

Agenda – Health, Social Care and Sport Committee

Meeting Venue:

For further information contact:

Committee Room 1 – Senedd

Claire Morris

Meeting date: 3 October 2018

Committee Clerk

Meeting time: 09.15

0300 200 6355

SeneddHealth@assembly.wales

Informal pre-meeting (09.15– 09.45)

1 Introductions, apologies, substitutions and declarations of interest

(09.45)

2 Autism (Wales) Bill: Evidence session with The National Autistic Society Cymru and Autistic Spectrum Connections Cymru

(09.45 – 10.30)

(Pages 15 – 46)

Jane Harris, Director External Affairs and Social Change, The National Autistic Society Cymru

Meleri Thomas, External Affairs Manager, Wales, The National Autistic Society Cymru

Gareth Morgan, Projects Manager, Autism Spectrum Connections Cymru

[Consultation Responses](#)

Research Brief

Paper 1 – The National Autistic Society Cymru

Break (10.30–10.35)

3 Autism (Wales) Bill: Evidence Session with Dr Duncan Holtom

(10.35–11.20)

(Pages 47 – 53)



Cynulliad
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Wales

Dr Duncan Holtom, Head of Research, People and Work

Paper 2 – Dr Duncan Holtom

Break (11.20–11.25)

4 Autism (Wales) Bill: Evidence Session with Dr Dawn Wimpory & Dr Elin Walker–Jones

(11.25 – 12.10)

(Pages 54 – 67)

Dr Dawn Wimpory, Consultant Clinical Psychologist – Lead for Autism Spectrum Disorder, Betsi Cadwaladr University Health Board, and Lecturer, Bangor University

Dr Elin Walker–Jones, Consultant Clinical Psychologist, Betsi Cadwaladr University Health Board

Paper 3 – Dr Dawn Wimpory

Paper 4 – Dr Elin Walker–Jones

5 Motion under Standing Order 17.42 to resolve to exclude the public from the remainder of this meeting

(12.10)

6 Autism (Wales) Bill: Consideration of evidence

(12.10 – 12.20)

7 Forward work programme

(12.20–12.30)

(Pages 68 – 70)

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Response to the Autism (Wales) Bill consultation by the National Autistic Society Cymru September 2018

Introduction

We welcome the publication of the Autism (Wales) Bill and fully support the need for specific autism legislation in Wales.

Wales has had an Autism Action Plan for ten years now and yet autistic people and their families are still being let down and not having their needs met. Autistic people in Wales continue to experience poor outcomes and it's not right that this continues. For example:

- In a report we published in 2011, some 58 per cent of respondents said they'd waited too long for a diagnosis. In a similar report published in 2016 the figure had risen to 63 per cent.
- In 2011, some 53 per cent of respondents said that getting a diagnosis was stressful. In 2016 that figure was 56 per cent.
- In 2011, some 24 per cent of respondents said that they were satisfied that the information given to them afterwards helped them get the support they needed. In 2016 that figure was 21 per cent.

It's time to ensure that key changes that will make a tangible difference in the lives of autistic people are made mandatory so that public services don't view them as 'nice to have's'. This would include training for professionals, ensuring that data is collected, and support is available wherever people live in Wales.

We believe that if passed, this Bill will show real leadership by the National Assembly for Wales and the Welsh Government. It could send a clear message to autistic people as well as public bodies in Wales that autism is a policy priority in Wales. This legislation is about giving autistic people a level playing field and getting the basic things right.

We were pleased to have contributed to the previous two consultations – both on the development of the content of the Bill and the subsequent draft Bill. This included holding a number of focus groups across the country with our members and supporters, many of whom are autistic adults themselves. The vast majority of those who took part in focus groups and who engaged in the consultation process supported autism legislation. In a report that we published in 2016, nearly 90 per cent of those who responded to our survey said that autism legislation is needed.

Meeting the needs of autistic people

We are pleased that the Bill covers both children and adults as autism is a lifelong disability. In our view the Bill is further strengthened by specifically mentioning the need to provide help during the transition between childhood into adulthood which should help ease the move between children's services and adult services.

The original Action Plan recognised the need for early diagnosis and further actions to improve waiting times through neurodevelopmental teams where announced in 2015. The refreshed action plan that was published in November 2016 introduced a new 26 week waiting time from referral to first assessment for children and young people.

However, we know that this isn't being met across Wales. According to the Hywel Dda Health Board the waiting time from referral to first assessment for the neurodevelopmental team in May 2018 was 18 months. Anecdotally, parents in Pembrokeshire in particular have told us that the actual waiting time is much longer. Furthermore one of the recommendations of the Children, Young People and Education Committee's 'Mind Over Matter' report published earlier this year was that 'the Welsh Government develop an immediate recovery plan for neurodevelopmental services in Betsi Cadwaladr to address unacceptably long waiting times faced by over a thousand children and young people.' Relevant data for the neurodevelopmental teams in the five other Health Boards is not currently available and so we do not know if the needs of autistic children and young people are being met. This is despite a commitment in the refreshed Action Plan that Health Boards should report a 26 week waiting time from referral to assessment by March 2017.

