

Autism Alliance

Mapping supply and demand for care services for autistic adults in England

November 2023



CordisBright

Table of contents

Key Messages	3
1 Introduction.....	5
1.1 Overview.....	5
1.2 About the Autism Alliance	6
2 Prevalence.....	7
2.1 Overview.....	7
2.2 Estimating the gap in care.....	7
2.3 Cost of closing the gap.....	9
2.4 It's not just about the money.	11
3 Barriers and enablers among local authorities.....	12
3.1 Overview.....	12
3.2 Barriers	12
3.3 Enablers	16
4 Barriers and enablers among service providers	21
4.1 Overview.....	21
4.2 Barriers	21
4.3 Enablers	27
5 Discussion and key areas for change	30
5.1 Discussion	30
5.2 Key areas for change.....	30

Key Messages

- This report finds that there is a substantial gap between available capacity and likely demand for specialist social care services among autistic adults in England. This gap in care relates primarily to autistic adults with a moderate learning disability.
- The estimated cost of closing the gap in provision for specialist social care services would be between £69.5 million and £139.2 million, equating to between 0.4% and 0.7% of current adult social care spend. Additional costs relating to recruitment, retention and training of specialist staff would need to be added to this estimate. Increased government investment is a key part of the solution for closing the gap between supply and demand for care services for autistic adults in England – but the investment required is relatively small for a significant payoff, particularly if seen as part of wider reform of adult social care funding and delivery.
- Alongside investment, local authorities, local NHS services, care providers, the CQC and mental health services can and should work more closely together to address the barriers holding back access to specialist care and support. These include supporting market development, strengthening accreditation, investing in staff training to improve understanding of autism, using experts by experience to inform commissioning and inspection, and continuing to improve the evidence base on effective interventions and support for autistic adults.
- Beyond the provision of adult social care, there is almost certainly an even larger gap in specialist community support for individuals with lower-level support needs and those accessing health-related services related to autism – e.g., mental health services, autism assessment and diagnosis. This support urgently needs attention, as without it needs can escalate, leading to poorer outcomes for autistic adults and greater use of higher cost, crisis-focused services.

Thank you

The research that underpins this report would not have been possible without the helpful assistance of the Association of Directors of Adult Social Services (ADASS) - and in particular, the members of the ADASS Autism and Learning Disability Group. These local authorities took a particular interest in this work and supported the project through participation in the survey and also by members agreeing to be interviewed.

We would also like to thank the provider organisations from across both the for profit and not-for-profit sectors for their participation in this research.

Finally, we would like to thank the Autism Alliance and its members for their generous contributions of time and insight.

1 Introduction

1.1 Overview

Autistic adults represent a significant and growing proportion of the population in England. Despite improved legal recognition through the Autism Act (2009), Equality Act (2010) and Care Act (2014), autistic adults continue to experience stark inequalities across many areas of their lives, from health and education to employment and justice. Autistic people can have hugely diverse needs and experiences. Recognising this, autistic adults benefit from specialist care and support from professionals with autism-specific knowledge, understanding and practice experience. Receiving specialist support appears to benefit autistic people's health and wellbeing¹ and a small but growing evidence base indicates that specialist care may also offer long-term economic benefits.²

Adult social care in England, like the rest of local government, has experienced an extreme and sustained reduction in funding since 2010-11. The National Audit Office has estimated that local government spending power (government funding, council tax and businesses rates) reduced by 29% between 2010-11 and 2021-22.³

This reduction in funding has created a 'gap' in spending on adult social care between the demand for services driven by needs and the ability of local authorities to adequately respond. Estimates of this gap vary from £7 billion up to £14 billion - both estimates that the Levelling Up, Housing and Communities Committee described as credible.⁴

This report draws on original research to understand the impact of this funding gap on autistic adults, focusing on those who have a moderate learning disability. The report explores the demand for and supply of specialist social care provision for autistic adults (i.e., individuals aged 18 and over) in England and the barriers and enablers which contribute to this gap in provision of care.

The purpose behind this report is to provide new evidence about the needs of autistic adults and their families by defining the scale of the gap between supply and demand in specialist social care provision in England more clearly. In addition, this report aims to explore the factors that contribute to this gap to better

¹ Beresford et al. (2020). Evaluating specialist autism teams' provision of care and support for autistic adults without learning disabilities: the SHAPE mixed-methods study. *Health Services and Delivery Research*; National Institute for Health and Care Excellence (2016), Autism spectrum disorder in adults: diagnosis and management. Retrieved from <https://www.nice.org.uk/guidance/cg142>.

² Buescher et al. (2014). Costs of autism spectrum disorders in the United Kingdom and the United States. *JAMA pediatrics*, 168(8).

³ House of Commons Library, 2023. *Adult Social Care Funding (England)*. [pdf] Available at: <https://researchbriefings.files.parliament.uk/documents/CBP-7903/CBP-7903.pdf>.

⁴ House of Commons Library, 2023. *The spending of DLUHC on adult social care*. [pdf] Available at: <https://researchbriefings.files.parliament.uk/documents/CDP-2023-0047/CDP-2023-0047.pdf>.

understand why it exists and explain the consequences of this gap and how it might be addressed.

This report includes findings based on the following research activities:

- A review of documentation to inform calculations of the demand for specialist social care services for autistic adults and the supply of services available.
- 99 responses to a survey shared with 160 specialist social care services for autistic adults in England. This was open to responses between 9 May and 16 June 2023.
- 12 interviews with stakeholders who completed the survey above, conducted in July 2023.
- A focus group with members of the Association of Directors of Social Services' (ADASS) learning disability and autistic people policy network, held during their monthly meeting on 19 July 2023.
- 33 responses to a survey disseminated among the members of the ADASS learning disability and autistic people policy network. This survey was open to responses between 12 July and 31 August 2023.
- Six interviews with local authority stakeholders who completed the survey above, conducted in the period August-September 2023.

1.2 About the Autism Alliance

The Autism Alliance is a UK partnership of not-for-profit organisations supporting autistic people and their families. They work with government to influence policy, campaign nationally on issues that affect autistic people and their families and work together to improve services and practice. The vision of the Autism Alliance is a world in which autistic people can thrive and live their lives as part of their communities.

2 Prevalence

2.1 Overview

In summary, we are exploring a specific aspect of the gap between demand and provision in adult social care as it affects autistic adults with a learning disability.

