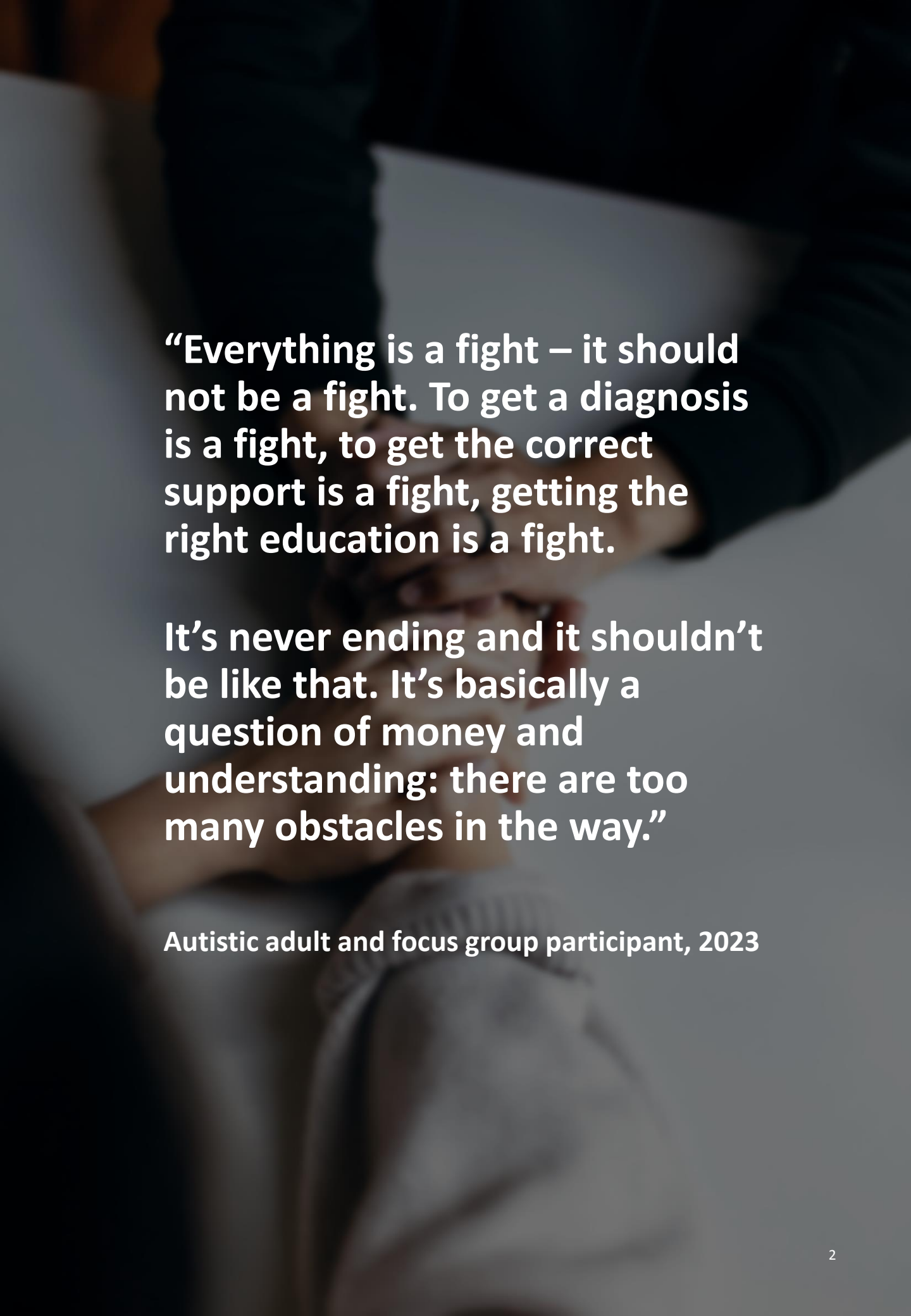




Breaking point:

Closing the gap in care and support for autistic adults in England

November 2023



“Everything is a fight – it should not be a fight. To get a diagnosis is a fight, to get the correct support is a fight, getting the right education is a fight.

It’s never ending and it shouldn’t be like that. It’s basically a question of money and understanding: there are too many obstacles in the way.”

Autistic adult and focus group participant, 2023



Introduction

This report shows there is a significant gap in care for autistic adults in England.

Facing some of the greatest inequalities of any group, autistic people are further disadvantaged by a system of care that cannot meet their needs, preventing them from living well and actively in their communities and taking up employment. Autistic adults face a double disadvantage, and too many reach crisis point before care is provided, leading to family breakdown and the risk of confinement in mental health hospitals.

The Care Act 2014 is clear that needs for care should be met, but the law is being broken daily across England because of a lack of Government investment. Autistic adults and their families are being pushed to breaking point.

Although the gap in care is significant, affecting over 10,000 autistic adults across England, it represents a fraction of the national budget for adult social care, and could be paid for by addressing inefficiencies in current spending across health and care. However, closing the gap will require reform as well as investment. Real collaboration between health and social care commissioners; a stronger approach to market development in specialist care and support; acceptance and understanding of autism at all levels of the system; and clear accountability, are all required to enable autistic adults to thrive.



Closing the gap in care is vitally important now: the Government needs to act to end this unacceptable failure of policy, and deliver real change for autistic people and their families. Looking ahead, it is simply critical, as the number of people being identified as autistic continues to rise, with large numbers of adults still undiagnosed.

The issues faced by autistic people in accessing care are symptomatic of the wider crisis in social care across England. Autistic people have reached breaking point, and the social care system is close to breaking too. But crucially, the principles that would improve care for autistic people will also improve care for everyone, and the Government should use the voices of autistic people as a guide for wider reform.

The findings of our work are echoed by leaders and commissioners in local government. The Association of Directors of Adult Social Services Spring Survey 2023 revealed that three quarters of social care directors across English councils say they 'aren't confident' about being able to fully offer the minimum social care support in their communities required by law, such as the availability of the right care, in the right place, at the right time.

This report is not only a call to address the unacceptable treatment of autistic adults and their families in our model of care: it is also a rallying cry for deeper reform. **Social care should be a marker of our country's commitment to inclusion, wellbeing and opportunity.** Through real engagement with reform, and bold political vision and leadership, we can create the system of care that autistic people need, and that the whole country needs.



