Cynulliad Cenedlaethol Cymru | National Assembly for Wales
Datblygu Bil Aelod | Development of Member Bill
Y Bil Awtistiaeth (Cymru) - Datblygu'r Bil | The Autism (Wales) Bill - Bill Development
DMB(5) AWB68
Ymateb gan Cyngor Trydydd Sector Caerdydd
Evidence from Cardiff Third Sector Council (C3SC)

Introduction

Cardiff Third Sector Council (C3SC) is a registered charity and umbrella body working to support, develop and represent Cardiff's third sector at local, regional and national level. We have over 1,000 members, and are in touch with many more organisations through a wide range of national and local networks. We are a part of Third Sector Support Wales (TSSW) – a body of membership organisations constituting WCVA and Wales' CVC's; our mission is to provide excellent support, leadership and an influential voice for the third sector and volunteering in Cardiff.

C3SC is committed to a strong and active third sector building resilient, cohesive, active and inclusive communities, giving people a voice, creating a strong, healthy and fair society and demonstrating the value of volunteering and community action.

We welcome the opportunity to respond to the consultation on *The Autism (Wales) Bill – Bill Development*.

This response is drawn together by C3SC's Health and Social Care Facilitator from experience and knowledge of related issues through their working role, and contributions from C3SC's Senior Management Team. C3SC promoted the consultation to members; we will confirm through Network meetings if member organisations, as is very likely, have contributed via other avenues.

Consultation questions

a) What are your views on the effectiveness of the current arrangements for improving autism services in Wales?

The introduction of the Integrated Autism Service Integrated Care Fund alongside the revised Welsh Government Autism Spectrum Disorder strategy has seen autism raised up the agenda within the Cardiff and Vale Regional Partnership Board. This has included the representatives at Senior Management and Councillor levels taking an interest and leading change in their service areas, including monitoring of progress. However, the current approach is very directed by Welsh Government and WLGA which ignores the existing set up and services, and does not appear to have consulted with service users. Materials are being produced which are below the standard of materials already in use in the region and there is no acknowledgement or opportunity for the skills and knowledge from the third sector to be included. Integration is purely between the local authorities and health, often providing a more expensive solution and removing ongoing support and engagement with wider community services. This means that instead of improving services there is a risk that services in Cardiff and the Vale could be made worse, as a region we are working together across all sectors to try and prevent this from occurring.

We will be interested in seeing any monitoring reporting from WLGA on what they are providing for the funding they have received. The region provide quarterly reporting as part of the receipt of funding, as there was no visible procurement process for the WLGA we would be interested to see their reporting and justification for monies being taken out of frontline autism services to fund the team.

Currently, services retain a focus on treating people, rather than supporting people to care for, manage and prevent or limit any negative impact as a result of their autism spectrum disorder. There is the potential to therefore create greater alignment with existing legislation – the Wellbeing of Future Generations (Wales) Act 2015 and Social Services and Wellbeing (Wales) Act 2014 – and their focus on prevention.

b) Do you believe Wales should have legislation requiring the Welsh Government to publish a national autism strategy for children and adults and issue guidance to local authorities and NHS bodies on implementing the strategy?

An Act would be costly, time consuming and add to the levels of bureaucracy. This could lead to services reducing their output where there isn't a regulatory requirement and reducing the creativity to develop services based on need as opposed to legislation. The Integrated Autism Service ICF is already delivering the commitment and stifling local innovation due to its rigidity and not acknowledging the starting point of services across the different regions, an Act would risk these further.

There is already a National Autism Spectrum Disorder Strategy therefore it is not clear how legislation would add to this.

Instead of focussing on investing in legislation and associated penalties, we suggest the benefit of re-focussing investment on research, support and sharing knowledge. Welsh Governments' role could usefully be that of facilitating support, development and sharing of knowledge and expertise and ensuring connection – through TSSW for example – of local citizens. This will also benefit from bringing in the diversity of voices and experiences, incorporating equity of access and opportunities to influence irrespective of ethnic, cultural, social, economic etc. background and the development of provision that responds to the diversity of need. This could be articulated through a standard, possibly at increasing levels that service providers should be supported to aim for, possibly through recognition and accreditation. Accreditation at the highest end of the standard should include how services share knowledge and best practice at local, regional and national levels.

c) To what degree of detail do you think the content of a national autism strategy should be defined in legislation?