This work suggests that there is a significant group of people, probably amounting to around 11,600 autistic adults with a moderate learning disability, that local authorities do not currently have the resources to support.

2.2 Estimating the gap in care

The most recent data on adults supported by local authority social services indicates that there were around 142,000 people whose primary reason for accessing adult social care was a learning disability.⁵ We have assumed that the majority of this group will have a learning disability defined as being moderate, severe or profound rather than mild. We have made this assumption on the basis that local authorities are expected to prioritise who they support on the basis of need.

The prevalence of all types of learning disability among adults in England is around 2.16% of the population, which suggests around 967,000 adults have a learning disability in England.⁶ Of this group, around 85% will have a mild learning disability. This leaves a group of around 145,000 adults with a moderate, severe or profound learning disability.

Research supported by the Department of Health and undertaken by Eric Emmerson and Susannah Baines estimated the prevalence of autism among adults with a learning disability to be between 20% and 33% of people.⁷ This research focused on people who were in receipt of services, suggesting that it is reasonable to apply this prevalence rate to current recipients of adult social care.

This suggests that of the 142,000 adults whose primary reason for accessing social care was a learning disability, somewhere between 28,400 and 46,860 will be autistic.

⁵ Short and Long Term (SALT) data sources for the Adult Social Care Outcomes Framework (ASCOF) 2021-22 (March 2022), NHS Digital. Available at: <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/social-care-collection-materials-2022/salt-sources-for-ascof-2021-2022>.

⁶ Mencap, 2023. *How common is learning disability?* [online]. Available at: <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability>.

⁷ Emerson, E., & Baines, S. (2010). The estimated prevalence of autism among adults with learning disabilities in England. *Improving Health and Lives: Learning Disabilities Observatory, Durham*. Available at: http://www.wecomunities.org/MyNurChat/archive/LDdownloads/vid_8731_IHAL2010-05Autism.pdf.

Current research suggests that around 1 in 67 people are autistic.⁸ Clearly, the impact of autism can vary greatly and this level of prevalence relates to all autistic people. There is further research which suggests that there is a degree of underdiagnosis of autism, particularly among older people.⁹

For the purposes of this report, we will use the prevalence rate of 1 in 67 people. There are around 44.7 million people in England aged 18 and over. This suggests that around 668,000 adults in England will be autistic.

A proportion of this 668,000 will, in addition to autism, also have a learning disability. Most research agrees that this will be around 40% of people who are autistic, or 267,000 people.¹⁰

Like autism, a learning disability can vary significantly in terms of its impact on an individual.¹¹ Around 1-2% of people with a learning disability have a degree of disability defined as profound; somewhere between 3-4% of people with a learning disability have a degree of disability defined as severe and around 10% of people with a learning disability have a degree of disability defined as moderate. The remaining 85% have a degree of learning disability defined as mild.

There is some evidence to suggest that autistic people may be more likely to have a learning disability defined as profound, severe or moderate. However, for the purposes of this report, we will apply these figures without attempting to quantify this.

Therefore, we are assuming that of the 267,000 autistic people with a learning disability, that the learning disability would be defined as 'mild' for around 85%, or 227,000 people; that it would be defined as moderate for around 10%, or 26,700 people and defined as severe and profound for somewhere between 10,700 people and 16,000 people respectively.

As we have already said, we are assuming that the vast majority of people who receive support from adult social care for reasons of a learning disability will have a level of disability defined as moderate, profound or severe and we further

⁸ [What is autism | Autistica](#). The Office for National Statistics (ONS) Census and Disability Data (December 2020) reported 989,000 autistic people aged 16-64 years in the U.K., which supports an estimated prevalence rate of 1 in 67 people.

⁹ O'Nions, E., Petersen, I., Buckman, J. E., Charlton, R., Cooper, C., Corbett, A., ... & Stott, J. (2023). Autism in England: assessing underdiagnosis in a population-based cohort study of prospectively collected primary care data. *The Lancet Regional Health—Europe*, 29; Emerson, E., & Baines, S. (2010). The estimated prevalence of autism among adults with learning disabilities in England. *Improving Health and Lives: Learning Disabilities Observatory, Durham*.

¹⁰ [Learning disability - Autism | Autistica | Autistica](#).

¹¹ *Valuing People* (2001). A new strategy for learning disability for the 21st century. A White paper presented to Parliament by the Secretary of State for Health by Command of Her Majesty.

assume that this applies equally to autistic adults in addition to a learning disability.

If we take the lower estimate of prevalence of autistic people with a learning disability, this suggests that of the 142,000 people in receipt of support from adult social care services, around 28,000 will also be autistic. We assume that most autistic people who have a severe or profound learning disability will be in receipt of a service. This would account for around 13,000 of those 28,000 people. This means that the remaining 15,000 autistic people are likely to have a degree of learning disability defined as moderate.

However, the number of autistic people with a learning disability defined as moderate is likely to be around 27,000 people, of whom we estimate 15,000 are in receipt of adult social care provision. We therefore estimate that local authorities do not have sufficient resources to support around **11,600** autistic adults with a moderate learning disability – and therefore, they do not receive any services.¹²

2.3 Cost of closing the gap

Clearly our estimate of 11,600 people not in receipt of adult social care would be a group with diverse needs. Not everyone would need very intensive support, although some would. We have assumed somewhere between 5 hours and 10 hours of support a week, which for most people would equate to 1 to 2 hours of support most days of the week.

The recent Fair Costs of Care exercise undertaken by local authorities shows an average hourly cost for domiciliary care as £23.28.¹³ This means that a 5 hour per week package of support would cost just over £6,000 per year, and a ten-hour package twice this amount.

If this were applied to the 11,600 autistic people we believe are likely to have a moderate learning disability and are not in receipt of an adult social care service, the annual additional costs would be **between £69.5 million and £139.2 million**.

