A History of Developmental Disabilities: Lessons Learned, As We Begin The Journey Forward

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1/16/2015
Historical Terms & Events

- To reflect the historical time periods, words and labels describing an individual with intellectual disability may be viewed as offensive. Please note that any terms or labels used during this webinar were used in that time period, and are not in any way meant to be offensive.

- There are many critical events and important leaders that were part of the history of the disability movement. Due to the length of this webinar, instrumental people and events have been omitted. This webinar provides an overview only. Attendees are encouraged to complete further research to fully grasp this amazing part of our history.
1800-1950: THE INSTITUTIONAL MOVEMENT
Houses or institutions for the poor, supported by public funds were established as a means of removing economic outcasts from society. Some poorhouses were still in use until World War II.

“In those days, we didn't clearly conceptualize mental retardation, or mental deficiency, or feeble mindedness. We dealt with inadequate people, who we put into poorhouses. Now poorhouses were not just for people who were poverty stricken, but rather people who were inadequate. And were outcasts. And inconvenient. And uncomfortable.”

Gunnar Dybwad on Poor Houses
As early as 1842-46, training schools for children with disabilities were established in Berlin and London.

In 1844, Doctor Edouard Seguin, was considered the first great teacher in the field of disabilities. Following Seguin's teaching methods, pupils would receive physical training to improve their motor and sensory skills, basic academic training, and instruction in social and self-help skills. His methods and positive results served as a foundation for similar efforts throughout Europe and America.

Among those later influenced by his teaching methods was Maria Montessori (1870-1952), a pioneer in teaching children with and without disabilities.

In 1850, Seguin left France for the United States, and worked with Dr. Samuel Gridley Howe and others in developing training schools.
1840-1880: Dorothea Dix

- There became an increased interest in persons with disabilities in the early part of the 19th century. At this time, social reformers such as Dorothea Dix were advocating for better services for all persons with disabilities, many of whom were living in appalling conditions.

- Dix spent two years visiting jails, almshouses, poorhouses, and asylums across the United States. “More than nine-thousand idiots, epileptics, and insane in these United States, destitute of appropriate care and protection.”

- Since it was unthinkable in 1848 for a woman to address Congress, Dix had Samuel Gridley Howe, a well-known social reformer, present her speech. Her specific appeal – that the United States set aside 5 million acres of land throughout the nation to accommodate persons with disabilities – was passed by both houses of Congress but vetoed by President Pierce. Through her passionate appeals, and with only the best intentions for persons with disabilities, Dix helped to prepare the way for public institutions.

Compiled by Kirsty Groff; photo courtesy of the Library of Congress
In America, Dr. Samuel Gridley Howe (1801-1876) was involved in many social causes. He was concerned about the conditions of persons with mental illness, persons with a hearing loss or who were blind, slaves, and groups of people who were politically oppressed.

In 1848, Dr. Howe, founded the Perkins School for the Blind. The first sheltered workshops can be traced back to the Perkins Institution.

These early reformers firmly believed in the importance of family and community, and wanted their schools to prepare children with disabilities to live with the rest of society.

Between 1847-1857 schools for "feeble-minded youth" opened across the country. Training schools were considered an educational success, offering hope to many families with children with disabilities.

Compiled by Kirsty Groff; photo courtesy of the Library of Congress
The experimental training schools were a success. Many pupils with mild and moderate disabilities profited from their training; they developed the necessary skills to return to their families and communities.

Unfortunately, during the economic troubles of 1857 and as a result of the Civil War, there simply were no employment opportunities for returning pupils. Competition for jobs was already high, with immigrants willing to work for low wages. Pupils who returned to their communities looking for work usually ended up in poorhouses or jails.

At the same time, there was an increasing demand for placement in training schools. Many parents had heard success stories and some believed that child could even be cured. Existing training schools expanded their facilities and began serving persons with all types of disabilities.
1870-1880: From Training School To Asylum

- While the number of training schools increased, the commitment to training did not. The schools quickly became asylums, providing custodial care for an increasing number of individuals with developmental disabilities. As enrollment increased, the commitment to education was largely abandoned.

- By 1875, a number of states began building custodial institutions.

- In order to exist, the institutions had to change their focus from a training environment to a custodial environment. Pupils became "inmates."

- The goal of educating pupils for life in the community was changed to training inmates to work inside the institution. Instead of an education, higher-functioning inmates were taught functional skills and worked for the institution, to reduce costs. Slave labor would be a good term to explain this.
Institutional Self-Sufficiency: Free Labor

- Superintendents began asking the states to pay for this custodial care. Providing persons with disabilities safety and shelter, they argued, was the best that could be done, relieving communities of this burden.

