

Deaf-Blind Perspectives

Volume 6, Issue 3

Spring 1999

In Australia: Placing Parents and Families at the Center of Our Planning

Dr Mike Steer
Renwick College
Royal Institute for Deaf & Blind Children
North Rocks, NSW, Australia

In Australia, we have learned much from our American colleagues and in particular from the 1997 amendments to the Individuals with Disabilities Education Act (IDEA). On our vast continent, with its 17 million population, children who are deafblind or have multiple disabilities (i.e., have two or more disabilities in the areas of vision, hearing, physical ability, intellect, and behavior), are at the center of what might well be the most exciting and challenging development in education today. Less than a decade or so ago, few administrators and teachers in Australian schools were concerned with the needs of children who had been so identified, and indeed neither the term deafblind nor multiple disability would probably have been widely recognized outside special education and special school circles anywhere in our country. Until relatively recently, few such children received any kind of sustained education and training outside the provisions of such charitable-sector, specialized agencies as the Royal Institute for Deaf and Blind Children in Sydney and its counterparts in the other Australian states and territories. Since the provision of “care” was the essence of the community’s expectation of their developmental program requirements, such children and young adults were either kept at home or placed in settings generally beyond the responsibility of our generic school systems. Many, as is now well-known, were widely believed to be “trainable” rather than “educable,” and many were deemed to be ineducable. The legacy of this perspective is, to our national shame, that in many parts of Australia, deafblind young adults and adults can still be found vegetating in nursing homes and even as residents in euphemistically named “Training Centers” for people with intellectual disabilities.

Today, the compass needle of change has swung the educationist position to the opposite pole. A dramatically different educational philosophy prevails. We now believe that **all** children are able to learn and that even those with the most pervasive disabilities **can** and **do** learn. In consequence, it is becoming increasingly likely that at some point in their career, every regular school teacher in Australia will encounter a student with one or other sort of significant disability in his or her class and with increasing frequency, will, for better or worse, be-

come responsible for the education of a student who is deafblind or has multiple disabilities. Deciding **what** to teach this student and **how** to teach him or her can pose seemingly insurmountable problems for administrators, classroom teachers, and supporting specialist educators.

This is partly because the majority of children, particularly students with vision impairments, have so many things to learn that educational planning teams, whether in regular or special school, often find it difficult to decide which goals will be most important for the coming year. Other students, whose parents are increasingly seeking their enrollment in the local neighborhood school, have limited response repertoires and a variety of sensory and motor impairments, often with an intellectual disability thrown in for good measure, so that they challenge the

In This Issue

In Australia: Placing Parents and Families at the Center of Our Planning	1
Research-to-Practice: Reducing Behavior Problems in Students Who Are Deaf-Blind	4
NTAC Area Updates	6
A Woman of Her Time—and Ours (Book Review)	8
Graduate Programs That Offer Opportunities In Deaf-Blind Education	9
For Your Library	12
Health Information Websites	13
Announcements	15

creativity of both school and itinerant staff to design effective teaching strategies to meet their needs.

It is perhaps trite to state in 1999 that curriculum decisions for children who are deafblind should be based on a shared understanding of each individual student's needs, strengths, and abilities, and on the important questions families want answered. Determining just what, where, and when to teach should, however, be based on shared values about the goals of education. What do teachers, friends, and family believe the child *should* be doing when she or he graduates from school into adult life? What is school preparing the student for? If, for example, administrators, teachers, and parents believe that the individual will be totally dependant life-long and not particularly in need of friends or a job, then what the student is taught while at school is not particularly important. If, on the other hand, those on the educational planning team are able to share a picture in which the individual is a valued, contributing part of community life, with friends and perhaps even some form of employment in the offing, then curriculum content and teaching method become vitally important. Bearing in mind that an Individualized Educational Plan (IEP) is in Australia, as it is in the USA, at the core of the planning process and that it must reflect the input of an entire team, it becomes important to recognize (a) that each student requires individually tailored supports and resources and (b) that whatever teaching strategies are decided

upon, these should be effective, inclusive, and humane.

What Should Be Taught?