This is a significant sum of money, but it represents a tiny fraction of current adult social care spend as reported by ADASS, equating to somewhere between 0.4% and 0.7%.¹⁴ Even as an element of an estimated funding gap of between £7

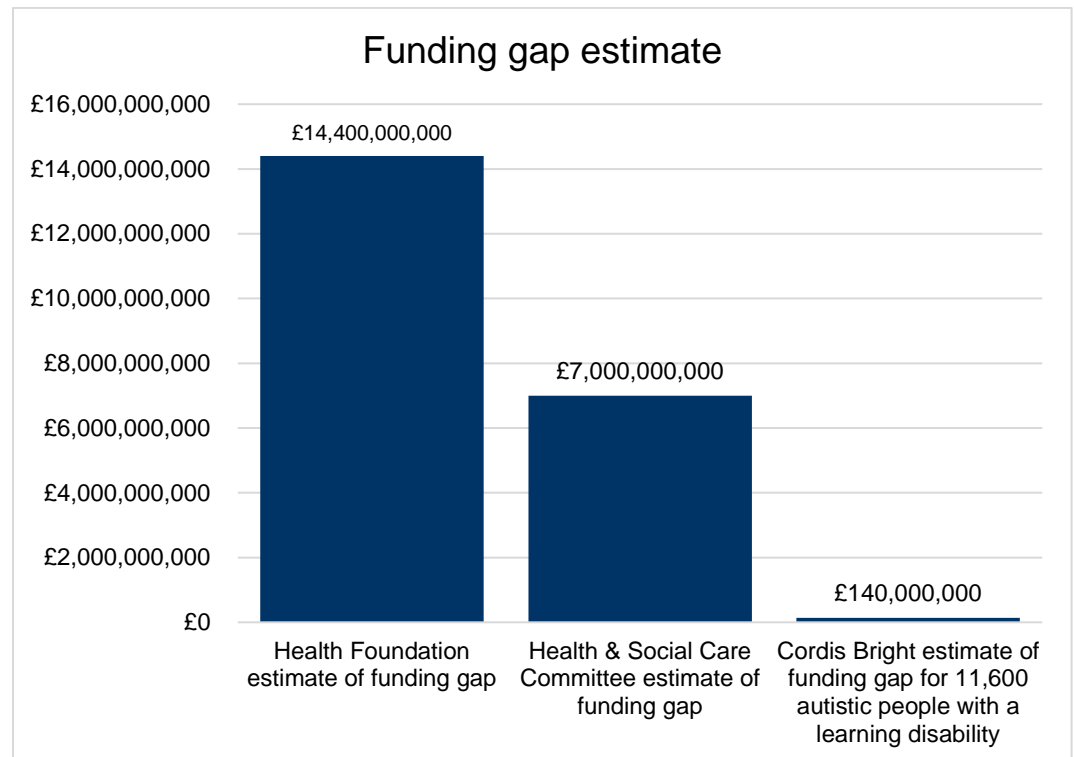
¹² We recognise that there is a known cohort of autistic people with a learning disability currently supported within the NHS. The majority of these people are in the care of the NHS for the purpose of assessment and treatment. This group of autistic people number around 475 and represent some 22% of the total which was 2,180 at the end of March 2023. We do not have any information as to the severity of their learning disability, but recognise that there is some limited potential for double counting. If this has occurred, then we estimate it can be no more than approximately 300 people.

¹³ Cordis Bright, Review of all Fair Costs of Care reports across England, 2023.

¹⁴ Association of Directors of Adult Social Services (ADASS), Spring Survey 2023. Available at: <https://www.adass.org.uk/adass-spring-survey-2023-final-report-and-press-release>

billion and £14 billion, it represents between 1% and 2% of current adult social care spend.

As well as the core costs of provision, costs relating to staff recruitment, retention and training will also need to be factored in. These are significant costs, but very much within reach if national government engages with meaningful reform of adult social care funding.



In other words, additional funding equivalent to less than 1% of current expenditure would enable local authorities to extend support to over 11,000 autistic people likely to have a moderate learning disability and not in receipt of any service.

It is important to note that the gap in care is likely to be increasing. The analysis in this report is based on data from 2021-22, but research has shown that rates of autism diagnosis increased by 787% between 1998 and 2018.¹⁵ Assuming rates continue to increase at all age ranges, and recognising there is a potentially large population of currently undiagnosed autistic adults, the cost of closing the gap in care presented here should be seen as a starting point for a wider discussion about planning, in the context of wider reform of adult social care.

¹⁵ Russell G, Stapley S, Newlove-Delgado T, Salmon A, White R, Warren F, Pearson A, Ford T. (June 2022). Time trends in autism diagnosis over 20 years: a UK population-based cohort study. *Journal of Child Psychology and Psychiatry*.

2.4 It's not just about the money.

Sufficient funding is, of course, key to meeting the needs of this group of people, but funding alone does not fully explain why so many autistic people are not getting the support they need. The following sections of this report draw on the experiences and expertise of local authorities as commissioners and on the experience and insights of independent organisations as service providers.

3 Barriers and enablers among local authorities

3.1 Overview

This section reports what local authority stakeholders involved in commissioning services for autistic adults perceive as key barriers and enablers for meeting the needs of autistic adults.

Overall, stakeholders expressed concerns at their local authorities' performance in meeting the needs of autistic adults. Over a third of respondents to our survey believe their local authority is poor or very poor at meeting the needs of autistic adults. Only 16% of respondents felt their local authority was good or very good at meeting the needs of autistic adults.

Several key barriers to meeting these needs were identified by stakeholders: the inaccessibility of autism diagnoses and assessments in their localities; insufficient supply of services – in particular residential care; and dissatisfaction with the quality of some service providers. In addition, some stakeholders reported that they felt their local authorities could be more consistent in their support of autistic adults' carers.

Stakeholders also identified some key enablers of effective service provision. Some highlighted creative efforts by their local authorities to reduce the length of time individuals wait for an autism assessment and diagnosis. Accreditation was flagged by many local authority stakeholders as a useful marker of service quality, along with evidence of high-quality staff training. Finally, a number of suggestions were made for how the CQC should approach inspecting and registering providers to ensure accountability, whilst working in partnership with specialist services, rather than against them.

3.2 Barriers

3.2.1 Accessibility of autism diagnoses and assessments:

Two thirds of survey respondents thought autism diagnoses and assessments were not very accessible or not at all accessible in their locality. Several references were made to the fact that access to services is contingent on having an autism diagnosis, which means that there are autistic adults across England who are not in receipt of services due to being unable to access autism assessments.

“The diagnosis rates are really low...autistic people are grouped into the general neurodiversity pathway along with ADHD and depression. Unfortunately, a lot of funding and support comes with the diagnosis.”

Local authority stakeholder

“Every government initiative that comes out needs people to have a diagnosis.”

Local authority stakeholder

This lack of accessibility was attributed to:

- Diagnoses not being shared automatically by GPs with local authorities – which means that available information about diagnoses is often poor-quality and inconsistent.
- Long waiting lists for autism assessment diagnoses, which leads to delays in people receiving diagnoses. One stakeholder attributed delays to insufficient diagnostic clinics in their area.
- Local authorities not having direct contact with professionals carrying out autism assessments and diagnoses, which in turn slows down information sharing.