The experiences of autistic adults in the social care system in England



77%

of autistic adults reach crisis point before care and support is provided.

48%

of autistic adults receiving social care say it does not meet their needs.

44%

of autistic adults wait more than 2 years for care and support to be provided.

58%

of autistic adults receive poor support during the process of trying to get social care.

56%

of autistic adults don't try to get care and support because they don't think they'll get it.



Source: Autism Alliance survey of autistic adults and parents/carers, summer 2023 (n = 232).

Figures for autistic adults (n=128).
Figures for parents/carers (n = 104):
40% of parents/carers waited more than 2 years for care and support to be provided for the autistic adult they care for; 48% think the support they receive when trying to secure social care for the autistic adult they care for is poor; 67% of parents/carers say the social care received by the autistic adult they care for does not meet that adult's needs; 52% of parents/carers don't try to secure care and support for the autistic adult they care for because they don't think they'll get it.

Autistic adults face a double disadvantage



Autistic people comprise between 1% and 2% of the population¹, and face some of the greatest inequalities of any group in society. Despite increases in autism awareness², there is continuing discrimination and barriers are evident everywhere in the system.

The figures are stark. Autistic people's life expectancy is 16 years lower than the rest of the population³, and autistic adults without a learning disability are nine times more likely than the general population to die from suicide⁴. 79% of autistic adults will experience poor mental health⁵, and 42% of autistic children experience anxiety compared to 3% of non-autistic children⁶. Educational outcomes for autistic children are persistently worse than for pupils in most other groups⁷. Autistic people have one of the lowest employment rates of any group⁸, and experience a gap in pay with non-disabled employees of almost 34%⁹. These effects are compounded for autistic women and autistic people from Black, Asian and minority ethnic communities¹⁰.

Adult social care (eg. home care, supported living, residential care) and **community-based support** (eg. peer support groups, advocacy) play an essential role in helping autistic people live happier, healthier, more fulfilling lives. Specialist care and support providers that understand autism and use person-centred approaches can help autistic adults live in their communities, take up work, and prevent deterioration in their mental and physical health.

However, the adult social care system in England is in crisis. Years of underfunding have left local authorities and care providers unable to meet demand, against a backdrop of rising costs, and despite recent commitments of additional funding from the Government, estimates of the continuing gap range from £7 billion to £14 billion¹¹.

The crisis in care affects many groups of people, but for autistic people and their families, the consequences are profound. Without the right care and support, many autistic adults reach crisis point. Some see their mental and physical health deteriorate. Others are admitted to mental health hospitals, where they have traumatic experiences¹² and can face waits of many years to be discharged¹³. Parents and carers face exhaustion and family breakdown.

Without the right support, in the right place, at the right time, autistic people face a **double disadvantage**: the inequalities they already face are magnified, with severe impacts on their lives. Many autistic adults can work, and all can live well and actively in their communities, but this potential is lost. The human cost of the social care crisis for autistic people is unacceptable. The system needs to change.



**The gap
in care
means
the law
is being
broken**

New research commissioned by the Autism Alliance, and published alongside this report¹⁴, estimates that **around 11,600 autistic adults in England** – most likely autistic adults with a moderate learning disability – are not receiving the social care they need. The cost of this gap is between £70 million and £140 million, which equates to between 0.4% and 0.7% of the social care budget in England¹⁵. Alongside this, there is likely to be an even larger gap in community-based support, which can be vital for autistic adults without a learning disability or with a mild learning disability.

The Care Act 2014 is clear that adults with a need for care and support must have their needs assessed, and that needs which meet eligibility criteria in the Act must be met. **But this law is being broken daily across England**, because Government underinvestment means there is not enough money in the system to pay for the care and support required to meet demand.

Autistic adults frequently have needs which match the criteria set out in the Care Act 2014, meaning that appropriate care and support should be provided. The reality is different: a struggle at every point in the process, to be recognised, to have needs assessed, to secure care, and to ensure care recognises and meets their needs. **Every day is spent fighting a system which is not resourced to carry out its core purpose.**



What the Care Act 2014 says

The Care Act 2014 sets out the legal framework for adult social care in England. It places duties on local authorities to promote the wellbeing of individuals and prevent, delay or reduce needs for care and support.

It also says that local authorities **must**:

1. Conduct a needs assessment for any adult who appears to have a need for care and support (Section 9)
2. Determine whether any of the adult's needs meet the eligibility criteria (Section 13)
3. Ensure that those eligible needs are met through care and support (Section 18)
4. Prepare a care and support plan (Section 24).

In Section 2(1) of the Care and Support (Eligibility Criteria) Regulations (2015) eligibility is defined in these terms:

1. The adult's needs arise from or are related to a physical or mental impairment or illness
2. As a result of the adult's needs, the adult is 'unable to achieve' two or more defined 'outcomes'
3. As a consequence, there is or is likely to be a significant impact on the adult's wellbeing.

'Outcomes' are defined as:

- a) Managing and maintaining nutrition
- b) Maintaining personal hygiene
- c) Managing toilet needs
- d) Being appropriately clothed
- e) Maintaining a habitable home environment
- f) Being able to make use of the home safely
- g) Developing and maintaining family or other personal relationships
- h) Accessing and engaging in work, training, education or volunteering
- i) Making use of facilities/services in the local community
- j) Carrying out any caring responsibilities the adult has for a child.

'Unable to achieve' is defined as:

- Unable to achieve without assistance (e.g. support/prompting)
- Able to achieve but causes significant pain, distress, or anxiety
- Able to achieve but endangers/is likely to endanger the health and safety of the adult or others
- Able to achieve but takes significantly longer than would normally be expected.



Beckii and Elliot's story

Beckii Davis, 30, spent more than four years campaigning for her autistic brother Elliot Dodds, 28, to be released from long-term segregation in hospital after he suffered a mental health crisis. Elliot also has epilepsy and a moderate learning disability.

Becki said: "Elliot was living at home happily with me and our mum, but a series of events, including our grandmother dying, our parents separating and then me moving out meant that his life changed in lots of ways. His behaviour became more challenging and mum and I asked for help.

"We had one, then two, then three carers at home, but none of them had an in-depth understanding of autism, or had any training or support in how to work with someone like Elliot.