- Unlike the early training schools, the new institutions no longer encouraged interaction with the community. They were located in rural areas and away from the view of most people.

- Inmates with mild disabilities were used as free labor to help care for others. Rather than prepare inmates to return to the community the focus changed to training inmates to work for the institution.

- One method of institutional expansion was the development of farm colonies. Hard physical labor was required of both staff and inmates to assure that the farms produced enough food and dairy products to feed the large institutional population.
1928-1936: Worsening Conditions

- By 1936 federal census reported a patient population of almost 107,000 in approximately 80 public institutions.

- Over 10,000 new admissions per year.

- In 1928, the U.S. Supreme Court had ruled the practice of compulsory sterilization to be constitutional with the famous Buck v. Bell case, resulting in tens of thousands of forced sterilizations due to misguided fears about people with disabilities and as a method of social control.

- Overcrowding of institutions worsened as the 20th century proceeded. People could spend their entire day in one room and often slept on the floor.
1896-1923: Beginning of Special Education

- This period was marked by the emergence of special education. As teachers in public schools became aware of the increasing numbers of students with learning disabilities who were labeled "backward" or "feebleminded," they called for special classes and teachers to educate them.

- Rhode Island opened the first public special education class in the U.S. in 1896. By 1923, almost 34,000 students were in special education classes.

- In search of training techniques for these children, the schools turned to the institutions. Some institutions expanded their facilities to incorporate "special" schools. Other institutions offered classes to school teachers on training techniques.
1920-1938: Economic Depression And Lack Of Education

- During the 1920s and 1930s, special education classes were offered primarily in large cities. Many families sent their children to institutions because they believed that only there they would receive training.

- Lack of community services and negative attitudes about persons with disabilities resulted in an increased demand for institutional placement.

- By 1938, the country was deeply embedded in the Great Depression. The Great Depression placed a financial strain on all Americans, especially those individuals and families with special needs.

- Institutions continued to grow in size and number. One reason for this growth was the inability of many families to meet the financial needs of their sons or daughters with disabilities and the lack of educational services.
1939-1945: Worsening Conditions During World War II

- When the U.S. entered World War II, many attendants at public institutions were drafted, leaving a shortage of workers. Admissions to public institutions, however, continued to increase.

- While our country continued to house large numbers of people in institutions, the theme of abandonment reached its extreme in Germany in the 1930s.

- We know of the Holocaust and the killing of 6 million Jews, Poles, Gypsies, and other groups by the Nazis. What is less commonly known is that 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 during this time.
1955: Half a Million in Institutions

- In 1955, state mental institutions in the U.S. housed nearly 560,000 patients, according to William Gronfein, an associate professor at Indiana University-Purdue University.

- By this period, the state of Indiana had built six institutions specifically for the disabled population.
1843-1961: Indiana’s Institutions for Disabled

Indiana State School for the Deaf

- Established: 1843
- Current Status: Active
- Building Style: Single Building
- Architect(s): Rubush & Hunter
- Location: Indianapolis, IN
- Architecture Style: Classical Revival
- Alternate Names:
  - Willard School
  - Indiana Asylum for Deaf and Dumb

Fort Wayne Developmental Center

- Construction Began: 1887
- Opened: 1890
- Closed: 2007
- Demolished: 2011
- Current Status: Demolished
- Building Style: Cottage Plan
- Location: Ft. Wayne, IN
- Peak Patient Population: 2,700 in 1964
- Alternate Names:
  - Indiana Asylum for Feeble Minded Children
  - Indiana School for Feeble Minded Youth
  - Fort Wayne State Hospital

New Castle State Developmental Center

- Opened: 1907
- Closed: 1998
- Demolished: 2001
- Current Status: Demolished
- Building Style: Cottage Plan
- Location: New Castle, IN
- Peak Patient Population: 1,100 in 1952
- Alternate Names:
  - Indiana Village for Epileptics
  - New Castle State Hospital
Indiana’s Institutions for Disabled

**Muscatatuck State Developmental Center**

- **Opened**: 1920
- **Closed**: 2005
- **Current Status**: Closed
- **Building Style**: Cottage Plan
- **Location**: Buterville, IN
- **Alternate Names**:
  - Indiana Farm Colony for Feeble Minded
  - Muscatatuck State School
  - Muscatatuck State Hospital and Training Center