Additionally, a number of stakeholders raised that diagnosing autism, learning disabilities and mental health conditions respectively can be challenging, leading to misdiagnosis or individuals missing out on dual diagnoses.

3.2.2 Limited availability of services for autistic adults – in particular accommodation-based services:

While challenges relating to accessing autism diagnoses were flagged as a major barrier by nearly all local authority stakeholders, many identified that even where individuals have received an autism diagnosis, support may not be available to them. Nearly half of survey respondents reported challenges with the availability of services for autistic adults, specifically home care, residential care, nursing care and supported living. Nearly one in five respondents reported that nursing care and residential care specifically were unavailable in their locality.

“The availability of autism service providers really needs work. ICBs and local autism trust providers need to have better conversations about the demand for services from a health perspective.”

Local authority stakeholder

A lack of available residential services to discharge people to was reported as the biggest barrier local authorities face when attempting to discharge autistic adults from Assessment & Treatment Units (ATUs). This was flagged as having long-term negative ramifications for autistic adults' wellbeing.

“A lack of low-level housing is an issue, especially as community discharge grants finish this year. While we have managed to discharge lots of people, now we have a very complex group left in hospital – who are likely to bounce in and out of hospitals due to mental health conditions.”

Local authority stakeholder

“One of the most difficult things for discharge [from ATUs] is availability of accommodation. One, it can take a good 12 months to sort out appropriate accommodation. Two, if you can sort it out, it’s hard to support the care for the person in their accommodation. You desperately need care providers engaged and helping with the transition from hospital to the place they will live. There is a bit of a chicken and an egg situation.”

Local authority stakeholder

A number of stakeholders also flagged challenges with insufficient data sharing between local authority teams and NHS colleagues:

“We’ve been talking to our local mental health trust; they can’t tell us who is and who isn’t autistic, as their system is unreliable for diagnosis, but what they do know is admissions [to ATUs] are longer for autistic people. It’s about move-on provision lacking – and they don’t reliably use dynamic support registers. We suspect some OOA [out of area] placements aren’t using the CTR [Care and Treatment Reviews].”

Local authority stakeholder

One stakeholder described a project undertaken with NHS colleagues to monitor people in ATUs who had completed safe and wellbeing reviews. They praised this collaborative project as having successfully identified many individuals who did not need to be in hospital and tracked how their discharge was progressing – but noted that they felt NHS commissioners in particular need to be made aware of the need for improved discharge pathways:

“We are just starting a piece of work to see if there are top tips for NHS commissioners to make them more aware of housing [as one of the biggest stumbling blocks], they can join in to start conversations about it. There are things adult social care can, but also health commissioning colleagues are further back on that road than we are.”

Local authority stakeholder

Local authority stakeholders also reported that a lack of specialist services has led to some autistic adults receiving overly generalised support offers.

“People need tailored approaches. At the moment, a lot of mental health services don’t have the skills for dealing with autistic people. This leads to autistic people drawing on learning disability services because there’s nothing else in the area.”

Local authority stakeholder

“To be totally frank, there is nothing in my area commissioned specifically for autistic people, and too many autistic people are asked to fit into older people services especially. Social workers are thinking in terms of practical assistance rather than different forms of support that people might need. They don’t want personal care, over perhaps

other things, and we haven't as a system got our heads around that...as a result, people end up at the hard end of the mental health system when something else could have been more sensible."

Local authority stakeholder

For individuals with both a learning disability and autism, it was flagged that there can be confusion about which services are best placed to provide support for each diagnosis:

"...we need to adjust the needs of services for the dual diagnosis. It's not really working well because there is a push and pull about what is the primary need – if it's autism that drives behaviour, mental health [services] don't want to take it on, so we're not positioned well in this."

Local authority stakeholder

Finally, a number of stakeholders discussed that their local authorities are unable offer support to many autistic adults because there is a lack of provision for adults with lower levels of need:

"As we are still developing our preventative service, we don't have much to offer to people with lower levels of need. All we can give them at the moment is signposting."

Local authority stakeholder

3.2.3 Concerns regarding the quality of local specialist services:

While several local authority stakeholders rated the specialist services in their areas as very good or good, indicating that there are clearly some specialist care providers providing high-quality support, it is notable that over half of survey respondents reported that their services were neither good nor poor, but 'reasonable'. A similar number reported that the quality of specialist services outside of their local authority area was reasonable.

Nearly half of respondents felt that service providers offer poor value for money. One interviewee reported that negative perceptions of the cost attached to commissioning specialist autism services had affected commissioning practices in their locality:

"I have heard from colleagues that specialist services often claim to be specialists, but they just charge more and offer the same support as more general learning disability services."

Local authority stakeholder

In addition, although 24% of respondents believed that the level of expertise of service providers was good or very good, 48% of respondents believed that the level of expertise was poor or very poor. This view was attributed to challenges securing qualified staff.

"The main problem is staffing arrangements – there is a huge recruitment drive underway, but it is really difficult to recruit people."

Providers are losing experienced staff in the top end due to poor pay and difficult working environments. Companies like Amazon provide better pay and providers are struggling within our local market. We need staff with forensic backgrounds to deal with more complex needs.”

Local authority stakeholder

The barrier described above around insufficient providers supplying residential accommodation is compounded where these services have been closed due to failing CQC inspections.

The extent to which autism-specific expertise is present among some providers also arose during an online search we conducted of service providers’ websites. We found that many providers of services for adults with learning disabilities also claimed to offer support for autistic people, but regularly did not provide any evidence of autism-specific expertise or accreditation. The topic of accreditation – and whether this may represent a marker of the range of quality among service providers – is discussed in more detail in Section 3.3. Both the website review and survey data indicate that the question of service quality warrants further exploration to gauge if perceptions of a substantive issue with some services’ provision are shared more widely beyond this specific sample.

3.2.4 Inconsistent quality of support for carers of autistic people:

Stakeholders reported that local authorities’ performance in supporting carers of autistic people varied substantially. Some areas of good practice were highlighted, such as autism-specific social care teams doing awareness-raising work around caring for autistic individuals; funding of carer associations and access to short-term counselling support and one-off grants. However, stakeholders tended to characterise support for carers as reactive rather than proactive and only rarely specific to autism.

