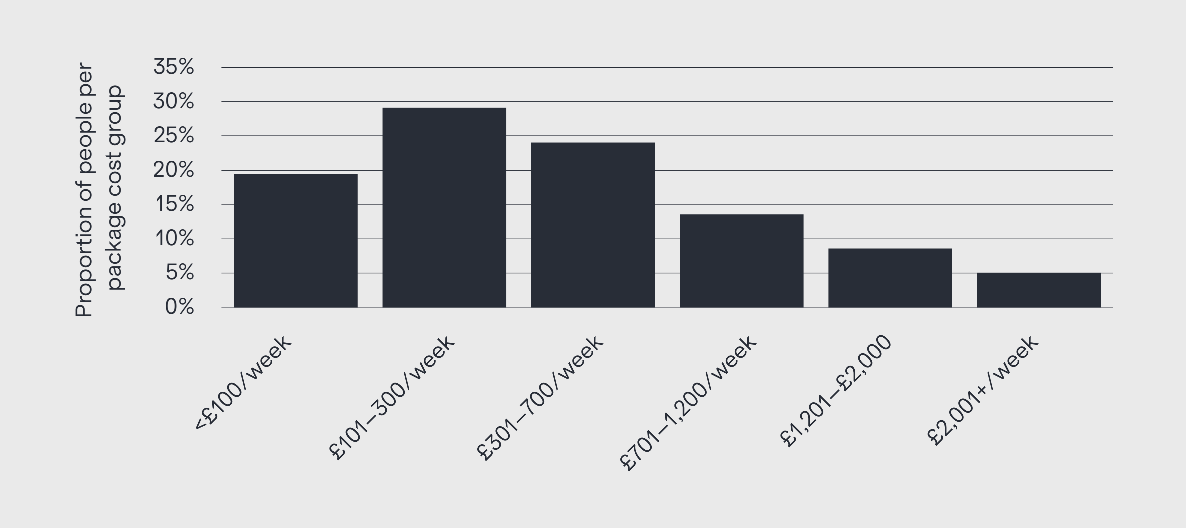
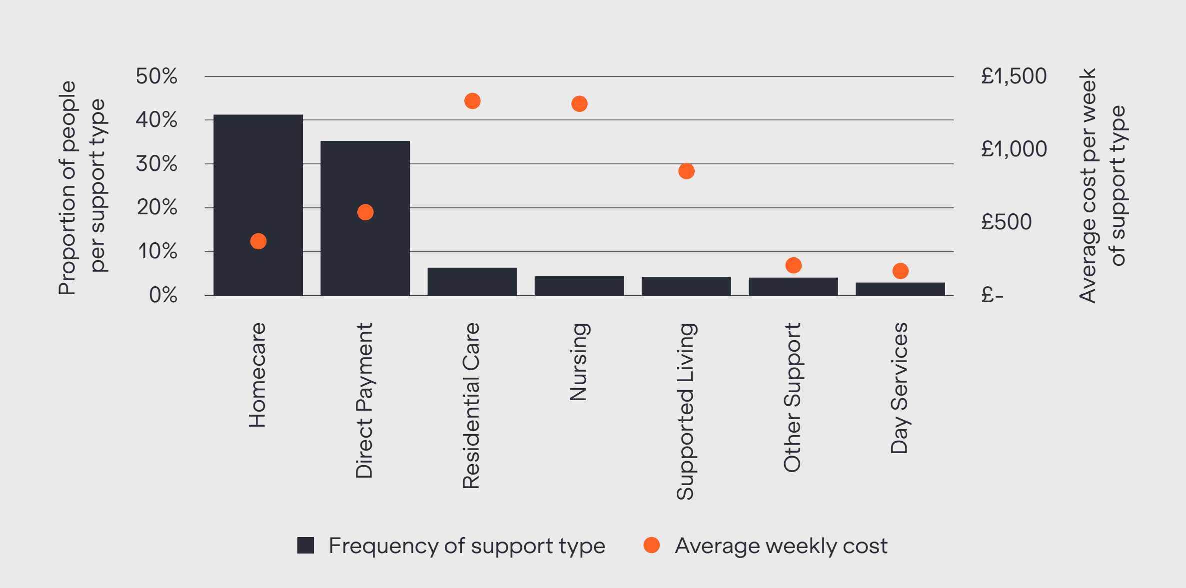


Figure 30: Distribution frequency and average weekly cost of support types



The following section breaks down individuals with a physical disability into three specific cohorts who share similar characteristics, namely:

- **PD Cohort One**: 40–65-year-olds with average levels of need and whose packages of care are not changing in cost
- **PD Cohort Two:** 40–65-year-olds with average levels of need and whose packages of care are increasing in cost
- **PD Cohort Three:** 26–39-year-olds with higher levels of need and whose packages of care are increasing slightly in cost

To inform improvement activity and the prioritisation of effort, evidence is provided about the reasons why these different groups require social care support, the volumes of individuals receiving different types of social care support, and the costs associated, in addition to other factors such as age, gender, and levels of deprivation in the local area which may contribute to need and outcomes. Insight into the extent to which any of these factors are staying constant or changing is also provided.

