

# 20<sup>TH</sup> CENTURY PROJECT



# **SIGNIFICANT CONTRIBUTIONS OF THE 20<sup>th</sup> CENTURY**

## ***IN THE FIELD OF MENTAL RETARDATION/ DEVELOPMENTAL DISABILITIES***

A Project of:  
The National Historic Preservation Trust on Mental Retardation  
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## TABLE OF CONTENTS

Dedication

Acknowledgements

The Century Recognition Project

The National Historic Preservation Trust On Mental Retardation

Major Contributors

Letter of Introduction: Michael R. Dillon

Letter of Introduction: Margaret J. Gould

### THE 20<sup>th</sup> CENTURY

- The 20<sup>th</sup> Century by Margaret J. Gould
- The Only Constant Is Change by Val Bradley, Ph.D.
- Legal Laws and Landmarks of the 20<sup>th</sup> Century  
by Stanley Herr, JD, D. Phil.
- Biomedical Advances in Mental Retardation by Robert E. Cooke, M.D.
- The Role of Parents in Bringing Change by Quincy Abbot
- Preserving the History of Mental Retardation by Marcia Bryan, Ed.D.
- The Emergence of Self Advocacy by Michael Dillon, Ed.D.

### HONOREES

- Alfred Binet, Ph.D.
- Henry Goddard, M.D.
- Charles Bernstein, M.D.
- Walter E. Fernald. M.D.
- Ava Percival
- Joseph T. Weingold
- Elizabeth Monroe Boggs, Ph.D.
- President John F. Kennedy
- Representative John E. Fogarty
- Senator John H. Chafee
- Jerome Lejeune, M.D.
- Robert E. Cooke, M.D.
- Robert Guthrie, Ph.D., M.D.
- Geraldo Rivera
- Burton Blatt, Ph.D.
- Hon. John R. Bartels
- Hon. Raymond J. Broderick
- Hon. Judge Johnson
- Class Members
- Wolf Wolfensberger, Ph.D.

- B.F. Skinner, Ph.D.
- Marc Gold, Ph.D.
- Robert Perske
- Martha Perske
- Frank Menolascino, M.D.
- Eunice Kennedy Shriver
- Richard Scheerenberger, Ph.D.
- Gunnar and Rosemary Dybwad
- H. Rutherford Turnbull, III, L.L.M.
- Ann Turnbull, Ed.D.
- James W. Ellis, J.D.
- Robert M. Gettings, Ph.D.
- Paul A. Marchand
- Bernard Carabello
- Chris Burke

LEGACY STATEMENTS

CLOSING CREDITS AND REMARKS

## **DEDICATION**

The Century Recognition Project wishes to dedicate its efforts to all of those individuals with disabilities whose lives serve as an inspiration and reason for our best efforts.

# ACKNOWLEDGEMENTS

The Century Project acknowledges the hard work and dedication of the Century Recognition Committee members and their tireless efforts in assembling the materials, information, and ideas that were used in completing this project.

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## THE CENTURY RECOGNITION PROJECT

In 1991, a group petitioned the AAMR Board of Directors to form an Ad-Hoc Committee on Historic Preservation specifically charged with ensuring that materials, memorabilia, and important items to the field be protected. The effort came about because of the mass destruction of critical materials especially those housed at the older, large institutions that were being closed or dramatically downsized.

By 1992, the Ad-Hoc Committee grew into a consortium that represented membership from: AAMR, ANCOR, AAUAP, The Arc/US, the Joseph P. Kennedy, Jr. Foundation, the NASDDDS, and the President's Commission on Mental Retardation. TASH was also a member during the early period of the committee's work.

In 1998, the Ad-Hoc Committee incorporated into a 501(c)3 organization, The National Historic Preservation Trust on Mental Retardation.

At the close of the 20<sup>th</sup> Century, many initiatives began to appear throughout the country describing significant contributions and events in the United States. It was clear that the mental retardation/developmental disabilities field was underrepresented in these national efforts. To ensure that the work of people in the field was acknowledged, and information about the century retained for educational and research purposes, the National Trust on Mental Retardation developed the Century Recognition Project.

The Century Recognition Project sought to recognize contributions of people living in the 20<sup>th</sup> century whose efforts broadly affected people with mental retardation/developmental disabilities and the field as a whole. The Committee wanted to ensure that nominations reflected the entire 20<sup>th</sup> century, not simply the second half.

Criteria for nominations were distributed widely throughout the field in the fall of 1998. To include a broad range of individuals in the nomination process was a major objective of the Committee. This was to ensure that submissions reflected the multiple disciplines and interest groups within the field.

Over 160 names were submitted for consideration. An 18-member Selection Committee reviewed personal contributions and recommended 36 Honorees. Honorees are listed in the Commemorative book with a short passage outlining their work and success.

The Century Recognition Committee created national forums to recognize the Honorees, and produced a major multi-media presentation. In addition, The Century Recognition Committee published Commemorative books for distribution within the field.



# **THE NATIONAL HISTORIC PRESERVATION TRUST ON MENTAL RETARDATION**

**The National Historic Preservation Trust on Mental Retardation is a 501(c)3 organization expressly committed to historical preservation efforts in the field of mental retardation/developmental disabilities.**

## **CONSORTIUM MEMBERS OF THE TRUST INCLUDE:**

- \* AAMR**
- \* AAUAP**
- \* ANCOR**
- \* The Arc/US**
- \* NASDDDS**
- \* Joseph P. Kennedy, Jr. Foundation**
- \* President's Commission on Mental Retardation**

## MAJOR CONTRIBUTORS

The Century Recognition Committee would like to express its gratitude to each of these companies and organizations listed below for their financial contributions. Their support enabled the Committee to develop materials that have created awareness of the history of the field and the major work of people involved in the field of mental retardation/developmental disabilities in the 20<sup>th</sup> Century. Thank you.

### LEADERSHIP GIFT:

Irwin Siegel Agency, Inc.

### GOLD LEVEL GIFT:

The Chimes, International

The VISIONS Center for Creative Management

### SUSTAINING GIFT:

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New Horizons Resources, Inc.

### SUPPORT GIFT:

The Arc of the United States

Community Living Concepts, Inc.

NYSARC, Inc.

Opportunities Unlimited of Niagara

Region IX

AAMR

South Texas Community Living Corporation

Westchester ARC

The National Historic Preservation Trust on Mental Retardation is proud to have sponsored the Century Project, which seeks to identify some of the significant developments in the field of mental retardation in the 20<sup>th</sup> century.

It is clear from the participation of literally hundreds of people throughout the country that there is a great deal of interest in the history of our field. That is very encouraging because it is such awareness and interest that is needed to ensure that the history is not lost.

The vast contributions made by the individuals recognized in this project are but a sample of the wonderful people and accomplishments that touched our field in this century. Those identified in the Century Project would be the first to recognize their lessor-known associates for their work.

One objective to the Trust's sponsorship of this project was to increase awareness of the importance of the history of the field and the need to actively preserve it.

The materials of this project will be housed at the National Archives on Mental Retardation at the Institute of Developmental Disabilities at the University of Illinois at Chicago.

Remember that we all have a responsibility to preserve this history.

Sincerely,

Michael R. Dillon

President, National Historic Preservation Trust  
on Mental Retardation

## TO THE FIELD OF MENTAL RETARDATION:

It has been a privilege to serve as Chair of the Century Recognition Project. Although the task was daunting, the importance of recognizing leaders within the field provided an opportunity for reflection and learning.

The 20<sup>th</sup> Century has been a period of great change, from the early days of professional debate, to the current system of supports and empowerment. As you read through the personal accounts of the Honorees, you realize how impressive the body of work in the field truly is and the number of disciplines that had to interact to create permanent change. The field of mental retardation is a specialty and its importance, although often clouded by other social sciences, is extremely unique. The commemorative process sought to highlight some of the major accomplishments and to raise the level of understanding throughout the field of the importance of our continued growth and reform.

The future continues to unfold as we face new challenges within a modern era. People with mental retardation and developmental disabilities emerging from special education have a new level of skill and new expectations. Our challenge is to retain a person-centered focus that truly reflects a partnership among self-advocates, families, professionals, work sites, and the community. Our emphasis will be on technology, profitability, enhancing personal competitiveness, and self-determination and choice.

As Harry S. Truman so appropriately stated: "our goal must be-not peace in our time, but peace for all time." May we respect the peace associated with a high quality of life, and may our legacy be one that solidifies this for people with mental retardation and developmental disabilities in the future.

With warmest regards,

Margaret J. Gould

*THE  
20th  
CENTURY*

## THE 20<sup>TH</sup> CENTURY

By Margaret Gould

The 20<sup>th</sup> Century was a period of great philosophical debate, devaluation, legal rights, and reform. It encompassed a reformation made possible by the recognition of human rights and the value for people with mental retardation in our society.

The opening of the 20<sup>th</sup> century was replete with major debates fostered in the 19<sup>th</sup> Century. In the 1840's, programs were initiated in Massachusetts and New York to offer educational and medical supports to children with cognitive delays. But, by the late 1800's, the altruistic leanings were being challenged as intellectual testing created classification through scoring systems, the term feeble-mindedness was given additional meanings, and on-site work was developed ensuring isolation.

In his book, A History of Mental Retardation, Dr. Richard Scheerenberger summarized the issue as follows: "In other words, the negative professional debates of the nineteenth century became the social reality of the twentieth with grave consequences for those deemed or suspected to be mentally retarded." This legacy of professional debate was pervasive throughout the 20<sup>th</sup> Century and framed the causes of many of the major events to come.

During the early part of the 20<sup>th</sup> Century, services to people with feeble-mindedness (the term used for mental retardation) varied greatly. Large congregate settings sprung up across the country with the express purpose of isolating individuals from society. The Eugenics movement perpetrated the belief that feeble-mindedness would infest a society if not controlled. The work of Dr. Henry Goddard including his famous Kallikak study was seen as solid proof of the Eugenics' theory.

At the same time, major community initiatives were developed such as Dr. Charles Bernstein's community residential and vocational efforts in Rome, New York and Dr. Walter Fernald's clinics in Massachusetts. The basis of these efforts framed an entirely different picture of people with feeble-mindedness and their worth.

By the mid-1940's, society was changing under the New Deal, and these changes were solidified in the post-World War II era. America began to emphasize a new sense of social justice and community concern. With these changes, came the development of a strong parent movement. In 1950, 88 parent groups formed throughout the country with a combined membership of 19,300.

In the same year, the "Parents and Friends of Mentally Retarded Children" formed (now known as The Arc/US).

Parents lobbied, budgets fluctuated in large institutions, community alternatives developed, and the debate continued. These were the prevailing forces at the time President John F. Kennedy was elected in 1960. His administration opened the plight of people with mental retardation to public policy reform. Over the years, elected officials in Congress such as Representative John E. Fogarty and Senator John H. Chafee stimulated reform. This reform was supported by new breakthroughs in medicine such as Dr. Jerome Lejeune's identification of trisomy 21, Dr. Robert Cooke's pediatric research, and Dr. Robert Guthrie's PKU screening test.

Reform took hold, but not soon enough to significantly alter the conditions at many large, congregate settings in the United States. Geraldo Rivera and Burton Blatt exposed the horrifying conditions to the public, leading to major lawsuits across the country. The judicial branch served as the center for debate now, and professional beliefs were challenged as clear alternatives were identified in community-based settings fostering a higher quality of life. The debate focused on human rights.

As we close the 20<sup>th</sup> Century and move into a new millennium, the questions of our legacy arise. What are we passing on to the next generation?

As the millennium approaches, the field faces a series of challenges such as: inclusive education, supported employment, medical advances, support options, assisted technology, and an ever-expanding group of self-advocates pushing us forward in the 21<sup>st</sup> century.

