

Out of the Darkness and Into the Light

Nebraska's Experience With Mental Retardation

Edited by

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AAMR

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Dedication

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.

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FOREWORD

During the first 50 years of the 20th century, life for people 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 people before they died.

Some failed to recognize a single painful fact: All human beings have flaws. So when people with obvious disabilities came into their view, their self-deceptions 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 cast-aways 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 in 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 — as 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 ener-

gized 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. Because 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 that they once again had to look outside themselves for help.

Professionals Arrive and Lock Arms With Parents

The responses were mind boggling. Verlin Boldry left church ministry to become the first executive director of the Nebraska Association of Retarded Citizens (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 (NPI). He became well loved by parents as their personal political powerbroker. When the parents got into deep trouble, he often appeared like Punjab for Little Orphan Annie.

Wolf Wolfensberger also came from NPI. Today many star-struck folks in the field overemphasize 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 was like a breath of fresh air to the groups working for change. 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 Center, 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 ground breaker 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 Gov. Norbert Tiemann, he became caught in the movement too. He empowered a citizens' committee to study the situations of people 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 lent 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 lend a staff member to GOARC for 3 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 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 Governor's Citizens' Committee on Mental Retardation. It became clear that an evolving standard of decency toward people 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 people 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 hired only 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 uni-

versities 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 that 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 people.

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.

Eager teenagers attended Summer Work Experience in Training (SWET) 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.

The Pilot Parent Program, where veteran parents were matched with new parents, was well organized. The pilot parents were so good at what they were doing that they promised to get back within 24 hours to any parent calling for help.

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

How does one describe the punched down people who came out of Beatrice State Home who were supported and mentored by others who had left the institution earlier? They came to deeply love, as brothers, advisers such as 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 until 9 AM. At the same time, my wife, Martha Perske, began to draw the faces of Nebraskans being served by the new community agencies. She drew with just a pencil, and the illustrations appeared on brochures and in newsletters across the state. This was her way of adding to the movement.

