

# FOCUS *on* EXCEPTIONAL CHILDREN

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## The Ross and Marianna Beach Distinguished Professor Inaugural Lecture: Self-Determined Learning, Personalizable Education, and Strengths-Based Approaches to Educating All Learners

University of Kansas

October 12, 2022

*Michael Wehmeyer\**

Tom Gilhool died in late August 2020 at the age of 81. Making that observation may seem an odd way to begin an article, but for anyone engaged in the special education enterprise, Tom Gilhool's name is worth knowing and his passing worth observing. Temple University has compiled an oral history of his life and work<sup>1</sup> and rather than cite numerous scholarly texts to document the importance of his life, readers should go to that to hear from him and learn more about his importance to the field. I had the privilege to get to know him when I worked at The Arc of the United States in the 1990s, because he had been the attorney acting on behalf of the Pennsylvania Association for Retarded Citizens who litigated one of the landmark right to education cases (PARC v. Commonwealth Pennsylvania) that paved the way for the passage of federal legislation ensuring that students with disabilities had a right to a free, appropriate public education.

In November of 2019, I delivered the Ross and Marianna Beach Distinguished Professor Inaugural Lecture at the University of Kansas. The focus of that lecture were ideas I discussed in a book published through Teachers College Press earlier in that year titled *Strength-Based Approaches to Educating All Learners with Disabilities: Beyond Special Education* (Wehmeyer, 2019). I talked about Tom Gilhool in that book and the revolutionary impact of PARC and the parent movement on the opportunity for children and youth with disabilities having access to a free, appropriate education. In the book and the lecture, I discussed the fact that the context in which Gilhool and his peers created federal legislation to education learners with disabilities was significantly different than today, and that forces were converging that created opportunities to create meaningful change in how we educate all learners, including students with disabilities; how we go beyond special education, as the subtitle of the book suggested. In transcribing my inaugural distinguished professor lecture into a paper for this issue of *Focus on Exceptional Children*, I have opted to try to capture the experience for which that lecture was designed. That is, in my lecture, before an audience that included many people who do not know the field, I wanted to tell a story in equal part through words and images. This article will, as such, rely on images and a narrative that emphasizes a broad treatment and interpretation of historical events and future prognostications.

On Nov. 29, 1975, then-President Gerald Ford signed into law the *Education for All Handicapped Children Act* (Public Law 94-142).

It is worth noting that even at the onset, the legislation was received with less-than high praise. President Ford's statements from on the event of signing EHA were:

I have approved S. 6, the Education for All Handicapped Children Act of 1975.

Unfortunately, this bill promises more than the Federal Government can deliver, and its good intentions could be

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**Figure 1:** Gerald Ford signing the Education for All Handicapped Children Act in 1974. In public domain from <https://www.fordlibrarymuseum.gov/library/speeches/750707.htm>.

thwarted by the many unwise provisions it contains. Everyone can agree with the objective stated in the title of this bill -- educating all handicapped children in our Nation. The key question is whether the bill will really accomplish that objective.

Even the strongest supporters of this measure know as well as I that they are falsely raising the expectations of the groups affected by claiming authorization levels which are excessive and unrealistic.

Despite my strong support for full educational opportunities for our handicapped children, the funding levels proposed in this bill will simply not be possible if Federal expenditures are to be brought under control and a balanced budget achieved over the next few years.

There are other features in the bill which I believe to be objectionable and which should be changed. It contains a vast array of detailed, complex, and costly administrative requirements which would unnecessarily assert Federal control over traditional State and local government functions. It establishes complex requirements under which tax dollars would be used to support administrative paperwork and not educational programs. Unfortunately, these requirements will remain in effect even though the Congress appropriates far less than the amounts contemplated in S. 6.

Fortunately, since the provisions of this bill will not become fully effective until fiscal year 1978, there is time to revise the legislation and come up with a program that is effective and realistic. I will work with the Congress to use this time to design a program which will recognize the proper Federal role in helping States and localities fulfill their responsibilities in educating handicapped children. The Administration will send amendments to the Congress that will accomplish this purpose.<sup>2</sup>

Hardly an effusive sendoff. And, because I am on the faculty at the University of Kansas, I want to note that Kansas Senator Bob Dole played an important role in the passage of this Act (and can be seen on the far left of the picture in Figure 1), as he did on much of the disability legislation of that era. P.L. 94-142, or EHA, was based in

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large measure on state policies created in the aftermath of *PARC v. Commonwealth*. Fully implemented in 1978, despite Gerald Ford's pessimism, the EHA opened the doors to public schools for millions of children who had to that point been denied such access.

I was among the first wave of teachers hired to meet the demand created by the law, entering the field in 1980 as a teacher of adolescents with the most extensive support needs; students who were labeled as having "severe and profound handicaps" at the time. During the seven years I spent in the classroom, I taught several students who, although in their late teen years, had never before stepped foot in a school building. Despite the fact that even though the original language of EHA prioritized the education of learners with disabilities alongside their same age, non-disabled peers, my students were segregated, in separate classrooms designated by severity of intellectual impairment, on a separate campus building. My experience was not unique. What is referred to as 'special education' has always been separate.

I live only half an hour from Topeka, Kansas, and a few years ago made an overdue visit to the Brown versus Board of Education Museum. On the wall on your left as you enter the former Monroe elementary school building, which was one of four segregated schools for African-American children in the Kansas capital city, there is a plaque that memorialized the now familiar statement delivered by Chief Justice Earl Warren: "We conclude that in the field of public education, the doctrine of 'separate but equal' has no place. Separate educational facilities are inherently unequal."

I believe that this is true in the education of learners with disabilities, and yet today, documented by recent reports to Congress on the implementation of what is now titled the Individuals with Disabilities Education Act, only 17% of students labeled with intellectual disability spend most of their day in regular education environments. The experiences of the vast majority of students with intellectual, developmental, and multiple disabilities like the students I taught remains one of segregation. So, I want to begin at the beginning to try to understand why the special education system in America was immediately separate, why it remains separate for far too many students, and why I think this is a function of how we understand disability itself.

## FROM HABILITATION TO SEGREGATION AND STERILIZATION

The first schools for people with cognitive disabilities in the United States were inspired by the efforts of French physician Edouard Seguin in the early 1800s in



**Figure 2:** An ad for the Institution for the Education of Feeble-minded Youth in Barre Massachusetts. Photo of advertisement from author's collection.

