

Whose Normal Is It Anyway?

By Dinah Murray

Autism is by definition a condition in which society plays a role (see Chapter 2); some aspects of what that role is are considered in this chapter. Using several of the ‘signs of autism spectrum’ adapted from a website list intended to help people recognize autism, I show how little translation they require in order equally to be applied to non-autistic behaviour. This will make it explicit how the value judgements involved depend on one’s point of view. I suggest that inappropriate behaviours perpetuated by Others contribute to the social climate which turns autistic spectrum conditions into disorders (Jordan 2007; and see Wendy’s discussion in Chapter 4).

All the ‘inappropriate behaviours’ of which young autistic people are accused are mirrored by adults on the typical side, who inflict them upon the young autistic people as they grow up: non-communication; repetitive behaviours; obsessions with alien topics; failure to appreciate distinct points of view; insensitivity to personal space; etc. If Others can learn to recognize when they are producing harmful behaviours such as those discussed below, then fewer ‘crises of disorder’ will happen to autistic people. As a result, their (as well as the Others’) abilities will be maximized rather than suppressed.

Extreme difficulty in learning language

It is hard to learn another’s language unless it is being used to express meaning in a shared context. Spoken language needs to relate to

common interests if it is to be effective communication. Likewise, tuning into another person's interests gives one a chance to learn their language. Others typically stop doing this once a child has acquired a basic vocabulary. Instead they begin using the acquired words invasively and directly.

People routinely seek to get children involuntarily involved in externally imposed would-be common interests. They expect children to disengage from their own current interests and move willingly into the imposed spheres of interest. In fact this is a key dynamic of social life – language reaches, arouses and informs other people's interests and, as a result, people become involved with each other's projects and enter into many shifting communities of interest.

Keeping up with the flux of normal social discourse involves a capacity to switch topics comfortably. People with deep interests may be so absorbed in each current interest that this rapid switching is deeply uncomfortable or impossible to adjust to. Much of the difficulty for autistic children and adults in learning verbal language may be attributed to failure on the part of Others to tune in and make them comfortable with the speech offered them by using it to address what they are interested in. Similarly, Others may fail to allow enough processing time to adjust to a necessary change of topic.

Others' failure to note and adjust to where the autistic interests are guarantees that their every attempt to communicate on the autistic person's own terms is doomed. They thus deprive themselves of learning the autistic person's language. It is tuning in to another's interests that provides the chance to learn *their* meanings. Many non-autistic people also have extreme difficulty in picking up autistic people's non-verbal language and may take years longer than another autistic person would to tune in successfully (see the YouTube video 'In My Language' for a powerful statement about non-verbal language and meaning; Baggs 2006b).

Here is Amanda Baggs, a young woman with autism, writing about how someone – another autistic person – eventually used words successfully to communicate with her:

...she used language in a way I understood. She used it based on a context that she could perceive that most people could not. A context close enough to what I perceived to make it work...

One thing that helped a lot was communication with me. Most people before that did not communicate with me. They communicated *at* me. They either were telling me what to do, or attempting to hold a conversation with something that from what I could tell was three feet away from me, or inside their own heads, and nothing to do with me at all. I was stunned that someone was talking to me instead of to all kinds of hallucinations in their minds that were not really there, and getting to know me instead of telling me what to do. (Baggs 2006c)

Inappropriate response to people, and invading Others' personal space

Others typically shun autistics, mock them, or try to fix them. Even the most well meaning tend to address autistics as though from a superior position, which confers the right to instruct and direct them. They generally attempt to invade autistic personal space with vigour, determination and an air of righteousness, and they use speech to attempt to dominate thought processes. They invade autistic space by forcing eye contact, by preventing chosen movements such as flapping, rocking or other behaviours currently judged inappropriate by the majority.

Some Others weep and moan and deplore their autistic child's existence; they wallow in self-pity and congratulate each other on admitting how Truly Dreadful it all is. They exchange sympathetic talk about considering murdering their children (see Thierry and Solomon 2006) – or at least normalizing them at any cost (cost to be borne by the health/insurance system if possible). They describe their plight and that of their families as 'The worst thing that can happen to a family'.