We know that getting a diagnosis can be the key that unlocks support and services for autistic people and welcome the proposal to link to the relevant Quality Standard issued by the National Institute for Health and Care Excellence (NICE). We welcome the inclusion in the Bill of the need to ensure that support is in place regardless of whether a person has a diagnosis, and that support should include wider family.

We therefore welcome the certainty in the proposed legislation gives around the diagnosis process in its entirety.

We welcome the fact that the Bill seeks to address the wider needs of autistic people including support around meeting employment and housing needs. More than half (55 per cent) of autistic people who responded to our 2016 survey said that they'd like more support around employment and only one in ten were in full time paid employment.

Recent development in services to address the needs of autistic children and adults are welcome, particularly the creation of Integrated Autism Services in each Health Board region. These teams are best placed to deliver many of the provisions contained in the Bill and therefore the legislation supports the role of these new services and is designed, we feel, to help ensure they can become embedded in local health and care services. We feel that this would be better than the Integrated Autism Service having to be reliant on short-term funding up until 2021.

Similarly, while some good work has been done in the development of awareness resources and training, uptake in accessing these has in our view been too slow and is inconsistent across the country. For example, not all local authorities are taking up the 'Learning with Autism' programme for schools. And since the scheme was extended in September 2017, only three secondary schools have achieved the 'Learning with Autism Award.'

We believe that legislation should clearly set out which professionals need what levels of training to ensure that autistic people are supported by professionals who understand them.

Current initiatives recognise the importance of collecting the necessary data to plan future support and services. For example there is a requirement on Regional Partnership Boards to include autism and learning disabilities as a key theme in regional plans. However, this is difficult as very little data

on autism is collected in practice and existing plans focus heavily on learning disabilities. Making the data collection mandatory through legislation will make sure that services understand that this is not just a nice to have and give strength to the hand of Regional Partnership Boards and other public services to ask for the data.

In our view, one opportunity in this legislation in ensuring that autistic people's needs are met is by offering an opportunity to embed the necessary training for relevant professionals while obtaining their initial professional qualification and through subsequent continuous professional development. The aim here is not to make things more onerous or difficult for professionals but to provide them with support and clarity, for example, through access to the right training for the right professionals. Professionals we talk to say they want this training and autistic children and adults should at the very minimum expect to be supported by professionals who understand them.

Protecting and promoting the rights of autistic people

As stated on the face of the Bill, this legislation makes provision for meeting the needs of children and adults with autism spectrum disorder in Wales and protecting and promoting their rights. This is consistent with the social model of disability. We believe that this will ensure that societal barriers faced by autistic people are removed. Training and the awareness campaigns are examples of this and we welcome the inclusion of both of these elements in the Bill. Similarly, the Bill makes provision in relation to social issues such as housing and employment. We welcome the ambition in the Bill to look at an autistic person in a holistic way throughout their lifetime as well as the needs of their families and careers.

We note the specific reference in the Bill to have regard to the UN Principles and Conventions. This would bring this piece of legislation in line with the duties on co-existing legislation including most recently the Social Services and Wellbeing Act, and the Additional Learning Needs Act.

We welcome the ambition in the legislation to enable autistic people to live as independently as possible through ensuring that relevant bodies ensure the rights of autistic people to access the provisions listed in section 2 (1) (g). While the list is not limited we particularly welcome the inclusion of social inclusion.

We know from our own research that one of the main barriers facing autistic people in particular is social isolation. For example, nearly four of every five autistic people (79 per cent) who responded to one our surveys said that they felt socially isolated.

We also note the specific mention in the Bill that autistic people should be able to access Welsh Language Services. This combined with the Welsh Government's Active Offer framework strengthens the rights of autistic people to access services in the language they choose.

Autism is a spectrum condition. All autistic people share certain difficulties, but being autistic will affect them in different ways. This Bill will ensure that where autistic people don't fit into current existing structures, local services will be under a duty to make sure there is a pathway for them to get the support they are entitled to, helping create a level playing field for autistic children and adults. Furthermore we welcome the explicit duty in the Bill that adults with autism cannot be denied access to services because of their IQ. This will make it clear to services that the needs of autistic people across the spectrum need to be identified and met.

We recognise that the Bill links to the WHO definition of autism and NICE guidelines and Quality Standards. This means that if and when our understanding of autism improves and develops, any

changes made to the WHO definition or NICE guidelines will be reflected in the interpretation of the Bill, and its subsequent guidance and we welcome its inclusion.

We are also pleased that the Bill requires an independent report on the autism strategy, including its ongoing implementation and progress. Furthermore we particularly welcome the requirement to reflect on recommendations made by the independent review. Although the Welsh Government's Action Plan has been evaluated, recommendations have not always been taken on board or implemented in the development of support. This means that many of the issues autistic people face now are exactly the same as they were when the original action plan was first developed in 2008 and which this Bill seeks to address. Examples include getting a timely diagnosis, collecting data for planning services, raising awareness, and training for practitioners.