France. In 1843 Samuel Gridley Howe, the superintendent of the Perkins School for the Blind in Boston, visited some of Seguin's schools in France and in 1848 opened a wing of the Perkins School for students who, as the terminology of the day dictated, were feeble-minded. In fact, though, a physician in Barre, Massachusetts, Hervey Wilbur, who had read an article authored by Howe about his observations in France, opened the first American school for "the feeble-minded" in his home six months before Howe opened his school at Perkins (see Figure 2). So, the first public and private schools opened in the U.S. in 1848. These were habilitative in nature, by and large, actually intended as schools.

These mid-19<sup>th</sup> century efforts at habilitation transmogrified into what, by the first two decades of the 20<sup>th</sup> Century, had become a medically-oriented, custodial care system of state-run institutions designed to keep people with severe disabilities separated from the general public so as to combat societal fears of the purported *menace of the feeble-minded*; fears that were promulgated under the guise of the pseudoscience of eugenics. Spurred by the US Supreme Court verdict in *Buck v. Bell* in 1927 (see Figure 3) declaring involuntary sterilization as constitu-



**Figure 3:** Carrie Buck (left) and her mother, Emma Buck, on the grounds of the Virginia State Colony for Epileptics and Feeble-Minded near Lynchburg, Virginia. This photograph was taken in November 1924 by Arthur H. Estabrook, a eugenics researcher who interviewed the two women before testifying in a legal case that resulted in the forced sterilization of Carrie Buck. Permission granted for educational use by the owner (<https://archives.albany.edu/concern/images/9s161d76t#c=0&m=0&s=0&cv=0&xy-wh=-1429%2C-1%2C5764%2C2907>).

tional for some citizens, these institutions became the focal point for so-called asexualization operations.

One of the first such operations was performed at the Kansas State Home for the Feeble-minded in Winfield, Kansas. A wire story on April 3, 2000 in the Wichita (KS) Eagle newspaper noted:

The effort to sterilize the unfit in Kansas began in 1894 with F. Hoyt Pilcher, then superintendent of Winfield's Kansas State Asylum for Idiotic and Imbecile Youth. By 1895, Pilcher had developed a reputation as a trailblazer. The Winfield Courier reported: "The unsexing of one hundred and fifty of these inmates -- male and female -- was an innovation that received the endorsement of the entire medical profession of the world, and the plaudits of right thinking people everywhere." (Tanner, 2000)

In October of 1928, after the *Buck v. Bell* U.S. Supreme Court ruling, the Supreme Court in Kansas upheld its sterilization law as constitutional (Wehmeyer, 2003). By the 1970s, it is estimated that between 40,000 and 50,000 Americans labeled as feeble-minded had been forcibly and involuntarily sterilized. Nazi Germany modeled its sterilization program on American laws, passing the Law for Prevention of Offspring with Hereditary Defects Act in July of 1933. This law allowed the government to remove people with disabilities from their homes and institutions, and ultimately, almost 300,000 Germans with

disabilities underwent *Hitlerschnitte*; literally Hitler's cut (Smith & Wehmeyer, 2012). As we noted in our book:

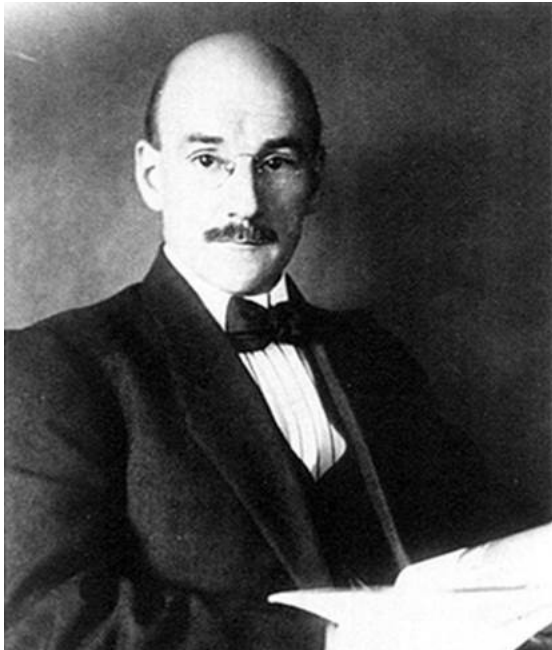
In 1939, the abomination that was the forced sterilization of hundreds of thousands of disabled Germans became unspeakably worse; and it began with the children. The Führer ordered subordinates to initiate the systematic murder of infants and children with disabilities (p. 12).

Over 5,000 infants and children were systematically murdered by physicians and nurses. The program, called the T4 program after the address of its headquarters (Tiergarten Strasse 4) expanded to include adults, ultimately resulting in the *disinfection*, as the murders were called by the Nazi's, of 80,000 Germans with disabilities (see Figure 4) (Smith & Wehmeyer, 2012).



**Figure 4:** Disabled prisoners photographed for Nazi propaganda purposes. Copyright: United States Holocaust Memorial Museum, used in accordance with museum permitted uses (<https://www.ushmm.org/copyright-and-legal-information/terms-of-use>)

One of my contributions to understanding the injustices of this era involved a book I co-authored with a colleague, David Smith (Smith & Wehmeyer, 2012), which tells the story of *The Kallikak Family*. Published in 1912 and authored by psychologist Henry Herbert Goddard (Figure 5), director of the research laboratory (Figure 6) at the Training School for Feeble-minded Children in Vineland, New Jersey, *The Kallikak Family* told the tale of a supposedly 'degenerate' family from New Jersey, beginning with the story of Deborah, a woman who lived at The Training School.



**Figure 5:** Henry Herbert Goddard. Photograph public domain ([https://commons.wikimedia.org/wiki/File:Henry\\_H.\\_Goddard.jpg](https://commons.wikimedia.org/wiki/File:Henry_H._Goddard.jpg))



**Figure 6:** The Research Laboratory (formerly Wistar Hospital) on the Vineland Training School Grounds. Image from author's collection.

Like most books in the eugenic family studies genre—which purported to report on the characteristics, and behavior that ran in certain families to show the heritability of eugenic traits and to support the conclusion that forms of negative eugenic interventions would be socially and economically beneficial—*The Kallikak Family*

described generations of illiterate, poor, and supposedly immoral Kallikak family members who were described as chronically unemployed, feebleminded, criminals, prostitutes, and, in general, as threats to ‘racial hygiene.’



