

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

Negative. The current arrangements fall short as many LAs can choose to do nothing, inform no-one, provide no services for adults, nor have any numbers or information available. In my personal experience the current arrangements are totally ineffective here in Gwynedd. It's as if the ASD SAP never existed for adults with Autism in Gwynedd.

**We want the Bill and the new service to resolve** the issue of no adult services in some areas necessitating more monitoring of these LAs than of those who have already begun to make improvements following the ASD SAP.

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

We definitely need legislation providing statutory guidance to change this. If the legislation requires the Welsh Government to set up and publish a strategy, what legislation will there be to enforce that strategy county by county if it is only a strategy? Local Authorities **MUST** be required to act under statutory guidance else they will continue to ignore the strategy or work around it as some LAs have been and still are doing.

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

I would want to see a rigid framework with no ambiguities. Cover all the main points i.e.

- i. Besides the barrier to services by way of IQ, there are other barriers which also need addressing: age when requesting services, age when diagnosed, gender, diagnosed in England, not on any list, their post code or location in Wales, availability of a local service, location of an appropriate service, cost of an appropriate service over an inappropriate one, lack of information or contact etc.

- ii. As many details as are feasible again without ambiguities. There are too many ways of interpreting details, so we want it all sewn up so every LA & HB is bound by law to stick to the guidelines, something Gwynedd have a poor record of doing in my own experience.
- iii. Legislate that every LA must publish these details on their website, on asdinfo.wales website (and any other they think appropriate) to keep us all well informed of their progress and their services.

**We want the detail** in the legislation to remove all these barriers.

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

Consultation with organisations like the NAS and with other interested parties like those with Autism and parents, teachers, carers etc. which is likely to paint a truer picture than just figures from the LA or LHB. There must be contributions from the relevant departments in the Welsh Health Service and in ALL local councils, leaving out no-one. Councils and Health Boards should be obliged to reply within a specified time-frame giving reasons for their comments and/or omissions. Maybe their involvement at that stage would mean they would be more aware of the needs and more understanding of the finished document. There should be a **mailing list** of interested parties available at a local level to keep everyone informed and up to date. We should not have to keep asking (and getting no response).

**We want the new Bill** to make sure we as interested parties are consulted and kept informed.

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

**I believe the Bill should be reviewed** annually but that legislation should state at least biennially, and updated if and when necessary.

f) Do you have any views on how the 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?

Ask each local authority for numbers by diagnosis, gender, age etc. to maximise provision fairly across all these groups.

- i) Ask the service users first hand, autistic people, parents, carers, support workers. For this to happen of course you need that **mailing list** (as in d) so this is the number one priority. Publish details on the asdinfo.wales website with a link from each LA's website. If the ASD SAP is anything to go by there will be no local information or updates publicly available from some LAs including ours.
- ii) The person in charge of the new ASD Service locally should complete a questionnaire which asks exactly what has been done in each of the areas listed in the strategy, giving numbers of service users in a given service with dates diagnoses etc. to avoid anomalies and to help streamline service provision. They also need to attach the relevant costs to each new service they are implementing so WAG know exactly where the funds are going. WAG should then be able to give advice on any bad practice, suggesting or enforcing change if necessary.

Monitoring has not happened here but is extremely important to those of us who have been let down by our LA and LHB.

**The Bill must provide for regular monitoring of LAs and LHBs.**

### **Pathway to Diagnosis 14,15**

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

I have no experience of the diagnostic pathway so cannot comment on how easy it is.

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

We also need a pathway for adults and for all those already diagnosed but refused a service in the past or unaware of the services they may be entitled to whether or not those services are available locally.

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?

Most certainly YES. This should definitely be published, how else is anyone to know about it? There is a pathway following diagnosis but no pathway for those previously diagnosed and refused a service or unaware of the services available. There should definitely be a process where the information we require, until it is readily available on LAs websites, should be given in reply to a direct request? We should not have to request this through the FOIA where we are trickle fed over months and months of asking. Most of the answers being 'we do not have that information, or 'we cannot give it due to Data Protection' when all we want is basic information not names. How can we make the LA talk to us? They won't even turn round and say 'we don't know', or 'we don't have any of the services you require' they most often just ignore us. See also (f) & (h) above.

