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Book review

New Voices: Self-Advocacy by People with Disabilities

Gunnar Dybwad and Hank Bersani Jr., Cambridge, MA: Brookline, 1996, 273. pp, soft cover \$29.95.

Every social change movement has a history beginning with a point of conception and evolving into stages of greater maturity and influence. The self-advocacy movement throughout the world now has a history eloquently edited by Gunnar Dybwad who, with his wife Rosemary, were ever present as world changes in perception and attitudes toward and by people with disabilities unfolded in the 20th century. In close collaboration, Hank Bersani, has been a student of both Gunnar and Rosemary as well as Burton Blatt. These two editors have assembled 21 chapters that detail the progression of the self-advocacy movement.

1. The general highlights of this book

- The context of self-advocacy is clearly articulated by Gunnar Dybwad in his opening chapter titled 'Setting the Stage Historically'. In the brief personal information about the editors Gunnar Dybwad is referred *by many to be the 'grandfather of the self-advocacy movement'....* This publication is a testament to this fact as empowerment and self-determination find their roots in the events outlined in this opening chapter.
- The editors bring an international perspective to prominence with the arrangement of the chapters in Sections 2 and 3. Representatives from Canada, Sweden, Norway, New Zealand,

Austria, Great Britain and Australia share the elements of the path to self advocacy in their respective countries. The similarities among these stories emphasize the worldwide scope of this social change movement.

- A major catalyst in the self-advocacy movement has been People First. Started in 1973 by a group of former residents of Fairview Training Center in Oregon, this organization has evolved into one of international influence. Leaders and members of People First are speakers at conferences, members of boards, writers of publications and trainers of self-advocacy organizational skills throughout the world.
- One format I found appealing in a few of the chapters was the interview structure in which a self-advocacy leader responded to a series of questions which were followed by contextual information by the person who initiated the questions, i.e. Nancy Ward and Bonnie Shultz.
- The self-advocates who contributed information for this book state that their organizations maintain a primary emphasis to promote people first language, close restrictive, institutional living environments, teach leadership skills for its members and influence litigation and legislation on both the local and national levels.
- One chapter is devoted to the evolution of participation by self-advocates at the World Congress of the International League of Societies for Persons with Mental Handicap (ILSMH). From initial efforts facilitated by Rosemary Dybwad in 1978–1992 when Bar-

bara Goode, a self-advocate from Canada, was elected a regular board member, this international organization has made slow, but steady strides in recognizing the importance of full presence and participation by self-advocates on an international level.

- Bob Perske eloquently reflects on the history of self-advocacy by relating vignettes of significant events in the history of the movement, a partial list of which includes the first People First meeting in Otter Crest, Oregon, in 1974; the formation of Project Two in the Omaha, Nebraska, area; the exposure by Geraldo Rivera of the inhuman conditions at Willowbrook State School in New York City; the music of the self-advocacy revolution in song as composed by Karl Williams. Perske (p. 32) ends his chapter '*So how can we understand and help these people who call themselves self-advocates? Only by watching them — simply watching them ... and cheering them on*'.
- In the concluding chapter Bersani outlines three waves of leadership in the field of developmental disabilities. The first wave is labeled professionalism and consists of leaders who were medical doctors and university professors who assessed and diagnosed individuals and clearly defined the issues of the day. After World War II the second wave of leaders emerged in which parents were seen as partners with the professionals and parent advocacy groups were started. The third wave, however, is quite different from its predecessors and is labeled self-advocacy. This third wave is characterized by people with disabilities being at the forefront of the change movement. Bersani quotes Ed Roberts; the founder of the World Institute on Disability, who said, '*I am convinced that we are making the most profound social change that our society has ever seen*'.

2. Areas in which this publication can be enhanced

- Three of the references mentioned throughout the book have been part of my previous

reading and enhanced my appreciation of *New Voices*:

- Edwards, J.P. (1982) *We are people first our handicaps are secondary*. Portland, OR: Ednick, Inc.
- Williams, P. and Shoultz, B. (1982; reprinted 1991). *We can speak for ourselves*.
- Williams, R. (1989) *In a struggling voice: The selected poems of Robert Williams*. Seattle, WA: The Association for Persons with Severe handicaps.
- As I am writing this review I received some excellent publications in the mail from Inclusion Press and readers are encouraged to explore their web site at www.inclusion.com to locate additional books that promote the message of self-advocacy prominent in *New Voices*. Of particular interest are the books *Yes She Knows She's Here* by Nicola Schaefer, *When Spider Webs Unite: Challenging Articles and Essays on Community, Diversity and Inclusion* by Shafik Assante and *All My Life's a Circle: Using the Tools: Circles, MAPS and PATHS* by Mary Falvey, Marsha Forest, Jack Pearpoint and Richard Rosenberg.
- Read this book slowly... very slowly, as if the authors are speaking the words and you are taking them in as a member of an audience at a conference. This is not a book to skim through and it took be a long time to digest its content. This was also a hard book to read. It shakes the foundation of what I have been taught to do and encourages me to transfer those skills to others who have traditionally been the recipients of my supports.