**Figure 7:** Deborah Kallikak as depicted on the frontispiece of *The Kallikak Family*. Image in public domain.

In the first chapter of *The Kallikak Family*, Goddard introduced the pseudonymous Deborah Kallikak (Figure 7), an inmate of the Vineland Training School. Goddard’s tale of Deborah and her ancestors, reigned as seemingly conclusive proof of the hereditary nature of intelligence, feeblemindedness, criminal behavior, and degeneracy for decades, and was used by American eugenicists to justify their racially and politically charged rhetoric and policies, resulting in the institutionalization and forced sterilization of many of this nation’s most vulnerable citizens. Goddard derived the name Kallikak from the Greek words Kallos (beauty) and Kakos (bad); Goddard’s dramatic way of capturing the essence of the story of the Kallikak family, one branch of which was good, the other bad: good blood, bad blood.

The story told in *The Kallikak Family* is simple and, given its significant influence at the time, obviously compelling. It begins with Deborah’s admission to Vineland, as described in the opening paragraphs of the book:

One bright October day, fourteen years ago, there came to the Training School at Vineland, a little eight-year-old girl. She had been born in an almshouse. Her mother had afterwards married, not the father of this child, but the prospective father of another child, and later had divorced him and married another man, who was also the father of some of her children. She had been led to do this through the efforts of well-meaning people who felt that it was a great misfortune for

a child to be born into the world illegitimately. From their standpoint the argument was good, because the mother with four or five younger children was unable to provide adequately for this little girl, whom both husbands refused to support. On the plea that the child did not get along well at school and might possibly be feeble-minded, she gained admission to the Training School, there to begin a career which has been interesting and valuable to the Institution, and which has led to an investigation that cannot fail to prove of great social import. (Goddard, 1912, pp. 1-2).

Goddard described Deborah's history as a worker (Figure 8) and a pupil, usually in terms that reinforced his presentation of her as a person of the 'moron grade.' Goddard



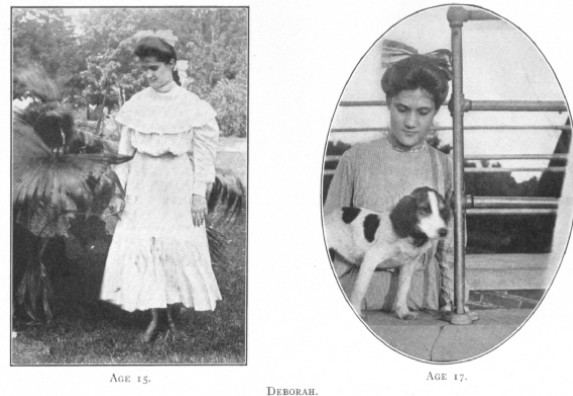
DEBORAH AT THE SEWING MACHINE.



DEBORAH AS WAITRESS.

**Figure 8:** Deborah Kallikak as depicted in images as sewing and setting a table in *The Kallikak Family*. Image in public domain.

had coined the term 'moron' to refer to people who appeared normal, but were defective and, as such, a greater danger to society than people who were (in Goddard's view) obviously disabled. If one looks up the term moron in the Oxford English Dictionary, not only is the first use of the word attributed to Goddard, but a quote from *The Kallikak Family* about Deborah is identified as the first use in written English. Goddard constantly refers to the danger Deborah poses because she is attractive and, in his terms, a moron (Figure 9).

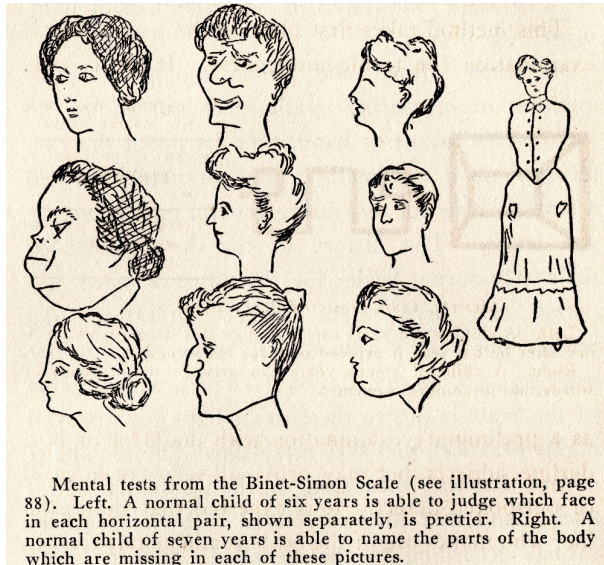


**Figure 9:** Deborah Kallikak as depicted in images in *The Kallikak Family*. Image in public domain.

Goddard became caught up in the eugenics fervor of the time, aligning with eugenicists like Charles Davenport and Harry Hamilton Laughlin. Goddard and a field worker who worked closely with him, Elizabeth Kite, translated and introduced the Binet-Simon intelligence scale (see Figure 10) to America, and Goddard conducted research using the scale to identify and segregate people deemed feeble-minded.

A primary initiative of the Eugenics Records Office, the hub of eugenic activity in the country, was the documentation of family histories so as to trace the supposed degenerate effects of so-called poor hereditary stock. An infamous example of activities from this that has a Kansas connection were the *Fitter Families for Future Firesides* competitions held at state fairs and originating in Kansas and Iowa by Kansas University professor Florence Sherbon. The Kansas State Fair provided a building for the display on the fairgrounds (Figure 11).

Fitter Family contestants waited in front of the exhibit building for their turn, and when that time came, the whole family entered and underwent a series of medical, dental, and psychological exams to determine their eugenic fitness. Celebrity volunteers and judges included notable Kansans as Dr. James Naismith, the inventor of



Mental tests from the Binet-Simon Scale (see illustration, page 88). Left. A normal child of six years is able to judge which face in each horizontal pair, shown separately, is prettier. Right. A normal child of seven years is able to name the parts of the body which are missing in each of these pictures.

**Figure 10:** Illustration of task from Binet-Simon scale from Binet & Simon (1916).



**Figure 11:** Eugenic Health Exhibit at Kansas State Fair. Used in accordance with copyright restrictions from owner: [http://www.eugenicsarchive.org/eugenics/view\\_image.pl?id=1563](http://www.eugenicsarchive.org/eugenics/view_image.pl?id=1563)

the game of basketball and the first basketball coach at the University of Kansas and Dr. Karl Menninger, a pioneer in the field of mental health and founder of the internationally known Menninger Clinic, who volunteered in the psychiatric examining room. The State of Kansas laboratories did all urine analyses. When the winner was selected, they received a medallion (Figure 12) stating: “Yea, I have a goodly Heritage.”