There are already a number of Acts which have to be applied to citizens with austism, as services do not sit on their own. The key ones being:

- Social Services and Wellbeing (Wales) Act 2014
- Wellbeing of Future Wellbeing (Wales) Act 2015
- Additional Learning Needs (Wales) Bill – which is currently going through Welsh Government.
- Prudent Healthcare.

We do not feel that more needs to be added to these, however if there was a need then the advice of senior clinicians within the field along with carers and those with autism should be sought to provide a robust clear set of guidelines that will stand the test of time as developments in assessment, treatment and interventions emerge within the field of Autism and other neurodevelopmental conditions. The engagement should include people from black and ethnic minority communities to ensure that any developments are culturally appropriate and accessible to all.

d) What (if any) consultation do you think the Welsh Government should be required to undertake, when developing, reviewing and updating a national autism strategy?

Consultation needs to cover all statutory, private and third sector agencies including those who specialise in autism services, as well as citizen engagement which is accessible to everyone including those with autism and their carers including those from black and minority ethnic communities and those whose first language is other than English or Welsh or use alternative communication methods.

e) Do you believe that legislation should define how often a national autism strategy should be reviewed and updated? If so, how often should it be reviewed and updated?

If legislation is introduced, it should not specify the frequency of the strategy being updated, but should define the conditions of when a review should be started – linked to the implementation of other legislation which impacts on services.

f) Do you have any views on how Welsh Government should monitor what progress is being made and how public services should be held accountable for how they support autistic people and their families?

There should be agreed achievable outcomes and a sensible reporting mechanism. Some of these are in place through the Integrated Autism Service ICF, though unfortunately what can be reported is limited to what is being funded by ICF and does not take into account work undertaken under other funding sources that are going into autism services. A holistic account of progress rather than one silo'd by funding sources would be welcome, and time needs to be given for the current system to become embedded to make sure that the correct data is being collected which can demonstrate how people with autism are supported and if this is effective. Measures that are reported on should include the views from autistic people and their families about their experience of support, with key trends identified as targets against which services should be required to show how they will improve and demonstrate improvements made.

g) What are your views on how easy it is to access a diagnostic assessment where you live?

Cardiff and the Vale have been improving this process over a number of years. As a result it is accessible with support services available for those who may find the process difficult. We are aware that this may not be the case in other areas of Wales.

h) What key challenges around how the diagnostic process works would you like legislation to address?

We are not aware of any challenges which are not being met. The integrated autism service provides further guidance on the diagnostic process, with close links to Cardiff University to ensure that practice is evaluated and best practice learned from.

i) Do you believe that Local Health Boards and Local Authorities in Wales should be required to publish information on the pathway to diagnosis for children and adults living in their areas?

Cardiff and the Vale already have a pathway in place which is continuously improved and amended through a regional steering group.

j) What are your views on the sufficiency of services, currently provided to meet the needs of people with autism spectrum conditions in Wales?

There is a need to allow the Integrated Autism Service to settle into place before this question can be answered in full.

The current emphasis is on statutory sector services and there needs to be a wider acknowledgement and focus on cross-sector collaborative approaches that include the innovative, person-centred services that are developed within the third sector. It is important to have autistic specific services but with increased demand on funding and other resources people with autism should be enabled to access services close to their home that support all individuals. The services need to be developed and delivered locally based on population needs assessments and encourage innovation and integration across sectors through agreed delivery pathways not just with the statutory sector.

k) The legislation I am proposing would require the Welsh Government to issue statutory guidance that would put duties on local authorities and local health boards on how they should be delivering services for autistic children and adults and their families.

