SUBMISSION FROM LYNNE MOFFAT

- I would like to detail why I believe the passing of Autism (Scotland) Bill is vital for people affected by autism in Scotland, whether they have the condition personally or have a person with such difficulties in their lives. I would also care to express why I believe the Bill would not only benefit these affected by autism directly but also be advantageous to society at large.
- 2. I speak mainly from personal experience but also from general understanding I have gained from speaking with others affected by this disability.
- 3. Firstly, I do not know what understanding the recipients of the evidence will have regarding autism but for me an important thing to highlight is that although individuals can seem very able in certain regards eg fluent articulate speech or academic accomplishment, there are marked differences in the manner in which our brains process information. This means that although we can seem "normal" in appearance, and often in conduct, we are often struggling significantly to function in areas in which people unaffected by autism deal with with relative ease.
- 4. It is these differences in processing which contribute largely to the "presentation" of autistic spectrum disorder (ASD) and therefore what is looked for in diagnosing it, namely social, communication and imagination difficulties. In addition to these, people on the spectrum, because of this atypical processing often, although not always, have what I dub "commonsensical" difficulties. I for instance, have significant difficulty with organising, prioritising, planning, sequencing and initiating which makes life very tiring and frustrating. Sensory issues are also common a problem, such as not being able to filter out background noise to focus on a relevant task or conversation (selective attention). For some individuals sound/noise can even evoke feelings of physical pain.
- 5. Although I have often experienced people say things along the lines of "everyone's different" this can be detrimental as it serves to detract from the very real and marked difficulties people with ASD experience. The often "invisible" nature of the condition can be a curse as there can be a tendency to underestimate the severity of the struggling and downplay the impact on everyday living and quality of life.
- 6. Taking a simplistic example, despite many years of confusion and painstaking effort I cannot maintain concentration on a task whilst simultaneously holding a conversation of any sort. For myself, even working at a supermarket checkout and maintaining small talk ("small talk" in itself being difficult for people with ASD) with the customer I was serving was

very difficult as I find it remarkably difficult to think about what I am doing and process additional information in order to perform a task even of such a basic nature. As you can imagine, this kind of difficulty causes me all manner of hardship both in a work environment (supermarkets highly rate customer interaction at the till point) and socially (I struggle even to make a cup of tea and chat at the same time). I mention this not to seek sympathy but to highlight how pervasive the difficulties can be in leading everyday life.

- 7. As it stands, people in general, although there is an increasing awareness for which I am eternally grateful, fail to acknowledge that the way in which individuals behave is not always down to will alone (eg lack of effort, apathy, indifference) or down to a lack of intelligence, but rather inconsistencies in information processing. Despite my best efforts, and believe me I spent many an agonizing hour trying to work out why I could not "get a grip" - I just CANNOT function and communicate in a manner that falls within the confines of "normal". I cannot multi-task at all (do more than one thing at once or even change between tasks and "demands" fluidly, I cannot concentrate productively in an environment where there is noise or disruption or where I have to communicate and receive a lot of information from other people. Although I believe my work in terms of "finished product" is of a reasonable standard it takes me a considerably long time to produce it due to my deficits in sequencing and "staying on task". This is not because I do not desire to, believe me I'd like nothing more, but simply because the manner in which my brain operates will not allow it.
- 8. One major problem, as I touched on earlier, is that because some of us on the spectrum are educated to a reasonable level and can come across as articulate and able, social and communicative deficits can often be misinterpreted as lack of thought or care for another as opposed to a lack of innate ability and intuition to understand, interpret and essentially see another's standpoint (needs, wants, motivations). This is not the same as not caring, about the above, which is a common and sore misconception.
- 9. I genuinely believe that passing the Bill to ensure local authorities and NHS bodies make relevant provision for the acknowledgement, assessment of needs and implementation of support will literally save lives and vastly improve the quality of many. The stress of trying to perform under "normal" conditions without accommodation or awareness in a "normal" environment is hard to underestimate. I know for myself if I had had a diagnosis/knowledge of a "driver" for my torment and appropriate help at a young age I would not have had the history of mental health issues I have had, which culminated in a complete mental breakdown. Had my difficulties been recognised, addressed and appropriate assistance been given, not only would it have saved mine and my family's own personal pain and anguish but would also have saved in resources and expenditure on medication and mainstream mental health services and, in addition, would

