

The Story of Intellectual Disability

An Evolution of Meaning,
Understanding, and Public Perception

edited by

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with contributions from

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About the Editor

Michael L. Wehmeyer, PhD, is professor of special education; director, Kansas University Center on Developmental Disabilities; and senior scientist, Beach Center on Disability, all at the University of Kansas. He has published 30 books and 290 scholarly articles and book chapters on topics related to self-determination, special education, intellectual disability, and eugenics. He is coauthor of the widely used textbook *Exceptional Lives: Special Education in Today's Schools*, published by Merrill/Prentice Hall, now in its seventh edition. His most recent book, coauthored with J. David Smith, is *Good Blood, Bad Blood: Science, Nature, and the Myth of the Kallikaks*, published by the American Association on Intellectual and Developmental Disabilities (AAIDD). Dr. Wehmeyer is past president (2010–2011) of the board of directors for and a fellow of AAIDD and co-editor of the AAIDD e-journal, *Inclusion*; a past president of the Council for Exceptional Children's Division on Career Development and Transition (DCDT); a fellow of the American Psychological Association (APA), Intellectual and Developmental Disabilities Division (Div. 33); a fellow and Vice President of the Americas of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD); and former editor-in-chief of the journal *Remedial and Special Education*. He is a coauthor of the AAIDD *Supports Intensity Scale* and the 2010 AAIDD *Intellectual Disability: Terminology, Classification, and Systems of Supports* manual.

About the Contributors

Ellis M. (Pat) Craig, PhD, retired in 2003 after 36 years of service from the Texas Department of Mental Health and Mental Retardation. Dr. Craig currently consults as a psychologist for intellectual disability programs, conducting diagnostic assessments and behavior programming. In addition to authoring 22 book chapters and articles in professional journals, Dr. Craig has made presentations at numerous conferences. He has served as president of the AAIDD Psychology Division as well as president of state and regional AAIDD chapters and is a coauthor of the AAIDD *Supports Intensity Scale*.

Dianne L. Ferguson, PhD, is professor and director of program improvement and accreditation at Chapman University. She brings expertise and experience in the areas of school reform, inclusive practices, teacher education, families, and disability studies. She is experienced at preparing teachers and designing systems and approaches that support and sustain ongoing school improvement efforts that are inclusive of very diverse groups of children, youth, and their families. As a parent of a young man with significant disabilities, she has worked with families, schools, and service systems. She is currently on the board of a nonprofit organization that provides self-directed support services to adults with disabilities in Eugene, Oregon. Dr. Ferguson has taught classes and provided consultation for general and special educators in Canada, Iceland (as a Fulbright Scholar), Finland, Norway, Sweden, Denmark (also as a Fulbright Scholar), New Zealand, and India as well as in numerous states in the United States. Her areas of interest and expertise include issues and strategies for school inclusion for students with disabilities, family experience and the relationships between school personnel and families, administrator and teacher support for licensure and professional development and collaboration, and use of interpretivist research methods in education. She has served as a college administrator and consultant on higher education reform, teacher education reform, licensure reform, and ongoing assessment of teacher quality. Dr. Ferguson has published widely, is the author or co-editor of seven books, and serves as an associate editor or on the editorial board of four professional journals.

Philip M. Ferguson, PhD, is a professor in the College of Educational Studies at Chapman University in Orange, California. In addition to the history of disability,

of information can quickly overwhelm a reader (or writer), is irregular in that we didn't intend to review every important point or to discuss every important person. In fact, to the extent possible, we avoided the "history as a litany of great people" narrative that is so easy to fall into when writing about intellectual disability.

In general, we were really interested in questions about how the intellectual disability construct was understood and defined across time, how that affected the lives of people experiencing intellectual disability and the supports available to them, and what the lives of people with intellectual disability were like during different eras. This provided a more manageable task; for one, we did not have to document exhaustively every major event in the history of intellectual disability. Furthermore, we could bring in the voices and perspectives of people with intellectual disability and their families along with those of professionals and examine how intellectual disability was depicted in cultural artifacts.