**Silvercrest Children’s Developmental Center**

- **Established**: 1924
- **Opened**: 1936
- **Closed**: 2006
- **Current Status**: Preserved
- **Building Style**: Single Building
- **Location**: New Albany, IN
- **Architecture Style**: WPA
- **Alternate Names**:
  - Silvercrest Sanatorium
  - Southern Indiana Tuberculosis Hospital
  - Silvercrest State Hospital

**Northern Indiana State Developmental Center**

- **Established**: 1950
- **Opened**: 1961
- **Closed**: 1999
- **Current Status**: Closed
- **Building Style**: Single Building
- **Location**: South Bend, IN
- **Alternate Names**:
  - Northern Indiana Children’s Hospital
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1950-1980: THE DEINSTITUTIONALIZATION MOVEMENT
1940-1950: The Right Time for Organizing

- The United States was enjoying an economic boom following the Great Depression and World War II.

- Although conditions were improving for most people in our country, including persons with disabilities, public institutions were overcrowded and understaffed.

- Parents of children with disabilities began to form their own support and advocacy groups because few supports and services were available in the community.
1953: “The Arc” is born

- During the late 1940s and early 1950s, there was a reawakening of hope and possibilities for persons with disabilities. Frustrated and angry over poor living conditions and the lack of community services, parents began to organize and demand services for their sons and daughters.

- The National Association of Parents and Friends of Retarded Children was first registered as a nonprofit organization in 1953 and named the National Association for Retarded Children. In 1992, the national organization became known as The Arc.

- The Arc continues to be one of the largest voluntary organizations comprised of family, friends, self-advocates, and professionals.
Normalization involves the acceptance of people with disabilities, offering them the same conditions as are offered to other citizens.

It involves the normal conditions of life – housing, schooling, employment, exercise, recreation and freedom of choice.

This includes “the dignity of risk,” rather than an emphasis on “protection”.

It involves an awareness of the normal rhythm of life. The principles of normalization:
- A normal rhythm of the day (eating, sleeping);
- A normal routine (living, work, school);
- A normal rhythm of year (holidays);
- Normal developmental experiences;
- The chance to make choices;
- The right to live heterosexually (not segregated into "men only" or "women only" accommodations);
- A normal economic standard;
- The right to live, work and play in normal communities.
1960: Wolf Wolfensberger
Social Role Valorization (SRV)

- (History note: Wolfensberger worked at Muscatatuck State School in Indiana)

- Influential writers like Dr. Wolf Wolfensberger greatly expanded the concept and wrote about "social role valorization."

- Wolfensberger's contribution was a description of the role perceptions of people with disabilities.

- The theory is based on the idea that society tends to identify groups of people as fundamentally 'different', and of less value than everyone else.

- Work lead people to evaluate their own thoughts about 'devaluation' and analyzes its effects.
One of the earliest uses of the “people first” terminology, six years before the first national People First chapter was started in Oregon in 1974:

“There are mentally handicapped people living in every community of our state. With a degree of special help from the community at key times in their lives they can lead useful lives as workers, neighbors, and friends… The mentally handicapped people are people first and handicapped secondly….”
"We as a nation have long neglected the mentally ill and the mentally retarded. This neglect must end..."

– President John F. Kennedy

- President John F. Kennedy, whose sister Rosemary had mental retardation, launched the President's Panel on Mental Retardation and developed a "plan to combat mental retardation."

- Actions were begun to close public institutions and assure that people with disabilities could live in and be a part of the natural community.
1964 Public Outcry

Around this time, Niels Erik Bank-Mikkelsen, Director of the Danish National Service for the Mentally Retarded, visited a state institution in California. His report was read across the country. "I couldn't believe my eyes," he said. It was worse than any institutions I have seen on visits to a dozen foreign countries ... **In our country, we would not be allowed to treat cattle like that.**

Much of the problem could be related to the gross underfunding of facilities. **In 1964, the per diem rate for a person living in an institution was $5.57, about one-half the amount devoted to tending animals in a zoo.**
In 1965, Senator Robert Kennedy, accompanied by a television crew, toured the Willowbrook State School in New York and described what he saw during his visit.

Kennedy said that residents of these institutions were “being denied equal access to education and deprived of their civil liberties.”

In 1966, Burton Blatt, a professor at Syracuse University, using a hidden camera, captured life inside the public institutions and wrote a photographic essay entitled Christmas in Purgatory.