The first step in deciding what to teach is to initiate a process that will discover what the child's special qualities are, what are his or her interests and aspirations, and what are the hopes and aspirations of the family and people closest to the child. A highly effective way of doing this, and one that is gaining increasing currency in Australia, is through the development of "action plans" which result from the *McGill Action Planning System*, or *MAPS* (Forest & Lusthaus, 1989; Forest & Pearpoint, 1992; Orelove & Malatchi, 1996; Vandercook, York, & Forest, 1989). MAPS takes its name from McGill University in Montreal and is based to some extent on earlier "lifestyle planning" procedures developed by O'Brien & Lyle (1987) and O'Brien (1987) of Responsive Systems Associates in Georgia. It is a system designed by Marsha Forest and Judith Snow of the Canadian Association for Community Living (CACL), that grew out of the need to actively support students with severe and pervasive disabilities (Ford & Davern, 1989).

MAPS is a group, problem-solving, collaborative team approach to program planning. It is a tool, that in the hands of a creative facilitator is designed to help individuals, organizations, and families move

Deaf-Blind Perspectives

Volume 6, Issue 3

Spring 1999

Executive Editor

John Reiman
Teaching Research

Managing Editor

Peggy Malloy
Teaching Research

Production Editor

Randy Klumph
Teaching Research

Consulting Editors

Janice Adams, Deaf-Blind Consultant; Harry Anderson, Florida School for the Deaf and Blind; Vic Baldwin, Teaching Research; Chigee Cloninger, University of Vermont; Mike Collins, Perkins School for the Blind; Bruce A. Dalke, Teaching Research; June Downing, California State University - Northridge; Joyce Ford, Parent; Bud Fredericks, Editor Emeritus; Jay Gense, Oregon Department of Education; Karen Goehl, Indiana Deaf-Blind Project; Lori Goetz, San Francisco State University; Richelle Hammett, Wisconsin Office for the Deaf and Hard of Hearing; Monica Kleeman, Perkins School for the Blind; Gail Leslie, Teaching Research; Betsy McGinnity, Perkins School for the Blind; Barbara A. B. McLetchie, Boston College; Kathy McNulty, Helen Keller National Center; Robert Moore, Parent; Nancy O'Donnell, Consultant; Marianne Riggio, Perkins School for the Blind; Art Roehrig, Gallaudet University; Rosanne Silberman, Hunter College.

Deaf-Blind Perspectives considers all unsolicited manuscripts and employs a review process to consider whether they will be published. Some manuscripts may receive anonymous peer review. Send both a printed copy and a disk copy (Windows format) to:

Teaching Research Division
345 N. Monmouth Ave.
Monmouth, OR 97361

Deaf-Blind Perspectives

www.tr.wou.edu/tr/dbp

Ph. (503) 838-8391
TTY (503) 838-8821
Fax (503) 838-8150

into the future effectively and creatively. There are eight key questions in the process and they must all be asked by the process facilitator. The order in which they are asked may, however, be quite flexible, based on group dynamics and the flow of the planning meeting. MAPS planning sessions have been held in classrooms, school cafeterias, organizational boardrooms, small meeting rooms, community centers, church halls, and so forth. The system has been used not only with children of all ages, but also with adults (Rosenkoetter, Hains, & Fowler, 1994; Shauls, 1991). It results in a personalized plan of action that assists in bringing the student and family closer to the daily life of the school (Forest & Pearpoint, 1992). A MAP is not, however, an IEP, nor is it a substitute for an IEP. It is a process that best precedes an IEP and provides the school's transdisciplinary team with important information that will be useful when constructing an IEP. This element of the MAPS process is important because it attempts to portray the child to the best possible advantage and focuses attention on capabilities rather than deficits. The positive emphasis generates important benefits throughout the program planning and implementation phases.

How to Use MAPS

A MAPS meeting generally begins with invitees seated around a table or in a semicircle facing a wall or whiteboard. Each participant is given a notepad and pen or pencil. A facilitator (sometimes two), welcomes the group, explains the process, guides questions, and keeps the session on track. The second facilitator or an assistant serves as a "graphic guide" and records the business of the meeting, sometimes creatively and colorfully, generally on manilla or butcher's paper, which is then mounted with tacks, tape, or pins onto the walls of the room to produce a pictorial record. Sometimes meetings are audiotaped. These records, written, pictorial, or audio are essential to the process.