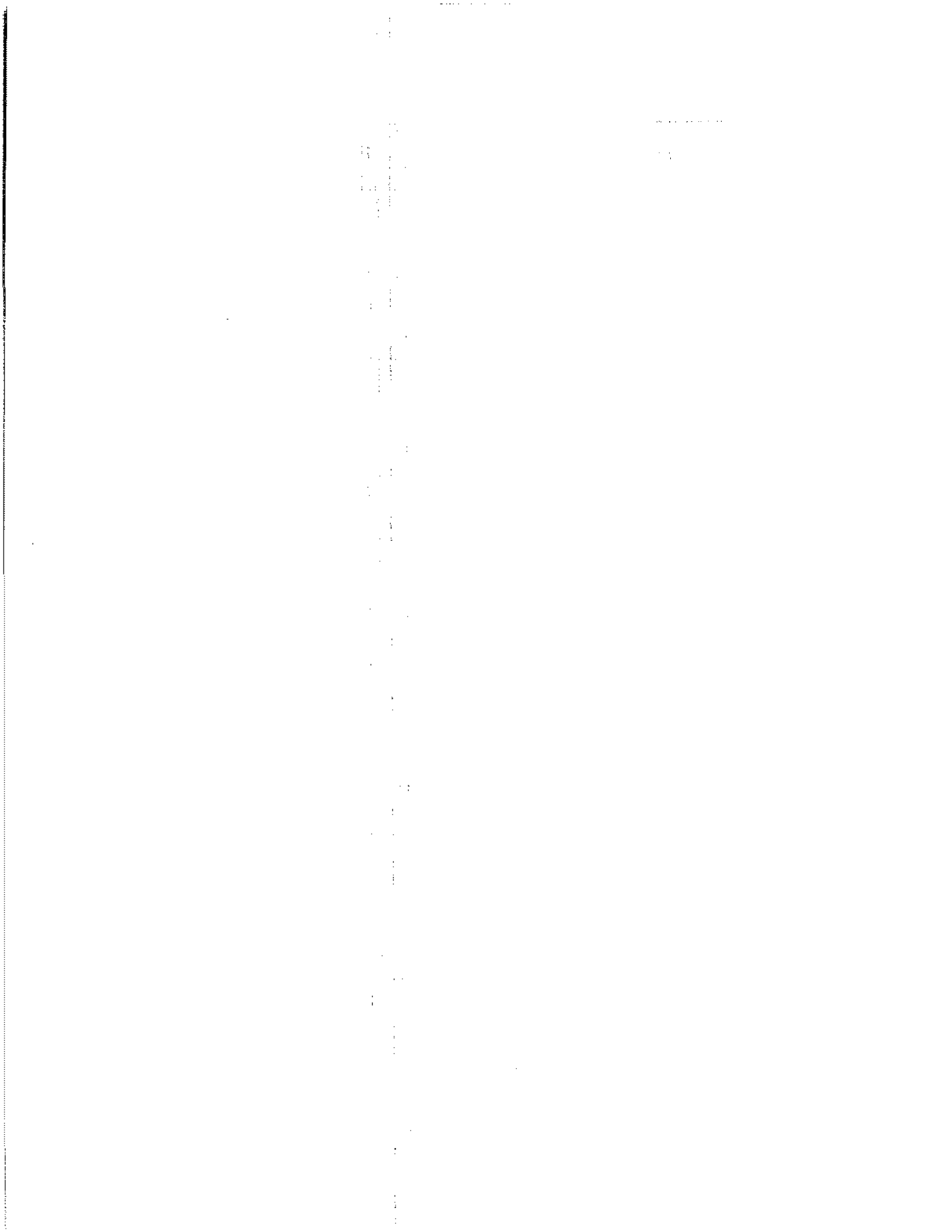
The Power in This Book

This brief opening statement can serve merely 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 people with retardation worth living.

Robert Perske
Perske & Associates
April 2001

Robert Perske previously served as Executive Director of the Greater Omaha Association for Retarded Citizens (GOARC).



PART 1

Introduction

*Justice must not only be done;
it must be seen to be believed.*
— J. B. Monton¹

Readers of this book will encounter a number of feelings as they share with the authors their own perspectives and experiences about people with mental retardation and their role in society. The first two chapters of our story establish the context for the journey taken by those who have contributed to this book. Chapter 1 introduces the book, its timelines, and explains the editor's commitment. Chapter 2 orients the reader to Nebraska and its culture and proposes why the experiences related here occurred in a state that many people prefer not to live in or drive through.

The authors of these two chapters approach their task from different perspectives. Bob Schalock (chap. 1) discusses the impetus for the book and frames the Nebraska experience with mental retardation within the context of a changing conception of people with mental retardation and Nebraska's personality. At the end of this chapter (Appendix 1.1), the reader will also find a useful chronology of significant state and federal actions in the field of mental retardation from 1848 to 2000. In chapter 2 Wolf Wolfensberger discusses in more detail "Why Nebraska?" As one of the great pioneers in Nebraska's (and the world's) experience with mental retardation, Wolfensberger discusses Nebraska's cultural values and how he and other "giants" about whom you will read were able to capitalize on these values to advance Nebraska so far and so fast.

As you read this section, prepare yourself for the power of stories and the experiences that we have had in Nebraska.

¹ as cited in Gross, 1987, p. 111.

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CHAPTER 1
About This Book

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*Robert L. Schalock served as program consultant to Mid-Nebraska
Mental Retardation Services.*

*Man's attempt to deal with deviance can be classified into
three categories: destroying the deviant, making
him undeviant, or segregating him.*

— W. Wolfensberger¹

This book is about people, places, philosophy, politics, advocacy, and hard work. It is both a historical account of the changing approach to people who historically have been considered to be less than others, and a story of their successful movement from darkness to light, from despondency to hope, and from patients to people.

The impetus for this book came from a number of sources including:

- A challenge from David Braddock, editor of the American Association on Mental Retardation book and research monographs, to chronicle the history of Nebraska's experience with establishing community-based services for people with mental retardation. This service model has provided guidance, inspiration, and a road map for countless other states and nations.

¹ 1970, p. 51.