"We begged the mental health team for help from someone who had experience in working with autistic adults, but all they suggested was more and more medication, for things like bi-polar disorder or schizophrenia, neither of which Elliot had and which seemed to just make Elliot worse.

"Eventually, in April 2018 he was sectioned by the community mental health team and taken to a mental health hospital for a medication and treatment review. No learning disability beds were available so Elliot was put onto a psychiatric intensive care unit. We thought he'd be in and out after the review, but in fact it was more than four years until he came home.

"The team who made decisions about Elliot's care were adamant that he needed a house without stairs, as he couldn't be safely managed on the stairs if he became distressed, but nothing was available. After eight weeks on the psychiatric intensive care ward he was transferred to a learning disability ward in Co Durham, a 140 mile round trip from my home in Thirsk, North Yorkshire.

"Unsurprisingly Elliot struggled to cope in the new environment and would frequently become distressed and have meltdowns. He spent almost all of his time alone in one single, open-plan room, with a bathroom. He became drained and guarded, I could tell he didn't feel relaxed or safe there.

"Being segregated and alone was really hard for him. Elliot loves to be around family and friends, he likes games nights, FaceTiming, trampolining and swimming. He loves to go on days out where he sees coaches, trucks and wind turbines.

"Elliot can wash and dress himself, and he can talk to us to let us know his needs. Mum repeatedly said she would be happy for him to come and live back at home, with support, but the request was continuously blocked.

Photo: Beckii and Elliot on the day of Elliot's discharge from hospital.



“I knew Elliot had to come home, he didn’t want to be at the hospital at all. He was restrained several times, injured and he damaged property. I was spending hours every day in meetings and phone calls as well as looking after my two young children and holding down my job. I was exhausted and it took a huge toll on my own mental health, but if I didn't do it then who would?”

“Finally with the help of my brilliant solicitor and support from charities and campaign groups we managed to find suitable accommodation for Elliot and he was discharged in July 2022, four years and three months after his first admission.


“Elliot is now doing well. He enjoys living in his own flat and has support from three carers around the clock. I’m hoping that will reduce in time as they get to know him better and he continues to settle in. He went through a lot of trauma in the hospital which he can't really explain, so we need to figure out how to help him get through that.

“I fully support the Autism Alliance’s call for more funding for social care. If we’d had access to professionals who understood autism, and how to work with an autistic adult, then we would have been able to better help Elliot and he might not have reached crisis point.

“With the right support in place autistic people would be less likely to get to crisis and be taken away from their homes and families. This causes even more distress, huge family heartache and financial cost.

“The fight to get Elliot out of hospital was hard for me, but it was worse for Eliot. I’m just grateful he’s still here today.”





The consequences for autistic people are profound

Alongside the assessment of the gap in social care for autistic adults, the Autism Alliance has surveyed families and carried out focus groups with autistic adults and parents/carers. These have shown that:

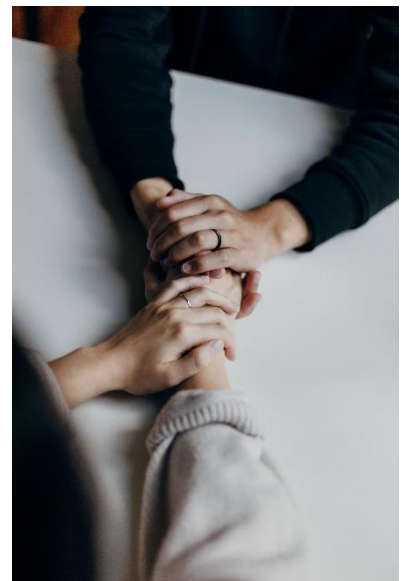
- **Over three quarters of autistic adults reach crisis point before care is provided.** The consequences for their lives are profound, including family breakdown, admission to long term inpatient care, and avoidable deaths.
- **Where care is provided it frequently fails to meet their needs.** The wrong care risks deterioration in mental and physical health, again increasing the incidence of reaching crisis, and prevents autistic adults from living well and actively in their communities, and for many, taking up employment.
- **Autistic adults and their families have a poor experience of trying to secure care.** They can wait years for their needs to be recognised, many care assessments aren't suitable for autistic people, and at every point they face barriers in making progress.

We need reform as well as investment

It is clear that investment will be required to close the gap in care for autistic adults and their families. Much of this could be paid for by addressing inefficiencies in current spending, as part of a new funding settlement for social care. But investment needs to be accompanied by reform. Both the new research commissioned by the Autism Alliance, and the testimony of autistic adults and parents/carers in this report highlight the clear need for reform, focusing on the following areas:

- **Joined up commissioning** – the lack of collaboration and co-ordination between local authorities and local NHS services means that commissioning remains weighted towards crisis intervention rather than preventing the escalation of need and helping people live well and actively in their communities.
- **Availability of specialist community-based support** – a weak focus on the sustainability of specialist care provision, and a lack of support for providers under pressure, means there is often a shortage of the specialist social care, and wider community-based support, required to help autistic adults thrive.
- **Workforce reform** – despite progress in awareness of autism, there is a persistent lack of acceptance and understanding of autism at all levels of the system, and a lack of specialist skills in the social care workforce: a concerted push on training is required.
- **Accountability** – the Care Act 2014 is clear that needs should be assessed and met, yet families have to fight for needs to be assessed and for care to be provided.

It is vital that the Government in England improves the availability and experience of social care and specialist community-based support for autistic people, by investing additional funding and by working with local authorities, NHS services and the Care Quality Commission to address the areas of reform identified above. **This should be part of a wider programme of social care reform** to ensure the system works for all those with a need, both working age people and those in later life.





Reform of social care is needed at a national level, and the crisis in social care and the need for Government to act have been well documented. Social care plays a critical role in the economic and social fabric of the country, and its continuing failure is having profound consequences. But the principles of reform that have been identified by local authorities, care providers, and by autistic people and their families, are **principles that should apply across the whole social care system**, for everyone at every stage of life: person-centred care, a thriving provider market, a workforce which is valued, trained and remunerated appropriately, and commissioners able to improve the health, wellbeing and employment opportunities of the people they serve.