Looming are new challenges...many of which begin with our own views. Like professionals, families, and people with developmental disabilities at the turn of the last century, we are products of what came before us. The central tendons of the debate of the last century linger; although the basis is more community and person-centered now rather than size and systems oriented. We are driven by a new set of philosophies; now entrenched by the sheer number of permanent forces at play. We debate many divergent thoughts: Normalization vs. Isolation; Person Centered vs. System Centered; Supports vs. Programs; Community vs. Institution; and Facilitation vs. Care Taking. Our debates are no longer isolated to professional will, but include a wider audience within a wider world with new challenges.

The 21<sup>st</sup> Century will require a new viewpoint and a period of convergence. Inclusion and normalization will be less focused on community vs. institution than on the convergence of philosophy coupled with a high quality of life for people with mental retardation. It will focus on a new concept of community development and include such forces as: computers and internet technology; competitive position within a work place; organizational profitability; and self-determination and choice.

Convergence will require us to walk the walk, not just talk the talk, in a modern era.

Convergence will meld together the concepts of person-centered supports as vehicles to achieve high quality of life for people with mental retardation. We will no longer be debating size of a group home, but rather the appropriateness of what goes on in the home to support the people who live there.

As we close this century, each of us will be a part of defining this convergence. May we each learn from our history, and may that history bring with it enlightenment and compassion.



## **THE ONLY CONSTANT IS CHANGE**

Valerie Bradley, Ph.D., FAAMR

The impetus for continual improvement in the field of mental retardation is a constant and not the property of any generation. In fact, the aspiration for reform and the hope for revolutionary change have existed throughout the Twentieth Century.

The early part of the century saw the expansion of notions of "moral treatment" and the assumption that the society had a role to play in providing for the welfare and "asylum" of people with mental retardation, albeit in segregated settings sufficient to preclude reproduction. While mental retardation was seen as hereditary and almost always permanent, notions of "positive reinforcement" and the enhancement of self-esteem were goals shared by some of the more progressive educators.

By 1930, a professional consensus had advanced far enough to embolden a White House Conference on Child Health held that year to set as a goal: "For every child who is blind, deaf or crippled or otherwise physically handicapped, and for the child who is mentally handicapped, [there should be] appropriate measures to reduce his handicap, and training to become a useful member of society."

Unfortunately, these early signs of a more progressive approach to the treatment of people with mental retardation were overshadowed by the catastrophic depression of the 1930's, the growth of the eugenics movement, and the approach of World War II. The period after the war saw an era of reconstruction. One of the major events was the creation of a national parents movement, the National Association of the Parents and Friends of Mentally Retarded Children (now the Arc).

By the mid 1960's, there was a growing interest in the needs and circumstances of people with mental retardation as exemplified in the use of federal class action law suits to generate reform and the passage of legislation in many states creating the beginnings of a community system. The introduction of two amendments to the federal Social Security created a basic safety net for people with disabilities: the Supplemental Security Income (SSI) program which provides a modest monthly income for children and adults with disabilities, and Medicaid which provides medical insurance.

These were followed by additional federal legislation that profoundly affected the lives of all citizens:

- the Rehabilitation Act of 1973 whose Section 504 prohibits discrimination on the basis of disability in a wide variety of activities;
- the Education of All Handicapped Children Act in 1974 which guaranteed a free public education individually designed to meet the needs even of children who had previously been excluded as "un-teachable" or "untrainable";
- the 1988 Amendments to the Fair Housing Act which prohibited communities from using exclusionary zoning and other practices to keep people with disabilities from living in the home of their choice because not all the individuals were related or were a business;
- and finally the Americans with Disabilities Act in 1991, with its far reaching requirement that requires proactive efforts on all parts of society to open itself to participation by all its citizens, including those with disabilities.

Using these federal laws as a basis, the alternatives for people with disabilities grew by leaps and bounds. Parents and families began to have the same expectations for both their typical children and their children with handicapping conditions for "the good life" in a community of their choice. The expansion of advocacy entitled some to federally mandated protection and Advocacy organizations and developmental disabilities councils meant professional help was available when needed services were not forthcoming.

The challenge for us all as we move into the next century is how to increase the participation of people with mental retardation and their families in the design of services and in the allocation of resources. Reformers are now concentrating on ways to alter the priorities of the service system by placing the choices, preferences, and individual gifts of people with mental retardation at the center of the system. This next step toward the full citizenship of people with mental retardation will require perhaps the most radical change yet - the shift of power from professionals and "systems" to the beneficiaries.

# LEGAL LAWS AND LANDMARKS OF THE 20<sup>TH</sup> CENTURY

By Stanley S. Herr, J.D. Phil., FAAMR

In terms of legal rights and roles of the courts, the 20<sup>th</sup> century began as a period of shame. Because rights and remedies reflect the attitudes of society and the leaders of professions, this dismal legacy should come as no surprise. For example, at the Association's 1903 annual meeting then President J.M. Murdoch urged that "the state segregate all the feeble minded whose presence in the home and community is a constant source of danger" (Sloan & Stevens, 1976, p. 52). With the field being asked to act as "missionaries" for the viewpoint and as educators of the people, "particularly our legislators, in matters pertaining to the feeble-minded and the importance of their segregation and control under state supervision," repression was at its zenith. Judges were asked to support this push for "permanent institutionalization" and by 1915 magistrates, operating with scant safeguards, were authorized to commit any child "appearing to be feeble-minded" (Herr, 1983, p.24).

The nadir of this legal approach of containment for people with intellectual limitations - and certainly its most infamous judicial opinion - was *Buck v. Bell* (1927). In the judgment of contemporary scholars, this constituted a rigged test case - a collusive "judicial charade":—to have the U.S. Supreme Court uphold the legality of a state's involuntary sterilization law despite dubious facts, flawed legal reasoning and the absence of council truly representing the interests of the unfortunate Carrie Buck (Lombardo, 1985, p. 56; Burgdorf & Burgdorf, 1977).

Even after the first stirrings of the international human rights movement in response to Nazi horrors, the mid-20<sup>th</sup> century was a quiescent, even legally apathetic period. The courts were silent. The legal profession was unengaged. The law on mental disability was a backwater, and its tributary on mental retardation was its most stagnant pond.

The start of the revolution for the rights of people with mental retardation was finally sparked in 1972. In that year, right-to-education cases in Washington, D.C. (*Mills v. Board of Education*) and Pennsylvania (*PARC v. Commonwealth*) declared that children with mental retardation and other disabilities were guaranteed an education appropriate to their needs under the constitutional rights of equal protection and due process.

Later in 1972, the federal court in *Wyatt v. Stickney* broke new legal ground in upholding the constitutional right to habilitation.

In quick succession, other major class action suits were launched at New York's Willowbrook (NYSARC v. Rockefeller, 1973) and Pennsylvania's Pennhurst (Halderman v. Pennhurst State School and Hospital, 1974) that would, after decades of litigation, produce institutional closures and the creation of community-based services for its ex-residents and others.

In the ensuing decades, literally hundreds, if not thousands, of cases pertaining to people with intellectual disabilities have been published at all levels of the judicial system. As the 20<sup>th</sup> century's positive legacy to the next, there is now case as well as statutory law that goes from birth to death; crime to punishment; education to idleness; liberty to guardianship; inclusion to zoning exclusion; child well-being to child neglect; self-determination to discrimination; and law in countless other domains.

The measure of these legal developments is not in the sheer volume of cases or laws. Their true mark on the field is that a sustained era of human and legal rights concern shows no signs of abating. It is now internalized by all who advocate for and support the people so variously named in the 20<sup>th</sup> century but, so consistently vulnerable to society's indifference and the sting of individual's discrimination.

# **BIOMEDICAL ADVANCES IN MENTAL RETARDATION**

By Robert E. Cooke, M.D.

Until the middle of the nineteenth century, mental retardation (usually called cretinism or idiocy) was thought of as a unitary condition. By the end of the century, numerous physicians began to recognize characteristics of mental retardation in a variety of clinical conditions. One of better know is John Langdon Down, who in 1866 made the landmark observation, "A very large number of congenital idiots are typical Mongols."

The technique for the early diagnosis of mental retardation must certainly be attributed to Arnold Gesell. By 1915, Gesell had published descriptive scales for infant development which complemented the early work of Binet and Simon with older children and adults.

Ivar Foiling, Ph.D., ushered in the era of awareness of inborn errors of metabolism by his discovery of phenylketonuria in 1932, as well as the identification of the toxic effects of phenylalanine in such cases. In 1943, Kanner described a group of children formerly labeled as non-specific mental retardation as examples of a distinct diagnostic category: autism.

In the 1950's, Jerome Lejeune followed the research of others who postulated a genetic basis for Mongolism. In 1959, based on the recent finding that the proper human chromosome number was 46 (not 48), he opened the world of science to the importance of chromosome analysis. Lejeune's description of Trisomy 21 (now Down Syndrome) laid the foundation for modern molecular biology which has now clarified the diagnosis of Fragile X, Angelman's, Prader-Willi and many other disorders.

Alan Gregg, a practicing ophthalmologist in Australia, correlated cases of retinopathy and mental retardation with a prior epidemic of rubella in 1939 and 1940. His brilliant deduction not only led to a realization of the role of virus infection in pregnancy in producing mental retardation, but also stimulated the development of retrospective epidemiology.

The discovery that hyperbilirubinemia in Rh disease was a cause of kernicterus producing athetoid cerebral palsy as well as mental retardation led to exchange transfusion as an effective treatment. These results culminated in the prevention of Rh disease by Rhogam, the product of research by the National Institute of Child Health and Human Development.

Landmarks in prevention are largely the result of basic laboratory research applied clinically.

Thus, iodine in cretinism, low phenylalanine diet, and immunizations are just a few of the small steps that have been made in the 20<sup>th</sup> Century to prevent mental retardation. In vitro culture of viruses led to the development of the Rubella vaccine and the influenza type B vaccine as well. The detection of PKU in newborn children through the use of Robert Guthrie's filter paper spot test has become the standard worldwide in the last quarter of the century.

A recent preventive measure supported by the Center for Disease Control and Prevention for the use of folic acid during pregnancy to prevent neural tube defects such as hydrocephalus and spina bifida is a product of epidemiological research. This discovery is a landmark in the field of mental retardation because folic acid is the first vitamin to be used to prevent birth defects.

In spite of significant advances in the 20<sup>th</sup> Century, treatment of mental retardation lags far behind diagnosis, etiology and prevention in the history of biomedical landmarks. The therapy of several inborn errors of metabolism which would otherwise produce mental retardation (i.e., maple sugar urine disease, galactosemia, urea cycle disorders) offers a positive pathway for future prevention efforts.

The mechanisms of higher cortical functioning are the gaps in our knowledge that prevents adequate treatment of many disorders producing mental retardation. The brain is an assembly of hundreds of interdependent organs and systems - all with unique biochemical and physiological actions. How people learn, how people think remain mysteries to be solved through behavioral and biological collaboration in the next millenium.

## **THE ROLE OF PARENTS IN BRINGING CHANGE**

Quincy S. Abbot, Past President, The Arc/US

In the first half of the 20<sup>th</sup> Century, placement in a state operated institution or in one of the few privately run institutions was the only alternative for a family who could not care for a child with disabilities. It was not unusual for physicians and other professionals to advise parents to do so "for the sake of your other children." But following World War II, a growing tide of parents rejected this advice.

Advertisements began to appear in local newspapers: "A meeting will be held for parents of children with disabilities at 7 PM Friday, in the basement of the Main Street church." This was the beginning of the parent movement and the rise of community involvement directed at ending isolation and segregation for people with mental retardation.

The individuals living at home were children, so the immediate focus of parents was on services for children: education. Some of those same church basements where parents first met became home to local chapters of the organizations that were to become The Arc. They also contained classrooms funded personally by parents or through local charities such as the United Way.

But these parents were not content with these voluntary efforts, so they organized politically at local and state levels. In 1950, The National Associations of Parents and Friends of Mentally Retarded children elected Alan Simpson of Washington State, as its first president. Through The Arc, parents convinced local school districts, then state legislatures, and finally the United States Congress that their children had a right to a public education. In 1975, Public Law 92-142 (now known as IDEA) guaranteed "a free and public education to all." Later amendments in 1986 expanded this mandate to early intervention and pre-school programs.