3. Common threads throughout this publication

- The voices of individuals with disabilities are not 'new voices' but they are being heard in a new way. They are being heard from a position of strength as members of self-advocacy organizations whose members are speaking out at conferences, as members of boards, citizens in their communities and collectively as a new social movement.
- The role of advisor is critical to the image of

self-advocacy. Much of the criticism toward self-advocacy comes from people who claim that individuals with disabilities have been manipulated by others whose own agenda is being fostered. The way in which individuals are assisted and the nature of the decision-making process within organizations of self-advocates, especially individuals with limited cognitive functioning, are worthy issues of caution.

- This book is about history but as Hank Bersani quotes from Shakespeare in his concluding chapter, *'What is past is prologue'*. There is more to come. Welcome to the future. Celebrate where we have been and study how we got there. Then, continue on. This message is the common thread throughout this book.

4. Specific areas of excellence

- Bob Williams, who at the time of this publication was the Commissioner of the Administration on Developmental Disabilities for the US Department of Education, wrote both the introduction and several poems that are placed throughout the book. Bob's poetry, extracted from one of his collections *In a Struggling Voice*, contains insightful, powerful images based on his observations and experiences both as a self-advocate and professional working to improve the quality of supports for individuals with disabilities.
- *'We are people first. People first means that we are seen as a person first before we are seen as different'* (p. 175). This recurrent theme weaves its way throughout all chapters of this book. Action, based on this value, ranges from using people first language when referring to an individual with a disability (i.e. a person with mental retardation, an individual with cerebral palsy) to recommending the end of the word 'retarded' altogether as a useless term when used to describe someone. For example, self-advocates were instrumental in the name change of a national organization from The Association for Retarded Citizens/US to a

more neutral The Arc/US with the letters A-r-c no longer used as an acronym.

- *'Being able to speak for ourselves is called autonomy. Autonomy means we have OUR OWN VOICE. It means we have OUR OWN IDEAS'* (p. 119). This quote originates from an article written by People First of Canada in 1992. In stating what autonomy means, self-advocates wanted to distance themselves from the Association for Community Living because they didn't want professionals and parents speaking for self-advocates.
- In one chapter, *'The Wheels of Self-Advocacy in Australia'*, the progress of self-advocacy is referred to as *'one of apparent support but in reality a relationship of convenience and shallow commitment'* (p. 162). This statement was from a worker in the department of Community Services Victoria. I believe this statement contains a caution many advisors and professionals need to heed. Are we interested in supporting the self-advocacy movement in areas that are safe and non-threatening to our own survival as professionals? Or, do we truly embrace the tenets of self-determination and greater choices among receivers of support? Our response to these questions signifies our stance and positioning relative to self-advocacy organizations and how ardently we each support their agenda.
- The international perspective is captured in several of the chapters and I sense much of the subtle influence of Rosemary Dybwad in this book. The words in this book are a legacy to many people including Rosemary Dybwad, John Patrick, Todd Kilroy, Ed Roberts and countless other pioneers in the self-advocacy movement. Their steadfastness to a commitment to the ideals of self-advocacy live on and the stories in this book only begin to scratch the surface of what is to come.

5. Recommendations of its utility to rehabilitation professionals

- I received a phone call this week to be invited to speak to the annual meeting of a major

union of healthcare workers in Connecticut about the future of people with disabilities. I plan to bring this book with me and quote extensively from its chapters. This book is a resource from which you will find excellent insights to share with people in whatever capacity you function in your current role.

- Every discipline has a history of significant events that shape the context of current circumstances. In the field of supports for individuals with disabilities a history has been

chronicled for the self-advocacy movement. This book should be on each person's shelf as part of important volumes of work that represent the specific discipline of our careers.

- I will use this book as a supplemental text in courses I teach that introduce students to current trends in supports for individuals with disabilities.

Ernest L. Pancsofar
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