On this basis, it is important to recognise that a **system of social care that works for autistic people can work for everyone**. Any Government engaging with reform should therefore apply a test: will this work for autistic people? Because if it will, it is almost certainly the right reform.

What works for autistic people can work for everyone





There needs to be Real Change

In [Real Change for Autistic People and their Families](#), published earlier in 2023¹⁶, the Autism Alliance highlighted the lack of progress in improving outcomes for autistic people in the UK during the past 15-20 years, despite dedicated legislation, successive Government strategies and many commitments. The gap in social care and community-based support is a clear example of this failure, and highlights the system-level barriers that still need to be addressed for autistic people to thrive and live well in their communities.

At the highest level, the failure of care for autistic people is a failure of this country's ability to support the opportunity and wellbeing of its citizens, to promote equality and to stamp out discrimination. Every failure of care for an autistic person is a personal tragedy: damaging life chances and reinforcing inequality.

Across the country, there are commissioners, social workers and care practitioners committed to helping autistic people thrive. They need the funding, tools and incentives to carry out their roles effectively. As well as complying with the law, providing the social care that autistic adults need makes strong economic sense. But most importantly, closing the gap in care will enable autistic people to have happier, healthier, more fulfilled lives – and for any person, organisation or Government that believes in human rights, this is a goal of the highest importance.

Closing the gap also makes economic sense

In 2023/24 total planned spending on adult social care in England was £19 billion¹⁷. The new research published alongside this report shows that the cost of closing the gap in social care in England for autistic adults with a moderate learning disability would be **between £70 million and £140 million**, representing between 0.4% and 0.7% of current adult social care spend. This assumes spending on domiciliary care rather than care homes or supported living, recognising the relatively lower level of need amongst autistic adults with a moderate learning disability. Additional costs relating to the recruitment, retention and training of staff in specialist care and support providers would need to be added, but even then closing the gap remains achievable within meaningful reform of the care system.



As well as this, there is likely to be an even larger gap in community-based support for autistic adults without a learning disability or with a mild learning disability. This also needs to be quantified and addressed as part of wider social care reform.

As well as promoting inclusion and opportunity, investment in the right social care will drive economic benefits. Autistic adults who are active and empowered will be able to stay healthy for longer and participate in their communities. Many will be able to take up employment. Fewer autistic adults will have extended stays of confinement in inpatient mental health settings, and there will be reduced contact with the justice system. The benefits are likely to be considerable¹⁸, and the Autism Alliance is working with the London School of Economics on a new analysis of economic value, which should be available in early 2024.

Furthermore, closing the gap could be paid for by addressing inefficiencies in existing spend. As an illustration, 1,335 autistic adults are currently confined in mental health hospitals in England¹⁹. Using data from the 2022 report on funding flows commissioned by the Department for Health and Social Care²⁰, this provision likely costs in the region of £276 million per year. **Redirecting these funds into high quality specialist social care, delivered in communities, could close the gap for autistic adults between 2 and 4 times over.**

How the system is failing autistic people and their families

During summer 2023, alongside preparation of the new research, the Autism Alliance surveyed autistic adults and parents/carers of autistic adults about their experiences of the social care system. The survey received responses from over 230 autistic adults and parents/carers. Their responses show that the adult social care system in England is failing autistic people and their families, and point to specific areas in which reform is required.

Crucially, the data in this report should be seen in the context of a continuing failure to meet the needs of autistic people over time. In 2019, a report from the All-Party Parliamentary Group on Autism²¹ found that 71% of autistic adults said they are not getting the support they need, and a survey by the National Autistic Society in 2003 found that 60% of parents of autistic children and adults found it difficult to get the support they needed from social services. This is a long term, system-level problem, and in [Real Change for Autistic People and their Families](#), the Autism Alliance proposed system-level reforms that could help address the barriers that hold back progress.

The key findings of the survey are summarised below.



Autistic adults and parents/carers wait too long for care and support to be provided, and too many autistic adults reach crisis before this point.

77% of autistic adults reached crisis before care and support was provided.

44% of autistic adults and **40%** of parents/carers had to wait more than 2 years for care and support to be provided.

“We are currently battling with the LA to get the right support for our daughter. They seem to delay to save money. Currently we have been waiting 14 months. Once before she was at home for 3 years waiting [for care and support to be provided].”

“It has been a battle and [we] had to go the legal route.”

“They have a beautiful supported living flat which has been ready for them to move into some time. Unfortunately the 'goal posts' for their moving date kept changing and sent them into mental health crisis. They have been [sectioned] under Section 3 of the Mental Health Act twice since.”

“[The] care we were given was very limited – two organisations to talk to – both purported to be person-centred care but that did not prove to be the case. So it was just catastrophic from the beginning, not properly managed. There are [152,000]²² vacancies in social care at the moment so no continuity of staff, people turning up who she didn't expect to be on duty, which would throw her into meltdown. Just the whole organisation of it is catastrophic. Her mental health is at rock bottom – her default is to call the police. And the actual cost is just expanding because she hasn't had the care she needs to keep her safe.”



Even if social care is provided, it is frequently not meeting the needs of a substantial proportion of autistic adults.

48% of autistic adults and **67%** of parents/carers say that the care they receive does not meet their needs. This reflects the lack of sufficient specialist care provision for autistic people.

“The personal budget helps to pay for a cleaner and a gardener to help keep on top of the house and the garden. But there is no occupational therapy for me, or help with other practical day to day tasks.”

“I have full time care which in principle is working well, but I don't have enough specialist support and my carers aren't trained enough to be able to support me in that way. My carers are self-employed but they really need training to understand my autism and sensory and communication needs.”

“My support is from the local [community mental health team, CMHT] – who traditionally do not provide long term support. The service is not specifically for people with an autism diagnosis but as there is no other service available the CMHT is left to deal with it.”

*“I receive six set hours but if those hours fall on a bank holiday, I don't get support.”
“Not enough staff, staff constantly leaving, social work driven targets rather than genuine person centred.”*

“I would welcome more communication from the home, my son has very limited speech, often if I ask how a particular activity went the person will say I wasn't on shift that day.”





Autistic adults and parents/carers have a poor experience of the social care system overall, although individually some professionals are effective.

58% of autistic adults and **48%** of parents/carers thought the support they had during the process of trying to secure care was poor.

