



The Rt Hon Rishi Sunak MP
Prime Minister
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The Rt Hon Victoria Atkins MP
Secretary of State for Health and Social Care
Department of Health and Social Care
39 Victoria Street
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Dear Prime Minister and Secretary of State

Breaking Point: closing the gap in social care for autistic adults in England

As a coalition of partners led by the Autism Alliance, we are writing to draw your attention to the experiences of autistic adults in the social care system in England.

Autistic people represent between 1% and 2% of the population. This is around 1 million people, and the majority are adults. Autistic people experience and process the world differently, and every autistic person is completely individual.

Many autistic adults are able to work, and bring specific and sometimes exceptional skills which support our country's productivity.

However, autistic people experience some of the greatest inequalities of any group in society. Life expectancy is 16 years lower than the general population, and autistic adults without a learning disability are 9 times more likely to die from suicide. Almost 80% of autistic people will develop poor mental health, and autistic adults have one of the lowest employment rates of any group (29%).

Social care can make a huge difference for autistic people and their families. Specialist care providers, and social workers, with specific knowledge of autism and the right approaches can help autistic people live well and actively in their communities. The right care also enables many autistic people to enter employment, and reduces reliance on costly long term mental health inpatient services.

However, the social care system does not have sufficient resource to meet demand, and across commissioning and social services there are still gaps in understanding autism. As a result, too many autistic people experience deteriorating mental health, leading to crisis: some are confined in mental health hospitals, where they face medication, restraint and trauma; others experience family breakdown.

Despite the Government's National Strategy for Autistic Children, Young People and Adults, and despite repeated pledges to build the right support in the community, the number of autistic people in inpatient facilities has risen year on year since 2015, and now stands at over 1,300.

The Autism Alliance, representing autism charities, has launched a campaign to bring to public attention the profound impact of the gap in social care for autistic adults in England. Through new research, the Breaking Point campaign has found that:

- Over 10,000 autistic adults with a need for social care are not receiving any care at all. The Care Act 2014 is clear that every adult with an eligible need for care should have this need met: this means that effectively, the law is being broken every day in England.
- Over three quarters (77%) of autistic adults reach crisis point before care is provided, leading to confinement in mental health hospitals and the breakdown of families.
- 44% of autistic adults and their families wait over 2 years for care and support – the Local Government Social Care Ombudsman recommends no more than eight weeks – and even where care is provided, almost half (48%) say it does not meet their needs.

The system of social care in this country should support opportunity and productivity. Across England, there are commissioners, social workers and care workers committed to understanding needs and providing the best care, including for autistic people. But without adequate resources and pay, they cannot realise these objectives. Rather than promoting opportunity and participation as it should, the current system is reinforcing and deepening inequality.

We believe strongly that these problems are avoidable. But to make progress will need political will and a bold commitment to action.

We call on you to address this unacceptable failure of the system for autistic people and their families: and in the process, to support many other people to have better lives and make their strongest contribution to our country's future.

We have estimated that closing the gap in care for autistic adults in England would cost between 0.4% and 0.7% of total annual national spending on adult social care. The amount spent on confining autistic people in mental health hospitals would pay for this between 2 and 4 times over: showing that the money is there, but is not in the right place. Redirecting this funding to specialist social care would save considerable public funding and unlock additional productivity. It cannot be right that more is spent on responding to crisis than preventing it, when the long term cost of prevention is lower and the benefits greater.

However, this investment, or re-investment has to be part of wider reform. The signatories to this letter are not alone in calling for the Government to finally and definitively engage with social care reform; but we are confident that the reforms which would help autistic people would help everybody. We consulted local authority commissioners, care providers, and autistic people and their families, who all agreed on the solutions required:

- Faster progress on increasing acceptance and understanding of autism, as part of a compassionate, person-centred approach to care. Awareness of autism is now almost universal, but autistic people continue to face stigma and discrimination.
- Flipping the funding model across health and social care, so that investment is directed to preventing crisis rather than reacting to it.
- More support for specialist care providers, particularly in the not for profit sector, who face huge financial pressure and are subsidising publicly funded care from their reserves.
- Stronger accountability, with a step change in the data available about autistic people's outcomes with which to hold local commissioners – and the Government – to account.

Other relevant reforms include the resourcing and implementation of a named social worker for autistic adults, as advocated by the British Association of Social Workers (England).

We have a coalition of partners ready to work on developing and delivering these solutions, including co-signatories to this letter. We can do this efficiently and effectively. But the work needs to be enabled and commissioned by the Government, as part of a programme of reform.

Social care plays a fundamental role in the economic and social fabric of this country. Its deepening failure is having serious and lasting consequences for individuals, families, and communities, just at the time when we need it most. We urge you to be bold, and act. The benefits of getting this right are huge, for autistic people, and for everyone in England.

Yours sincerely,

Jolanta Lasota, CEO, Ambitious about Autism.

Kari Gerstheimer, CEO and Founder, Access Social Care.

Clive Parry, Director, ARC England.

Robert Shanahan, Chief Executive, Aspens.

Adam Micklethwaite, Director, Autism Alliance.

James McQuiggan, CEO, Autism Anglia.

Emma Reade, CEO, Autism Bedfordshire.

Jane Howson, Chief Executive, Autism East Midlands.

Dr Sarah Broadhurst, Director, Autism Education Trust.

Andy Grainger, CEO, Autism Initiatives.

Kerry Boyd, CEO, Autism NI.

Siún Cranny, CEO, Autism Unlimited.

Dr James Cusack, CEO, Autistica.

Tom Harrison, Chief Executive, Autism West Midlands.

Sara Heath, Founder and Facilitator, Autonomy Self-Help and Social Groups.

Jo Land, Group Chief Executive, Avenues Group inc. Autism Hampshire.

Ben Higgins, Chief Executive, BILD.

Viv Cooper OBE, Chief Executive, The Challenging Behaviour Foundation.

Maris Stratulis, BASW England National Director.

Belinda Schwehr, Centre for Adults' Social Care – Advice, Information and Dispute Resolution.

Neeraj Sharma, CEO, Daisy Chain.

Rachael Dodgson, Chief Executive, Dimensions.

Christine Edwards-Daem, Chief Executive, Kent Autistic Trust.

Jackie O'Sullivan, Chief Executive (Acting), Mencap.

Caroline Stevens, Chief Executive, National Autistic Society.

John Phillipson, CEO, North East Autism Society.

Ryan Campbell CBE, Chief Executive, Prior's Court.

Robin Bush, Chief Executive, Remarkable Autism.

Dolyanna Mordochai, Chief Executive, Resources for Autism.

Dr Conor Davidson, Royal College of Psychiatrists Autism Champion.

Cheryl Simpson MBE, CEO, Space4Autism.

Geoff Doncaster, Principal Officer, Speakup.

Tim Cooper, Chief Executive, United Response.

Jonathan Senker, Chief Executive, VoiceAbility.

Rhidian Hughes, Chief Executive, Voluntary Organisations Disability Group (VODG).

Eric Heath, Peter Hopkins, Susan Kirkman, Rachel Moody, Experts by Experience, DHSC Autism Strategy Implementation Group.

*Enclosed: Breaking Point: closing the gap in care and support for autistic adults in England (Autism Alliance, 2023).
Mapping supply and demand for care services for autistic adults in England (Cordis Bright, 2023).*