That is the intent and structure of *The Story of Intellectual Disability*. As noted, the impetus for this text began with conversations within AAIDD, the oldest professional association in the field of intellectual disability. AAIDD publishes three journals, one of which, *Intellectual and Developmental Disabilities (IDD, formerly Mental Retardation)*, focuses on issues often associated with the history of intellectual disability and how the construct is understood. The royalties from this text go to AAIDD, and in cases in which an essay that has appeared in *IDD* that informs our attempts to examine the understanding of the construct, we have included the essay or article in its entirety. Finally, it should also be noted that in attempting to write about how a construct such as intellectual disability has been understood throughout history, it is almost impossible to do so without using the language particular to the particular era. Terms referring to people with intellectual disability—ranging from *idiot* to *feble-minded* to *moron* that today are highly offensive—were at the time clinical terms, widely accepted. The terms used also help in understanding how people thought about individuals with disabilities at that time. As such, we have opted to use the terms appropriate or applicable to the particular era, and we trust the reader will understand the need so to do.

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Isolation, Enlargement, and Economization

Intellectual Disability in Late Modern Times (1930 CE to 1950 CE)

J. David Smith, Steven Noll, and Michael L. Wehmeyer

Before the end of World War II, the problems set in motion during 1900–1930 exploded. The number of institutions in America increased by 50%. The size of these institutions dramatically increased, with the population of people who were institutionalized more than doubling. These mega-institutions, heavily regulated but still underfunded by state bureaucracies and struggling to hire and retain workers, came under increasing attack, and the impact of the Great Depression exacerbated conditions. The lack of privacy, gross overcrowding, and restrictions of freedoms of the inmates resulted in dehumanizing conditions, violations of basic human rights, and a diminution of basic human dignity. Unsanitary conditions, inadequate medical and nursing staff, fire and safety hazards, improper use and regulation of medication, poor nutrition, and the lack of staff

created health and safety hazards for residents. The lack of habilitative and educative efforts in facilities resulted in the deterioration of physical, cognitive, and communication skills and abilities among inmates, and the use of involuntary sterilization escalated. Budget pressures resulted in too few paid employees, which led to the use of inmates as unpaid labor. The growing professional class in the field continued to make all decisions pertaining to the lives of people with intellectual disability. There was, however, some progress. Conceptualizations of intellectual disability changed from the prevailing use of the term *moron* to *mental deficiency*, and professionals began to use difficulties in adaptive behavior and daily living to understand the construct. Additionally, at the end of World War II there emerged a ray of light that became the parent movement.

In 1930, the American novelist Pearl S. Buck left her daughter, Carol, at the Vineland Training School, in Vineland, New Jersey. Buck first came to the attention of the American public when *East Wind, West Wind* was published in 1930. It was a novel that portrayed the conflicts created by cultural change in China. She wrote with the authority of personal experience and actual observation, because she had grown up in China as the daughter of Presbyterian missionaries. In 1931, *The Good Earth*, a novel about Chinese peasant life, brought her increasing fame and a Pulitzer Prize. For the next 40 years, Pearl Buck continued to be a prolific and respected writer, and in 1938 she was awarded the Nobel Prize in Literature, the first American woman to receive this honor.

In addition to her writing, Buck was known for her humanitarian actions. She worked to foster racial tolerance and to promote the welfare of immigrants to the United States. She was a visible advocate for disadvantaged Asian people, particularly children. In 1941 she founded the East and West Association, with the goal of promoting greater harmony and understanding among people of different cultural backgrounds. In 1949 she founded Welcome House, an adoption agency for Asian American children. She and her second husband had raised a large family of adopted children of diverse racial and ethnic origins.