As the children grew up, so did the parents' organization. It renamed itself in 1974 as the National Association for Retarded Citizens as it expanded its concerns for adults in its local, state and national agendas. Parents fought for civil rights and funding for people with mental retardation of all ages that would allow them to live, learn, work and play in the community with their non-disabled peers.

The model parent advocate was Elizabeth Boggs, who actively participated, in every significant piece of federal legislation affecting the lives of people with mental retardation from the 1950s through the early 1990s.

The parent movement played the key role in the second half of the 20<sup>th</sup> Century in bringing children out of the segregated, isolated institutions into the inclusive world of the community. As long as negative biases remain, parents will continue their key role as advocates shaping a world where individuals with mental retardation are respected and included.



# **PRESERVING THE HISTORY OF MENTAL RETARDATION**

Marcia B. Bryan, Ed. D., FAAMR

"Those who do not remember the past are condemned to repeat it."

George Santayana, Life of Reason, 1905

The preservation of the history of mental retardation may at first seem to be a perverse activity: Why keep reminders of the shameful way people with mental retardation have been treated in the twentieth century in our culture? Santayana reminds us of what may happen if the lessons of history are not understood. Indeed we must recognize that the infinite variety of human beings peopling our world is a treasure that enriches us all; one to be valued, appreciated and celebrated.

With the approach of the next century, professionals in the field of mental retardation have been motivated to reflect on what has changed in the lives of people with mental retardation. In the last decade, these reflections crystallized into a series of historic preservation efforts by individuals and organizations such as the American Association on Mental Retardation (AAMR), The Arc of the United States (Arc/US), the American Association on University Affiliated Programs (AAUAP), the American Network of Community Options and Resources (ANCOR), the National Association of State Directors of Developmental Disabilities Programs, the National Association of Directors of Public Residential Facilities, the President's Committee on Mental Retardation and The Association for the Severely Handicapped (TASH).

"Historic Preservation" can be an imposing concept, but what we are talking about is people's stories. We are fortunate to be living in a time when we have so many ways in which to tell each person's story: photographs, movies, videotapes, diaries and journals, oral tapes, official records, art work, letters, mementos, furnishings, publications, clothing, adaptive equipment, internet pages, even postage stamps.

Regardless of the original purpose of the item, its usefulness for the future is in the story it tells of the person, the events, the experiences of a lifetime in a community that may be very different from that of the next millenium.

Some individuals in the field have had the foresight to leave their papers, books and other memorabilia to the institution where they worked or to a university with which they were associated. Such repositories continue to be valuable, if often difficult to access, sources for education research and public policy development.

Since 1993, AAMR has recognized individuals and institutions for their efforts at such historic preservation through the establishment of the annual Harvey B. Wilbur Award.

With the assistance of the Joseph P Kennedy Foundation, the AAMR Ad Hoc Committee on Historic Preservation issued a Request for Proposals to seek a sponsoring organization which would become recognized as both an international site as well as a coordinating point for existing and future collections.

The National Archives in Mental Retardation became a reality in 1997 with the designation of the Department of Disability and Human Development of the University of Illinois at Chicago as the site. The university has demonstrated its support by donating space in the Department's building and then refurbishing it to create an environment conducive to both browsing and in-depth research.

Within a year, about 5,000 texts, monographs, journals, research papers, letters, videotapes, audio tapes, slides, photographs, directories, bibliographies and other memorabilia from nearly 50 countries had been entrusted to the Archives.

A second major task of the Historic Archives has been to identify the location of other repositories and begin to link those sites to the internet. See for yourself how rapidly this effort has grown by accessing the Archives web page at <http://www.uic.edu/depts/idhd/archives> which is maintained by staff of UI-C.

Every individual whose life is touched by mental retardation has a contribution to make assuring that we remember the past and are not condemned - nor condemn others - to repeat it.

# **THE RISE OF SELF ADVOCACY IN THE 20<sup>TH</sup> CENTURY**

Michael R. Dillon, Ed. D.

Self Advocacy, at the end of the century, has emerged as a movement of enormous potential for transforming services throughout the world.

Persons with disabilities, coming together to support one another and to work together to elect change, represent a very natural evolution that has occurred within other groups as they have gained acceptance in society at large.

For much of this century, advocacy efforts on behalf on persons with disabilities were championed by parents and by progressive social visionaries. Much of the gains made in this arena mirrored and followed similar changes that were produced by and for other larger and politically potent groups such as racial minority groups.

Issues such as abolition of segregation in the schools based on race, laid the foundation for similar successful movements for persons with disabilities decades later.

But, however well intentioned, advocacy is never a substitute for self advocacy. As in other groups, as acceptance is slowly advanced, individuals begin to speak out for themselves.

In the 1960's, several tentative steps were taken in Sweden to provide a forum for persons with disabilities to speak out on their own.

In 1974, People First was organized in Oregon. It grew out of the dissatisfaction that people felt in not having a direct voice on things that affected their own lives.

In the next ten years, the People First success was quickly spread all over the United States, Canada, Sweden and Australia.

In 1991, Self Advocates Becoming Empowered was established as the national organization in the United States.

By the advent of the new millennium, self advocate organizations will be existing in all 50 States with hundreds of local chapters.

This movement has had a profound effect as the message of the individual has been increasingly being presented directly by those individuals.

Efforts are being made to ensure that Self Advocates are members of all boards of organizations providing service, supports or having influence on the lives of persons with disabilities.

Self Advocates have been most articulate in calling for the closure of institutions for persons with mental retardation. They have been leading promoters of more person-centered means of planning and service design.

It seems quite sure that Self Advocacy will play a much more influential role in the new century. If this is so, then we look forward to more personal options, with the person making the critical decisions that will affect each person's own life.

This will result in a more responsive array of service and support options. Both individual as well as agency have much to gain in these developments.

**HONOREES**

## ALFRED BINET

Alfred Binet's importance in the history of mental retardation rests principally on his contribution to an understanding of the nature of intelligence. By 1900, Binet had written four books in the areas of reasoning, personality, hypnosis, and suggestibility, and he had established the leading French psychological journal. But it would be his work in the definition and measurement of intelligence that had the greatest impact on the field.



Binet developed the first intelligence test to identify feeble-minded children, a method that was counter to the traditional method of the time in which mental deficiency was analogous to a physical disease. Binet showed how physicians were unable to reliably diagnose mental deficiency using a medical model, and he argued that an evaluation of mental processes would yield more useful and accurate information. Binet and Victor Henri developed methods to assess memory, attention, imagination, and comprehension, among other mental processes that they hypothesized.

In 1905, with the help of Theodore Simon, a new collaborator, the first intelligence test appeared. It was a scale based on a sample of children and consisted of a series of tests of increasing difficulty, starting with the lowest intellectual level and extending to that of the average level. In 1908, the scale was revised and improved, using the concept of mental age for identification and training.

In a broad sense, Binet advanced objective measurement in the field of psychology. Perhaps more than any other figure, Binet demonstrated the superiority of objective assessment over clinical diagnosis made without such instruments. The Binet Scales and their derivative instruments have been indispensable in educational, medical, and social settings.

## HENRY GODDARD, M.D.



Goddard developed a major research program at the Vineland Training School in 1906. He was appointed as director and established the program as a psychological laboratory for the study of people with mental retardation.

Goddard is well known for two major projects. First, the development of intelligence scales for the military in World War I; and second, for his famous Kallikak study. Goddard believed there was a link between heredity and mental retardation. At Vineland, Goddard studied the lineage of a female resident, Deborah Kallikak. The name Kallikak was invented by Goddard to protect her family.

The Kallikak study traced Deborah's family back to her great-great-grandfather, Martin, Sr. The senior Kallikak fathered a child with a "feeble-minded girl." Goddard's research traced the children from this line and concluded that all of the resulting children were of questionable character and low intelligence. Deborah was from this family line.

At the same time, he traced the upstanding women who married Martin, Sr. and all the children from this line. The resulting descendants were all upstanding citizens with high intelligence.

Goddard concluded: "The Kallikak family presents a natural experience in heredity: a young man of good family becomes through two different women the ancestor of two lines of descendants, —the one characterized by thoroughly good, respectable, normal citizenship,...the other being equally characterized as mental defect in every generation."

When the study was issued, Goddard was widely praised for his landmark work. This praise became short lived, however, when severe defects were found in his study.

His prominence and his work at Vineland went far beyond the Kallikak study and eugenics. As President of A A M R, he brought a research component to the organization and developed a standard of professional debate that supported changes in the field for many years to come. His work underlies issues we still face today including: intellectual and adaptive behavior assessment, heredity and inheritance, education, juvenile justice, and quality of life. Henry Goddard has a profound and lasting effect on this field, and as such, is among the most significant people of the 20<sup>th</sup> century.

## CHARLES BERNSTEIN, M.D.

Sensitive and progressive for his time, Dr. Charles Bernstein strongly advocated for the development of individual and personalized programs. No method of treatment or training was deemed appropriate for all people with mental retardation.



Expressing strong concerns about institutionalization, he asserted: "The State should set aside a certain amount for the foundation of homes for the subnormal; they need a different line of treatment or training...If we are going to put these children in an abnormal environment from the time of birth, they will not be saved..."

His belief in community options intensified throughout his career. He was a strong advocate for the "colony system" and development of community based systems residential options. He rented homes in the City of Rome, New York and staffed them from the institution. Bernstein felt that his objective was to save the residents from "lives of institutional servitude."

By 1935, Dr. Bernstein created 52 local homes or "colonies" serving both children and adults. He also planned to open homes for women with IQs of 11-30.

By 1920, half of the public institutions in the United States had started a colony-type program. Such initiatives gave impetus to expanded alternative placement possibilities.

Dr. Bernstein was a man of his time. Although there had been many negative images of people with mental retardation at the close of the 19<sup>th</sup> century, there were many professionals, such as Dr. Bernstein who promoted alternative viewpoints. Dr. Bernstein was a major figure in moving the debate forward in the 20<sup>th</sup> century. His non-traditional view of community-based alternatives proved a successful option for many people formerly institutionalized in large congregate care settings.



## WALTER E. FERNALD, M.D.



The first resident superintendent of the Massachusetts School for the Feeble-minded, Dr. Fernald devoted his life to the development of facilities and educational programs for people with mental retardation.

His contributions to the field of mental retardation were both positive and negative. Reflective of his earlier teachings, he asserted in 1903: "The brighter class of feeble-minded with their weak willpower and deficient judgement are easily influenced for evil, and are prone to become vagrants, drunkard and thieves.

The modern scientific study of deficient and delinquent classes as a whole has demonstrated that a large proportion of our criminals, inebriates, and prostitutes are really congenital imbeciles, who have been allowed to grow up without any attempts being made to improve or discipline them. Society suffers the penalty of this neglect..."

Unlike some of his colleagues, Dr. Fernald grew in his understanding of and appreciation for persons with mental retardation. He even reversed earlier positions of the attributes of individuals in his care. This is reflected in a statement made in 1918 that "there are both bad feeble-minded and good feeble-minded. We know many who are generous, faithful and pure-minded... some of the sweetest and most beautiful characters..."

He is also responsible for some of the most progressive legislation passed in Massachusetts during this time such as: requiring his clients to be included in the State census, establishing psychiatric clinics, permitting parole from the State Schools, and making separate provisions for delinquents in the mental retardation system.

Dr. Fernald provided opportunities for more humane treatment and education for people with mental retardation.

## AVA PERCIVAL

Mrs. Percival was a tireless advocate and a strong influence in the early parents' movement.

Mrs. Percival began the Children's Benevolent League in 1935-36, the first parent organization formed in the world. Her husband served as the organization's first President. The Children's Benevolent League was a powerful voice in raising concerns about abuses and poor conditions at many institutional facilities.

