

CARELESS



The National
Autistic Society

**WILL THE
GOVERNMENT
PROTECT
VULNERABLE
PEOPLE WITH
AUTISM FROM
ABUSE, NEGLECT
AND LONELINESS?**

Accept difference. Not indifference.

CARELESS

“MY BRAIN GETS SO BUSY THAT IT DOESN'T LISTEN TO MY BODY SO I DON'T KNOW I AM HUNGRY, TIRED, THIRSTY OR DIRTY. THIS HAPPENS A LOT.”

Will the Government protect vulnerable people with autism from abuse, neglect and loneliness?

They're changing the care system, but their plans risk leaving adults with autism unfed, unwashed or afraid to leave the house.

Left unsupported, many are taken advantage of, manipulated or abused, often by people who they think of as friends.

Please help us to change this.

About autism

Autism is a serious and lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives, but others may need a lifetime of specialist support. People with autism may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours. More than 1 in 100 people in the UK have autism.

About Careless

The new Care Act commits the Government to introducing a new national eligibility threshold for care and support. This will tell local authorities when they must provide adults with support. Until now, local authorities have had the power to set eligibility for support against one of the eligibility bandings (low, moderate, substantial and critical) which reflect different levels of care need. The new national eligibility criteria are intended to be comparable to the current 'substantial' eligibility banding. A national threshold should make the care system fairer.

However, the Government's plans do not take into account the basic needs of many people with autism. Their proposed national threshold fails to acknowledge how difficulties faced by people with autism can impact on their everyday lives and excludes some needs currently defined as 'substantial'. We are also concerned that, under the Government's current proposals, professionals who assess whether someone should receive support would not be required to have sufficient expertise in autism. Our Careless campaign aims to change this.


Case study: Adrian

Adrian was diagnosed with Asperger syndrome when he was 14. Social services assessed his need for support at the age of 18. His parents were concerned that he was putting himself at risk because of the people he was spending time with and they thought he needed help with the transition to adulthood.

The assessment found that Adrian had difficulty interpreting other people's motives and actions and was easily led, which could place him at risk within the community. However, the local authority decided the risks were not sufficient for him to receive support.

Adrian was later bullied and intimidated. His parents continued to contact social services, as well as the police, asking for a reassessment and support for him. After Adrian reported being raped by one of the people who had befriended him, his parents appealed again to the police and social services. Eventually, a small package of evening support was approved. However, five days later Adrian was murdered by the same person he had accused of rape.

Under the Government's proposed criteria, Adrian would not have been eligible for support.



“HE WAS HUGELY FINANCIALLY EXPLOITED OVER A TEN-YEAR PERIOD BY PEOPLE WE KNEW OF, BUT NEVER MET. WHEN WE DISCOVERED WHAT HAD GONE ON HE WAS FACING BANKRUPTCY.”

Abused

Abuse of adults with autism is common and often serious. Many are abused over time by someone they trust and think of as a friend.

Someone with autism may not initially recognise that they are being abused or manipulated. They may not question the intentions or honesty of the person who is befriending them, and will simply do as they are asked. They can also fear displeasing people so much that they comply with someone’s wishes even if it harms them.

This leads to some people taking advantage of adults with autism. Many are subjected to long-term financial abuse, physical abuse or are forced to do things they don’t want to do, including criminal behaviour or having people stay in their home.

In our recent survey:

- **49% of adults with autism (or parents/carers responding on their behalf) told us they had been abused by someone they thought of as a friend¹**
- **27% have had money or possessions stolen by someone they thought of as a friend**

- **37% have been forced or manipulated to do something they didn’t want to do by someone they thought of as a friend.**

“SOME OF THE PEOPLE I THOUGHT WERE MY FRIENDS ONLY USED ME TO GET THINGS FROM ME.”

Abuse can have devastating consequences. In the worst cases, it has led to people with autism, like Adrian, losing their lives. It contributes to mental ill health and social isolation. In our survey, **44% of adults with autism said they stay at home because they are afraid of being abused or harassed.**

Vulnerable people at risk of abuse need support. Until now, someone has been judged to have substantial need under social care eligibility criteria if ‘abuse has occurred or will occur’. This ensures local authorities put in place support to prevent people from being exploited or abused. The Government is proposing to remove this entitlement through their new criteria. This would make it much harder for people to get this kind of support.

The Department of Health must include the need to stay safe from abuse or neglect in the eligibility criteria for care and support.

¹‘Abuse’ includes physical, sexual and financial abuse, or being forced or manipulated to do something they didn’t want to do.



“WITHOUT ANY SUPPORT, HE WAS FINALLY FOUND AT HOME SUFFERING FROM SEVERE MALNUTRITION AND WITH MOULD GROWING ON HIS SKIN.”

Unfed and unwashed

Many people with autism need someone to prompt them to wash, dress or feed themselves. They may be physically able to do these tasks, but without prompting will not know to pay attention to these basic needs.

- **65%** of adults told us they need prompting to wash, dress or prepare a meal.
- **86%** of adults who need prompting have **not washed**, **70%** have **missed meals** and **69%** have **not got dressed** because they didn't get this help.

