

Cynulliad Cenedlaethol Cymru
Bil Awtistiaeth (Cymru) drafft
Llythyr Ymgynghori DAB29
Ymateb gan | Evidence from Barnardo's Cymru

National Assembly for Wales
Draft Autism (Wales) Bill
Consultation Letter DAB29

Please refer to questions in the [Consultation Letter](#).

Barnardo's Cymru has been working with children, young people and families in Wales for over 100 years and is one of the largest children's charities working in the country. We currently run more than 90 diverse services across Wales, working in partnership with 16 of the 22 local authorities.

Every one of our services is different, but each believes that every child and young person deserves the best start in life, no matter who they are, what they have done or what they have been through. We use the knowledge gained from our direct work with children to campaign for better child and social care policy and to champion for the rights of every child. We believe that with the right help, committed support and a little belief, even the most vulnerable children can turn their lives around. We aim to secure better wellbeing outcomes for more children by providing the support needed to ensure stronger families, safer childhoods and positive futures.

This consultation

Barnardo's Cymru supports some autistic children and young adults; we also support some parents who may be autistic through our family support services. We do not provide any autism specific support services. As such this contribution is submitted on the understanding that other organisations such as the National Autistic Society Cymru focus solely on the issues faced by individuals and families through autism.

Barnardo's Cymru welcome and support the development of the proposed Autism (Wales) Bill and recognises the efforts of Paul Davies AM and Assembly support staff thus far.

Response overview

Barnardo's Cymru does not support the development of legislation without clear need and feel the case for this legislation is well made. The passing of this bill would not however achieve all of the change required and we would therefore advocate for additional provisions be considered through the Social Services and Well-being (Wales) Act.

Barnardo's Cymru recognises the progress made in the decade since the first Autism Strategy and more latterly the Integrated Autism Service. It appears to Barnardo's Cymru that it is possible more progress could have been made if both strategic and service developments had been made within a clearer statutory framework. As such Barnardo's Cymru suggests that the aim of the Bill would be better served if there was a clear expectation of positive change for autistic people on the face of the bill.

Rights

Pleasingly, page one line two of the bill, refers to protecting and promoting rights; however the content and style of the bill does not reflect this. We would welcome specific reference to the duty of due regard to the international instruments of the UNCRC, UNCRDP, UDHR, and UN Principles for Older People in particular.

Autism definition

Barnardo's Cymru welcomes the inclusion of a definition of autism on the face of the Bill. Further we recognise the benefit of utilising the WHO definition. There is always a need with definitions to review and ensure their relevance which may require stipulation on the face of the bill.

Barnardo's Cymru also recognises the need to consider other neurodevelopmental disorders, welcoming their inclusion in the bill.

Relevant bodies

In recognising the life long experience of autism and therefore the changing nature of particular care needs, should this list also include, in some form, regulated social care and residential services, such as elderly and nursing care and secure accommodation?

We are aware of significant representation in the secure estate, whether for welfare or justice issues, of people with autism whether diagnosed or not. This is a situation that would benefit from appropriate early intervention and diagnosis.

Duty to have regard to the strategy and guidance

Barnardo's Cymru recognises the difficulty in crafting legislation that is clear on expectation but not prescriptive in delivery of services to reach those expectations. These expectations or aims might be included and described in the long title.

Section two, in suggesting the contents of the strategy, usefully describes objectives in achieving the aim. The duty placed on relevant bodies to have regard to the strategy, and, we would argue human rights instruments, would be enhanced by the power of direction held by Welsh Ministers.

Timescales

Whilst Barnardo's Cymru will always advocate for reductions in the periods of waiting for assessment and service, we recognise the value in the pragmatic nature of setting achievable timescales and would agree with the suggested use of the NICE guidelines.

Barnardo's Cymru would however suggest any period of waiting for an assessment of care and support needs should be triggered simultaneously with that of diagnosis so as to reduce any delay in appropriate intervention.

Multi-disciplinary team

Barnardo's Cymru are less able to comment to any significant degree on this having little experience of involvement around diagnostic processes. We do however feel that the list would benefit from ensuring the involvement of,

wherever possible, the individual. We would also welcome the requirement of independent advocacy for the individual and separate independent advocacy for a family. Barnardo's Cymru would further suggest that due to the nature of Autistic Spectrum Disorder, consideration be given to the involvement of any worker already supporting the individual and known to them. Inclusion of this nature would be more in keeping with a rights approach and co-productive in nature.

Equity of access

Barnardo's Cymru would again advocate for due regard to human rights instruments and equality objectives within the Equalities Act. Article 9 of the UNCRDP outlines state party responsibilities in relation to accessibility and the equality objectives include:

“5. Tackle barriers and support disabled people so that they can live independently and exercise choice and control in their daily lives.”

Barnardo's Cymru are aware of the experiences of some autistic people having difficulties in accessing appropriate support services because of a lack of evident disability and the presence of a normal to high IQ. We should expect that this will be eradicated in relation to statutory or social care services; however, it may prove more difficult to address in the provision of wider commercial services which points to the need for comprehensive awareness raising campaigns to challenge understanding.

Barnardo's Cymru supports the call for an awareness and understanding campaign on a three year basis with review. This also features as an obligation in article 8 of the UNCRDP.

Conclusion

There has undoubtedly been improvements in the provision and experience of services for and received by autistic people. It remains the case that further improvements are required to continue the drive towards equity of opportunity and experience for autistic people. It is also evident that we are experiencing the most challenging financial climate whilst seeking to increase the quality and volume of support against a rising identification of need.

Within this environment Barnardo's Cymru welcomes the development of this bill seeing it as an opportunity to clarify the national aim as well as the framework of delivery and accountability for services to autistic people.

Barnardo's Cymru would welcome the inclusion of specific rights duties and related actions such as provision of advocacy and requirement to enable individual engagement where possible.

In closing Barnardo's Cymru welcomes the development of the Autism Bill and see this as a necessary progressive step in the provision of improved services to people with Autistic Spectrum Disorders.