It was her experiences with her own child, Carol, however, that shaped the future for people with intellectual disability. Pearl Buck's first child, Caroline Grace Buck, was born in May of 1920. It soon became apparent that Carol's rate of development was noticeably slower than that of other children. When the Buck family returned to the United States, Pearl sought the opinions of physicians more knowledgeable about developmental problems than those she had consulted in China. At the Mayo Clinic, in Rochester, Minnesota, she received the news that her daughter was "severely retarded" (Buck, 1950, p. 21). Although Buck would not learn it until much later in her life, her daughter was born with a metabolic disorder called phenylketonuria, or PKU. Left untreated, the blood stream of children with PKU accrues high levels of unsynthesized phenylalanine, an amino acid found in a host of foods—including breast milk, meat, chicken, fish, nuts, and dairy products—resulting in, among other symptoms, cognitive disability as a function of neural damage.

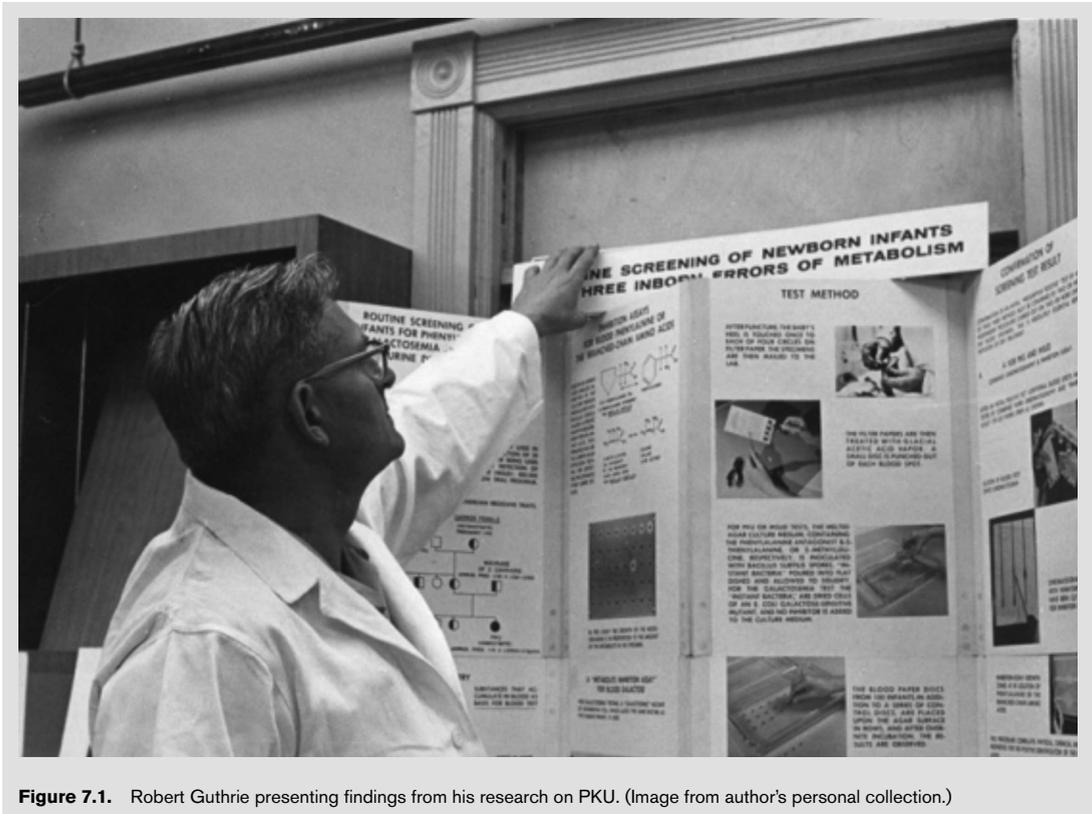


Figure 7.1. Robert Guthrie presenting findings from his research on PKU. (Image from author's personal collection.)