“I agree that it [support for carers of autistic people] is patchy and the communication and information for carers isn’t great. They might not know how to navigate different services, which can be really frustrating. We need to make information accessible across all services, and we should bring in specialist social workers who have expert knowledge.”

Local authority stakeholder

3.3 Enablers

3.3.1 Initiatives to speed up the autism assessment process and provide support to individuals on waiting lists:

Stakeholders highlighted a number of initiatives they had pursued in their local authorities to address the years-long waiting lists many autistic adults currently face while awaiting an autism assessment. In one area, the NHS had commissioned voluntary sector services such as workshops for individuals on

waiting lists. In another, implementing a self-referral process where people could refer themselves for assessments had allowed them to bypass going to a GP first, which had reduced waiting lists significantly. Nevertheless, all local authority stakeholders were clear that nationally, significant waiting lists for autism assessments demonstrate a large surplus of demand relative to capacity.

3.3.2 Value of accreditation as a marker of service quality:

76% of survey respondents believe it is essential or important that providers of specialist social care services for autistic adults are formally accredited. Many respondents flagged specific accreditations as especially important, including those provided by SPELL, PBS and NAS.

“Given that a lot of providers call themselves autism specialists, maybe accreditation would help. For more generic services like schools, autism-friendly kitemarks could also be useful.”

Local authority stakeholder

Beyond accreditation in and of itself, local authority stakeholders reported the importance of regular monitoring, as well as building in more co-production to the accreditation process. In addition, the importance of ensuring local authorities' autism strategies are informed by the national autism strategy (summarised below) emerged as a recurring recommendation. This may indicate that local authorities feel more comfortable devising their own local autism strategies on the back of national guidance.

The national strategy for autistic children, young people and adults: 2021 to 2026: the road map for the next five years

Improving understanding and acceptance of autism within society

We will significantly improve the public's understanding and acceptance of autism and show that autistic people feel more included and accepted in their communities. We also want the public to understand how autism can affect people differently, including the difference in how autistic women and girls present, and to help change people's behaviour towards autistic people and their families. We want many more businesses, public sector services and different parts of the transport system to become more autism-inclusive, so that autistic people can access these spaces and services, just like everyone else.

Improving autistic children and young people's access to education and supporting positive transitions into adulthood

We want the SEND system to enable autistic children and young people to access the right support, within and outside of school. We want schools to provide better support to autistic children and young people, so they are able to reach their potential, and to show that fewer autistic children are permanently excluded or suspended from school due to their behaviour. We will make improvements to the support autistic people get in their transitions

into adulthood, so that more autistic people can live well in their own communities, find work or higher education or other opportunities. This is important in preventing more young people from avoidably reaching crisis point or being admitted into inpatient mental health services.

Supporting more autistic people into employment

We will make progress on closing the employment gap for autistic people, ensuring that more people who are able and want to work can do so and that those who have found a job are less likely to fall out of work. We want more employers to be confident in hiring and supporting autistic people, and to improve autistic people's experiences of being in work.

Tackling health and care inequalities for autistic people

We want to reduce the health and care inequalities that autistic people face throughout their lives, and to show that autistic people are living healthier and longer lives. In addition, we want to have made significant progress on improving early identification, reducing diagnosis waiting times and improving diagnostic pathways for children and adults, so autistic people can access a timely diagnosis and the support they may need across their lives.

Building the right support in the community and supporting people in inpatient care

We will achieve the targets set out in the NHS Long Term Plan to reduce the number of autistic people and people with a learning disability being admitted into inpatient mental health services. We will do so by improving the treatment of autistic people in mental health legislation to prevent people from being avoidably admitted to inpatient care and improving the provision of community mental health and crisis support. We will also improve the suitability and availability of housing support and social care. In addition, for people who do need to be in inpatient mental health settings, the quality of care will be better and more tailored to their individual needs and people will be discharged back into their communities as soon as they are well enough to leave.

Improving support within the criminal and youth justice systems

We will build a clearer understanding of how autistic people come into contact with the criminal and youth justice systems, and the type of support they may need across court, prison and under probation supervision. We will improve the police and wider criminal and youth justice system staff's understanding of autism so that autistic people are more able to receive the right support, adjusted to their needs, as well as ensuring that different parts of the justice system – from prisons to courts – become more autism-inclusive.

3.3.3 Value of high-quality training to ensure services for autistic adults can meet their diverse needs:

A number of local authority stakeholders brought up training as a key enabler for building staff competence, confidence and knowledge amongst services for autistic adults. Among them, several suggested that the training options on offer would benefit from being updated to reflect diverse presentations of autism, and some suggested that updated training should also be provided for the CQC.

“[What should additional funding be spent on?] Provide some really robust training for staff so that they can feel empowered. This training needs to cover what it’s like to live with autism and the experiences of carers...we have received some really good training on autism and have pockets of it throughout our services, but it needs to be delivered as part of social work training.”

Local authority stakeholder

“They [the CQC] need to make sure their training approach is broad to include lots of different presentations of autism, especially within women, and those with mental health difficulties.”

Local authority stakeholder

In general, local authority stakeholders view Oliver McGowan training – a training programme which has been mandatory for NHS health and care staff who work with the public since November 2022 – as an important accreditation. However, due to the complex and varied presentations of autism, stakeholders admit that the training “*can only go so far*”. Furthermore, there are concerns regarding who will pay for the Oliver McGowan training, as local authorities state they have had “*no additional funding to cover this expense*”.

Oliver McGowan Mandatory Training on Learning Disability and Autism

The training is named after Oliver McGowan. Oliver was a young man whose death shone a light on the need for health and social care staff to have better skills, knowledge and understanding of the needs for autistic people and people with a learning disability.

The Oliver McGowan Mandatory Training on Learning Disability and Autism is the government’s preferred and recommended training for health and social care staff. Oliver’s training is delivered in two tiers. Staff need to complete either Tier 1 or Tier 2:

- Tier 1 of the training is for people who require a general awareness of the support autistic people or people with a learning disability may need.
- Tier 2 of the training is for people who may need to provide care and support for autistic people or people with a learning disability.

For both tiers of training, participants must complete the e-learning session which is mapped to the Tier 1 learning outcomes of the Core Capabilities Framework for Supporting Autistic People and the Core Capabilities Framework for Supporting People with a Learning Disability.

