

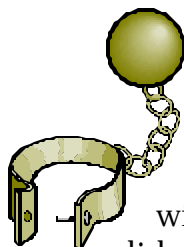
Normalization

A Person is Normalized if:

1. Experience a certain degree of societal acceptance that is not below average range.
2. A degree of personal autonomy and choice.
3. Access to the valued experiences and resources that “normal” people would.
4. Input to lifestyle, goals and desires “as much as possible.”

A Walk Down History

Individuals with mental retardation have had many, 100s of years of self discovery. Their roles have been defined by others throughout history. Those definitions have been holy innocents to exploited cost efficient workers to real human beings with equal rights.



18th Century

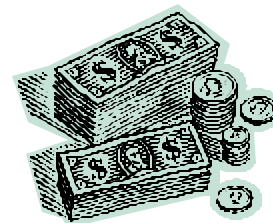
Individuals with mental retardation were hidden from society. It was felt these individuals would violate the comfort level of others. They were viewed as less than human, had little emotion and chained in cellars without basic provisions. This was the society view and therefore families didn't know better.

1818

The first institution was built. It was called the asylum for the Deaf and Dumb which was to house and instruct “idiot children”. It made an effort to develop and educate but all individuals ended up being treated under the poor laws which depleted services.

19th Century

This could be characterized by apathy. Individuals were sold to low bidders for work purposes. This allowed for the individuals to be cared for as cheaply as possible with the least amount of public support.



Mid 19th Century

Two early advocates Dorothea Dix and Thomas Griddley Howell arrive on the scene. They are advocates for humane treatment.

Dorothea Dix visits an institution and sees some disturbing sights. She views individuals chained to walls, cold and naked. When she asks for care for these

individuals she is told “they don’t need it they can’t feel”. Because of these visits we end up with our first legislation in Pennsylvania. Money is appropriated by the state to open The Pennsylvania Public State Lunatic Hospital and Union Asylum. This gave the state direct responsibility not the local government.

The Asylum

- Meet the Warden -

Dorthea Dix

Dorthea Dix became interested in the way insane people were treated after teaching a Sunday school class in prison. It is reported that Bubba and the Reverend Sung Long Noone were two present in the cell at the time of her teachings. A quiet and gentle but very determined person, she inspected the places where insane people were held. She found such people mixed in with criminals. She found others hidden away in closets, small sheds, attics, or cellars. In 1843 she sent her report of her findings to the Massachusetts legislature, which at first ignored her but later passed a law aimed at improving conditions. Some say that Noonie Jana was picked up by this MA legislature and involved in some of the first shock treatments.

Dix then visited other parts of the country. Between 1845 and 1852, she persuaded nine southern states to set up public hospitals for the insane. As a result for Dorthea’s lobbying, the insane were housed in clean hospital rooms and were treated more humanely. Dorthea also passed the bill that allowed wild noonatics to enter club noonatic at any time of the day. She felt that frequent visits by noonies would ensure their good health. The asylum is just one of Dorthea’s fine correctional facilities. (If you happen to pass her in the hall, please warn her of the crayon covered stairs. She does not know yet.)

1852

Pennsylvania Training School for the Feeble Minded Children (now Elwyn Institute) was opened in Germanstown/Media.

The view now was the mentally retarded, who were innocents in the public eye were now social parasites. With an increase in immigration, the worry became about “the influx of the blood of the mentally retarded”. The country attempted to prohibit marriage and procreation.

This resulted in the creation of more institutions. This also marked the change in Dorthea Dix’s vision of humane treatment to isolation.

1897

The State Institution for the Feeble Minded in Western Pennsylvania opened or Polk. This was conceived as a training school. It would be a self-sufficient colony, an 800 acre compound commune style. Focus was on keeping people dry, safe and fed. Current standards are certainly more advanced but at the time this was all they knew.

Prolonged institutionalization/preservation was seen as a preventative measure. This would keep people in custody until they were past childbearing age. They were able to keep cost down by having higher functioning people to do all jobs like laundry, cooking, cleaning etc for all the population.



1900

The medical community's view was that "feeble mindlessness" was hereditary and total segregation/confinement for life should be the course of treatment. There was no focus on individualization. Fear revolved around contaminating the gene pool. Marriage laws became unenforceable and forced sterilization occurred.

1920

In Lewisburg Pennsylvania The Laurelton Home of Feeble Minded Women of Child Bearing Age opens. Thousands of people were rushed into institutions. Again this was contrary to Dorothea Dix's vision of a humanlike environment and her philosophy was abandoned. Focus became "How cheap can we do things". 1000 to 3000 people made up the population of these institutions. There was severe overcrowding, even by the lack standards of the day.

Depression Era produced strained resources and placed thousands on wait lists. There were dozens upon dozens of beds in each dorm. The cribs were crammed end to end. This period reflects dehumanizing conditions, abuse, sickness and deaths. People living in the institutions at the time are quoted as saying "They're not sick, these people ended up dying".



1930

Beginnings of different views in the field of mental retardation. This came about because universities began to teach about the exceptional child.

