

Response to the Social Services and Well-being [Wales] Bill

About Us

The National Autistic Society Cymru [NAS Cymru] is Wales' only member-led charity for people affected by autism¹. The National Autistic Society was founded in 1962 by a group of parents who were passionate about ensuring a better future for their children. In Wales, since 1994, we have been providing local support, services and actively campaigning so that people with autism get to lead the life they choose.

Across Wales we have over 900 members, 11 local branches and provide:

- Information, advice, advocacy, training and support for individuals and their families;
- Information and training for health, education and other professionals working with people with autism and their families;
- A telephone helpline, free to use;
- Specialist residential, supported living, outreach and day services for adults;
- Out-of-school services for children and young people; and
- Employment training support and social programmes for adults with autism.

NAS Cymru believes that the right support at the right time makes an enormous difference to the lives of those affected by autism and we are committed to ensuring that their voices are heard.

About autism

Autism is a lifelong developmental disability that affects the way 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 three main areas of difficulty, their condition will affect them in different ways. The three main areas of difficulty are:

- Difficulty with social interaction. This includes recognising and understanding other people's feelings and managing their own. Not understanding how to interact with other people can make it hard to form friendships;
- Difficulty with social communication. This includes using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice; and

¹ The term autism is used throughout this document to refer to all people on the autism spectrum including Kanner autism, Asperger Syndrome and high-functioning autism.



Accept difference. Not indifference.

Gwahaniaeth. Nid difaterwch.

- Difficulty with social imagination. This includes the ability to understand and predict other people's intentions and behaviour and to imagine situations outside of their own routine. This can be accompanied by a narrow repetitive range of activities.

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 some form of sensory sensitivity or under-sensitivity, for example to sounds touch, tastes, smells, light or colours. Asperger syndrome is a form of autism.

Research has shown that 1 in 100 people have autism². By applying the 1 in 100 figure we estimate that over 30,000 people in Wales have autism. Together with their families, they make up over 100,000 people whose lives are touched by autism every single day.

General Comments

NAS Cymru is pleased to be given the opportunity to respond to this consultation. We welcome the broad aims and overarching principles outlined in the Social Services and Well-being [Wales] Bill. In our view, the Bill offers a clear opportunity to improve support for both children and adults with autism in Wales, their families and their carers. We also believe that the Bill will help clarify the duties and responsibilities around social care in order to better meet the needs of people in Wales now and in future.

We are very pleased that the Bill includes an obligation on local authorities to promote the well-being of children and adults. We believe that the definitions included in the Bill encompass an individual's wider health, social, educational and economic needs to the extent that they may enjoy an independent and fulfilled life.

For people with autism, who, because of the nature of their condition can find dealing with change difficult moving from childhood into adulthood can be a period of great uncertainty and can be particularly challenging. We hope that including children and adults in the Bill will mean that local services are able to work more closely together to ensure that transition, especially into adult services, is more effective and efficient.

Our response considers issues that specifically relate to people with autism, their families and carers. In developing our response, we drew on research from two NAS surveys: *I Exist: The Message from Adults with Autism in Wales* and *The Life We Choose: Shaping Autism Services in Wales*. We also consulted with NAS branch members and staff.

² Brugha, T et al (2009) *Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007* London: The NHS Information Centre for Health and Social Care

Assessing, Understanding and Meeting Needs

In 2011 we published the results of the largest ever survey of experiences of people with autism and their families in Wales. The report 'The Life We Choose' shows that of the people with autism who took part in our research, more than half [54 per cent] felt that their needs were not being met.

We therefore welcome the duty placed on local authorities and health boards to assess and meet the care and support needs of the general population in their geographical area. This assessment will aim to give each local authority and health board a top-level indication of the current and future requirements of people and how they may meet those needs.

In order to do this effectively for people with autism, additional focus will be needed on ensuring that local authorities and the NHS have accurate data on the local needs of people with autism.