Barriers and unintended consequences

The Bill is clear that a diagnosis shouldn't prevent support from being made available either for the autistic person themselves or their families and carers, from the point at which their needs first become apparent. Support should be available regardless of a diagnosis.

As currently written, the Bill says that the waiting time from which a referral for diagnostic assessment of autism is made and an initial diagnostic appointment should be no longer than 13 weeks. This is in line with NICE guidelines and has been developed by experts, including clinicians and commissioners, as well as autistic people, and their families.

Welsh Government already base many of their guidelines for autism provision on NICE standards, such as the use of multi-disciplinary teams. This suggests that they are already content with the NICE evidence base. This Bill seeks to ensure full compliance with the NICE recommended timeframe.

This isn't about taking up resources to focus only on diagnosis at the risk of not being able to provide other pre and post diagnostic support. The Bill is clear that a diagnosis shouldn't prevent support from being made available either for the autistic person themselves or their families and carers, from the point at which their needs first become apparent. Support should be available regardless of a diagnosis.

The Welsh Government has had an autism Action Plan in place for the past ten years. There is no evidence to suggest that these provisions have privileged autism above other conditions or are responsible for demands for other condition-specific policy.

Autism legislation already exists in Northern Ireland and in England. There have been specific challenges in implementing the Northern Ireland Act and the suspension of the Assembly and wider political issues have also had an impact on the legislation. In addition, the Act hasn't made as much impact as we would have liked because it didn't result in legally binding duties for local delivery bodies in the same way as the England Act.

Where the England Act has made significant impact has been around making sure that there is a pathway to diagnosis in every area. In 2016, a survey of local authorities found that only three local authorities reported not having an adult diagnostic pathway. This simply wasn't the case before the Act and one of the reasons we argued for it.

Before the Act, our autism services directory could only identify 14 NHS teams/individuals who diagnosed adults in the whole of England. There is also clearer 'infrastructure' at local level in terms of local leadership and local planning, including an autism lead in more than 90 per cent of local authorities.

It is also important to remember that we are not suggesting taking the England Act and the Northern Ireland Act and implementing them in Wales. From the Northern Ireland Act, we learn that we need clear duties on local public services to deliver. In terms of the England Act we want to make sure that the Wales Act is all ages.

Notably, despite the England and NI Act being in force since 2009 and 2011 respectively, there hasn't been a recognised link between this and campaigns for other condition-specific legislation.

As mentioned above we welcome the proposal in the legislation to address the barriers facing autistic adults in accessing services because of their IQ.

Financial implications

The Explanatory Memorandum is clear in where costs would occur. A net initial cost of around £7million is estimated. However, this needs to be measured against the cost effectiveness of current provision, resource and policy. It is also anticipated that there will be longer term savings due to the effective identification and support of individuals with autism.

The Explanatory Memorandum also states that 'There is little information in the public domain to estimate the current provision and future plans with regard to both the administrative costs of providing services to people with ASD... The Welsh Government was unable to provide specific information regarding the cost of the status quo.' It's therefore difficult to estimate the current costs of provision in its entirety due to a lack of reliable data, which is something the Bill seeks to address.

While we recognise that there will be some cost involved in introducing and implementing legislation, we believe that introducing autism legislation will not result in significant burdens. This must also be balanced against the cost of not intervening and the economic impact of having to access acute services.

Economic modelling in England by the National Audit Office showed that identifying and supporting a relatively small number of autistic adults would bring about significant cost savings to the public purse. In their model, they suggested that if just a 14 per cent of the autistic adult population were identified and supported, the savings that could be made would be £5,000 per 1,000 working age population. In Wales, this could mean that a 14 per cent identification and support rate would save £10 million a year to the public purse in Wales. These figures from the NAO are from 2009 and need refreshing and updating for a Welsh context, but do indicate that significant savings can be made from the proper identification and support for autistic adults.

Subordinate legislation

We are content with the affirmative procedures to make subordinate legislation in the three areas listed in Part 2 of the Explanatory Memorandum.

Conclusion

As mentioned above, 10 years of the autism Action Plan hasn't achieved the necessary changes to the lives of autistic people in Wales. We believe that changes that will make a tangible difference are mandatory. Legislation is supported by our members and supporters and the overwhelming majority of the hundreds of responses to both the consultation on both the development and the draft autism bill. The Bill has therefore been shaped by autistic people who will be directly affected by it. We believe that legislation will give autism support parity with other existing support provided to

those with learning disabilities and mental health, whilst ensuring better outcomes for autistic children and adults.

In drafting our comments we have done so based on the experience of learning from what works and what hasn't worked so well in other countries that have implemented autism-specific legislation. It's also important to note that this is a Wales bill and should be fit for purpose for the benefits of autistic people in Wales.

