

## *Chapter 5*

# **CONSIDERING ADULT OUTCOMES FROM A SOCIETAL PERSPECTIVE\***

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Autism is a condition which was first identified as dysfunctional in the Twentieth Century. Two out of three of the main diagnostic criteria for autism involve social relating: society is the other side of the equation in each of those. Therefore, rather than focussing on the idea of autism as a dysfunction located within individuals, this chapter examines the possible impact of society and social changes on autistic capacities to cope well and contribute to the common good in the Twenty First Century.

Most of those changes have had a negative impact but one area of growth has created a flourishing new autism-friendly environment: information technology and the Internet.

Focussing on correcting dysfunction is counterproductive. Effective communication is a key need for all human beings. Wide ranging research findings and personal accounts of autism both suggest many reasons why speech tends to be a particular challenge for autistic communicators. Computers circumvent most of those problems. In spite of this, at present the odds are stacked against autistic adults having access to computers or the Internet. In the UK new disability rights legislation establishes a right to technological help for everyone who has a communication disability

Autism is currently identified solely by its dysfunctionality (see the diagnostic criteria<sup>1</sup>). This focus on what is wrong means that autistic strengths are systematically ignored. This essay does not deny that autism can be hard to live with, but it focuses on the benefits of the autistic disposition rather than the problems it may cause all concerned. The emphasis on dysfunction and the label of illness have primed public expectations of "a cure". The idea that this is a fundamental misunderstanding of autism underpins this essay.

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\* Some parts of this chapter originally appeared in the AWARES online conference in a much shorter piece entitled "Culture and Ignorance".

<sup>1</sup> Diagnostic and Statistical Manual of Mental Disorders, DSM IV, (APA,1994) and the International Statistical Classification of Diseases, 10th Revision, ICD-10 (WHO,1992).

Of course we need to connect with these young people who are so likely to be excluded, and of course we need to support them and give them opportunities to experience a shared world with us, and flourish in it. But there is no illness to cure – rather there is a way of being, thinking and perceiving to accommodate. Even what gets referred to as “the seriously handicapping condition” is not an illness – it is someone having a very difficult time because of the world they live in as much as because of who they are. It is important to be aware of that, or the world risks losing the distinctive concentration and commitment of the autistic disposition; the world risks exterminating a vital and productive strand of human diversity. A eugenic steamroller is heading towards those atypical bumps.

Lorna Wing, long identified with “the triad of impairments” in autism, has indicated<sup>2</sup> that the triad is inadequate as a tool for picking out classes of person unambiguously and that a multidimensional model is essential to deal with actual diversity. A category is identified by at least two dimensions - two is enough in principle to identify a position on a matrix. But reality and effective thinking both require more. If you think of anything purely as a category member then *ipso facto* you will be ignoring other dimensions along which it may be distinguished – for example its current position in space and time, or its causal history, or its colour, or the fact that it shines in a particular way when viewed from a particular angle. It can be argued that cultural unanimity – often thought of as “common knowledge” - is as much composed of mutual ignoring as anything else. In the case of the cultural identification of autism this conspiracy of ignorance has grave practical ramifications.

However difficult autistic children may be, however hard it may sometimes be for families to cope, autism is not all bad. Yet research results that find autistic strengths are persistently ignored or interpreted negatively. A characteristic example of this trend would be the interpretation of greater accuracy from the autistic subjects in an experiment as “a failure to apply top-down processing”. Two sources for information about a range of these typical distortions are Mottron et al 2006<sup>3</sup> and a presentation<sup>4</sup> by, psychology professor, President of the American Psychological Association Morton Gernsbacher, who is also mother of an autistic child. Given that researchers are working within a context determined by the value laden and culturally biased diagnostic criteria the interpretive bias Mottron, Gernsbacher and colleagues expose is hardly surprising.

Applying the diagnostic criteria entails making assumptions about the typicality and desirability of certain behaviour patterns. Being identified as autistic entails being identified as doing all sorts of deviant things in deviant ways. How do we recognise the typical from which these behaviours deviate? There are two ways of doing that, one being explicitly subjective and value laden, “this seems typical [ergo *fine*] to me, this not...”, The other way of discriminating typicality from atypicality depends on deviation from a statistically derived norm. In this latter case the values in play derive from the idea that it is right and desirable to be as near the middle of the bell curve of normality as possible – ie it is seen as desirable to be as much like everybody else as possible. This is an inherently puzzling idea. It also runs counter to what we know about essential diversity from the study of ecology – species need

<sup>2</sup> Wing, L (2005) “Reflections on Opening Pandora’s Box,” *Journal of Autism and Developmental Disorders*, 35, 2, 197-20.

<sup>3</sup> Mottron, Laurent, Dawson, Michelle, Soulières, Isabelle, Hubert, Benedicte, Burack, Jake (2006) Enhanced Perceptual Functioning in Autism: An Update, and Eight Principles of Autistic Perception. *Journal of Autism and Developmental Disorders*, Volume 36, Number 1, pp. 27-43(17).

<sup>4</sup> [http://qstreamer.doit.wisc.edu/autism/Core%20Deficits\\_300k.mov](http://qstreamer.doit.wisc.edu/autism/Core%20Deficits_300k.mov)

variety in order to prosper and flourish long-term. Peter Allen and colleagues makes a formal (but easy to follow) case that human creativity and exploration are enhanced by synergy between individuals with varied properties<sup>5</sup>. Ballastexistenz's typewriter analogy makes almost the same point: "Society would not be what it is if everyone in it were the same. The typewriter in my room would not work if it were made entirely of screws and nothing else."<sup>6</sup>. The strong genetic component in autism suggests naturally occurring diversity is at work when autistic children are born.

