



reading about

Reading about self-help books on autistic-spectrum disorders (autism, Asperger syndrome)

Books by and for people with autistic-spectrum disorders

Until relatively recently, most books on autistic-spectrum disorders (ASD) were written for and by researchers, clinicians or educators. It was not until 1992 that the first book by an author with autism appeared in print. This was by Donna Williams and was entitled *Nobody Nowhere*. The author attempts to explain why people with autism behave as they do and provides practical suggestions as to how their difficulties, particularly those related to the social impairment, desire for sameness and sensory defensiveness, may be overcome. The book was hailed as 'unique', 'remarkable', 'the most extraordinary book published... this decade'. However, such a book would now have far less impact because there have since been many books written by people with autism or those living or working with them. The publishers, Jessica Kingsley, have almost 200 books on autism and Asperger syndrome on their current list, many of these being of a self-help nature. The websites of the National Autistic Society (<http://www.nas.org.uk>) and the Autism Society of America (<http://www.autism-society.org>) also provide extensive lists of potentially useful publications. Many are written by and for people with autism and cover topics such as growing up, coping with school and college, finding and keeping employment, dealing with social relationships, sexuality, marriage and parenthood. There are also books on mental health, and emotional and sensory difficulties. The age of authors ranges from childhood to late adulthood, with at least one recent book written by a man who only discovered he had autism after he retired.

Intervention and management approaches for those living or working with people with ASD

Many parents have also written about their experiences of raising a child with ASD. Some books deal with the problems posed by children who also have severe intellectual and communication difficulties, others are written by parents of children with high-functioning autism or Asperger syndrome. It is often the latter who face

the most problems in obtaining a diagnosis or receiving appropriate help because the less-obvious problems of their children are frequently attributed to failings in the parents themselves.

Other topical issues include diets and vaccines, or guidance on how to obtain a diagnosis, adequate support or appropriate education. There are books for siblings, partners, teachers, college staff, employers, care workers and clinicians. There are books on dealing with challenging behaviour, increasing social skills, improving emotional understanding, aiding communication and facilitating learning. More recently, story books and novels specifically about autism have also appeared. These are often written with the aim of increasing the child's self-esteem and highlighting the positive aspects of the logical thought processes associated with the condition. The best known of these novels, Mark Haddon's *The Curious Incident of the Dog in the Night Time* (2003), is not a self-help book but none the less provides an extremely vivid picture of the experience of having autism.

Quantity v. quality: can you judge the book by its cover?

Although the huge increase in self-help publications has helped to heighten public awareness of ASD and provides much needed practical guidance for those directly affected, there are some problems. The principal difficulty is that it is now almost impossible to judge which books, among the dozens published every few months, are worth buying. Upbeat titles such as *You're Going To Love This Kid* (a book about teaching pupils with autism in inclusive classrooms; Kluth, 2003) or more whimsical ones such as *Autism – The Eighth Colour Of The Rainbow* (Stone, 2004) do not provide much information about content, and it is extremely difficult to choose a book for any one individual's particular circumstances. The national autistic societies also tend to list the publications irrespective of their quality. There is among many professionals working in the field an uneasy feeling that autism is a very successful money spinner for some publishers, and that almost any book with a title incorporating autism or Asperger syndrome is likely to do well, at least in the short term. (The recent trend to combine autism and sex in the title may prove even more profitable.) Certainly, standards, both of writing and editing, are variable. In one recent book of a parent's experiences of coping with a child with Asperger syndrome the child's name inexplicably and confusingly, changes mid way through the book. Many books,

understandably, are written from a very individual perspective and may have limited wider relevance. Some books by parents of very able children may give rise to unrealistic hopes in parents whose children have more severe cognitive impairment. Others, written by parents of older, more disabled children, may lead to unnecessary feelings of despair for families with younger children. The accounts by some individuals with autism, about the nature, causes of and solutions to their difficulties may not apply to others. It is important to be aware that, although specific strategies may have worked well for the individuals themselves, in very few cases is there any empirical evidence of their general effectiveness.

Some recommendations also need to be treated with considerable caution. For example, a recent book on facilitated communication (*Now You Know Me Think More*; Hundal & Lukey, 2003) stresses the value of this approach for the individual concerned. However, most readers are unlikely to be aware that the American Psychological Association (1994) and the American Academy of Pediatrics' Committee on Children with Disabilities (1998) have concluded that facilitated communication is both ineffective and potentially harmful. Other books, written by parents or professionals, although containing much sound, practical information may also offer advice that is more questionable. Recommendations that children with autism should be placed on specific diets, given particular vitamins, avoid having vaccinations etc, because these have worked for one child or family, may not be widely applicable. Cultural differences also need to be taken into account. Advice on how to take legal action against your child's school if educational practices are less than perfect may be appropriate for families in the USA, but in the UK this course of action is unlikely to make school staff more sympathetic to the family's needs.