- A promise to tell the story of those who have come out of the darkness and into the light. This story includes important social forces, political factors, and personal efforts that impacted the process of deinstitutionalization and the development of community-based alternatives. In that sense, the book can be read as a study of public policy and a study of history.
- A commitment to those parents, professionals, and politicians who preceded us in moving people out of darkness and into the light and who, in the process, made a significant difference in the lives of so many.
- A desire on the part of the monograph's authors to catalog this story while most of the key players were still available.

A Changing Concept and Approach

The story that unfolds on the ensuing pages cannot be separated from a changing mindset about mental retardation that began in the middle of the 20th century. This changing mindset, which is reflected in our language, our changing conception of mental retardation, and our changing service delivery system, has a number of common characteristics:

- Our language is changing. Bruce Chatwin (1987) in *The Songlines*, for example, states that "people make their territory by naming things in it" (p. 10). That statement is very true of the term *mental retardation*. Similarly, Wittgenstein, in *Philosophical Investigations* (1953), states that "to imagine a language is to imagine a life" (p. 4). Over the years our language has changed to reflect a different life for people with mental retardation — a language characterized by inclusion, equity, choice, and community living. The reader will experience this language change. Despite the authors' commitment to people-first language, we have used the "language of the times" throughout the text. We trust that this editorial decision will offend no one.
- Our conception of mental retardation is changing. Over the past century, we have shifted from a "trait" approach to mental retardation to a broader conception of the critical role that the interaction between the person and his or her environment plays in the condition of mental retardation. Similarly, we have shifted from a deficit model of disability to a growth model, based on person-centered planning, person-environmental interaction, and environmental supports (Smith, 1997).
- Our service delivery system is changing. In many countries the 1960s and before were times of "maintenance" of people with mental retardation; the period from 1965 to 1985 was a time of "treatment" and the rehabilitation continuum; and in the 1990s, the supports paradigm allowed for community living and

employment. The net result of this paradigm change in Nebraska — and elsewhere — is to emphasize the individual's level of independence and interdependence, productivity, community integration, satisfaction, and quality of life. The change is also characterized by the powerful concepts of equity, inclusion, and empowerment that served philosophically as the basis for Nebraska's community-based movement.

In addition, the story that unfolds on ensuing pages reflects the significant changes in how society has viewed and dealt with people who carry the label "mentally retarded" and our state's attempt to deal with those considered "deviant." To quote DeKraai (1984), "The history of mental retardation services in Nebraska can be seen as reflecting the emergence, conflict, and dominance of seven models . . . undifferentiated, educational, asylum, social control, community, normalization/developmental, and the human rights movement" (p. 8). These progressive changes that reflect Nebraska's experience with mental retardation have evolved within a social context characterized by a changing concept of mental retardation and a changing approach to person and place.

A Changing Concept of Mental Retardation

During the 150 years covered in this book, the concept of mental retardation has changed significantly. As stated by Sarason (1985), "mental retardation is never a thing or characteristic of an individual, but rather a social invention stemming from time-bound societal values of ideology that make diagnosis and management seem both necessary and socially desirable" (p. 233). Similarly, Trent (1994) suggests that the mental retardation construct has sometimes been used in the name of science, other times in the name of care, and in other instances in the name of social control. This changing construction of the concept of mental retardation is shown clearly in the time capsule shown at the end of this chapter (see Appendix 1.1) that reflects Nebraska's experience with both the concept of mental retardation and those so diagnosed. Key points along this continuum reflect the changing construction of the concept of mental retardation:

- Nebraska's first service provision, enacted in 1858, required that people afflicted with "idiocy, lunacy, or other unavoidable causes" were to be supported by either their families (if possible) or by the county in "poor houses."
- In 1873 the legislature distinguished between "idiots" and "insane" people and removed them from the state Lunatic Asylum to their county of residence where "the same services as to those for the poor" were to be provided.
- By 1898 there was evidence that the state facility ("Nebraska Institution for Feeble-minded Youth") was implementing a dual standard of services — educational and custodial.

