

SUBMISSION FROM PEOPLE WITH HIGH FUNCTIONING AUTISTIC DISORDERS (PHAD) IN FIFE

1. My name is Charlotte Farmer and I live, breath and work with autism. Over the past few years I have worked tirelessly devoting all of my time providing support not only to my own family but to many people within our communities affected with autism, their families and those who work alongside them.
2. Autism can be one of the most challenging, most misunderstood and least visible disabilities for anyone to live with. It is especially difficult in today's socially minded society which (to the person with autism) is full of confusing rules and gestures. This often makes their experiences of everyday life frightening and confusing, overloading their sensory perceptions and locking them into debilitating dead-end behaviour patterns. They make little or no progress and put immense pressure on everyone around them. I don't want to go into great detail about each area of pressure as most people do not have time or the inclination to absorb such a massive, daunting amount of information. I have therefore created a visual mind map of the affects of autism on communities to show the costs and challenge it presents. (Please see mind-map on page 5 for reference)
3. A sad but true reality is that, due to their own communication difficulties and a lack of external support, many people with autism do not have their voice or needs recognised. They often struggle on alone and unacknowledged, with few educated people available to help them.

So how can we help them?

4. Invest more money to create a strategy which may address the issues and set guidelines? In reality such a strategy may be left gathering dust on the bookshelves right next to the autism toolkit. Yes, it might look good but how would it ensure or deliver results? The demands of legislation may seem daunting to managers concerned about their ability to provide a suitable service especially during today's climate of breakneck economic and cultural change. Many may feel that this will place even more pressure on our overstretched economy and failing services. However we must not lose sight of the fact that we need a strategy to help break the costly cycle of failure and find a new democratic solution, for it will surely cost us more to ignore this problem than to solve it! It is time to think in the long term and find a solution rather than cut costs in the short term. A long term solution will have worthwhile and beneficial social and economic results if support is provided where and when needed. For example, by incorporating compulsory autism content within training packages and evaluation systems to ensure properly tailored service provision.

How much will it cost? Or rather how much can we save?

5. Without the correct support, autism will be a huge drain not only on government funds but also – and more worryingly – a costly detriment to good quality of life, health and relationships in society. So much valuable time and money is constantly wasted on dealing with the *effects* of autistic behaviour, rather than

being properly utilised to alter the factors which can *cause* such behaviour. Modifying educational and workplace environments to ensure people with autism are properly integrated in the first place, more able to contribute to society and more able to have the better quality of life to which we all aspire, can break this negative cycle of cause and effect. We as a society will continue to go round in circles until we can provide the necessary strategies needed to break this tragic cycle.

The benefits of investment

6. To implement guidelines and strategies incorporating training opportunities, to equip service providers with the tools and knowledge they need to support people with autism appropriately, to get positive outcomes and ultimately to save money and improve lives *does* seem to be a daunting proposition.
7. Hence the reason most authorities do not want such legislation: the fear they may have to face that which they have swept under the carpet for so many years – the hard and harsh realities we, the parents and partners of people with autism, see every minute of every day!
8. It is all too easy for many to forget that after a work day finishes our day does not. It goes on and on at weekends and on holidays, often with no one to turn to for respite. We have no time to become complacent when supporting autism. We deserve to be recognised, not forgotten, ignored and misunderstood. At the moment we have to rely on individual opinions which are often misguided.
9. We need the guidelines and strategies contained within the Autism (Scotland) Bill, for it will surely cost both society and government much more in terms of broken lives and wasted potential than it may well save if we begin to deal with the cause of the problem rather than its tragic effects!
10. Having doors opened at all levels via autism coordinators who work in partnership to create opportunities where voices can be heard and the genuine and real experiences of people with autism and their families in their everyday life assist a process in reflecting on existing services to ensure they are fit for purpose, catering for this population. Additionally to open discussion on the development of new services as required.

The hidden reality

11. When a child is born the bond of love between mother and child (in most cases) continues through each day of their lives with each new experience, sharing the joy and simplicity of the world around them. The autistic infant is a wondrous child with many great qualities. They are often happy and content in their own little world, generating little concern or demand from their parents. That is, until the need to develop social skills and change their routine comes along... Then it's time to wash, time to dress, time to sit at table, time to eat, time to go to the toilet, and time to do different things.

12. We all recognise that these developmental steps are challenging for most parents and children, but are unaware of the huge challenges they present to the child with autism. Most people misunderstand an autistic child's anxieties, totally unaware that their pressures leave the child feeling frightened by their confused sensory perceptions of the world in which they live.
13. Until people learn about autism how can they begin to understand and support these children? Most parents are relieved when their child is diagnosed. It feels like someone is shining a light on the strange patterns of daily behaviour they face, helping them realise and gain comfort from the fact that they are not some mad parent getting it all wrong!
14. So now they have a diagnosis. What next? They still have to continue with their everyday lives. They still have to juggle the demands of supporting a family, often struggling financially, frequently exhausted and feeling as if they have no one to turn to.
15. Coming to terms with the fact that they have a child with a disability brings periods of uncertainty to some. They grieve for, in some ways, what may feel like the loss of a child.
16. Parents need help to come to terms with and accept the fact their child is autistic. There is a need for professional counselling which sadly not many people are equipped to give.
17. Most parents continue to struggle on alone and unsupported. Some may be fortunate enough to come across local charitable organisations which can supply or direct them to support services. But more often than not even these services (and they are rare) do not cater for the needs of the family as a whole, leaving them even more in despair.
18. Most families living with autism want one main thing:

To have people around them who are educated about and supportive of the challenges autism brings.
19. They need people around when times are difficult to listen to them and help them to find solutions without judging and/or making accusations.
20. We as a family have taken each day as it comes, using all our time and energy to face these challenges. I will strive every minute of every day until I know that my child and all the other children and adults with autism related disorders here in Scotland can be integrated into a mainstream society which provides not only equality and understanding but guaranteed autism education and tailored service provisions.

21. If we as a society are not willing to accept people with autism into our lives, what hope is there for all the families throughout Scotland struggling to cope day after exhausting day?

Charlotte Farmer

Vice-Chair

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