SOCIAL REFORMERS PUSH FOR BETTER LIVING CONDITIONS

- In the nineteenth century, social reformers in Massachusetts such as Dorothea Dix and Samuel Gridley Howe pushed for the establishment of the first institutions for people with mental retardation in a spirit of optimism and good will. After traveling across the state and observing the deplorable living conditions of people living in almshouses, Dix came before the Massachusetts legislature to plead their case.

> I come to present the strong claims of suffering humanity. I come to place before the Legislature of Massachusetts the condition of the miserable, the desolate, the outcast. I come as the advocate of helpless, forgotten, insane, and idiotic men and women; of beings sunk to a condition from which the most unconcerned would start in real horror; of beings wretched in our prisons, and more wretched in our almshouses. And I cannot suppose it needful to employ earnest persuasion, or stubborn argument, in order to arrest and fix attention upon a subject only the more strongly pressing in its claims because it is revolting and disgusting in its details…I proceed, gentlemen, briefly to call your attention to the present state of insane [and idiotic] persons confined within this Commonwealth, in cages, closets, cellars, stalls, pens! Chained, naked, beaten with rods, and lashed into obedience.

> Dorothea Dix, 1843

- Public funds were secured to start “state schools” for people with mental retardation with the expectation that they would receive education and training suitable for the agrarian economy and then return to their communities with the skills necessary to be economically self-sufficient and lead productive, satisfying lives.

HOWE WARNS AGAINST DANGERS OF INSTITUTIONS

- In just a few decades public institutions for people with mental retardation had burgeoned in states across the country, and the institutions had grown dramatically in size. By 1890 there were twenty residential “state schools” in fifteen states. The number of people with mental retardation living in state institutions would peak at nearly 200,000 in 1967.

- As early as 1866, however, the warning signs were there. In a public address, Samuel Gridley Howe, who in 1848 had read Dix’s statement to the U.S. Congress advocating for the setting aside of five million acres of land for people with disabilities, warned of the dangers of creating human warehouses.

> As it is with individuals, so it is with communities; and society, moved with pity for some special form of suffering, hastens to build up establishments which sometimes increase the very evil which it wishes to lessen…There are many such already in this country; and unless we take heed there will be many more.

> Samuel Gridley Howe, 1866

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1 The title uses terminology that is considered correct today, but the term “mental retardation” is used in the earlier pages of this history so as to conform to the language that was in use at the time. “People First” language is used throughout even though it did not gain favor until recently. See note 8 on “People First” language.

NEW PROFESSIONAL ORGANIZATION STARTED BY SIX SUPERINTENDENTS

- In 1876 six superintendents of state institutions, all medical doctors, met to establish the first professional organization: the Association of Medical Officers of American Institutions for Idiotic and Feebleminded Persons. The custodial and medical model upon which their organization was based would persist for the next century.

INTELLIGENCE TESTS USED TO DETECT MENACE TO SOCIETY

- Two French psychologists, Dr. Theodore Simon and Dr. Alfred Binet, developed the first intelligence test in 1905. Using the test, they classified individuals with mental retardation as “idiots,” “imbeciles,” and “morons.”

> First, we have admitted to this country...a proportionally large number of mental defectives from abroad. Secondly, we have admitted into this country a relatively large number of mentally defective producing stock...relatively few mental defectives or individuals of mentally defective stock are Scandinavian, French, Spanish, Welsh, Scotch [sic], German or English. On the other hand a relatively large number come from the following groups: Negro, Italian, Hebrew, Irish, Polish, Russian and S.E. Europeans.

- Goddard’s work coincided with anti-immigration and compulsory sterilization laws designed to protect American society from the “moral menace” of people with mental retardation. People with mental retardation were blamed for poverty, drunkenness, prostitution, and crime.
- By 1926 compulsory sterilization laws were in effect in twenty-three states.

PARENTS OF CHILDREN WITH MENTAL RETARDATION JOIN FORCES

- Parents of children with mental retardation began to organize as early as the 1930s. The first official organization of parents was the Cuyahoga County (Ohio) Council for the Retarded Child, established in 1933.
- Parents were the first group to realize that people with mental retardation deserved a different life. No longer would they accept the dictum: “Nothing can be done for your child.”
- Advocacy groups sprang up all over the country in the next few decades and in 1953 came together to form the National Association for Retarded Children. The organization subsequently became the National Association for Retarded Citizens (NARC) in 1973, The Association for Retarded Citizens of the United States in 1981 and simply The Arc in 1992.