The diagnostic criteria of course do not create the values they enshrine; but they legitimize those pejorative values. They give the stamp of authority to playground contempt for the atypical:

"Children bullied and teased me incessantly for many years. They called me names, threatened me, ignored me and rejected any efforts I made to join group conversations. I felt as if I were an alien on a planet that was not my own. I often became very sad and depressed, although I continued tenaciously to produce my best academic efforts in school and brought home mostly A's (and some B's)."<sup>7</sup> Scott Robertson

The theme of alienation recurs again and again in personal accounts of autism, see for example Ooops!... Wrong Planet Syndrome (an early classic autistic site, only available as archive now), O'Neill's "Through the eyes of Aliens"<sup>8</sup>, Williams's "Nobody Nowhere"<sup>9</sup>, Gerland's "A Real Person"<sup>10</sup>, Lawson's "Life Behind Glass"<sup>11</sup> and many more.

In her book 'Children under Stress' (1973)<sup>12</sup> Dr. Sula Wolff has several pages dealing with autism. She says, "Once the diagnosis has been established parents and teachers find it easier to decrease their demands for conformity, to educate the child by building on his particular interests and aptitudes and to insist on the essential requirements of social behaviour with less hostility."<sup>13</sup> This humane and optimistic take on the role of diagnosis implies that people may typically enforce those social requirements in a way that seems hostile to the young person on the receiving end. A friend with autistic twins asked one of them when he was about eleven, "Why were you two always running away when you were little?" His unhesitating answer was, "because you hated us". Even when we don't think that's what we're doing, how does a child distinguish between hostility towards his or her behaviour (biting and climbing everything in this case) and hostility towards his or her very being?

"Inappropriate behaviours" tend to figure large in descriptions of autism. Both the involuntary and thus uncontrolled communication of strong emotion, and direct attempts to

<sup>5</sup> Allen, P.M. and McGlade, J.M. (1987) Evolutionary Drive - The Effect of Microscopic Diversity, Error Making, and Noise (pdf) in *Foundations of Physics* Vol. 17, No. 7.  
Evolutionary Drive - New Understandings of Change in Socio-Economic Systems (pdf) by P.M.Allen, M.Strathern, J.S.Baldwin.

<sup>6</sup> <http://ballastexistenz.autistics.org/?m=20060226>.

<sup>7</sup> Life with Asperger's: One man tells his story. Scott Robertson on [www.northjersey.com](http://www.northjersey.com), by-line Bob Ivry.

<sup>8</sup> O'Neill, J.L. (1999). *Through the eyes of aliens: A book about autistic people*. Philadelphia, PA : Jessica Kingsley.

<sup>9</sup> Williams, D. (1992). *Nobody nowhere: The extraordinary biography of an autistic*. New York : Avon.

<sup>10</sup> Gerland, G. (1997). *A real person: Life on the outside*. Souvenir Press, London, UK.

<sup>11</sup> Lawson, W. (1998). *Life behind glass*. Philadelphia, PA : Jessica Kingsley.

<sup>12</sup> Wolf, S. (1973) *Children under stress*. Harmondsworth: Pelican.

<sup>13</sup> Cited by Philip Ashton on The Misbehaviour of Behaviourists discussion board.

communicate which do not draw from a standard repertoire of expressions, are likely to evoke negative reactions. These negative reactions tend to exclude recognition or acknowledgement of legitimate issues and responses; they tend to ignore efforts to get things right. Yet making the effort to perform so as to fit in is often exhausting and likely to be at the expense of other capacity (see discussion of monotropism at [www.autismandcomputing.org.uk](http://www.autismandcomputing.org.uk) and see <http://ballastexistenz.autistics.org/?p=156> where there is a version of 'spoon theory' which also builds on the idea that there is a limited supply of processing resources). So what is seen as socially enabling by the carers/educators can actually be personally disabling. Here is what highly articulate autistic intellectual Larry Arnold has to say about this:

"For all the veneer of civilisation that I have as a 'high-functioning' autistic person, at least I can choose when to be 'normal' and when not. Not everyone with autism has that choice, either because they cannot appear normal - despite whatever therapeutic goals have been forced upon them - suffering the inevitable consequences of society's condemnation, or because they have been so rigidly punished for being abnormal that the mask [of normality] is all they know. I could easily have been the second of those two, and perhaps in spite of myself I am often the first, as well."<sup>14</sup>

This pattern of autistic experience is a result of seeing autistic children as defective and focussing excessively on fixing the defects, especially those around the presentation of self, which include spoken language (Goffman<sup>15</sup>, Murray<sup>16</sup>). Focussing on the negative in this way is likely to be counterproductive, and sometimes at least may precipitate a decline in areas of strength with little or no gain in areas of weakness. Kuschner et al (2006) conclude, "Recognizing stark discrepancies in abilities is particularly important in diagnostic and cognitive evaluations. Treatment and educational planning for individuals with autism must consider a range of abilities, rather than a single domain."<sup>17</sup>

Below are some figures extracted from Lynn Mawhood's thesis<sup>18</sup> on adult outcomes. I am not qualified to analyse these in statistical terms but I believe there are some discernible trends. Indeed these trends fall into a well recognized pattern, "An uneven pattern of cognitive abilities has previously been demonstrated in individuals with autism spectrum disorders (ASDs). This pattern suggests that evaluation of overall intelligence scores may actually mask a unique profile of strengths and weaknesses within this population." (Kuschner et al 2006 – op. cit.) What my analysis here adds to that is change over time.

Bearing in mind that the WISC and WAIS IQ scores are not strictly comparable, the only area in which almost everyone in Mawhood's study improved appears to be in verbal IQ (we don't know about h, and a's verbal IQ was more or less stable). We may assume that this trend is a result of social pressure and educational focus, while those in turn stem from a natural longing to communicate successfully with these hard-to-reach children and help them achieve ways of communicating their needs. However, the effect of this can be a demand for

<sup>14</sup> "What is Normal? The perils of doing it society's way" Larry Arnold, AWARES online conference, 2006.

<sup>15</sup> Goffman E(1956) *The Presentation of Self in Everyday Life*. New York: Doubleday.

<sup>16</sup> Murray D, (1997) Normal and Otherwise, paper presented to Conferences on Autism in Durham, organised by the Autism Research Unit Sunderland; available online at [www.autismandcomputing.org.uk](http://www.autismandcomputing.org.uk).