Goddard was urged to contribute to these efforts to determine the importance of hereditary fitness by con-



**Figure 12:** Medallion awarded to winner of the Fitter Families for Future Firesides competition. Photo by the author from medallion in the author’s collection.

ducting field research on the backgrounds of the inmates that resided at the Training School. He noted:

The Vineland Training School has .... employed field workers,” Goddard continued. “As a result of weeks of residence at the Training School, they become acquainted with the condition of the feeble-minded. They then go out ... to the homes of the children and there ask that all the facts which are available may be furnished ...” (p. 13).

To Goddard and his fieldworkers, there appeared to be an almost inexhaustible supply of what they believed to be degenerate families to inform their studies. “The surprise and horror of it all,” he wrote, “was that no matter where we traced them ... an appalling amount of defectiveness was everywhere found” (p. 16). One family, however, stood out even in this sea of so-called degeneracy. Goddard wrote:

In the course of the work of tracing various members of the family, our field worker occasionally found herself in the midst of a good family of the same name, which apparently was in no way related to the girl whose ancestry we were investigating. ... these cases became so frequent that there gradually grew the conviction that ours must be a degenerate off shoot from an older family of better stock (p. 16).

This was Deborah's family. Goddard went on to explain that:

The great-great-grandfather of Deborah was Martin Kallikak," Goddard explained. "That we knew. We had also traced the good family back to an ancestor belonging to an older generation than this Martin Kallikak, but bearing the same name. He was the father of a large family. Deeper scrutiny into the life of Martin Kallikak Sr. enabled us to complete the story. When Martin Sr., of the good family, was a boy of fifteen, his father died... Just before attaining his majority, the young man joined one of the numerous military companies that were formed to protect the country at the beginning of the Revolution. At one of the taverns frequented by the militia he met a feeble-minded girl by whom he became the father of a feeble-minded son. This child was given, by its mother, the name of the father in full, and thus has been handed down to posterity the father's name and the mother's mental capacity. This illegitimate boy was Martin Kallikak Jr., the great-great-grandfather of our Deborah, and from him have come four hundred and eighty descendants. One hundred and forty-three of these, we have conclusive proof, were or are feeble-minded, while only forty-six have been found normal. The rest are unknown or doubtful (pp. 17-18).

If the Kallikak story had ended here, it would be just another of the now nearly forgotten eugenic family fables and would have had little to say about heredity that could not be explained by poverty. But here the tale takes a twist that, Goddard realized, distinguished it from anything published up to that time:

Martin Sr., on leaving the Revolutionary Army, straightened up and married a respectable girl of good family, and through that union has come another line of descendants of radically different character. These now number four hundred and ninety-six in direct descent. All of them are normal people. All of the legitimate children of Martin Sr. married into the best families in their state, the descendants of colonial governors, signers of the Declaration of Independence, soldiers and even the founders of a great university. Indeed, in this family and its collateral branches, we find nothing but good representative citizenship... respectable citizens, men and women prominent in every phase of social life."

Kallos and Kakos. Good blood and bad blood.

It is important to understand both the intent of *The Kallikak Family* and the book's impact on the eugenics movement in the U.S. Eugenics, a term coined by Charles Darwin's half-cousin, Sir Francis Galton, was



**Figure 13:** The influence of heredity as demonstrated by the good and bad Kallkaks. From Garrett (1955).

the so-called science of the improvement of the human race by better breeding. In America, negative eugenics (focusing on keeping some people, deemed as unfit, from reproducing) became the primary focus: the *unfit* included immigrants, people with intellectual or other disabilities, people of color in general, and often, just poor people. *The Kallikak Family* was a national best seller. Eugenicists embraced the book as illustrating their contention of the heritability of feeble-mindedness and the need to enact eugenic measures like segregation, marriage restriction laws, and sterilization. The book was received with acclaim by the public and by much of the scientific community and was in print as late as 1939. It is difficult to locate a biology or psychology text in the years immediately following the publication of the Kallikak book that does not cite the study as conclusive evidence of the hereditary nature of feeble-mindedness. I



have copies of texts from as late as 1951 that continued to cite the “study” as fact. It was cited in the 1927 Buck vs. Bell Supreme Court ruling, which, as I mentioned earlier, declared that involuntary sterilization of some people in America, including the so-called feeble-minded, was constitutional.

*The Kallikak Family* was reprinted in German in 1914 and 1933, the latter the same year that Nazi Germany passed the aforementioned Law for Prevention of Offspring with Hereditary Defects Act. It became an important document as the Nazis rolled out their genocidal T4 program, and images from the book were converted to the German context (see Figure 14).



Figure 14: Kallikak image from German translation of *The Kallikak Family*.

The story that Dave Smith and I told in *Good Blood, Bad Blood* was a different story. *The Kallikak Family* tells Deborah’s story, which was a story Goddard told to fit his needs. The story of Emma Wolverton, whom the world had known only as Deborah Kallikak, is much richer, much more complex. Fundamentally, Goddard portrayed Emma’s ancestors and their descendants in incendiary, hyperbolic terms, christening them with stigmatizing names; Martin Jr. was referred to, for example, as the “Old Horror” (p. 19); his fourth child, a daughter, was called “Old Sal, mother of morons” (p. 21).

In fact, as we discuss in *Good Blood, Bad Blood*, most of Emma’s ancestors and their descendants were hard working, if not prosperous, people. The real story of the disfavored Kallikaks, the ‘other Wolvertons,’ is not free of troubles and human frailties, but the family also had its strengths and successes. The tragedy of the disfavored Kallikaks is that their story was distorted so as to be interpreted according to a powerful myth, the myth of eugenics, and then used to further bolster that myth.

Deborah’s story was constructed by Goddard to fulfill the need for a eugenic-narrative to fit his worldview. Emma Wolverton’s story was the story of many American families; people living simply in a rural, mainly agricultural setting who, at the end of the 19<sup>th</sup> Century and start of the 20<sup>th</sup> Century, were forced from rural lives into urban America and into a life that was beset by hardships and for which they weren’t adequately prepared.

There is one more reason, however, that this was not Emma’s story. As we discuss in *Good Blood, Bad Blood*, Goddard got the genealogy wrong. Martin Kallikak, Jr. was not the illegitimate son of Martin Kallikak, Sr. Whether the dalliance with a feeble-minded barmaid was fiction or fact, Goddard’s natural experiment never occurred. There were no Kallos, no Kakos ... and no Kallikaks. One line of Wolvertons had access to resources... money, education, health care. Another line of Wolvertons had none of those and were relegated, with millions of rural Americans and immigrants, to the bowels of America’s urban areas, into lives that were often barely livable.