Following this e-learning session, participants will proceed on the basis of the appropriate tier for their job role:

- Tier 1: a one-hour online interactive session co-delivered by experts by experience and a subject matter expert facilitator; or
- Tier 2: a one-day face to face training co-delivered by experts by experience and a subject matter expert facilitator.

3.3.4 Potential for the CQC to take specific steps in relation to the inspection and registration of autism services which could improve services for autistic adults:

Some suggestions flagged by local authority stakeholders for steps which the CQC could take in relation to inspecting and registering autism services included:

- Working more closely with service providers to improve standards of care and prevent services from closing down.

“The CQC have an instrumental role. They’ve closed a few private hospitals. By having facilities OFSTED and CQC regulated, individuals could stay in placements for longer. They need to work with providers more.”

Local authority stakeholder

- Requiring health services to have a mechanism for identifying autistic people, such as an autism register, to ensure they are provided with specialist support.
- Developing an autism specialist accreditation for service providers to improve accountability.

4 Barriers and enablers among service providers

4.1 Overview

This section explores what providers of specialist services for autistic adults perceive as the key barriers and enablers to their service users receiving the support they need.

Stakeholders reported that major barriers included the absence of a partnership approach between local authorities and providers; local authority commissioners lacking a full understanding of the complexity and individuality of autistic adults' support needs and how this affects service delivery; the gap in support for autistic individuals with lower support needs; and the need for more support for smaller providers to preserve market sustainability and prevent them from collapsing.

Key enablers identified by service providers included the potential for ringfenced funding specifically for autistic adults – though this was not viewed the same way across all stakeholders – and, as with local authority stakeholders, the value of accreditation as a marker of service quality. Specific steps which the CQC could usefully take for improved regulation of services for autistic adults were also discussed.

4.2 Barriers

4.2.1 Lack of regular collaboration between local authorities and specialist service providers:

Several service provider stakeholders expressed frustration at what they perceived to be a distance between local authority professionals and service providers.

“I think there’s a need for local authority professionals to be more present. You don’t get a sense that they’re there. We need more physical engagement from them in terms of building relationships.”

Autism service provider stakeholder

Some stakeholders discussed this sense of distance in the context of a deficit in social services workforce, with a high number of agency staff and high turnover both noted as barriers which lead to reactive, rather than proactive, responses and hinder being able to work together more collaboratively.

“You can’t get a meeting with an adult social care social worker anymore. They don’t have a real idea of what’s happening on the ground.”

Autism service provider stakeholder

The pressure on staffing within local authorities, which has led to a loss of specialised staff in recent years, was also flagged by one stakeholder as contributing to lack of knowledge concerning autistic people's unique needs.

“As commissioners have moved away from hiring specialists, there is a huge lack of understanding what having autism is and how it impacts people.”

Autism service provider stakeholder

Other stakeholders spoke about a feeling of distance in relation to commissioners, in particular around stimulating the market and a lack of “creativity” around addressing workforce availability.

“There’s a lack of imagination in local authorities. If they could think more creatively about employability, it would relieve current pressure... There’s a preventative aspect they need to explore: joining up pieces of the workforce they have access to.”

Autism service provider stakeholder

“Commissioning ... on the basis of broad assessment of people's needs and then commissioning of number of hours... doesn't enable providers to be very creative or innovative. It makes the whole thing a bit more like a sausage factory; inputs rather than what are we trying to help this person to achieve.”

Autism service provider stakeholder

Of these stakeholders, several expressed interest in working directly with local authorities in order to provide a more “creative” approach to service provision within a partnership approach::

“We want to have a dynamic conversation with commissioners, based on knowledge and passion.”

Autism service provider stakeholder

“Commissioners need to understand who the local providers are, use us more, and trust the expertise of those who work on this.”

Autism service provider stakeholder

4.2.2 Local authority commissioners lacking full understanding of autism:

A key area of improvement highlighted by many service provider stakeholders was for local authority commissioners to strengthen their basic understanding of what autism is, and how it affects people's needs and experiences.

“I often sit in meetings with commissioners who don’t understand why they can’t do the same things for autistic adults as they do for the elderly.”

Autism service provider stakeholder

The complex support needs of some autistic adults, the unpredictability of those needs, which are often triggered by changes to their environments, and the fact that individual’s needs may change over time, also requires staff with a high level of training. Stakeholders indicated that the full extent of these training needs is not always fully appreciated.

“The investment necessary to prevent bigger issues is far greater with individuals with autism [than with individuals with a learning disability]: coaching, reviewing, staff training, preventing safeguarding issues, preventing disaster.”

Autism service provider stakeholder

In addition, stakeholders noted that staff within services require ongoing training, which can be expensive, reducing the number of qualified staff.

“More autism-specific trained staff are needed to make sure that autistic people are not traumatised or neglected within services.”

Autism service provider stakeholder

“The status of the care sector needs proper qualified staff.”

Autism service provider stakeholder

4.2.3 Lack of services available for individuals with lower support needs:

Stakeholders reported that some individuals diagnosed with autism but who have lower-level needs are unable to currently access support as very few services are commissioned with their needs in mind.

“There’s a whole new population of autistic people who don’t have a learning disability, but do have support needs- but there’s no service for them. They end up in mental health services. We have services for people at the top of the pyramid, but nothing below. This group would benefit from universal, enhanced support, e.g., one-stop shops to prevent escalation. We need to think differently about the universal enhanced level: there’s intensive pressure coming from people with lower-level needs and no service is meeting their needs.”

Autism service provider stakeholder

Stakeholders expressed concerns that not providing support for autistic people with lower-level needs is likely to cost more in the long-term, as it elevates the risk of a deterioration in individuals’ wellbeing which then precipitates a crisis leading to the individual ending up in A&E, police being called out, or even ending up homeless.

“A lot of the costs are masked. These individuals end up having to use services that become more specialised. Low-level support costs peanuts, but not having that can wind up being really expensive.”

Autism service provider stakeholder

Showing how costs can be saved

The Autism Alliance is working with the London School of Economics and Political Science (LSE) on research which quantifies the cost to the state of supporting people with autism. The total cost associated with autism across the U.K. economy in terms of treatment, lost earnings and care and support has been previously estimated at £32 billion.¹⁶

This new research, due to be published in 2024, is exploring how a different configuration of spending could improve outcomes for autistic people and lead to a long-term net cost saving across the economy. Meeting unmet demand through preventative support is likely to prevent the escalation of need, which typically leads to expensive, long-term inpatient care.