SOCIAL FORCES GATHER MOMENTUM FOR CHANGE

Several important social developments led the way for significant changes in the lives of people with mental retardation:

- The medical needs of wounded GIs returning home after World War II prompted the passage of vocational rehabilitation legislation that would have positive spillover effects for people with all types of disabilities, including those with mental retardation.
- In 1954 Congressman John Fogarty was introduced to the Rhode Island Association for Retarded Children. When he realized how few services there were for children with mental retardation, Fogarty conducted extensive legislative hearings to find out what federal agencies could and should be doing.
President John F. Kennedy, whose sister Rosemary was born with mental retardation, was instrumental in the promotion of new research, the training of professionals, and the development of services in the field. In the first twenty years after he had appointed the first President's Committee on Mental Retardation in 1961, 116 new federal acts or amendments providing support to people with mental retardation were passed.

“ENOUGH IS ENOUGH!” ADVOCATES SAY

In 1966 Burton Blatt and Fred Kaplan published Christmas in Purgatory, a pictorial essay on the deplorable conditions in institutions for people with mental retardation.

“We need to empty the institutions. The quicker we accomplish that goal the quicker we will be able to repair the damage done to generations of innocent inmates. The quicker we get about converting our ideologies and resources to a community model, the quicker we will learn how to forget what we perpetuated in the name of humanity.”

Burton Blatt, 1966

In 1965 Senator Robert F. Kennedy visited the Willowbrook State School in New York and was aghast at what he found. A young journalist named Geraldo Rivera, who accompanied the senator, did an extensive exposé on the plight of people incarcerated in public institutions.

PEOPLE WITH MENTAL RETARDATION FOUND TO HAVE RIGHTS

In 1971 the United Nations adopted the Declaration of General and Specific Rights of Mentally Retarded Persons, which said that people with mental retardation have the same rights as other human beings.

The civil rights movement of the 1960s gave way to the disability rights movement of the 1970s. Based upon the “due process” and “equal protection” clauses of the Fourteenth Amendment to the U.S. Constitution, cases brought in federal district courts argued for a “right to education” and a “right to treatment” for people with mental retardation.

The first “right to education” suit was brought in 1971 by the Pennsylvania Association for Retarded Children against the Commonwealth of Pennsylvania.

In 1972, in the first “right to treatment” case, expert witness Professor Gunnar Dybwad testified that electrified cattle prods had been used on “inmates” with mental retardation living in an Alabama institution.

A NEW SERVICE MODEL COMES ABOUT

Gradually, as more court battles were won, the “deinstitutionalization” movement came about. States were mandated in federal court decrees to improve the conditions of people living in the institutions and to find community placements for others.

In 1969, the President's Committee on Mental Retardation had published Changing Patterns in Residential Services for the Mentally Retarded, a collection of articles by Americans, British and Scandinavians who had come together to share their experiences as parents and professionals. In these documents, a different way of life for people with mentally retardation was described.

The principle around which Sweden and Denmark had designed their community-based services since the early 1960s was “normalization.”

\[3\] Today the committee is the President's Committee for People with Intellectual Disabilities (PCPID).
Along with Nirje and several others, an American from Nebraska named Wolf Wolfensberger developed the concept further in 1972 in the book, *The Principle of Normalization in Human Services*.

Normalization means a normal rhythm of the day for the retarded...a normal rhythm of the week. You live in one place, go to work in another, and participate in leisure activities in yet another...a normal rhythm of the year. A vacation to break the routines of the year...normal developmental experiences of the life cycle...having a range of choices, wishes, desires respected and considered...living in a world made of two sexes...the right to normal economic standards...living in housing in a normal neighborhood.

*Bengt Nirje, Swedish Parents Association for Mentally Retarded Children, 1969*

- Adopting the normalization principle meant that the medical model of services that had prevailed for over a hundred years would now give way to a new, developmental model of community-based services.

- Children with mental retardation were thought capable of learning and developing. Special education programs were expanded, and, with the impetus of the federal Education for All Handicapped Children Act in 1975\(^4\) guaranteeing the right to education, students with “special needs” were increasingly “mainstreamed.”\(^5\)

- Whereas people with mental retardation had essentially been subjected to involuntary servitude in institutions, they now had paying jobs in the community. In addition, some individuals no longer worked just in “sheltered workshops” but in “supported employment” or “competitive” jobs as well.

- Prodded by court action and the bait of federal funding for services in the community, states began to empty the institutions. Large “state schools” in remote areas gave way to group homes in regular neighborhoods. In 1989, expenditures for community services first exceeded those for institutions. The first state in the nation to eliminate institutions completely was New Hampshire in 1991. Between 1991 and 2001, the District of Columbia, Vermont, Rhode Island, Alaska, New Mexico, West Virginia, Hawaii and Maine also completed the process of de-institutionalization.\(^6\) By 2009, Michigan and Oregon had joined this group.\(^7\)

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\(^4\) This law was PL94-142. In 1990 it became the Individuals with Disabilities Education Act (IDEA), PL101-476.