In 1911, the year before *The Kallikak Family* was published, 22-year old Emma Wolverton was described in institutional records as a skillful and hard worker who lacked confidence in herself. She excelled in woodworking and dressmaking. Academic subjects were difficult, but the records indicate that across the years at the Training School, she made considerable progress in academic and non-academic areas. She became an avid letter-writer and learned to play the cornet, performing in the Training School band. She was an active participant in outings and in the life of the institution.

At the age of 25, having lived at the Training School for 17 of those years, Emma was transferred to the New Jersey state women’s institution across the street, which provided a custodial situation in which feeble-minded women could be placed to keep them from propagating their kind. Emma Wolverton (see Figure 15) died at the state women’s institution in 1978 at the age of 89 years. She had lived in an institution 81 of those years.

We concluded *Good Blood, Bad Blood* with the following words:

It is my name. If somebody mispronounces it in some foolish way, I have the feeling that what’s foolish is me. If somebody forgets it, I feel that it’s I who am forgotten.

—Frederick Buechner, 1973 (p. 48)

When we strip people of their names, we strip them of their dignity, their value, their selfhood. It allows us to then talk about “them” in anonymity, referring to our pejorative name for them or the number



**Figure 15:** Emma Wolverton at age 73. Photo from the author's personal collection.

we've tattooed on them, as if they were not people, not human. We can refer to them as morons, criminal imbeciles, or degenerates as if they were not really sentient beings. We can lock them away for the rest of their lives or sterilize them without their knowledge. We—we humans—can march them into gas chambers by telling them that they are going to take a shower.

Her name was Emma, not Deborah.

Emma Wolverton.

We at least owe her the respect of calling her by her name (Smith & Wehmeyer, 2012, p. 216).

I believe that Emma's story is important not only to illustrate that the history of segregation and discrimination that has pervaded America's treatment of people with disabilities from the earliest years, but also to emphasize that how we conceptualize disability has meaningful consequences in how we treat people and the lives they live.

## OF THE COMMUNITY: THE PARENT MOVEMENT

In 2000, my colleague Hank Bersani and I co-authored a chapter on self-determination and self-advocacy (Wehmeyer, Bersani, & Gagne, 2000). In that chapter, titled *Riding the Third Wave*, Hank (who is pictured in Figure 16 with Bernard Carabello, a self-advocacy pioneer featured in Geraldo Rivera's expose of Willowbrook<sup>3</sup>) and I overviewed the history of the disability movement as characterized by three waves. The first, lasting roughly 100 years from the mid-1800s to the end of World War II, was the professional movement, aspects of which I previously covered. In this wave, professionals set the rules, defined the constructs, and designed the systems.



**Figure 16:** Hank Bersani and Bernard Carabello. Photo from the author's personal collection.

But by the 1950s and 1960s, the institutional system that had been created by the professionals during the first wave was overburdened and antiquated. Institutions built to house 1000 people housed thousands more. Willowbrook, an institution on Staten Island, housed nearly 6,000 people. Among examples of the many gross injustices perpetrated on people with disabilities in that era was the injection of residents of Willowbrook, without any knowledge or consent from them or their families, with the hepatitis virus to study the effects of gamma globulin in preventing or combating the disease. When Senator Robert Kennedy toured Willowbrook in 1965, he referred to it as a snake pit, asserting that the children live in filth and were suffering tremendously (<https://mn.gov/mnddc/parallels/five/5b/bobby-kennedy-snakepits.html>).

I have two stories of the abuses of the institutional era that are more personal. The first is from a friend, Ray Gagne. Ray was the third author on the chapter that

Hank Bersani and I wrote, and in that chapter, he told his personal story. I became friends with Ray during the ten years I worked at The Arc of the United States, which is a parent association focused on disability. Ray was a man who had a significant disability who lived in a state institution for people with intellectual disability for many of his early years. Ray eventually moved from the institution and became a valued member of his community and served as chair of The Arc's self-advocacy committee and a national board member for many years, where I got to know him. Ray came to me one day with his autobiography that had been dictated and typed out. He asked if I would enter it into his augmentative communication device, which I gladly did. Before his untimely death in 2003, Ray would sometimes accompany me when I made presentations to tell his personal story. In his autobiography and in the chapter, Ray told a personal narrative of the abuses of institutions:

My name is Raymond J. Gagne. This is my story about my life and why self-advocacy and self-determination are important to me. I was born on January 10, 1945. I am a person with cerebral palsy. I lived with my mother, grandmother, uncle, two brothers, and a sister in a large house in Attleboro, Massachusetts. My mother felt there was something wrong with me. She took me to many doctors and hospitals to see if they knew how to help me. They told my mother I would never walk. At the time, there was no school for me. I stayed home with my grandmother, who took care of me. When I was 8, my mother told me I was going away. She put my name on my clothes and packed my new suitcase. I remember the night before I left. I was bathed and my fingernails and toenails were cut. On February 19, 1953, two ladies picked my mother and me up for the drive to a state school. I didn't know where we were going. My mother had just told me I was going away and that I would be better off.

After arriving at the state school, I was put in Building 7. An orderly brought me to a ward. He put me in a bed and took all my clothes off. Later, I was moved to Building 15. An attendant would help me put on the clothes he had laid out the night before. I didn't have any say about what I wore. What they put on, I wore. The staff never seemed to prepare me for living outside the institution. They didn't seem to think I would make it on my own. I never had support, role models, or mentors to guide me in growing up. Very few of the staff ever assisted me in developing my identity, creativity, or self-esteem.

The day I moved from the institution to an apartment that I shared with two other men, some staff told me I would be back in a month. They may still be waiting

for me to come back. I lived in an apartment for 3 years on my SSI income and the income from my job at the institutions workshop. After I had shared an apartment for 3 years, the staff asked me to move into a halfway house to help five men move out on their own.

That same year I went on a vacation to Washington, D.C., by myself. This was the first time I had ever done this. During that fall I moved to my own apartment after a counselor at a camp for people with cerebral palsy told me she thought I could. I did well in living alone for 3 years. After living alone for 3 years, I decided to move near the city where my sister lived. While there I began to volunteer with a local chapter of the United Cerebral Palsy. While there I learned about Section 504 of the Rehabilitation Act and helped found an advocacy group named the Massachusetts Coalition of Citizens with Disabilities. I learned the skills of leadership, advocacy, consumer organization and assertiveness by watching people, participating in group meetings, and asking questions.

