

Questions

- a) What are your views on the effectiveness of the current arrangements for improving autism services in Wales?
- 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?
- c) To what degree of detail do you think the content of a national autism strategy should be defined in legislation?
- 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?
- 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?
- f) Do you have any views on how Welsh Government should monitor what progress is being made and how public services should be held accountable for how they support autistic people and their families?

Comments

- Current arrangements for assessment of Autism are not good enough; not equitable across Health Boards and not enough post-diagnostic support, different areas have different demands for assessment. Needs to be cross HB agreement on what services should look like and how they should perform. Current arrangements have made progress towards developing services but more progress would be better.
- Concern was expressed around this Bill being centred around a diagnosis rather than being a needs led service. This will have several negative consequences:

- Will increase the demand for assessment as more families will be seeking a diagnosis as they will see diagnosis as a gateway to additional services
- Demand for assessment is already huge, this Bill will increase it further and in the environment of finite funding, there is likely to be reduced available monies for intervention work
- People/families who don't receive a diagnosis will have increased distress as they will perceive themselves as missing out on services
- There are other groups of people who have social communication type difficulties who need a similar service but will miss out. Whilst lots of people do fit into the diagnosis of autism, there are a lot of people who do not but whose difficulties are just as complex and deserving of services
- Groups of people who will miss out will be people with difficulties such as Foetal Alcohol Syndrome, semantic-pragmatic type difficulties, soft neurological difficulties etc.
- Education services should be meeting the educational needs of a young person regardless of diagnosis; the Autism Bill would contra-indicate this as it would be diagnosis dependent.

Suggestions

- It is a very good idea to have such a Bill but it needs to be broadened out to include 'Developmental Difficulties' so it does not exclude other groups of people whose needs are equally important but do not fit neatly into a particular diagnosis
- Should be able to access the service without the need for a diagnosis; any assessment should be more about what the person's needs are and not about diagnosis itself (as per Education philosophy). This would significantly reduce the need for 'diagnosis' and would free up resources for intervention work instead. If the huge resources put into 'diagnosis' could be put instead into 'an understanding of the person's difficulties' and support for this, then it would be much more helpful for the person and the people around them.
- Training for teachers in particular around autism would be really useful as many young people in school are missed, and girls in particular. Because

they are late being picked up as having difficulties, then they are developing mental health difficulties and presenting at Sp CAMHS. Picking them up earlier would reduce the amount of mental health problems they experience.

- Having a needs led (rather than diagnostic) service for people with developmental difficulties would reduce the number of referrals coming into Sp CAMHS
- It would be good for any national strategy to be reviewed regularly