Figure 31 shows the way in which the overall group of individuals with a physical disability aged 18–64 is broken down into various specific cohorts, with 40–65-year-olds with average levels of need and whose packages of care are not changing in cost (cohort one) being the largest sub-group (66%).

Figure 32 shows that this cohort accounts for 61% of expenditure.

Figure 31: Breakdown of the PD cohorts by volume

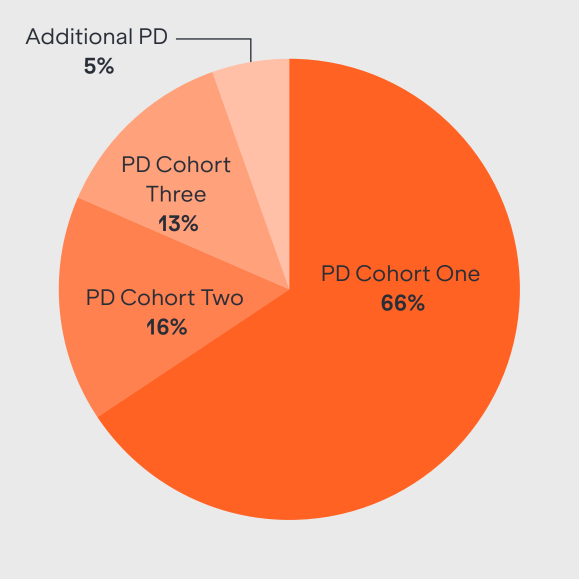
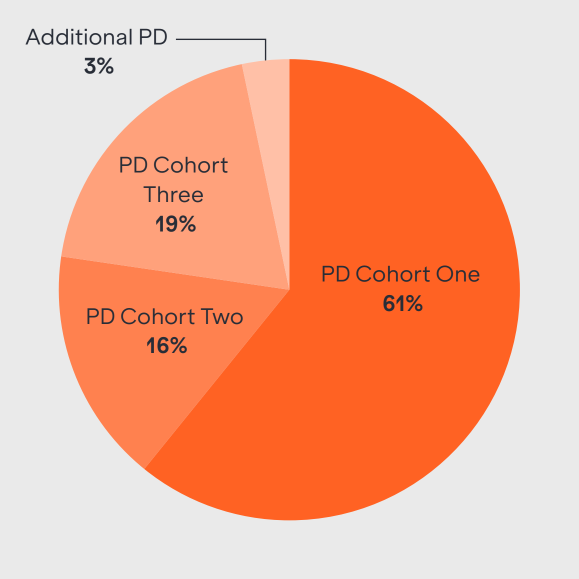


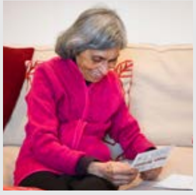
Figure 32: Breakdown of the PD cohorts by expenditure



PD Cohort One: 40–65-year-olds with average levels of need and whose packages of care are not changing in cost

Cristina is 63 years old. She has always valued living independently and has worked her whole life without support. However, as she has got older, her health has declined. She has developed severe arthritis and breathing problems, which have severely impacted her ability to get out bed safely without help.

After an assessment from adult services, a homecare package of two calls a day was put in place to help Cristina get up in the morning and go to bed safely. This has worked well for her, as it allows her to remain in her home that she loves.