- In 1915 the Nebraska legislature enacted a civil commitment law to prevent reproduction by people with mental retardation and passed the state's sterilization law.
- In 1929 the Nebraska legislature passed a statute eliminating the consent requirement for sterilization.
- By 1935 graves of deceased residents of the state facility were identified only by number, which reflected the disassociation of people from their families due to the "genetic scare."
- In 1949 the Nebraska legislature provided for community educational services to children with mental retardation.
- In 1969 the Nebraska legislature passed laws that provided for the creation, funding, and coordination of community-based programs throughout the state.

These changes — and others summarized in Appendix 1.1 — reflect not just the changing construction of the concept of mental retardation, but also a changing approach to person and place that is described in the following section. In time, they also reflected the legal pursuit of liberty, equality, and community. In Appendix 1.1 state actions are in boldface type.

A Changing Approach to Person and Place

Between 1919 and 1959, a total of 5,420 residents were admitted to our state facility (known as Beatrice State Home at that time) and 3,108 were separated, leaving 2,312 unseparated residents "on the books" (Kurtz & Wolfensberger, 1969). Separations were of five types: death, parole (release into the community while remaining on Beatrice's rolls), discharge (release into the community without any kind of affiliation with Beatrice), escape, and a residual "other" category. This trend toward very large numbers for a small-population state reflects the impact of the Act of 1921 that changed the name of the Nebraska Institution for Feebleminded Youth to the Nebraska Institution for the Feebleminded, with its objective to provide "custodial care and humane treatment for those who are feebleminded, to segregate them from society, to study to improve their condition, to classify them, and to furnish training."¹ The net result was a huge increase in the number of residents and the eventual "overflow" of many of these people to state (mental health) hospitals and even to a deserted tuberculosis hospital.

However, the need for a change in person and place was beginning to emerge and is potentially best reflected in Nebraska by the 1949 decision by the legislature to provide for community educational services to children with mental retar-

¹ Act of April 25, 1921, ch. 241, §.41, 1919-1921 Neb. Laws 842.

dation, and Legislative Bill 855 (Act of July 28, 1969)² that provided for the creation, funding, and coordination of community-based programs throughout the state. This legislation reflected the emerging paradigm shift in services to people with mental retardation that was facilitated greatly by the parents' movement of the 1950s and the normalization and the civil rights movements of the 1960s.

It is interesting to speculate as to whether the profound changes that occurred in this state regarding people with mental retardation, and the places within which they lived, would have occurred had it not been for the legal pursuit of liberty, equality, and community. The reader is reminded that during Nebraska's experience with mental retardation, there were also significant legal and policy changes brought about by the following (Turnbull & Turnbull, 2000):

- The call for access to a free, appropriate public education that was provoked by the *Pennsylvania Association for Retarded Citizens (PARC) v. Commonwealth* (1971) and *Mills v. D.C. Board of Education* (1972) that resulted in the Individuals With Disabilities Education Act (IDEA) (PL 94-142 of 1975; PL 105-117 of 1997).
- The requirement of active treatment and institutional reform as reflected in *Wyatt v. Stickney* (1971).
- The call for equal protection and access to the community as reflected in institutional prevention (*Parham v. J. R.*, 1979), institutional discharge, and community support (*PARC v. Commonwealth*, 1972).
- The belief that people with disabilities should have not only equal treatment but also opportunities to be integrated and included — that is, to be part of their communities. With those opportunities came the liberty rights to be free of professionally directed dominance in education and treatment, and to be free of discrimination based on disability alone (e.g., § 504 of the Rehabilitation Act Amendments of 1975 [PL 93-112] and the Americans With Disabilities Act of 1990 [PL 101-336]).

Why Nebraska?