From our work with local authorities, we are aware that there is currently a lack of consistent and clear data collected on the needs of people with autism in social care. Local areas find it particularly challenging to develop a clear picture of need for adults on the spectrum. As a result people with autism are often 'hidden' in our social care system. Many areas have no idea how many people with autism use services in their area and, because of this, they fail to plan for their needs. This leads to people either failing to receive support until they fall into crisis, or receiving support that does not meet their needs.

Because of this challenge, mapping prevalence and collecting information about the individual needs of children and adults with autism was one of the key objectives outlined in the Welsh Government's Autistic Spectrum Disorder Strategic Action Plan, published in April 2008. A review of progress on the Strategic Action Plan³ identified data collection and information on local need as a key area that required further attention. The report stated:

There is a need for greater consistency in the methodology of data collection within and between Local Authorities and LHBs. This will require guidance and support facilitated by the Welsh Assembly Government. The outcome will provide more accurate evidence of numbers, needs and services which can be used to tailor on-going implementation of the ASD Strategic Action Plan. The gathering of such information on ASD from local to national level will be unique within the United Kingdom.

We believe that the Welsh Government should take forward this recommendation. In addition to help further the implementation of the Strategic Action Plan, the Bill should also be strengthened to include a statutory duty on local authorities and health boards to:

- Accurately record the number of children and adults with autism in their area and that they be provided with a level of guidance, as recommended by the Welsh Government⁴, to enable them to do carry out this requirement; and
- Maintain a mandatory register to include all people with disabilities, including autism

³ OBE Morgan, H (2011) *The ASD Strategic Action Plan for Wales (2008): Evaluating the Foundation Phase* Welsh Government

⁴ Ibid

We believe that amending the Bill in this way would allow for a more accurate picture of the local need, encourage the sharing of information between different bodies and improve the delivery of services. It would also put Wales in a unique position in the way that it looks after the social care needs of all disabled people in Wales, in comparison to the other nations of the UK

Eligibility Criteria

NAS Cymru believes that the development of new eligibility criteria are a crucial part of this Bill, as they will be used to establish who can qualify for services and what type of provision they can expect.

We welcome the establishment of national eligibility criteria as we believe that it will go some way in helping ensure parity of provision regardless of where people may live.

We are however concerned that the detail surrounding the new regulations is not currently available for comment.

The current eligibility criteria have posed a particular problem for people with autism. Too often, because of a lack of understanding of the needs of people with autism by community care assessors and a misunderstanding of the importance of social participation within the current eligibility framework, many people with autism (especially those with high functioning autism and Asperger syndrome) are not eligible for social care support.

Adults with autism have told us that they thought the lack of understanding of autism among professionals prevented them from accessing support. Local authorities and local health boards have also told us that they thought that training for staff could be improved⁵.

Training for community care assessors is particularly important, as without a clear understanding of the condition, they cannot assess people with the condition fairly and accurately. This means people with autism will not qualify for the support they need. Difficulties with communication are a defining feature of autism, meaning people with the condition often struggle to understand and respond to questions about the support they need.

Some people with autism may also lack the self awareness to understand the support they require, so may, unintentionally, misrepresent their needs to assessors. People with autism may also answer questions too literally. If they were asked by a care assessor whether they can make a meal, for example, they may say yes, but omit to mention that this is only with prompting and support from their carer.

In England, statutory guidance puts a duty on local authorities to ensure that there is specialist training for specific groups of people, including community care assessors. We believe a duty is also needed in Wales.

Where people with autism are not assessed as eligible for social care support, we know that they may become eligible for support later on when, as a result of a lack of support their needs become

⁵ Withers, L (2008) *I Exist: The message from adults with autism in Wales*. The National Autistic Society

particularly acute, and they require more intensive, high level interventions and crisis management. Nearly half (49 per cent) of adults with autism responding to our *I Exist* survey said that they had developed serious mental health problems as a result of a lack of support.⁶ As the National Audit Office (NAO) in England found in their report into the cost of support adults with autism: “*Beside the negative impact of such crises on a person’s life, acute services are also expensive, with inpatient mental health care costing between £200 and £300 per day.*”⁷ It is therefore vital that not only is there a greater investment in low level preventative services [see next section], but also that the criteria includes the specific needs of adults with autism, including in particular support with social participation. If adults with autism are given this type of support, it can prevent them from needing crisis support.