Unlike the staff at the institution, the human service professionals I met at this job treated me with respect. They gave me a chance to contribute my input and feedback, and believed in many of my ideas. My colleagues also adapted the working environment to help me communicate with them. After several years I became the staff liaison to a self-advocacy group of adults.

Ray's story is certainly about the abuses of institutions. However, to him it was not just the physical, sexual, and psychological abuse that left a lasting scar. He titled the three sections of his autobiography *A Life of Power*, *A Life of No Power: 18 Years in the Institution*, and *A Life of Growing Power*. He closed his autobiography with the following words:

I wrote this story to let people know what it was like growing up in an institution from the 1950s through the 1970s. The total lack of power in making decisions about my life made me angry and I was treated as an outcast. I feel that what has happened to me should never happen again.

What Ray's story says to me is that the abuses of institutions were not simply about physical, emotional, or psychological abuse, but about the lack of dignity, respect, and power over one's life that are inherent in such contexts. It is, fundamentally, the same story that we told about Emma Wolverton's life.

Second, in 2000, I co-edited a text that was celebrating the 50th anniversary of The Arc of the United States.

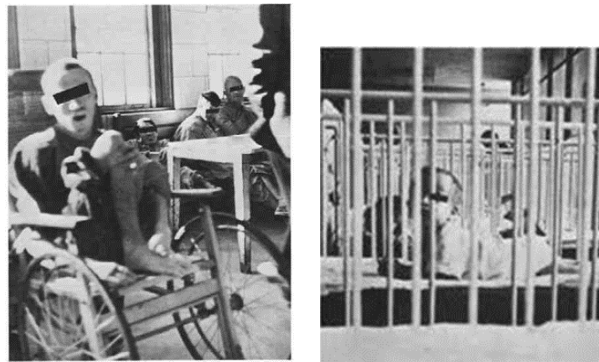
As that process wrapped up, I asked Dr. Gunnar Dybwad to write the epilogue for the book. Gunnar was an early director of The Arc, and with all due respect to those who followed him, probably the association's most important director.<sup>4</sup> Professor Dybwad agreed, though by that time, because of his health, he needed the support of his student and friend, Hank Bersani. I believe his epilogue in that book was the last published work by this pioneer in civil rights. He wrote:

I would like to present some thoughts from the viewpoint of an 89-year-old with 64 years of experience in the fields of human services and disability. Thus, I have a vivid memory of conditions that to most readers will only be historical facts that they have read. I saw firsthand the dismal conditions in the overcrowded institutions that originated in good intentions, to give asylum and protection, and quickly became warehouses to offer society protection from the so-called "mental defectives." I saw in the late 1930s overcrowding with all its dire consequences. The actual Holocaust story is kept alive because of a strong belief that this is necessary to prevent a repetition in years to come. Likewise, the institutional horrors must be kept alive by eyewitnesses, as it is in Burton Blatt's trailblazing *Christmas in Purgatory*, which he published at great risk to his professional reputation. It must not be forgotten, it cannot be erased from our professional history (Dybwad, 2000, p. 221).

Gunnar fled Hitler's Germany in 1934, so the horrors of the holocaust were not just an academic exercise to him, and when he drew parallels between the Nazi atrocities and the ways in which people with intellectual and developmental disabilities were treated through much of our history, we should understand that this is not just hyperbole. It is, Gunnar Dybwad is saying, a history of gross injustice and indignity.

Gunnar references one of the landmark publications contributing to the beginning of the end of the institutional era, *Christmas in Purgatory* by Burton Blatt and Fred Kaplan (1965). Blatt was an influential advocate who, at that time, was chair of the Department of Special Education at Boston University. In 1964, Blatt arranged to tour four institutions in the northeast United States, none of which were named but one of which was almost certainly Willowbrook, and brought with him photographer Fred Kaplan, who surreptitiously snapped photographs of the horrific conditions in the facilities. The resulting photoessay showed the stark, black and white photographs of naked, apparently starving, severely disabled inmates or rows of iron beds with children confined to them (Fig-

ures 17 and 18), juxtaposed with poetry verses and essays selected by Blatt.



**Figures 17 & 18:** Images from *Christmas in Purgatory*. Used by permission.

"There is hell on earth," began *Christmas in Purgatory*, "and in America there is a special inferno. We were visitors there during Christmas, 1965" (Blatt & Caplan, 1965, p. i).

*Christmas in Purgatory* was first released in limited distribution to parent leaders within the Association for Retarded Citizens, as it was then called. The parent movement was born out of the hope of post-World War II and the frustration of parents with the options they had for their son or daughter. The formation of the Association for Retarded Children in 1953 provided a national organization within which to create change. Parent advocates like Dr. Elizabeth Boggs and professional allies like Gunnar Dybwad and Burton Blatt began to work to change the status quo. Those efforts gained a powerful ally when, in 1960 President John F. Kennedy, with the urging of his sister, Eunice Kennedy Shriver, established the President's Panel on Mental Retardation, which included Elizabeth Boggs and Dr. George Tarjan, President of the association from 1959 to 1960. The panel issued 97 recommendations, many of which formed the basis for legislation and funding streams that benefit people with intellectual disability and their families to this day. Only weeks before his assassination, President Kennedy signed legislation (Figures 19 and 20) taking this nation's first steps toward a community-based system of supports that incorporated many of these recommendations.

When P.L. 94-142 was signed in 1975, it became the crown jewel of the parent movement. It was the efforts of parents and family members beginning in the 1950s, culminating in legislation resulting from court challenges like those that Tom Gilhool led, that created the special education system.



**Figure 19:** President John F. Kennedy gives Eunice Kennedy Shriver the pen he used to sign intellectual disability legislation in October, 1963. Photo from the collection of David Braddock, used with permission.



**Figure 20:** President Kennedy addresses the 13th Annual Convention Luncheon of the National Association for Retarded Children on October 24, 1963 at the Mayflower Hotel, Washington, DC. Photo from the author's collection.