The facilitator attempts to generate a personal, comfortable, informal group mood and generally urges mutual trust and the avoidance of confusing jargon and acronyms. Each person attending introduces himself or herself and shares information on their relationship to the student who is the focus of the meeting. The facilitator then takes the group through a process which involves generating answers to the following eight questions:

Question #1: What is a MAP? The facilitator describes the ways in which a map is used and links the MAPS process, by analogy, to a road map that will provide directions for the student's life. The result of

the meeting will be a chart which will guide that direction, so that it becomes important for participants to answer all questions.

Question#2: What is (the student's name) history? Answers to this question describe the student's life, particularly focusing on highlights or milestones. Information is included on medical, educational, communication, and social issues. It is often possible for the facilitator to collect much of this information in advance, to avoid spending too much time on the question, requiring only that group members add anything that is missing.

Question #3: What is your dream for (student's name)? Participants are asked to describe their dreams for the student for the next 5 years, 10 years, and as an adult, including dreams about where he or she will live and work, and about the various relationships in his or her life. Dreams need to be conceived as images of what might be possible.

Question #4: What is your nightmare for (student's name)? It is not possible to avoid nightmares if they remain undiscussed. It is important that participants not become despondent if the realities of institutional "care" are raised, or the threat of social isolation or poverty as an adult. Dreams and nightmares are of equal importance to the discussion. Many programs and projects fuel the nightmares rather than the dreams. The entire aim of the MAPS process is to discuss both dreams and nightmares so that the former can be realized and the latter avoided.

Question #5: Who is (student's name)? This is a brainstorming phase of the process. Everyone is invited to provide words that the facilitator records as a portrait of the person. Not merely good or bad words, but words that convey important impressions of the student's identity. The facilitator might also ask, "What other words have persons not present here today used when describing (student's name)?"

Question #6: What are (student's name) strengths, gifts, and talents? In this phase of the meeting the facilitator will record likes, dislikes, preferences, what works, successes, and so forth. The concept of "giftedness" in association with the student, is stressed not in relation to academic ability, but as one of the attributes of the student's personality.

Question #7: What are (student's name) needs and challenges? In answering this question, participants must think about the people and resources necessary to make the dreams come true.

Question #8: (a) What action plans are needed to meet these needs and avoid these nightmares? This phase requires the facilitator, working with group support to pull together finite, specific follow-up plans. These will include defining who will do what, and when and where. For example, when will the IEP session be held, who should attend, when will Circle of Friends activities begin?

(b) What would an ideal day at school look like? Using the information generated in the above process, a matrix can be constructed for use in school program scheduling.

The entire MAPS “machine” can, if efficiently prepared and managed, take about 90 minutes to conduct, with none, or few of the participants bored or overly tired as a result. In many instances, the students themselves have sat through the entire sessions. Facilitators have even invited very young children to be present for as long as they like and have arranged child care if they have decided to leave. Many have stayed for the entire session. This particular outcome merely affirms the notion that most people, including those with multiple disabilities, are vitally interested in their own lives. Those who designed the process claim that the best time to use MAPS is as part of the IEP cycle, or at crucial transition points in the student’s schooling, for example, preschool to primary school, primary to high school, high school to adulthood.

MAPS can be a highly positive process through which the resources of school administration and staff, nondisabled peers, family members, and a variety of supportive people can be harnessed to develop a plan for the inclusion of children with disabilities into regular community school life. The process, which is by no means an arduous one, can be the vehicle for bringing regular and special educators together in the quest to build more inclusive school communities. MAPS has now been used with success in Canada, Britain, and increasingly in Australia for some years, generally with salutary overall impact on the lives of students and families and to the benefit of an increasingly large number of educational agencies.