In the early 1960s, pediatrician and microbiologist Robert Guthrie, with funding from the National Association for Retarded Children, a parent advocacy organization, developed a blood test that could detect the presence of PKU. Known as the Guthrie Spot, newborns worldwide are screened for the presence of PKU. If detected early, children with PKU can be placed on phenylalanine-restricted diets and experience typical developmental outcomes (see Figures 7.1 and 7.2).

Of course, this knowledge did not exist in the 1920s, and circumstances and the times soon made it seem to Buck that she would have to institutionalize Carol. In 1929, Buck sojourned back to the United States to locate an institution in which Carol could live the remainder of her life. Her quest led her, eventually, to the front porch steps of the Vineland Training School (see Figure 7.3).

“I knew,” wrote Buck about the end of her search, “when I entered the office and shook hands with the quiet, gray-haired man who greeted me with a gentle voice that I had found what I wanted. He was sympathetic, but not with effort. He was not eager. He said diffidently that he did not know whether I would be satisfied with his school, but we might look around. So we did look around, and what I saw was that every child’s face lit when he came into the cottages, and that there were a clamor of voices to greet him and call his name—Uncle Ed, they called him” (Buck, 1950, p. 44). “I saw a certain motto repeated again and again on the walls, on the stationery, hanging above the head’s own desk. It was this: Happiness first and all else follows” (Buck, 1950, p. 45).



Dr. Robert Guthrie cares

You may have never heard of phenylketonuria (PKU) and thanks to Dr. Robert Guthrie, you probably never will. PKU is a crippling metabolic disorder that can cause severe mental retardation if not diagnosed early. Dr. Guthrie's simple blood-spot test for PKU is widely used and is the basis for broader screening to detect other inborn errors of metabolism.

This ounce of prevention is already saving lives around the world and pays for itself. Dr. Guthrie's pioneering effort in preventive medicine research is an ex-

ample of the progress that promises a better tomorrow through a more careful today.

Help dedicated men like Dr. Guthrie help protect our most important national resource — the next generation. Support the National Association for Retarded Citizens.



National Association for Retarded Citizens
2709 Ave. E East, Arlington, Texas 76011

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Figure 7.2. Advertisement of Robert Guthrie's PKU test.

Image from author's personal collection from the National Association for Retarded Children and
Excerpted from *The Story of Intellectual Disability: An Evolution of Meaning, Understanding, and Public Perception*

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Brookes Publishing | www.brookespublishing.com | 1-800-638-3775

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Figure 7.3. Maxham Cottage, Vineland Training School for Feeble-minded Children, Vineland, New Jersey. (Image from author's personal collection.)

Edward Ransom Johnstone was the superintendent of the Vineland Training School, and his motto for the institution had won Pearl Buck's heart. "You must remember," Buck recalled Johnstone telling her, "that these are happy children. They are safe here. They will never know distress or want. They will never know struggle or defeat, nor will sorrow ever touch them. No demands are made upon them which they cannot meet. The joys which they can appreciate they have. Your child will escape all suffering. Will you remember that and let it be a comfort to you?" (Buck, 1950, p. 47).

In 1932, Buck donated \$50,000 to Vineland for the construction and maintenance of a cottage, called Carol's Cottage, on the campus in which her daughter could live (Trent, 1994, p. 233). She was a long-time member of the board of directors for the Training School, and even after her death, in 1973 from lung cancer, her contribution to the Training School continued in the person of her adopted daughter, Janice, who became Carol's guardian and an active member of the Vineland board of directors (Finger & Christ, 2004, p. 50).

As important as Pearl Buck was to the Vineland Training School, it was her impact on other parents of children with intellectual and developmental disabilities for which she is most remembered by disability advocates. In an article in the *Ladies Home Journal* in May 1950 titled "The Child Who Never Grew," Buck told the story of her daughter, Carol (see Figure 7.4). Later that year, the article was reprinted as a book by John Day Publishing, and it was condensed for inclusion in the September 1950 issue of *The Reader's Digest*.