Pwyllgor Iechyd, Gwasanaethau Cymdeithasol a Chwaraeon
Health, Social Care and Sport Committee
HSCS(5)-26-18 Papur 2 / Paper 2

Written submission to the Health, Social Care and Sport Committee

Dr Duncan Holtom, Head of Research, People and Work

This response draws primarily upon our evaluation of Wales' first ASD Strategic Action Plan (ASD SAP) (WG, 2016)

<https://gov.wales/docs/caecd/research/2016/160218-evaluation-autistic-spectrum-disorder-strategic-action-plan-en.pdf> and

the ongoing evaluation of the Integrated Autism Service (IAS) and refreshed autism strategy (WG, 2018) <https://gov.wales/statistics-and-research/evaluation-integrated-autism-service-autistic-spectrum-disorder-strategic-action-plan/?lang=en>

General principles of the Autism Bill

An autism strategy: Evaluations of the original (WG, 2016) and refreshed autism strategies (WG, 2018) demonstrate that many children and adults with autism (and also their families), have unmet needs, so there is a need for action. Without a national strategy, there is a danger that action to meet those needs will be piecemeal, inadequate and inconsistent. The evaluation of the first autism strategy (WG, 2016) identified widespread support for having a national strategy, and also highlighted how having such a strategy had raised the profile of autism. However, it also identified weaknesses in the original strategy (e.g. a lack of clear prioritisation; and weaknesses in the infrastructure for delivery/implementation of the strategy); weakness which the revised strategy set out to address.

Neither evaluation examined the question of whether there needed to be a legal requirement to publish a strategy, in order to “secure a measure of permanence and sustainability in care and support services of people with autism”. (p5 of the Explanatory Memorandum).

Assessment and diagnosis: The evaluation of the original autism strategy (WG, 2014) highlighted the importance of getting a diagnosis to adults with autism and to the parents and carers of children with autism. Diagnosis provides insight and understanding of the difficulties people with autism and their families face and,

particularly for children, can improve access to services¹ and provision. The evaluation of the original strategy (WG, 2016) highlighted improvements in assessment and diagnosis for both children and adults in some areas. However, it also identified considerable inconsistency in practice across Wales, with long waiting lists in some areas; an excessive reliance upon individuals with an interest in and commitment to autism (which contributed to the fragility of services); and, in some areas, a lack of clarity about referral pathways.

The interim evaluation of the Integrated Autism Service (IAS) and refreshed autism strategy (WG, 2018) confirms the need for action to strengthen assessment and diagnosis services as well as enhancing the sustainability of services; minimising inconsistencies in provision across Wales; and establishing clear referral pathways.

Although it is still too early to measure the effectiveness and impact of the IAS, the interim evaluation (ibid.) identifies encouraging evidence that the establishment of an IAS in each region will strengthen services; improve assessment and diagnostic practice for adults² (in line with NICE guidelines); reduce inconsistencies across Wales and establish clear referral pathways. The evidence for improvement is strongest for adults diagnosed and referred by the IAS, and weaker for those assessed and diagnosed by learning disability or mental health services (the intention is that the IAS will support improvements in these services, but it is too early to assess likely impact). The interim evaluation (ibid.) also identifies that the IAS has increased the profile of assessment and diagnosis within Local Health Boards (and Regional Partnership Boards) and markedly improved accountability for provision for those referred and diagnosed by the IAS. However, the evaluation (ibid) also identifies fears that demand for assessment and diagnosis could exceed the capacity of the new IAS and/or side-line or undermine the other important aspects of the IAS's work, such as post-diagnostic support.

Data collection: The evaluation of the original autism strategy (WG, 2016) evaluated work by the local ASD infrastructure to identify the number of people with

¹ In contrast, the lack of services for adults, meant the impact of diagnosis upon adults' access to services was much more limited.

² The interim report did not consider children's neurodevelopmental services (this will be considered as part of the final report, due in January 2019).

ASD in their area and their needs. The evaluation identified the need to improve understanding of the needs of people with autism. However, it also identified that:

- efforts to create databases of individuals with autism proved extremely difficult, due to the fragmentation of data across multiple databases (e.g. health, education and social services);
- the databases that were created were often incomplete and could rapidly become out of date, as people's needs changed over time; and
- the databases that were created were of limited value to commissioners of services (and little used).

The evaluation (ibid.) considered how data on the numbers of people with autism in a given area could be used in the commissioning cycle. It identified that:

- for targeted services, estimates of the numbers of people with autism in a given area, based on a 1% prevalence rate, coupled with existing evidence on the needs of people with autism, would normally be sufficient to inform service planning. For example, detailed data on the numbers of people with autism in a given area would not be required to identify the need to provide information and training and support for people with autism in that area.
- for specialist services, there was a need for rich data on individual people's needs and aspirations (data rarely captured in the databases produced) to inform the commissioning of often bespoke services. Structures such as complex needs panels were felt to be proved reasonably effective in collecting this data (ibid), although other research (see e.g. Holtom and Sophocleous, 2016)³ suggests that there may be a case for improving data collection and analysis to inform commissioning of these specialist services; and
- for universal, targeted and specialist services, there was a strong case for collecting more qualitative data on the experiences of different groups of people with autism, in order to inform the 'review' phase of commissioning (and service development) (WG, 2016). For example, if information and training and support is provided, it is important to understand how effective it is.