“I DON'T EAT, I DON'T CHANGE CLOTHES, NOTHING EXCEPT MAYBE GET A DRINK OF WATER AND GO TO THE BATHROOM WHEN I CAN'T HOLD IT ANYMORE. DON'T TAKE MY MEDS EITHER. I CAN LOSE ENTIRE DAYS AND NIGHTS THAT WAY.”

The Government has proposed that people will be eligible for support if they need 'assistance' to carry out essential everyday tasks. This must be broadened to include prompting or supervision so that the particular support needs of people with autism are not overlooked.

The Department of Health must include the need for guidance or prompting to carry out essential activities in the eligibility criteria for care and support.

Case study: Nick

Nick² has Asperger syndrome and was living on his own in a flat with regular support from his mother. He could physically carry out everyday tasks, but often required prompting, for instance to eat, wash and manage his finances. After his mother died, he gradually lost contact with the rest of the family, eventually having to cope without any support.

He stopped paying his bills, claiming benefits and eating meals. Over several years, his health, his ability to look after himself and his home environment all deteriorated. Finally, social services found him at home suffering from severe malnutrition, poor mental health and with mould growing on his skin.

Nick was sectioned, and then left hospital in January 2014 to receive support at a residential home run by The National Autistic Society. He is developing the skills to live more independently and will return to his flat in January 2015. He will initially need support to prompt him to look after himself and therefore prevent his life from slipping back into crisis. **We are concerned that Nick would not be eligible for support under the proposed eligibility criteria.**

²Name has been changed



“I DON’T HAVE ANY FRIENDS AND WHEN MY PARENTS DIE, I WILL HAVE NO ONE.”

Alone

People with autism are particularly vulnerable to social isolation. One in four adults with autism has no friends,³ and some have no personal relationships at all. The type of support most wanted by people with autism is help to improve their social skills,⁴ but this is rarely available.

Social isolation has a significant impact on people’s quality of life. It can damage mental and physical health. At least one in three adults with autism experiences severe mental ill health due to a lack of support.⁵ Social isolation also contributes to people’s risk of being abused or neglected.

- **41% of adults with autism told us they often feel lonely, compared to 11% of the general population.**⁶
- **36% do not leave the house most days.**
- **66% of respondents have felt depressed because of loneliness.**

“HE HAS NO FRIENDS. HE IS DEPRESSED BECAUSE HE WANTS TO MEET OTHER PEOPLE, BUT DOESN’T KNOW HOW.”

The proposed eligibility criteria include maintaining family or other relationships as an activity for which people may need support. Many adults with autism need specific support to form and develop personal relationships **in the first place.**

The Department of Health must include the need to form and develop relationships in the eligibility criteria for care and support.

³Bancroft, K. et al (2012). *The way we are: autism in 2012*. London: The National Autistic Society

Misunderstood

The basic support needs of adults with autism will not be recognised unless the person assessing their care and support needs has the necessary expertise in autism. However, only one in three adults with autism thinks that social workers have a good understanding of autism.⁷

Assessors can easily misunderstand the needs of people on the spectrum if they do not have experience and knowledge of how to communicate with them, or of the impact of the condition on someone’s day-to-day life. People with autism can lack insight into their own condition and may struggle to define their needs themselves.

Training requirements for assessors are clear and strong in the Autism Act statutory guidance.⁸ However, autism is not explicitly included in the Government’s proposed new requirements for expertise and training of community care assessors. The Government needs to send a clear message that each person with autism must be assessed by someone with expertise in autism.

The Department of Health must require that adults with autism are assessed for care and support by someone with expertise in autism.

⁴The National Autistic Society (2013). *Push for Action*. London: The National Autistic Society

⁵Rosenblatt, M. (2008). *I Exist: the message from adults with autism in England*. London: The National Autistic Society

⁶Griffin, J. (2010). *The Lonely Society*. London: The Mental Health Foundation

⁷The National Autistic Society (2013). *Push for Action*. London: The National Autistic Society

⁸Department of Health (2010). *Implementing “Fulfilling and rewarding lives”: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy*. London: Department of Health

**“I CAN’T GIVE UP
WORK TO CARE FOR
MY SON, BUT HE
IS UNDERWEIGHT
BECAUSE HE ONLY
GETS ONE MEAL A
DAY. IF HE TRIES TO
COOK HE FORGETS
AND WALKS AWAY
WHICH HAS RESULTED
IN FIRES.”**



Our recommendations

Our Careless campaign is calling for the following four changes.

The Department of Health must:

- Change the proposed national eligibility criteria for care and support to include:
 - the need to stay safe from abuse or neglect
 - the need for guidance or prompting to carry out essential activities
 - the need to form and develop relationships.
- Change the proposed assessment regulations and guidance to require that adults with autism are assessed for care and support by a community care assessor with expertise in autism.

Methodology for the survey

The survey for this report was carried out online in April 2014. It was completed by 1,344 adults with autism in England, or parents/carers responding on their behalf.

**For more information please contact the NAS at
campaign@nas.org.uk or call 020 7923 5799.**

Find out more at: www.autism.org.uk/careless

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