



Comisiynydd Plant Cymru Children's Commissioner for Wales

Ymateb i Ymgynghoriad / Consultation Response

Date / Dyddiad: 13th September 2018

Subject / Pwnc: Autism (Wales) Bill Stage 1 inquiry

Background information about the Children's Commissioner for Wales

The Children's Commissioner for Wales' principal aim is to safeguard and promote the rights and welfare of children. In exercising their functions, the Commissioner must have regard to the United Nations Convention on the Rights of the Child (UNCRC). The Commissioner's remit covers all areas of the devolved powers of the National Assembly for Wales that affect children's rights and welfare.

The UNCRC is an international human rights treaty that applies to all children and young people up to the age of 18. The Welsh Government has adopted the UNCRC as the basis of all policy making for children and young people and the Rights of Children and Young Persons (Wales) Measure 2011 places a duty on Welsh Ministers, in exercising their functions, to have 'due regard' to the UNCRC.

This response is not confidential.

My response to this Stage 1 inquiry is split into two main sections; the first part discusses the potential disadvantages in introducing a Bill of this kind. I have however also included a second part regarding the merits of the Bill as currently drafted, for further consideration should the Bill proceed beyond stage 1.

At the start of this response, I wish to make it clear that I am convinced that autistic children and adults and those with related autistic spectrum conditions are often failed by our public services. This includes lengthy waiting lists for diagnoses and an inability in some cases to adapt services such as education, therapeutic services and mental health services to meet the needs of those with autism spectrum conditions.

Despite these considerable challenges, I have also been pleased to meet autistic children and young people who say that their diagnosis has been liberating in helping their self-understanding and improving the attitudes of others towards them. They have expressed pride in their uniqueness and state that they are comfortable in not being 'neurotypical'. There is some indication of a reduction in stigmatisation and a gradual increase in public understanding of autism.

Key questions, however, are whether a specific additional piece of legislation will make a significant positive difference to autistic children, young people and their families' experiences, and also whether it may serve to unintentionally exclude others without a specific diagnosis.

Potential disadvantages

In my response to the pre-legislative consultation, I noted some of my concerns regarding the introduction of an Autism Bill. These concerns relate to the general policy issues, but are informed by cases that come into my office's Investigation and Advice service. This is an independent source of advice and support for children and young people, or those who care for or work with them. Often people will contact my team when they feel they have nowhere else to go with a problem and have exhausted all other avenues.

Since my time as Children's Commissioner we have received a number of contacts related to autistic spectrum conditions. These include but are not limited to: the referral process and length of waiting time for diagnosis by Child and Adolescent Mental Health Teams, the Special Educational Needs process (Additional Learning Needs), availability of school support before and after diagnosis, school exclusion and the appeals process, availability and changes to Social Services including at the point of transition, and the availability of services to support children and families more widely in their day to day lives.

These casework issues also impact negatively on children with other neurodevelopmental conditions and learning disabilities, often without a clear diagnosis even after assessment. It is therefore a matter for debate as to whether what

is required is a specific Bill for children and adults living with an autism spectrum condition, or wider measures that ensure that all of our public services are person-centred and aim to remove barriers facing those who are not neuro-typical or who have a learning disability, in order that all citizens are enabled to fulfil their potential.

Many families I speak to tell me about their need to fight to obtain a diagnosis for a child's difficulties, as this is very often seen as the gateway to receiving services and support. This is not unique to autism; it relates to other matters as well such as mental health services and support for a child with learning difficulties. It should not be the case that a diagnosable condition is seen as a 'golden ticket' to receiving a suitable service. An assessment of autism is not always definitive, and another unintended consequence could be a trend towards diagnosing larger numbers of children whose behaviours and experiences of everyday life show some traits associated with autism but where it is not definitive. Some parents that I have met have found that even with a diagnosis, some agencies including CAMHS and schools dispute this, and the diagnosis does not always guarantee access to particular services in any event.

In my response to the *Mind Over Matter* inquiry report I have issued a paper¹ which sets out the importance of providing children with early help, when and where they need it, without needing to be referred to specialist services.

In my 2018 report *Don't Hold Back*² I highlighted the 'battles' parents and carers regular speak about to obtain diagnoses and services for their children. The report noted that there is currently a strong legislative framework in place to plan for and provide person centred care and support services. My report highlighted areas where the Social Services and Well-being (Wales) Act 2014 could be used more effectively, and I believe that this could also be the case for services for people with autism. Using the current legislative framework means that children and young people with similar levels of need to young people with autism, but who don't have a diagnosis, should have an equal opportunity to receive assessments and services.

I am aware that similar concerns have been raised in a briefing prepared by the Royal College of Psychiatrists, Royal College of Speech and Language Therapists, Royal College of Paediatrics and Child Health (RCPCH), The Royal College of Occupational Therapists (RCOT) and the Welsh NHS Confederation at the time of the plenary debate introducing the Bill.