³ <http://www.wwcp.org.uk/wp-content/uploads/2017/02/complexneedsfinalmps.pdf>

As a consequence, the evaluation (ibid). concluded that the only real value in collecting data on the total numbers of people diagnosed with autism in a particular area, was as a measure of the extent to which autism was being recognised and diagnosed in that particular area. It is important to note that this analysis relates to the collection of quantitative data to create databases, and that for example, there is a real value in collecting qualitative and quantitative data on people's expectations and preferences, in order to help develop and design more person centred services.

Holistic services: The evaluation of the original autism strategy (WG, 2016) identified gaps in services for people with autism, particularly for adults who were not eligible for support from mental health or learning disability teams.⁴ This lack of services contributed to poor outcomes (e.g. in relation to employment) and poor experiences for adults with autism. In some cases, following transitions from education, the loss of the structure education provided, difficulties finding employment and the absence of support services, meant that their level of disability increased, when, for example, social skills learnt in education were lost as result of withdrawal and social isolation.

The interim evaluation of the IAS (WG, 2018) identifies consistent support from stakeholders for the IAS model as part of the means for filling this gap in services. The IAS is not a panacea though, and cannot and should not seek to address all gaps or weakness in services.

Information: The evaluation of the original autism strategy (WG, 2016) identified how the local 'ASD Infrastructure' (most notably ASD leads and groups) had improved mapping of services and dissemination of this information. However, this remained patchy across Wales; it proved difficult to keep directories up to date; and the evaluation identified that parents and carers consistently reported difficulties identifying support services. To a large degree, this was caused by the absence of services, rather than weakness in service mapping and/or dissemination of information about services. However, there was also widespread frustration with the systems and processes for accessing care and support for children and adults with

⁴ Autism is neither a learning disability nor mental health disorder, and the evaluation also identified weakness in mental health and to a lesser degree, learning disability services. Nevertheless, those able to access support from these services, were generally able to access more support than those who were not eligible or did not need support from mental health or learning disability services.

autism, which were felt to be complex and difficult to understand.⁵ Feedback from parents and carers interviewed as part of the ongoing evaluation of the refreshed strategy paints a similar picture.

Parents and carers frequently call for very responsive information and support, most commonly someone with whom to talk through their immediate problems and concerns. Because autism is a lifelong condition and needs can change, as for example, people's circumstances change. Therefore, whilst training and time limited support can help people learn new skills and knowledge, and was valued, people also often want access to support when they needed it (e.g. in a crisis or simply when they encounter a new problem). In the absence of responsive support services, many people rely upon more informal networks (e.g. talking to support groups and/or posting questions on forums) to access information and advice. These informal networks are very much valued, but there are risks that the information and advice given may not be evidence based.

Training: The evaluation of the original autism strategy (WG, 2016) identified the need for training to improve the responsiveness and sensitivity of services and enhance the experiences/wellbeing of people with autism and their parents/carers. It identified the provision of training as a key achievement of the original strategy, but also highlighted the scale of the challenge (e.g. in terms of the numbers of people to be trained). Other research, such as an Assessment of SEN Workforce requirements (WG, 2015)⁶, suggests a responsive training and professional development/learning model in which, for example, additional learning is undertaken and/or advice and support is provided when needed, may be required to complement initial training.

The interim evaluation of the IAS (WG, 2018) highlights the important role the IAS is expected to play in providing training and support for services.

⁵ The evaluation identified that “the reasons why people cannot access services and experience such high levels of stress are complex. In part they reflect informational barriers, where carers do not know what services are available, or do not realise they would be entitled to support. However, they also reflect institutional barriers, including the absence of appropriate services, thresholds for eligibility for interventions (rationing access to services), cultural divides between professionals and users and carers, which can lead to misunderstanding and even conflict and a lack of awareness or understanding of ASD” (p 82, WG, 2016).

⁶ <http://dera.ioe.ac.uk/22888/1/150330-sen-en.pdf>

Potential barriers

The evaluation of the original ASD SAP highlighted the failure to allocate resources to achieve many of its objectives as a significant weakness. This appears to apply to the Autism Wales Bill too.

Unintended consequences

Because assessment and diagnosis is perhaps the easiest area to legislate and set clear targets for, there is a danger that the Bill means this area is privileged over other important areas. Although (as outlined above) assessment and diagnosis is important, the evaluation of the original autism strategy (WG, 2016) identified the often limited value of assessment and diagnosis without post-diagnostic support. The evaluation of the IAS (WG, 2018) identified the risk that the IAS could struggle to meet demand for assessment and diagnosis and increasing pressure and accountability around assessment and diagnosis, could mean resources intended for post-diagnostic support, are reallocated to assessment and diagnosis.