42% of autistic adults and **44%** of parents/carers thought the care assessment itself was poor.

However, **35%** of autistic adults thought the knowledge, skills and understanding of the person carrying out the assessment was good or excellent (only **22%** of parents/carers).

“When I was diagnosed, literally I was given no information. There’s all these things listed in the NICE guidelines but you don’t get any of it – when they did my assessment they said there’s nothing really for adults. It’s just impossible.”

“[It’s a] massive bureaucratic system – enough to bring anyone to tears.”

“My son is not a piece of cake, we can’t slice him up, he’s a person, you have to look at the whole of him – but this is not what’s happening.”

“Within adult social care in my experience there’s a learning disability team and a mental health team but nothing specifically around autism and supporting autistic people who need care and support. There doesn’t seem to be any specialism within those teams.”

“I would like to see my local council acknowledge my ASD diagnosis by at least assessing me, even if there is no money available to provide actual support. At least I would know they care about me and I would understand about their financial position.”

“Since I’ve been diagnosed, no-one from a GP practice, nobody’s gotten me in to say what can we do. They send you away after your assessment and there’s no help or support. They put stuff about social care in the pack, sent that to the council, done that twice, nobody’s even bothered to get back to me.”



Autistic adults and parents/carers are not positive about the system, and many are discouraged from even trying to secure the care and support they need.

74% of autistic adults and **60%** of parents/carers say that trying to secure care and support is very difficult.

Of those not seeking care and support, **56%** of autistic adults and **52%** of parents/carers say this is because they don't think they'll get it even if they try.

"For 17 months [my daughter] has been without proper support. The social worker just stalls things in order to save money. It's just been a complete nightmare for the whole family but especially for my daughter – she's had no quality of life at all. We're both getting older and our ideal is to get her settled in a secure environment so she can live her best life, which is her human right – yet the local authority does not appear to agree with this. They ignore our requests although there is a statutory obligation there, and just refuse to do anything until we [get legal aid and] get a solicitor involved."

"Everything is a fight – it should not be a fight. To get a diagnosis is a fight, to get the correct support is a fight, getting the right education is a fight. It's never ending and it shouldn't be like that. It's basically a question of money and understanding: there are too many obstacles in the way. Good care should be about having adequate funds, person centred support and really should not be a fight."

"They have no empathy and understanding of people's behaviour, the unique behaviour of autistic people and how they manage their world. [There's no] understanding of our barriers and why we can't communicate – we just shut down and they don't get that."

"It's just really tiring and I'm really fed up."

Autistic adult and focus group participant, 2023



A plan for reform

The new research published alongside this report shows that there is a gap in care and support for autistic adults in England, and that the cost of closing the gap is not beyond the reach of Government to address.

However, through surveying and interviewing local authorities and care providers, the new research also identified a need for reform: highlighting a range of additional **barriers** holding back access to specialist care and support, and the **enablers** that could address these barriers. Together, these enablers provide a pathway to reform that could enable the social care system to meet the needs of autistic adults and their families, in line with the Care Act 2014: and also help everyone to get better care.

Local authorities and care providers highlighted the following **enablers**:

- Better sharing of data on autism assessment/diagnosis to support the planning of services.
- A collaborative model of commissioning and service design, based on partnership between commissioners and care providers.

- A stronger focus on the sustainability of specialist care and support provision, including a stronger role for the Care Quality Commission in working with providers under pressure.
- Greater clarity around the quality of specialist care and support, potentially through stronger accreditation of providers. This could also include a focus on assuring quality through data on service effectiveness and satisfaction for autistic people and their families.
- A stronger use of co-production for planning, inspection and service delivery for autistic adults and their families.
- A concerted push on training to increase acceptance and understanding of autism, amongst commissioners, social workers and care providers, as part of wider workforce investment and reform.

As well as surveying autistic adults and parents/carers, the Autism Alliance ran focus groups to gather more detailed information about families' experience of the social care system. **Both the barriers and the enablers identified in the new research were strongly reinforced by autistic people and parents/carers taking part in the focus groups, and their voices offer an equally powerful guide to reform.**

The Autism Alliance ran two online focus groups, each comprising ten people, with autistic adults and parents/carers of autistic adults. The focus groups explored three questions:

1. Why is it important to have good care and support?
2. What does good care and support look like to you?
3. What needs to change to enable autistic adults and parents/carers to get the support they need?

For each question, focus group participants were encouraged to speak freely about their experiences and their ideas for change. It was important to engage with parents/carers as well as autistic adults, both to hear the voices of families and also to enable those without a voice to contribute.

1. Joined up commissioning

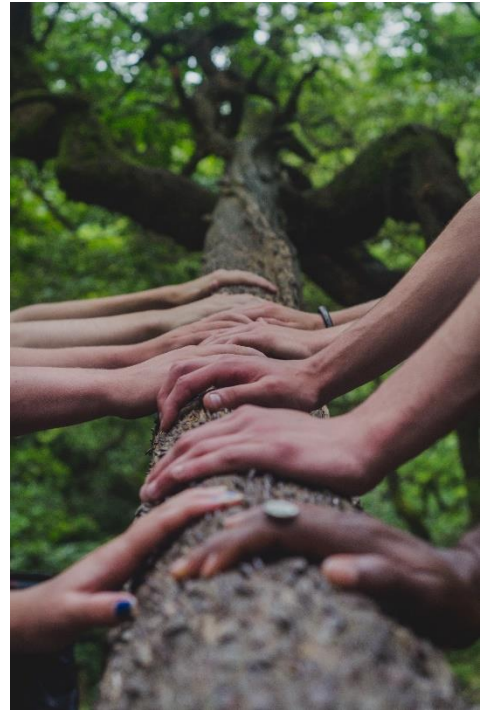
Focus group participants reinforced the need for true integration in commissioning across health and social care, to shift investment away from crisis interventions and towards community-based support that can promote wellbeing and prevent the escalation of needs, as set out in the Care Act 2014. This has been the aim of the Government's Building the Right Support programme²³, but there is little evidence that it is delivering the changes required. Commissioning also needs to join up with education and employment services, to support well-managed transition points for autistic people as they move into adulthood, and for many to provide support as they move into work.