In addition, a clear challenge in accessing services for adults with autism is that they quite often fall between mental health and learning disability teams in local authorities. Autism is a developmental disorder, not a learning disability or a mental health issue, so people with autism do not fall easily under either of those teams. Although the Welsh Government has made it clear to local authorities that they must not base access to health and social care services for adults on their IQ, more than a third [38 per cent] of adults told us that not meeting the criteria for a learning disability team has stopped them from getting support⁸.

We do not know how the new criteria will differ from the current guidance. While questions remain unanswered around the regulations it is difficult to respond to the consultation as it stands.

We would therefore seek assurances from Welsh Government that:

- Sufficient time and opportunity is given for scrutiny of the draft regulations by stakeholders, including third sector organisations and Assembly Members;
- Measures are put in place to ensure local authorities provide services for people with autism, and that there is closer cooperation between Learning Disability Services and Mental Health Teams to ensure continuity of service;
- Eligibility assessments can be transferred from one Local Authority to another authority; and
- Include in the regulations an obligation for people undertaking a needs assessment to be fully trained in identifying autism in children and adults

Preventative Services

For people with autism, providing the right service at the right time can lead to them living more fulfilling and independent lives.

NAS Cymru fully supports the inclusion in the Bill for local authorities and health boards to provide a ‘range and level’ of preventative services, centred on the needs of the individual, that will prevent people with disabilities, like autism, from developing more complex needs. Providing preventative services can

⁶ Ibid

⁷ NAO (2009) *Supporting people with autism through adulthood*, The National Audit Office.

⁸ Evans, R (2011) *The Life We Choose: Shaping autism services in Wales*: The National Autistic Society

benefit people with autism, their carers and families and reduce the pressures on them. In turn, this can mean that further trauma can be avoided, crisis points averted and costs reduced.

While demand for preventative services for people with autism in Wales is huge, current provision is low and there is also a discrepancy between the types of services available to people with autism and what they actually want.

NAS Cymru would expect preventative services to include a number of low-level services which are be relatively light to administer but have significant impact. Examples would include social skills support, developing life skills, advocacy, befriending and respite; but this is by no means an exhaustive description of what is meant by preventative services.

NAS Cymru would seek to ensure that the Bill includes:

- Guidance on what is meant by preventative services and the types of provision it includes;
- A duty on Local Authorities and Health Boards to allocate adequate resources to preventative services; and
- Clarity in the regulations around the charging for preventative services

Direct Payments

NAS Cymru supports the right of individuals and parents to take up a Direct Payment if they choose. Direct Payments can offer flexibility and choice for individuals, but it is important to recognise that some people may need additional support to use a Direct Payment effectively. Local authorities should consider setting up brokerage schemes to help people to manage their Direct Payment.

It is also important that Direct Payments are flexible enough so that additional funding can be applied for if the service an individual chooses is initially more costly as, for example, it may require a higher skill level or expertise. Providing the right service may actually reduce the level of support and cost over time.

We would therefore seek assurances from the Welsh Government that:

- Consideration is given to introduce Personal Budgets to give people with autism independence and real choice and control over services;
- Any payment model is designed to meet the person needs; and
- The regulations contain specific quality guarantees for support and care purchased

Care plans

Preparing, maintaining and reviewing a care plan for individuals who need access to health and social care should be the minimum action taken by authorities to support vulnerable people in their area. Taken together, these three stages should ensure that a person's needs are identified and they are provided with the appropriate services and support, now and in future.

We strongly support the duty on Local Authorities to design a care plan, as outlined in the Bill, and the continued benefits this will bring to people with autism in Wales.

While the Bill does not currently contain specific regulation in this area, NAS Cymru would press Welsh Government to ensure that:

- The individual is consulted with, their views listened and acted upon and their needs fully considered as the plan is prepared, maintained and reviewed; and
- Mechanisms are in place to ensure that a person's care and support plans are transferred easily and in good time should that person moves to a different authority, so that continuity of care is sustained.

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