4.2.4 Smaller providers risk collapsing without more support – with no one to replace them:

While service providers saw the value in CQC regulation, there was a feeling shared among several stakeholders that where smaller providers receive inadequate ratings, the CQC could provide more support to prevent them from closing altogether.

“They [the CQC] do nothing to help small providers. Some of the small providers collapse because of poor leadership and governance, but they’re the only folks in town and they’re good folk. Someone should come along and provide space for their development.”

Autism service provider stakeholder

“What is the plan? [It’s] just crushing provision; no one else wants these adults because they’re expensive and challenging. There isn’t a plan when you shut down 30 providers.”

Autism service provider stakeholder

One stakeholder suggested that regulation in the care sector could draw from precedents set in other sectors, such as the allocation of mentors and coaches to boards of housing providers by the housing regulator.

¹⁶ Buescher, A. V., Cidav, Z., Knapp, M., & Mandell, D. S. (2014). Costs of autism spectrum disorders in the United Kingdom and the United States. *JAMA pediatrics*, 168(8).

“We should be inspecting in terms of how the service is dealing with a problem, not punishing them because of the problem.”

Autism service provider stakeholder

In addition to the regulatory role of the CQC, local authorities have a core role in the sustainability of specialist social care services, given their mandate under Section 5 of the 2014 Care Act (see box below) to lead on developing a sustainable market of provision. Service provider stakeholders discussed wanting both local authorities and the CQC to work in partnership around market development, as well as ensuring autistic people and their families are meaningfully involved in co-production of services.

“Local authorities need to collaborate with providers and hold more strategic discussions about making changes to services or opening new services.”

Autism service provider stakeholder

“In their [the CQC’s] new role of oversight and monitoring local authorities, they need to have a really good look at their commissioning strategy, specifically on how they’re working with providers. It’s not just about what they’re regulating. They also need to bring in the person and their family into conversations more.”

Autism service provider stakeholder

Care Act 2014

Section 5: Promoting diversity and quality in provision of services

- (1) A local authority must promote the efficient and effective operation of a market in services for meeting care and support needs with a view to ensuring that any person in its area wishing to access services in the market—
- (a) has a variety of providers to choose from who (taken together) provide a variety of services;
 - (b) has a variety of high quality services to choose from;
 - (c) has sufficient information to make an informed decision about how to meet the needs in question.
- (2) In performing that duty, a local authority must have regard to the following matters in particular—
- (a) the need to ensure that the authority has, and makes available, information about the providers of services for meeting care and support needs and the types of services they provide;

- (b) the need to ensure that it is aware of current and likely future demand for such services and to consider how providers might meet that demand;
 - (c) the importance of enabling adults with needs for care and support, and carers with needs for support, who wish to do so to participate in work, education or training;
 - (d) the importance of ensuring the sustainability of the market (in circumstances where it is operating effectively as well as in circumstances where it is not);
 - (e) the importance of fostering continuous improvement in the quality of such services and the efficiency and effectiveness with which such services are provided and of encouraging innovation in their provision;
 - (f) the importance of fostering a workforce whose members are able to ensure the delivery of high quality services (because, for example, they have relevant skills and appropriate working conditions).
- (3) In having regard to the matters mentioned in subsection (2)(b), a local authority must also have regard to the need to ensure that sufficient services are available for meeting the needs for care and support of adults in its area and the needs for support of carers in its area.
- (4) In arranging for the provision by persons other than it of services for meeting care and support needs, a local authority must have regard to the importance of promoting the well-being of adults in its area with needs for care and support and the well-being of carers in its area.
- (5) In meeting an adult's needs for care and support or a carer's needs for support, a local authority must have regard to its duty under subsection (1).
- (6) In cases where a local authority performs the duty under subsection (1) jointly with one or more other local authorities in relation to persons who are in the authorities' combined area—
- (a) references in this section to a local authority are to be read as references to the authorities acting jointly, and
 - (b) references in this section to a local authority's area are to be read as references to the combined area.
- (7) “Services for meeting care and support needs” means—
- (a) services for meeting adults' needs for care and support, and
 - (b) services for meeting carers' needs for support.
- (8) The references in subsection (7) to services for meeting needs include a reference to services, facilities or resources the purpose of which is to contribute towards preventing or delaying the development of those needs.

4.3 Enablers

4.3.1 Ringfenced funding for services for autistic people:

As well as increased levels of funding to close the gap in care for autistic adults, making progress in addressing barriers relies on funding being spent in the right ways. Providers had varied views on whether ringfencing funding for autism services at a local level would be beneficial.

Out of twelve respondents, four interviewees stated that ringfencing funding for autism services would be a positive intervention. This is because the funding could be used for:

- Providing autism-specific training and intensive interaction courses for staff. This links to the general concern that social care commissioning is not specialised for autistic people, despite local authorities' duty under Section 5 of the Care Act to foster a sustainable market.

“We could use it to develop staffing. At the moment, this comes out of our own pocket.”

Autism service provider stakeholder

- Improving staff pay – providers mentioned that as the care sector requires more qualified staff to provide care for autistic people, offering higher salaries will help to attract them.

“Pay higher hourly rates for the right calibre of staff. We get nowhere with the going rate (£11.05 per hour). Good staff can get jobs anywhere and, once employed, you have to keep them.”

Autism service provider stakeholder

However, an equal number of interviewees expressed reservations about ringfenced funding for specialist social care services for autistic people. This perspective was attributed to the following concerns:

- That the focus should be on meeting needs, not on spending a particular sum of money. The priority should be ensuring that the duties set out in the Care Act around assessing and meeting eligible needs are followed.
- That if a certain amount of funding was set aside for autistic people, other groups might be disadvantaged as a result, or access to funding for other support (e.g., mental health, co-occurring conditions) might be reduced.
- That providers might lose their ability to pool resources, which could lead to a lot of duplicate expenditure.
- That ringfencing funding specifically for autistic people may promote a view that autistic people have identical needs and always use the same services, which is not the case.

The remaining four interviewees were undecided about whether ringfenced funding for specialist services for autistic people would be beneficial. They advised that to have an informed opinion, they would need to know what the funding is specifically ringfenced for and whether individuals would require a formal autism diagnosis to be able to access support.

“I would worry about the people who need support, but don’t have a formal autism diagnosis. We work with a lot of people who don’t have one, because they don’t want the label of being ‘autistic’.”