More broadly, given austerity and increasing demand for services as result of demographic changes and rising expectations (see e.g. Williams, 2014) ⁷ simply creating new duties in relation to autism without increasing resources, risks stripping or starving other important areas of resources.

Financial implications of the Bill

An autism strategy: In considering the cost of a strategy, it will be important to also consider the costs of evaluating the strategy.

Duty to act: the costs of effective action/support in areas like employment, where the evaluation of the original autism strategy (WG, 2018) suggests there are large gaps in support, are likely to be considerable. The costs of existing projects like Engage to Change may provide some indication of likely costs.

⁷ <https://gov.wales/topics/improvingservices/public-service-governance-and-delivery/report/?lang=en>

Training: The evaluation of the original ASD SAP highlights the scale of the challenge in relation to training, and the costs here could be considerable, depending on how broadly the definition of “key staff” is drawn.

Data collection: As noted above, the evaluation of the original autism strategy (WG, 2018) highlighted the difficulties of collecting data on the numbers of people with autism, given the fragmentation of this data across different IT systems (e.g. health, education and social services). This suggests that the costs of setting up and populating a database by drawing upon data from different systems/databases, may not be as “minimal” as the Explanatory Memorandum assumes.

DRAFT

Agenda Item 4, Wasanaethau Cymdeithasol a Chwaraeon

Health, Social Care and Sport Committee

HSCS(5)-26-18 Papur 3 / Paper 3

Autism Bill Consultation response from Dr Dawn Wimpory, Consultant Clinical Psychologist – Lead for ASD (BCUHB) and Lecturer (Bangor University)

I have held an autism-specific clinical and research joint post for the last 3 decades and have been invited to present evidence to the scrutiny committee for this bill on 3.10.18. (I was also asked by the Division of Clinical Psychology, for the British Psychological Society, to represent them in their response to this bill but had to decline as I shall be abroad on the date that my presence was required for that.)

- 1) The general principles of the Autism (Wales) Bill and the extent to which it will make provision for meeting the needs of children and adults with Autism Spectrum Disorder (ASD) in Wales and achieve the aim of protecting and promoting their rights

I think the general principles of the bill are sound and that they will help Wales to meet the needs of children and adults with ASDs, and achieve the aim of protecting and promoting their rights, more than previous strategies have been able to do. I was on the original strategic group for the first ASD action plan and have seen the level of impact of this and subsequent action plans over the last decade; as a result I think it is appropriate to bring in legislation to address the issues of concern.

- 2) Any potential barriers to the implementation of the provisions and whether the Bill takes account of them

I think that staffing and their organisation may represent potential barriers to the implementation of the provisions in the Bill in relation to waiting list times. Specifically this may include initial difficulty with commencing ASD assessments within 3 months of referral. However, I think it is inappropriate that Wales should have guidance of 26wk maximum Waiting List (WL) time (e.g. for children) whilst NICE guidelines from England specify 3months for adults and children. It seems appropriate that any ASD legislation for Wales at least matches NICE-issued guidelines. I think it is positive that individuals who appear inappropriate referrals can be advised of this promptly and possibly redirected to other services by clinicians.

I am concerned that discussions of the this Bill have been erroneously representing the 13 wks until *commencement* of assessment as 13 wks until a *diagnosis* should be made (this appeared to be how it was represented by the new WLGA national ASD Lead at a recent regional IAS strategic meeting and subsequent written communication reflected this misunderstanding). These are very different in terms of the implications/resources required for each and

I would be very disappointed if confusion around this issue influences receptiveness to the bill on a larger scale.

Currently, waiting lists, e.g. in children's ND services, are being clogged by inappropriate referrals that tend to be held there for too long. After such cases have waited for an unreasonable amount of time, there is a tendency to feel that they are 'owed' an ASD assessment even when other indicators show that this is not the most appropriate use of resources. I think that removing such cases from ASD WLs early on, as advocated in the bill, will ultimately reduce pressure on WLs and therefore proved helpful. Of course additional resources may well be necessary, especially initially, in order to assist in this reorganisation of how services/WLs are organised.

I also think it is important that clinicians can focus half their efforts on supporting families of clients with ASD, rather than be consumed by assessment work - I am not yet certain that the bill addresses the need to protect intervention time within services for these clients.

I welcome the bill's position in requiring services to record ASD diagnoses. Under my own direction, BCUHB has successfully collected and collated such diagnostic information for children over the last 6yrs and is therefore unique in Wales in being able to identify accurately whether or not research-supported internationally-recognised prevalence rates are being adhered to, or exceeded or failing to be reached. BCUHB's Autism Module enables examination of such figures within each of the 3 constituent areas of BCUHB and over the HB as a whole. Such figures are absolutely essential in Wales being able to identify whether diagnoses are being made at appropriate levels.