Do you agree that legislation should require statutory guidance? If so, does the following list cover the right areas to be included under the duties on local authorities and Local Health Boards?

i. The provision of relevant services for the purpose of diagnosing autistic spectrum conditions in children and adults.

This is already in place through the Integrated Autism Service guidance and the Autistic Spectrum Disorder Strategy.

ii. The fact that assessment of the eligibility of children and adults for relevant services cannot be denied on the on the grounds of the persons IQ.

Services for individuals in Cardiff and the Vale are based on need and not IQ. An individual requesting assessment of a neurodevelopmental condition is assessed on their presentation and not on their IQ. There are some services post diagnosis which can be accessed based on IQ, but these are typically learning disability services, and there is a threshold for care and support services based on needs of those with significant learning needs, including autism. In addition, services in the third sector rarely if ever collect information on IQ as services are based on needs of the citizen.

iii. Planning in relation to the provision of relevant services to people with autistic spectrum conditions, as they move from being children to adults.

This is covered in part of the guidance for the Integrated Autism Service. In addition, the planning of services for individuals with autism spectrum conditions is included in the Cardiff and Vale Population Needs Assessment which will be included in the Area Plan which is currently being developed.

iv. Other planning in relation to the provision of relevant services to children and adults with autistic spectrum conditions.

Acknowledgement, and a central record, of the breadth and depth of services that are delivered to children and adults via the third sector that complement and support services delivered by the statutory sector.

v. Local arrangements for leadership in relation to the provision of relevant services to children and adults with such conditions.

This is already included within the Cardiff and Vale Regional Partnership Board structure in line with the recommendations within the Social Services and Wellbeing (Wales) Act 2014. In Cardiff and the Vale the Disability Future Programme oversees the leadership and development of services for all children and adults with learning disability and reports directly into the Regional Partnership Board. Information is also fed back and additional input received via the Learning Disability Partnership Group which has it on the agenda for each meeting, the Group includes private, third sector, service users and self-advocacy services along with the statutory bodies.

l) Do you believe that Local Health Boards and Local Authorities in Wales should be required to establish and maintain new data collection practices around the numbers and needs of children and adults with autism spectrum conditions so that local areas can plan services accordingly?

With the development of the All Wales Solution, WCCIS, which will enable the sharing across the statutory sector – with developments under way this may already be covered. If it is not included, then it should be added to the WCCIS information and not be as a separate and additional data collection. In addition, access to WCCIS should be extended, defined by the nature of the service being delivered rather than by the sector that the service deliver is part of

m) Do you have a view on how data can most effectively be gathered, on the numbers and needs of children and adults with autism spectrum conditions in different Local Health Board and Local Authority areas in Wales?

The WCCIS system as mentioned above. In addition, information is provided through Daffodil per area based on prevalence. The purpose of collecting any additional data should be made clear and should be optional for citizens to sign up to, for example they may want to engage with research.

n) Do you have a view on the current scope and effectiveness of training in Wales for key staff working with people with autism spectrum conditions?

There is plenty of training which is high quality and effective, resources to train, release staff and implement is a challenge given pressures on services to do more with less. Training also needs to be made available to carers of those with autistic spectrum conditions, so they can provide relevant support which may prevent the need for more expensive services.

People with autistic spectrum conditions should be involved in the delivery of training, as they along with their carers are the experts. This is something that Cardiff University are increasingly using with their students, engaging with those who have or may require services in the future.

o) Do you believe that legislation should specify outcomes that training should achieve, thereby providing greater flexibility around the delivery of such training?

The Social Services and Wellbeing (Wales) Act 2014 is clear that services and outcomes should be person-centred. In addition, if training sets out outcomes then it would need to be amended every time there is a new piece of best practice evidence-based research. The only requirement should be for training to include the latest evidence-based research and be inclusive of those with an autistic spectrum condition and be person-centred focussed.

p) An alternative approach would be for legislation to specify that key staff working with people with autism spectrum conditions should undertake autism training.

