Evidence for the Autism Bill

General principles

Generally speaking an Autism Bill to enshrine the rights of individuals with Autism is long overdue: England and Northern Ireland already have such legislation. We need a consistent, Wales-wide strategy to ensure that individuals can access a timely and reliable diagnosis if they need so, as well as access to appropriate services and support. The Bill in its essence is therefore to be welcomed. However, there are a range of issues that need to be addressed in order to achieve this overall aim, and obstacles to be overcome.

1. *Background*

Autism or Autism Spectrum Disorder (ASD) is currently defined as:

"Persistent deficits in social communication and social interaction across multiple contexts...and restricted, repetitive patterns of behaviour, interests, or activities"

(DSM-5, 2013)

The National Autistic Society's (NAS) prevalence rates (NAS, 2018) indicate that more than 1 in 100 individuals in the UK are likely to be on the spectrum (e.g. Baird et al.,2006; Brugha et al., 2009), demonstrating that a significant number of the population are likely to be on the spectrum.

We know that ASD can cause persistent behavioural and management difficulties in children (Totsika & Hastings, 2009). These researchers found that typically parents report higher levels of stress when they have a child with autism than for example, other developmental disorders. We know that individuals with ASD have an increased susceptibility to challenging behaviours across the lifespan (Matson, Sipes, Fodstad & Fitzgerald, 2011, McClintock, Hall & Oliver, 2003), parental stress (Hastings & Brown, 2002, Estes et al, 2009) as well as being associated with mental health difficulties, more often with higher functioning individuals (Mazzone, Ruta & Reale, 2012) and indeed there is evidence to suggest that there is an increased likelihood that in-patients in psychiatric settings will have a diagnosis of ASD (Tromans, Chester, Kiani, Alexander & Brugha, 2018). Thus, any attempt by government to meet the needs of individuals with ASD and their families is to be welcomed.

2. *Diagnosis*

A timely diagnosis is acknowledged to be important so individuals with autism can make of their difficulties, access appropriate services and apply suitable strategies / learn techniques to manage any issues that can cause difficulties in their daily lives. The same issues are

relevant for families accessing a diagnosis for their child. Welsh Government have released funds to increase capacity for services to assess individuals and applied waiting times. However it appears that such investment has not necessarily reduced waiting times in the way expected; availability of assessment has increased expectations of ASD assessment and so often, the diagnosis of Autism is seen as a golden ticket, providing access to services and an explanation of any unusual behaviours. Services are thus under pressure to provide a diagnosis, and to complete assessments quickly, leading to possible concerns regarding taking shortcuts which could affect diagnostic validity. Families sometimes reject the notion of no diagnosis. There is a common perception that there is only one diagnosis (ASD) and that it is only a diagnosis of ASD that can explain developmental or behavioural difficulties, at the expense of other diagnoses, e.g. learning disability. ASD is seen as the diagnosis du jour. Parents seek answers to explain their child's behaviour, and sometimes seek a second opinion if they are not satisfied with the results of the assessment. Time spent conducting a second opinion assessment potenatilly increases waiting times, leads to additional costs if the second opinion is sought by a private agency and paid for by the NHS, and can cause a loss of confidence in diagnosis by public sector services, deskilling practitioners.

We know that ASD is a complex spectrum, and that prevalence is increasing although the reasons for this are not fully understaood as yet. Clearly we need diagnostic services and a better understanding of the needs of individuals on the spectrum. Despite this, this should not be at the expense of intervention and support services. We need cost-effective services that can provide ASD assessment and other neurodevelopmental conditions, learning disabilities etc, and there is an equal need for individual and family support services, providing cost effective interventions to improve the quality of life of those individuals on the spectrum and their families. The improvements in diagnostic services have led to an increased demand for diagnosis which could lead to questions about the value of a diagnosis, and how to manage demand. Should we prioritise building resilience in the population as a whole rather than labelling individuals?