The following year, the essay was published in Look magazine, and drew a large reader response. In this essay, Dr. Blatt declared that “there is a hell on earth, and in America there is a special inferno – the institution.”
1975: Deinstitutionalization

- In many ways, by 1970 one can see the beginning of a process that would play out over the next 30 years, ending with many closures by 2000.

- The exposures of the horrifying realities of the institutions prompted advocates to sue state governments on the grounds that their confinement and treatment of persons with mental retardation were unconstitutional.

- Initially, the public policy response was to "fix the institutions."

- Finally many states arrived at the "close them" stage and settled the lawsuits by agreeing to detailed, court-monitored plans to shift residents to smaller facilities and their own communities.

- In 1975, when a new federal law required that all children with disabilities be provided a free and appropriate public education, the populations at institutions began to plummet. Now that families could send their children to school, parents brought them back home.
### 1972: Census in Indiana’s Institutions

#### TABLE XVIII (B) - MOVEMENT OF PATIENTS ENROLLED IN INDIANA STATE HOSPITALS BETWEEN JULY 1, 1972 AND JUNE 30, 1973

<table>
<thead>
<tr>
<th>PATIENT MOVEMENT</th>
<th>HOSPITALS FOR MR &amp; DEVELOPMENTALLY DISABLED</th>
<th>OTHER STATE HOSPITALS</th>
<th>TOTAL ALL HOSPITALS</th>
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<tbody>
<tr>
<td></td>
<td>FORT WAYNE</td>
<td>MUSCATATUCK</td>
<td>N.I.C.H.</td>
</tr>
<tr>
<td>ENROLLED June 30, 1972</td>
<td>2,117</td>
<td>1,810</td>
<td>167</td>
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<tr>
<td>TRANSFERS</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>To Other Hospitals</td>
<td>10</td>
<td>54</td>
<td>2</td>
</tr>
<tr>
<td>From Other Hospitals</td>
<td>14</td>
<td>9</td>
<td>-</td>
</tr>
<tr>
<td>DISCHARGES</td>
<td>217</td>
<td>103</td>
<td>10</td>
</tr>
<tr>
<td>DEATHS</td>
<td>27</td>
<td>31</td>
<td>9</td>
</tr>
<tr>
<td>NEW ADMISSIONS</td>
<td>59</td>
<td>85</td>
<td>2</td>
</tr>
<tr>
<td>ENROLLED June 30, 1973</td>
<td>1,936</td>
<td>1,716</td>
<td>148</td>
</tr>
<tr>
<td>NET CHANGE</td>
<td>-181</td>
<td>-94</td>
<td>-19</td>
</tr>
</tbody>
</table>
Figure 1.3 Movement Patterns in Large State IDD Facilities, Selected Years 1950-2011

Residential Services for Persons with Intellectual and Developmental Disabilities: Status and Trends Through Fiscal Year 2011
A History of Developmental Disabilities

1970 – PRESENT: HOME AND COMMUNITY MOVEMENT
Federal financing of long-term care for persons with intellectual and developmental disabilities (ID/DD) began in 1971. In 1971, Congress authorized federal financial participation (FFP) for “intermediate care” provided in facilities for people with mental retardation (ICFs-MR). This new federal program, funded by Medicaid, provided substantial financial support to states. States quickly began to participate in the ICF-MR program. By June 1977, 40 states had at least one ICF-MR certified state facility and a majority (28) states had both public and private ICFs-MR.
In the late 1970s, there was a growing support for the development of community services. Advocates expressed concern that the ICF-MR program had created incentives for maintaining people in large institutions through Medicaid cost-sharing.

Funds were being diverted that could have been spent on community service.

The interest in community ICF-MR development, federal “Interpretive Guidelines” were issued in 1981 to support efforts to develop ICF-MR group homes in the community.

Immediately following the issuance, the number of such settings began to grow steadily.

(Lakin, Hill, & Bruininks, 1985; Prouty, Smith, & Lakin, 2003).
But a far more significant event in 1981, was the beginning of the Medicaid Home and Community-Based Services (HCBS) ‘waiver’ program.
1981: Katie Beckett

- Katie Beckett was a young child who was on a ventilator since birth and was unable to go home from the hospital. Katie, born in 1978, had already spent her first three years of life in an Iowa hospital.

- While Medicaid rules allowed for the continued payment of hospital costs, they did not allow Medicaid to pay for the cost of home care, even though home care would have been far less expensive.

- President Ronald Reagan invoked her case as an example of irrational federal regulation in 1981 — a crucial moment in the movement toward government support for home health care —

- Due to this advocacy on the part of Katie’s mother, the rules for using Medicaid were “waived” so that Kathy could receive services in her home rather than in an institution. The first Medicaid waiver was approved.

