

SUBMISSION FROM PATRICK AND SHARON O'ROURKE

1. My wife and I are carers for our seven year old son Matthew who was diagnosed with moderate to severe classical autism in June 2006. We have chosen to comment on the parts of the Bill which refer to young children with autism. We have been made aware of the problems facing teenagers and adults with autism, and sincerely hope this Bill resolves the difficulties we will face in the future, but our comments are based on our experience of raising a child with autism and hope our input can prevent future generations from facing the difficulties we faced.
2. We fully agree with the Autism (Scotland) Bill and below set out the reasons why. We have added some points where additional information on guidance would, we believe, ensure the robustness of the Bill. The additional information would prevent any future carers of autistic children experiencing the problems and setbacks we experienced and also ensure every child has access to the resources to enable them to reach their potential.

Section 1 - Autism strategy

3. We agree with the strategy as a whole and feel that it would greatly reduce the sense of helplessness and abandonment we faced as parents when we were given diagnosis.

Section 2 - Guidance by the Scottish Ministers

4. We are in agreement with section 2(1) to (4) and (6). In relation to section 2(5)—

Section 2(5)(a) - The provision of relevant services for the purpose of diagnosing autistic spectrum conditions

5. We feel a way of measuring the effectiveness of the level of provision is to include the waiting times for diagnostic appointment within the relevant health authorities advertised waiting times. This is based on our experience of being told the waiting time for diagnosis appointment is over one year, and then seeing literature advertising that the health authorities had achieved getting all waiting times down to within 12 weeks. This made us feel that autistic children don't count.

Section 2(5)(b) - The identification of persons with such conditions

6. We feel that all doctors and health visitors should be trained immediately in order to spot any obvious symptoms (such as lack of eye contact) and refer immediately for further testing. This is in relation to our own experience where our child's doctor sent my wife away telling her she was paranoid. It

took a change of doctor before our child was referred to a paediatrician and subsequently sent for diagnosis.

Section 2(5)(c) - The assessment of needs of persons with such conditions for relevant services

7. This we feel would be enormously beneficial to not only the child who would benefit in the long run, but it would give immediate support and reassurance to the parents, that all is not lost. When our child was diagnosed we left the centre not knowing where to turn. The diagnosis entitled him to help and support but it took us a time (a time that is lost forever) to find out where these services were available and who to ask for inclusion on them. We feel this process should be part of the diagnostic process, so that when parents find out the diagnosis they also find out how to improve the life of the child and help the child reach its potential. We feel the parents/carers are the biggest asset the child has at this stage and if the parents/carers feel abandoned (like we did) then the chance of the child accessing the resources which allow it to fulfil its potential are greatly reduced. There is also a danger from private companies who prey on the parent's sense of helplessness and offer treatments costing tens of thousands of pounds. Parents without a route map to resources are often bullied by companies using guilt as a tool and borrow money they do not have to access short term courses which have no scientific basis for cure.

Section 2(5)(d) - Planning in relation to provision of relevant services to persons with autistic spectrum conditions as they move from being children to adults

8. We agree that this planning is necessary but, do not feel we have the experience of current provision to comment.

Section 2(5)(e) - Other planning in relation to provision of relevant services to persons with autistic spectrum disorders

9. We agree that planning is a necessity and feel it would be beneficial if there was one point of contact, appointed to support the family in liaison with all agencies involved in the planning of support.

Section 2(5)(f) - Training of staff that provides relevant services to persons with such conditions

10. We feel that a minimum level of autism specific training should be insisted upon before any professional is allowed to work with a child on the autistic spectrum. We also feel that with more responsibility should come a requirement for a higher level of autism specific training e.g. a classroom assistant should receive the basic level of training set and a class teacher should be required to undertake a higher level. We do not feel we have the experience or knowledge level to comment on what the training level should be, only the principal that none of the child's time is wasted in professionals learning core skills on the job.

Section 2(5)(g) - Local arrangements for leadership in relation to the provision of relevant services to persons with such conditions

11. We have had many experiences of different agencies being non committal to resource because they cannot commit for another agency (eg education has dragged its heels in committing speech and language therapy resource because it is funded by the health service). We feel leadership is crucial here and this particular person must be given full authority to commit resources from any agency as long as it enables that child to reach its potential. Any delay in getting agreement has an effect on reducing the potential of the child, as much of the autistic child's ability to progress is based upon them having a solid foundation at the previous level. Any delay at the previous level has the effect of a bottleneck on the child's progress overall.

Section 3 – Local authorities and NHS bodies: duty to have regard to guidance

12. We agree completely

Section 4 – Interpretation

13. In relation to section 4(1), we think individuals such as ourselves who care for people on the autistic spectrum should be included within the "appropriate stakeholders" definition.
14. In relation to section 4(2), we agree.

Section 5 – Short title and commencement

15. Agree.

How helpful do you find the policy memorandum and financial memorandum accompanying the Bill?

16. The policy memorandum was helpful especially in outlining that the legislation will bring Scotland into a broad line with the rest of the UK. We feel however that we should not judge ourselves on the UK position alone, but should in fact look to being a world class example that other countries look to for best in service. We have an opportunity now to do this. The financial memorandum was informative in proving to the organisations that were against this bill, that there will be financial as well as personal benefits to be gained from it.

Do you have any comments on the consultation the Scottish Government carried out prior to the introduction of the Bill?

17. We feel as in the interpretation section that it should be widely advertised that the comments of autistic people and parents/carers of an autistic person should be welcomed.
18. To conclude, we note that some local authorities are against the Bill, we feel, through experience, that their objections are based on the short term financial implications on their staff budgets. We have had previous experience of education officers and speech and language therapy managers, refusing our requests based on budgets. Only when the law is quoted to these managers did we receive the quality resources required to help our son achieve his potential. These views are short sighted when you consider the costs placed on social services further down the line. The National Audit Office has made this point clear and can be seen in paragraph 34 of the Policy Memorandum.
19. We thank you for the opportunity to submit our comments and hope they are taken on board in your attempts to provide justice to those who cannot ask for it. We sincerely hope that this bill will give the people on the autistic spectrum the support required to achieve their potential. Helping them feel more inclusive and enabling them to contribute to our society.

Patrick and Sharon O'Rourke
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