Choosing wisely

Given these pitfalls, how should one go about choosing the right books and avoid wasting what could be very large amounts of money? For books written by professionals a quick internet search for their professional standing can be of help. Those with both clinical or educational and research experience in this field, and a strong academic publication record, tend to produce books that are better researched and practically relevant. Similarly, books by authors who are, or have been directly involved in educational/therapeutic programmes of established



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effectiveness are more likely to provide valuable advice. A good example here is John Clements' book on coping with behavioural and emotional disorders (Clements, 2002). For books by parents or teachers, it is important to try to find out as much as possible about the type of child or system being described, in order to determine whether the content will be relevant. Within the autobiographical literature, although there are notable exceptions, there is a tendency for some authors to publish two, three, four, or even more volumes, and there is often considerable overlap between these. Sometimes the earliest book is the most accessible. Authors' websites can also act as a guide to the likely content and readability of their books. Authors of websites with a clear, practical base are more likely to produce books of the same nature. For example, Wendy Lawson is a woman with autism who is an excellent teacher. Her website (<http://www.mugsy.org/wendy>) gives a good insight into her very practical approach to problems and ways of understanding the autistic condition, and her books are written along the same lines. For books advising the use of specific treatments, it is wisest to search academic databases (such as Medline, Psychinfo, etc.) for information on empirical data supporting the recommended treatments, before accepting, uncritically, everything the author might say.

Recommended books

For parents of young children

DICKINS, P. & HANNAH, L. (1998) *It Can Get Better... Dealing with Common Behaviour Problems in Young Autistic Children*. London: National Autistic Society.

For young children

VERMEULEN, P. (2000) *I Am Special: Introducing Children and Young People to Their Autistic Spectrum Disorder*. London: Jessica Kingsley.

For school children

SAINSBURY, S. (2000) *Martian in the Playground*. London: Lucky Duck Publishing.

For adolescents with ASD (and their parents)

JACKSON, L. (2003) *Freaks, Geeks and Asperger Syndrome*. London: Jessica Kingsley.

HOLLIDAY WILLEY, L. (2003) *Asperger Syndrome in Adolescence: Living with the Ups, the Downs and Things in Between*. London: Jessica Kingsley.

Helping to understand feelings and emotions

BARON-COHEN, S. (2004) *Mind Reading: The Interactive Guide to Emotions*. London: Jessica Kingsley.

For parents of adolescents

BOYD, B. (2003) *Parenting a Child with Asperger Syndrome: 200 Tips and Strategies*. London: Jessica Kingsley.

For siblings

BLEACH, F. (2001) *Everybody is Different: A Book for Young People Who Have Brothers or Sisters with Autism*. London: The National Autistic Society. (The National Autistic Society publications catalogue also lists a number of other useful booklets in this area.)

For adults

LAWSON, W. (2001) *Understanding and Working with the Spectrum of Autism: An Insider's View*. London: Jessica Kingsley.

For partners

SLATER-WALKER, G. & SLATER-WALKER, C. (2002) *An Asperger Marriage*. London: Jessica Kingsley.

STANFORD, A. (2003) *Asperger Syndrome and Long-term Relationships*. London: Jessica Kingsley.

For help with employment

MEYER, R. N. (2000) *Asperger Syndrome Employment Workbook: An Employment Workbook for Adults with Asperger Syndrome*. London: Jessica Kingsley.

Other references

AMERICAN ACADEMY OF PEDIATRICS (1998) Auditory integration training and facilitated communication for autism. *Pediatrics*, **102**, 431–433.

AMERICAN PSYCHOLOGICAL ASSOCIATION (1994) Resolution on facilitated communication. August, 1994. <http://soeweb.syr.edu/thefci/apafc.htm>

CLEMENTS, J. (2002) *People with Autism Behaving Badly*. London: Jessica Kingsley.

HADDON, M. (2003) *The Curious Incident of the Dog in the Night Time*. London: Jonathan Cape.

HUNDAL, P. & LUKEY, P. (2003) *Now You Know Me Think More. A Journey with Autism Using Facilitated Communication Techniques*. London: Jessica Kingsley.

KLUTH, O. (2003) *You're Going to Love this Kid: Teaching Students with Autism in the Inclusive Classroom*. London: Jessica Kingsley.

STONE, F. (2004) *Autism – The Eighth Colour of the Rainbow: Learn to Speak Autistic*. London: Jessica Kingsley.

WILLIAMS, D. (1992) *Nobody Nowhere*. London: Doubleday.

Websites

Autism Society of America. <http://www.autism-society.org>

National Autistic Society. <http://www.nas.org.uk>

Books, videos and other resources. <http://www.autismtoday.com>

For people with Asperger syndrome. <http://www.asperger.org>

For college students. <http://www.users.dircon.co.uk>; <http://admin@skill.org.uk>

Self-help groups. <http://ani.autistics.org>

For partners. <http://www.asperger-marriage.info>

Research. National Alliance for Autism Research, <http://www.naar.org>

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