Autism service provider stakeholder

4.3.2 Potential for the CQC to take specific steps in relation to the inspection and registration of autism services which could improve services for autistic adults:

Some suggestions flagged included:

- Using experts by experience to inform commissioning and inspection. Providers were concerned that their services could be marked down during inspections as CQC staff would not understand why certain restrictions were put in place to help service users with autism to self-regulate.

“If they have a background in disability, the inspector will have more knowledge and empathy.”

Autism service provider stakeholder

- The organisation as a whole improving their understanding of autism. Providers felt that CQC inspectors do not understand the wide range of autistic people’s needs and experiences, and that their view of what makes a service effective is limited, sometimes restricting the number of choices autistic people are allowed to make.

“There is little focus on autism. It appears to be more about the basic quality of service provided.”

Autism service provider stakeholder

“Services shouldn’t be penalised for allowing autistic people to make their own choices.”

Autism service provider stakeholder

- Establishing a dedicated set of criteria for inspecting services for autistic people. While this might entail setting up an independent body, providers expressed concerns about the similar inspection routines imposed across social care services.

Other steps service providers discussed that they would like to see the CQC take include hiring more staff, inspecting services more regularly and including more autistic people with severe/profound learning disabilities with limited means of

communication in inspection samples, as they are at greater risk of being neglected or mistreated.

4.3.3 Value of accreditation as a marker of service quality:

Nine in ten survey respondents reported that their service used approaches to working with autistic individuals with formal accreditation. Over half reported having Positive Behaviour Support (PBS) accreditation specifically.

Service provider stakeholders attach value to accreditation as a way of evidencing the skills and experience of their staff and ensuring their added value is recognised.

“There’s something about training, consistency, competency standards, the progression framework... We would learn from each other having something like an accreditation.”

Autism service provider stakeholder

A number of stakeholders also discussed the importance of accreditation in the context of the current market around service provision:

“Accreditation would help us keep up to date because autism practice is moving and changing rapidly. As a provider, it would push us to stay ahead of the market.”

Autism service provider stakeholder

“In terms of market positioning, there’s a race to the bottom. We can’t compete with that – so instead, we have to be specialist and evidence-based.”

Autism service provider stakeholder

This last point speaks to the fact that demonstrating evidence-based practice is viewed positively by commissioners. Yet despite the increasing emergence of practices designed for autistic people which are supported by evidence, there remain significant evidence gaps. One service provider stakeholder, for instance, highlighted the under-representation of non-verbal autistic people in autism research and interventions. Supporting efforts to improve the evidence base to shape the kinds of services provided must be a key strategic priority for all those who work with autistic people.

5 Discussion and key areas for change

5.1 Discussion

Our analysis shows that there is a substantial gap between current available capacity and likely demand for specialist social care provision for autistic adults in England. We estimate that a significant group of autistic adults with both autism and a moderate learning disability, amounting to around 11,600 people, are not in receipt of an adult social care service at present. The cost of closing this gap in provision would be between £69.5 million and £139.2 million, equating to between 0.4% and 0.7% of current adult social care spend. Additional costs relating to staff recruitment, retention and training would also need to be factored in, but even then, the total cost is achievable for government as part of wider reform of adult social care.

The 2014 Care Act includes a legal duty for local authorities to meet demand for social care from adults with eligible needs (Section 18), along with adults' wider need for support to promote wellbeing (Section 1), in order to *"help prevent, delay or reduce the development of care and support needs for adults in their area"*. This report has made clear that in practice, numerous barriers currently exist which mean this legal duty is not being met for many autistic adults in England.

Some of those key barriers are around lack of understanding of autism amongst commissioners, social workers and the NHS. First, that at a national and local level, autistic people represent a distinct group within adult social care from older people, and that they require a distinct model of commissioning. Second, that autistic adults present with different support needs to adults with learning disabilities and/or mental health conditions – and that commissioners and providers struggle with sourcing specialist support to meet those needs.

Other barriers relate to the absence of a partnership approach to commissioning between local authorities, the NHS and providers; the gap in support for autistic adults with lower support needs; and the need for more support for smaller providers to preserve market sustainability; the inaccessibility of autism diagnoses and assessments; and insufficient supply of services – in particular residential care; and dissatisfaction with the quality of some service providers.

Both local authority stakeholders and care provider stakeholders cited a range of potential enablers that could support closing the gap and improving outcomes for autistic people. These centred on joined up commissioning, market development, accreditation, inspection, co-production, and continuing to improve the evidence base relating to interventions.

5.2 Key areas for change

This report proposes two key areas for change:

First, action should take place at a local level in order to reduce barriers to access to social care amongst autistic adults. The evidence suggests that by

working more closely together on **market development, accreditation, staff training and co-production**, commissioners and care providers could address some of the barriers currently contributing to the gap in care. This partnership-based model would also need to involve local NHS commissioners and health services, including mental health services. Specifically, this report recommends:

- Integrated planning and commissioning of specialist care and support for autistic adults, delivered jointly by local authorities and local NHS services and carried out in partnership with specialist care providers.
- A clearer system of accreditation to signal specialist care provision in the market, and a dedicated set of CQC criteria for inspecting specialist provision for autistic people.
- A concerted push on training across commissioners, social workers, CQC inspectors, and mental health services so that there is increased understanding of autism and the specific and wide ranging needs and experiences of autistic people.
- Recognition of the increased cost of recruiting and retaining the specialist workforce required to provide high quality care and support for autistic adults.
- A stronger approach to market development delivered by local authorities and the CQC, supporting the sustainability and availability of specialist services, and;
- Involving experts by experience directly in commissioning and inspection activity, putting the needs and experiences of autistic adults centre stage and promoting understanding.

Secondly, while these actions would allow for some progress towards closing the gap between supply and demand for specialist autism social care services, **increased government investment** will be required to make significant progress. This report has estimated the scale of the gap in care for autistic adults with a moderate learning disability. As well as the core costs of provision, costs relating to staff recruitment, retention and training will also need to be factored in. These are significant costs, but very much within reach if national government engages with meaningful reform of adult social care funding.

Beyond this, the gap in specialist community support for autistic adults with a mild or no learning disability is likely to be greater still. As part of the next phase of the National Autism Strategy, the government should engage with this wider gap. There are strong economic, as well as social, reasons for investing in preventative support and early intervention.



CordisBright Limited

23/24 Smithfield Street, London EC1A 9LF

Telephone	020 7330 9170
Email	info@cordisbright.co.uk
Internet	www.cordisbright.co.uk