With no national parent organization, Mrs. Percival turned to AAMR (then known as AAMD) to bring national attention to the needs of parents and family members. She advocated within AAMD for systemic reform and for the development of community-based options as alternatives to long term institutional care. She became the first parent member of AAMD and worked within the structure to create, debate, and promote a new approach to service delivery.

Mrs. Percival was an author, lecturer, and leader. In many ways, she represents the number of parents who felt their child needed something within their home community that allowed parents and family members to be included in the care and decision-making aspects of their child's life. As a result of parent leaders like Mrs. Percival, the field of mental retardation changed forever.

## JOSEPH T. WEINGOLD



Mr. Weingold, a graduate of Cornell and Columbia Law school and parent of a son with mental retardation, was the prime architect, first president and first executive director of the New York State Association for Retarded Children Inc., now known as NYSARC, Inc. NYSARC has grown into the largest not-for-profit organization serving persons with mental retardation and developmental disabilities in the nation. Mr.

Weingold was a fervent exponent of parent political activism on behalf of their children with mental retardation.

For thirty years, Mr. Weingold pioneered policy achievements in New York State which significantly shaped national mental retardation policy.

Mr. Weingold advanced the concept that mental retardation should have a distinct legal status separating it from other disabilities. He believed that the status of persons with mental retardation could never progress as long as the medical profession, which viewed and treated mental retardation as an incurable illness and made it a secondary priority after mental illness, controlled mental retardation policy.

Consistent with this belief, Mr. Weingold originated the concept of a separate state agency responsible for mental retardation.

Mr. Weingold was the center of policy developments in the area of mental retardation in New York State from the late 1940's to the early 1980's under Governors Harriman, Rockefeller, Wilson and Carey. Those developments spurred similar developments across the nation.

The primary such development was Willowbrook. As important as Willowbrook, Mr. Weingold used the New York State Association for Retarded Children to pilot community services to persons with mental retardation from prenatal/preventative care through every phase of life. This model has gained universal acceptance.

In 1950, he was one of the primary founders of the National Association of Parents and Friends of Mentally Retarded Children, now known as The Arc of the United States.

## **ELIZABETH MONROE BOGGS, Ph.D.**

Elizabeth Boggs was a brilliant scholar and mathematician. In 1945, with the birth of her son, David, she shifted her focus from the career in mathematics for which she had been prepared to advocacy and the development of public policy for people with disabilities. A founder of the National Association of Retarded Children, Elizabeth served as the Association's first woman President. Throughout her career, she continually remained involved with The Arc's Governmental Affairs Committee and its activities.



She held numerous national positions. She served on the President's Panel on Mental Retardation and as Vice-Chair of the Task Force on the Law. She also served on the President's Committee on Mental Retardation.

She was a major contributor to AAMR's Consent Handbook; and with Justin Dart, Elizabeth co-chaired the congressionally-appointed Task Force on Rights and Empowerment of People with Disabilities, an important impetus to the development of the Americans with Disabilities Act.

Elizabeth served on the SSI Modernization Project, and at the time of her death, was serving on the Social Security Administration's Task Force on Representative Payees.

Elizabeth won many national awards including the Kennedy International Award for Leadership, the Distinguished Public Service Award HEW, the Distinguished Service Award UCPA, the Wallace Wallin Award CED, and the N. Neal Pike Prize for service to People with Disabilities. She is a Life Fellow of AAMR, and an Honorary Fellow of the American Psychiatric Association and the American Academy of Pediatrics.

Everyone who knew Elizabeth had great respect for her intellect and her ability to directly go to the heart of the matter. She was a great friend to many, a mentor to most, and a strong advocate of reform. She crafted many of the changes in the field of mental retardation during the second half of the 20th Century. Her vision and drive served as an inspiration to everyone who met her.

## PRESIDENT JOHN F. KENNEDY



President John F. Kennedy became, at the age of 42, the youngest elected president of the United States. He said at his inauguration that the torch had been passed to another generation, a generation committed to representing those who were unrepresented, the disenfranchised and the powerless.

President Kennedy became the first head of state to concern himself with the challenges facing persons with mental retardation.

He stated shortly after he took office,

"Can you imagine that 2% of our children live with mental retardation who could be saved if we had the programs and the recognition of the needs... And those of us who have seen children live in the shadow know that a country as rich as ours can't possibly justify this neglect.

I have today announced my intention to appoint a panel of outstanding scientists, doctors and others to prescribe a program of action in the field of mental retardation. This condition strikes those least able to speak for themselves."

With his urging, Congress passed a bill with large majorities, which established the National Institute of Child Health and Human Development at the N.I.H., focusing on the health of mothers and babies.

Efforts to implement the President's recommendations were embodied in far reaching pieces of legislation. The first, Public Law 88-156, was the Maternal and Child Health Mental Retardation Planning Amendments of 1963. These were aimed at the state planning to determine actions needed to combat mental retardation and personnel needs. Seven days later, Public Law 88-164, the Mental Retardation Facilities and Community Mental Health Construction Act of 1963 was enacted. This act authorized the construction of University Affiliated Facilities (UAF's) which would conduct research, provide services and conduct clinical training.

Community clinics and services began to replace the isolation that persons with mental retardation had so long suffered in state institutions. And most importantly with outside support, persons with mental retardation began to start back to their homes and their families.

## **REP. JOHN E. FOGARTY**

John Fogarty was a member of Congress from the state of Rhode Island for 37 years. He was one of our country's leading advocate for health care and research in the United States. He was not only a key legislator for a national agenda but he had a vision, which was international in scope as well.

His untimely death at the age of 53 cut short a brilliant career, which had been most productive. His accomplishments include being the designer of the National Institute of Health.

A bricklayer, Fogarty became active in union activities, and through this he entered politics. He was elected to Congress in 1940 and served continuously until his death in 1967. He served as the Chairman of the House Labor-HEW Committee, where his deep commitment to health and welfare issues were demonstrated.

During his tenure, an explosion of legislation was passed which brought the health needs of the nation to the front of the political agenda for the first time.

During the Presidency of John F. Kennedy, Fogarty was a primary participant in the passage of federal legislation which created the President's Committee on Mental Retardation, provided for the development of comprehensive state plans for services to persons with mental retardation, created the University Affiliated Programs, and funds for the development of community services for persons with disabilities.

He was also a proponent for the support of training for teachers and other workers in the field of mental retardation and many other initiatives to improve services.

John Fogarty never forgot his home base in Rhode Island, and his concern for the individual was legendary, but he saw beyond the individual, the state and the country to address the illness, the suffering and the conditions that were harming people everywhere.

The problems presented by mental retardation were no less in New Mexico than in Rhode Island, any less in other parts of the world than in our country. He applied himself with equal vigor to these issues wherever they were.

## SENATOR JOHN H. CHAFEE



During nearly five decades of distinguished public service, John H. Chafee has been a forceful and articulate advocate for people with developmental disabilities. Today, tens of thousands of individuals with lifelong disabilities live productive lives in communities across the nation because of John Chafee's persuasive support for their cause in the United States Senate.

A graduate of Yale University and Harvard Law School, Chafee served for six years in the Rhode Island House of Representatives, where he was chosen Minority Leader by his colleagues. He was elected Governor in 1962 and won reelection in 1964 and 1966. During his six years as Rhode Island's chief executive, major strides were made in developing community mental health and mental retardation services, an accomplishment which decades later Chafee recalls with justifiable pride.

A senior member of the Finance Committee, over the past twenty years Senator Chafee has fought for expanded health care coverage for low-income women and children and community-based services for individuals with developmental disabilities.

Senator Chafee was the main proponent within the Senate Finance Committee for various changes in the Medicaid home and community-based waiver authority which, collectively, were aimed at broadening the community living opportunities available to Title XIX-eligible individuals with chronic illnesses and disabilities.

With a self-effacing quality that is highly uncharacteristic of a politician who has spent decades in the national limelight, Chafee has quietly but persistently given voice to the aspirations of a frequently overlooked and politically powerless group within American society.

## **JEROME LEJEUNE, M.D.**

Dr. Lejeune was a medical researcher who made a profound impact on the field of mental retardation because of his incredible series of scientific discoveries.



Working for many years at the University of Paris, he discovered the chromosomal abnormality in mongolism. Under the direction of Professor Turpin, an eminent French pediatrician who for some 40 years studied prenatal factors in the causes of diseases, Dr. Lejeune studied problems of mongolism and human genetics in general, as well as the effects of radiation upon germ cells and the developing embryo.

In 1959, Dr. Lejeune published his paper showing that the cells of mongoloids contain 47 chromosomes, one more than the 46 demonstrated to be in the normal human complement. This condition resulted from trisomy 21. Following this discovery, he concentrated most of his research on chromosome abnormalities in man.

Dr. Lejeune also discovered the "Cri du chat" (cat cry) syndrome and the concept of "translocation."

In recognition of his exceptional research work, Dr. Lejeune was awarded the 1962 Joseph P. Kennedy, Jr. Foundation International Award.

His broad range of study and subsequent genetic breakthroughs advanced the field of mental retardation toward an era of prevention and greater understanding of the conditions and causes of mental retardation and appropriate treatments and interventions.



## **ROBERT E. COOKE, M.D.**

Dr. Robert E. Cooke is one of the nation's preeminent leaders in the history of pediatrics.

At the Yale School of Medicine, he collaborated in the investigations elucidating the importance of replacing electrolytes in diarrheal states. These studies ultimately prevented death and brain damage in untold millions of children. Dr. Cooke was the co-discoverer of the test, for diagnosing cystic fibrosis. He was a clinician/teacher with legendary skills, and at age 35 was named Pediatrician-in-Chief at the Johns Hopkins Hospital, a position which he held from 1956 to 1973.

His awards include the Mead Johnson Award of the American Academy of Pediatrics; the John Howland Award, (the highest award bestowed by the American Pediatric Society); and the Kennedy International Award for distinguished service in mental retardation.

His most significant achievements involve advancing knowledge and services to promote the well being of persons with mental retardation.

In 1960, Dr. Cooke led the effort to organize pediatric, obstetric and public support for the establishment of the separate institute within the National Institutes of Health - the National Institute for Child Health and Human Development.

In 1963, he conceived of and carried to fruition a section of the federal Mental Retardation Facilities Construction Act, which created funding for University Affiliated Facilities of research, service and training directed to people with developmental disabilities.

In 1965, he organized and directed the initiation of Project Head Start as chair of the National Head Start Planning Committee.

In the 1970's, he played a major role in the emerging bioethics movement, including the public airing of controversial cases and the development of research and training programs in medical ethics. He strongly advocated for fellowship programs, which produced future leaders in bioethics, particularly as it involved people with mental retardation.

One of Dr. Cooke's most enduring contributions may be found in his 1973 farewell address at John Hopkins, "The Gorks Are Gone", which refers to an offensive dehumanizing term that disappeared from vocabulary.

## **ROBERT GUTHRIE, M.D., Ph.D.**

Dr. Robert Guthrie, an outstanding medical researcher, is best remembered for developing the screening test for PKU. The development of this test, besides saving many thousands of children from mental retardation, was particularly important because as Dr. Guthrie stated, "it provided a stimulus for a change in attitude toward mental retardation...Doctors had felt negative about mental retardation because the medical profession had no treatment or prevention to offer." The development of this test spawned a greater interest in research on finding other causes and treatments.



In 1984 after researching kohl, the black eyeliner used to decorate the eyes of women, children and infants in many Middle Eastern and South Asian countries, Dr. Guthrie working with Dr. Shaltout found seriously elevated levels of lead in these populations. This resulted in the development of a lead program and lead clinic in such countries as Kuwait.

Dr. Guthrie's career spanned working in such places the Division of Experimental Biology and Medicine at the National Institutes of Health as a research scientist, the University of Kansas as Department Chairman, the Department of Chemotherapy at the Sloan-Kettering Institute and the University of Buffalo as professor of pediatrics and microbiology.

