

## Autism, Health Care and Society

This essay is a follow up to my entry of last year entitled "Health Care and Society". In my previous submission I concentrated on society's awareness towards mental health and I wanted to explore one of the areas I covered briefly i.e. autism in more depth. This subject is of particular interest as I have a 10 year old cousin who has autism and is bipolar. I have spent a lot of time with him and he lived with us for a short period and I therefore have some insight into this challenging condition.

Autism is a complex subject and much has been written about its diagnosis and treatment but my essay will concentrate on whether or not it is a significant issue in relation to healthcare and society and the importance of early diagnosis. In addition to the theoretical research, I have carried out a small piece of qualitative research from parents of children diagnosed as being on the Autistic Spectrum. This case study is too small to have any scientific basis. The intention was to gain a few views and opinions from parents or carers of a small group of seven autistic individuals to provide some further insight into the condition. The case study is too small to have any scientific basis and the findings are only valid within the group studied. It cannot be regarded as representative of autism as a whole. (Yin 2009, p.9)

The word autism comes from the Greek word "autos" which means "self" and a range of disorders fall under the autistic spectrum these are termed the Autistic Spectrum Disorders (ASD). These are namely: Autism, Aspergers, Childhood Disintegrative, Retts and Pervasive Development (Exkorn, 2006, p. 6).

Autistic individuals have social, communication and imagination problems together with repetitive patterns of behavior. Autism has been described by some people as a jigsaw with a missing piece; an adult described her own autism as:

***"One bucket with several different jigsaw in it all jumbled together and all missing a few extra pieces that didn't belong to any of these jigsaws"***

(Williams 1996 p.1)

Until the 1960s autism was viewed as a relatively rare disorder. Over the past few years, professional's recognition of autism has soared and it has been described as almost an epidemic with 1 in 100 people on the autistic spectrum. A study carried out last year by the Department of Education found there were

61,570 schoolchildren in the state-funded sector but just 5 years ago the number was classified as just 39,465. Several reasons have been put forward for this increase but improved diagnosis is quite likely to be a major contributory factor (Telegraph Friday 22<sup>nd</sup> March 2013)

Autism is not a psychological disorder or a disease as was first believed by the German psychiatrist Leo Kenner in his 1943 report on autism. It is now recognised as being a neurological disorder caused by structural or functional abnormalities in the brain which probably develop in the womb. It is four times more common in boys than girls, the reason is believed to be genetic. It is five times more common than Down's syndrome. (Exhorn 2005, p.7)

Autism lasts for life and has a profound effect on a child's intellectual, social and emotional development. It affects every child differently, some have higher intellectual functioning, some are able to function in the community, some will never speak, others are quite articulate, and many have profound social difficulties. The effects of autism do not really show until the toddler stage but parents often say:

***“They felt something was different about their baby from the start”***

An ASD can affect a child's ability to communicate, use his or her imagination and connect with other people including their parents and siblings. ASD ranges from mild to severe, a child on the severe end of the spectrum may be unable to speak and have mental retardation. Whereas a child on the mild end, may be able to function in a normal classroom and may even reach the point where he or she no longer meets the criteria for autism. (Sheldon, 2004, p.1)

It could be argued that as autism is not a disease or illness it is more of an issue for education and social services than health care professionals .However, in my opinion it is primarily a health care issue as parents who notice difficulties or unexpected changes in their developing pre-school child, would generally first consult a healthcare professional, i.e. General Practitioner (GP), health visitor or local health clinic nurse. A wide range of health care professionals may become involved in an autistic child's diagnosis and subsequent treatment, these include:

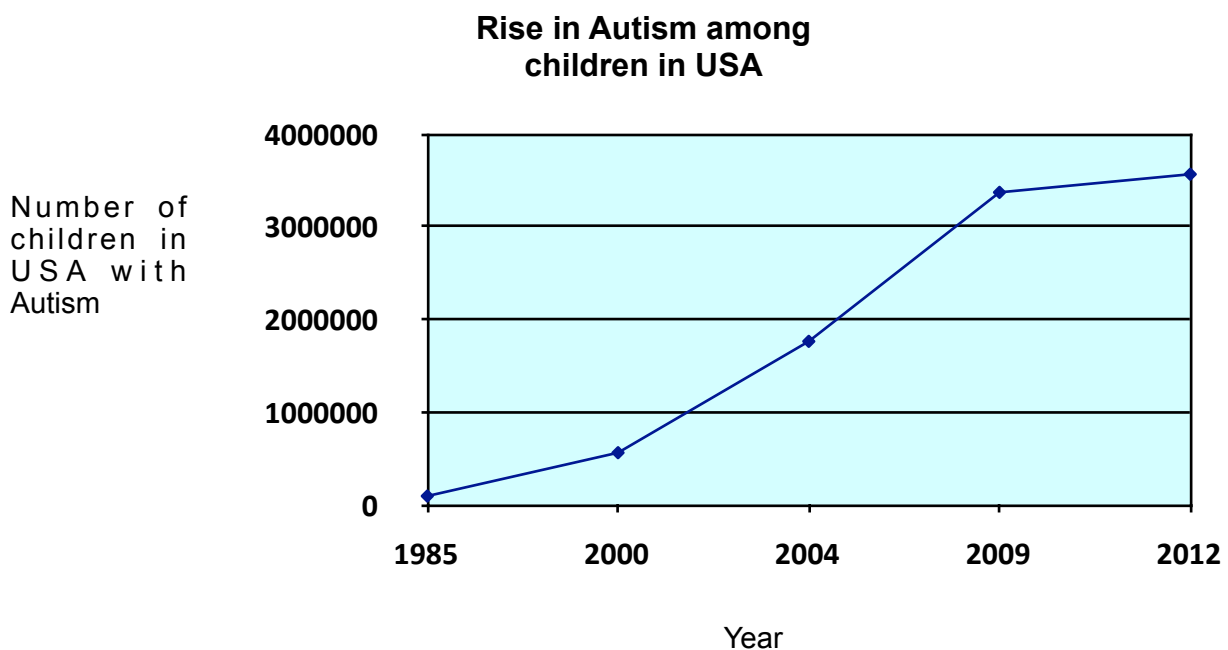
- Health visitor
- GP

- Paediatrician or consultant
- Clinical psychologist
- Physiotherapist
- Occupational therapist
- Speech and language therapist
- Audiologist.

(Wall, 2004, p.47 &53)

Another reason why I believe autism is an important healthcare issue is that people with autism or Asperger syndrome are particularly vulnerable to mental health problems such as anxiety and depression, especially in late adolescence and early adult life. Surveys by Tantam & Prestwood (1999) Ghaziuddin and others (1998) found that 65 per cent of their sample of patients with Asperger syndrome presented with symptoms of psychiatric disorder. (NAS website). Although there is no doubt that social services and education specialists have an important role to play in a growing child, autism is in my opinion primarily a healthcare issue.

The sheer number of the population on the Autistic spectrum estimated at more than 1 in 100 seems to indicate that it is a significant issue for society. This figure does not account for close family members caring for the autistic individual affected by association. There is no exact register for the number of people diagnosed with autism in the UK. However, there is a record kept in the USA between 1985 and 2012. ([www.child-autism-parent-cafe.com](http://www.child-autism-parent-cafe.com))



Social impairment is one of the main characteristics of autism and affects almost every aspect of a child's functioning from screaming, tantrums,

undressing in public, making strange noises and an inability to play with other children. This lack of social understanding means the child may fail to judge correctly everyday situations, emotions and relationships and become excluded from society. (Howlin 1998, p51)

In my previous essay on Mental Health Awareness I covered the issue of social stigma and am of the opinion that this likewise applies to individuals with autism as Exhorn, 2005, p.103 states:

***"An autistic child mimics all the British traditionally hate most about children- imperious to discipline, demanding and antisocial. The dictum that children should be seen and not heard does not apply here"***

One of my case study respondents commented:

***"Autism is a hidden disability. The public can be mean and assume you're a bad parent with a naughty child"***

Social stigma towards autism is re-inforced by negative publicity, an example being the scare-mongering about the Measles Mumps Rubella vaccine and claims that it triggers the condition. This link has now been disproved, but many parents still chose not to have their child vaccinated and this has recently led to a measles epidemic. News reports of the recent tragic event in Connecticut where 27 people including 20 children were killed heavily emphasized the fact that the killer was autistic. The reasons behind the killer's actions will probably never be fully explained; however social violence is not a feature of autism.