<sup>17</sup> Kuschner E, Bennetto B & Yost K (2006) Patterns of Nonverbal Cognitive Functioning in Young Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, epublication September 2006.

<sup>18</sup> Mawhood, L. (1995) *Autism and Developmental Language Disorder: Implications from a Follow-up in Early Adult Life*, unpublished PhD thesis, University of London.



achievements in conformity with social norms in areas where the autistic children struggle the most. Confidence is an important issue here.

According to Wikipedia, "Raven's Progressive Matrices are widely used non-verbal intelligence tests. In each test item, one is asked to find the missing part required to complete a pattern. Each Set of items gets progressively harder, requiring greater cognitive capacity to encode and analyze. The test is considered by many intelligence experts to be one of the most g-loaded in existence." That is to say, if there is such a thing as "general intelligence" then these matrices are thought to be exceptionally good at measuring it.

Each of these young people starts life with a higher Raven's than verbal IQ, in many cases strikingly higher, see for example a, b and m. That is least true of n, who is the only one to have a higher performance IQ than Raven's at Time 1: from a fairly low overall base n does well in every area, improving by 44 points on the Raven's IQ, and is the only individual in this set who made a significant gain in the "performance IQ" dimension. L, whose Raven's and WISC performance scores are almost the same as each other follows a similar but less notable trajectory of slight over all improvement. In marked contrast, a, b, h, k and m experienced steep declines (range -39 to -78) in Raven's IQ scores and less startling drops in performance IQ scores (-7 to -24). These five all had Raven's IQs well above normal, from 117 (m) to 181 (a), in early childhood (q with a similar but less extreme trend had a Raven's IQ of 103 at time 1). It seems as though a large area of intelligence and potential in these young people may have been ignored and discounted; one might even conclude that they have been actively stupefied by some of their encounters with life.

These are likely to be children with strong and persistent interests which don't fit stereotypical expectations, and who may not consequently adapt their interests even when they are aware they don't fit. Knowing you don't fit is neither sufficient for knowing what it is that makes you anomalous nor, if you do find that out, for adapting accordingly.

Kanner et al.<sup>19</sup> (1972) found that what had been labelled "excessively narrow interests" or "isolating obsessions" were often built on later in life to become the foundations of employment and to make connections with other people. If we see "uneven skills profile" and "unusual interests" in autism as inherently maladaptive, we may fail to accommodate those differences constructively. We may fail to give the children opportunities to learn through observation, exploration and discovery, to learn in the ways that suit them best. We may fail to give them access to ways they communicate best, and we may insist on the spoken word even when it is clearly effortful for the individual and ineffective as a communicative tool because of articulation or processing issues. As Von Teschner commented in response to feedback to his online conference paper (2006)<sup>20</sup> "Even if spoken language is always hoped for, the best should not be the enemy of the second best. It is important to regard alternative communication skills (manual and graphic signs) not only as a sign of language impairment but also of ability and true achievement."

If we wish these children to flourish as well as fit in, then giving them time and tools to develop, share, and explore their interests might in the long run inspire successful communication and be more productive than focussing on fixing their behaviour.

<sup>19</sup> *How far can autistic children go in matters of social adaptation?*

Kanner L, Rodriguez A, and Ashenden B (1972) *Journal of Autism and Childhood Schizophrenia*, 2(1):9—33.(available free from the superb library at [www.neurodiversity.com](http://www.neurodiversity.com))

<sup>20</sup> Von Teschner S (2006) "Graphic communication may support comprehension and use of spoken language in children with autism" AWARES online conference.

**Individual Psychometric Scores at Time 1 – young children, and Time 2 – young adults  
(individuals who did not have Raven's scores at Time 1 have been omitted) – Figures  
from thesis of Lynn Mawhood (op. cit.)**

	WISC Verb IQ T1	WAIS-R Verb IQ T2		WISC Perf IQ T1	WAIS-R Perf IQ T2		Raven's 'IQ' T1	Raven's 'IQ' T2	
a	84	81	-3	110	86	-24	181	103	-78
b	72	122	+50	117	100	-17	150	117	-33
h	-	59	-	82	58	-23	120	67	-53
k	103	121	+18	113	94	-19	156	113	-43
l	67	75	+12	93	96	+3	95	110	+15
m	48	57	+9	94	87	-7	117	78	-39
n	57	79	+22	80	92	+12	67	111	+44
p	55	70	+15	92	79	-13	97	108	+11
q	61	75	+14	89	82	-7	103	92	-11
s	52	61	+9	82	76	-7	93	98	+5

Kuschnier et al (op. cit.) postulate a connection between perceptual and conceptual/social development and say, "If this connection... is supported, then treatment planning should focus on using the nonverbal strengths identified here to ameliorate other areas of weakness. By tapping into perceptual strengths, for example, picture schedules or visual instructions can be used to help enhance the formation and initiation of new ideas or goals." Indeed that is just the sort of procedure described in Von Teschner's case study (op. cit.) "Graphic communication may support comprehension and use of spoken language in children with autism".

Both articulation and processing issues evidently play a role in making speech harder for many autistic children than graphic communication. In addition to those issues, many children may be averse to a particular way language is used, ie to impose other people's interests. In an online interview with Adam Feinstein of Autism Connect, Professor Uta Frith suggests of the phase of speech regression in early development which appears often in autistic children (see Rapin 2006 for a discussion<sup>21</sup>):

"This theory is still untested. The basic idea is that there are two ways of learning language. One very ancient way relies simply on making associations between sights and sounds and learning these associations in a rote fashion. This system, in principle, works for children with autism and can start from an early age. But it is not the way normal children learn language, which takes off from about 18 months onwards. The second way is by tracking the speaker's intention and making associations only in certain situations, that is when the spoken word maps on to the world in the speaker's eyes and in the listener's eyes."

<sup>21</sup> Rapin I (2006) *Language heterogeneity and regression in the autistic spectrum disorders – overlaps with other childhood spectrum disorders and overlaps with other childhood language regression syndromes* AWARES online conference.