Standing these nationwide movements aside, and remembering the model that Nebraska's community-based mental retardation programs were to become to other states and nations, the logical question to ask is "why Nebraska?" Why was it, to quote Wolfensberger and Menolascino (1970),

that in early 1968, there were virtually no community services for the mentally retarded in Nebraska, and the State's remotely located single public institution was

² LB 855, an act relating to community-based mental retardation services.

in deplorable condition and crowded with over 2300 residents . . . and that today, in late 1970, early 1968 seems eons away; a whole new system of services is developing; the institution is rapidly declining in size; Nebraska has leap-frogged many states in the sophistication of its approach; and leaders in the field are beginning to visit and study the developments in the State[?] (p. 20)

I would suggest a four-part answer to the question "why Nebraska?": (a) its landscape and politics, (b) its values, (c) its desire to regionalize services, and (d) its empirical ("show me") mindset.

Its Landscape and Politics

Despite its size (420 air miles long, 200 wide, 500 diagonally across), certain conditions in Nebraska facilitated the process of communication and change. Among these were: (a) a relatively homogeneous and small population (1.5 million in the late 1960s), with a very broad base of subuniversity education; (b) a very small legislature (the only unicameral in the United States) that makes for direct responsiveness, intimacy, and communication among legislators and with their constituencies; and (c) an egalitarian history and political mindset.

Its Values

The development in 1964 and 1965 of the Nebraska Plan to Combat Mental Retardation reflected Nebraska's values (Nebraska Psychiatric Institute [NPI], 1966). The more important of these included:

- The values of equity and dignity that increasingly flew in the face of the reported conditions at Beatrice State Home, which were shown graphically in the TV exposé *Out of the Darkness and Into the Light* (L. Terry, 1968).
- The principle of normalization that was a part of the Nebraska mentality and explains why the state so readily accepted the principle of normalization (Nirje, 1969).
- The pride in fiscal conservatism, social activism, and local action. For example, throughout the Nebraska Plan (NPI, 1966) there was almost a paranoia about duplication of services and the proliferation of new human services and the belief that quality local services could be delivered at reasonable costs, especially when contrasted with the high costs of dehumanization (Wolfensberger & Menolascino, 1970).
- Its commitment to communication and teamwork. For example, the first edition (February 1970) of the *Nebraska Contributor*, published by the Nebraska State Office of Mental Retardation, included this statement as to the publication's purpose: "The *Nebraska Contributor* is designed to provide the State of Nebraska the latest concepts, information, and innovations in the field of men-

tal retardation" (p. 1). Key to the success of communication and teamwork were articles on ideology power, implementing Legislative Bill 855 (Act of July 28, 1969)³ (which provided for decentralized services), and citizen advocacy (which was considered "an innovative approach"). The key roles that the Nebraska Psychiatric Institution and Meyer Children's Rehabilitation Institute played in this communication, publications, teamwork, and academic-parent alliance cannot be stressed too much.

Nebraska's values regarding people with mental retardation are reflected in the five basic principles (see Table 1.1) that formed the basis for much of the revolutionary changes that occurred during the late 1960s and early 1970s. Gov. Norbert Tiemann reacted to a recommendation of the Nebraska Association for Retarded Citizens (NebARC) by appointing the Governor's Citizens' Study Committee on Mental Retardation (a subcommittee of the Governor's Citizens' Committee on Mental Retardation) in August 1967. After surveys, hearings, meetings, deliberations, and consultations, the process yielded a report summarized in a seminal document entitled *Into the Light* (Nebraska Governor's Citizens' Committee on Mental Retardation [NGCMR], 1968a).

The Study Committee's work was founded on these "five basic principles," worded in the language of the time. Today offense would be taken at the term *retardate*, now replaced by *people with mental retardation*, or, more broadly, *people with developmental disabilities*, of which mental retardation is only one type. Nebraska statute itself has been purged of the all male pronouns of the principles, as originally published.

Its Regionalization

It is important to our story to explain (a) how and why regions were created in Nebraska and (b) the impact regionalization had on our community-based movement. In the late 1960s the federal government commissioned a nationwide study in an attempt to determine local retail trade patterns and various sociodemographic information regarding how states could be defined in terms of building blocks of a loosely homogeneous nature. This information would eventually be useful in the prevention of political gerrymandering for patronage purposes and for the implementation and targeting of federal funds for areas with particularly acute unmet needs (Menolascino, Schalock, & Harper, 1980). Once completed, regions became a logical extension of the building-block concept inasmuch as they became larger blocks based on larger numbers of people with fewer idiosyncratic features. In Nebraska, for example, a large geographic area with a small population was divided into five geographically large and primarily rural regions and one small

³ LB 855, an act relating to community-based mental retardation services, Session Laws — Nebraska 1970.