1940

WWII begins. In Germany the mentally retarded were starved to death. When this became insufficient and not timely enough, death was accelerated by the gas chamber. In this country the war served as a wake up call. FDR held a White House Conference on Mental Retardation and called for more humane treatment. This is also where we begin to hear about community services. Appropriate education and suitable employment in community are frequently the best treatment for persons with mental retardation. Goodwill services and sheltered workshops/schools were developed. But again it was difficult to get well trained staff and there were gaps in public support.

1946

National Institute of Mental Health is developed. This served to initiate the idea of direct funding for training and research.

1949

Pennsylvania Association for Retarded Children ARC (later become Association for Retarded Citizens). A new generation of advocates had arrived. Started out as eight people. There was at this time no right to education. The ARC was instrumental in this initiative. They found out that they could not be nice, they couldn't be a pleading hand, they needed to approach situations with a clenched fist. They became a force to be reckoned with.

In spite of this, 75% of institutions were built after 1950. Conditions continued to be poor due to lack of public support. Medical advances increased the survival rates of people with disabilities. The institutions were unable to keep up. There were no staff, so capable individuals who resided in institutions were assigned the care of

individuals. They provided direct care. Along with this the movement of community employment angered the institutions because “community employment took their work boys and girls” from them.

With these long stays, dehumanizing conditions continued to develop. Cemeteries had only numbers on them, not names.

More money was allocated to take care of the barn where the animals lived in. More money was given to the staff who cared for the animals than the people. Reports of beatings, punishments and lock ups were rampant. Pennhurst became a symbol of all institutions.

1950

Hilda Banks/F. Hackbush arrive on the scene as advocates. “Placement in an institution for mental defectives is a serious matter and should only be made after measures have been taken to prevent unnecessary and unjust institutionalization. Legal commitment procedures should be designed to protect civil rights of individuals”.

1958

First Legislation that approves federal money for universities to specialize in training personnel.

1961

John F. Kennedy Administration. Sister who was mentally retarded thus he had an interest. He established a Panel on MR, which presented 112 sweeping recommendations. These redefined admission and quality of life issues.



1963

The President’s Panel on Mental Retardation presented a national plan establishing a trend toward community care and away from large facilities.

The Mental Retardation Facilities and Community Mental Health Centers Construction Act (P.L. 88-164) provided money to build community facilities.

1965

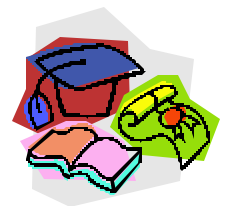
Social Security Act Amendments (P.L. 88-97) established Medicare and Medicaid. Recipients of aid to the Permanently and totally Disabled were made eligible for Medicaid.

1966

The Pennsylvania MH/MR Act established a system of community services.

1971

The decision in the Pennsylvania Association for Retarded Citizens vs. the Commonwealth of Pennsylvania affirmed the right to public education and due process for children with disabilities.



1972

In Alabama, the federal Wyatt vs. Stickney decision set forth the constitutional right to treatment and rehabilitation in the least restrictive environment.

Right to Education Consent Degree of Pennsylvania.

First community based home opens.

1973

Section 504 of the Rehabilitation Act (P.L. 92-603) barred discrimination based on disability by any entity receiving federal funds.

1975

The Education for All Handicapped Children Act (P.L. 94-142) mandated free, appropriate and individualized public education for children with special needs in the least restrictive environment.

The Developmental Disabilities Assistance and Bill of Rights Act (P.L. 94-103) set forth a list of rights and required every state to establish a protection and advocacy system as a condition for receiving certain federal funds.

1977

In *The Pennsylvania Association for Retarded Citizens vs. The Pennhurst State School and Hospital*, a federal court ruled that institutionalization is a violation of constitutional rights to equal protection.

Halderman vs. Pennhurst



✍ 1977

✍ Class action

✍ The only justifiable purpose for commitment of the retarded is habilitation

✍ If habilitation is not provided, the nature of the commitment bears no reasonable relationship to its purpose this the individual's due process rights have been violated.

1982

Speaking for Ourselves was founded.

1986

Amendments to the Education of the Handicapped Act (P.L. 99-457) mandated pre-school programs for three to five-year-olds and planning for early intervention programs.

Amendments to the Rehabilitation Act (P.L. 99-506) established a state grant program for supported employment, and expanded eligibility for basic state vocational rehabilitation programs.

The Employment Opportunities for Disabled Americans Act (P.L. 99-643) made permanent the parts of the Social Security Act allowing Supplemental Security Income recipients to work and maintain their SSI eligibility and Medicaid.

1987

Pennhurst Center closed.

1988

The Fair Housing Act (P.L. 100-430) brought people with disabilities under the protection of the Federal Fair Housing Law.

1990

The Americans with Disabilities Act (P.L. 100-430) was enacted. It prohibits discrimination on the basis of disability in employment, public services and public accommodations. It requires new buses and trains to be accessible and telecommunications companies to operate systems that will allow persons with hearing and speech impairments to use telephone services.

Governor Robert B. Casey signed the Early Intervention Services System Act into law. It assures the availability of services to all children identified as developmentally delayed, and the screening and tracking of all children at risk.

THE WAY HAS BEEN PAVED