**The Bill must provide legislation** for information to be published and readily available to all.

#### **Delivery of Services 16,17,18,19, 20**

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

Completely insufficient. Services for adults with autism without an accompanying learning disability (i.e IQ over 70) in my area and probably others are none existent. Even after 9 years of the ASD SAP. I do not believe services for those with ASD and an LD are much better.

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

Do you agree that legislation should require statutory guidance? If so, does the following list cover the right areas to be included under the duties on LAs and LHBs?

Most definitely numbers (i) to (v) require statutory guidance.

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

I agree most emphatically that it is critical to have children diagnosed early

and provided with the necessary services to afford them a better future. But don't let adults with autism continue to be ignored, they deserve a chance in life too.

**We want the new Bill to ensure** adult services will improve alongside children's services.

(ii) The fact that assessment of the eligibility of children and adults for relevant services cannot be denied on the grounds of a person's IQ.

Although some Autism services for children in Gwynedd may have improved, from the point of view of adults with ASDs nothing had really changed in the 15 years we have been seeking support for our adult son after he failed to cope at university because of his Autism, having had educational and parental support up until then.

We believed the ASD SAP would change that but have been very disappointed to find our LA sadly lacking. They may now have changed their tactics from 'he is ineligible due to his IQ' to, and I quote "He is being supported for his mental health and not for his Autism", when we complained about the withdrawal of 60% of his support without reason or cause. The support though not exactly autism based was at least giving him some help while he had it. Do they really believe the two can be separated?

The extra funding through the ASD SAP ring-fenced for adults with ASD didn't appear to make any difference to adults with ASD in Gwynedd, whose Autism is still being ignored. Rather than gaps in services in Gwynedd there are no services for adults with autism spectrum conditions, even with an associated mental illness, if they do not have a co-existing learning disability in the IQ sense.

**So we wish for the new Bill to provide** certainty that services for adults with ASDs will be implemented alongside those for children? Specifically adults who are over 25, and/or diagnosed as children, and/or diagnosed outside of Wales, and/or never had ASD support, and/or been refused support, and/or don't have a learning disability in the IQ sense, and/or may have or may have had a mental illness, but who all need day to day support to make the same progress through life neuro-typical adults do and which autistic adults could also be capable of doing with the right support.

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

This will be an important step as in the past this transition has left a huge gap from having many educational support services and parental support to having nothing even to support the parent/care in his/her role.. This will surely also lessen the future demand on adult services as well as the demand on the health services for the parent/carer, and will also save money in the long term.

**We want the new Bill to stipulate** the delivery of consistent, continuous, compulsory support throughout transition to improve outcomes.

(iv) Other planning in relation to the provision of relevant services to children and adults with autism spectrum conditions

Begin the planning with real-time numbers of adults and children with ASCs in each LA. Your document assumes this has already been done in all 22 LAs through the ASD SAP but this did not happen here in Gwynedd.

**We want the Bill and the new service to resolve** the issue of no adult services in all areas necessitating more monitoring of these LAs than of those who have already begun to make improvements through the ASD SAP.

Whilst I understand each autistic person has differing needs, I think 'relevant services' has been and will continue to be misinterpreted as whatever generic services are already in place, however inappropriate or inadequate they may be for people with ASCs. Generic services have not and cannot provide the required services without more ASC knowledgeable staff, but have been totally relied upon to do so. So often we have been told of a current generic service which has specific ASC support, but this has always proved to be untrue. Some staff in Gwynedd in these generic services have an Autism title but have insufficient understanding of, and no training in ASCs so cannot adequately perform the role they have been given by the LA.

The Bill must ensure there is at very least a properly ASC trained person readily available in all generic services if generic services are to be relied upon at all.

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

This should begin with the ASC lead who should be available to speak to anyone who wishes more information about ASC services.

After a great deal of difficulty searching out the latest Autism lead for Gwynedd recently she does not reply to my emails, 5 so far, or to mine forwarded by previous ASC Leads. It appears she doesn't want to answer our questions about services as they have no services to offer so they just ignore us which is totally unacceptable. I am told by my son's care coordinator they are also ignoring her questions.