References

- Ford, A., & Davern, L. (1989). Moving forward with school integration. In R. Gaylord-Ross (Ed.), Integration strategies for students with handicaps (pp.27-28). Sydney: Paul H. Brookes.
- Forest, M., & Lusthaus, E. (1989). Promoting educational equality for all students: Circles and MAPS. In S. Stainback, W. Stainback & M. Forest (Eds.), Educating all students in the mainstream of regular education (pp. 43-58). Baltimore: Paul H. Brookes.
- Forest, M., & Pearpoint, J. (1992). MAPS: Action planning. In J. Pearpoint, M. Forest, & J. Snow (Eds.), The inclusion papers: strategies to make inclusion work (pp. 52-56). Toronto: Inclusion Press.
- O’Brien, J. (1987). A guide to lifestyle planning. In B. Wilcox, & G. T. Bellamy (Eds.), A comprehensive guide to the activities catalog (pp. 175-189). Baltimore: Paul H. Brookes.
- O’Brien, J., & Lyle, C. (1987). Framework for accomplishment. Decatur, GA: Responsive Systems Associates.
- Orelove, F.P., & Malatchi, A. (1996). Curriculum and instruction. In F. P. Orelove, & D. Sobsey (Eds.), Educating children with multiple disabilities: A transdisciplinary approach, (pp. 379-387). Sydney: Paul H. Brookes.
- Rosenkoetter, S.E., Hains, A.H., & Fowler, S.A. (1994). Bridging early services for children with special needs and their families: A practical guide for transition planning. Sydney: Paul H. Brookes.
- Shauls, L. (1991). Integrated family-centered birth to 3 services: MAPS (rewritten) to get you there. In R. Paisley (Ed.), Interagency transition guide. Cumberland, WI: Northern Pines Area Early Intervention Project.
- Vandercook, T., York, J., & Forest, M. (1989). The McGill action planning system: A strategy for building a vision. Journal of the Association for People with Severe Handicaps, 14(3), 205-215.

Research-to-Practice: Reducing Behavior Problems in Students Who Are Deaf-Blind

V. Mark Durand, Project Director
Christie Tanner, Project Coordinator

“If only he could talk!” Michael’s mother said as she expressed her helplessness over her son’s apparent frustration. Michael, who is deaf-blind, was screaming and biting his hand while his teacher tried to get him to participate in some schoolwork. “If only he could just tell us what he wants, what’s bothering him!” There was no blaming here, only a feeling that Michael held the secret to satisfying his own needs—if only we could get inside his head and crack the code.

Our project is designed to “get inside” Michael’s head, as well as the heads of 23 other students with deaf-blindness to determine *why* they exhibit problem behaviors such as aggression, self-injury, and tantrums. Once we determine why the students are displaying problem behavior, we attempt to teach them another way of telling us what they want, using vocal output communication aides (VOCAs) in an approach we call “functional communication training.” Finally, the third stage of our project is to assess whether our efforts at teaching these students specific communication strategies in school might be effective outside the school environment.

Finding Out Why Behavior Problems Occur

It is now widely agreed that treatment efforts for behavior problems should be based on the reasons why the student is misbehaving. In fact, the Individuals with Disabilities Education Act (IDEA) now requires such assessments (functional behavioral assessments) for all students with significant behavior problems. Unfortunately, despite this widespread agreement to look at why our students misbehave as the basis for any program, many professionals continue to make such assessments in informal ways, such as through conversations with teachers and parents and brief informal observations of the student. We always begin with informal observations of and interviews with significant others, but we continue the process using *multiple forms of assessment*, including the Motivation Assessment Scale (MAS)¹ and structured observations in the student’s classroom. The MAS is a questionnaire that we can give to teachers, paraprofessionals, family members, or anyone else who has a great deal of contact with the student. The MAS asks questions about where, when, and under what conditions problem behaviors occur and determines their motivations. Information from the MAS, along with other forms of functional behavioral assessments is used to design plans for reducing the behavior problems. Michael’s assessments suggested that his screaming and hand biting occurred more often when demands were placed on him. This told us that he might be acting this way because his behavior sometimes got him out of tasks in his class. His teacher might end work earlier than usual if he got upset. This taught him to get upset when he did not like the work. Clearly, this information was very important to us in designing a plan for reducing his behavior problems.

