

Julie Burton submission

In response to the [Consultation on the proposed Autism \(Wales\) Bill](#)

By way of background, I am a solicitor with over 25 years' experience in community service provision for people with disabilities. Please see my website www.julieburtonlaw.co.uk for more information. An increasing number of our clients, both children and adult, present with needs arising from autism.

There are real and very serious problems obtaining adequate diagnoses. There are now more health professionals who are trained in a basic form of diagnosing ASD – the ADOS assessment – but there is a continuing reluctance by health professionals to label people, and especially young children as having ASD – and this failure leads to a refusal of any service provision.

The Social Services and Wellbeing (Wales) Act 2014 does not call for any specific diagnosis before services are required – rather the process is supposed to depend on needs flowing from personal and wellbeing outcomes - but the reality is that currently (and for many years) without a clear diagnosis it can prove almost impossible to obtain support or even a recognition that support may be needed. This is strictly unlawful but is the reality of trying to obtain support services in a post austerity society.

It is the experience of my firm that those with ASD who also have a learning disability will (eventually) be recognised as having support needs and will receive a service in some form. If the person is a small child it may prove very hard indeed for the adult parent/carer to obtain recognition and proper services but if there is an associated LD this usually does end up with some sort of service response at some stage.

The problems really arise however with those people who are on the autism spectrum but do not have a recognised learning disability. The fact that their autism may result in crippling social isolation or anxiety or an inability to take care of even the most basic ADLs will not prompt a service response.

This is because, in our experience, social care services, and to a lesser extent health care services, are rigidly divided into silos and if a service user does not fit into any of the rigidly identified silos then that service user will not get a service. Rather they or their parents will be blamed and even criminalised for odd/unusual/maladaptive behaviours. The existing silos are:

- 1) Physical disability
- 2) Learning disability
- 3) Old age
- 4) Mental health
- 5) Children at risk of harm

As can be seen, those on the autism spectrum do not neatly fit. Currently, if someone with ASD but without LD gets a service at all it will be from the CMHT – whose expertise lies in the care and support of those with functional mental disorder not those with a lifelong developmental disorder which will not respond to treatment with medication. The CMHTs frankly do not know how to deal with or provide support

to someone with ASD who would rather not eat than leave the home because of anxiety. Nor do the CMHTs (or wider social services departments) appear to have any recognition of the need for holistic assessment of people with possible support needs as required by the SSW(W)A 2014, preferring, it seems, to rely purely on the minimal requirement of the Mental Health Measure when it comes to assessment and support – this looks only at mental health needs, not wider social functioning.

So there is currently a massive gap when it comes to assessing and then meeting the support needs of those with ASD.

Even if needs are recognised here in N Wales there is a dearth of specialist resources for those with ASD. We have virtually no dedicated support services – save for Autism Initiatives who have some form of provision in Flintshire, plus one state school and one private school in Denbighshire/Flintshire. There has been talk for years of dedicated support provision but nothing is in place. High functioning autists end up, at best, receiving support from people who work mostly with people with LD and have no idea how to support someone of high intellect but no clue about social functioning. At worst they get nothing and desperate families are left to do what they can.

It is my view that there is already adequate blackletter law to ensure that needs are met. However what is lacking is adequate funding for, and proper leadership, to ensure a full service response to those specifically with this condition. In my view this need could and should be properly met if there were adequate funding and specifically trained and designated leads in every social care area whose role is to coordinate, and properly commission, the service response for this group.

This would need to be linked in with more responsive educational resources able to recognise and work with the families of children with ASD who refuse school.

We have had an autism strategy for years but I have yet to see this translated into anything other than words on (very many) pages.

As regards your specific consultation questions, please excuse me for not responding to all of these save for generally in my above comments. But I do respond to a few:

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?

- yes I think LAs should keep records of all those who approach them asking for support who suggest that they may have needs relating to ASD – and how they respond to these requests

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

- it is hard, very hard, to get a diagnosis (unless there is an associated LD)

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

- GPs should be able readily to refer (i.e. act as gatekeepers) for assessment and if they do then there should be access to full expert assessments readily available with no further hurdles/"criteria"

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?

- yes

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

- see above. Woefully inadequate

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?

- yes – provided this has teeth – as I am not convinced that the SSWWA has really resulted in improvements for general service provision thus far.....