- have preserved any ability I may have had to work and hence be "economically active".
- 10. Judging from a considerable number of people I have been in contact with since I become aware of ASD as an explanation of my own "unravelling", it is apparent that mine is a far from a unique scenario. Individuals try to function in the "mainstream" in terms of thought flexibility, interaction and communication despite marked differences in mental "wiring" and after a time, despite pulling on every physical, mental and emotional reserve within them, their psychological wellbeing, to put it rather colloquially "conks out"! Another familiar tale is that people resort to somewhat unhelpful self medicating behaviours, such as alcohol consumption or drug misuse, to alleviate the anxiety and confusion. These difficulties are often coupled and exacerbated by social failure, rejection and isolation which come from an impaired ability to form and sustain social relationships.
- 11. Not only do people with ASD really struggle but they often have marked difficulty articulating and remediating their problems themselves as this type of action involves realms of thinking in the abstract as well as utilising dimensions of the imagination which are characteristically problematic for people with autism.
- 12. This is why it is fundamental that there should be appropriately trained individuals to help and offer advice in order that needs be appropriately assessed and plans and structures put in place in a multi-faceted manner occupationally, recreationally, domestically and socially.
- 13. As it stands, and as I am sure you have been made aware there is next to no provision for ASD in Scotland. Indeed many "mainstream" mental health professionals are ill informed and unable to recognise (unless the individual presents in a classic "textbook" manner), far less diagnose and offer support where ASD is concerned. Indeed I myself was told by two psychiatrists and a psychologist that I was not autistic prior to my diagnosis due to a lack of adequate appreciation for the way the condition can present. It is my strong belief that often the manifestation of autism, in terms of coping mechanisms/resultant behaviours such as eating disorders or addictions, are identified and treated rather than the root cause.
- 14. Although I am fortunate in that since my diagnosis I have had access to the Autism Resource Centre in Glasgow where the staff are extremely helpful, the services it is able to offer have been cut significantly of late, "drop in" times formerly available 9-5 Monday to Friday now only run four hours per week. I strongly believe that without legally enforceable governmental intervention many people stand to suffer markedly (and I mean suffer in the true sense of the word) from lack of diagnosis and lack of appropriate support and services. This in turn will inevitably lead to more people being

treated for the mental health problems that materialise and more people claiming state benefits as they are unable to cope with the demands of unsupported everyday living and working in a world of ever increasing biz and chaos.

- 15. I think I can speak for many when I say that we are not seeking plush facilities in state of the art buildings but rather to be met by understanding; adequately trained staff who are able and willing to help us where we struggle to help ourselves. Areas such as help to access housing, advice on how to go about approaching the job market, how to resolve job related difficulties (including educating employers and other staff regarding the of ASD and arranging appropriate workplace nature adaptations/accommodations), general domestic skills (managing finances and household matters) and general advice and support on everyday issues which can often seem somewhat insurmountable to someone struggling with an ASD. The value of having a social facility where those affected by ASD can meet and interact; where they are accepted and encouraged to work on socialisation and relational skills can not be downplayed. The vast majority of people affected by autism do not seek an easy deal in life or society but assistance, understanding and accommodation to function to their potential and remediate their shortfalls/weaknesses.
- 16. I do not wish to put forward the argument that everyone with an ASD is a "closet genius" as has sometimes been, somewhat comically, portrayed in the media, obviously this would not be valid, but I do believe that there is substantial ability and potential that could be harvested for the benefit of society if autism was identified, diagnosed and appropriate help and support given. Not only might a greater number be able to sustain employment but increased understanding and assistance would go someway to maximising productivity and effectiveness in the work place. In addition, those unable to partake in paid employment may be facilitated to pursue voluntary work, hence contributing and themselves gaining a sense of satisfaction and worth.
- 17. Perhaps the value of atypical "wiring" is underestimated at present. Many suspected, or indeed diagnosed autistics have been pivotal in the furtherance of many fields from computing (Bill Gates) music (Beethoven and Bach), science (Newton, Einstein, Marie Curie), invention (Alexander Graham Bell, Thomas Edison, telephone and light bulb respectively), literature (Emily Dickinson, Jane Austin, Mark Twain) art (Van Gogh, Da Vinci). Who knows what, as yet untapped, talent and ability may precipitate if this bill is endorsed, passed and enforced...

Lynne Moffat 6 October 2010