This culture of non-acceptance is very harmful to autistic people, leading to their alienation, exclusion, persecution and even murder (see Smith 2007). And what, one wonders, may be the effect on the developing psyche of hearing oneself discussed in this way?

In my view, all the behaviours just described are at least as inappropriate as anything produced by an autistic child who is still trying to figure out 'What's going on?' and 'What are the rules?'

Given the above, is it inappropriate or even surprising if children with autism avoid eye contact, resist being picked up or cuddled, and seem to tune out of the world? In addition to all those possible reasons for social avoidance, autistics of all ages may have particular sensitivities to sensory experience which make them aversive, for example, to certain ways of being touched or to the intensity of eye contact. They may be terrified by the suddenness of the rude Other breaking into their attention tunnel and subjecting them to strange feelings – and sometimes doing this again and again in spite of distressed autistic reactions which should be obvious to the Other.

Others may be unbearably noisy – and as the autistics try to block them out, Others may also tend to get louder and louder in trying to get their attention, thus violently attempting to invade the child's auditory space.

Then again, there are Others who tune autistics right out of their world and see them, if at all, as aliens. Mostly Others avoid looking at or engaging in any way with people whose behaviours they find odd, unless they are trying to change them – or perhaps treating them as theatre.

So to sum up, Others tend either to avoid eye contact completely or to impose it inappropriately. They also generally fail to tune in to autistic interests and therefore do not notice or make any attempt to understand autistic meanings.

Inability or reduced ability to play cooperatively with other children or to make friends

Non-autistic children appear to have a reduced ability to accept children who won't be bossed about, or who find make-believe games puzzling or alarming. They need special training to help them recognize how to cooperate successfully with autistic children instead of being annoyed or alienated by them. Others need to learn to give autistic children time, and show them clearly what is the current potential fun. Research has demonstrated that autistic children are happy to join in and imitate their peers when the social context is simplified for them and the means of imitating the Other are obvious (Field *et al.* 2001).

Tendency to form obsessions and perform repetitive actions

'Restricted' interests are in the diagnostic criteria for autism. The model of mind as an interest system which Wendy and I are using in this book is based on my PhD thesis (Murray 1986) and was further extensively developed in collaboration with Mike Lesser (see Lesser and Murray 1998). In Murray *et al.* (2005) we showed how the monotropism idea first discussed publicly in 1992 could underlie all the diagnostic criteria for autism. According to this idea, autistic children are specially inclined to give their full attention to what they're doing – just so long as the task is where their interest is, not imposed from without.

Rather than having lots of rather diluted mild interests constantly a bit aroused, autistic children and adults tend to have powerful, wholly absorbing ones that arise from within themselves in relation to what they are personally drawn to. Because their interests are often so much less deeply felt, Others can change direction very lightly and easily and tend to expect everyone to be equally fickle. Since the wholly absorbing interest may also occupy an unusually large proportion of the autistic individual's time and processing resources, and will not be easily displaced, it may attract the 'obsession' label – perhaps especially if it is not socially approved.

However, Others do tend to have strong *social* priorities, which show themselves as persistent interests in matters concerning presentation of self and judgements of the acceptability or otherwise of behaviour. Those priorities are embedded within a much larger discourse, which sustains and reinforces them. Some people, caught in this social trap, seem to the more autistic of us to be able to see nothing outside a very limited set of issues, which they become obsessed with fixing. That is, these issues occupy a very large proportion of their time and their processing resources, leaving these Others unable to see positive aspects of their situation. This inability can be harmful for all concerned, causing repetitive behaviours and utterances that make no sense to the autistic observer.

Need for a rigid, highly structured routine

It is often noted that autistic children need to take part in their own structured routines. This would not be noteworthy, since everybody likes to do that – ask yourself about your own life and what it's like to have your expectations thwarted. The problem may be that these children tend to have unusual routines – routines not modelled on Others' routines, or which have no obvious purpose to Others. Once again, Others' failure to understand autistic minds, and their inability to accept non-imitative behaviour as worthwhile or meaningful, can have a strongly negative impact on communication, cooperation and motivation.

