### SUBMISSION FROM JOHN MOONEY

# My background

- My name is John Mooney and I am 52 years old. I was diagnosed with Aspergers Syndrome in 2007. I am educated to doctoral level with a background in medical research. I worked for almost 30 years in the NHS before retiring because of ill-health. I had a long history of chronic, cyclical depression before diagnosis. I have an IQ of 155 according to MENSA, putting me in the top percentile. I am both disabled and "super-enabled".
- 2. My disabilities include easy distractibility, inability to concentrate for extended periods in social environments such as the typical workplace, inability to read subtle social cues, literal-mindedness, inability to multi-task in certain ways, sensitivity to red light, inability to cope with noisy environments, extreme sensitivity to hot and humid environments, and not understanding or valuing complex systems of personal allegiance which appear very important to "neurotypical" people. I should explain that the nature of my condition is usually rather subtle. This usually leads to the perception that I am "difficult" rather than that I have a "problem". In this context, it should be pointed out Aspergers is a developmental condition rather than a learning difficulty. However, in my case, the problems I have encountered appear to arise from my inability to "learn" social rules that others take for granted.
- 3. On the other hand, my ability to process information is excellent, and I have the ability to see patterns very quickly that others don't see at all. In my opinion, individuals come up with ideas and collectives implement them. Apergers individuals are more likely to come up with new ideas, and neurotypical people are more likely to successfully work collectively.
- 4. I was born into a poor socioeconomic background and attended the first generation of comprehensive schools. My experience of this was rather negative. These schools appeared to have no strategy for those with learning disabilities or those with developmental conditions which made them "gifted" but "socially obtuse".
- 5. I have been out of paid employment for over two years, and have had to fight for my entitlement to incapacity benefit and disability living allowance. I have to say that I found my employer, the NHS, to be lacking in sensitivity, sympathy or even good business sense in dealing with my condition. Even simple adjustments that would have helped me were ignored, there was no ongoing flexibility in working hours which is very important to people with Aspergers, and I would describe the typical management attitude as "pathologically normative". Currently, I do some voluntary work for a housing association, of which I am now the Secretary, and a local museum.
- 6. I have been married twice, and have a four-year-old daughter to whom I

am a "full-time daddy". My experience of diagnosis has been positive. I can now see clearly that any mental health problems I have had are secondary to my style of thinking and interaction. Armed with this knowledge, I can deliberately and with great effort perform adjustments to my behaviour that most people do unconsciously. It is said that the brain typically uses 20-40% of the body's energy. In my case it is more like 60% - "normal" levels of social interaction are quite exhausting. I do not agree, however, that anxiety and depression are inevitable in Aspergers individuals. The proper, targeted support would help us to no more susceptible than "neurotypical" individuals.

## My experience of the lack of support for people with Apergers

7. I believe that the fact that I was not diagnosed until the age of 49 speaks volumes about the historical lack of understanding of Aspergers. There is no appropriate mental health provision for people with Aspergers. Although everyone with Aspergers is different, we all have common problems which arise from our thinking style and mode of interaction. These problems differ significantly from those generally encountered by "neurotypical" people. Similarly we have particular problems in our working lives and personal relationships which differ significantly from the norm. These are just three examples of areas where people with Aspergers require tailored services to help them achieve their full potential - mental health provision, support in the workplace and back into the workplace, and personal counselling.

### My view of the need for an autism strategy

- 8. People with Autism Spectrum Disorders (ASD) require support services that differ significantly from those required by "neurotypical" people. Therefore, an autism strategy is required to cover education, provision of mental health support, counselling, employment support, interaction with the criminal justice system, housing, and other services where people with ASD have different needs. There is also a need for the autism strategy to include a strategy for research into ASD.
- 9. Finally, a robust and comprehensive autism strategy will reduce disability discrimination and greatly increase the contribution to our society by people with ASD.

John Mooney 3 October 2010

### SUPPLEMENTARY SUBMISSION FROM JOHN MOONEY

- 1. I strongly disagree with the submissions by Fife Council, South Ayrshire Council, Angus Council, and Aberdeenshire Council and think that these require to be rebutted.
- 2. I would contrast these submissions with the thoughtful and helpful comments from Glasgow City Council.
- 3. As I have pointed out in my own submission, there are many aspects to a robust and comprehensive autism stategy other than education, including targetted mental health support, personal counselling, employment support, housing and interaction with the criminal justice system. Moreover, these submissions appear to overlook the needs of adults with autistic spectrum disorders (ASD). In my opinion, these are ill-informed and badly thought-out submissions from public bodies which should have exercised better judgement.
- 4. I would also question whether elected members of these councils were consulted before making these submissions.
- 5. Finally, and on a personal note, my brother died in his late 20s. An important contiributory factor in his tragically premature death was, in my opinion, the lack of appropriate services for adults with ASD. In his case, he had severe problems arising from the lack of appropriate mental health support and support with housing and employment.
- 6. To imply that a comprehensive autism strategy is just about education or just about children belies a staggering lack of understanding. I would urge the committee to disregard these submissions on the grounds that they contain serious factual errors, and to support the autism strategy within the context of the Autism (Scotland) Bill.

John Mooney 7 October 2010