Functional Behavioral Assessment Hints

- Conduct two or more *different* functional behavioral assessments for a student’s behavior problems. This will increase your confidence that you have picked the right reasons the problems are occurring.
- Conduct these assessments in *all* settings where you expect to begin a program.
- Be aware that behaviors can occur in different settings for different reasons.
- Sometimes knowing what can make a student well-behaved (e.g., sitting next to the teacher) can tell you why the student is misbehaving (e.g., to get teacher attention).
- Behaviors that appear to occur for sensory reasons (e.g., repetitive behaviors) can over time be used by a student for social reasons (e.g., to avoid demands).

Using the Assessment to Design a Plan

There are many different ways to reduce behavior problems. For example, with Michael we could have simply stopped giving him any challenging class work. We knew from our assessments that making these changes in the classroom would have stopped almost all of his outbursts. But where would this have left him? Obviously, almost all educational goals would have been thwarted. Rather than remove the situations that seem to set off behavior problems, we try to teach the student how to handle these situations. Therefore, at the heart of our efforts to reduce behavior problems is the approach that teaches students other ways to tell us what they want—“functional communication training.” As we saw before, our functional behavioral assessments indicated that Michael’s screaming and hand biting were most likely efforts to escape work. Our solution was to teach him to use a vocal output communication aide (VOCA) to ask his teacher for help when the work was too difficult.

We taught Michael to communicate using his VOCA in much the same way we teach the other students in the project. Since we begin by placing the student in the situation that seems to be causing difficulties, we began by having Michael work on difficult tasks. *Be-*

¹ Information about the Motivation Assessment Scale is available from the publisher; Monaco and Associates, Inc., 4125 Gage Center Drive, Suite 204, Topeka, KS 66604 (800) 798-1309, (785) 272-5501, (785)-272-5152 (fax); www.monacoassociates.com/products/

fore he had time to get upset, we would take his hand and help him press the VOCA, which was programmed to say "Help me!" We then gave him some assistance on the task to make it easier for him. Although he could not hear the voice output, it soon became clear to him if he pressed the button on the device, the task became easier for him. After a few weeks during which time we reduced the amount of help we gave him, he began to use the device with no help each time tasks became too difficult. And, when this happened, his behavior problems were reduced significantly. Although students progress at different rates, if we pick the right situation to begin teaching based on our functional behavioral assessment we are often very successful in teaching students to ask for what they want. Their problem behaviors are in turn reduced.

Reducing Behavior Problems Hints

- Always include strategies for teaching more appropriate skills in any plan to reduce behavior problems.
- Do not rely simply on avoiding situations that lead to problem behavior.
- Be sure the communicative efforts of the student are understandable to others.

Moving Out into the Community

One of the biggest challenges to designing a plan to reduce behavior problems is to create a program that will work outside special settings and with untrained persons. We need plans that will not only work with specially trained teachers and family members at school and at home, but also with the cashier at fast food restaurants, a bus driver, or the stranger on the street. To be successful in the community means that we cannot simply rely on avoiding problem situations; instead, we must teach our students how to adjust and respond to settings that are often unpredictable.

The functional communication training we just described is an ideal way to help students adapt to the community. Thus, our project extends the work in the classroom by taking the students out into their community where we identify situations that may cause them to become upset and then teach them to ask for what they might want. Because the VOCAs can be programmed to clearly communicate the students' requests, they provide a good way to bridge the communication gap between the child who is deaf-blind and the rest of the world.

Reducing Behavior Problems with Functional Communication Training is a three-year granted project from the U.S. Department of Education, Office of Special Education Programs, Model Demonstration Projects in Deafblindness, Grant Number H025D60008. The contents of this article do not necessarily reflect the opinions of the U.S. Department of Education.



NTAC Area Updates

The National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind (NTAC) provides technical assistance to families and agencies serving children and young adults who are deaf-blind. NTAC's purpose is to assist states in improving the quality of services for deaf-blind individuals (birth to age 28) and to increase the numbers of children, young adults, their families, and their service providers who benefit from these services. Assistance is available to each of the 50 states and the U.S. territories and jurisdictions. Services are provided by technical assistance specialists located in four different areas of the U.S. Below are some examples from each area of current activities in which NTAC is involved.