3. *<u>Support</u>*

The need for social support is paramount. Many of our families lack the necessary resources to cope without additional support. Indeed research demonstrates that marital and family breakdown may be correlated with rearing a child with autism, and the stress and strains that can accompany such developmental difficulties (Totiska & Hastings, 2009)

The Incredible Years parent programmes (IY) (e.g. Webster-Stratton, 2013) have been very successful in teaching parents how to apply behavioural strategies to manage their children and develop play and early learning skills. It's a 12 week parenting programme, and it is common for parents of children with conduct disorders to be referred to the group. There is significant evidence for the effectiveness of the programme.

The IY programme has expanded in its range of applications (e.g. see the Dinosaur school, etc., e.g. Webster-Stratton, 1991) to include a programme which applies to the parents of children with Autism and Language delays. This focuses on building desirable skills and some sessions on learning to manage challenging behaviours. The emphasis is on creating and maintaining a positive group atmosphere which reflects a positive context for the relationship between the parent and the child.

This programme has been evaluated in North Wales (Hutchings et al., 2016). As such, it is recommended that IY ASD parent programmes continue to be evaluated to refine their relevance and efficacy with such families, and are also routinely made available as one aspect of interventions available to parents, alongside others such as PACT ((Parent-mediated social communication therapy for young children with autism (Pickles et al. 2016), Early Bird (NAS), etc.

4. *<u>Other Interventions</u>*

Early Intensive Behavioural Intervention (EIBI) is a programme of intervention that has produced promising results; decreasing challenging behaviours and increasing prosocial, pre-academic and play skills in young children with Autism. Original studies were conducted by Lovaas (1987) however since those early days psychological treatments have developed and moved on, becoming more refined and allowing more naturalistic teaching. There is local and international evidence to suggest that behaviour analytic approaches continue to have a significant effect on the development and behaviour of autistic individuals (e.g. Kovshoff et al., 2011; Eldevik et al., 2009) since those early days.

In the US, state-wide interventions are routinely provided to young children with autism however EIBI have not yet become routinely available in many countries in Europe to the same degree (Keenan et al., 2014). In the UK, the growth of EIBI has been mainly within the private sector, with increasing numbers of affluent, educated and vocal parents accessing such approaches, particularly in the South East of England. Similar services in Wales tend to have been related to University-led provision (e.g. clinic provision at the University of South Wales), or state-run educational establishment provision, which tends to be less intensive, but with promising results (Grindle et al., 2012; Foran et al., 2015; Jones & Hoerger, 2011).

Recent studies have demonstrated continued effectiveness, and long term outcomes are particularly promising when parents are included in the delivery of such programmes (Kovshoff et al., 2011). There is wealth of evidence to demonstrate the effectiveness and justification in terms of cost of delivering an EIBI programme to young children with Autism (e.g. Chasson et al., 2007).

It is recommended that health, social care services and education collaborate to support the use of early interventions to support parents to manage their children, teaching them play skills, prosocial and pre-academic skills, as part of a package, whilst also learning to manage challenging behaviours. There is world-wide evidence to suggest that early interventions are

crucial and highly effective when applied with a high degree of fidelity, by trained, well-supervised individuals.

In addition, currently behavioural specialists are a vital component of Neurodevelopmental teams however often practitioners do not have specific qualifications although Positive Behaviour Support (PBS) and Active Support (AS: Jones et al, 1999) are approaches that are already well established in adult learning disability services.

It is recommended that behavioural specialists seek a qualification in, for example, Applied Behaviour Analysis (ABA) so that service quality can be measured. Behaviour analysis is not recognised as a discrete profession in the UK at present. There exists an international qualification, the BCBA (Board Certified Behaviour Analyst) which denotes accredited Behaviour Analysts. There needs to a structure in place to ensure effective regulation as this is important for public protection. It is recommended that the HCPC (Health Care Professions Council) takes responsibility for regulation of behavioural practitioners as a profession. This would need to be achieved in conjunction with the other nations of the UK. The UK-SBA (UK Society for Behaviour Analysis) is already working on this.

5. *<u>Education</u>*

Any attempts for joint working to provide seamless services are to be welcomed. Too often there are examples, evidence, anecdotes that families find themselves turned away from services due to ineligibility and lack of co-ordination, or they appear not to be anyone's responsibility. The Bill states that the Autism Bill would "complement" the work of the ALN Act. This is to be welcomed.

