Inclusion through technology for autistic children

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15 Inclusion through technology for autistic children

Dinah Murray and Wendy Lawson

Mary Warnock (2005) argues, 'Inclusion is not a matter of where you are geographically, but of where you feel you belong' (pp. 41–2). We suggest that for a child to feel, day in, day out, that he or she does not belong, is tantamount to feeling rejected. Baumeister (2005) identifies the consequences of rejection as: demotivated self-regulation (including lashing out, lack of cooperation and self-defeating behaviours), and numbed emotions. He asks: 'Given the dramatic short-term effects of rejection, what do you think would be the long-term effects of chronic rejection?' and 'Are there some people who won't mind being rejected or excluded . . . Or is the aversion to social rejection universal?' He goes on to argue that 'modern Western cultures intensify', while 'collectivist cultures reduce', feelings of non-belonging or rejection. In this chapter we link Baumeister's argument to the issue of educational inclusion and exclusion, and suggest that computers and the Internet have enabled inclusive and collectivist cultures to re-emerge in modern Western life, from which children with autistic difficulties can benefit in many ways.

For people born in the latter part of the twentieth century, familiarity and competence with computers, digital cameras, scanners, printers, the Internet, and email can be essential aspects of the feeling of belonging. All teachers know that these can be learning tools, and we explore diverse ways in which they may be used as tools to promote inclusion.

Baroness Warnock rightly observes that 'if educated in mainstream schools, many [autistic] children are not included at all. They suffer all the pains of the permanent outsider. No political ideology should impose this on them' (p. 45). Like anyone else, autistic children need to feel they belong (see Leary and Baumeister's 2000 review of research into the universal 'need to belong'). But these children tend not to get the point of the social realm in the same way as typically developing children. By the time they have cottoned on to it, if they do, they are likely already to be identified by other children as not belonging, and are at risk of becoming outcasts who are treated with scorn or hostility. As Warnock says, they may be on the receiving end of bullying they do not understand. Gunilla Gerland, a highly able and intelligent autistic woman, describes (Gerland, 1997) how, when she started at secondary school, she became the target of bullying and physical abuse that went on for years. One of the boys told her that he and

some others were going to beat her up every day. She reports that when they missed a day, she would go and remind them. It was only years later that she understood what had been happening.

As Wittgenstein (1953) observed, language in its everyday uses goes beyond the strict rules of literal meaning and truth-conditional logic: there is a complex and dynamic relation between meaning and social context. People make sense of each other by assuming the general rule that each participant is contributing to a common interest (Murray, 1986; Grice, 1989). Without this background assumption, non-explicit information is likely to be missed and metaphor, sarcasm and jokes are likely to be confusing or senseless. A child with autism tends to take words literally and might not 'get' the intention proposed by the non-literal sense. If you don't grasp the pragmatic rules, people around you won't make much sense. From failure to understand those rules to exclusion from the immediate community of interest is a short step. Such practical exclusion within theoretically inclusive school environments is commonplace.

What constitutes the common interest varies from moment to moment and culture to culture, but the force of the obligation to contribute is constant within every community of interest, however transient (Murray, 1986). We suggest that opportunities to contribute to common interests are key to acquiring the sense of belonging that is at the heart of inclusion (which we have seen is a universal human need: Leary and Baumeister, 2000).

Children's first sense of belonging usually comes from the experience of long-term interest within the community of their immediate family. How can these tiny inarticulate humans make a contribution to that community? In the first months, care givers usually put the baby's interests first. They try to tune into the baby emotionally, follow the baby's gaze, and use words constantly, exclaiming and naming the baby's objects of interest. They treat every interest that the baby shows as a common interest; they actively share it. The baby is not expected to tune into the carer's interests at this stage of development, but it won't be long before that ceases to be true. The baby responds first to the emotions of its carers, then to the direction of their gaze, and finally to their words (Stern, 1985; Bruner, 1983). Now, instead of the baby being the dictator of every common interest, the baby will find that others use words to dictate new interests (see Gernsbacher, 2005 and Murray, 1986). When the baby is playing with blocks, the adult may interrupt with exclamations about cats, dogs or butterflies, if and when these come onto the scene. This may be the first moment of social alienation for some autistic children: the moment when the sense of belonging in a community of common interest is first threatened.