Rather than this being a dysfunction of the child, I suggest (also an untested theory) it is a result of a shift in how language is used by carers at around the same time. In the first phase of encouraging language use with infants we use it to express our shared interest with the baby, ie we use words which refer to what the baby is showing an interest in at any given moment. That is how babies learn what words mean. During the next phase we spontaneously start to use these words the baby has learnt in order to re-direct their attention. For example, we will naturally be inclined to draw the baby's attention to, say, a cat coming into the room. If the baby has already learnt the word for cat, then we will use that word to take the baby's attention from its current focus to our chosen topic of the cat. This may be an aversive experience if one's attention is focussed elsewhere<sup>22</sup>. In the terms of my PhD thesis, this is a transition from speech used purely as a way of expressing interest to its socially developed role as a tool for manipulating (not intended in its pejorative use, just means, "taking hold of and doing things with") other people's interests.

So I suspect what happens to some of these children is that they embark happily on the language project, which they enjoy so long as it doesn't interfere with the directionality or focus of their interests. When they realise that speech can be used to impose other people's topics it may become strongly aversive. Many children find it fun to be told the cat has arrived when they are paying attention to something else, others find it invasive. An analogy I find helpful is with tickling: some children love being tickled, others find it alarming and invasive. In either case there are appropriate and inappropriate moments: for the sensitive children tickling will only ever be appropriate when they are relaxed and 100% comfortable with the people doing it. I suggest that what makes for comfort in being on the receiving end of speech as opposed to tickling is how close the subject matter is to one's own interests. It is inherently rewarding and agreeable to experience other people sharing one's interests. To illustrate that this is true for autistic children as well as anyone else, consider the following event.

A special needs teacher and myself are visiting a special school class for under fives. She engages the school's teacher while I look around. I encounter a boy sitting at a computer absorbed in a game and sit down beside him. I watch as he plays and comment occasionally on the events on screen. When he has finished the game, the boy turns towards me and makes brief eye contact. He starts another game, again I watch and comment appropriately, following his focus of interest throughout (very easy to do on a computer). Again, when the game is over he turns towards me and makes eye contact, this time for rather longer; it is a decidedly friendly contact and we settle down amiably to a third game. Then the word "Trevor" starts to be heard, being repeated at frequent intervals, and getting louder and louder. The teacher has decided Trevor must pay attention to her, Now! Neither Trevor nor I can identify a reason for this disruption. He huddles closer to the game and tries to go on playing it. As she comes right up to us, every bit of his body language tells us he is shrinking away from her. The teacher has been raising her volume as she approaches; finding Trevor still not complying when she gets there, she bends over and thrusts her head between him and the screen, her face eyeballing his. Very briefly he raises his eyes to meet hers then cowers back down again. She stands up, crosses her arms and says smugly, emphatically, and derisively "That's what you have to do with Trevor".

<sup>22</sup> For more of the argument see, [www.autismandcomputing.org.uk/normal.en.html](http://www.autismandcomputing.org.uk/normal.en.html)

Unfortunately little Trevor has learnt completely the wrong lessons from his encounter with this teacher (constantly reinforced I imagine) – if what we want is for him to see other people as potential companions, that is (if compliance is all that is aimed for, then – in my view – the teacher is on the wrong course). Trevor may learn how to fend off these bullying ways with superficial compliance, but he is not going to *like* people any the better for it, it is not going to make him even want to *be* with people, let alone interact with them. Everything about the exchange he has had with his teacher is alienating for him.

“Stubborn”, “obstinate”, “un-cooperative”, “non-compliant”, are often used to describe autistic people, of all ages. All those words assume that some other people have the right to tell you what to do, and that learning to do what other people tell you to do is an essential element of learning – what is sometimes called “learning to learn” but is really “learning to be taught”. From that perspective getting a child to sit down is a huge social achievement. But it may not be the best way for autistic children to learn, they may do particularly well when they have opportunities to learn for themselves. Not all children benefit from being taught, and there are reasons to think that giving children opportunities to find things out for themselves has the potential to greatly benefit the education of many autistic children. The case study by Von Tetschner (2006) mentioned above shows how well such an approach can work. Here is something Kanner said about this in a 1951 follow up study on the children he had diagnosed,

“One may even say that these children learn while they resist being taught. Several children kept on crawling at a time when the parents felt that they could be walking! Much effort was expended in propping them up and encouraging them to make steps. There was no success. But one day, suddenly, when it was least expected, the children got up and walked. The parents of Frederick W. spent hours each day “teaching” him to talk. They begged him to repeat words after them. He remained “mute,” except for two words (“Daddy” and “Dora”) that he had never been taught to say. But one day, at about 2-1/2 years of age, he spoke up and said: “Overalls,” a word which was decidedly not a part of the teaching repertoire.”<sup>23</sup>

There are further reasons for questioning compliance as a leading goal. Doing what everyone else does is not necessarily a good thing: we need explorers, see (Allen & McGlade cited in footnote v) and we need non-conformists and individuals who will stand out against the crowd because they see things differently<sup>24</sup>. Learning always to do what you are told can make you inappropriately compliant and potentially a passive victim of abuse of all sorts (personal reports from autistic females frequently reveal sexual abuse). “Persons with autism are at greater risk for sexual abuse than persons without autism. Many cannot communicate what happens to them. Many cannot consent or refuse sexual advances effectively. Many cannot discern danger signs.”<sup>25</sup>

In addition to the personal issues about compliance and vulnerability, there are cultural issues about non-compliance and pejorative language. The very characteristics which get called obstinate in one context will be called committed, dedicated, resolute and determined in another. For some examples of obviously admirable autistic persistence and determination see some of the short videos in the Posautive Youtube group.<sup>26</sup> You will also find there

<sup>23</sup> Kanner L. (1951) The Conception of Wholes and Parts in Early Infantile Autism *American Journal of Psychiatry*. 1951 Jul;108(1):23-6 (available free from the superb library at [www.neurodiversity.com](http://www.neurodiversity.com))

<sup>24</sup> For an example of why see [www.youtube.com/watch?v=40XpnCqZnhQ](http://www.youtube.com/watch?v=40XpnCqZnhQ)

<sup>25</sup> <http://groups.msn.com/TheAutismHomePage/autismandsexualissues.msnw>

<sup>26</sup> [www.youtube.com/groups\\_videos?name=posautive](http://www.youtube.com/groups_videos?name=posautive) is the link for the whole group.



plentiful evidence of sociability, affection, and creativity which further contradicts the prejudiced stereotype of autism fostered by the diagnostic criteria. As for compliance, in my observation, when a person – autistic or not, child or adult – can appreciate the point of a task and is invited to help carry out that task they will do so with good will – hopefully in a spirit of cooperation rather than compliance.