"All the support seems to be around crisis, so it's like nothing seems to be in place for people through early intervention or preventative services to assist and support people in the way they want to live and have access to life. It only seems to come into play when it's crisis and emergency intervention, which isn't the same as care and support."

Participants also highlighted the importance of specialist support for mental health, sometimes through NHS services and sometimes through community and voluntary sector provision.

"[There needs to be] Support for people who are on the pathway [to diagnosis] and whose care and support needs aren't necessarily about independence. I don't have any support needs with regard to independent living, I have a family, child, job, I can get myself out and do all those things – but I need support about my personal journey of self-discovery and self-understanding, all of which feeds into mental health and mental wellness. That type of support is not always considered yet it can be really helpful for mental health and overall wellbeing for autistic individuals."

"Peer support is a really helpful support mechanism, and the options for people to just have those conversations with people who are at different stages of the journey and share experiences and insights, it can be really useful and helpful."





Participants were clear that funding is critical. Without investment that keeps pace with demand and reflects the cost of care and support for autistic adults, commissioners will always be challenged to secure the high quality specialist services required to help autistic people thrive and live their lives in their communities.

“It’s no good having the Autism Act – what has it done to change the lives of autistic people? Because there has been no funding with it. If there’s no funding with it to implement it, it doesn’t make any change for us.”

“The system needs more money, more training – ultimately it all boils down to money and I think people have good intentions but nothing changes.”

2. Availability of specialist community-based support

Focus group participants highlighted the importance to their lives of having the right support, in the right place, at the right time through social care and community-based support, and how this affects autistic people’s outcomes across health, wellbeing, opportunity and fulfilment.

“[Why is it important to have the right care and support?] The simple answer is it keeps me alive. Bad care and support puts that at a huge risk. It also enables me to live my life, participate in society, have a family relationship rather [than] one of carer, reduces risk of hospitalisation, enables me to live in my own home, makes the most out of my energy and capabilities.”

“For the person themselves, basically it leads to better wellbeing for that person and a more fulfilled life if their needs are met. A lot of times their needs are not met through a lack of understanding, funding, training. Personally I feel social care should be under the umbrella of NHS care: it should all be one.”

“[Why is it important to have the right care and support?] We wouldn’t have been left vulnerable. It’s mental health and wellbeing – we would have reached our full potential and been a full member of the community.”

“It [good quality care and support] gives you better health equality.”





Participants wanted to point out the crucial importance of specialism in providing care and support for autistic adults, and that specialist practice has some key characteristics.

“It’s about specialism – people who actually have a really broad understanding of what it means to be autistic and how massively diverse the experiences of autistic people are, and how it can present. Within a lot of professionals there’s still a very narrow view of what it means to be autistic, what care and support is needed and how that should look.”

“Good care looks different for every [autistic] individual - but it most generally means to meet someone’s needs. So whether this is access to a one-to-one support worker or supported accommodation, or a different form of physical care or mental health support or financial support for instance. Often people need a sensitive care level where they may need one-to-one 24 hours a day at times and be able to manage until there is some form of challenge – fast targeted support then needs to be put in place. Also staff should be appropriately trained and experienced not just ‘oh my nephew is autistic so I know everything’.”

Participants also highlighted the importance of a wide range of provision that can respond to autistic adults’ individual needs, and the dangers of assuming that there is only one type of autistic person or that support can necessarily meet an individual’s needs.

“Good care and support needs to be person centred and provided by people who have a really good understanding of autism in its broadest, most diverse sense, and also not a one size fits all which is what the care and support [currently] is – it needs to be bespoke to different people’s needs.”

“If I had someone there, maybe once a week, not there all the time, to call and say I’m having a bit of trouble with this, can you have a look at it for me. One day a week, just to meet up with somebody and do social things. ... and to fall back on from an emotional perspective.”

Participants wanted to stress the importance of a sustainable local market of care providers offering specialist services for autistic people, including not for profit organisations working in the community, and that sustainable provision should be an overarching priority for commissioners.

“It’s charities who are picking up the pieces and filling those gaps, and it shouldn’t be – charities can only do that to a limited extent with limited funding and resource, generally on time-limited grant funding for a year or two years. When it comes to an end what happens to that service?”

“Social care and all the powers that be almost rely on the VCSE to provide support and provide areas that are really their responsibility to fill. They should be commissioning VCSE organisations to deliver that support so it becomes a funded part of what society can offer in terms of care and support needs.”

3. Workforce reform



Focus group participants underlined the fundamental importance of accepting and understanding autism, and having the right specialist skills and the right values and behaviours amongst the social care workforce, commissioners, and social workers. These were seen as powerful enablers and vital in ensuring autistic adults and their families can access the social care they need.

“It’s not just awareness, it’s acceptance – so when we ask for reasonable adjustments whether in education, healthcare or social care assessments, this happens, or you can have a social worker for short period of time to assist with housing move or apply for a service.”

“We feel empathy and compassion, but I think we don’t always know how to respond socially, which creates additional fear and anxiety for us.”

“There’s more awareness now which is great, but it’s still difficult for a lot of people.”





Participants stressed the need for professionals to listen to autistic people, without making assumptions, and work with them to design care and support packages that meet their needs. They also stressed that autistic adults can't be 'divided up' – services and professionals need to engage with the whole person and push against bureaucratic boundaries that do not reflect reality.

"Support to work out what you need, that is all part of the process as well."

"[It's] about having the conversation with the individual and asking them what they need and not going into that conversation with any assumptions that just because the person is autistic the professional knows what type of support they need. That just isn't the case. Seeing people as people not as a diagnosis, working with them collaboratively, asking them and letting their lived experiences and preferences drive the support that's provided."

"Part of the problem is you don't know the help you need until you start working with somebody. I was used to just coping but because I was doing everything I was just burning out. When you've got nobody there to know you've misunderstood some things – if the support's not available, it's almost like you've got to make it."

"Care and support need to encompass that we're still learning about [autism] as a personal experience and as a society and there can't be like a fix in supporting and caring for autistic people because it's still so broad and unknown. There are things we know help and things that definitely don't help."

Participants felt that training and supporting the workforce is a crucial part of increasing acceptance and understanding of autism amongst professionals in the social care sector.

"We need really good education and training, done by people like us with lived experience, [showing] when it went good for us and when it was negative and the impact on our lives, when it left us with low self-esteem, confidence."