Area 1

Hawaii and the Pacific Basin Jurisdictions - The Pacific Basin and Hawaii Deaf-Blind Projects recently worked together, in collaboration with NTAC, to present a workshop called "Communication for students who are Deaf-Blind or Multihandicapped" to teams of educators from Hawaii and several jurisdictions in the Pacific. The two deaf-blind projects, NTAC, and the workshop consultant, Terry Rafalowski-Welch, also provided ongoing support to the teams after the workshop ended to ensure implementation of the training.

New Mexico - The New Mexico Deaf-Blind Project, with the help of in-state consultants, is currently adapting training materials into an Internet course to be offered through New Mexico State University. The course, which uses the "Hand in Hand" materials published by the American Foundation for the Blind and the theories and practices of Jan van Dijk, has been presented in a traditional classroom format to local school districts and other agencies across the state for the past two years. The new web-based course will be available to all students enrolled at the university.

Utah - Beginning in the fall of 1999, Corry Hill, a Utah parent and the Family Support Specialist for the Utah Dual Sensory Impairment Project, will facilitate discussions with other family members in the state about important practices for deaf-blind individuals and how to implement those practices for Utah's children and young adults. The discussions will focus on a list of the 10 most important practices in the areas of communication, behavior, and instructional strategies that were developed by family members at the NTAC/NFADB National Parent Workshop held in July 1998.

Area 2

Iowa, Kansas, Missouri, and Nebraska - Several states in Area 2 have begun using a training model called "State and Local Team Partnership Training." This model, developed by the HKNC-TAC (Helen Keller National Center - Technical Assistance Center) Project, focuses on training teams to facilitate successful transitions from school to adult life for youth who are deaf-blind. Each state has adapted the model to fit its own unique needs. Iowa is training in-state trainers to provide ongoing support to teams within the state. Kansas and Nebraska are training teams by using a case-study approach centered around specific youth who are deaf-blind. Missouri is setting up employment teams that focus solely on placing youths who are deaf-blind in appropriate jobs that match their interests and abilities. The NTAC Technical Assistance Specialists in Area 2 and the directors of each of the state deaf-blind projects are providing follow-up support to teams through onsite consultation and training, sharing of resource information, and frequent telephone and e-mail contact.

Area 3

Florida - Florida has also developed a unique approach to the State and Local Team Partnership Model by forming a transdisciplinary state team called the Florida Network on Deaf-Blindness. The team meets regularly to provide support to local transition teams that work with individual students who are deaf-blind. Through collaborative efforts with local school districts, the Florida Outreach Project on Deaf-Blindness, NTAC, and adult services personnel, these teams are implementing best practices for transition and creating positive outcomes for students who are deaf-blind and their families. Another organization currently being established in Florida is the Family Network on Deaf-Blindness which will strive to raise awareness about issues and needs regarding deaf-blindness, and work with

the state and local partnership teams to enhance transition services in the state.

Area 4

New Jersey - Several groups are working together to strengthen parent-to-parent activities in New Jersey that will provide support and empowerment for parents and advocacy on behalf of children and young adults who are deaf-blind. These organizations include the New Jersey Technical Assistance Project, NTAC, Prism Organization, Inc. (the current state parent organization), and the New Jersey Commission for the Blind and Visually Impaired. In March 1999, 15 families will meet for a weekend retreat to determine the needs of parents of children who are deaf-blind, evaluate Prism's current value and mission statements, learn about existing state and national resources, and determine next steps.

Rhode Island - In September 1998, Rhode Island held its first-ever statewide conference on deaf-blindness called "Keeping In Touch: A Statewide Conference on the Needs of Individuals with Combined Hearing & Vision Loss." The conference was supported by numerous agencies including L.I.F.E., Inc. (Living In Fulfilling Environments), NTAC, Rhode Island Services to Children with Dual Sensory Impairments, and the Helen Keller National Center. The conference was well attended by service providers from across the state.