In their follow-up report by on children they had seen and diagnosed, Kanner and colleagues at John Hopkins quote one employer saying of his autistic worker, that he is “outstandingly dependable, reliable, thorough, and thoughtful towards fellow workers.” (Kanner, Rodriguez & Ashenden 1972<sup>27</sup>) More recently Hagner and Cooney’s study of fourteen “successfully employed individuals with autism” found “...superlative evaluations of employees with autism... . Individuals with autism clearly have skills and talents valuable to the business world in a wide variety of community jobs, and in the worksites studied, most were viewed not merely as successful but as outstanding employees.” They go on to say that, “Another unexpected finding, and one that tends to disconfirm to some degree a common stereotype about individuals with autism, was how social the employees were perceived to be. Most employees had frequent, meaningful interactions with their co-workers and were regarded as friendly and sociable.” pp 95-96 (Hagner & Cooney 2005<sup>28</sup>).

Autistic people are often accused of lacking empathy. It would appear from the discussion so far that a lack of empathy is widespread. If empathy involves “tuning in” to another’s feelings then my observation - based on thousands of hours of one to one with a variety of autistic adults at every level of apparent ability - is that autistics do learn to do this. That is, they learn to pick up on basic positive and negative feelings as we all do, possibly on a similar timescale, possibly earlier, possibly later. One mother reports, “shortly after being diagnosed at age just 3, [my daughter] showed distinct signs of empathy. I was talking to a “coordinator” for her daycare at home, and I was highly upset by the diagnostic experience. I began to cry – it was a sympathetic ear. My daughter saw me crying and brought me a Kleenex. The coordinator said ‘Autistic children don’t do that.’ But, [she] had always done things like that.” It may be that more fine-tuned emotional discrimination between different positive or negative feelings will emerge at a later age than average, if at-all. But that thumbs up/thumbs down polarity underlies all emotional states, and autistic people are not indifferent to this. Fitting in and not fitting in are about being on the receiving end of those social meanings. Autistics don’t fit because we tend not to accommodate them even when they’re doing their darnedest to accommodate us.

Outside the therapeutic context, “empathy” tends to be used to describe direct person-to-person feeling responses – you feel bad, I feel bad; you feel good, I feel good, and vice versa – thus we understand how each other feels. Friendly personal feedback loops can be created in which shared feelings are expressed to mutual recognition and affirmation. It is about understanding Otherness by identifying Sameness. Possibly empathy has assumed more prominence and acquired such cultural value because societal changes have tended to remove other (non-logo) sources of a sense of common identity (see Bauman 2005)<sup>29</sup>. It is also

<sup>27</sup> Kanner L, Rodriguez A, and Ashenden B (1972) *How far can autistic children go in matters of social adaptation?* *Journal of Autism and Childhood Schizophrenia*, 2(1):9–33.(available free from the superb library at [www.neurodiversity.com](http://www.neurodiversity.com))

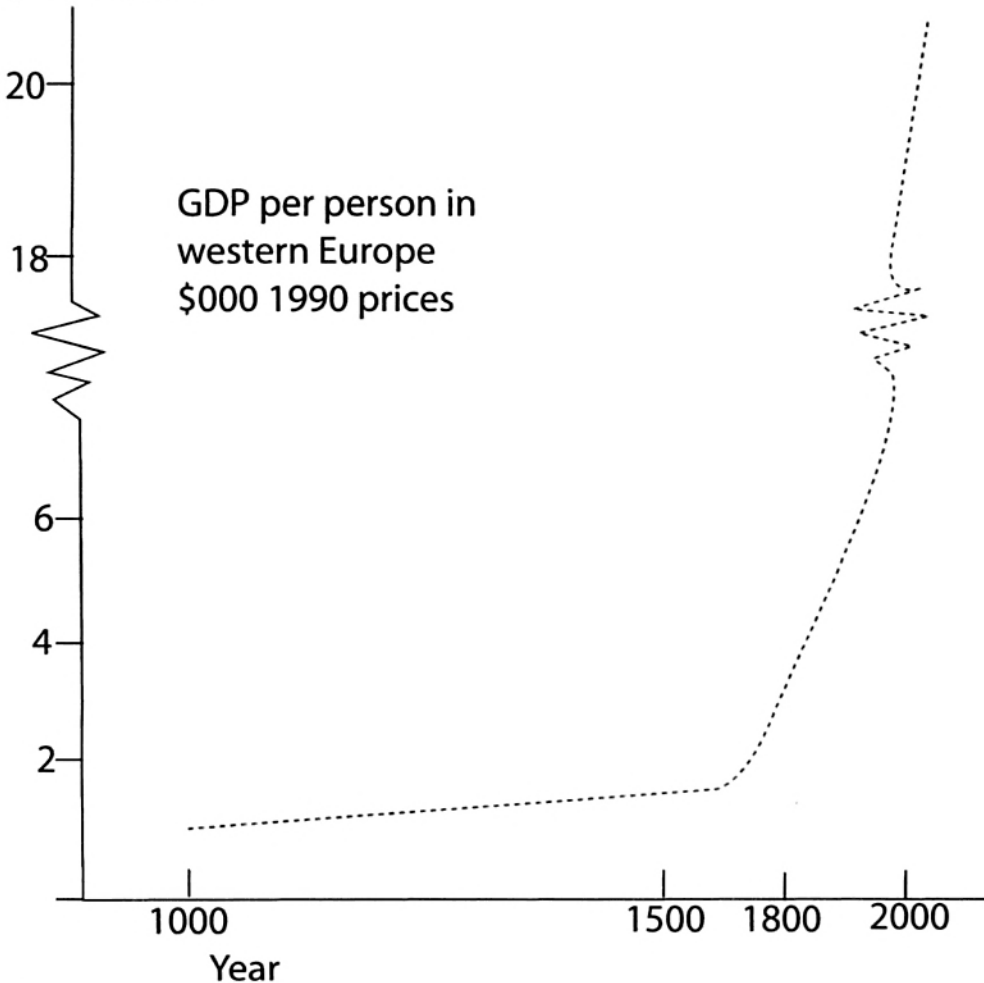
<sup>28</sup> Hagner, D, and Cooney, B F (2005) “I do that for everyone” *Focus on Autism and Other Developmental Disabilities*, Volume 20, Number 2, Summer, pp. 91-97(7)