What is more, Others too will tend to have their own rigid, highly structured routines. An example from a school environment: 'When the bell rings you must stand up and leave the room; before the bell rings you must stay sitting, be silent unless spoken to, and not leave the room.' This is confusing and un-obvious, and yet Others will become furious and show every sign of distress when these routines are not rigidly adhered to.

People of all sorts truly do *start* life preferring to avoid trouble if they know how, but Others do not always explain the rules very clearly. Much autistic frustration may arise from attempting to follow the rules as far as one understands them, without having had them properly explained or defined.

Others appear generally to be content with high levels of blurriness and uncertainty, in exchange for the comfort of doing what everybody else is doing. That comfort is no protection against the icy blasts of inconsistency and contradiction that can so trouble the autistic child or adult, yet go unnoticed by Others. We shall return below to examine more closely this defective response to inconsistency in the majority of Others.

Inability to understand other people's feelings

To illustrate how problematic Others' understanding of autistic feelings can be, here is Amanda Baggs again, this time being reminded

of the time I came in while we were picking someone up from a day program that took place at an institution (she and I were both clients of the same agency, and that agency often doubled up on rides). I hadn't realized it was a live-in institution until we got inside, and I was visibly jumpy I guess. The woman we'd come to pick up was crying. This made me even jumpier, because I thought she might get punished for crying. So I was sitting there afraid of the staff, and all the staff rushed to reassure me that there was nothing scary about *the woman who was crying*. (Baggs 2006a)

Others may need special training before they are capable of overcoming their inability to understand autistic feelings. For example, they may benefit from social skills training specifically targeted at this deficit. They are likely to need help in 'reading' non-standard expressions of emotion and picking up on communications before the frustrations of not being understood boil over and reduce still further the chances of mutual understanding.

Frequent crying and tantrums for no apparent reason

Others exhibit these behaviours constantly. For example, somebody flaps a bit, spins a bit, rocks a bit – and the Other repeatedly physically intervenes. When the action is renewed again, the Other may start to shout repeatedly, saying the same sorts of thing over and over again, or even to shriek and scream uncontrollably.

Some Others also cry a lot while talking or writing about their autistic children – and they may do so right in front of the children. Others may burst into tears again and again while railing against behaviours the autistic little person sees and feels as completely harmless and agreeable. Others may even phone a friend for affirmation of the horrors they share, conversation in which both Others can be heard by their children expressing their autism-hostile views.

I recently heard an unnamed woman on the television summing up what may be a universal truth about human beings: 'What do we all care about most? – getting the affirmation that you're doing the best you can...'

Those parents who are busily seeking such affirmation for themselves from each other are not registering the fact they are denying

such affirmation to their children. For a penetrating account of the harm done to autistic children by this sort of attitude and behaviour, please see Jim Sinclair's eloquent text 'Don't mourn for us' (Sinclair 1993).

Some autism charities raise funds by talking about plagues, epidemics, and cancers, or quoting unhappy parents like James Watson of DNA fame who says 'nothing worse [than autism] can happen to a family' (Autism Speaks 2006). Yet, even on a website such as Autism Speaks, some Others, who rejoice in their autistic children's goodwill, have started a thread. One posted about the joy of her moment of acceptance: 'When I finally prayed to God not to change my child but to change me so I could help my child.'

All the contributors to the Posautive YouTube group (which I own) repudiate the attitude of mourning and despair which can so corrupt Others' capacity to cooperate and communicate constructively. It appears that this attitude change may occur in almost anyone who uses direct observation rather than relying on received opinion.

Inappropriate or absent emotional responses

Given the points we have been discussing, it is likely that Others are unaware of much autistic emotional responding, only noticing it when it disturbs their peace of mind.