It is both inappropriate for ASD diagnoses to be missed and for people without ASD to be erroneously diagnosed as having ASD. These are real dangers and can only be addressed through accurate data recording and analysis in a constant manner. BCUHB's database, conceived originally by WG, as a pilot for the whole of Wales, has demonstrated that such data can be efficiently and routinely recorded/analysed. I understand concerns from other services that this may be an impossible task but 6yr's experience with our ASD database proves otherwise. Software for this database, via CCH2000's database system of electronic records, already exists throughout NHS Wales. CCH2000 is currently migrating to an upgraded system, CYPRIS. ABHB are the first Health Board to use the Autism Database Module on CYPRIS.

3) Whether there are any unintended consequences arising from the Bill

My experience of successive ASD all-Wales strategies is that they have not drawn attention away from, eg, ADHD, so I do not envisage this as an unintended consequence of the Autism Bill. However, IF diagnoses of ASD were to proceed without prevalence levels being checked (as the Bill sets out to avoid through the data collection referred to above) then there might be a

risk that resources are not allocated appropriately to the correct service users. But the latter risk already exists without the Autism Bill anyway.

It would seem essential that the bill is applied to private services as well as to statutory services so that the former adhere to standards required of the latter; this is particularly important to help address any over-diagnosis of ASD in private provision, possibly through less thorough assessment strategies.

4) The financial implications of the Bill (as set out in Part 2 of the Explanatory Memorandum)

My understanding of the bill is that it has been supported through appropriate research and reviewing of available information, including financial elements; I particularly welcome the involvement of Professor Martin Knapp at LSE as appropriate international expert in this aspect of ASD. The data collection/analysis elements of the bill are based on experience of 6yrs piloting an ASD Database Module that was piloted by WG in anticipation of All Wales roll out.

5) The appropriateness of the powers in the Bill for Welsh Ministers to make subordinate legislation (as set out in Chapter 6 of Part 1 of the Explanatory Memorandum)

Unlike NICE guidelines that advocate both ICD-10 and DSM5, the Bill employs just DSM5, this seems regrettable as there have been some criticism of this system (e.g. that it may be too influenced by insurance issues in US). It seems surprising, and perhaps too bold, that ministers will be able to extend the client group to whom the Autism Bill applies, in addition to ASD in the future.

I welcome a bill that identifies the unique difficulties and challenges presented by autism to services and their uses. It seems too wide that ministers might expand the neuro-developmental conception of service users to whom the bill might apply in the future. As a related example, the current strategic inclusion of ADHD child referrals along with those for ASD has been not been helpful in my experience. This is because approximately half of those children with diagnosed with ADHD have an emotional or environmental basis for their diagnosis (as outlined by Dr. Elspeth Webb, Consultant Paediatrician, ND national presentation), whereas this is not the basis of ASD. Clinicians working with each group of children therefore require a different skill set and, in my experience, services for children with ASD can be slowed down by the contrasting needs and challenges presented by those with ADHD.

Hopefully ministers would not be defining the boundaries of ASD. Instead it seems appropriate that research-informed leaders of the ASD clinical field should take that responsibility, with research-evidenced prevalence figures in mind. As a disability, even in high functioning individuals, ASD should only be

diagnosed (through the NHS or private services) where there is a level of impairment that warrants clinical recognition.

Dr Dawn Wimpory

Consultant Clinical Psychologist – Lead for ASD (BCUHB) and Lecturer

([REDACTED]) ([REDACTED])

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 potentially 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 understood 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. Support

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. Other Interventions

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. Education

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. Welsh Language services

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.

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

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 Isit 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. Raising Awareness

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

8. Equality and human rights impact: Individuals with a Learning Disability

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. Data Collection

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. Service User Consultation

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.