He received many national and international awards including the Kimble Methodology Award from the Association of State and Territorial Laboratory Directors (1965), a Science Award from the American Association of Mental Deficiency (1970). The Fifth Annual Career Research Scientist Award for the American Academy on Mental Retardation (1981), and the Distinguished Research Award from the Association of Retarded Citizens—USA(1983). In 1986, Dr. Guthrie received a Kennedy International Award.

Dr. Guthrie's medical breakthrough has had a significant affect on the field and upon children throughout the world. A quote from writer Emily Dwass perhaps put it best, "A newborn's best friend: Buffalo's Robert Guthrie, M.D.

## GERALDO RIVERA



A quarter century ago, using a stolen key, Geraldo Rivera entered the Willowbrook State School for persons with mental retardation. His investigative report was aired on WABC-TV. It showed persons living in their own filth, with barely any care, often unclothed and ridden with disease.

Rivera's documentary changed forever the nation's perception of treatment for persons with mental retardation and developmental disabilities.

Rivera, in a documentary on Willowbrook, "Unforgiven," wept saying the experience was the "defining moment of my life."

"You can't treat humans like a dog in a kennel," he said. "The assembly line works for cars and not people."

Rivera's report turned out to be much more than an indictment of Willowbrook, but of the entire concept of institutionalization and the treatment of persons with mental retardation. While institutional versus community living up until that point was a matter of academic discussion, Rivera's report propelled it into the arena of public policy debate. It gave enormous impetus to the Willowbrook lawsuit against New York State, to federal requirements to either clean up or reduce New York's institutional population and to a movement throughout the nation to accord persons with mental retardation and other developmental disabilities the rights of other citizens.

Rivera turned Willowbrook into a major historical event and symbol as significant in its own way as Pearl Harbor was. After Rivera's expose, no politician could turn away from Willowbrook. Institutionalization and the entire philosophy of treatment for an entire group of individuals were changed forever.

Additionally, through his friendship with former Willowbrook residents, Rivera helped to establish the self-advocacy movement, which has become a real national political force for persons with mental retardation and developmental disabilities.

## BURTON BLATT, Ph.D.

Dr. Blatt, affectionately known as Burt by those who knew him, certainly ranks as one of the most influential leaders in the history of mental retardation in America.



Dr. Blatt's contributions fall into three Categories: Scholarships, Leaderships, and Humanitarian Concern.

Burton Blatt was a prolific scholar and researcher. His books, Christmas in Purgatory, Exodus from Pandemonium, and Souls in Extremis created an awareness and exposure to the devastating conditions people with mental retardation were enduring in isolated and inadequate care.

Perhaps Burton Blatt's greatest contribution was his strong commitment to the rights and dignity of people with mental retardation. He was one of the first professionals in the field to speak out against the system that held back people with mental retardation.

Seymour Sarason wrote, "Burt saw the world and those associated with him in optimistic terms. Although he did not believe that in every way the world was getting better and better, he did believe that it was a person's obligation to act as if he or she were capable of making it better."

Anyone who knew Dr. Blatt would concur. He touched the field and instilled in many young leaders a belief that they did not have to accept conditions as they were. His leadership in AAMR opened the doors for debate and challenge.

As Steven Taylor wrote when describing Dr. Blatt's work, "Do great leaders make history or does history make great leaders? This perhaps is a question best left to historians to ponder. For the rest of us, it is sufficient to know when history is being made and to appreciate the persons who are prominent at the time."

Indeed, Dr. Burton made his mark during a time when the system required reform. He was man of his time that changed his era and those that followed.

## HON. JOHN R. BARTELS

Judge John R. Bartels presided over a number of high-visibility cases as a federal judge from 1959 to 1997, but his best known and longest case was the Willowbrook class action. In the early 1970's, Willowbrook was the largest institution of its kind in the country. Approximately 5,700 people with mental retardation were crowded into subhuman conditions making it impossible to receive proper care and treatment, adequate food and medical services, and proper staffing and supervision. The people at Willowbrook were neglected, abused, injured, injected with hepatitis, and subject to other medical experimentation. Judge Bartels later described the situation as "tragic." In desperation, the Willowbrook parents sought the attention of state and federal officials and the media but remained unable to effect any meaningful change to the horrible conditions until they filed a federal class action lawsuit in 1972.

Due to Judge Bartels' vigilance and guidance for more than twenty years in the Willowbrook case, the implementation of the Consent Judgment [393 F.Supp. 715 (EDNY) 1975] and other orders laid historic legal groundwork and began a social revolution changing the way people with mental retardation will live and participate within our society for all time.

Over the years, Judge Bartels' attentiveness to the case resulted in historic agreements (settlements) between the parties and signed by the Judge that adapted the core principles of the Consent Judgment to a new era. The Judge later described the substance of these agreements as a "pioneer model" being followed throughout the State of New York and throughout the country. The focuses of the agreements were the standards for the quality of community homes and services for all class members. In addition to living in small homes in the community, class members are to receive appropriate habilitative and professional services, case management services, advocacy and representation by a consumer advisory board for as long as they live, and quality monitoring and systemic planning related to their individualized services. To protect these entitlements, the agreements provided that the plaintiffs might return to the court as necessary to seek enforcement of the provisions.

While presiding over the Willowbrook case, Judge Bartels upheld the fundamental constitutional rights of people with mental retardation at a time when case precedent and statutory laws were almost nonexistent for that purpose. He stood on the principles of equal protection and due process even though these legal concepts had not been commonly applied to institutionalized persons with mental retardation.

## **HON. RAYMOND J. BRODERICK**

On May 30, 1974, a class action suit was filed on behalf of the people living at the Pennhurst State School and Hospital in Spring City, Pennsylvania, approximately 30 miles from Philadelphia. The suit alleged the violation of the constitutional, federal and state rights of the people with mental retardation confined to the institution. The case, *Halderman, et al v. Pennhurst State School and Hospital et al.*, was assigned to Judge Raymond J. Broderick. In the 25 years that have followed, Judge Broderick has been an unceasing advocate whose landmark decisions have served to uphold and, in many instances, strengthen the rights of people with mental retardation. The judge's orders have paved the way for the de-institutionalization of and provision of appropriate community supports to literally thousands of people with mental retardation. His personal commitment to righting the wrongs experienced by people with mental retardation is truly remarkable.

On December 23, 1977, after a 32-day trial, Judge Broderick issued findings of fact and conclusions of law which found that the defendants had violated the constitutional and statutory rights of Pennhurst class members by failing to provide them with minimally adequate habilitation in the least restrictive environment. As a result, on March 17, 1978, an injunction relief order was issued by Judge Broderick requiring the defendants to provide each class member with minimally adequate habilitation in accordance with an individualized habilitation plan.

Pennhurst State School and Hospital finally closed on October 27, 1987. However, the Pennhurst story was far from over. Plaintiffs filed motions for contempt and after several years of unsuccessful efforts to resolve the issues, Judge Broderick issued two contempt motions. The first on August 28, 1989, required the Commonwealth of Pennsylvania in conjunction with Delaware and Montgomery Counties to ensure the provision of community living arrangements to class members residing in large facilities. On March 28, 1994, the judge issued a contempt order against Philadelphia County and the Commonwealth of Pennsylvania. This order required that sweeping reforms be made to Philadelphia's system for the provision of protections and supports to class members as well as to the Commonwealth's system for monitoring such protections and supports. Judge Broderick's March 28, 1994 Contempt Order made it clear that the mere de-institutionalization of people was not enough, and that of paramount importance was the provision of adequate protections and supports once people moved in to the community.

## **HON. JUDGE JOHNSON**

Profound changes occurred in the field of mental retardation as a result of the Wyatt vs. Stickney case in Alabama. This landmark litigation raised a series of key issues that required states to take a new approach in supporting people with special needs.

In the Wyatt vs. Stickney case (1971), the court ruled that state hospitalized mentally ill patients had the right to receive adequate and appropriate care based upon their particular needs. The case resulted in the establishment of standards for treatment and care, and created a base line for standards throughout the country. In his ruling Judge Johnson expressed deep concern whether large congregate facilities could offer adequate and appropriate care and treatment.

In 1970, the Wyatt vs. Aderhold case found that hospitalized mentally ill patients received inadequate treatment and that the habilitation approach used at the facility represented a violation of people's constitutional rights.

## CLASS MEMBERS

Without a doubt, court cases and litigation have played a major role in bringing about change in services in the last half of the twentieth century. In education, work, housing, and living the courts have had enormous influence in determining more progressive approaches and supports.

The judges, lawyers, and advocates have all received justifiable recognition for the important roles that they played in this evolution. Yet, the persons with disabilities themselves played a central role, one that is all too often overlooked.

Those people who lived in the inadequate institutions, who were excluded from school, or who were denied jobs became the true heroes of this stage. Denied opportunity, often denied what we would consider basic conditions for a safe and satisfying life, these people come forth despite this deprivation and demonstrate the gains that could be made when given a chance and some modicum of support.

People denied education when given a chance learn what they did not before. Those denied jobs make productive workers when they are afforded the opportunity. They demonstrate in life the points that were so hotly debated in the courts.

While there are some names on the titles of the court papers, the class members are mostly not known. Yet, all have made a most important contribution to these critical developments that have shaped the future of services in this century.

And without a doubt, it will be the continued activities of persons with disabilities who will demonstrate over the long course of their lives and over their own personal development just how profound is the impact of these hard fought for rights and opportunities.



## **WOLF WOLFENSBERGER, Ph.D.**



Wolf Wolfensberger, Ph.D., has made many contributions to the field of mental retardation.

In the late 1960's to early 1970, Dr. Wolfensberger spearheaded the normalization reform movement. His efforts at teaching normalization helped forge the way for de-institutionalization and the development of services and supports for people in community settings.

In the 1980's, Dr. Wolfensberger realized the limitations of normalization and abandoned it for his social role valorization theory. Both normalization and social role valorization courses have been taught throughout the United States, Canada, Great Britain, France, Germany, Scandinavia, and Australia.

Dr. Wolfensberger's normalization and later social role valorization work were intended to assist people to better understand how to provide quality services to persons who are disabled. To even better accomplish this work, he developed, with associates, the PASS and PASSING evaluation tools based upon the social role valorization theory, which measures human service quality from atrocious to ideal. These tools help determine whether a service meets the genuine needs of an individual.

Since 1973, Dr. Wolfensberger has been a Professor in the School of Education at Syracuse University, NY, and Director of the Training Institute for Human Service Planning, Leadership and Change Agency there.

Dr. Wolfensberger has been a prolific writer on services to people who are mentally retarded and their families. He has authored or co-authored about 40 books and monographs, and 250 chapters and articles.

Dr. Wolfensberger continues to present workshops that are controversial and challenging to participants; to fine tune his previous works and concepts, and to be a voice raising our consciousness to issues that if not explored and addressed could become serious problems for the leaders of the future.

## BURRHUS FREDERICK SKINNER, Ph.D.

The work of B.F. Skinner has influenced educational programs and methods for people with cognitive disabilities. Skinner's discovery of operant conditioning and its ramifications have also reached far into philosophy, economics, social issues, and even politics. Often dubbed as a philosopher-psychologist, Skinner promoted behaviorism as "a formulation, which makes possible an effective experimental approach to human behavior." Skinner's behaviorism was individualistic, empirical, and non-statistical. Most controversial, however, was his contention that the causes of behavior originate in the environment rather than inside the person.



B.F Skinner received his Ph.D. from Harvard in 1931. After teaching at the University of Minnesota and Indiana University, he returned to Harvard in 1947, where he continued his career until retirement. In 1969, he was awarded the National Medal of Science, and in 1972, the Humanist of the Year Award.