TABLE 1.1

Five Basic Principles of Citizens' Study Committee on Mental Retardation

1. No matter how handicapped, a retarded person or institution resident is not an animal, vegetable, or object, but a human being and a citizen, deserving of respect, and in possession of certain human, legal and social rights. As much as possible, retarded persons, whether institutionalized or not, should be treated as ordinary persons of their age are treated in the community. Every effort should be made to "normalize" retardates, that is, to diminish those aspects that differentiate a retardate from a typical citizen of comparable age.
2. There should be maximal continuity of contact and atmosphere between all phases of service agency (including institution) functioning in the community.
3. Continuity of contact between a retardate and his family should be maximal, limited only by liberally interpreted considerations for the welfare of the retardate, his family, and the agency (for example, institution) serving them.
4. Service agencies (including institutions) should provide an environment conducive to their retarded clients' physical, intellectual, social, and emotional well-being and growth, with special emphasis on the development, welfare, and happiness of children.
5. Each retarded person, particularly if he resides in an institution, should have a special relationship to a competent individual citizen who will act as his personal advocate, vigorously representing his interests and safeguarding his welfare.

Note. From *Into the Light* (p. 5), by Nebraska Governor's Citizens' Committee on Mental Retardation, 1968, Lincoln: Nebraska Department of Public Institutions.

but highly populated region serving Omaha and the surrounding area.

It was from this regional designation that concerned citizens in Nebraska made plans for a statewide system of community alternatives for people with disabilities. The following ARC Board Resolution (adopted November 8, 1970) is an example of how this was achieved:

- **MOTION:** That the Custer County ARC designate Mid-Nebraska Mental Retardation Services, Inc. (MNMRS) as the responsible party for delivering services to the mentally retarded citizens within the area known as Administrative Region Three which includes the county of Custer. MNMRS shall have a board of directors comprised of elected members from the ARC groups within Region Three until such times as the local county boards shall enter into interlocal agree-

ments to insure perpetual funding of this organization. At the completion of the interlocal partnership the Board of MNMRS shall be comprised of county commissioners which shall be appointed by their local boards and the current ARC board shall assume the role of Advisory Group to the MNMRS board of directors. The Custer County ARC subscribes to the concept that the original intent of The Association for Retarded Citizens was not to provide services for the retarded, but to promote these services by a public agency. The public agency which will provide said service will be named Mid-Nebraska Mental Retardation Services, Inc. (p. 3)

This concept of regionalization was also supported by the state government, because it became clear that dealing with 6 entities would be more manageable than dealing with 60 or 100. It was this partnership of state government, local ARCs, and local counties that created the Nebraska regional system of service delivery for people with mental retardation. Once implemented, these regions resulted in a number of significant advantages to the community-based movement including responsiveness, equalization of service patterns, responsibility centers, innovation and communication, and economic incentives (Menolascino et al., 1980).

Its Empirical Nature

Successful social movements, such as the development of Nebraska's community-based movement, involve three roles that all came together in the 1950s and 1960s: a theoretician, an organizer, and a promoter. You will read about these people in subsequent chapters, but it is important here to point out the key role that the Nebraska Psychiatric Institute (NPI) played in our story and how the theoretician (Wolf Wolfensberger), the organizer (Bob Clark) and the promoter (Frank Menolascino) personified the state's values and empirical nature, and thereby advanced the community-based movement. In the early 1960s, NPI established a research center for the study of mental retardation. Initially, a 10-bed ward for children was established, which became the site of research concerning the detection, prevention, and treatment of mental retardation. In addition, NPI created a research program at the Beatrice State Home. Right across the street from NPI, Meyer Children's Rehabilitation Institute (MCRI) was founded in 1968 and provided interdisciplinary education for personnel, interdisciplinary service programs, and basic and clinical research on the prevention and treatment of handicapping conditions in children. As discussed by DeKraai (1984), "This research setting was to become the context within which normalization and development were applied as theoretical models for treatment in Nebraska. . . . Professionals from NPI along with professionals administering the community programs initiated a zealous advocacy of this new ideology" (p. 49).