Shockingly after contacting a string of people to find who the ASC lead is in Gwynedd, all of whom redirected my emails to 'the lead'; and after I sent many direct emails over many months when I learnt her contact details, I eventually received a reply telling me (like all those I previously contacted) that she was not the lead but she would forward my email to the right person. The titles change, the names change, it seems no-one will take the responsibility to reply to our questions. There is no other ASC contact in Gwynedd LA that I can find.

**We want the bill to ensure** this person is accessible and accountable and perhaps even ASC trained.

Yesterday my son's care coordinator (social worker) told me ASC is not in her remit, it is not a social services issue but is NHS. She then went on to say my son is being supported because of his mental health not his autism so he is under the mental health team which comprises staff from social services and the NHS! She suggested asking learning disability for advice on suitable placements but of course they will turn him away because he has no LD in the IQ sense. We were led to believe this would change with the ASD SAP but it did not.

**We want the Bill to ensure** there is specific leadership for ASC services so each service can no longer just pass the buck to another, and that this person is also be accessible and accountable.

We would also like the following to be included:

(vi) **Information & Resources.** I am unable to find any ASD 'information and resources' here in Gwynedd. I was sent a basic leaflet explaining briefly what Autism is when I requested information re services. This was no help to me at all, there was nothing about services, nor a named local contact person. The information we require is not readily available anywhere, not on the Council website nor any other we have used.

Regardless of the Social Services Wellbeing Wales Act 2015<sup>4</sup> my LA have so far done no collecting or establishing of information, advice and assistance to people on the autistic spectrum, their families and carers, despite this being a statutory duty, so they will have to start from scratch.

Each and every authority must be held responsible for providing relevant, up to date information on their ASD services with contact details should we require them. We even had to ask to see the ASD SAP through the FOIA which took months and months of questions. Much of the information we requested was not even available through the FOIA, meaning they either don't have it or don't want to share it. Either way is unacceptable.

There must be a process where the information we require as interested parties, until it is readily available on the LA's website, should be given in reply to a direct request? LAs cannot be allowed to continue to ignore us.

**We therefore want the Bill to specify** how information must be provided and shared with the public in general and with ASD interested parties in particular.

(vii) **Time frame.** As Gwynedd, and maybe others too, will have further to go to 'catch up' with other Welsh Authorities in providing any services for adults with ASD, should we still be able to expect them to achieve the same results in the same time frame or will we have to wait another 15 years?

**We therefore want the Bill to stipulate** a given time frame in these cases.

(vii)

(viii) **Awareness raising** is sadly lacking here. My GP's surgery is full of leaflets regarding many different conditions but with no mention of ASCs and we have to rely on luck to find a GP, psychiatrist, social worker, mental health worker, care coordinator, dentist, etc. with any ASC knowledge.



**We also want the Bill to advocate** promoting more awareness among all medical professionals with training available to them.

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

Definitely. I believe there should be a statutory obligation for health boards and local authorities to compile a register of adults with autism with the consent of the autistic person (or their parent/carer as appropriate). If no consent is given, including him or her in the numbers of adults with autism should not be a problem. The register should also state which persons are receiving what type of service for reasons of accountability and future planning.

**The Bill must give a statutory duty** for LAs and LHBs to collect this data by whatever means are necessary. This should have begun with the ASD SAP but clearly has not happened in some areas.

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

What won't work is just asking each LA for their numbers because mine have told me (through the FOIA) they don't have any numbers, they don't keep the numbers of those turned away, they have no numbers by diagnosis, by age or gender, or by services. I'm sure they must have some but I fear they will be far lower than the reality.

I believe this to be a mammoth task yet it is imperative. Here are some Media ideas  
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- i) Start with the internet. Asdinfowales, National Autistic Society Wales, and other legitimate ASD and Aspergers websites. Many people with high functioning AS will want to get involved but may require incentive, appeal to their sense of doing something which is very important, maybe asking if they wish their name to be included in the credits.