Skinner's position that behavior is a function of an individual's genes, history, and current circumstances and his contention that the environment selects behavior rather than merely being modified by it, oriented many applied researchers and teachers toward changing the environment and measuring the effect of those changes on the individual's behavior. Early attempts at teaching and therapy using operant principles with people with disabilities took place on the back wards of mental hospitals and state institutions in the 1950's and 1960's. Token economies, self-management systems, and even direct shaping of behavior were shown to be beneficial. In 1968, applied behavior analysis (ABA) became a recognized method for making improvements in socially important behavior.

B.F. Skinner was a prodigious author. A few of his books included, The Behavior of Organisms, Walden Two, Science and Human Behavior, and Beyond Freedom and Dignity. In addition, a number of journals have been developed to disseminate operant research including Journal of the Experimental Analysis of Behavior and Journal of Applied Behavior Analysis. The research and behavioral technology deriving from B.F. Skinner's work has been applied to a broad range of settings. His formulations were elegant, precise, and practical and they will continue to have an enduring and significant influence.

## MARC W. GOLD, Ph.D.

Marc Gold is best known for his innovations in teaching vocational skills, but he was also a pioneering advocate for community inclusion, and he proposed a definition of mental retardation that shifted the disability from the consumer to the training procedures and adaptations required of society. This viewpoint is reflected in his statement, "If the student fails to learn, the teacher fails to teach." Combined with the technology of systematic teaching, this formed the foundation for Dr. Gold's system of teaching, "Try Another Way."

The "Try Another Way" training approach combined the research and principles of applied behavior analysis with a rigorous consumer-focused values base. It incorporated many of the procedures in use today, including systematic correction, minimal prompt assistance, and numerous other stimulus factors. Dr. Gold's powerful audience demonstrations inspired teachers to try new ways of teaching people who were thought to be un-teachable. Many of the progressive ideas that he promoted in the 1960's and 1970's were forerunners of today's New Paradigm in developmental disabilities.

After receiving his Ph.D. in Special Education from the University of Illinois, Champaign-Urbana in 1969, he joined the University of Illinois faculty as a research professor working at the Institute for Child Behavior and Development. There, he applied stimulus control research findings to vocational training for people with learning difficulties. His book, Did I Say That appeared in 1980, two years before his untimely death. During his career, Dr. Gold was a national officer of AAMR and TASH. He served as consulting editor or board member for the American Journal of Mental Retardation, Mental Retardation, and Education and Treatment of Children.

Another element underlying Dr. Gold's philosophy and teaching was his competence-deviance hypothesis, which posited that the more competence an individual has, the more deviance will be tolerated in him by others. This notion helped to explain society's overreaction to minor infractions by people with disabilities. Using this rationale, Dr. Gold attempted to shift our focus on eliminating deviant behavior to developing competence.

Marc Gold personally touched many people with warmth, sensitivity, and enthusiasm. Many of our inclusive vocational strategies in use today, including job coaching and supported employment, are a direct outgrowth of the pioneering efforts of Marc Gold.

## ROBERT PERSKE

Robert Perske is a novelist, author, and advocate with an international reputation who has been involved with people with disabilities for over 40 years.

Mr. Perske has been involved in the activities of The Arc since 1960 when he was a Fellow in Religion and Psychiatry at the Menninger Foundation, and a Chaplain at the Kansas Neurological Institute in Topeka, Kansas. He was the Executive Director of The Arc of Greater Omaha.



Mr. Perske won the Rosemary Dybwad International Award in 1968. This enabled him to travel and study in Sweden and Denmark. He reports that after that study tour he was a changed person.

In the late 1970's, he was elected President of The Arc of Connecticut, and has held other positions (formal and informal) within The Arc ever since.

He met his wife, Martha, in Topeka and they were married in 1969. They were both single parents with a total of five children. Martha's illustrations of Bob's books have earned her the nickname, "the Norman Rockwell of the Disability Movement."

Bob and Martha collaborated on two major reports for two United States Presidents. They worked on "Mental Retardation: The Leading Edge," for President Carter and "Mental Retardation: Century of Decision" for President Nixon.

In 1987, Bob and Martha shared the United Nations Healing Community Arts and Letters Award.

Bob's four books include: Show No Mercy, Circle of Friends, Deadly Innocence, and Unequal Justice. Martha has published Perske Portraits 1971-90. She also has several illustrations in Mario Thomas' best seller, "Free To Be...A Family." In 1989, Martha presented one of her portraits to Princess Diana at a ceremony in Liverpool.

In 1998, Bob and Martha were honored at The Arc/US Convention with the prestigious President's Award for their contributions to the field of mental retardation for over four decades.

## MARTHA PERSKE



Martha Perske is a self-taught illustrator with a marvelous gift for showing a person's disability and natural beauty at the same time. She does it with a pencil - just a pencil.

Martha's art is known worldwide for helping to give wings to the words of others who spoke out on behalf of persons with disabilities.

Martha Perske's work has been recognized by most of the major disability organizations in the Western world. She illustrated major reports on mental retardation for Presidents Nixon and Carter, designed the International Year of Disabled Persons commemorative stamp, and drew the persons with disabilities for Mario Thomas's "Free to Be.....A Family."

She was commissioned to present an autographed drawing to Diana Princess of Wales, and she drew the illustration for an attitude change campaign jointly sponsored by Johnson and Johnson and the Arc of the United States. She received the Healing Community Arts and Letters Award at the United Nations in New York.

Martha Perske is a unique individual. Her work has brought joy, recognition, and hope to many. The warmth of her drawings create emotional responses that have positively promoted the abilities and role people with mental retardation achieve as we develop systems of supports based upon a person centered focus.

Martha Perske has added a truly unique feature to the landscape within the field.

## **FRANK J. MENOLASCINO, M.D.**

Dr. Menolascino helped establish the first psychiatric program for persons with mental retardation in a medical school in the United States in the early 1960's after attending one of the first post-graduate fellowships for psychiatrists at Letchworth Village for the Retarded in New York.



As a research psychiatrist at Nebraska Psychiatric-Institute, he established the first in-patient program in the country and started the first national research project devoted to both in-patient and outpatient care of this underserved population.

In the late 1960's, he helped establish the Principles of Normalization in North America (along with Wolf Wolfensberger). Together they worked to create and acquire funding for the Eastern Nebraska Community Office of Retardation (ENCOR). ENCOR was recognized as one of the most pioneering community-based programs which later became a model as a service, research and training program for visitors from all over the world.

Dr. Menolascino's seminal book Psychiatric Approaches to Mental Retardation was instrumental in explaining the mental illness aspects of persons with mental retardation. His additional 20 books significantly increased our knowledge of the psychiatric causes and treatment needs of persons with mental retardation.

Dr. Menolascino served as a visiting professor to more than 30 universities, provided over 200 seminars to professionals at all levels, and assisted with intensive training of thousands of medical students, psychiatric residents and visiting dignitaries from around the world.

His honors included significant contributions to the Presidents Committee on Mental Retardation, the N.I.M.H, and many other national and international groups.

In summary, his collective impact on the field of mental retardation was enormous. Along with George Tarjan, he was the most influential psychiatrist in the world to improve the understanding and care of persons he devoted his life to.

## EUNICE KENNEDY SHRIVER



Chosen by Ambassador Joseph P. Kennedy 50 years ago to lead the Kennedy Foundation in its efforts on behalf of persons with mental retardation, Eunice Kennedy Shriver has fulfilled the expectations of many who care about individuals with disabilities and their families.

With her husband, Sargent Shriver, she initiated the creation of university research centers dedicated to the prevention and amelioration of mental retardation at Harvard, John Hopkins, Stanford, Wisconsin, University of Chicago, Peabody and many other prestigious institutions.

Following the election of John F. Kennedy to the presidency in 1960, Eunice Shriver engineered several legislative and administrative proposals that led to the establishment of the National Institute of Child Health and Human Development, the University Affiliated Facilities and Mental Retardation Research Centers. She also proposed the formation of, and guided the President's Panel on Mental Retardation, which established guidelines for research, service, law and education for persons with mental retardation.

Realizing the importance of societal attitudes toward the less powerful, Eunice Shriver established programs in ethics at several universities, which emphasized the problems of families affected by mental retardation. Those efforts culminated in the inclusion of programs in medical ethics in almost every medical school in this country.

Her seminal magazine article concerning her sister with mental retardation helped relieve the feelings of isolation experienced by thousands of parents of children with mental retardation.

Her personal interest in sports was the impetus for Special Olympics, which started out as a competition amongst children and adults with mental retardation held at her family's home. Today, millions of individuals with disabilities have participated in Special Olympics activities at locations throughout the world.

Over the past decade, Eunice Shriver's pace has not slackened. She has pioneered efforts in religious education for persons with mental retardation, in problems affecting aging disabled individuals, and in public special education.

## **RICHARD SCHEERENBERGER, Ph.D.**

Dr. Scheerenberger's remarkable career spanned 40 years. Among his many accomplishments, he gave the field of mental retardation many written contributions. His book, A History of Mental Retardation, offers one of the most comprehensive and important collections of information regarding the field, its leaders and significant changes over the years.



Graduating from the University of Wisconsin at Milwaukee in 1952, Dr. Scheerenberger worked in classrooms within institutional settings. Within a few years, he was appointed Director of Special Education for the public schools of Minot, North Dakota. In that city's school system, he developed special classes for people with disabilities.

As the Director of the Documentation Service on Mental Retardation at the University of Wisconsin at Madison, he developed a series of publications that brought many professionals and experts together.

As Assistant Director to the Division of Mental Retardation Services in the Illinois Department of Mental Health, he continued to exemplify leadership qualities particularly with direct service personnel.

In their article, "Necrology: A Point of Light Extinguished", Stephen Jones, Al Baumeister, and Ross Porter described Dr. Scheerenberger's work: "Under his enlightened leadership, Central Wisconsin Center has long stood as a beacon of hope, blazing the path toward more compassionate and effective training and care techniques for all citizens with severe disabilities. An aggressive client-centered approach to programming that began at Central Wisconsin Center by the early 1970's since has been codified in federal 'active treatment' standards and has spread to residential facilities across the Country."

An administrator, writer, President of AAMR from 1978-1979, lecturer, change agent and advocate, Dr. Scheerenberger has demonstrated powerful spirit and leadership.



## GUNNAR AND ROSEMARY DYBWAD



Dr. Gunnar Dybwad is a Professor Emeritus of Human Development at the Heller School of Brandeis University, in Waltham, Massachusetts. His wife, Rosemary F. Dybwad was his constant companion and collaborator for over six decades.

This husband and wife team were major players in building organizations, passing the legislation and deciding the litigation that shaped the development of rehabilitation and human services.

By 1964, as the director of the organization then known as the National Association for Retarded Children, Dr. Dybwad had published numerous major papers and given countless important addresses.

The book titled The Challenge of Mental Retardation, included essays such as "Are We Retarding the Retarded?" Originally published in 1960, this essay was an indictment of low quality services, which forced low expectancies and stereotypes on people with cognitive impairments.

In 1969, Dybwad published a paper entitled "Action Implication: the USA Today." In that paper, he called for better training and pay for direct care staff.

His most recent effort, dedicated to Rosemary's memory, is "New Voices: Self-advocacy by Persons with Disabilities." This collection addresses the emergence of self-advocacy from across the globe.

Dr. Rosemary Dybwad, in addition to typing and editing Gunner's manuscripts for decades, was also a prolific writer in her own right. In 1990, in honor of her 80<sup>th</sup> birthday. Brookline Books published an edited volume of her most important papers: Perspectives on a Parent Movement: The Revolt of Parents of Children with Intellectual Limitations.

The walls of their family home, including the basement, are lined with proclamations signed by presidents and international figures, photographs with President Kennedy and other governmental leaders.

Gunnar is a Fellow in the American Association on Mental Retardation, the American Sociological Association, the American Orthopsychiatric Association, and American Public Health Association. He is also an honorary Fellow of the American Academy of Pediatrics.

Rosemary served on the Massachusetts Developmental Disabilities Council, was a consultant to the Canadian National Institute on Mental Retardation, and the Eunice Kennedy Shriver Center.