- Katie finally made it home on December 19, 1981, after Medicaid was pushed to adopt an exception to their home care policy.
Katie Beckett

- Today, this monumental legislation is still referred to as the “Katie Beckett law” and now over a million individuals who would be living in hospitals or care centers are cared for at home and in their communities.
- Katie’s life and legacy will long be remembered. She became an advocate and spokesperson for people with disabilities and special health care needs.
- Katie’s mother is now known as “a pioneer in the civil rights movement for people with disabilities” and the inspiration for regulations that have allowed more than 500,000 disabled children to live at home since 1981.
Katie Beckett, Who Inspired Health Reform, Dies at 34, May 22, 2012

Died on Friday, May 22, in Cedar Rapids, Iowa, in the hospital where she was born. She was 34, more than three times the age her doctors had predicted she would reach.

Thank you, Katie!
1981: Waiver Services Began

- The Omnibus Budget Reconciliation Act of 1981 granted the authority to waive certain existing requirements of Medicaid. Home and Community Based Services for the aged, blind, and disabled began.

- HCBS services including case management, personal care services, adult day services, residential and habilitation services, respite care, and other services became available.
Following the authorization of HCBS, states quickly recognized it to be a significant resource for funding community alternatives to institutional care for persons with ID/DD.

<table>
<thead>
<tr>
<th>State</th>
<th>Year</th>
<th>Persons with ID/DD Living in ICFs-MR</th>
<th>Persons with ID/DD Receiving HCBS</th>
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<tbody>
<tr>
<td>IN</td>
<td>77</td>
<td>1,026</td>
<td>0</td>
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<tr>
<td>IN</td>
<td>82</td>
<td>2,798</td>
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<td>IN</td>
<td>87</td>
<td>4,068</td>
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<td>91</td>
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<td>IN</td>
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<td>5,986</td>
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<tr>
<td>IN</td>
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<td>5,855</td>
<td>1,590</td>
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<td>IN</td>
<td>04</td>
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<td>IN</td>
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<td>4,042</td>
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<tr>
<td>IN</td>
<td>11</td>
<td>3,886</td>
<td>12,283</td>
</tr>
</tbody>
</table>
People With Developmental Disabilities Can And Do Make Positive Contributions To The Life Of The Community

The evidence and experience of people indicate that life in the community is better than life in institutions in terms of:

- Family contact
- Frequency and diversity of relationships
- Employment
- Individual development
- Community Connections
- Leisure
- Recreational
- Spiritual resources
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2011 AND BEYOND: LOOKING FORWARD
On the 12\textsuperscript{th} Anniversary of the Olmstead decision, June 22, 2011, President Barack Obama reaffirmed the thrust of this landmark United States 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.

He reinvigorated the Department of Justice’s (DOJ) efforts to crack down on states.
All states must evaluate HBCS and within five years ensure:

- All settings must demonstrate the qualities of Home and Community Based (HCB).
- Ensure the individual’s experience is HCB and not institutional in nature.
- Does not isolate the individual from the broader community.
CMS Regulations: Home and Community

Questions we must ask?

- The setting is **integrated** in and supports **full access** of individuals receiving Medicaid HCBS to the greater **community**.
- The **setting is selected by the individual** from among setting options including non-disability specific settings.
- The **setting ensures an individual’s rights of privacy, dignity, and respect, and freedom from coercion and restraint**.
- The setting optimizes, but does not regiment, individual initiative, autonomy, and **independence in making life choices**.
- The setting **facilitates individual choice** regarding services and supports, and who provides them.
Build Stronger Community Capacity

- We have just left a century that saw the unimaginable growth (and decline) of institutions in every state in the country. We have just begun a century that may very well see the last one close down.

- As a society, we are now embarked on a slow but steady movement to building stronger community capacity and inclusion for all.
In Closing

- Thank-you for your contribution to this story. Due to each of your work, effort and dedication to the field of disabilities, you are part of this story and are able to watch it continue to unfold. The Disability Movement, is a human rights movements, which has taught us many things about our past, the present and the amazing future that awaits all of us!
References

- Philip M. Ferguson, Ph.D., Dianne L. Ferguson, Ph.D., Meredith M. Brodsky, Ph.D. (2008). “Away From The Public Gaze” A History Of The Fairview Training Center And The Institutionalization Of People With Developmental Disabilities In Oregon.


