Book review

*Making Sense of Interventions for Children with Developmental Disorders: A guide for parents and professionals, by Caroline Bowen and Pamela Snow*


Reviewed by Bronwyn Hemsley* and Pat Gordon-Smith

Bronwyn Hemsley is a certified practising speech pathologist working at the University of Newcastle, Australia, with 29 years’ experience working with people with developmental disability and their families. She is currently doing research on finding credible sources of information on autism in collaboration with Caroline Bowen, a colleague with whom she also administers a rotation curation Twitter account @WeSpeechies (see www.twitter.com/wespeechies). Pat Gordon-Smith is managing editor of *Research for All* and, as a parent, has spent years trying to enable a smoother path through life and education for one of her children. In that time, she has talked and listened to many other parents and met with several professionals as she and her family navigated the twists and turns of service-provision and treatments on offer. Together, Bronwyn and Pat have reviewed this book, honouring the inclusive writing ethos of the journal and aiming to reflect the views of the two audiences the authors aim to reach with the book: parents and professionals. They acknowledge that great diversity in family situations and related emotions and interests cannot be captured or considered, either in this review or in the book itself. Their separate reading and reflection, followed by discussion about the book, yielded very different views and emotional responses to the text and, in crafting this review, they have been challenged to communicate these views in one voice. Indeed, the two authors of the book may have faced similar challenges, not only as co-writers but also in writing for both parents and professionals.

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It is important for parents and professionals to question any claims made about treatments, and there is a good deal here that should enable them to do so. Questioning claims of treatment benefit is vital, particularly for professionals who must know what is required for good evidence-based practice, and understand that even well-regarded interventions must be interrogated constantly in the light of new research evidence. It is good to see a book that allows readers to question a large number of the treatments that are so frequently suggested to families by teachers and therapists – as it is so hard as a parent to doubt the word of professionals and to know where to focus one’s energy in questioning professionals on their recommendations.

Supporting the rationale for the book, the long list of acronyms and abbreviations in the opening pages reflects the volume of terms that confront parents as they access services, discuss treatments on social media and seek credible information online. Given the proliferation of questionable therapies over time, one wonders whether for every treatment covered in the book there are two or three other incarnations or rebrandings of the same waiting in the wings. To illustrate the complexity in the relationship between various factors underpinning children’s skills in speaking, understanding, listening, reading, writing and using social language, Bowen and Snow provide textual descriptions, graphics, figures and tables. This allows the reader to see how the authors located and evaluated the different types of evidence to arrive at their conclusions. The book reflects a startling number of sources that the authors considered, appraised and drew together, using several guiding principles. Bowen and Snow rightfully do not refrain from laying bare the false claims of many treatments, bolstering logical thinking and reliance on research and clinical evidence, to empower parents and professionals towards more critical questioning of the claims, and more evidence-informed decision-making. However, the message about why evidence matters could be delivered more succinctly, and the book’s authors risk labouring the point about non-evidence-based treatments in parts, giving proponents of these treatments more oxygen than they deserve.