Social acceptance of a person with ASD is complicated by the fact that they look normal. Autism is known as an" invisible disability" as you can't tell that a child has an ASD simply by looking at a picture of him or her, (Wall, 2004, p.7)

One respondent in my case study commented:

***"People need to realise just because someone looks the same as any average child it does not mean they think like them"***

These two pictures show two 10 year old boys born within a few days of each other, both look perfectly normal happy boys;



....However, the boy of the left lives with his family and attends mainstream school. The boy on the right has been diagnosed with autism and lives in a residential autistic centre in Cardiff. (*Permission received by parents for photo and information*)

Several comments in my case study in response to a question asking for ideas on improving society's view of autistic individuals emphasized the need for "*more understanding*". Ideas from parents questioned for improving this understanding and reducing ignorance include; TV advertising, inclusion in the Personal Social Education section of the school curriculum, youth or sports group involvement etc. One respondent stated:

***"More needs to be done to make society aware of mental illnesses...as a nation we are really ignorant"***

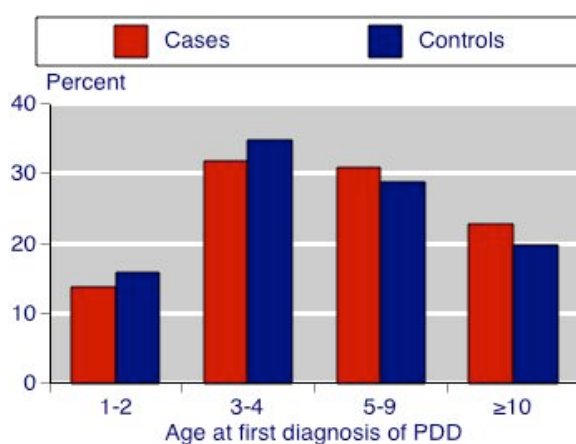
Recent estimates suggest that autism costs the UK economy around 28.2 billion per year. Only 15% of adults with autism are in full-time employment which has a negative effect on individuals and their families both financially and in terms of social inclusion. These high unemployment figures have a significant effect on the public purse due to the benefits claimed. (Mental health network NHS confederation 2010)

Most of the research I have come across emphasises the importance of early involvement by healthcare professionals in particular GPs. Wall, 2004, p. 52 states that if they are involved with the child as early as possible they should be able to give proper referrals as well as contribute valuable information to the diagnostic assessment. Early diagnosis is essential if families are to be provided with the help and support they need from when their child is very young. Problem behaviors that are established at the age of 3 years may well persist until the child is older and will become increasingly difficult to handle. If effective intervention techniques can be implemented before problem behaviors become too difficult to manage the outlook both for the child and family is likely to be far more positive.

A study by Howlin and Moore in 1997 found that although most parents of autistic children suspected something was wrong before they were 2 years old, most reported delays in formal diagnosis. In the case of Aspergers, a few individuals were not diagnosed until they were in their forties. The authors' commented that undiagnosed adults often only gained contact with services when their needs became acute and by this time they required more intensive high level treatment such as psychiatric inpatient care. (Wiley, 1998, p.56)

Early diagnosis is important not just for providing support for the child. It will also help to reduce stress on parents and other family members. In addition if they are planning other children they can have access to genetic counselling (Wall, 2004, p.35). Temple Grandin PhD 2005, p.20, a highly successful autistic adult states in her autobiography about her troubled early years:

***“I cannot emphasis enough the importance of a good early childhood educational program. Little children with autism need many hours of activities where their brains are kept connected to the world”***



Graph showing Age of Diagnosis of one of the Autistic Spectrum Disorders (Pervasive Developmental Disorders)

Source L. Smeeth, Lancet 2004, 364:963-969

Within my case study the age range of diagnosis was from 2 to 23 years

but the majority were in the 4-7 age range. Interestingly, one respondent commented that the father of one of the autistic children was diagnosed at age 43 with the same condition shortly after his son. The diagnosis procedure took between 6 months to 2 years and in all cases was made by a consultant. One of my respondents added a comment about support throughout the diagnostic procedure:

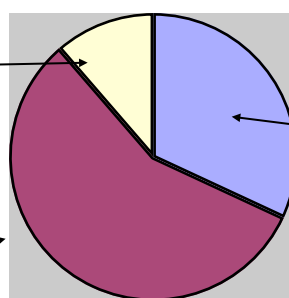
***“Each individual with autism should be assigned a health or social support worker as early as possible, who can give you the necessary information rather than you spending valuable time trying to find it out for yourself”***

Wall 2004 p.52, points out that professionals need the specialist training required to understand the difficulties experienced by children with autism in order to ensure correct diagnosis. Autistic children and adults are often unable to communicate feelings of disturbance, anxiety or distress which means that it is often very difficult for untrained medical staff to diagnose depressive or anxiety conditions. The author states:

***“The diagnosis of autism is highly specific and requires considerable expertise to undertake appropriately but the final diagnosis should not rest solely with one professional”***