It is also the case that some autistic people report control issues in this area, and are unable to adjust their facial expressions to fit social expectations, even when they have grown up and become increasingly aware of those expectations. There are many personal reports of autistic people smiling or laughing uncontrollably in response to being horrified; they have no intention to offend, and they are feeling very bad in themselves at such times (Lawson 2006). In these cases, Others have strong cultural expectations which they can have great difficulty setting aside, and which may provoke inappropriate anger or disgust in them. Here the autistic emotional response is appropriate but its outward appearance is not adjusted to be socially meaningful, while the Others' inappropriately hostile emotional responses are insensitive and even deliberately hurtful.

Once again, Others may need some training to help them avoid these alienating behaviours by better understanding what's going on for the autistic person – an area in which Others are typically mind-blind, though that is not necessarily a lifelong feature of their condition.

Apart from the differences of presentation just discussed, there is also a self-reported difference in the general quality of emotional response. Sometimes this is referred to as being 'emotionally flat', sometimes as being 'uninvolved', 'just an observer', 'behind glass' (Lawson), life as a video, etc. You can hear Elizabeth Culling and her partner Paul, who are soon to be married, talking about emotion on YouTube as part of the National Autistic Society's Think Differently Campaign (Wady and Culling 2007). Elizabeth says 'I describe myself as being emotionally flat' and finds this in many ways a satisfactory and sometimes rewarding way to be.

Yet it is clearly not quite as simple as that. For one thing, there is research to show autistic people who are able to speak, and therefore in principle able to self-report, experience the same emotional reactions viscerally, but without the reactions having an impact on what they say or perhaps on what they think (Shalom *et al.* 2006). For another thing, what about excitement? Anger? Curiosity? Enthusiasm? Fear? These are all emotions which I have often seen displayed, usually with intensity, by people on the autism spectrum.

I propose that emotions can helpfully be divided into three levels of activity for the purposes of clarifying some of the reported differences between autistic and Other emotional experience:

1. Observer's emotions.
2. Participant's emotions.
3. Para-participant's emotions.

Observer's emotions

At the most basic level I place 'observer's emotions' – those arising from non-active engagement with the world, including forming a judgement about what's going on, curiosity, desire to understand, find out and discover ('pure' interest).

I label these confidently as emotions mainly because they are experienced more or less intensely, like any other emotion (a view supported by the well-known work of Plutchik (1962, 1982)).

Truth is the object of most of these observer emotions, and their satisfaction consists in certainty. According to Dewey: ‘The quest for certainty is a quest for peace which is assured, an object which is unqualified by risk and the shadow of fear which action casts’ (Dewey 1929, p.12). Dewey argued that certainty was a human need, an essential basis for the courage needed to repeatedly overcome the fear of action. Unresolved issues are as psychologically potent as any other passions – they drive cognitive action until satisfaction is achieved. These are the emotions that initiate cognition.

Simple wonder, another observer viewpoint but without active concern for understanding, is the remaining Level 1 emotion. In this model of emotions, wonder is the only emotional state that imposes no personal or social meaning. Even truth-seeking has an agenda. Wonder has no agenda (there is nothing to be acted upon).

Participant’s emotions

Aversion/attraction, fear, anger, hope, enthusiasm, despair, sorrow, boredom, love, hate, joy, frustration and fulfilment – these are the emotions that

- initiate action and therefore involve risk
- have a direction towards the future and a relationship with the past
- have direction beyond perception and affect, and are affected by expectations
- can create multiple and potentially conflicting agendas
- direct observation, and determine what aspects of a situation are noticed.

Level 2 emotions belong primarily to the living of life, to the people taking part in its drama, rather than to any audience or witness there may be. As shared emotions they are often attached to shared purposes and outcomes; it is a self-evident truth that people performing tasks together cooperate most effectively when in

emotional harmony. Occasions for sharing Level 2 emotions face to face are surely much rarer in the 21st century than ever before.

Autistic single-mindedness may mean that Level 1 and Level 2 emotions will tend not to occur simultaneously for an autistic person: they may either be observing or participating in what they do, not both at once. The exception is of course when the desire to know yields that beautiful synthesis of curiosity and action that leads to experiment and discovery.

Para-participant's emotions

These include any Level 2 emotions *experienced from an observer's point of view*, plus some which themselves imply the involvement of Others: embarrassment, approval, pride, scorn, derision, shame and envy.

