

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Gwella mynediad at gymorth i ofalwyr di-dâl](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [Improving access to support for unpaid carers.](#)

UC25: Ymateb gan: National Autistic Society Cymru | Response from: National Autistic Society Cymru



About autism: Autism is a lifelong disability which affects how people communicate and interact with the world. There are over 700,000 autistic adults and children in the UK. Without the right support or understanding, autistic people can miss out on an education, struggle to find work and become extremely isolated.

About us: The National Autistic Society is here to transform lives, change attitudes and create a society that works for autistic people. We transform lives by providing support, information and practical advice for the 700,000 autistic adults and children in the UK, as well as three million family members and carers. Since 1962, autistic people have turned to us at key moments or challenging times in their lives, be it getting a diagnosis, going to school or finding work. We change attitudes by improving public understanding of autism and the difficulties many autistic people face. We also work closely with businesses, local authorities and government to help them provide more autism-friendly spaces, deliver better services and improve laws. We have come a long way but it is not good enough www.autism.org.uk

The National Autistic Society welcomes the opportunity to respond to the Health and Social Care committee's inquiry into improving access to support for unpaid carers.

We fully endorse the consultation response of Carer's Wales, who have accurately detailed many of the issues that are also faced by carers of autistic people.

We have one specific point that we wish to focus our response on. Autism is likely to have a genetic component to it, and this means that the carers of autistic people with significant support needs may also be autistic themselves. This is an important consideration that should be better recognised by social services and public services more widely, especially when tensions in the relationship between those families and services develop.

Having a child with significant support needs means that the parents/carers of that child are entering a long-term relationship with many public services, and the quality of this relationship is crucial. When that relationship is characterised by trust, respect, and mutual support, outcomes for both the carer and the person being cared for are positive. However, when the relationship is strained, adversarial, or dismissive of carers' experiences and own needs, outcomes are significantly poorer in terms of health, education, and overall quality of life.

Public services may sometimes struggle to maintain a healthy relationship with parents of autistic children with significant support needs (including when the child becomes an adult and transitions to adult service). Not only have those public services faced significant financial challenges and thus often been unable to fully support those families, but sometimes those parents are labelled as 'difficult', 'challenging', and may even be blamed for the behaviour of their child by social services staff who lack specific knowledge about autism.

This is supported by the Autism and Parental Blame project¹ that found:

- Parents feel judged rather than listened to and feel dismissed and disbelieved by professionals.
- Blame from professionals' manifests as accusations of poor parenting, disbelief in parents' accounts, and accusations of neglect.
- An autism diagnosis reduces parental blame on average for most parents but not for all parents, and for some, blame gets worse after their child's diagnosis.
- The current support offered to parents is often unhelpful and sometimes reported as doing more harm than good.
- Parental blame has a lasting detrimental impact including families experiencing symptoms of post-traumatic stress disorder.

This isn't just an issue parents face with social services. The Stolen Lives Task and Finish group report² has highlighted experiences of parents having to constantly fight with mental health services to get their (adult) children home from inpatient units, and highlighted a culture where parents have been threatened with court action in response to complaints or the threat of complaints, and have not had any official institution take the issue seriously prior to the campaign group's protests outside the Senedd.

In education, parents of children with additional learning needs have often told us of how they have had to fight for their child's needs to be taken seriously. That often, schools have treated autism as a behavioural issue (with the implication that poor parenting is to blame), have not accepted an autism diagnosis as having validity, and the Education Committee³ reported that schools feel parents have 'unrealistic' expectations of the support their child should get.

Navigating public services that have faced significant financial challenges in order to get the basic support needs of your child met is going to be a stressful and worrying process for anyone. For an autistic parent (diagnosed or not) having to navigate such a system, not necessarily understanding how the system works, and not having any support to do so is likely to be even more difficult. Labelling such parents as "difficult" or "unrealistic" only increases the risk of adversarial relationships, and further undermines trust in services. The seriousness of these dynamics can be understood through an analogy with abusive relationships. Carers and families are effectively bound into long-term relationships with public services: they cannot realistically leave, there is a power imbalance, and the possibility of withdrawal of support can act as a sanction. The impact of a relationship going sour can also be long lasting and damaging

We recommend therefore that:

¹ Blamed Instead of Helped How parents of autistic children experience parental blame when they approach services for support. Fergusson and Hollingsworth, Nov 2024, <https://www.wm-adass.org.uk/media/xprf2qx3/adass-autism-rep-oct24-final-fp7-approved-online.pdf>

² Forthcoming publication

³ Implementation of education reforms, interim report, available from <https://senedd.wales/media/c2sjtv5b/cr-ld16588-e.pdf>

- All public services should ensure that staff are trained on autism as part of professional development, and this is especially important for staff who may be dealing with autistic people as part of their role (i.e: Social Workers, Mental Health Professionals, ALNCOs and Headteachers).
- Public services should be mindful that autistic children may have autistic carers in their lives.
- The Welsh Government should ensure that for those occasions where relationships between autistic people, their carers, and public services have broken down, alternative arrangements can be found to support those families. These alternative arrangements could involve a combination of the right to request a new team of professionals, different service providers, independent advocacy, and/or direct payments.
- We also call for implementation of the recommendations of the Stolen Lives Task and Finish Group.

We are happy to discuss any of these issues further.

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