Auditory issues often compound difficulties with processing spoken language. The effort of deploying speech and trying to articulate clearly enough for other people to understand is often huge for autistic individuals, and frequently unsuccessful and unrewarding. A. M. Baggs, who is autistic, writes:

> Don't get me started on the emotional importance some of them have placed
> on hearing air pass through my vocal cords – an importance that is more

deeply hurtful to me than they can probably imagine. I've been able to communicate – actually communicate and know what I'm saying, and attach words to what I'm thinking, and all kinds of other things that I haven't always been able to do – with the use of a keyboard. This has had a positive impact on my life that cannot be overstated. But other people . . . have often had more of an overt emotional reaction to hearing me make noises with my mouth than to watching me type. I've been praised for making nonsense sounds at times.

(Baggs, 2005)

Having other people's interests imposed on them, with no apparent negotiation, is likely to be a persistent problem for most autistic individuals. People with autism or Asperger's syndrome are often accused of imposing their own interests insensitively on others, but after years on the receiving end it may not be obvious to them that this practice is socially disapproved. For an autistic person, the result is likely to be feelings of alienation and negativity which demotivate attempts to be included in the society of others, and may even turn speech right off (Lawson, 1998). Being demotivated in this way is not the same thing as not *wanting* any social engagement; the need is still there, but the sense of belonging is not – and its possibility may not seem within reach. We have to engage with the interests of autistic people to make that mutual connection happen, and not always expect them to be led by the concerns that *we* prioritise.

One approach to this issue is to try teaching explicitly the rules of social negotiation and cooperation. Role play (see the discussion below) and social stories (Gray, 2000) can help to repair omissions in autistic social understanding. Consciously applying rules may be useful in helping a child or adult to avoid trouble and blame – but may not be the best way to create or establish a common bond. A more effective way to do that is to find a common interest that connects you. A narrow range of interests is a diagnostic criterion for autism (DSM IV, ICD-10); this points to the significance of common interests for relating with autistic individuals. To get that feeling of belonging which everyone needs we have to foster interests that can readily be shared. If we can do that, real inclusion may be possible.

Though we are not proposing the use of computers as a magic ticket to inclusion, their use can address several difficult issues for autistic children. Autistic children may socialise most effectively in the structured environment of a computer. At a computer every keystroke yields a visible sign of itself so the precise current focus can always be identified. Friendly partners or companions can identify and appreciate the point of what's going on; the autistic child can observe those companions creating the same sorts of effect. Mutual respect and even empathy can emerge. We have often observed this happening.

It may be thought that computer use will make autistic children less social. However, this is not the case. On the contrary, it can put them on an equal footing with their peers, allowing them to process and respond to communications in their own time with minimal pragmatic, expressive, or auditory issues

getting in the way. It gives them a chance to make a favourable impression on their peers and to win their respect. It provides opportunities for creativity as well as expertise, and enables comfortable interaction around a common interest to occur, both in person and at a distance. Further, computers may be the *only* way to communicate effectively for those who find speech unmanageable. Learning IT skills in itself ticks curriculum boxes, and it can open a way to explore other areas of the curriculum in a supportive environment. E-learning can be a route towards the acquisition of all sorts of qualifications.

A computer monitor is also a great medium for showing images, and many though not all children on the autism spectrum appreciate that. But one should never *replace* the written word with pictures, however convinced one is that the child in question is 'non-verbal'. Becoming verbal is often a piecemeal process for autistic children. It is crucial to provide opportunities to access non-spoken language with visual help such as photographs, symbols, and actual written words that children can process in their own time. More than one autistic writer has commented on the gap they experienced as a child between speech and writing – the written word may make sense quite independently of speech (Lawson, 1998; Williams, 1992; Blackman, 1999). Individuals with autism may become very expert in specialised symbol systems such as slide rules or computer languages, before they have figured out the ebb and flow of speech.

A computer environment removes some of the most difficult aspects of communication and makes it much more achievable. Role-playing games can help develop more pragmatic skills; many are available to play online, or they can be played without a computer using special packs of cards. The events that are experienced virtually have many shared properties with real-life events; they will call forth the same emotional reactions and present the same sorts of issues and opportunities in a sphere of mutual interaction and cooperation. But these events have clear and explicit rules, and the relationships do not have to outlast the game, although they may, because of course real people are playing. So these may be a fruitful source of social skills for linguistically able autistic children in a relatively manageable, non-rejecting and just social climate.

A recurrent issue for many autistic children is connecting the present to the future and understanding the potential impact of their actions. They have difficulty holding alternative states simultaneously in mind, as you need to if you are to grasp the idea of consequences. Outcome flowcharts on a computer, or interactive PowerPoint shows displaying for children the potential consequences of their actions, can be very helpful. New options can be added at any time to these choice charts. Consequences desirable to the child, to other children, or to grown-ups, can be spelled out alongside their opposites. These words can be supplemented with pictures, and colour can be used to add a further layer of meaning within the flowchart or show. Undesirable outcomes can be shown crossed out.

