

Barnardo's Cymru Consultation Response

Stage one scrutiny of the Autism (Wales) Bill

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Barnardo's Cymru introduction

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 around 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.

Barnardo's Cymru, Autism and the Bill

For the purposes of this response when using the term ASD we include other neurodevelopmental conditions.

Barnardo's Cymru supports some autistic children and young adults; we also support some parents who may be autistic through our family support services. While it could be argued that Barnardo's Cymru do not provide any autism specific support, services we provide for disabled children and families with one or more disabled child are experiencing a significant increase in the volume of referrals with ASD as an issue. Barnardo's Cymru may also have contact with families affected by ASD through young carer, substance misuse, Child Sexual Exploitation, Emotional Health and Wellbeing, Child Sexual Abuse, Harmful Sexual Behaviour, Care and Leaving Care services.

We are aware of the consultation response submitted by the National Autistic Society Cymru and both support their response and recognise their specific expertise.

Having contributed to the consultation on the previous draft Barnardo's Cymru remains supportive of the Bill believing the experiences of people and families affected by ASD should be improved by placing services within a statutory accountable framework.

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 amendment to 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.

While Barnardo's Cymru recognise the progress made, the lack of an accountability framework with clear outcome expectations of local provisions will promote 'postcode' variation, not necessarily in the nature of provision but in the outcomes experienced.

In a recent consultation in one local authority Barnardo's Cymru were surprised by the frequency that families affected by ASD said they avoided Social Service contact afraid that they would be seen as not coping and putting their families at risk. While there is no evidence to support this belief or that it is as pronounced in other areas, a legislative framework may go some way in addressing this issue.

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.

Rights

Barnardo's Cymru is pleased to see the inclusion at Section 8 of the duty of due regard to the UNCRC, UNCRDP and the UN Principles for Older Persons. While this inclusion gives strength to the promotion and protection of Human Rights Barnardo's Cymru argue that this could be further strengthened in the style and wording of the Bill, for example in section 2 the need for the inclusion of the person with ASD and their families and carers taking account of their goals and aspirations could be more explicit than 2 (1).

Section 2 could also require consideration of advocacy for each party and further recognise the role of familiar known workers in supporting engagement.

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.

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.

However, Barnardo's Cymru suggest in legislating for diagnosis the Bill might unwittingly promote diagnosis as a threshold for other services or support. We recognise that the wording around this suggests that assessment of or provision of care and support should not be delayed by the need for diagnosis but feel it would be better if this was more explicit if possible.

Multi-disciplinary team

Barnardo's Cymru suggest that the role of independent advocacy for each party, and, due to the nature of Autistic Spectrum Disorder, the role of any worker already supporting the individual and known to them could be considered at 4 (6)(d).

Inclusion of this nature would be more in keeping with a rights approach and co productive in nature.

Data collection

Barnardo's Cymru agree with the requirement to gather data; however, while recognising the catch all statement at 6 (6)(j) we would suggest that further data sets should be listed as well as a duty on bodies other than NHS such as local authorities should be considered. We would argue more usable data would be obtained if we included data such as:

- Age now
- Age at first indication
- Numbers waiting for diagnostic assessment
- Waiting times for diagnostic assessment
- Period undiagnosed
- Family role, parent/carer etc
- Numbers of families known with ASD indicating behaviours not referred, refusing or not seeking diagnostic assessment.

Given the focus on reducing ACEs and early intervention this data could prove invaluable.

Equity of access

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 provision in the Bill requiring the provision of awareness and understanding campaigns. 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 welcomes the inclusion of specific rights duties and hope for further development in the provision of advocacy and requirements 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 or affected by Autistic Spectrum Disorders.

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