West Virginia - West Virginia is currently in its second year of a Model Sites Team Training Project, a collaborative effort between NTAC, the West Virginia Deaf-Blind Project, and the Kanawha County School District. Its purpose is to train teams who work with students who are deaf-blind to utilize effective educational practices. The projected outcome in years three and four of the project is to have the currently involved classrooms and programs serve as model sites for teachers and service providers in the state.

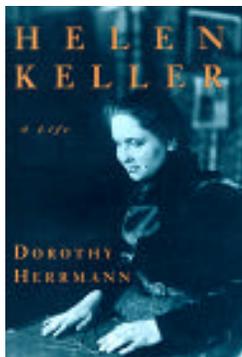
Delaware - NTAC and the Delaware Program for the Deaf-Blind, in collaboration with other state agencies, are in the process of field testing a community employment initiative for persons with severe disabilities, including deaf-blindness. The purpose of this research-based initiative is to identify barriers that prevent individuals access to working in the community and to develop strategies that lead to systems change. The findings of the field test will be documented in an executive summary outlining statewide policy and procedural issues, and recommendations for personnel training and outreach.

The following is from the Jan./Feb. 1999 issue of Ragged Edge magazine. Reprinted with permission.
<http://www.ragged-edge-mag.com>

A Woman of Her Time—and Ours (Book Review)

Sally Rosenthal

Helen Keller: A Life by Dorothy Herrmann. New York: Knopf, 1998. Hardcover, 394 pages, \$30



I know who you are. You read Ragged Edge. You're disabled and hip, a cool crip. You expect your favorite crip magazine to be just as cool. So I know what you're thinking when you see that this issue's review is of a Helen Keller biography. Yet another one. Another able-bodied dissection or sanctification of the ultimate historical icon of feminine disability. Believe me, I know what you're thinking. At best, you want to turn the page; at worst, you're already contacting the subscription department to cancel further delivery. If there's one thing cool crips don't need in the 1990s, you figure, it's another look at Keller's life.

Oh, how wrong you are.

Another look—a radically different look—at arguably the most famous disabled woman of the twentieth century is just what you do need. And you will find it in *Helen Keller: A Life*, a fresh, riveting interpretation of Keller's life and work by Dorothy Herrmann.

Don't feel bad, though; I almost dismissed Herrmann's book, too, when I heard the promotion of it on my local National Public Radio station. Herrmann was scheduled to be interviewed about the new biography on an upcoming talk show. This particular listener, never a fan of other Keller biographies which seemed to paint her as a saint or hopelessly enmeshed in a symbiotic relationship with her teacher Annie Sullivan Macy, wasn't overly enthusiastic about a new book. Recalling all the childhood "inspirational" accounts I had read of Keller's life

(as well as the occasional adult memoirs), I wrote off Herrmann's new work before the talk show began.

Oh, how wrong I was.

Dorothy Herrmann, a biographer who did not describe herself as disabled (leading me to assume she was nondisabled—and the book information on her gave me no information to the contrary), surprised me with her insightful, new slant on Helen Keller—who emerged from Herrmann's interview as more of a mover and shaker than a plaster saint. The woman Herrmann described was a staunch supporter of labor unions, the Soviet revolution and her fellow disabled comrades in arms—certainly not the heroic figure of grade-school library books who "triumphed" over her disability. Herrmann, I began to suspect as I listened to the interview, just might be on to something.

What ultimately won me over, however, was the manner in which the author spoke of Helen Keller in connection with other disabled people, disabled women in particular. The Keller she wrote about was a woman with her own deaf-blind reality, a reality Herrmann reported was just as valid as any nondisabled reality. Without denying the very real limitations of Keller's life, Herrmann was able to bring her subject to life as a passionate, vital woman, albeit one whose life might always remain somewhat of an enigma. Herrmann's astute observations and articulation of them changed my mind about her subject. No longer a shadowy disabled saint, Helen Keller became both my foremother and sister.

I picked up Herrmann's book a day later on a visit to my local bookstore. And I was not disappointed. *Helen Keller: A Life* turned out to be just as fascinating as the radio interview.

