A CENTURY OF CHANGE

Milestones in the History of Intellectual Disability, 1900–2013

1900 **What's in a name:** Accepted clinical terms for intellectual disability include "imbecility," "feeble-mindedness," and "mental deficiency."

Segregation & isolation are the norm. The popular belief is that intellectual disability is synonymous with poverty, sloth, crime and sexual profligacy.

1904 **First textbook about intellectual disability:** Martin Barr publishes *Mental Defectives*, the first text to suggest that hereditary factors play an important part in intellectual disability.

1907 **Involuntary sterilization law:** Indiana becomes the first state to pass a sterilization law for people with intellectual disability held in state institutions.

1912 **Rise of eugenics:** Armed with *The Kallikak Family* (1912) and other pseudo-scientific case histories on the heritability of intellectual disability, eugenicists aim to isolate people with disabilities from the community and establish forced sterilization laws.

"The wards are so crowded we are having to place some of the patients on an open sleeping porch, during both summer and winter.

–Superintendent of Florida Farm Colony, 1939

1930–1950 **Institution overcrowding:** Number of people with intellectual disability in state-funded institutions grew from around **60,000 in 1930** to nearly **140,000 in 1950**.

1946 **"Slaves or Patients?"** An article detailing the poor conditions inside Maryland's Rosewood State Training School is published in *The Catholic Worker.*

"Twelve hundred patients, many of whom should be capable of ultimate return to society, are trapped there . . . It should be to the shame of every person that such a situation can exist.

–Gordon C. Zahn, The Catholic Worker, October 1946

1959 **What's in a name:** The American Association on Mental Deficiency's 1959 manual uses the term "mentally retarded" in place of "mentally deficient."

"The best way I can put it, it was like being in prison.–Former resident of Fairview Training Center in Salem, Oregon

1967 **Institution census peaks,** with 194,650 people with intellectual disability living in state-run institutions.

1968 **The first national Special Olympics games** are held in Chicago, with athletes from 25 states and Canada.

1972 **Willowbrook exposed:** Journalist Geraldo Rivera airs a series of investigative reports about the horrific conditions at Long Island's Willowbrook State School. The stories spark outrage–and action.

1975 **Separate is never equal:** President Gerald Ford signs into law the Education for All Handicapped Children Act, or PL 94-142 (now IDEA), compelling schools to provide full educational opportunities to all children with disabilities.

1979 **Community inclusion:** The Center on Human Policy at Syracuse University issues *The Community Imperative*, a declaration affirming the rights of all people with disabilities to live in and be part of a community.

"In the fulfillment of fundamental human rights . . . all people, regardless of the severity of their disabilities, are entitled to community living.

–Center for Human Policy, *The Community Imperative,* 1979

1987 **Willowbrook closes its doors.**

"Nothing about us, without us.

–Rallying call of self-advocacy movement

1991 **Self-advocacy soars:** Self Advocates Becoming Empowered (SABE), a national umbrella organization for self advocacy, is established at a conference in Nashville. Within two years, SABE has affiliated chapters in 37 states.

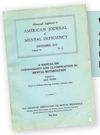
What's in a name: The National Association for Retarded Citizens changes its name to The Arc in response to the growing stigma surrounding the term "retarded."

2013 **More opportunities–and more to come.** Professionals, families, and self-advocates are working together to advance inclusive education, college and career readiness, and real jobs for real pay.

"The inmates of this institution are commonly referred to as 'children' regardless of their ages.

–Dr. Benjamin Whitten, Superintendent, South Carolina Training School 1920

1920 **The institution system expands:** Nationwide, institutions for people with intellectual disability rapidly reach capacity.



1933 **What's in a name:** American Association for the Study of the Feeble-Minded changes its name to the American Association on Mental Deficiency.

1935 **State-sanctioned sterilization skyrockets:** Efforts reach their peak during the Great Depression. By 1937, a reported 27,869 people with intellectual disability have been forcibly sterilized.

"Without sterilization, we would not dare to have patients of both sexes dance together, view movies together, work and play together.