Autism spectrum conditions are not experienced in isolation, therefore training should be made available for all staff, including those providing support services in the community. There could be autism friendly communities set up in a similar way to how the dementia friendly communities are being set up supported by the third sector.

q) Do you have any suggestions for additional action that could be taken through legislation to improve the rates of employment of people with autism spectrum conditions (bearing in mind that the National Assembly for Wales does not have the power to make changes to employment law)?

No additional suggestions.

r) Do you believe that a definition of autistic spectrum disorder should:

- Be included on the face of legislation (which makes it more difficult to change in the future);
- Be included in an autism strategy;
- Be included in guidance; or,
- Not be stated at all?

The definition of autism spectrum is the domain of clinical guidance and should be left to the arrangements already in place and not be part of primary legislation. This enables any changes to be fully analysed and researched. There is a clear definition in legislation of carers, yet the term is constantly misused by politicians and the media when referring to paid social care workers, therefore having it in legislation does not prevent this kind of misuse.

s) Can you identify any possible unintended consequences which could arise as a result of this legislation? If so, what steps could be taken to deal with them?

Yes, legislation can limit innovation and tie more resources up within the statutory sector limiting the opportunities for more intergenerational and condition services out in the community which meet the needs and interests of the citizens who access services. There should be a focus on ensuring that existing legislation around prevention, innovation and person-centred services are delivered across all sectors, including promoting best practice evidence-based services from whichever area delivers them.

t) Do you believe that the proposals in this consultation would give rise to

any substantial costs, in addition to the cost-areas already noted in this consultation? How can such costs best be mitigated?

Potentially, yes but without more detail it is not possible to say how much and how to mitigate them.

u) What would the impact of costs be in terms of:

i. producing a national autism strategy

ii. placing duties on local authorities and NHS bodies to act under guidance;

iii. creating and maintaining data collection practices on the numbers and needs of adults and children with autism spectrum conditions; and,

iv. providing training for key staff?

The Social Services and Wellbeing (Wales) Act 2014 has incurred a large amount of resource to embed the new legislation which is still ongoing. A lot of resource has been required to set up the new Integrated Autism Service, it is unclear what the advantage of spending more resources on implementing more legislation would reap benefits for those who require access to services. There is a risk of resources being directed away from services and to implementing legislation which would have a detrimental effect for the people the legislation was planning to help.

v) Do you envisage any other additional administrative and regulatory costs as a result of this legislation and if so, how can such impacts be mitigated?

Yes, evidence to date is that costs are not mitigated but obsorbed with more monitoring and associated administration required. Citizens want more services, services cost money. The Welsh Government need to consider if they want to increase service delivery or more back office administration, our recommendation would be for more services to meet people’s needs with proportionate, responsive levels of administration and that are delivered across all sectors and not limited to statutory services.

w) What factors should be measured to determine the cost-benefit analysis of this legislation should it become law?

How would this be measured and identified separately to the Integrated Autism Service which is still in the process of being set up and is yet to be measured. There should be a stronger focus on the need to deliver person–centred services that meet the needs of those with an autism spectrum condition, whether these be specialist or more general services. This should be delivered within existing resources and if possible more funding identified to enable more community based solutions and activities to be delivered through coproduction with those who need and want the services.

x) Do you have any views on how savings that might arise from the legislation can most effectively be identified and calculated?

We think it is unlikely that savings will be achieved through the implementation of legislation, savings will be achieved through regional and integrated services which are already being developed under the Social Services and Wellbeing (Wales) Act 2014 and are anticipated with the Additional Learning Needs (Wales) Bill.

y) Do you wish to make any other comments on my proposals?

We do not support the introduction of legislation in this area. There is a range of other, and in some cases pre-existing, options and legislation that should cover the requirements adequately without the need to introduce more. There is a lack of acknowledgement of the role the third sector already plays in delivering services and of any possible future innovation and role that the third sector will and should play. There is a lack of focus on care, management and prevention or limiting any negative impact as a result of their autism spectrum disorder.