

BOOKS

By Louis Baworowski

Louis Baworowski's career has included social work, academic research and journalism. For several years, he also worked as a volunteer writer for the National Autistic Society, preparing abstracts (summaries) of scientific and general articles on ASD for the Society's database. He is the father of Osian, a 24 year-old with autism. The aim of this regular column is to cover works of interest to readers of *Autism London Bulletin* irrespective of publication date. Where non UK-English spellings appear in titles, names or quotations, it is due to the spellings employed in the relevant sources.

Douglas Biklen et al., *Autism and the Myth of the Person Alone* (New York University Press, 2005) ISBN 0-8147-9928-0 pbk. edtn.

Douglas Biklen, a professor of education at Syracuse University, does not regard autistic people as “essentially” socially disengaged. He also rejects the notion that the oddity of the outward *behaviour* of an individual is necessarily a sign of inadequate or distorted *understanding* (ps. 31-4). In addition, he considers the terms high- and low-functioning to be very problematic, when used with the implication that people with ASD who can carry on a spoken conversation are intelligent, whilst those who cannot are not (p. 26). Because of the complex and important issues that *Autism and the Myth of the Person Alone* raises, I am devoting the whole of my column this month to this one work.

The book comprises discussion by Biklen himself, as well as contributions by seven people with an autism diagnosis, who “traditionally have not been published” (p. 3). Although Biklen is best known as an advocate of the controversial technique known as facilitated communication, we are assured that all the contributors to this book had “developed an independent way to communicate, either through speech or through writing and typing” – with the sole exception of Larry Bissonnette, who needed a facilitator’s hand on his shoulder, to give him “confidence and focus” (ps. 7-8 and 10). The contributors include Richard Attfield, Lucy Blackman, Jamie Burke, Alberto Frugone, Tito Rajarshi Mukhopadhyay and Sue Rubin.

Biklen states that none of the authors in the book fulfils the stereotype of the “person with autism alone” (p. 256). While this appears to be true, it does not make them indistinguishable from each other. At one extreme, we get Richard Attfield and Alberto Frugone, who reveal themselves to be strongly social. Attfield wishes to “adapt until it hurt” and of wanting to be “the me that no one other than myself knew, the me that I could have been, outgoing, eloquent, vivacious, passionate” (ps. 229 and 231). Faced with the physically daunting task of having to walk to the front of an audience at college to accept an award – he has been diagnosed as having ataxia (neurological problems affecting the control of movements) and cerebral palsy in addition to autism (p. 199) – he experiences powerful feelings for others and a determination not to let his college lecturers down (p. 236-7). Frugone too doesn’t conform to any usual conception of autism: “Nobody,” he writes, “would have bet I could become the social person that inside me I wanted to be ...Communication freed me from the pain of compressing the human dimension into empty silences...And now, once I overcome moments of great anxiety, affectionately my friends cheer me up and I intend to reciprocate their love.” (ps. 195 and 196)

Sue Rubin is more ambivalent: “...it was not until I became an active communicator that I wanted to be around people...Autism is not a social way of life. Many times, solitude is one’s best friend. Other times it can be my own worst enemy, spinning me into an autistic mind-frame, which is very much like an echolalic pattern which will not stop...As I have matured I have learned that in order to be recognized as a thinking, feeling adult, I must learn to be social. Setting aside my desire to be alone...is something I have had to struggle with...My way of being anti-autism is to stay as close to reality as I can...I try not to spend too much time alone, but to be with friends and not get caught up in my own head” (ps. 85, 89, 100 and 84). Tito Mukhopadhyay feels, “a general discomfort when it comes to people” (p. 142) – but is far from indifferent as to how he is perceived. He tells us what a “terrible thing” it was to have a

doctor pronounce him mentally retarded (p. 127). His poetry and other writing is, perfectly naturally in such talented person, of great importance to him, and he is disarmingly open about finding “one-way communication better than a dialogue” (p. 124). His autobiography, *Beyond the Silence*, which I reviewed in the April 2003 edition, is one of my favourite autism books.

A significant theme in *Autism and the Myth of the Person Alone* is that of the contributors’ relationship with their own bodies. Frugone writes that his difficulties are not with thinking and knowing, but with doing or acting (p. 25). Mukhopadhyay stresses that he knew what to do, the problem was getting his body to do it (p. 138). He says that it took him many years to realise he had a body and that at one time he was, “as if watching everything from a distant moon without actually being part of everything” (p. 137). The main reason he could not point was because he had very little sensation of his body, and he cannot help rocking back and forth at times because of his need to feel his body (ps. 133 and 113). Attfield tells us he tried so hard as a child to walk and speak; that autism takes total control so that “one becomes a prisoner in one’s own body;” and that he gets “so frustrated in this useless body” (ps. 206, 198 and 58). In Attfield’s case, we are informed that one of the doctors he saw angrily told his mother that he was not autistic, but that his problems were physical (p. 205). Rubin observes how hard it is to explain autism to those “who can easily turn off the peculiar movements and actions that take over our bodies” and that, unless she happens to be in one of those moments “where my body and mind coincide,” she needs to be prompted in order to “get a device for communication purposes” (ps. 83 and 85). Blackman refers to an incident when, on being asked by a stranger if she was all right, she was so confused by the fact that a response was expected of her, that she began to run around in a circle. She comments that the “strange thing was that I could see the ridiculous and comic scenario in my mind’s eye, but I could not alter the behaviour.” (p. 56)

“Autistic aloneness” is certainly no myth. It is attested to in innumerable descriptions by parents, professionals and people with ASD themselves. It is not for nothing that works about autism include such titles as *The Child in the Glass Ball* and *Children Apart*. An autistic person, looking back on his childhood, writes: “I spent a great deal of my time alone in my bedroom and was happiest when the door was closed and I was by myself. I cannot remember ever thinking about where my mother, father, brother and sister were, they did not seem to concern me. I think this was because I did not for a time realise that they were people and that people are supposed to be more important than objects” (T. Jolliffe, R. Lansdown and C. Robinson, “Autism: A Personal Account,” *Communication*, Vol. 26 (3), December 1992, p. 12). However, changes can take place with increased maturity. We have only to read the opening pages of *Emergence Labeled Autistic* and *Nobody Nowhere* – taking note of the spinning object fixation of Temple Grandin and the desire to lose herself in “spots” of Donna Williams – and compare this with the nature and scope of their present day involvements, to realise that substantial development can occur. To be fair, Biklen does not claim that the book’s contributors demonstrate that autistic aloneness is *entirely* a myth, but merely that: “...being alone is never presented [by them] as the essence of autism, and certainly not a permanent or single condition.” (p. 269)

One obvious question, is the extent to which the book’s contributors are representative of people with autism. Biklen maintains that it is constructive to assume that persons we are attempting to help are competent, even if, like the authors in his book, they appear substantially disabled (ps. 34, 136 and 258). He is aware, however, that going beyond open-mindedness strikes many as unwarranted (p. 136). Why, if competence in such cases is common, did Biklen have to go all over the world (USA, UK, Italy and Australia) to find his autistic co-authors? On what basis should we assume that a very large number of people are as capable as the individuals in his book, with the exception only, that they have not found the *means* to express themselves? – because unlike Attfield, Blackman, Frugone, Mukhopadhyay and Rubin, they have not had the benefit of sufficiently intensive and skilled intervention by exceptionally determined parents.