## CHANGING PERSPECTIVES ON UNDERSTANDING DISABILITY

Which leads me to ask why, after more than a century of negative experiences with segregation and decades of advocacy by family members rebelling against the segregated systems of institutions, did the special education system immediately emerge as separate, mainly segregated system. I think the answer is twofold. First, there were special education classes in America dating from the early 1920s, and in all cases, those classes were segregated, so segregation was the only model that had ever been tried. All disability systems had been segregated up to that point, so why would schooling be any different? Second, and more importantly I think, is that it was consistent with how disability was (and, I would argue, mainly still is) understood. Disability has been understood within a model that was an extension of the medical model, which viewed health problems as an individual pathology: as a problem within the person. The person was seen as broken or atypical; as somehow outside the norm. Because this was the way disability had been understood in the 125 years prior to the passage of P.L. 94-142 and was still the way it was understood in the mid-1970s, the special education system rolled out based upon an implicit and largely unquestioned understanding that disability was a problem that resided within a child; that the intent of the education system was to fix that child; and that by separating children from their non-disabled peers and grouping them together, highly specialized services and equipment could be provided.

What we should have learned from our history is that when we segregate students, we tell them that they are different, which predictably results in segregation and discrimination. For all its advances and successes, the parent movement did not fundamentally change how disability itself was understood. It took another significant actor in the disability movement to begin to remove the barriers of low expectations and discrimination: people with disabilities themselves.

The third wave of the disability movement, beginning in the late 1970s and 1980s, was the self-advocacy movement. As civil protections, such as the ADA and IDEA, paved the way for greater community inclusion; as the community inclusion movement became a civil rights issue, championed by disability leaders like Ed Roberts, the father of the independently living movement, and Bengt Nirje (Figure 21), the originator of the normalization movement; there emerged a self-advocacy



**Figure 21:** Bengt Nirje. Photo from the author's collection.



**Figure 22:** Tia Nellis and Elizabeth Weintraub. Photo from the author's collection.



**Figure 23:** Nancy Ward. Photo from the author's collection.

movement, spearheaded by leaders like Bob Williams, Tia Nellis, Elizabeth Weintraub (Figure 22), and Nancy Ward (Figure 23), among others.

By the end of the 20<sup>th</sup> Century the patina of the medical model of disability began to lose its sheen. With legal antidiscrimination protections in place, people with disabilities became more and more a part of society; and as they held jobs, succeeded in education, and became contributing members of society, conceptualizations of people with disability as broken or diseased no longer made sense.

Thus, over the past three decades, medical conceptualizations of disability have begun to be replaced by models of disability that focus on the interaction between a person's capacities and the demands of the context in which they must function. In 2001, the World Health Organization introduced the International Classification of Functioning, Disability, and Health, or ICF, which conceptualized disability as a function of the interaction among and between a person's health and personal characteristics and factors and environmental and contextual factors, and the impact of such interaction on engagement in daily activities and participation in society.

These social-ecological or person-environment fit models conceptualize disability as residing not in the person, but in the gap between a person's capacities and the demands of the environments and contexts in which that person wants to live, learn, work, and play. Our challenge becomes to reduce that gap by providing supports that enable people to function successfully in typical contexts.

Changes to how we understand disability impact how we approach education. First, as noted, this is a strengths-based approach; we begin by talking about what people can do, rather than what they cannot do. Second, these person-environment fit models emphasize disability only within the context of typical human functioning (in typical contexts) and not as apart from the typical human experience. Third, by defining the disability as a function of the reciprocal interaction between the environment and the person's capacities, the focus of solving the 'problem' shifts from fixing a deficit within the person to the identification and design of supports to address the person's functioning within typical contexts. Fourth, there is an emphasis on the design of personalized supports, rather than homogenous programs. These supports include electronic and information technologies that are increasingly a part of all of our lives. And these models emphasize the inherent dignity of all people and there is a focus on autonomy and self-determination.

## SHIFTING TO A SUPPORTS PARADIGM

I will begin with the issue of designing supports instead of programs. Rather than basing services and systems on proxy measures of personal incompetence (IQ or adaptive behavior) and grouping people together based upon those measures, as has been the case for most of the history of disability services, these person-environment fit models emphasize the design of personalized supports that enable people to function successfully in typical activities that, in turn, enable them to fully participate in society. And by organizing systems around personalized supports, it becomes unnecessary to diagnose and label students, thus making the entire notion of disability unnecessary in designed educational systems and supports.

Supports are resources and strategies that enhance personal functioning (Thompson et al., 2009). More specifically, supports refer to “resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and that enhance individual functioning” (Luckasson et al., 2002, p. 151). Supports are, really, anything that enables a person to function successfully, participate in society, pursue meaningful goals, and live self-determined lives. We all use supports in our day-to-day lives, from smartphones to plan out a travel route to the internet to get information about a topic to calling a friend to ask advice. Education is an important form of supports and within education a myriad of supports are available that are effective in improving student learning (Thompson, Walker, Shogren, & Wehmeyer, 2018). Supports are personalized, although specific types of supports may benefit a wide array of students, with and without disabilities. Still, not every student requires or will benefit from every support, so it becomes important to assess what supports are needed and to incorporate planning for the use of supports into the educational planning process.

A group of us at the University of Kansas, led by Jim Thompson, have been engaged in efforts to develop and measure a person’s support needs as a means to determine what supports a person requires to function successfully. Instead of measuring personal incompetence, we have developed measures that provide information about the types and intensity of supports people need across typical domains (from employment to education to community living). Both the adult and children’s versions of the *Supports Intensity Scales* (Thompson et al., 2016; Thompson et al., 2015) have been adopted across the U.S. and internationally as one component of systems that focus on identifying supports to close the gap between what a person can do and what they want to do,

and to move such systems from a focus on diagnosis and classification of impairments to systems that look at the support needs of people, independent of type of disability or diagnosis.

## IMPLICATIONS FOR EDUCATION

Further, these person-environment fit models and their emphasis on supports have implications for how we design educational efforts and lead us to emphasize strengths-based approaches to educating learners with disabilities. Again, colleagues in the Department of Special Education and in the School of Education are at the forefront of efforts that apply these models to the education of learners with disabilities. These innovations, about which I will discuss individually subsequently, include Universal Design for Learning and the use of technology to promote student success; the implementation of schoolwide applications like Multitiered Systems of Supports; and the promotion of self-determined learning, student agency, and autonomy-supportive interventions. All of these take an approach consistent with person-environment fit models of disability by focusing on enhancing personal capacity, modifying the environment and the context, and providing supports.

## UNIVERSAL DESIGN FOR LEARNING

The principle of universal design emerged from the field of architecture and suggested, quite simply, that all buildings/built environments should be accessible to all people without the need for modification or adaptation. Buildings are designed with adequate ramps, wide doors, or accessible restrooms. These principles were subsequently applied to the design of curricular and instructional materials for students with disabilities. Orkwis and McLane (1998) defined UDL as “the design of instructional materials and activities that allows the learning goals to be achievable by individuals with wide differences in their abilities to see, hear, speak, move, read, write, understand English, attend, organize, engage, and remember” (p. 9).