### Percentage of state spending on autism in UK

It may be argued that additional specialist help for adults is not cost effective in challenging economic times. £3.2 billion spent on autistic children in UK. £10 billion spent on services for autistic adults in UK. Over a third of the £28.2 billion mentioned above costs the UK, the majority of attributed to adults. Over a third of this figure is attributed to lost autistic adult and the



the costs of providing autistic children and for society in these challenging economic times. However, of the £28.2 billion mentioned above, £9 billion is spent on autistic adults in UK which autism currently costs the UK £25 billion. Over a third of this figure is attributed to lost employment for the autistic adult

- Money spent on unemployment for autistic adults (32%)
- Money spent on services for autistic adults (57%)
- Money spent on autistic children (11%)

remainder to the cost of support services. (Mental Health Network briefing 2010)

Dr Andrew Mc Culloch, Chief Executive of the Foundation for People with

Learning Disabilities recently stated in response to research led by the London School of Economics into the cost of autism:

***“Very few people with autism are in employment- it will be no easy task to achieve higher employment rates but the figures suggest that the government should try...Early intervention would help individuals with autism and their families experience a better quality of life and reduce the high costs in later years, saving public money”***

This piece of work is not intended to be a negative view of autism in relation to healthcare and society. During my research I found several positive and encouraging developments for the condition, these include the setting up of specialist residential homes and schools for autistic sufferers. Dr Judy Gould and Lorna Wing have studied autistic children since the 1970s and later set up Elliot House which is supported by the National Autistic Society. It was the first centre in the country to provide a complete diagnostic assessment and advice for people of all ages although the centre is mainly for children adults are often referred who missed the diagnosis in childhood. (Davies 2007, p.61) My 10 year old cousin was fortunate to gain a much sought after place at Ty Coryton in Cardiff which is a specialist residential autistic school. They provide tailored techniques for individuals with autism including Makaton teaching methods. Their goal is:

***“To provide opportunities and experiences for each individual, regardless of ability, to prepare them for later life”***

(Ty Orbis website)

It has been recognised that some of the features of autism could be advantageous to certain careers. Autistic males often have psychological tunnel vision and rigid behavior-patterns such as lining up toys and following strict routines and rituals. If the individual has a high IQ these behaviors can be useful in areas such as engineering and science which require heightened attention to detail. (Exhorn 2005, p.76)

The National Autistic Society (NAS) charity founded in 1962 has a number of specialist facilities to provide support, education and advice to autistic people and their families. They promote awareness of the condition and run regular campaigns such including recently ***“I exist”*** and ***“don’t write me off”*** which aims to help enrich the lives of adults with autism. Several local authorities such as Lewisham, Leicestershire and Workingham have been



encouraged by these campaigns to carry out a future needs analysis of autistic people within their areas to enable them to have a clear idea of who might need services in the future. In 2009 the Autism Act was passed with the aim of meeting the needs of adults on the autistic spectrum. The 6th annual World Autism Awareness Day was held on 2<sup>nd</sup> April 2013 and the Lyceum theatre in London held the first ever UK autistic friendly showing of the Lion King.(NAS website April 2013) These positive developments will hopefully help to allow autistic individuals to fit more successfully into society.

This research into Autism in relation to health care and society has provided some background information on this complex and challenging condition. I have considered whether or not it is a significant healthcare issue and concluded that it was, whilst acknowledging the input of education and social services. I am of the opinion that it is often misunderstood by society and more public awareness is needed to improve perception about autism. My research placed particular emphasis on the need for early diagnosis to provide the best support for autistic individuals which will ultimately benefit society.

My qualitative research added a few personal insights into the condition, the views cannot be generalised but if I had the opportunity I would like to carry out larger, more valid research into the condition within the UK. I found it particularly difficult to find recent UK studies into autism which did not link it to MMR uptake, more American research seems to be available on the condition. During my study I found many positive steps have been taken in recent years in the diagnosis and treatment of autism but further improvements could be made. The following quote provides an appropriate summary to my research: *(Moore, p.13, 2007)*

***“Despite a huge increase in awareness autism remains a mysterious condition”***

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Katy Baran

**Autism Survey**

1. At what age was your child diagnosed with autism?

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2. How long did the diagnosis procedure take

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3. Was your child diagnosed by a GP/hospital/specialist/other? (If other, please state how your child was diagnosed.)

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4 Do you feel you have had enough support from the health care and other services? Provide details if possible.

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5 What additional support if any do you think you could have been given

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6 Do you feel your child is accepted and understood by society?

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7 If no, please can you give a reason why not?

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8 How do you think we could improve society's view of autistic children and adults?

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