6. *<u>Welsh Language services</u>*

The Autism Bill refers to Welsh Language provision (5.8, explanatory memorandum). Specifically, the Bill refers to the 'Active Offer' and the need for public services to recognise and respond to language need as an integral element of care without the need for service users having to ask for Welsh language services. The Welsh Language Commissioner has cited examples of barriers to appropriate Welsh medium service provision, e.g. poor workforce planning and lack of linguistically appropriate testing resources as have others responding to the consultation.

<u>The situation in Conwy & Denbighshire: Betsi Cadwaladr University Health Board Central area in my experience as a practitioner.</u>

BCU has appointed a Welsh language tutor. The needs of the service will inevitably exceed the tutor's capacity, so an analysis of service need may help to target key areas for intervention (in this case, Welsh lessons).

ASD is a social communication disorder. It would be reasonable to suggest that therefore staff need to have competencies in the languages that the child /family use. In Wales we are required for services to provide Welsh and English services, according to need, providing an

Active Offer (Welsh Government, 2012). In the case of any additional languages, the NHS provides an interpretation service.

There is even a suggestion that as social-communicative behaviours are culturally-bound, and high functioning autism may be linked to cultural competencies and that therefore to diagnose reliably one would need an understanding of the linguistic and cultural context of that individual (Gillberg & Gillberg, 1996).

Currently in Central BCU (Conwy & Denbighshire), there are three possible routes to an ASD assessment. The Neurodevelopmental team undertakes assessments for children and young people without intellectual disabilities aged between 5-18 years across both counties. Conwy Social-Communication Panel undertakes ASD assessments for all children aged between 0-5 years and for children and young people aged between 5-18 years. Denbighshire Social-Communication panel also undertakes ASD assessments for all children aged between 0-5 years and children and young people aged between 5-18 years with an intellectual disability. The plan is for there to be a SPOA (single point of access) for an ASD assessment in due course.

A limited number of fluent Welsh speaking staff currently work into the three services. In addition, it is commonly thought that recruiting Welsh speakers into the service is very difficult.

An audit was conducted of team members' Welsh language skills, collated with ASD assessment skills. Team members about their Welsh language skills: as follows:

- *I am a Welsh speaker,*
- *I understand Welsh but cannot speak it,*
- *I can speak a bit of Welsh, say with young children,*
- *I can understand Welsh well enough to write words when spoken,*
- *none.*

It was demonstrated that some team members had some Welsh Language skills, appropriate for possibly assessing young children particularly non verbal children. In addition, it was found that some team members had receptive Welsh Language skills, suitable for undertaking school observations.

Such an undertaking makes possible the pairing of staff competencies with service needs and also identifies targets for up skilling the workforce. This level of analysis could be generalised to help with every aspect of service delivery and could also help with workforce planning.

ASD assessment typically includes a validated direct assessment of communicative and interactive skills such as the ADOS (Autism Diagnostic Observation Schedule, Lord & Rutter, 1989), which provides a semi structured context to evaluate an individual's social-communication and language skills as well as potential for eliciting repetitive behaviours, following the DSM diagnostic criteria for ASDs. I have managed a project to translate the

ADOS into Welsh. Validation of this assessment needs to be completed and it also needs further funding.

We are also in the process of organising Welsh lessons with the BCU Welsh language tutor specifically to address the needs of those practitioners who have some Welsh and therefore could upskill to undertake ADOS assessments, especially with young children with limited language abilities.

With regards to other aspects of assessment, typically a practitioner does not follow a structured protocol for school observations and thus there are no validated assessments currently available, although there are local guidelines.

In terms of the developmental history interview, the gold standard for such an interview is commonly agreed to be the ADI-R (Autism Diagnostic Interview – Revised, e.g. Rutter et al, 1994). However NICE guidelines do not require this assessment to be used in every case, and rather, have published a set of guidelines as to the required content of such an interview. Therefore practitioners undertake this interview using the NICE guidelines and /or locally used instruments as well as the ADI-R. A Comprehensive lsit can be provided if necessary.

In this respect the delivery of the interview can be in Welsh by an appropriately linguistically skilled clinician however at present to my knowledge there is no structured, validated DHI available in the medium of Welsh.