4. Accountability

Focus group participants were clear that accountability is crucial for an effective system of care and support that meets the needs of autistic adults and their families, and that commissioners and social workers should take a proactive approach to their legal duties and the expectations that these establish.

"[Why do we need good care and support?] Because we deserve it and we legally should have it and we don't have it – I just feel like it's a constant fight on all angles, constant barriers and I'm so exhausted. So we can thrive and actually manage our lives better and our wellbeing. 'Access to work': I get that but actually we need access to live."

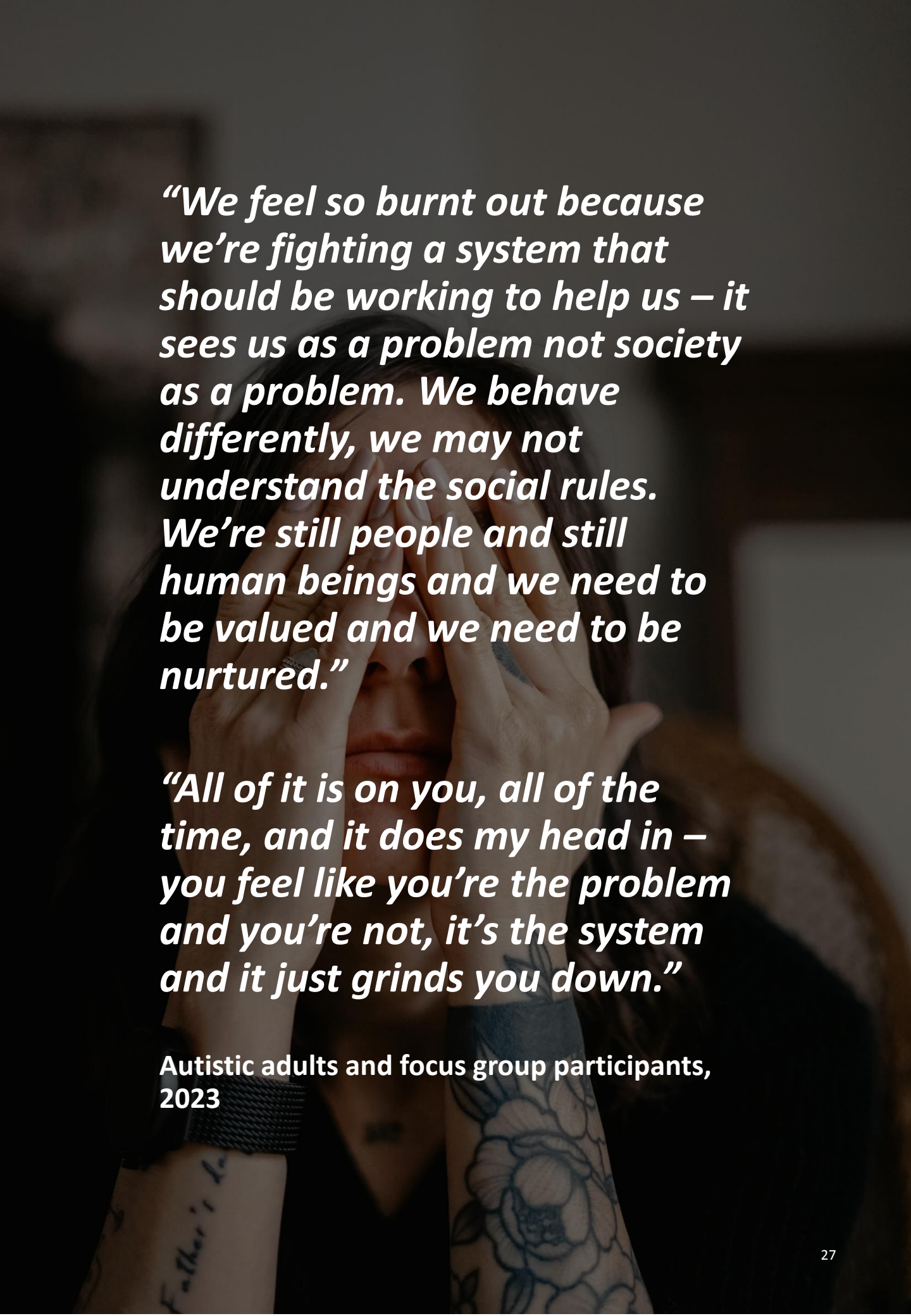
"I think we need to learn how to listen to autistic voices in an inclusive manner and I think this would be a huge help to create structural and cultural changes."

"[Autistic] people who are isolated or marginalised – people from different cultures, non-verbal, kind of get shoved to one side. When you've got a door open, you have to kick it wide open, you have to hammer."

"I think it's important that all people have chance to have a say in their own lives, and if people with additional needs don't have support to do that, they have wasted lives in which they can't do anything they wish to do, and their mental health and physical health suffer for this."

"It almost feels like sometimes somebody being autistic is a real barrier to accessing support and its almost seen as an excuse to close cases and signpost into organisations, and I think that's a big part of what needs to change."





“We feel so burnt out because we’re fighting a system that should be working to help us – it sees us as a problem not society as a problem. We behave differently, we may not understand the social rules. We’re still people and still human beings and we need to be valued and we need to be nurtured.”

“All of it is on you, all of the time, and it does my head in – you feel like you’re the problem and you’re not, it’s the system and it just grinds you down.”

Autistic adults and focus group participants,
2023

Reflecting on these findings



Across both the new research published alongside this report, and the evidence collected by the Autism Alliance, local authorities, care providers, and those who have need for services have confirmed that the social care system is not working for autistic adults and their families in England. They have all said clearly that reform is required, as well as investment, in order to build a system of social care that can meet the needs of autistic adults and their families now and in the future.

The new research published alongside this report shows there is a significant gap in care for autistic adults in England, most likely for autistic adults with a moderate learning disability, and estimates the cost of closing the gap. Additional costs relating to the recruitment, retention and training of staff in specialist care and support providers would need to be added, but even then closing the gap remains achievable within meaningful reform of the care system, and by addressing inefficiencies in spending across health and care.

There is most likely an even bigger gap in community-based support for autistic adults without a learning disability or with a mild learning disability, and this also needs to be quantified and addressed by the Government.