It must be acknowledged that any book aimed at parents and professionals is constrained by not having full permission to prioritize the information needs of one audience over the other. Bronwyn viewed that the authors’ focus on treatment choices being directed simultaneously at parents and professionals, and the provocative writing style, could stimulate thoughtful discussion. In her view, professionals would benefit from reading the book, through being exposed both to the arguments provided by proponents of treatments lacking evidence and the counterarguments that make good sense when considering the available research evidence. As such, this made the book unique and of great value to professionals. However, as a parent, Pat had deep reservations about its usefulness, even as a joint frame of reference in a therapeutic context. For her, the goal of addressing two vastly different audiences created problematic tensions, disrupting the book’s central purpose for both. For example, use of the diagnostic term ‘disorders’ in the title signals a stance towards ‘impairment’ and labels, which may be the orientation of many professionals. However, the term could alienate parents, particularly if readers interpret ‘disorder’ through its usual definition as being ‘deviant’, ‘undisciplined’, ‘wrong’ or ‘unnatural’. Finding a term that suits both parents and professionals is important if materials are addressed to both audiences. Terms conceptualizing this domain include ‘health conditions’ and ‘developmental conditions’ – both of which align with the International Classification of Functioning, Disability and Health (WHO, 2001), a framework that recognizes the importance of multiple factors – beyond the person’s medical diagnosis (if they have one) or health issues – as influencing outcomes.
Parents and professionals meet most often when children are encountering developmental issues, but the children with whom they are working, and the rooms in which they meet, may be all they share about the experience. In most other ways, they and their needs differ substantially: in approaching information on treatments, one may be calm, the other may be scared, angry or frustrated and without hope; one may be part of a team, the other may be alone; one is trained to know more about what is likely to happen next and act upon this, the other may feel clueless; one can allow themselves to be detached, the other must hold on; one is an insider, the other is out on the edge. Furthermore, the culture and language of research translation for parents and health professionals differs markedly. Speech and language therapists have undertaken training in evidence-based practice, while parents have a rich lived experience of practice – some of which is based on research. The two groups also navigate knowledge and information about treatments very differently – parents might look to a book for strategies and what to do rather than what not to do; whereas professionals might use the book more like a textbook, to support their own views, or to help them know how to explain treatments to parents. Nonetheless, Bronwyn considered that this book would be useful as a joint frame of reference, were these two intended audiences to discuss the information presented.

Parents will no doubt also apply their own values and beliefs in reading and interpreting the book, and find alignments and connections with their own experiences and encounters. The sensitivity with which Bowen and Snow write about behaviour issues in children, and the gentle steps they take in measuring expectations about interventions for behaviour, make it clear that they care deeply for the feelings of the parents involved. However, the authors’ praise for the ‘rational’ parent who makes ‘good’ therapy choices for their child, might be a characterization that is more suited to the professionals who must take a rational approach to their work and treatment decisions. Parents can be rational or irrational and emotional or intuitive in ways that benefit their children. By foregrounding all that is rational in treatment decisions, the writers do not, perhaps, fully harness the power of a parent's emotional involvement, knowledge and experience in relation to their child and family situation. Additionally, and regardless of anecdotal reports that services often let families down with few good choices on offer, this also gives the impression that parents have a meaningful choice when it comes to interventions for their children – when their options might be limited.

In the book, Bowen and Snow are clearly aiming to help parents and professionals share an understanding of scientific method so they may work together for the benefit of children. While there are ostensibly two audiences for the text (parents and professionals), there is a third and possibly even more attentive bystander audience: the proponents of treatments that lack evidence. These parties are being put on notice to lift their game and show irrefutable evidence for their so far unfounded or false claims of treatment benefit. Bowen and Snow appeal to proponents of some promising practices to ‘try harder’ to evidence their claims with controlled trials. Even so, Pat viewed that the satirical tone used, reminiscent of Simon Singh and Edzard Ernst’s (2008) searing attacks on pseudoscience, relied too much on parents having a sense of humour on the subject, and this might be in short supply. In the authors’ enthusiasm to take down the snake oil merchants who sell unproven trademarked salves, the tone might not suit those parents who have been – or recognize that they could easily have been – taken in. Nonetheless, being pitched at both, the text provides a shared frame of reference for stimulating inclusive discussions in a therapeutic context, supporting deeper and critical consideration of the arguments put forward by proponents of various treatments.
Bowen and Snow dedicate their book ‘to the children we have assessed, thought about, planned treatment for, worked with, researched, agonized over, enjoyed, and bid farewell’, and note ‘the privilege of knowing their amazing families for a while’. In Making Sense…, they have joined forces and drawn on their substantial knowledge of the evidence base to support parents towards making good informed decisions on behalf of their children. Their words will buttress readers against the false claims of the larger, louder and even more insistent voices of proponents of non-evidence-based and harmful therapies for children.

References