The situation for intellectual assessment in Welsh is dire: there are no validated Welsh language versions of any intellectual assessments such as the Wechsler Adult Intelligence Scale (WAIS), Wechsler Intelligence Scale for Children (WISC), and so on. This means that there is no reliable and valid method for identifying the intellectual capacities of Welsh speakers in Wales. Any undertaking to validate such instruments would need to consider the bilingual nature of individuals' language skills, as well as the long term nature and costs of such an undertaking. It is recommended that a Centre for Validation of Assessment and Psychological Therapy is set up as a centre of excellence, based at Bangor University. This university already has long and respected history in pioneering in Welsh medium / bilingual research and developments, (e.g. The Centre for Bilingualism, Canolfan Bedwyr and Uned Technoleg Iaith). The costs to the public sector could be mediated by grant funding. Such a Centre would allow cross-cultural collaboration with speakers of other minority languages, and could become a world leader in research in this field.

7. *<u>Raising Awareness</u>*

Raising Awareness of the needs of individuals with ASD is useful. There are excellent resources on the Welsh Government ASDinfoWales website.

8. *<u>Equality and human rights impact: Individuals with a Learning Disability</u>*

Contrary to what is stated in the Equality and human rights impacts (section 10.2) the identification of ASD and provision of services specifically for individuals with ASD does not necessarily make "a significantly positive contribution in relation to people with a disability" (p.135) as it potentially creates a disability hierarchy. The needs of other individuals with a range of other disabilities could possibly be ignored as a result of this Bill. The needs of those individuals with learning disabilities have traditionally and historically been disregarded, and thus, concerns regarding increasing the invisibility of people with learning disabilities need to be monitored carefully, and provision should be made to ensure that this vulnerable group are not left behind.
The needs of the general learning disability population are not within the scope of this Bill but the case of a disability hierarchy must be addressed. – not just neurodevelopmental disorders but any others with disabilities.

9. *<u>Data Collection</u>*

Clearly the effect of any legislative change needs to be monitored to evaluate its impact on vulnerable individuals, services, demand, and costs. Data collection regarding prevalence rates needs to be rigorous and consistent across the geographical regions of Wales, an across services. Staff training and ongoing monitoring need to be carried out to avoid procedural drift and to iron out any anomalies and differences in diagnostic rates.

10. *<u>Service User Consultation</u>*

This is paramount. It is crucial that service users consider themselves essential members in this process, and that this population feels that those who are responsible for developing and providing services are listening what they have to say. Empowerment should be a key aspect of this process.

Author details

My evidence is presented as an experienced bilingual clinician /academic in the field of Autism Spectrum Disorders. This includes my expertise in Applied Behaviour Analysis / Positive Behaviour Support, as well as reference to the clinical work, research and consultation regarding service users' Welsh language needs.

I am employed as a Consultant Clinical Psychologist working for Betsi Cadwaladr University Health Board, working into and leading a small team of clinical psychologists in Children's Learning Disability services in the Central (Conwy & Denbighshire counties) area of North Wales. Clinically at present I work with mostly Welsh speaking families, as I am the only fluent Welsh speaking clinical psychologist in the Central area working in Child LD. I have worked within NHS services mostly with children and adults with learning disabilities, and autistic individuals for over thirty years. I have been contributed to Welsh Government strategic groups to enhance the experience of Welsh speaking individuals using NHS services.

I have recently resigned from my University post due to work pressures. My post at the University was that of a lecturer on the Master's course in Applied Behaviour Analysis /Positive Behaviour Support, teaching the academic coursework requirements of postgraduates wishing to qualify as behaviour analysts (Board Certified Behaviour Analysts). I have contributed to developing Welsh medium teaching, vocabulary and services within the field of Applied Behaviour Analysis.

I have confined myself to referring to examples regarding the services to which I contribute rather than citing BCU-wide/North Wales examples: that would be beyond the bounds of my responsibilities as I am not the lead clinician for services Autism Spectrum Disorders for BCUHB.

Dr Elin Walker Jones, D.Clin.Psy, BCBA-D

Consultant Clinical Psychologist, Betsi Cadwaladr University Health Board
Lecturer in Applied Behaviour Analysis, Bangor University (2011-2018)

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