Alongside this, local authorities, care providers and families have all reported that there are some specific barriers contributing to a lack of access to social care amongst autistic people. There is strong consensus on how to address these barriers, and all those consulted identified a set of enablers that, if taken forward could increase access to the right support for autistic adults and their families, in the right place, at the right time.

We need to see:

- **Joined-up commissioning** – strong collaboration and co-ordination between local authorities and local NHS services (and with education and employment services) to commission the social care and community-based support that prevents the escalation of need and helps autistic people to live well and actively in their communities.
- **Availability of specialist community-based support** – a strong focus on the sustainability of specialist social care provision, with targeted support for weakening providers to maintain services, ensuring there is sufficient specialist social care and community-based support to help autistic adults thrive.
- **Workforce reform** – a concerted push on increasing knowledge, acceptance and understanding of autism amongst commissioners, social workers, NHS services and care providers, so that more informed person-centred care can be provided for autistic adults and their families. This needs to be part of a funded workforce plan for social care in England.
- **Accountability** – a proactive approach to the legal duties in the Care Act 2014 amongst commissioners and social workers, so that families do not have to fight for an assessment of needs and for care and support to be provided. This may need to be underpinned by additional actions or roles to further strengthen accountability, as well as more legal education for families, and could go wider than the Care Act 2014 to embrace ‘Section 117 aftercare’ and Continuing healthcare.

As well as investment, delivering this reform is likely to require:

- Partnership between commissioners, care providers and autistic people and their families at a local level to **improve the functioning of the specialist social care market providing services for autistic people** – and within this, to achieve clearer identification of high quality specialist provision for autistic adults.
- Changes to the funding model for social care to create **stronger incentives for local authority and NHS commissioners** to prioritise and fund the right support, and to shift the overall distribution of funding towards preventative support and away from crisis intervention.

**Closing the
gap in care:**

**Investment
Partnership
Accountability
Acceptance
Understanding**

Running through these actions, there is also a continuing need to improve the identification and understanding of **good care and support for autistic adults** across all parts of the system. There is more work to do in reviewing practice, commissioning new research evidence, and considering the potential for better quality assurance and clearer accreditation of specialist care providers. At the present time, using the voices of autistic adults and parents/carers and the expertise of specialist care providers as a guide, we can say that good care and support is likely to be based on:

- A strong, overarching focus on safety and wellbeing.
- Learning about the person from first-hand experience and relationship building.
- Not making assumptions about the individual.
- Listening and continuing to listen to the individual without imposing views, and frequently checking understanding.
- Doing everything possible to enable the individual to communicate and express themselves. This is particularly vital for autistic people who are non-speaking, or have a severe or profound learning disability, but is important for all autistic people.
- Making adaptations that increase opportunity for the individual to benefit from support, and that maximise their quality of life.
- Listening to and working with the individual's family wherever possible.



Conclusion and recommendations

Social care is vital in enabling many autistic adults to live well. But the social care sector in England has been chronically underfunded for over a decade, and the evidence that autistic adults and their families are being systematically failed could not be clearer. The impact of the social care crisis on their lives is profound, reinforcing existing inequalities in life expectancy and mental health, and preventing them from living well and actively in their communities and seeking employment. Autistic adults face a double disadvantage.

Social care should be a compassionate, enabling service, reducing inequality and fostering wellbeing and opportunity, but underfunding and neglect means it is not allowed to fulfil this role: in fact, the gap in care for autistic adults is driving poorer outcomes and widening inequality.

Through the Care Act 2014 this country legislated to ensure the availability of high quality care for those with eligible needs, promoting wellbeing and delaying or preventing future needs for care and support. The Act sets a clear expectation for the social care sector: but it is one that the sector finds it impossible to live up to. Without sufficient funding to meet demand, let alone commission the best possible care, the law is not being followed, and the Care Act may as well be sitting on a shelf.

This is not at the door of local authorities. Their budgets have not increased in order to meet rising demand and rising costs, and the maths is not difficult. As well as impacting the availability and quality of services, the financial starvation of the system has affected staffing levels and skills in social care commissioning, and in social work. Ultimately, accountability for the social care crisis, and responsibility for addressing it, lies with Government.

The social care sector is hugely significant in both social and economic terms. The sector's economic value has been estimated at close to £50 billion²⁴. Care is not just about helping people in later life: it has a broader function in society, supporting inclusion, opportunity and productivity for those of working age. A failure of care has serious consequences for the social and economic fabric of this country, and the writing is very clearly on the wall.

The reforms proposed in this report – alongside investment – also have a broader significance. The principles of excellent care and support for autistic people are the principles of better care and support for everyone: and the Government should use these principles, and the voices of autistic people and their families, as a guide for wider reform. Doing this would support both the recommendations in the 2022 House of Lords Adult Social Care Select Committee report on social care²⁵, and the vision of the Social Care Future movement: “We all want to live in the place we call home with the people and things that we love, in communities where we look out for one another, doing things that matter to us.”

Reflecting the new research published alongside this report, the feedback received from local authorities and care providers, and the testimony of autistic people, parents and carers, the Autism Alliance recommends:

- **That as an urgent priority, Government closes the funding gap in social care for autistic adults, recognising the unacceptable outcomes they face and the economic benefits of providing the right care.** This is likely to be between £70 million and £140 million, or between 0.4% and 0.7% of total adult social care spending across England. Additional costs relating to the recruitment, retention and training of staff in specialist care providers would need to be added, but this is achievable for Government within meaningful reform of adult social care and through addressing inefficiencies in spending across health and care.
- **That Government commits to and engages with wider reform of social care, using the principles of good care for autistic people as a guide to good care for everyone.** This should cover how care is commissioned, the values, culture and understanding of all players across the system, and a new funding settlement for the system. As part of this work, **Government should also quantify and address the likely larger gap in community-based support for autistic adults and their families.**
- **That local authority and NHS commissioners, together with the CQC, build a new partnership with care providers, and with autistic people and their families,** to remove the barriers affecting access to specialist social care, and access to community-based services providing early support. This ‘partnership for change’ should focus on the enablers of reform set out in this report, working together to ensure local access to high quality specialist care and support, and reinforcing and informing wider Government reform of the social care system.



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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. (www.autism-alliance.org.uk)