<sup>29</sup> Bauman, Z (2005) *Liquid Life*. Cambridge: Polity Press.

perhaps part of the 'therapising' of daily life discussed in the Ballastexistenz blog.<sup>30</sup> It is just one of the ways in which life in society has become less accommodating to people with an autistic disposition.

Gross National Product and correlative social, cultural and sensory changes have increased exponentially during the last century or so, according to an article in *The Economist* timed to greet the new Millennium, cited in Hodgson & White (2001)<sup>31</sup>

Problems with change feature in the third main diagnostic criterion, Kanner himself placed great emphasis on these autistic difficulties, and they are frequently reported both by autistic people themselves and by those who work with them. The increasing rapidity of change we have noted is likely to make a disposition averse to change less adaptive. Among the changes which are likely to have had the most impact on opportunities for autistic people are changes in the labour market. In *Relax! It's only Uncertainty* (2001) Hodgson & White (op.cit.) suggest "An increasing level of global ambiguity (like global warming) has produced a rise in the sea levels of uncertainty. The inhabitants of the planet, having previously been accustomed to life on firm ground, now need to adapt to the more fluid environment in which they find themselves."



<sup>30</sup> <http://ballastexistenz.autistics.org/?p=169>

<sup>31</sup> Hodgson P, and White RP (2001) *Relax, It's Only Uncertainty*, FT Prentice Hall, London

A feature of these rapid and destabilizing changes is a great increase in the service sector with its demands for social versatility and a correlative decline in jobs that do not make such demands, eg those such as farming, manufacture and mining. This must decrease the chances of people with poor social versatility being able to find a valued role in society. Between 1841 and 2001 labour market demand for social versatility rose from 32% to 75%<sup>32</sup>.

Even within the ostensibly autism-friendly sectors, such as the type of job advertised in the New Scientist (where I carried out some informal research on this), team work and good communication skills are almost universal requirements. Social versatility without effective communication is impossible. All these factors tend to militate against autistic success or even acceptance.

One autistic man describes his situation as follows:

'I am a 50 year old adult with so-called "high functioning" autism. I live in virtual isolation, even though I crave to have friends. I am on permanent disability, even though I could learn almost any job, no matter how technical. I have simply been exiled from today's "on the go" "multi-tasking" society'.

This is a sadly typical case, posted as a comment on the extraordinary website [www.gettingthetruthout.org](http://www.gettingthetruthout.org) created by a non-speaking autistic woman.

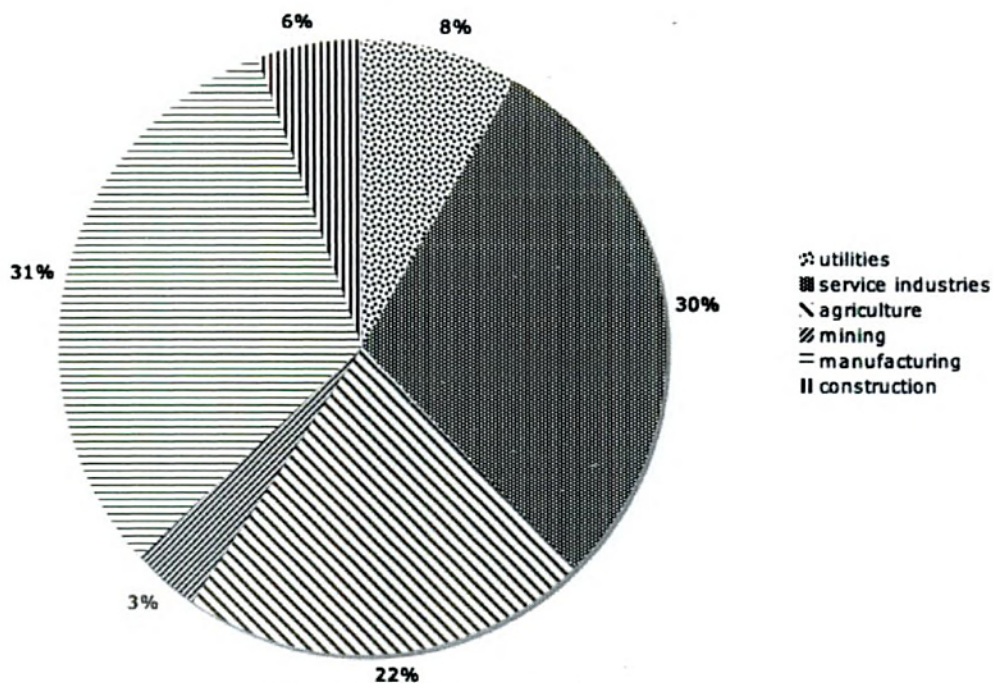
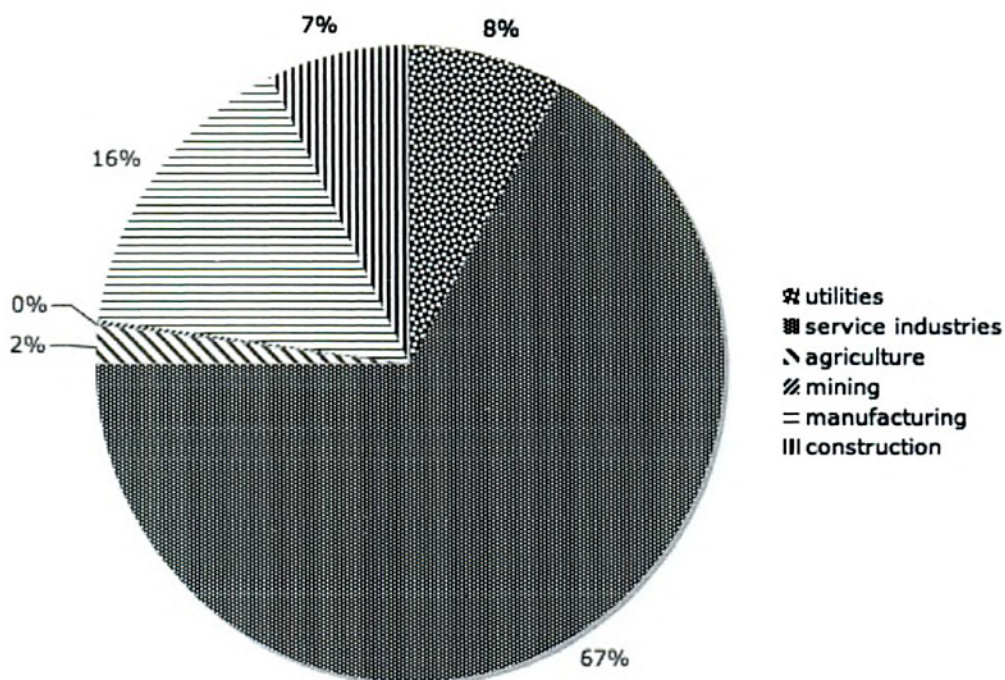
As we have been discussing above, many features of the world we live in have made it less and less autism friendly – the rapid changes have included loss of ritual and loss of rules as well as an increasingly hostile labour market and a paranoid and unstable society. However, one area of rapid change has provided a compensatory autism-friendly environment, ie the growth of digital technology. As we have seen, for various reasons graphic rather than spoken use of language tends to be favoured by autistic individuals, perhaps especially when young. Computers offer that graphic interface which is preferred, and lots of other features that can help autistic people to be truly included and able to contribute.