Other people's judgements can directly determine the nature of these emotions. Because these have an observer's point of view – the observer becomes the audience – they can completely replace Level 1 emotions. These emotions can override the desire for truth, and the values they imply can override truth values. Since they do not require real participation, with its inevitable risks, they need not cause real suffering, and they can subsist at a low level at the same time as other emotions.

Level 3 emotions presumably relate to the development of theatrical imagination that I have noted elsewhere (Murray 2000). They may be a particularly prominent feature of late 20th- and early 21st-century life, as more and more of life is led second-hand and at the same time more and more attention is devoted to passing fashions.

These Level 3 emotions are likely to be the least accessible to autistic thinking, since they incorporate Others' attitudes. Their propensity to co-exist with a range of other emotions may also be problematic given the autistic preference for single-mindedness. In contrast, Others appear to find it difficult or impossible not to prioritize Other-oriented values (see Lawson 2001).

In line with Michelle Dawson's proposal (in Mottron *et al.* 2006) that higher-order processing is optional for autistic thinkers and obligatory for Others, I propose it is only with effort and unusual

focus that Others can keep Level 3 feelings out of their cognitive processes.

Overall, as Mitchell *et al.* (2007) demonstrate, emotions use processing resources. Therefore, having many emotions aroused at the same time means reduced resources available and hence reduced intensity of feeling. The monotropic strategy of concentrating processing resources rather than spreading them thin may produce a smaller range of stronger feelings than Others typically experience.

When autistic people describe themselves as emotionally flat, or seeing life as a video (Lawson 2000), they may be describing their most typical pattern of emotional engagement at Level 1: watching and noting, and doing so with greater accuracy than Others do (Mottron *et al.* 2006), perhaps because they are not feeling the pull of all those other concerns and desires to please. They are 'merely observing', which Others find so hard. This is the emotional state behind the scientific attitude that Marc Segar (1997) singles out as a key identifying feature of autistic ways of thinking. It abhors inaccuracy and contradiction.

Autistic people may also be atypical in more frequently experiencing simple wonder, as discussed above, if our premise about autistic single-mindedness is correct.

I suggest the other most typical pattern of emotional arousal found in autism is wholehearted engagement at Level 2 in actions of some sort, without regard to risk or opinion. It is possible that there may be a spontaneous oscillation between Level 1 and Level 2 basic states. In contrast, Others can have all the emotion boxes lit at once and be unable to turn them off.

It is also likely that emotional awareness at Level 3 becomes accessible to many or most autistic people as well as Others, as they grow up. It just may take usefully longer if you're autistic, ensuring that access to these complex and mixable emotions is only acquired when personal cognitive strategies are already firmly in place. Therefore, for autistic people, all experience is not inescapably placed within the social sphere and warped by the social prism.

In my view, this extract from Gerard Manley Hopkins' poem 'God's Grandeur' (written in the 19th century but not published till 1918) summarizes this difference from a poet's standpoint:

Generations have trod, have trod, have trod;
And all is seared with trade; bleared, smeared with toil;
And wears man's smudge and shares man's smell: the soil
Is bare now, nor can foot feel, being shod.

And for all this, nature is never spent...

In the market place, Level 3 emotions rule, and the capacity to model Other minds is an imperative. But having a different type of emotional distribution and commitment does not equate to not having emotions.

When attempting to embrace points of view beyond their own, Others may need to be trained in identifying and adapting to emotional patterns that attach more importance to accuracy than theirs do, or that may be engaged with the pursuit of unfamiliar goals.

The attitudes encapsulated at Level 3 are enmeshed with Others' judgements, and so they may not be easily dislodged. However, a more enlightened take on autistic points of view, and a more tolerant take on what to disapprove of, greatly reduces the mismatch between these contrasting emotional styles.

The culturally relative value judgements of Level 3 emotionality currently inform both the diagnostic criteria for autism and the assumption that a certain limited way to be normal is The Right Way. It is hoped this book will demonstrate that such a view is distorted, detrimental to both autistics and Others, and just plain wrong.

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