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Cyfeiriadau / References

- ASDinfoWales. <https://www.asdinfowales.co.uk/home>
- Autism: recognition, referral, diagnosis and management of adults on the autism spectrum (2012). London: National Institute for Health and Clinical Excellence. The management and support of children and young people on the autism spectrum. (2013). London: National Institute for Health and Clinical Excellence
- Baird, G. et al. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *The Lancet*, 368, 9531, 210-215.
- Brugha, T. et al (2009). *Autism spectrum disorders in adults living in households throughout England: report from the Adult Psychiatric Morbidity Survey, 2007*. Leeds: NHS Information Centre for Health and Social Care. <http://www.hscic.gov.uk/catalogue/PUB01131>
- Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X-H. & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism*, 13, 4, 375-387. <https://doi.org/10.1177/1362361309105658>
- Foran, D., Hoerger, M., Philpott, H., Walker Jones, E., Hughes, J.C., Morgan, J. (2015). Using applied behaviour analysis as standard practice in a UK special needs school. *British Journal of Special Education*, 42, 1, 34-52. <https://doi.org/10.1111/1467-8578.12088>
- Gillberg, I.C. & Gillberg, C. (1996). Autism in immigrants: a population-based study from Swedish rural and urban areas. <https://doi.org/10.1111/j.1365-2788.1996.tb00599.x>
- Hastings, R.P. (2002) Parental stress and behavior problems of children with developmental disabilities. *Journal of Intellectual and Developmental Disability*, 27, 149-160. DOI: 10.1080/1366825021000008657
- Hastings, R.P. & Brown, T. (2002). Behavior Problems of Children With Autism, Parental Self-Efficacy, and Mental Health. *American journal of mental retardation: AJMR* 107, 3, 222-32. DOI: 10.1352/0895-8017
- Hastings, R.P., Kovshoff, H., Ward, N.J., degli Espinosa, F., Brown, T. & Remington, B. (2005). Systems Analysis of Stress and Positive Perceptions in Mothers and Fathers of Pre-School Children with Autism. *Journal of Autism and Developmental Disorders*, 35, 5. DOI: 10.1007/s10803-005-0007-8
- Hutchings, J., Pearson-Blunt, R., Pasteur, M-A., Healy, H. & Williams, M.E. (2016). A pilot trial of the Incredible Years® Autism Spectrum and Language Delays Programme. *Good Autism Practice*, 17, 1, 15-22.
- Jones, E., Perry, J., Lowe, K., Felce, D., Toogood, S., Dunstan, F., Allen, D. Pagler, J. (1999). Opportunity and the promotion of activity among adults with severe intellectual disability living in community residences: the impact of training staff in active support. *Journal of Intellectual Disability Research*, 43, 3, 164-178
- Lord C, Rutter, M., Goode, S., et al. (1989). "Autism diagnostic observation schedule: a standardized observation of communicative and social behavior". *Journal of Autism and Developmental Disorders*, 19, 2, 185–212. DOI:10.1007/BF02211841
- Lord, C., Rutter, M., & Le Couteur, A. (1994). Autism diagnostic interview-revised: A revised version of a diagnostic interview for caregivers of individuals with possible

- pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, 24, 5, 659-685.
- Matson, J.L. & Nebel-Schwalm, M. (2007). Assessing challenging behaviors in children with autism spectrum disorders: a review. *Res Dev Disabil.* 28, 6, 567-79. Epub 2006 Sep 14.
 - Matson, J.L., Sipes, M., Fodstad, J.C., Fitzgerald, M.E. (2011). Issues in the management of challenging behaviours of adults with autism spectrum disorder. *CNS Drugs*, 25, 7, 597-606. DOI: 10.2165/11591700-000000000-00000.
 - Matson J. L., Rivet T. T. (2008) Characteristics of challenging behaviours in adults with autistic disorder, PDD-NOS, and intellectual disability. *Journal of Intellectual and Developmental Disability*, 33, 4, 3, 4, 323-9. DOI: 10.1080/13668250802492600.
 - Mazzone, L., Ruta, L. & Reale, L. (2012). Psychiatric comorbidities in asperger syndrome and high functioning autism: diagnostic challenges. *Ann Gen Psychiatry*. 2012; 11, 16. DOI: 10.1186/1744-859X-11-16
 - McClintock K., Hall S., Oliver C. (2003) Risk markers associated with challenging behaviours in people with intellectual disabilities: a meta-analytic study. *Journal of Intellectual Disability Research*. 47, 6, 405-16
 - National Autistic Society. (data retrieved: 14/09/2018). <https://www.autism.org.uk/about/what-is/myths-facts-stats.aspx>.
 - National Autistic Society. (data retrieved: 14/09/2018). <https://www.autism.org.uk/services/community/family-support/earlybird.aspx>
 - Pickles, A., Le Couteur, A., Leadbitter, K., et al. (2016). Parent-mediated social communication therapy for young children with autism (PACT): long-term follow-up of a randomised controlled trial. *The Lancet*, 388, 10059, 2501-2509. [https://doi.org/10.1016/S0140-6736\(16\)31229-6](https://doi.org/10.1016/S0140-6736(16)31229-6)
 - Research Autism. 2016. <https://www.researchautism.net/publicfiles/pdf/essential-guide-autism-challenging-behaviours.pdf>. March 2016. <http://tinyurl.com/gu87z7n>. Retrieved: 14/09/2018
 - Totsika V., Hastings R. P. (2009) Persistent challenging behaviour in people with an intellectual disability. *Current Opinions in Psychiatry*. 22, 5, 437-41
 - Tromans, S., Chester, V., Kiani, R., Alexander, R. & Brugha, T. (2018). The Prevalence of Autism Spectrum Disorders in Adult Psychiatric Inpatients: A Systematic Review. *Clin Pract Epidemiol Ment Health*, 14, 177–187.
 - Welsh Government (2012). More Than Words. Welsh Government strategic framework for Welsh language services in health, social services and social care. <https://gov.wales/topics/health/publications/health/guidance/words/?lang=en>
 - Webster-Stratton, C. (1991). Dinosaur social skills and problem-solving training manual. Unpublished manuscript
 - Webster-Stratton: *The Incredible Years* (2013). <http://www.incredibleyears.com/>
- The SCAMP studies: <http://www.researchautism.net/research-autism-our-research/research-autism-projects-completed/scamp>

Agenda Item 7

By virtue of paragraph(s) vi of Standing Order 17.42

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