

The History of Developmental Disabilities

Throughout history, society has struggled with how to treat people with developmental disabilities. The path that started at fear and ridicule has progressed to education and inclusion.

Ancient Times-Medieval Europe (1500 B.C. to 1500 A.D.)

Aristotle "As to the **exposure** and rearing of children, let there be a law that no deformed child shall live."

Children who were blind, deaf, or mentally retarded were reported to have been thrown in the Tiber River by their parents.

Children born with disabilities were left in the woods to die, their feet bound together to discourage anyone passing by from adopting them.

In the military city of Sparta, the abandonment of "deformed and sickly" infants was a legal requirement.

Colonial Times (1600-1800 A.D.)

Scientists began attempts to understand these individuals, but the general public still feared and ridiculed them.

People with developmental disabilities were kept confined at home for their own protection.

At the heart of the French Revolution (1792-1802) was the belief that one is worthy of dignity not because of wealth or status, but simply because one is a human being.

In 1798, Thomas Malthus advocated that all people "defective" in any way, who look or behave or function differently than the rest of society, should be identified and eliminated.

Industrial Revolution (1800-1900 A.D.)

Popular belief was that mental retardation and mental illness were completely genetic, and caused most, if not all, social ills such as poverty, drunkenness, prostitution, crime, and violence.

The response to this belief was to segregate or sterilize people who were labeled mentally retarded so that they could not reproduce and destroy the gene pool.

The Almosts: A Study of the Feeble-Minded was a popular textbook. The "Almosts" referred to people with mental retardation as almost human.

One of the earliest populations the Nazis set out to destroy was people with disabilities. One hundred thousand children and adults with mental and physical disabilities were exterminated. Some who managed to live were subjected to inhumane and unconscionable medical experiments.

1950s to 1980

Parents spearheaded a movement for the betterment of life for people with developmental disabilities around 1950 organizing community and legislative efforts to improve the lives of those with disabilities.

In the 1950s there were two major alternatives – living at home with family or going to an institution.

In 1965, Senator Robert Kennedy toured Willowbrook State School in New York, proclaiming that individuals in the facility were "living in filth and dirt, their clothing in rags, in rooms less comfortable and cheerful than the cages in which we put animals in a zoo".

In 1967, Burton Blatt and Fred Kaplan released a photographic essay entitled Christmas in Purgatory. Using a hidden camera, Blatt and Kaplan captured life inside the public institutions. Dr. Blatt declared that "there is a hell on earth, and in America there is a special inferno – the institution."

In 1972, Geraldo Rivera revealed conditions at Staten Island's Willowbrook in which developmentally disabled children were found to be living in their own filth, with a staff-to-resident ratio of 30- or 40-to-one, and residents had a 100% incidence of hepatitis within the first six weeks of entering Willowbrook.

In 1972, the NARC urged state governments to establish small, community-based, home-like residential facilities and these "take absolute precedence over further capital investments in existing or new large scale institutions."

The 1980s: Real Support for Community Living and Institutional Closures

Two major changes to federal funding opened the door for the expansion of smaller residential settings and the operation of such settings by nonstate agencies.

At the same time, the rate of institutional closures increased. In the 1980s, 46 State residential facilities closed.

In 1981, The Omnibus Reconciliation Act (P.L. 97-35) created the Home and Community Based (HCB) Waiver. Senator John Chafee, a Rhode Island Republican, spearheaded an effort that would allow Medicaid funds to be used for alternative community based responses on a large and broader scale.

By 1987, just under half (46%) of the people living in residential settings were in settings for 15 or fewer people. The other half were in settings for 16 or more, mainly state institutions.

1990s

New Hampshire, Vermont, Rhode Island, Washington D.C. and Maine had closed their public institutions, and many states had reduced the number and size of their institutions.

In 1982, only three states had a waiver for people with developmental disabilities. By 1987, over 30 states had at least one waiver, and by 1992, 46 states were participating.

In the 1990s, the impact of the Home and Community Based Waiver and the Community Supportive Living Arrangements really mushroomed. All together, 91 large facilities closed in the United States in the 1990s. All but 12 states had closed at least some of their institutions by the end of 2004.

The 2000s: Olmstead and the Struggle Over Rights and Resources

The right of people with developmental disabilities to live in the community was reinforced by the July 13, 1999 decision of the United States Supreme Court in *Olmstead v. L.C. and E.W. Lois Curtis and Elaine Wilson* wanted to receive services from the state of Georgia in the community instead of in a psychiatric institution.

In 2001, the federal government embarked on the New Freedom Initiative, a multi-agency effort to "remove barriers to community living for people of all ages with disabilities and long-term illnesses. It represents an important step in working to ensure that all Americans have the opportunity to learn and develop skills, engage in productive work, choose where to live and participate in community life."

By 2003, 63% of the people living in residential settings were living in settings of 6 or fewer people.

2010 and Beyond

On the 12th Anniversary of the Olmstead decision, June 22, 2011, President Barack Obama reaffirmed Supreme Court ruling, recognizing that "the unjustified institutional isolation of people with disabilities was a form of unlawful discrimination" under the Americans with Disabilities Act (ADA) and recommitted his administration to end all forms of discrimination. In the past, people with disabilities were segregated as a means to care for and control them.

Under the leadership of Missouri Governor Jay Nixon, the efforts of local county developmental disability boards and in collaboration with the Division of Developmental Disabilities, the **Partnership for Hope** waiver was initiated in 2010. Partnership for Hope makes a fundamental shift away from high cost, crisis oriented services, providing access to services much earlier.

Dangers

In the right political climate, we could easily return to a period of isolation and institutionalization.

The possibility of repeating our history remains until we, as a society, recognize and accept people with disabilities as individuals who possess the same rights and opportunities as people without disabilities.