During their career together, Rosemary and Gunnar Dybwad traveled the globe consulting in more than 30 nations. Together they were goodwill ambassadors known throughout disability rights circles throughout the world.

Since Rosemary's death, Gunnar continues to live in the house that was their home for so many years. He continues to tend the garden, not because he is a gardener, but because it is "Rosemary's Garden."

## H. RUTHERFORD TURNBULL, III, LL.M.



For more than three decades, H. Rutherford Turnbull has been a respected national and international advocate, an exemplary teacher and a courageous leader who has dedicated himself to an improved quality of life for those with mental retardation and their families. He has championed the de-institutionalization movement while calling for expanded home and community service options. He has advocated for the use of positive behavioral supports rather than aversive interventions. He has been a leader in calling for the medical community to cease the practice of withholding medical care

for newborns with disabilities and he has challenged the disability service network to expand family supports and provide opportunities for increased personal empowerment.

He has served as Secretary of The Arc/US, Chairman of the American Bar Association Commission on Mental and Physical Disability Law, Trustee of the Judge David L. Bazelon Center for Mental Health Law, a member of the National Commission on Childhood Disability, and Treasurer of the Association for Persons with Severe Handicaps. His leadership in these nationwide organizations had led to new, progressive disability legislation and improved regulations. Especially noteworthy, was his work as a Fellow at the Joseph P. Kennedy Jr. Foundation that, ultimately, resulted in the Technology Assistance for Individuals with Disability Act of 1988.

A prolific writer, Rud Turnbull has authored more than 150 articles, books, chapters and monographs including three leading special education textbooks, the first AAMD Consent Handbook and two editions of Parents Speak Out. He also holds positions as Professor of Special Education and Courtesy Professor of Law at the University of Kansas.

Rud Turnbull has received the Leadership Award of the American Association on Mental Retardation, the Distinguished Public Service Award of the International Council for Exceptional Children, The Distinguished Service Award of the Arc/US and the Leadership Award of the University of Kansas School of Education.

The father of J.T., a man with mental retardation and autism who serves as the "Polestar" for his dad, Rutherford Turnbull III is truly a leader of the century. As an individual, and in partnership with his wife Ann and his children, he has made a significant difference in the lives of persons with mental retardation and their families.

## ANN P. TURNBULL, Ed.D.

Dr. Ann Turnbull is recognized throughout the United States and the world as an exemplary special educator, a respected researcher, a staunch family advocate, and a loving mother who has fostered independence and full inclusion of her son, J.T., a man who has mental retardation and autism. By generously sharing her experiences, ideas and feelings, Ann has profoundly influenced disability professionals while inspiring and motivating thousands of families who respect her candor and admire her joyous enthusiasm and sense of humor.



In that quest for excellence, she obtained degrees in Special Education from the University of Georgia, Auburn University and University of Alabama. She has published hundreds of well-respected professional articles, books, and chapters, and, as a renowned speaker, has motivated countless audiences throughout the world. Currently, Dr. Turnbull is a Professor in the Department of Special Education at the University of Kansas and she serves as Co-Director of the Beach Center on Families and Disability. She directs comprehensive research and training designed to enhance the quality of life for families who have a member with a disability and serves as an advisor and consultant to federal and state policymakers. Specific areas of scientific interest and expertise include family systems research and intervention, family advocacy, educational policy, and school and community integration.

Dr. Turnbull has served extensively in professional and volunteer organizations including the American Association on Mental Retardation, the National Association of Rehabilitation Research and Training Centers, the National Center for Clinical Infant Programs, the National Self-Determination Alliance, Special Olympics International and the International League of Societies for Persons with Mental Handicaps. Her honors include the Rose Fitzgerald Kennedy Leadership Award, the Arc/Us Educator of the Year Award and the Outstanding Woman Teacher Award from the University of Kansas.

Dr. Turnbull is truly an exceptional individual in this century and, along with her husband Rud, they have shared their experiences and made a major difference to professionals and families everywhere.

## JAMES W. ELLIS, J.D.



James W. Ellis has made an immeasurable contribution in advancing equal justice and fair treatment of people with mental disabilities in this century. An expert in constitutional law, Dr. Ellis has devoted his unique personal talents and professional expertise in applying the Due Process and Equal Protection Clauses of the Fourteenth Amendment to important precedent setting cases before the United States Supreme Court and the Circuit Courts. A co-author and advisor on innumerable "Amicus Curiae" briefs, he has articulated the views of the disability community on a wide variety of critical issues including withholding treatment from newborns with

disabilities, imposing the death penalty on persons with mental retardation, eliminating discriminatory zoning against group homes, and assuring a defendant with mental disabilities is competent to stand trial. Of particular importance have been his efforts to prevent the execution of people with mental retardation. Thanks to his unique perspective, political savvy and unwavering commitment, twelve states have enacted prohibitions against executing people with mental retardation over the last decade.

In addition to teaching law at the University of New Mexico, Dr. Ellis has authored hundreds of chapters, books, articles, and papers, and delivered innumerable lectures. His written and oral work has included disability topics encompassing criminal justice system reform, the right to refuse treatment, the devaluation of human life, services in the least restrictive environment and children's rights. Particularly noteworthy among his many accomplishments, was his co-authorship on the groundbreaking Consent Handbook and The Least Restrictive Alternative: Principles and Practices.

Dr. Ellis is a member of the Bar of the Supreme Court of the United States and the District of Columbia. He is a Past President and Fellow of the American Association on Mental Retardation (AAMR), A Fellow in the American Orthopsychiatric Association and a member of the American Bar Association. He is the recipient of numerous awards including the AAMR Humanitarian Award, the Leadership Award of the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded and the Pool of Bethesda Award of Bethesda Lutheran Homes.

## ROBERT M. GETTINGS, Ph. D.

When knowledgeable people refer to Robert M. Gettings as "Mr. Medicaid," it is not done lightly. Medicaid is a Social Security program that provides a broad range of housing and health-related supports to people who are elderly or disabled. It is unlikely that any other individual in the United States knows as much as Gettings does about Medicaid law, regulation and policy as it affects people with mental retardation and other developmental disabilities.



Gettings came to the Washington, D.C. area in January 1968. Since 1970, he has served as Executive Director as what is now the National Association of State Directors of Developmental Disabilities Services.

One cannot underestimate the role that Gettings has played in assisting states move from systems that relied almost entirely on institutional care in 1970 to the broad and varied system of community supports that we see across the U.S. today. He has mentored many state directors who often had little experience in federal public policy or in the development of community supports.

He is a prolific writer, having authored or co-authored more than a dozen major publications.

Robert M. Gettings has demonstrated outstanding leadership in encouraging states to redesign their service delivery systems for people with mental retardation and other developmental disabilities. It is largely through his influence that so many U.S. citizens are today leading productive lives in our nation's communities, rather than wasting away in large, impersonal and stultifying institutional settings. The field is fortunate that he will be leading the way to yet greater improvements in the new millennium.

## PAUL A. MARCHAND



Chief among the people working in Washington, D.C. to assure that federal policy would enhance the lives of people with mental retardation and assure their right to full citizenship is Paul A. Marchand.

Marchand assists Federal agencies and the U.S. congress in formulating programs and benefits for individuals with disabilities and their families. He is a nationally recognized expert on public policy and disability, having been extensively involved in the passage of many vital federal laws, including the Americans with Disabilities Act, the Developmental Disabilities Act, Education for All Handicapped Children Act and its successor, the Individuals with Disabilities Education Act, amendments to the Rehabilitation Act, and many modifications to the Social Security Act.

In 1973, Marchand became the first elected chairman of the Consortium of Citizens with Disabilities, a position he has held continuously since that time. This important coalition has grown to include more than 100 national, Washington-based organizations.

Among his many leadership roles, Paul is a member of the Executive Board of the President's Committee on Employment of People with Disabilities, Board member of the American Association of People with Disabilities, the Coalition on Human Needs, and HISH. He was appointed by the Clinton Administration to serve on the National Commission on Childhood Disability, which explored ways to improve the 551 Program for children in this country.

Marchand is the recipient of numerous awards, including a Distinguished Service Award from President George Bush, one of the nation's highest honors for a civilian.

In the words of Justin Dart, a nationally known disability advocate, "Paul Marchand is one of the greatest leaders in the world, and I don't say that lightly. Without his leadership we couldn't have done all that we have on behalf of citizens with disabilities."

## BERNARD CARABELLO

Bernard Carabello has spent nearly all his life struggling to achieve freedom for himself and for all person with disabilities.

Bernard's accomplishments began on a personal level, in his own heroic saga to free himself from the confines of an abusive and wholly inadequate institutional system.



Bernard not only prevailed, but he translated his own experience into a positive example for others. Bernard provided his increasingly clear voice to the proponents for the litigation, which would eventually close the Willowbrook Developmental Center. This had profound impact throughout the country.

As an indefatigable worker on behalf of persons with disabilities, Bernard has spent the last 25 years advocating for the rights of others.

He has been an ombudsman in New York City for 18 years. In this role, he has not only represented individual and family needs and issues, but he has also educated a whole generation of direct care workers about the dignity and rights of all people. He has spoken, given training and provided consultation throughout the country. Wherever his message is needed, Bernard will strive to be there.

He is the founder and first Executive Director of the New York State Self-Advocacy Association. He continues to speak out for more personal and individually responsive supports. As he raised his voice to call for justice and rights, his example has become a beacon to others to do likewise.

Not everyone has supported this advocacy, particularly in the early days. Bernard has taken unpopular causes and he has been criticized as misguided and ungrateful. Yet he persists in tireless efforts to speak the truth as he sees it and to fight for the freedom of others, the same freedom that he holds so dear for himself.

Born in New York City in 1951, Bernard was placed at the Willowbrook State School at the age of 3. He spent the next 19 years of his life isolated from society. Yet, this deprivation led to his dedication to spend the rest of his life as a freedom fighter.



## CHRIS BURKE



No recognition of historically significant persons in the field of mental retardation could be complete without acknowledging the important contribution of Chris Burke. Born with Down Syndrome, Chris never let this reality deter him from achieving his goal of becoming an actor.

In 1987, Chris landed a role in the made-for-TV movie "Desperate." Then in 1989, he was given a starring role in a weekly prime time TV series. Through his portrayal of Corky in the ABC series

"Life Goes On," Chris was able to send a powerful message, to literally millions of people across this land, that the dignity, and the ability of people with mental retardation must be embraced.

As a spokesperson and advocate for persons with Down Syndrome, Chris has been an inspiration to individuals with mental retardation. Chris is the Editor-in-Chief of the National Down Syndrome Society publication of "News & Views." Through this vehicle as well as speaking engagements, Chris continues his message of empowerment and inclusion.

Chris has made numerous appearances on behalf organizations and has become a symbol of the self-advocacy movement.

Chris Burke has, through determination and the belief that no goal is too large or unattainable, forever altered the perception of an entire generation of Americans.

*LEGACY  
STATEMENTS*

**TONY ALVAREZ**

**Executive Director, Schoharie County Chapter of NYSARC**

Congratulations to the individuals and their families who have struggled to achieve their rightful place in our society. We thank you for the opportunity to dedicate ourselves to excellence and caring for the lives we touched. And, we are forever reminded, that when we treat those who are considered less fortunate as equals, they too can become our heroes.

**RAY C. ANDERSON**

**Vice President, VOCA Corporation**

Treat others with greater respect and dignity when faced with the most challenging of circumstances.

**LAURA B. BAKER**

**Founder, Laura Baker Services Association**

A pupil needs to wonder about a thing in order to learn about it. If one approach doesn't bring a response, another must be tried in order to open up an interest. It is necessary to begin where the child is and to go on from there with the very next step. Some of my pupils have gone on to become self supporting and three have graduated from college. I am happy.

**ALBERT W. BLEAU JR.**

**Executive Director, Greater Lynn Mental Health & Retardation Assn.**

The last century has seen great strides in the recognition from society that people with developmental disabilities can make a positive impact in the community where they live. By focusing on their abilities, we will continue to break down the walls of stigma.