What is known about this cohort:	
Volumes	Based on the data analysed for this programme from the participating authorities, this cohort makes up the majority of individuals aged 18–64 with a physical disability, accounting for **66% of individuals** and **61% of total working age physical disability expenditure**.
Demographics	58% of individuals in this group are **female**, which is slightly higher than the national proportion whereby 51% of individuals are female. Individuals in this cohort were 33% more likely to be from a **global majority background** than the average for the working age and lifelong disabled cohort. This is the largest variation in ethnicity trend of all the cohorts for the participating county authorities.
Expenditure	The average weekly package is **£456 per person**; there has been **little to no change** in average package cost over the last four years from 2020/21 to 2023/24.
Support types	**Homecare** is the most common support type for individuals in this cohort, with 44% of individuals in receipt of homecare. **Direct payments** are the second most common support type, accounting for 32% of the cohort.
Variation between authorities	The proportion of working age and lifelong disabled individuals in this cohort ranged from **8.2%** in one participating authority to **20.7%** in another. Significant variation in cost is evident for individuals in this cohort. The average cost of packages of care for individuals in this cohort ranged from **£390 per week** in one participating authority to **£1,179** in another.

How can improved outcomes be delivered for this cohort?

Individuals in this cohort are often experiencing many of the similar needs that individuals in older adults with frailty needs experience. Subsequently, delivering optimum outcomes for this group looks, wherever possible, like supporting individuals to remain in their own home, with any involvement from adult services focussed on promoting wellbeing, promoting independence and supporting independence.

This begins with an asset-based strategy aiming to make best use of voluntary and community sector services or providing support around any informal carers involved as part of the individual's network. This is then followed by making effective use of short-term services that help the individual with some form of recovery, rehabilitation, or reablement to reduce or prevent ongoing needs. This may involve regaining or improving aspects of their personal confidence or independence, their strength, or their health. Finally long-term services can be explored, ideally supported by multi-disciplinary input from occupational therapists and physiotherapists, to ensure that the individual's physical and mobility needs are best accounted for.

PD Cohort Three: 26–39-year-olds with higher levels of need and whose packages of care are increasing slightly in cost

Cameron is a 27-year-old with cerebral palsy. He lives in his own house, and draws on a direct payment for support from a PA to enable him to continue to use his home safely and to access the community.

How can improved outcomes be delivered for this cohort?

Individuals in this cohort are likely to have a lifelong physical disability that will require some form of support for life – whether this is mobility support, or adaptations to their home. Delivering optimum outcomes for this group tend to involve a focus on promoting independence, long-term planning and appropriate use of direct payments.

What is known about this cohort:	
Volumes	Based on the data analysed for this programme from the participating authorities, this cohort accounts for **13% of individuals** aged 18–64 with a physical disability, and for **19% of total working age physical disability expenditure**.
Demographics	Individuals in this cohort are slightly more likely to be **female** than male, but there is **no defined trend in the ethnicity** of individuals in this cohort nor in their levels of deprivation.
Expenditure	The average weekly package cost is **£731**. The majority of packages **increased** in cost in the years 2021 to 2024, with an average weekly change of £46 per year.
Support types	In terms of support types, 54% of individuals in this cohort are supported through **direct payments**, and 22% are supported through **homecare**.
Variation between authorities	The proportion of working age and lifelong disabled individuals in this cohort ranged from **0.8%** in one participating authority to **5.5%** in another. Significant variation in cost is evident for individuals in this cohort. The average cost of packages of care for individuals in this cohort ranged from **£535 per week** in one participating authority to **£1,440** in another.