The draft Bill

The draft Bill provides much detail for a new statutory Autism Strategy, but crucially it cannot guarantee access to particular services. Section 2(1)(h) requires the strategy to set out how relevant bodies will "make provision so that an appropriate range of services to deliver the autism strategy is available consistently across Wales" but this may not result

¹ <https://www.childcomwales.org.uk/wp-content/uploads/2018/07/Mind-over-matter-position-paper.pdf>

² <https://www.childcomwales.org.uk/wp-content/uploads/2018/07/Dont-Hold-Back.pdf>

in anything more than the current provision being available. I am not sure that the draft Bill, despite the best intentions of those who have contributed to it already, will meet the expectations of families.

It is open to the Welsh Government to recognise the criteria set out in Section 2(1) of the draft Bill and commit to incorporating some or all of these into their ongoing work on the existing strategy.

Additionally I would be concerned that the current draft of the Bill will focus a significant proportion of resources into assessments and data collection. This relates to my earlier point about not wanting families to have to pin all of their hopes on a diagnosis, but also means that there may be little resource remaining to actually help and support those assessed as having a need. That would be an unintended consequence of this Bill but it is necessary to highlight this at stage 1. A number of parents have expressed concerns about lack of provision even with a diagnosis of severe need. Parents have also expressed concerns that there may not be any access to services for those who fall “outside” of the Bill but still have a significant support need.

Section 1(7) provides for independent reports every 3 years to review implementation and progress. Related to the points above, I am concerned that this frequency may divert resources and attention away from delivery of services to support people. I understand the intention to ensure that there is independent scrutiny of the Bill but it may not be necessary to have full independent reports every three years. I would suggest perhaps a lesser frequency, and/or incorporating other methods of review such as post legislative scrutiny by Committees of the National Assembly. On a practical note my office has been engaged with work on an evaluation of the Social Services and Well-being (Wales) Act 2014. This is by far a larger piece of legislation, but it has proven complex and time-consuming to evaluate. It will take a number of years to engage with stakeholders to set the terms of the review, to put the work out to tender and to complete the review process itself so it may not even be possible to undertake such regular reviews in this way. On a related point, as that review has not yet concluded, it may be seen as premature to introduce further legislation of this kind at present.

Should the Bill progress, provision will need to be made to take into account the forthcoming Additional Learning Needs and Education Tribunal (Wales) Act 2018. I note that the Bill includes in Section 8(4) a duty of due regard to the UNCRC, drafted in the same terms as the duty contained within the ALN legislation which has now passed. Should this Bill pass through stage 1 I would support section 8 being retained in its current format, as due regard to children’s rights will ensure that individual needs are actively considered when decisions are being made. During the passage of the ALN legislation there was much debate over the impact of such a duty and I provided written and verbal evidence explaining why the duty was a necessary and positive addition to the legislation. This debate does not need to be rehearsed further in this submission as a clear consensus was reached in the committee stages of the ALN legislation, however I would be happy to provide further information as required.

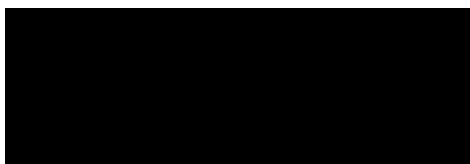
As this is a private members Bill, there is no statutory requirement to undertake a Children's Rights Impact Assessment (CRIA). This is not a criticism of the Member as I recognise that he would not have a team of civil servants to support him in preparing a CRIA. It does however highlight a potential flaw in the Children's Rights Scheme 2014. The compliance report prepared under the Scheme earlier this year noted that the Scheme is due to be revised, so this may highlight an opportunity to consider this point further as part of that work. There may be a way to introduce a CRIA during stage 1 once the Bill is introduced, as part of the ongoing scrutiny through the stages prior to any Bill being passed.

As Children's Commissioner for Wales it is part of my role to highlight the fact that children and young people are a distinct group of individuals in our society with unique strengths, perspectives and circumstances whilst also being one of the most vulnerable, often with the least powerful voice. As Commissioner I have a statutory role to safeguard and promote the rights and welfare of children and help their voices be heard, however under the UNCRC, all adults have responsibility to do what is in the best interests of children (Article 3).

As is increasingly becoming the case, the Bill provides for a person centred or all age approach. It is important that the particular needs and experiences of children are not lost or diluted within the legislation and guidance. My office, with expert advice from the Wales Observatory on Human Rights of Children and Young People, has published *The Right Way: A Children's Rights Approach in Wales*³. This document provides a principled and practical framework to integrate children's rights into every aspect of decision-making, policy and practice. It is underpinned by 5 principles; embedding Children's Rights, equality and non-discrimination, empowering children, participation, accountability. The application of this children's rights approach in the context of legislation concerning 'people' may also provide opportunities for these principles to be embedded more widely.

Articles 12 and 13 of the UNCRC provide children and young people with a right to express their views in all matters affecting them and to be provided with information. This is both relevant in terms of the Bill's further development and the provisions currently proposed for inclusion. Any guidance introduced under this Bill would need to be produced in consultation with children as well as adults, and be available in a clear and suitable format for all to understand and use.

Submitted by:



Children's Commissioner for Wales

³ <https://www.childcomwales.org.uk/wp-content/uploads/2017/04/The-Right-Way.pdf>