\(^5\) In turn, the concept of “mainstreaming” has gradually given way to that of “inclusion.” With mainstreaming, the child with special learning needs is to be mainstreamed as much as possible from the special education classroom into the so-called regular classroom; the child might be in the regular classroom for art and physical education, for example, but not for academic subjects. With inclusion, the child with special learning needs is simply included in the regular classroom as any child would be. An aide might be present to give special assistance to the child. School systems today vary a great deal both in the degree to which they aspire to either mainstreaming or inclusion and in the degree to which they have achieved one or both.


• “People First” language emphasizing the person, not the disability, began to be used.8
• The advocacy movement gave way to the self-advocacy movement. Individuals with mental retardation began to speak out for themselves in public forums and created self-advocacy groups such as People First and Self-Advocates Becoming Empowered.
• In 1990 Congress passed the Americans with Disabilities Act (ADA)9 affirming the rights of people with disabilities and prohibiting discrimination in employment and public accommodations.
• The term “mental retardation” came into disfavor. The terms “developmental disability” and “intellectual disability” came into use.
• In 2006 the American Association on Mental Retardation (AAMR), by a vote of its membership, changed its name to the American Association on Intellectual and Developmental Disabilities (AAIDD).
• In 2006 the United Nations adopted the Convention on the Rights of Persons with Disabilities. Provisions of the Convention covered important areas such as awareness-raising (Article 8), accessibility (Article 9), right to life (Article 10), equal recognition before the law (Article 12), living independently and being in the community (Article 19), personal mobility (Article 20), respect for privacy (Article 22), education (Article 24), health (Article 25), habilitation and rehabilitation (Article 26), work and employment (Article 27), adequate standard of living (Article 28), participation in political and public life (Article 29), and leisure and recreation (Article 30). As of June, 2012, there were 153 signatories to the Convention and 122 ratifications.10

THE WORK IS NOT YET DONE
• Many states have not yet closed their institutions, although current thinking is that everyone, even persons with severe disabilities, can thrive in a community setting. As of 2006, 38,299 remained in large state-operated institutions.11 As of 2009, the figure was 33,732.12
• The United States finally signed the United Nations Convention on the Rights of Persons with Disabilities on July 30, 2009, but has not yet ratified it and therefore has not yet assumed responsibility for implementing its provisions.
• Federal policies and funding influence a state’s progress from an institution-based system to a community-based one. Each state must file a plan with the federal government to qualify for a Home and Community-Based Waiver under Section 1915 (c) of Title XIX (Medicaid) of the Social Security Act to move federal Medicaid funds from institutions into the community. Some states have made remarkable progress, but others have not.
• Despite the case of Olmstead v. L.C. and E.W., a ruling on the Americans with Disabilities Act by the U.S. Supreme Court in 1999 in which the Court declared that persons with mental illness [and, by extension, people with other disabilities] had a right to services in the most integrated setting possible, progress in establishing

8 “People First” language focuses on the person, not the disability. Hence one would no longer say “the disabled” or “a diabetic” but “people with disabilities” or “a person who has diabetes.” This type of language shows more respect for the person being described.
9 PL101-336.
10 A signature merely affirms agreement with the Convention, whereas ratification amounts to a firm commitment to implementing the Convention’s provisions.
12 David Braddock et al., The States of the States in Developmental Disabilities 2011, 51.
community-based services has been slow. Constricted state budgets and a lack of political will have resulted in the number of community placements lagging well behind the need.

- When special education was legally mandated, it was a sweet victory for parents of children with special learning needs. In times of fiscal scarcity, however, tensions increase between parents of children who need special education services and those whose children do not. There is simply not enough fiscal support at the state and federal level to cover the high costs of special education services at the same time that fixed costs—such as teacher salaries, teacher benefits and utilities—are posing a heavy burden on local school systems.

- Some people persist in negative attitudes towards people with intellectual and developmental disabilities. Pejorative labels derived from the term “mental retardation” are still used in playgrounds, on television and in other settings. People also still have negative prejudices towards the establishment of community homes for people with intellectual and developmental disabilities; this attitude has been coined “NIMBY” (“not in my own backyard”).

- Fortunately many people with intellectual and developmental disabilities are now living well beyond the life expectancies that were prevalent in the institutions, where poor conditions led to more disease and morbidity, but services for aging individuals with disabilities are sorely lacking. In particular, individuals with Down syndrome often develop Alzheimer’s disease by age fifty and need additional specialized services.

- Increasingly, it is recognized that living in the community is not the same as being a part of the community. Many more opportunities for fuller community integration are still needed.

- Professionals in the field are increasingly recognizing that a model of service delivery centered on a person’s residence (even if it is a small group home in the community instead of a large, state-operated institution) does not best serve that person’s needs. A newer, person-centered model is preferable, but financial constraints hamper efforts in this direction.

- Self-advocates still need fuller roles to become equal partners in professional organizations such as AAIDD and citizen organizations such as The Arc.

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