–G.B. Arnold, Superintendent, Virginia's Lynchburg State Colony for the Epileptic and Feeble-Minded, 1937

1950 **Nationwide parent movement begins:** To offer help and support to parents across the country, representatives from 23 parent groups form the National Association of Parents and Friends of Mentally Retarded Children (now known as The Arc of the United States).

1950, 1953 **Parents in the spotlight speak out:** Author Pearl S. Buck ("The Child Who Never Grew") and actress Dale Evans Rogers (*Angel Unaware*) write candid stories about their daughters who were born with disabilities. Their stories quickly become touchstones for advocates of people with intellectual disability.

1958 **Landmark law:** President Dwight Eisenhower passes PL 85-926, the first federal legislation established to provide funds for university training programs in the field of special education.

1960 **President's Panel on Mental Retardation established:** President John F. Kennedy launches a panel to move the U.S. away from institutionalization and toward community-based support systems.

"We as a nation have for too long postponed an intensive search for solutions to the problems of the mentally retarded. That failure should be corrected.

–President John F. Kennedy, 1961 White House Statement on Mental Retardation

1971 **Landmark court case:** *Pennsylvania Association for Retarded Children v. Commonwealth of Pennsylvania* supports the right of all children with intellectual disabilities to a public education.

"We're going back to Willowbrook . . . again. [We're going to] look at those horrible wards. . . again. And show them to you . . . again and again and again. Until somebody changes them.–Geraldo Rivera, 1972

1981 **Bill opens eyes:** A TV movie about Bill Sackter, a man with intellectual disability who ran a popular coffee shop at the University of Iowa, advances the idea that people with intellectual disability can be productive, valued members of a community.

1990 **The Americans with Disabilities Act is passed,** protecting the civil rights of all people with disabilities.

1996 **Medical milestone:** Originally denied a heart-lung transplant because of her Down syndrome diagnosis, Sandra Jensen becomes the first person with intellectual disability to receive an organ transplant.

2000 **The institutional census drops to less than 50,000.**

2004 **Inclusion takes off:** The reauthorization of IDEA furthers the transition toward inclusive classrooms. All students receiving special education services must now also be involved with and progress in the general classroom.

2010 **IDEA celebrates 35 years:** The U.S. Department of Education commemorates the 35th anniversary of IDEA. President Obama calls the 1975 passage of PL 94-142 a landmark civil rights act.

What's in a name: The term "mental retardation" is replaced with "intellectual disability" in all federal legislation.

1 Image from author's personal collection. From Doll, EA, [1917], Clinical studies in feeblemindedness [p. 123]. Boston, MA: Richard G. Badger.• **2** From Smith, JD., & Wehmeyer, ML., [2012], Who was Deborah Kallikak? Intellectual and Developmental Disabilities, 50[2], 169–178. Washington, DC: American Association on Intellectual and Developmental Disabilities: reprinted by permission.• **3** Image from author's personal collection. From Doll, EA, [1917], Clinical studies in feeblemindedness [p. 55]. Boston, MA: Richard G. Badger.• **4** From Heber, R, [1959]. A manual on terminology and classification in mental retardation, American Journal of Mental Deficiency Monographs, 64[2]; reprinted by permission.• **5** Image from author's personal collection. • **6** Image from author's personal collection, From Rogers, DE, [1953], Angel unaware, New York, NY: Revell.• **7** From Braddock, D., [2010], Honoring Eunice Kennedy Shriver's legacy in intellectual disability, Intellectual and Developmental Disabilities, 48[1], 63–72; reprinted by permission.• **8** From Braddock, D., [2010], Honoring Eunice Kennedy Shriver's legacy in intellectual disability, Intellectual and Developmental Disabilities, 48[1], 63–72; reprinted by permission.• **9** Press release photo of Mickey Rooney as Bill Sackter, from author's personal collection.

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This timeline was created using information from *The Story of Intellectual Disability: An Evolution of Meaning, Understanding, and Public Perception,* edited by Michael L. Wehmeyer. Learn more about the book at www.brookespublishing.com

"There is much yet to be done, certainly, but there is every reason to believe that this vision of inclusion for people with intellectual disability is not just a wish, but is attainable if we commit ourselves to doing so.

–Michael L. Wehmeyer, *The Story of Intellectual Disability*