

**OUT OF THE DARKNESS AND INTO THE LIGHT:
NEBRASKA'S EXPERIENCE WITH MENTAL RETARDATION**
Edited by Robert Schalock (2002). American Association on Mental Retardation
Foreword by Robert Perske

Editor's Preface to the Foreword

I am personally delighted that Robert Perske's 'Foreword' to *Out of Darkness and into the Light: Nebraska's Experience with Mental Retardation* will be published on-line. There are 24 contributors to this volume. Each one played a significant role in the development and implementation of community-based programs for persons with intellectual disability during the 50 years from 1950 to 2000. These 24 contributors represent a wide range of perspectives including those of self advocates, parents, politicians, professionals, and direct support staff. Collectively, the contributors chronicle the events surrounding the changing approach to people who historically have been considered to be less than others, and who tell a story of the successful movement of persons with intellectual disability from darkness to light, from despondency to hope, and from patients to people.

The authors dedicated the book "to those giants who helped us out of the darkness and into the light, including those who were visionaries, risk takers, and pioneers of the human spirit." Bob Perske is one of those giants.

Foreword by Robert Perske

During the first 50 years of the 20th Century, life for persons with mental retardation in Nebraska was dismal and dark. Even though "Equality Before the Law," served as the state's motto, most Nebraskans were individualistic, self-reliant, conservative and determined to be Grade A persons before they died.

Some failed to recognize a single painful fact: all human beings have flaws. So when persons with obvious disabilities came close, the self-deceptions of others were rattled like wind through broken shutters.

As a counter move, these would-be perfectionists—officials, relatives and neighbors alike—shamed parents into keeping their children with disabilities out of the mainstream of the neighborhood. Some were sent far away to buildings containing large rooms with acres of beds, day rooms ringed with chairs, and noisy mess halls like those Charles Dickens described in his novels. These castaways lived there for the rest of their lives. At death they were buried in a cemetery called “The Potter’s Field” with only their medical record numbers etched on their tombstones.

Numerous parents, however, couldn’t bear sending their children away. So they hid them in the back rooms and attics of their homes. Again they had been essentially cast into an outer darkness—out of sight and out of the minds of the rest of the community.

Those dark days are almost gone. Today, in the towns and cities of Nebraska, people with mental retardation are seen on the front porches of their homes, on sidewalks, in public and parochial schools, at work, on buses, in theaters and coffee shops. We watch them cashing their checks, volunteering for charitable causes, loving and being loved. We observe them visiting their sick neighbors. Sometimes they even exercise their Constitutional right—like other citizens often do—by becoming obnoxious pains in the butts to those around them.

Flares in the Night

After 1950, a small number of parents began to agonize over what was happening to their children. They felt alone. So like distressed ships at sea that sent up flares, they began to look for other parents in the same fix. They put ads in papers. They conducted word-of-mouth searches.

Upon finding one another, they met, shared their feelings and became energized by a newfound solidarity. They organized state and local associations. They dreamed about a better life for their children.

Then—like saints or fools—they got cracking. They rented church basements and vacant houses. Since no one would help them, they developed programs themselves and they took turns running them. Some parents even took time off from their jobs to do stints at the centers they created. Eventually, the demand for such programs became so overwhelming they once again had to look outside themselves for help.

Professionals Arrive and Lock Arms with Parents

The responses were mind-boggling. Verlin Boldry came from the ministry as the first executive director of the Nebraska Association (NEBARC). Bob Clark left an institution in Glenwood, Iowa and became the executive director of The Greater Omaha Association of the Retarded Citizens (GOARC).

Dr. Frank Menolascino came from the Nebraska Psychiatric Institute. He became well loved by parents as their personal political powerbroker. When the parents got into deep trouble, he often appeared like Punjab used to do for Little Orphan Annie.

Dr. Wolf Wolfensberger came from NPI, too. Today, many star-struck folks in the field over-emphasize the “Doctor” in his title. But to us, he was just plain “Wolfie” and he was the greatest creator of fresh programs we ever knew in our whole lives.

Sweden’s Bengt Nirje and Denmark’s Nils Bank-Mikkelsen—aided by Wolfensberger—introduced “The Scandinavian Principle of Normalization.” It came to the groups working for change like a breath of fresh air. The principle was so easy to understand, so unifying, and so energizing; it became a common language that all parents and workers carried in their hearts.

Dr. Bob Kugel, Chairman of the President’s Committee on Mental Retardation and Dean of the University of Nebraska Medical School came forward. His involvement led to his and Wolfensberger’s editing of Changing Patterns in Residential Services for the Mentally Retarded (1969), a book that became the groundbreaker of the decade.

Dr. Robert Osborne, the medical director of the state Department of Public Institutions, became involved, as did George Thomas, the director of the state Division of Mental Retardation.

When the parents and professionals approached Governor Norbert Tiemann, he became caught in the movement, too. He empowered a citizens’ committee to study the situations of persons with mental retardation in both the institutions and the community.

After Tiemann became interested, county commissioners across the state joined in the fray. They inaugurated planning meetings, provided study funds and even loaned county workers to the planning groups.

For example, Douglas County commissioners Dan Lynch, George Buglewicz and John McCollister ordered their director of social services to loan a staff member to GOARC for three

months. The director sent Shirley Dean. Being far from happy about the loan, the director told Dean that this “crazy plan” would fizzle and she would be back in his department very soon.