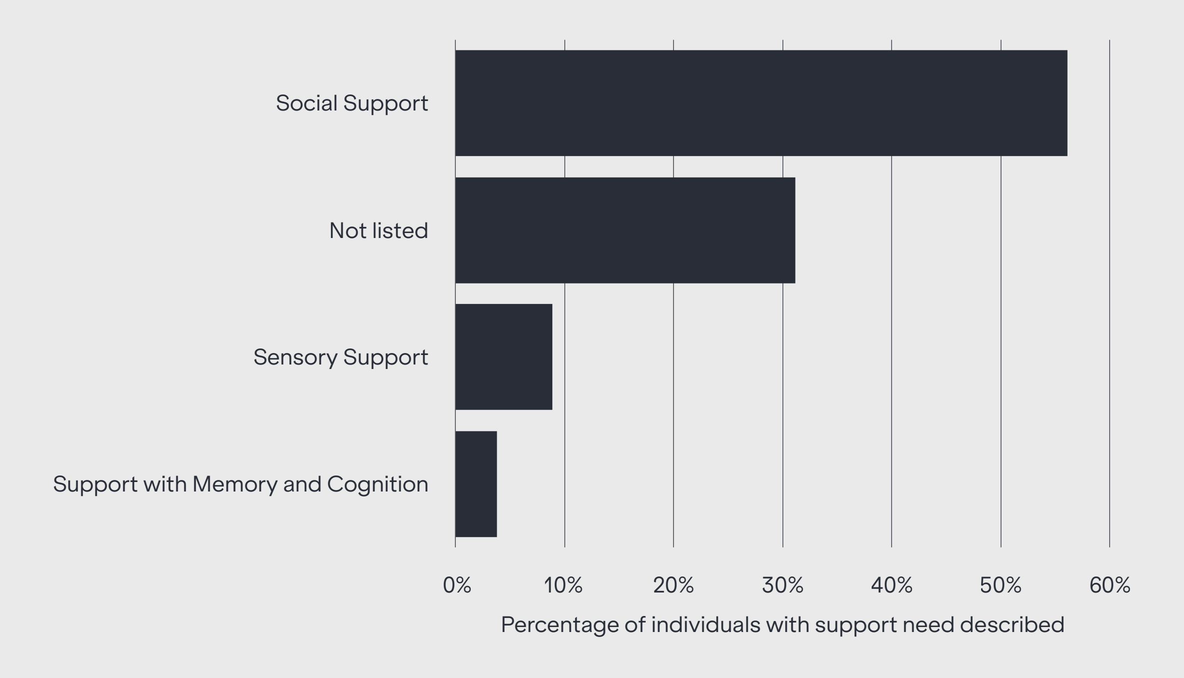
Other support reason cohorts

In addition to the cohorts outlined in this section, 18% of working age and lifelong disabled adults have another support need, as shown in Figure 33.

These individuals account for 7% of all expenditure on support for working age and lifelong disabled adults.

The average weekly package cost for these individuals is £245.07 per person per week. Within this average, 43% are individuals with a social support package costing an average of £21 per week, mostly as a direct payment. 49% of individuals in this group receive homecare at an average package cost of £380 per week.

Figure 33: Breakdown of 'other' primary support reasons



11: Glossary

This section provides an explanation of key acronyms and terms used in this report.

Acronyms

1. ADASS: Association of Directors of Adult Social Services.
2. ACCE: Association of County Council Executives.
3. CCN: County Councils Network.
4. CHC: Continuing Healthcare, referring to a package of care for adults which is arranged and funded solely by the NHS.
5. CPI: Consumer Price Index.
6. DWP: Department for Work and Pensions.
7. EHCP: Education, Health, and Care Plan, a plan for children and young people aged up to 25 who need more support than is available through special educational needs support. EHC plans identify educational, health and social needs, and set out the additional support to meet those needs.
8. ICB: Integrated Care Board.
9. LD: Learning Disability.
10. MH: Mental Health.
11. NHS: National Health Service.
12. NEET: Not in Education, Employment, or Training.
13. NIPT: Non-Invasive Prenatal Testing.
14. PA: Personal Assistant.
15. PD: Physical Disability.
16. SEND: Special Educational Needs and Disabilities.

Key Terms

1. Accommodated Support Types: types of care provided in residential or supported living settings.
2. Befriending: in this context, a service where individuals offer companionship and social support to others.
3. Care Act reviews: evaluations or reassessments of an individual's care needs under the Care Act.
4. Complex needs: in this context, refers to individuals who have multiple and often severe conditions that require coordinated care.
5. Cohort: a group of people with a shared characteristic.
6. Direct Payment: financial support provided directly to individuals to pay for their social care services.
7. Enablement: support aimed at helping individuals gain skills to improve their independence.
8. Extra Care: housing with care services available on-site.
9. Homecare: care provided in the individual's home.
10. Progression Service: a service focused on short-term interventions to help individuals with disabilities navigate barriers and move towards more independent living.
11. Recovery Plan: a strategy developed to help individuals improve their mental health and well-being.
12. Reablement: short-term support designed to help individuals regain independence after a hospital stay, illness, or accident

13. Section 117: Section 117 aftercare is a legal duty that is placed on health and social services to provide after care services for individuals who have been detained under Section 3, Section 37, Section 47, Section 48 and Section 45A of the Mental Health Act 1983 in England and Wales. It is the duty that comes in effect once the person has been discharged from the hospital.

14. Sectioned: when an individual is detained under a section of the Mental Health Act for assessment or treatment.

15. Shared Lives: a national scheme where individuals with disabilities live with approved hosts who provide care and support within a family and community setting.

16. Supported Accommodation: housing that provides support to help individuals live independently.

17. Supported Living: a service providing housing and support to help individuals live independently.

18. Transforming Care: an NHS programme aimed at improving health and care services so that more people can live in the community, with the right support, and close to home.

19. SEN Support: the system by which schools should assess the needs of children, and then provide appropriate additional support.

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