As these three roles were played out over the late 1960s and into the 1970s,

additional people built on the principle of normalization and combined the emerging professional paradigm with the strengths of the parents' movement, which was seeking to develop an alternative service, and the advocates movement that was pursuing human rights. These movements joined the system of state-supported community programs that served as both the catalyst and the experimental setting for the implementation of the normalization principle and the developmental model. The key role that research, evaluation, and publications played in this regard cannot be overlooked.

In summary, other states had similar early success with the development of community-based services. However, Nebraska was unique in that it in a very short time "leap-frogged" into national and international prominence. Part of our early success was our landscape and politics, part our values, part how we regionalized our services, and part our "show me" attitude. These are the ingredients of a great story, and it is that story that the authors of this book want to tell.

Our Commitment

In summarizing Nebraska's experience with mental retardation, the authors of this book have taken their work seriously. In *The Conquest of Mental Retardation*, Burton Blatt (1987) stressed the importance and power of stories. He asserted that "Every story can enhance life or destroy it. Every story can lift us or depress us. Every story can make a hero or a scapegoat. Stories sustain if not make a person's world. And thus, the storyteller holds a certain power (and responsibility)" (p. 141).

We have taken our responsibility seriously. Throughout our efforts, we have consulted the people actually involved in the process whenever we could and have used original source materials to describe the people, places, philosophy, politics, and advocacy that resulted in the significant changes over the last five decades in both Nebraska's mental retardation system and the lives of people with mental retardation. Those who have been most involved in this story are identified by name in the text. Undoubtedly, we have overlooked some and not mentioned others who were deeply involved in the story. Their omission was unintentional and we apologize for any oversight.

Although our work is not yet done, it has reached a point that we want to share it and tell our story of *Out of the Darkness and Into the Light: Nebraska's Experience With Mental Retardation*. A project of this magnitude has required considerable effort on the part of many people. To my collaborative authors, I say, "Thank you for a job well done." To Donna Menolascino we say, "Thank you for your generous financial support" as a tribute to Frank and his significant and unique contribution to the field. A special note of thanks to the encouragement and support given us by David Braddock, editor of American Association on

Mental Retardation's books and research monographs. We hope that this book will make a contribution to the excellent Archives and Library on Disability that Dr. Braddock has established at the Department of Disability and Human Development, University of Illinois at Chicago. And to Darlene Buschow, whose technical assistance we greatly appreciate, we say, "It could not have been done without you."

APPENDIX 1.1

Time Capsule — Mental Retardation and the Nebraska Experience

1850–1950

1848	Dr. Samuel Howe (Massachusetts) advocated for schools and educational institutions for people with mental retardation.
1858	Nebraska's first service provision: People afflicted with "idiocy, lunacy, or other unavoidable causes" were to be supported by their families or relatives; if not possible, the law required the county to provide support.
1865	Institutional care and commitment of insane people from Nebraska to the Iowa Hospital for the Insane.
1867	Nebraska statehood.
1867	State Lunatic Asylum established in Lincoln (included institutionalization of people with mental retardation).
1869	The first wheelchair patent was registered with the U.S. Patent Office.
1873	Legislation distinguished between "idiots" and "insane" to their county of residence where "the same services as to those for the poor" were to be provided.
1876	AAMR was founded as the Association of Medical Officers of American Institutions of Idiotic and Feeble-minded Persons.
1883	Governor Nance advocated for a separate institution to serve mentally retarded children.
1883	Sir Francis Galton in England coined the term <i>eugenics</i> to describe his pseudo-science of "improving the stock" of humanity. The eugenics movement impacted Nebraska policy and law in 1914–1915.
1885	Legislation established the Nebraska Institution for Feeble-minded Youth (NIFMY) at Beatrice as an educational facility.

continued

Note: Bold denotes state actions.