Dean never went back. She stayed and became known by many as “the quiet but powerful conscience of Nebraska’s normalization movement.”

A Cluster-Bomb Explosion of Light

In July 1968, Lee Terry, a newscaster for KETV (Channel 7, Omaha), became aware of the numerous parent-professional activities and he decided to go for a scoop. With the approval of the governor and the Department of Public Institutions, he appeared at Beatrice State Home with cameramen. He filmed extensive footage at the institution. Then for a couple of weeks, Terry aired segments in his newscasts that exposed the terrible conditions at the institution.

On the morning of July 16, the first county plan for community-based services was presented to the Douglas County commissioners in Omaha. In the afternoon, Governor Tiemann received the report of the Nebraska Citizens’ Study Committee. It became clear that an evolving standard of decency toward persons with retardation was beginning to soar, but they didn’t stop there. The groups conducted “Town Hall Meetings” throughout the state.

Although this massive flurry of information covered the state, it wasn’t always received with open arms. For example, the Beatrice Chamber of Commerce sponsored a town meeting in the city’s civic center. The center was filled with so many hecklers, the sponsors had to slip the parent and professional speakers out of a stage door in the back and help them to get out of town. Later, some of the speakers were so bewildered by the hate, they cried.

An Influx of Workers

The fresh light over Nebraska suddenly attracted hundreds of workers who longed for better respect and care for persons with retardation. They applied for jobs that opened up because of the state and county plans. I was one of them, walking away from an institution in Topeka, Kansas and taking a job with GOARC in Omaha. I never regretted this impulsive decision.

One personnel director openly admitted that he only hired fresh staff members who possessed a high level of “enthusiasm and hunger for the mission.” He also said, “If they ask about salary, I don’t hire them.”

Interestingly, most of the people who came were young people. By the time 600 workers were hired in and around Omaha, a study showed the median age to be 22.5 years of age. Many worked their shifts and studied at colleges and universities on the side. Based on the vivid things they were learning on the job, they groaned incessantly about how dumb their professors were. Today, many of those who groaned so loudly are professors in the field of developmental disabilities themselves.

It is also interesting to note that Nebraska workers went on to become directors of state mental retardation agencies in Arizona, Colorado, Connecticut, Kentucky, Massachusetts, Minnesota, Tennessee, Texas and Washington.

Excitement, Energy and Pain

How does one describe long planning meetings, night after night? Then, when the meetings ended, many were so energized, they gathered at local taverns to talk and dream until the places closed for the night. Some even had to drive many miles home, catch a few hours of sleep and get on their tractors at daybreak.

How does one describe monthly ARC membership meetings in which both parents and professionals were card-carrying members? In some cities, monthly membership meetings drew from 100 to 150 persons.

Eager teenagers attended Summer Work, Education and Training (SWEAT) programs that had been developed by Linda Glenn. Many of those who spent their summers in these warm-caring-but-tough bootcamps came back later as committed staff members after they graduated from high school and college.

An enormous statewide YouthARC organization contained both youngsters with disabilities and so-called “normal” ones. They were highly visible in high schools as well as ARC membership meetings and task forces.

Pilot Parents, where veteran parents were matched with new parents, were well organized. They were so good at what they were doing they promised to get back to any parent calling for help within 24 hours.

Citizen Advocacy was born in Nebraska, thanks to the vision of Wolfensberger and a cadre of CA coordinators who matched ordinary citizens with persons having disabilities.

How does one describe the punched down people who came out of Beatrice that were supported and mentored by others who left the institution earlier. They came to deeply love, as a brother, advisors like Tom Miller, a professional who worked in the community system during the day and volunteered with them in the evenings and weekends.

How can anyone forget five young men—Jesse Barber, John Hogan, Gary Olson, John Purnell and Ron Schultz—and their counselor, Tom Madsen? On July 2, 1972, these six and others were wading in the Missouri River in Southeastern Nebraska when they died trying to save themselves and others from an undertow current. At each of the six funerals, the churches were so packed; loudspeakers were set up for other parents, professionals and citizens who stood outside.

The excitement and energy was so high, individuals in the movement dreamed up their own little assists for keeping the precious process of change alive. For example, the first book I ever wrote, *New Directions for Parents of Persons Who Are Retarded* (1973 & 1981), was written in a back room of the GOARC office, morning after morning from 5 a.m. until 9 a.m. At the same time, my wife, Martha Perske, began to draw the faces of Nebraskans being served by the new community agencies. She did them with just a pencil and they appeared on brochures and in newsletters across the state. This was her way of adding to the movement.

The Power in This Book

This brief opening statement can only serve as a beckoning finger. The definitive story of the Nebraska experience awaits discovery inside this book. There, one can find the in-depth stories, the key actions, the formal documents, the chronologies and the references.

The book contains one point of sadness. There were so many parent heroes at work on this mission, it would be utterly impossible to name and honor all of them within the covers of this book. Unlike the many professionals who remained in the field and built a legacy, the parents rose to high and heroic leadership during specific occasions that usually involved their own children's critical situations. Then after exhausting their vigorous creative responsibilities, they moved back to their regular jobs and regular ways of living. Even so, the whole nation needs to know that without them, no good thing would have ever come out of the Nebraska darkness that made the lives of persons with retardation worth living.