Add links to all those I can find

Through the media ask interested persons, parents, carers, people with autism spectrum disorders to fill in a basic form to help you compile the database then email a more detailed questionnaire to them. I believe the NAS could advise and help here. Ask people to tell their friends on Social Media– Facebook and Twitter. Doesn't everyone use these today?

- ii) We quite often hear something about autism on the news. Ask your press office to get a piece on the Welsh news, and in local newspapers, about Autism and the need for a database and ask for help, but beware you may be inundated with replies.
- iii) Contact Autism and Aspergers websites and social groups. This may help discover some of the forgotten ones who have been turned away from services.
- iv) Contact heads of Mental Health & Learning Disability in each LA, and GP surgeries.
- v) You could even ask for volunteers from the higher functioning end of the spectrum to compile a local list by talking to others who they know.
- vi) Of course the problem with all these is verifiability and duplication:– Request permission from individuals through the questionnaires to
  - a) Either provide proof of their diagnosis, which could be the original letter of diagnosis, or a letter from their own GP, social worker, school learning support etc.
  - b) Or give permission for you to check their details against other databases, NHS, SS, school records etc. again stressing the importance of this task.

### **Training 21,22,23,24,25**

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

The current scope and effectiveness of training key staff seems not to have reached North Wales. In my experience of seeking support for my son I have yet to find any Social Services staff, or care and support staff or managers who have actually received any ASC training at all.

Answers to questions re their ASC training range from 'I would do any training they (heads of department) ask me to' to 'I don't have time to do any training'. Both these replies came from the same person, my son's social worker/care coordinator. When asked, all persons involved in my son's support say they have had no ASC training. It appears at the moment it is the responsibility of the support worker, social worker, care coordinator, to organise their own training, but when they all seem to be moved on after a year it is not worth them doing so. Of the many problems we have encountered in seeking appropriate support most are exacerbated by lack of staff ASC training from the top to the bottom. No-one will take responsibility for undergoing or encouraging support staff to undergo ASC training.

**We want the Bill to change this.**

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

Too much flexibility will again lead to some areas giving training while others continue to ignore it. Outcomes do need to be specified, maybe staff positions within the area of autism should be of minimum duration like 2 years for the training to be effective and worthwhile.

Outcomes should be identified. Achievements, successes and failures should be recorded in order to quantify results.

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

Key staff who work with all autistic people should be legislated to undergo ASC training. This should apply to all key staff working with all people with an ASC across the whole range of the autism spectrum not only those with an LD, and including those with a MH condition. I have it in writing from the MH team manager regarding my son 'we support his MH not his ASC'. This has to change the two cannot be separated. Complementary support for the ASC is also required. Without ASC training it appears this is not understood by anyone on his team.

**We want the Bill to legislate** that all key staff working with all people with ASCs must undergo ASC training as part of their regular training.

**Employment 26,27,28**

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

I am unaware if any training, awareness or employment support reached us in North Wales. I have been unable to find out anything from my Local authority regarding this. (Even through the FOIA). They will quote WAG but tell me no details of any local attempts or achievements.

The few schemes I have read about only support young people up to 25. There must be many more older people like my son who are still struggling to gain employment, including those who have been refused support for many years.

I do not know who would be giving the support to employers when there are so few, if any, fully trained ASC professionals in my LA.

It's a pity the obligation for all employers to employ a number of disabled people was withdrawn. If reintroducing that would need employment law to change then these are my suggestions –

- i) More awareness is given of the special contributions people with autism could make to the workplace. Again use the media to promote this.
- ii) I have seen on TV English employment agencies that promote disabled people to companies with some success. Set up a Wales wide employment agency for autistic spectrum people, where staff are properly trained in autism, matching people to jobs commensurate with their skill range.
- iii) What are the proposed measures to improve employment for people with Autism? How will we learn about any new schemes there are locally if we are not involved or kept in the loop? The database is imperative to keep us all informed by letter or email, opting out of receiving regular information if we so wish.

**We suggest taking this opportunity** to legislate to LAs and LHBs to include in the new Integrated Autism Service a key employment officer who will use his marketing skills to promote the skills of the ASC community to local employers.

