SPEAKING UP AND SPELLING IT OUT: PERSONAL ESSAYS ON AUGMENTATIVE AND ALTERNATIVE COMMUNICATION
Melanie Fried-Oken and Hank A. Bersani, Jr.
Paul H. Brookes Publishing Co.
2000
268 pages
ISBN 1-55766-447-1 (Paperback)
Price: £19.95

Speaking Up and Spelling It Out is a selection of personal essays on Augmentative and Alternative Communication (AAC). These personal essays are filled with the determination, knowledge, humour and insights of individuals as they progress in their quests for the ability for expressive communication. The authors discuss different stages in their lives, giving accounts of the effects of communication disabilities and the impact it has had in terms of education, employment and relationships. Furthermore, the same essays chronicle the history of AAC and its development as an area of research, raising many questions faced by developers, educators, parents and professionals as to how the power and speed of communication can be improved.

The book has been written to supplement earlier work by Beukleman and Miranda (1998) Augmentative and Alternative Communication: Management of Severe Disorders in Children and Adults, and while Oken and Bersani point out that Speaking Up and Spelling it Out is not intended as an accompanying text it represents a technical and philosophical complement to that work. A great deal of thought has gone into the planning and order of the personal stories. Oken and Bersani use what they call the ‘funnel approach’ organising their material into chapters that give the broadest, most inclusive ‘big picture’ of AAC which then guides the reader to more selective, single topic essays. A matrix chart at the beginning of the book provides a valuable guide to the topics covered by each author. Oken and Bersani believe that this approach avoids any form of categorising or pigeonholing AAC users, opting instead to offer a whole picture with all the ‘intertwining real-life experiences’ included.

Oken and Bersani argue that unlike many other textbooks on AAC, Speaking Up and Spelling it Out goes beyong the typical augmentative and alternative communication issues which tend to have a professional and technical focus, for example, clinical ‘how to’ books (Light and Binger, 1998) or research-based books (Romski and Sevick, 1996), written by ‘professionals for professionals’. Instead, many of the essayists discuss their early language learning skills, in some cases intimidating speech therapy lessons and the expectations of their teachers, parents and therapists when they were young. One writer tells about the cup she wore at the end of her chin to collect drool. She described the hours of speech therapy that went nowhere. For many augmented writers, the attitudes and perceptions of their teachers and therapists were greater obstacles to communication than their physical impairments. A significant but not surprising revelation was the lack of understanding by some medical professionals of cerebral palsy and
communication difficulties. Alan King, for example, remembers being a 'hot potato' going from neurologist to neurologist, with no eventual diagnosis. A number of essays also address personal care assistants and tell about the demeaning experiences when one person is dependent on another.

However, the main focus of the book confronts the challenges and barriers many people have overcome to communicate effectively. Lloyd, Fuller and Arvidson (1997) remind us that assistive technology tools are but one piece of the augmentative communication system. AAC remains a 'human communication process' with the tools and symbols and assistive technologies being just a few pieces of the puzzle. Yet for many of the authors, the introduction of communication tools to their lives was the start of a new life, of independence, of credibility, of self-esteem, of growth and learning, better health and productivity. In fact, it is only because of the assistive technologies that each author is able to tell their story. Many of the stories therefore have similar themes of uphill struggles to find the best tools for written and spoken communication.

Speaking Up and Spelling it Out is an invaluable resource founded on the perspectives of AAC users. Oken and Bersani are right to point out that as augmented speakers are becoming members of advocacy groups and speaking up increasingly within the public domain, we should be reading about their experiences and changing our policies, treatment approaches and designing devices appropriately. It is hoped that this collection of essays goes someway to facing these challenges filling the long silence of augmented speakers.

This is a fascinating book, full of humorous anecdotes, metaphor, poetry and autobiography. Although the book reflects the experiences of authors from across the United States and Canada, a similar text charting the British experience of Augmentative and Alternative Communication users would be extremely valuable. David Webster poignantly reflects the attitude of many of the writers’ experiences by saying ‘If all my possessions were taken from me with one exception, I would choose the power of communication, for by it I would soon gain all the rest’.

Craig Mill