As with any biography, the basic historical facts are there: Keller's birth in 1880 in a small Alabama town, her deaf-blindness before the age of two due to a still-debated cause, the arrival of a half-blind, poverty-stricken Annie Sullivan a few years later—and, the rest, as the saying goes, is history. What amazed and intrigued me as a disabled woman, however, were the aspects of Keller's life that had never quite made it into previous accounts.

As Herrmann points out, the Helen Keller with whom most people are familiar is a stereotypical sexless paragon who was able to overcome deaf-blindness and work tirelessly to promote charities and organizations associated with other blind and deaf-blind individuals.

A recent traveling photographic exhibition sponsored by the American Foundation for the Blind, an organization for which Keller spent much of the lat-

ter part of her life working, did nothing to dispel this common public legend (nor does the literature distributed by the AFB and other associations with whom her name and image are closely linked). Missing are the very things that those of us with disabilities would find interesting and empowering, aspects of Keller which would serve to make her a truly real and believable woman.

But Herrmann makes those missing details an important part of her book. Keller, a woman of staunch, radical convictions, supported many causes of her day. A believer in the universality of all people, Keller publicly espoused socialism, communism, radical labor unions and strikes, and spoke out against US entry into World War I. Not content to stop there, Keller managed to draw the conclusion that people of her day with disabilities were also part of the oppressed masses—and as deserving of dignity and liberation as other oppressed groups. Not exactly the stuff of which plaster saints are made—especially one who, in later life, was presented by her close circle of companions (and the organizations who benefitted from her endorsement) as a triumphant, cheerful (read: “almost normal”) woman.

Keller, Dorothy Herrmann concludes, might well have been a willing accomplice in the remaking of her image. Dependent both on her companions for all daily care and communication with the outside world and with the organizations for financial support, Keller might have had no other option than to downplay the beliefs that would have made her far more human than an able-bodied public wanted.

Another event in the younger Keller’s life might also, Herrmann suspects, have caused her to become more publicly compliant. Although she and a young socialist had fallen in love and applied for a marriage license, her hopes were dashed by a complicated set of circumstances—the family’s disapproval, Annie Sullivan’s fear of usurpation, and, possibly, the potential groom’s second thoughts. The Keller who longed for sexual fulfillment and the married life expected for most women of her time rarely appears in other accounts, making Herrmann’s biography the most complete and complex we have.

Complex? Yes. Admittedly, *Helen Keller: A Life* is a new look at an old subject, but the fact remains that very subject herself remains complex. Because of her very real severe disability and the historical context in which she found herself, Keller will always, to some extent, remain an enigma. Herrmann’s book does much to credit Keller with striving to carve out a personal and public image for herself, no small feat for any woman of her time. The controversies sur-

rounding her relationships with Annie Sullivan Macy, her other companions, her charitable organizations and a public both drawn to and repelled by her remain at the end of Herrmann’s book.

Perhaps the task of any first-rate biographer is to ask more questions than to provide concrete conclusions. No life, especially one as singular as Helen Keller’s, can be neatly parceled. Thanks to Dorothy Herrmann, however, it has emerged, thirty years after Keller’s death, as a life of much more than stereotype and legend.



Graduate Programs That Offer Opportunities In Deaf-Blind Education

Peggy Malloy

A number of universities in the United States offer graduate programs for training teachers to work with children who are deaf-blind. The following programs either offer degrees in deaf-blindness or have significant course content related to deaf-blindness incorporated within other degree programs. The descriptions below were compiled from information submitted by each program. Contact each program directly, for more information.

Vision Impairments-Deafblind Program

UAB School of Education
 Education Building
 University of Alabama at Birmingham
 Birmingham, AL 35294

Contact:

Dr. Mary Jean Sanspree
 (205) 934-3440
 Alabama Relay (800) 251-5325 (TTY)
 msanspree@icare.opt.uab.edu

The University of Alabama awards a master’s degree or graduate certification in teaching students who have visual impairments. Deafblind studies are embedded throughout all subject areas. Practical experience involves clinical hours in public schools as well as optional placements, so that students receive teaching experience in a wide spectrum of class-