**We would all like to know** what professions will be employed in this new service,

and will they be the same for all LA's? This information cannot be gleaned from anyone in Gwynedd.

## **Definition of Autism 29**

- q) Do you believe that a definition of autism spectrum disorder should:–
- Be included on the face of legislation (which makes it more difficult to change in the future)?
  - Be included in an autism strategy?
  - Be included in guidance?
  - Not be stated at all?

Whereas I understand your point about being difficult to change if it is in the legislation, I firmly believe there should be a nationwide definition, from Autism specialist clinicians, encompassing the whole spectrum, to allow for the movement of autistic people around the UK without problems. Autism should mean the same to all who come into contact with it. As you say there are already many appropriate definitions. Liaise with Autism England (perhaps through the NAS) to agree on a single definition. If and when it might need changing in light of new research so be it, it should change nationwide with everyone's agreement. If each area has their own definition an autistic person could find he or she no longer qualifies for support if he or she had to move from one area to another. Autism Spectrum Disorders are what they are. We want everyone to be singing from the same hymn sheet.

The Bill should include the definition in the autism strategy

## **Unintended Consequences 30**

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

## **Costs 31,32**

- s) Do you believe that the proposals in this consultation would give rise to any substantial costs, in addition to the cost-areas already noted in this consultation? How can such costs be mitigated?

t) What would the impact or costs be in terms of–

i. Producing a national autism strategy;

The biggest impact will be improving the lives of adults and children with autism spectrum conditions.

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

The biggest impact I foresee with the costs incurred to implement the new service, will be corner cutting by some LAs so close monitoring is essential.

LAs may want to cut other services in order to fund this one.

“Having a large ageing population who use up the social care budget” should not exempt an LA from providing services for people with ASCs as this will be common in most areas today.

Instead of imposing fines for an LA’s various mistakes, which just come out of our pockets as council tax payers, culpability and accountability should be taken by the individual decision makers responsible. Reducing LAs funds in such a way impacts on service provision.

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

This will be the most difficult yet one of the most important issues for the future of autism spectrum support. Engage local universities, and engage people already on autism databases in this task to keep costs down as in (m) above.

iv. Providing training for staff?

Initially it will take time to train support staff appropriately which will inevitably impact on their available support time. Proper planning is essential, with top level, decision making staff trained first by a recognised organisation like the NAS. Train staff to train others. Encourage autism courses in Welsh colleges and universities. Aim to promote Wales as a centre of excellence for autism training to draw in funding from other areas.

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

I am not qualified to answer these questions but I would assume management reorganisation in some councils may be necessary.

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

I am not qualified to answer these questions but I would assume management reorganisation in some councils may be necessary.

### **Savings 33,34**

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

There will be obvious savings as stated previously for the simple reason that early intervention and support will lead to better outcomes and a lower need of support in the future. We have read success stories from other areas where this is proven.

Those adults with Asperger's Syndrome or so called 'high functioning autism' are the ones who could be making the biggest savings for the LA by gaining employment and making contributions to their local community in many other ways if they are initially supported to do so yet they are the ones being left out in the cold at every juncture...high IQ therefore no need for support, how blinkered this has been.

How to identify and calculate the savings? Time will tell, until we know the numbers how can savings possibly be calculated? I just know if my son had received support when all we initially requested 15 years ago was respite care, our poor health would not be costing the NHS so much now. If he had received support when we first requested it we are certain our son would now be living more independently. No-one seems interested in the long term savings, but just in balancing the annual budget. Maybe you could lobby government to allow LAs to spread their extra costs over 2 or 3 years.

### **Other Issues 35**

I wish to ask what are the proposed measures to improve education for adults with Autism? Much has been achieved in schools but nothing has changed in FE colleges where the generic learning support is inadequate for those on the Autism

spectrum. Much has been talked about in stakeholder group meetings locally but nothing has been achieved. Education support should be available for all who require it including those over 25 with an ASC.

Can this be achieved within the autism strategy?

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

I have made many comments here but I am happy to see that in this proposed Bill notice has been taken of all the information we have all provided throughout this process. But the devil is in the detail. We thank you for the work done so far.