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Computers have the following attributes:

- Contained, very clear-cut boundary conditions
  - Naturally monotropic
  - Context-free
  - Rule-governed and predictable thus controllable
  - Safe error-making
  - Highly perfectible medium
  - Possibilities of non-verbal or verbal expression
  - A computer "joins the individual's attention tunnel"
- 

<sup>32</sup> Figures from the UK National Census.

**1841 UK labour market****2001 UK labour market**



Normal communication involves using standard forms (usually a common language) so that people can identify and share interests other people express. How to engender the desire to use a common tongue is often a central challenge for those who love an autistic child. How to acquire the skills of speech, with all its uncertainties and context-dependencies, may be an insuperable challenge for the child. But every computer program has its own self-limiting context and its own definite meanings. A large proportion of autistic people find the pace, structure, and lack of extra social signals make electronic communication viable when other means of communicating (receptive or productive) are impossible. This is notably true even of people who do not use spoken language.<sup>33</sup> Effective deployment and understanding of shared meanings can be much more easily achieved within that restricted context than in the woolly, waffly, world of speech. And of course these meanings are a two-way bridge - the non-autistic participants find communications much easier too. Without effort, each goes halfway to meet the other.

So computers have the potential to deliver language without the drawbacks of speech. Both articulation and processing issues are reduced or overcome, communication is promoted, and maximum control over who you communicate with, on what topics and when is conferred on the user. These features of computers all suit autistic people particularly well. Bölte (2006)<sup>34</sup> is a useful recent overview of studies of computer use in autism. It concludes that "computer-aided treatment of autism houses a large potential for helping affected individuals to acquire underdeveloped capacities". Individuals on the autism spectrum themselves emphasise the value of computer access both for communication and for research purposes. As one autistic researcher said, "X won't even communicate with autistics by email, the way most of us communicate best, this is like demanding that deaf people speak 'right' or that paraplegics climb the stairs" (Michelle Dawson, personal communication).

Despite all the drawbacks of 21<sup>st</sup> century life for autistic people, computers provide an environment which reverses the trend. As communication becomes more and more reliant on information technology autistic traits become more and more widely useful. Here is one recent comment on that from a mother:

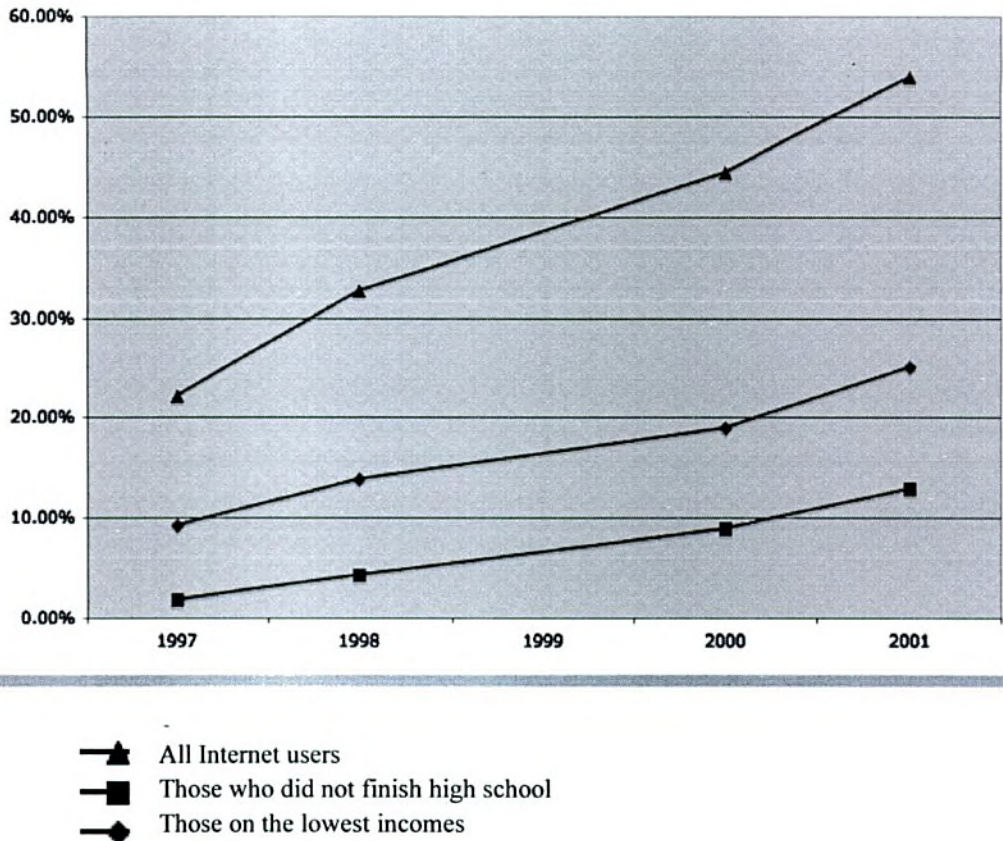
All of my children have a pc 6, 7, 10, 19, 22 they love them. My children can sit and do things on pc for hours, as a gift with our condition is hyperfocus, so we learn lots in one go, in fact none of us like to get off until we have finished what we are doing)... For my family the pc is a line to knowledge, nothing we cant find out about. Beats trying to talk to the NT world. The pc has helped my children to learn to read and do all sorts of things, I feel like we were born in time for the pc.<sup>35</sup>

Home computer ownership is now widespread and continues to rise. In one survey in the US, by 1999 nearly 90% of graduates were using computers. It seems reasonable to assume a general correlation in levels of computer use with levels of educational attainment and/or income. Certainly such a correlation obtains for Internet use in the US.

<sup>33</sup> [www.gettingthetruthout.org](http://www.gettingthetruthout.org)

<sup>34</sup> Bölte S (2006) *Computer-based intervention in autism spectrum disorders* in AWARES online conference

<sup>35</sup> Christine Heavey on AWARES online conference discussion board



According to these figures from the US National Telecommunications and Information Administration, Internet use, although rising in all sectors, is significantly lower among people with lower educational attainment and lower incomes.

A New York State Health Department study found “Compared to the general population, persons with disabilities were more likely to have reported lower educational attainment and more likely to be in a lower income bracket. They were far more likely to be unemployed, primarily because their disability prevented them from working”<sup>36</sup> Throughout the world, people with disabilities of every sort are most likely to be in the lowest income bracket. People with disabilities that affect communication are least likely to complete higher education and move on to further education, and a tiny percentage of autistic individuals are employed. According to Britain’s National Autistic Society, “Only six per cent of people with ASD have a full-time job compared to 49% of people with general disabilities.” The people who most need to access this technology are exactly those who are least likely to do so. This compounds their exclusion. Yet as we have seen there is plentiful evidence that these are the people who are most likely to benefit from access to the sort of assistive, and liberating, technology a computer can provide.

Happily, in the UK these arguments have been recognized, as have their implications for disabled people’s rights to support so they can realize their full potential. These rights are in

<sup>36</sup> [www.nyhealth.gov/nysdoh/prevent/chart/discussion.htm](http://www.nyhealth.gov/nysdoh/prevent/chart/discussion.htm).

the process of becoming enshrined in law. Wherever in the world the rights of disabled people are taken seriously these rights to communication support must eventually become legal rights.

Under the heading "Duty to make arrangements..." the legislation requires "practical assistance and support for [the disabled] person including, but not limited to— (xviii) the provision of, or assistance in obtaining, consumer communications apparatus and services such as a mobile or fixed- line telephone, a computer, a digital television receiver, a digital radio receiver, a broadband service or digital television service and any assistive equipment required in connection with this."<sup>37</sup> Support to use these must also be supplied as needed.

The adoption of these measures has the potential to transform long-term outcomes for autistic adults.

We have seen how damaging society can be to the chances of autistic fulfillment and success, and we have seen that keyboard communication may alter or even reverse that negative impact. I conclude with a true story of autistic fulfillment and success:

At 4 years old Alex didn't talk ... . Assessments around that time report little to no eye contact, frequent significant temper tantrums, no expressive speech, language, communicative intent or "appropriate social interaction". When Alex was diagnosed we did not view him as a collection of deficits. We accepted that we had a very different child with a very different road ahead than that of his siblings and peers. We assumed competence. We recognized and worked with his strengths.

He started talking when he was 6, mid-way through grade 1. A classmate taught him to talk. But just before he turned 4, using Augmentative Communication, Alex began to type [and later moved on to a laptop computer]... This June 27th, Alex will attend his high school graduation ceremony, where he will be graduating with honours....

Alex is proof that inclusion absolutely can and does work. Alex has been fully integrated, with a TA [teaching assistant] in most but not all classes, doing the regular curriculum, since grade 1. His average in high school, taking a mix of academic, general and open courses, is in the high 80's. He is graduating, with the peers he began school in grade one with when he was "the kid who can't talk", and he is on the honour roll. He's been on the Cross Country and Track and Field Teams all three years and I don't think he missed a single school dance, right up to and including the prom.<sup>38</sup>

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<sup>37</sup> Disabled Persons' Independent Living Bill, [www.parliament.the-stationery-office.co.uk](http://www.parliament.the-stationery-office.co.uk)

<sup>38</sup> Statement to the Canadian Senate (2005) by Janet Norman-Bain, (owner of Ooops!...Wrong Planet Syndrome mentioned above) <http://www.isn.net/~jypsy/AuSpin/senate05.htm>

Bardwell and Philip Ashton for their very useful research contributions to this essay in particular. Sebastian Dern also deserves special thanks.

All URLs were accessed between September 26<sup>th</sup> and October 17<sup>th</sup>, 2006.