**MARC BRANDT**

Joseph T. Weingold said it all, "We cannot change our children for the world's sake but we can change the world for our children's sake."

**DIANNE BREITBACH**

**Executive Director, Camp Albrecht Acres of the Midwest**

Camp Albrecht Acres was established in 1975 to provide "something better" in services and care to disabled individuals of all ages in a "smaller world" within a "larger world" where concentration is on their "ability", not their "disability," with the opportunity to reach his/her highest potential humanly possible.

**ALBERT BUSSONE**

**Vice President & Chief Operating Officer, Chimes International**

May each of us be remembered for what we achieved and how we positively affected the lives of the people whom we tried to serve.

**MARCIA B. BRYAN**

**President, The Interim Management Executive Solution**

I have been privileged to be one among many in a long tradition of outreach and support for children and adults with developmental disabilities. My life is richer for their friendship and more fulfilled living in the reflected light of their accomplishments.

**KARYL CAPLAN**

**Executive Director, Rockland ARC**

May we continue to forge a path upon which education, housing, recreation, employment, respect, compassion and opportunity are available in equal measure to all people.

**FRANK M. CAPONE**

**Executive Director, Liberty**

I have been in the field for 25 years, and I am just now beginning to understand what it's all about. The next 10 years will be even more interesting.

**PAUL CESANA**

**Executive Director, The Resource Center**

Founded in 1958, The Resource Center has long been a recognized leader in improving the lives of persons with developmental disabilities. Our dedication to helping every individual to lead as fulfilling a life as possible has led to many honors over the years, including our selection in 1985 as the most Outstanding Rehabilitation Facility in the nation.

**M. DOREEN CROSER**

**Executive Director, American Association on Mental Retardation**

Self-advocates, parents, friends, AAMR members and other professionals have worked together in this century for an improved quality of life. Much has been accomplished!

**MICHAEL DILLON**

Preserve History! Such a slogan should be taped prominently on our desks or perhaps our foreheads. Even now, important aspects of our history, things that have shaped who and what we are today are being lost. The Century Project is a reminder of our rich legacy. We have benefited from the accomplishments recognized, now we bear the responsibility to pass on this legacy to the next generation. Support the work of the National Historic Preservation Trust on Mental Retardation.

**S.M. EIDELMAN**

Parents and self advocates have become a powerful voice in the late 20th century. My dream is that empowerment and inclusive lives, lives with meaning, become the reality for all people with disabilities in the 21st century.

**LESA A. FICKIESEN**

**Administrator, Community Alternatives West Virginia (Rescare, Inc.)**

CAWV has been doing business in West Virginia for over 11 years. With continued dedication from all of our staff, we are able to give the people we provide supports to the opportunity to enable individual growth.

**GLENN L. FRICKE**

**MR/DD Division Directory, COMHAR, INC.**

Thanks to Judy Weick, who was the first special person I met and kept me going in my career. Thanks to Dave Austin, a mentor, friend and my conscience, who encouraged me to grow and take risks. Thanks to all moms, but especially mine-Mary Fricke.

**JONI FRITZ**

**Executive Director, ANCOR**

During the last quarter of the 20th Century, providers in the United States have been running at top speed to keep up with the fast-paced successes demonstrated by people with mental retardation who are given opportunities to direct their own lives. It will be exciting to see where they lead us in the New Millennium!

**BILL GAUENTA**

**Reverend, Boggs Center**

The AAMR Religion Division wishes to recognize and give thanks for the many isolated pioneers who worked on spiritual support for people with mental retardation in the first half of this century, and for the increasing appreciation for the spiritual gift and care of people with mental retardation.

**ROBERT GETTINGS**

**Executive Director, NASDDDS**

The second half of the 20th century has brought incredible changes in disability policy. But the creation of a society in which people with intellectual disabilities are truly valued, contributing members still poses enormous challenges that will require all the commitment and ingenuity we can muster.

**GEORGE GOULD**

Apathy into Advocacy  
Admonition into Advocacy  
Cowardly into Courageous  
Hopeless into Hopeful  
Lifeless into Limitless  
Patronizing into Personalizing  
Darkness into Dawn  
20 into 21

## **MARGARET GOULD**

The 20th Century will require a new viewpoint. The debate on quality of life will be less focused on community vs. institution than on the convergence of differing philosophies. As we look forward, we will be discussing a whole new set of forces and their affects on people with mental retardation such as computers and internet technology, competitive positioning within a work place, organizational profitability, and self-determination and choice. I look forward to the new challenges.

## **LARS GULDAGER**

### **Executive Director, The Connecticut Institute for the Blind/Oak Hill**

I am enormously proud of the role The Connecticut Institute for the Blind/Oak Hill has played in enabling people with mental retardation and developmental disabilities to live with pride, dignity and affirmation and to be contributing members of their community.

## **STANLEY HERR**

### **University of Maryland Law School**

"Those who cannot remember the past," George Santayana observed, "are condemned to repeat it." For people in our field, the 20th century has proved to be the worst of times and its best. I count myself doubly privileged to have helped launch the rights revolution that ushered in better times and to lead AAMR at century's turn toward a vision of just, lasting and global change.

## **STEVE HOLBURN**

Conversation from the future: "It all started with the self-advocacy movement. After listening, the humanists realized the solution was to change the contingencies. At the same time, the behaviorists discovered they had been focusing on the wrong ones. That's when the forward leap occurred."

## **IRENE S. HOWELL**

### **Corporate Administrator, Howell's Child Care Center, Inc.**

There have been significant changes in services for persons with developmental disabilities since 1974. I hope that the improvements which have been made will be maintained and that choices that are available now will continue for the clients and their families.

## **LUCY J. IDOL**

### **Executive Director, Lucy Idol Center For The Handicapped, Inc.**

"When no one else can help" is the motto of the Lucy Idol Center for the Handicapped, Inc. which was founded in 1954 by Lucy Joyce Idol, Executive Director.

**ROBERT HANCOCK**  
**Coordinator, MFOFC**

Massachusetts Families Organizing for Change would like to share a quote by Margaret Mead that has inspired our advocacy effort on behalf of individuals with disabilities and their families, "Never doubt that a small group of thoughtful, committed people can change the world. Indeed, it is the only thing that ever has."

**BOB LAUX**  
**President, Wild River Realty**

From institutionalization to a life of inclusion. From segregation to participation. From facility to home ownership. And from devaluation to citizenship. Let these lessons learned caution society never, ever to disrespect anyone as to exclude any of us as unworthy. The consequences put us all at risk.

**JOEL M. LEVY, D.S.W.**  
**Chief Executive Officer, YAI/National Institute For People With Disabilities**

"If one advances confidently in the direction of his dreams, and endeavors to live the life which he has imagined, he will meet with a success unexpected in common hours." Henry David Thoreau

**PHILIP H. LEVY, Ph.D.**  
**Chief Operating Officer, YAI/National Institute For People With Disabilities**

The potential of all human beings is unlimited when provided with the appropriate support and training. No individual's potential should ever be wasted or underestimated, rather it should be nurtured and encouraged.

**THOMAS M. LEWINS**  
**Executive Director, PVA, Inc.**

It has been a privileged opportunity to be involved in the significant improvements of supports and services to individuals with disabilities. We have come along way, but have much further to go.

**JOSEPH P. MAMMOLITO**  
**Executive Director, AHRC, Suffolk Chapter**

As we celebrate our 50th anniversary in 1999, we view our day and residential programs for more than 1,600 children and adults, throughout our 25 sites, as fulfilling a promise to our founding parents. Striving for greater opportunities, choices and dignity remain our goal.

**MICHAEL MASCARI**  
**Executive Director, AHRC, Nassau Chapter**

Nassau AHRC is proud to be the largest provider of residential services for adults with developmental disabilities in New York State. Founded in 1949 by a small group of parents, AHRC grew to a membership organization of 8,000 led by the indomitable Helen Kaplan. Mrs. Kaplan was instrumental in the passage of legislation in New York State that ensured the rights of all

### **YOSEF ROSENSHEIN, Ph.D.**

Dr. Joel Rosenshein developed the first screening program for handicapped people in the New York City Board of Education. This led to committees on he handicapped, one per district, and screening for over 50,000 clients a year. The **future of special education lies in individual services** for handicapped based on the individual needs.

### **MARIAN SAULINO**

#### **Executive Director, Community Interactions, Inc.**

Since 1973, we have strived to enhance the lives of people with disabilities, helping them to prosper at home, at work, and in their communities.

### **BOB SCHALOCK**

#### **Department of Psychology, Hastings College**

Each of us has a story to tell about our involvement in the field of mental retardation. Although our roles have differed, our commonality is great. What we have found is that we have been able to make a significant difference in our own lives, as well as the lives of others.

### **VINCE SCOTT**

#### **Executive Director/President, Arizona Training & Evaluation Center, Inc.**

The collective efforts and influences of Menolascino, Wolfensberger, Blatt, Stark, Schlock, et al., the professional organizations including AAMR and ANCOR, together with the advocacy movements of parents and consumers have provided significant systems change that will last well into the next century.

### **HOWARD SIEGEL**

#### **Chief Operating Officer, Irwin Siegel Agency, Inc**

Understanding the past will help to brighten the future.

### **JO ANN SIMONS**

Who would have believed that when my son was born almost 20 years ago, with Down Syndrome and four heart defects, that Jon would be a college student and his "handicap" would be the one he received from the PGA (Professional Golf Association).

### **DEBORAH M. SPITALNIK, Ph.D.**

#### **Exec. Director, The Elizabeth M. Boggs Center on Developmental Disabilities.**

At the mid-century mark, as parents coalesced as The Association for Retarded Children, we saw the dramatic impact that personal experience, turned into strategic, knowledgeable, unified advocacy could have on opportunities for people with disabilities and their families. It is deeply moving to me that as the century comes to a close, it is the voices of self-advocates and the aspirations of people with disabilities and their families that will move us forward into the new millennium.



We have been blessed in this century, with wise, compassionate and visionary leadership. Let us lovingly and indelibly remember Burton Blatt, Elizabeth M. Boggs, Rosemary F. Dybwad and Herb Lovett, as we continue to honor and learn from Gunnar Dybwad. May we be strengthened from having known them and honor them through the respect in which we hold each other and the ways we value each other's contributions as we continue to work for social justice.

**CATHY FICKER TERRILL**  
**Vice President, Ray Graham Association**

AAMR has been an advocate for people with disabilities for over 100 years. Our five year strategic plan offers solutions for the future. As researchers, policy makers, clinicians, administrators, family members, self-advocates, and others we must think strategically and go beyond the current boundaries. This will require all of us to look at the future as a continuous process which must adopt in this global world to environmental and policy changes.

**BERNARD R. WAGNER, Ph.D.**  
**AAMR President-Elect, Evergreen Presbyterian Ministries, Inc.**

As I consider the history of our field, I am proud of the role the American Association on Mental Retardation has played. Many of those making significant contributions have been active leaders in AAMR.

**STEVEN F WARREN, Ph.D.**  
**Professor of Special Education and Psychology, Vanderbilt University**

I wish to acknowledge the enormous contributions of countless behavioral and biomedical scientists to the lives of people with intellectual disabilities and their families. May their tireless efforts generate increasingly useful-knowledge in the new millennium.

## **CLOSING CREDITS AND REMARKS**

In any effort as broad as the Century Recognition Project, there are always individuals, organizations, or events unacknowledged. Any errors of omission were unintended and in no way reflect upon the quality of the contribution to the field.

Because of the incredibly large amount of material used to prepare the commemorative book and multi-media presentation, we were unable to credit all references and authors. We apologize for any omissions.

A major source of information used in the commemorative book and the script for the multi-media presentation were taken from A History of Mental Retardation by R.C. Scheerenberger. We attempted to acknowledge his work whenever possible throughout. We apologize for any omissions.

Respectfully,

The Century Recognition Committee

