



Maria Caulfield MP
Minister for Mental Health and Women's Health
Department of Health and Social Care
39 Victoria Street
London
SW1H 0EU

14 March 2024

Dear Minister

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

Thank you for your response of 3rd February 2024 to our letter of 18th December 2023 to the Prime Minister and Secretary of State for Health and Social Care, drawing attention to the profound impact of the gap in social care for autistic adults in England, and the opportunity to address this. I have shared the response with the co-signatories to our original letter.

It's good to know the Government is committed to improving the lives of autistic people, some of whom will have a learning disability, and positive that there is a National Strategy for Autistic Children, Young People and Adults. It is also positive to see the additional funding the Government has made available for adult social care.

However, the reality is that this is not translating into improved outcomes on the ground. Almost three years into the Strategy's implementation, and almost ten years since the separate Building the Right Support programme began, there is little evidence of significant changes to autistic people's lives, and continuing widespread evidence of autistic adults reaching crisis because they are unable to access the social care they need.

This is a system level problem, and can only be addressed by system level solutions. The National Strategy has the right ambition, but does not have the levers to deliver change, or targets against which progress can be measured and the system truly held to account.

For autistic people and their families to see real change in outcomes, we would need to see:

- Changes in accountability that introduce consequences strong enough to drive changes in behaviour at all levels across the system.
- Increases in funding that allow commissioners to meet need, rather than being forced to cut costs and impose local interpretation of eligibility that conflicts with national policy intent.
- Substantial progress in society's acceptance and understanding of autistic people. Stigma and discrimination remain widespread, meaning that in a system which assumes rational compliance with legislation and funding rules, autistic people and their families remain less likely to receive the support they need.

You mentioned the new duty on the Care Quality Commission to assess local authorities' delivery of the Care Act 2014 duties. Increasing transparency and accountability is to be welcomed. However, the impact of this new duty will depend on the clarity and specificity of the CQC's recommendations, and the extent to which the CQC's assessments expose the gap between resource and need. It is vital that this new duty helps to identify system-level barriers, rather than providing another set of general recommendations that prompt a 'by the book' response.

At this halfway point in its implementation (2021-26), there is an opportunity to review and rebase the National Strategy so that it is able to deliver real change for autistic people and their families. This will mean co-producing outcome targets with autistic people, developing a robust theory of change, and engaging with system-level reform across Government.

In adult social care, although the greatest impact for autistic adults and their families will come from the most substantial reforms – in particular, a sustainable funding settlement – some of the changes required are more straightforward to implement, yet would still have a positive effect. They were identified in the Breaking Point research, and include:

- Introducing stronger incentives in the funding system for Integrated Care Boards to channel funding towards early support in the community.
- A concerted push on autism training for all those involved in adult social care, including commissioners, going beyond the welcome plans for the Oliver McGowan Mandatory Training.
- Collecting data on autistic people's outcomes, and making this publicly available so that local systems can be held to account.
- Alongside this, the resourcing and implementation of a named social worker for autistic adults, as advocated by the British Association of Social Workers (England).

As we set out in our original letter, the Autism Alliance and co-signatories would be pleased to work with the Government, NHS England and local partners to co-produce, test and deploy these solutions. It would be helpful if your Department could confirm how this will happen.

Finally, we welcome the ongoing process of engagement from the Department for Health and Social Care on the updated autism statutory guidance, and look forward to continuing to work with the policy team. This is an important opportunity to clarify the Government's policy intent for autistic people in the Autism Act 2009, Care Act 2014 and Children and Families Act 2014. However, it is vital that the statutory guidance genuinely strengthens and clarifies accountability, without leaving any areas unclear. It is also vital that the statutory guidance is published in good time, and as far as possible before the expected General Election in 2024.

Yours sincerely,

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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.

Dr Sarah Broadhurst, Director, Autism Education Trust.

Siún Cranny, CEO, Autism Unlimited.

Tom Harrison, Chief Executive, Autism West Midlands.

Jo Land, Group Chief Executive, Avenues Group inc. Autism Hampshire.
Viv Cooper OBE, Chief Executive, The Challenging Behaviour Foundation.
Maris Stratulis, BASW, England National Director.
CASCAIDr, (Centre for Adults' Social Care – Advice, Information and Dispute Resolution).
Rachael Dodgson, Chief Executive, Dimensions.
Christine Edwards-Daem, Chief Executive, Kent Autistic Trust.
Caroline Stevens, Chief Executive, National Autistic Society.
Ryan Campbell CBE, Chief Executive, Prior's Court.
Dolyanna Mordochai, Chief Executive, Resources for Autism.
Julie Newcombe, Co-founder, Rightful Lives
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, Trevor Wright, Experts by Experience, DHSC Autism Strategy Implementation Group.