All autistic children should have their own folder on a school computer (backed up on a personal Flash drive), containing a choices chart as well a personal passport (see below). The teacher or teacher's assistant should not commandeer the

task of making this, but must support the chart's creation and ensure that the flow represents reality by involving the child as much as possible in the process. Without ownership of the process, its result may mean little or nothing to the child. Ideally, once a choices and outcomes file is created, a few minutes should be spent every day to review its events and locate them on the chart, or modify the chart accordingly. Some children may like to award themselves a score for each day's outcomes; again, they should own the process but may need guidance ensuring that those scores reflect the reality of what happened. A proportion of these children may not appreciate the point of representing what actually happened, or may feel that they can fix things in the world by changing its representation.

Used as described, computers can provide a way to help autistic children reflect on what they actually do, have done, and will do. Once reflection is achieved, self-regulation becomes possible. Making a personal passport, using a PowerPoint program, for example, can also encourage self-awareness and boost self-confidence and the capacity to participate. This widely distributed software was written for businessmen without specialist technical knowledge, and is exceptionally easy to use. It is a popular choice for empowering people with learning disabilities of all kinds (see Murray and Aspinall, 2006) because it is so easy and so flexible. You can incorporate pictures, sounds, video, and as much or as little text as you wish. Choosing and changing graphic formats is also simply done. This approach has been used with young people with Asperger's syndrome, who have good speech but usually poor social skills (Haugh, 2006). They have used it to present their personal histories, aspirations, and anxieties to other people. Just as businessmen do, they find a PowerPoint presentation can make a great impression, and convey a great deal of information. Giving young people a chance to control the way they are represented can transform both the way they are seen by other people and the way they see themselves. People who do not speak may benefit even more than others by having such control (see www.gettingthetruthout.org and Murray and Aspinall, 2006).

Being able to control how you are represented is also a feature of personal interaction on the Internet. Interest groups and specialised websites can be a great resource for people with passions of every sort. Even the most alienated child may find companionship and appreciative community on the Internet. As well as finding interest groups devoted to say, Thomas the Tank Engine, tram services throughout the world, or the structure of DNA, autistic young people may also enjoy the respectful and non-judgemental welcome they will get on the Internet from other autistic people, not to mention the ready supply of information and support about autism (see, for example, www.autistics.org or www.neurodiversity.com). This is a community in which many people find friendship, see their contributions valued, and fulfil the need to feel that they belong. Once again, those *are* real people out there. So long as all proper steps have been taken to ensure security, Internet relationships can blossom in the actual world. I know of many such happy relationships which were formed this way, including a number of marriages. (On this issue of security, www.spired.com/guide/law/online.htm is very helpful.)

So even those who have the greatest difficulties in standard classrooms or play-grounds may successfully participate in and contribute to a socio-cultural discourse in the right environment. I suggest that a fundamental rethink is needed about what constitutes the 'right environment' for autistic students (with whatever abilities), without losing sight of the goal of inclusion. That rethink has to begin with the architecture itself. Where can we locate these children within a mainstream building, so that they can *join in with, and also escape from*, mainstream activities in response to their fundamental needs? How can we offer them these possibilities in a rich learning environment? How can we place them so that the location is attractive to them and to other children, and avoids the terrible taint of stigma?

Traditionally schools have had libraries full of books (this is what 'library' means after all!). But a new model of library has been emerging in the twenty-first century (exemplified in Tower Hamlets' 'Idea Stores' – see www.ideastore.co.uk), in which books are just part of the scene. Such a library can have big windows, maximum daylight, no fluorescent lighting, and attention to reducing noise and maximising sound absorption. It has banks of computers and printers and laminators, as well as access to the Internet. There is a soft zone with indestructible books; there is a café; and there are quiet rooms of various sizes off the main space. There are electronic whiteboards in every room so that work on the computer can easily be shared. There are digital cameras, keyboards and audio-recorders, with software to edit the results. There is adaptive technology to suit every need, as well as computer games to share. As traditionally, there are also learning tools like slide rules, globes and skeletons. In one room there is a trampoline (why not have an outlet for surplus energy?). There is a sensory room with access to the soothing and beautiful Reactive Colours software (www.reactivecolours.org), inviting playful and intrinsically rewarding engagement.

Autistic children (however 'low functioning' they are judged to be) should be involved as fully as possible in running this learning zone. They should help file the books and software and maintain the hardware; they should also be responsible for making sure the paper is replaced in the photocopiers, and so on. It should not involve a great leap of the imagination to see that this is exactly the 'right environment' for such children, as outlined above. It is also an environment which is attractive to children generally; this is why it is the key to inclusion.

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