

SUBMISSION FROM NATIONAL AUTISTIC SOCIETY (WEST DUMBARTON BRANCH)

1. West Dumbarton Branch of The NAS is a parent support group part of a network of 105 branches across the UK. Semi-autonomous, the group has been in existence for 12 years, supporting numerous parents and providing much needed support for parents, carers, young adults and children affected by Autistic Spectrum Disorder (ASD).
2. NAS West Dunbartonshire fully supports the Autism (Scotland) Bill for the following reasons—
3. Whilst we recognise that West Dumbarton Council appears to be one of the better agencies with regard to its approach to autism, many parents continue to have to fight for the rights of their children and young people. The local picture seems to reflect the national situation where assessment of need, access to needs appropriate services and education and professional awareness and expertise varies considerably within the locale. A national strategy, led by the Minister and backed by legislation, would be a valuable start to ensuring that a set of minimum standards was developed and rigorously implemented locally and nationally and regularly reviewed by accountable agencies.
4. Autism legislation is needed because of the unique challenges that autism poses. The condition is described as pervasive in that it affects every aspect of the person's life and that of their family members and carers. The structures that are already in place, such as learning disability services and NHS, cannot meet the needs of the majority of people with autism because, with autism, one size does not fit all nor indeed can people with autism be easily categorised in order to fit existing service models. However, that option is usually the only one that people with autism can access – a “take it or leave it” approach. All too often people's needs are ignored and they are shoehorned into whatever services already exist. The counter argument that we cannot create a precedent regarding legislation and strategy that is disability specific is spurious; people with autism are already being discriminated against in the face of growing social acceptance of other forms of difficulty such as learning disability, physical disability and other forms of developmental disorder such as dyslexia. For example, a child with dyslexia will receive additional support in exam settings whereas the young person with autism will most often not.
5. The future well-being of our children is of great concern to us all, especially with regard to future life chances and mental health. For most of us, we see that our children have the potential to live full and meaningful lives and contribute to society but worry that without appropriate understanding and support at the right time they will end up unemployed, like 85% of other people with autism, or suffer mental health problems, which is four times more likely for people with autism than the general population. We have a choice; invest small amounts

now in innovative ways or face having to support many thousands of people in crisis intervention scenarios, such as mental health or criminal justice, in future years. Acting under legal duty, the Minister needs to take the lead regarding this and work closely with local authorities to ensure we create new ways of working that are adopted across local authorities and across the nation.

6. Although education is far from satisfactory for many, it is only a small part of the overall picture. The plight of the many thousands of adults who currently are struggling to cope without a diagnosis (or mis-diagnosed as schizophrenic) and without support is one of the major challenges we have to deal with if we are to improve society and relieve the strain on the public purse. Adults who have no access to appropriate housing or employment and who are supported by increasingly elderly parents is a time bomb that will inevitably impact on all of us. Why did it take a Danish entrepreneur to set up the first autism specific workforce in Scotland? Are we content to sit back and let others take on the responsibility for getting our able young men and women into work? Where is our national leadership and accountability?
7. Much will be made of the financial implications of tackling these problems, especially in the current financial climate. Put simply, it currently costs us a fortune as a nation through inappropriate service provision, unemployment, lost opportunities, poor transition to adulthood, homelessness, crisis intervention and maintaining people inappropriately within the criminal justice system. Repeated failure to get it right first time by one agency inevitably leads to increased costs for another and that would appear to largely avoidable with a little bit of investment and a lot of lateral thinking. However, we cannot expect to see any improvement in national standards unless national government takes the lead and helps and encourages local authorities to achieve these set standards. Without national leadership we will still be listening to 32 singers singing different songs at the same time ten years hence.
8. Finally, we were recently sent a copy of an autism strategy put forward by the Government. It appears to be merely a set of recommendations that can be ignored with impunity. No mention of accountability or compunction to ensure we get things changed for the better. Yet more calls for "more research". We are fed up with recommendations. Familiarity breeds contempt, the old saying goes, and believe us, we are very familiar with recommendations as that's all we seem to have had pressed on us for the last 20 years. We don't want recommendations; we want action and accountability.
9. We want an Autism Act for Scotland.

Brian Docherty

Branch officer on behalf of, and in conjunction with, NAS West Dunbartonshire Parents' Group

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