

SUBMISSION FROM NICHOLAS RICE

1. I am writing as a parent of a 10 year old son with a formal diagnosis of childhood autism, made privately by the National Diagnosis and Assessment Service (at the cost of £2,000), over three and a half years after he was formally referred for such an assessment within the NHS.
2. I believe that an autism bill is essential and urgent so that parents and those on the autistic spectrum such as my son, as a child now and into the future as an adult, have access to appropriate and reasonably local support.
3. What I have written relates to sections 1 and 2 of the Bill, illustrating how, in the absence of such a Bill, the type of good practice that you read about everywhere is not necessarily implemented in practice. It illustrates why I believe the general principles of the Bill are so important and that they be included in formal legislation and not just issued as guidelines - everyone knows good practice already and simply restating it will go nowhere towards "making" authorities adhere to it.
4. The system as it is has failed, and continues to fail, my son, providing for him no support in relation to his autism and no parental advice.
5. I have summarised below some of our experiences in relation to my son's diagnosis and subsequent provision of support (or rather the absence of support).
6. My son was born in September 2000 and formally referred for assessment for autism spectrum disorder (ASD) within NHS Forth Valley in January 2005, following many months of input by various education and health professionals working as a multidisciplinary team. My son had been admitted to pre-school where he had an Individualised Educational Plan (IEP) and external input to the school from Pre-5 Educational Support. The possibility of ASD had been raised several years earlier. Although I felt it took far longer than necessary to reach this point, given that my son met virtually, if not all, of the National Autistic Society's "red flag" criteria for assessment, services and parental advice within Forth Valley were good.
7. However, my son moved with his mother to Tayside (Angus) shortly after the referral, which was forwarded internally to NHS Tayside, who took it up. The remainder of this relates specifically and only to our experience with services in Tayside, Angus in particular.
8. Following his move, my son continued to have an IEP at his new school in Angus. In January 2006, his paediatrician produced a report in which she outlined various characteristics of my son that she wrote were indicative of high functioning autism and recommended a more detailed assessment. At that time this paediatrician moved on and a consultant paediatrician took over responsibility for my son's case. In May 2006, my son's IEP was reviewed at the school. It was

recommended that his IEP be continued, with various items included on the plan into the future.

9. In June 2006, the new paediatrician met my son for the first (and only) time, when he was taken to the clinic for his appointment by his grandparents. She advised there would be no benefit to my son in carrying out the assessment advised by her predecessor. The following day, and without first discussing the matter with either parent, the paediatrician wrote to the GP stating that the assessment would not be continued. Six weeks later she telephoned my son's mother and obtained her verbal agreement to this decision. My son's mother later wrote that she was advised that it was too early to conduct an assessment, "if ever". In the light of this advice, my son's IEP was then discontinued by the school.
10. In a subsequent meeting with the school and a representative from Angus Education Department, my wife (not my son's mother) and I were advised that my son's support and, in particular, whether there would be a benefit to re-introducing his IEP, would be reviewed in the light of the result of any future assessment.
11. My wife and I took advice from other professionals (my wife has a long-standing friend who is a qualified paediatrician and works with children on the autistic spectrum) and discussed this with my son's paediatrician. She dismissed this advice on the grounds that she did not consider that my wife's friend and colleagues were qualified to comment. She advised that the diagnosis procedure (as carried out by the NHS in Dundee) could be stressful and that my son would not benefit from having a diagnosis.
12. We then sought the advice of Prof. Tommy MacKay, a highly eminent consultant in Scotland with regard to children and autism who has acted as an advisor to the Scottish Government on the subject, I understand. On the basis of the most recent school reports and my son's medical and health visitor records, he advised that there was reason to conduct an assessment and that that could be carried out by the National Diagnosis and Assessment Service if necessary.
13. My wife and I raised this with my son's paediatrician but she declined to discuss it. In fact she reacted angrily and walked out leaving us, my son's speech and language therapist, and a parental support worker who was present at my request following our previous experience, in the consultation room.
14. My son was assessed personally by Prof. MacKay together with his colleagues Dr Jim O'Donnell, independent autism consultant, and Tina Shaw of the Scottish Society for Autism in October 2008, resulting in a diagnosis of childhood autism (high functioning). Prof. MacKay and Dr O'Donnell explained that, though high functioning, it was a very clear cut case.
15. I sent a copy of Prof. MacKay's diagnosis report to my son's paediatrician. She responded that she would file it and that if I or my son's mother (who was not

present for the assessment) wanted further advice we should seek that (privately) from the team that conducted the diagnosis. Apart from the expense, this would require my son's mother to make a round trip of over 120 miles to the New Struan centre in Alloa or considerably further to Prof. MacKay's practice in Glasgow, which is not practicable.

16. Since the initial report of January 2006, the NHS in Tayside has provided no advice whatsoever (except to advise against seeking a diagnosis), not even a leaflet. In the absence of any local paediatric advice or input, the school and education department have declined to conduct the promised review, also explicitly advised by Prof. MacKay in his report, except to affirm that they continually review the educational needs of all children.
17. That means the current situation remains that my son has no plan in relation to his autism and the school, I understand on the advice of the Angus Council Education department, will not even discuss that. The Education Department have also stated that the Autism Toolbox, as issued by the Scottish Government in the spring of 2009 to all schools in Scotland (though my son's school say they did not receive a copy) does not apply to my son.
18. My son was last seen by an NHS paediatrician in February 2007 (by a more junior paediatrician reporting to the consultant paediatrician referred to above), my requests to take him in having been turned down. It is my understanding that his next appointment date will at about the time he moves out of primary school in 2012.
19. My son's autism has not gone away but I feel as if the NHS in Angus have washed their hands of him.
20. I believe that the Autism (Scotland) Bill is needed to provide a legal framework to prevent this type of thing happening and to provide parents and those on the autistic spectrum a legally enforceable means to twist the arms of the public authorities to provide services so as not to be forced to pay for private advice some considerable distance away. (It is a coincidence that I happen to live close to Alloa. That is not the case for my son, however.)
21. (I can, of course, substantiate what I have written here from correspondence and copies of my son's medical and school records and am willing to provide copies on request.)

Nicholas Rice
5 October 2010