I do not know too many students, with or without a disability, who are not described to some degree by this list! UDL is about the design of instructional materials, and is a form of supplementary aids and services. Such materials are designed in ways that allow all students to benefit from the material. If a student had difficulty reading or can’t read and is in a 6<sup>th</sup> grade language arts class where the rest of the class is reading one of the myriad of young adult novels taught in that grade, simply providing a copy of the print book will be of little use to

that student. But we can do things to how the content of that book is represented—say, provide it in digital format so the student can ‘read’ the book using a digital talking book—that ensures that the student can participate with other students in the class. Further, universally designed materials benefit a lot of students, not only students with disabilities.

Wehmeyer (2019) noted that the principles of UDL “align well with the elements of personalizable education:

... providing multiple means of engagement includes tapping into a student’s interests and preferences, optimizing student agency, and promoting student self-regulation and self-directed learning.

... providing for multiple means of representation refers to flexibility in how instructional materials and environments are designed to provide multiple means of content delivery, support understandings of how content interacts and relates and what the big ideas are, and to use multiple ways to present content (e.g., video, audio, digital, print, etc.).

...multiple means of action and expression refers to varying the ways students respond to content, express what they know, and promoting agency through goal setting and attainment (p. 58).

Work at the University of Kansas is providing innovative ways to apply these design principals to education and teacher training and to apply technology to supporting teachers and students (see, for example, <https://udl-irn.org/>). And, in talking about the application of technology to the education of learners with disabilities, researchers in KU’s Achievement and Assessment Institute are developing innovative assessments based on “learning maps” that utilize technology to enable teachers to assess literacy, math, and science skills of students with the most extensive cognitive support needs (Karvonen, Kingston, Wehmeyer, & Thompson, 2021).

### **SCHOOLWIDE APPLICATIONS**

These new models demand that we look at contexts and environments as equally important in educating learners with disabilities. As such, interventions that focus only on a student in a single classroom are being replaced by schoolwide interventions that consider students across and within educational learning contexts. Once more, researchers at the University of Kansas are leading in efforts to design and validate models referred to as multi-tiered systems of supports. Such models combine schoolwide efforts focusing on high quality interventions to promote positive mental health, behavior, and

achievement for all students, and then, for students who are not succeeding, changing the intensity and type of instruction and supports provided. Historically, if a student had difficulty mastering content, either because of mental health or behavioral issues or due to learning difficulties, too often what changed was where they were educated. Multi-tiered systems of supports flip that to be consistent with person-environment fit models. That is, what changes is the type, intensity, duration, or dosage of instruction. All students receive high quality, Tier 1 evidence-based interventions; students who need more support are provided Tier 2 and Tier 3 interventions. Again, the tiers refer to the type, intensity, and dosage of interventions, not students. There are multiple efforts among researchers in the Department of Special Education to develop and evaluate multi-tiered systems that address behavioral and achievement outcomes for students, including the SWIFT education center (<https://swiftschools.org/>) and the Comprehensive Integrated Three-Tiered Model of Prevention (Ci3T; <https://www.ci3t.org/>).

### **SELF-DETERMINATION AND STUDENT-DIRECTED LEARNING**

One manifesto of a strengths-based approach is that instruction focus on promoting self-determination. The work I have done for 30 years and that of a number of colleagues here at KU has focused on understanding and applying the self-determination construct to the education of learners with (and increasingly without) disabilities. Over those three decades, evidence has accumulated of the importance of enhanced self-determination to more positive school-related performance and transition-to-adulthood outcomes (Wehmeyer, Shogren, Little, & Lopez, 2017). Further, evidence-based interventions and assessments have been developed and implemented to enable teachers to promote student self-determination (Shogren & Wehmeyer, 2020). A focus on self-determination is important for both personalized learning and in the context of person-environment fit models and strengths-based approaches. In personalized learning, students will have to become owners of their own learning; they will need to be able to identify what they do well and what they are interested in and use problem-solving and goal setting skills along with this knowledge to chart their own path toward their future. In the fields of vocational and career guidance and counseling and, more recently, in the field of transition services within special education, professionals are increasingly adopting a life design approach, which emphasizes students designing and constructing their own careers and lives (Wehmeyer et al., 2019). Acting in a self-determined manner is central to these processes.



## CAUSAL AGENCY THEORY

Through an iterative process over the past three decades, we have developed and refined a theoretical framework that describes the development of self-determination across the life course and enables us to develop and evaluate interventions to enhance that development. The most recent iteration of this theory is Causal Agency Theory (Shogren et al., 2015), which was proposed to describe a model of the development of self-determination to facilitate the development and validation of educational interventions to promote self-determination (Wehmeyer et al., 2017). Causal Agency Theory defines self-determination as a “dispositional characteristic manifested as acting as the causal agent in one’s life” (Shogren et al., 2015, p. 258). Causal agents make or cause things to happen in their lives.

## AUTONOMY-SUPPORTIVE CLASSROOMS AND INSTRUCTION

In recent years, we have used Causal Agency Theory to align our intervention work to promote causal agency with research in motivational psychology on autonomy supports and classroom contexts so as to better understand how environments and contexts impact student motivation, learning, and self-determination (Wehmeyer & Shogren, 2016). In this case, autonomy refers to the degree to which students regulate their actions based upon their own deeply held values, preferences, and interests, not just how ‘independent’ they are (Wehmeyer & Zhao, 2020). Our particular contribution to such efforts since the mid-1990s has been on the development and evaluation of a model of teaching, the Self-Determined Learning Model of Instruction (SDLMI, Wehmeyer et al., 2000; Wehmeyer et al., 2012) to promote student self-regulated problem solving to set and attain goals and to promote autonomy and self-determination. Most models of teaching teach teachers to teach students. What we wanted to do when we developed the SDLMI was to develop a model of instruction that would teach teachers to teach students to teach themselves.

## EVIDENCE FOR IMPORTANCE OF SELF-DETERMINATION

Through our research, we have established a strong evidence base in support of the importance of enhanced self-determination for more positive school and post-school outcomes for youth with disabilities; on the efficacy of multiple interventions, but particularly on the SDLMI, to promote student goal attainment and self-determination; and on the positive benefit of efforts to pro-

mote self-determination on raising teacher expectations for students (Shogren & Wehmeyer, 2020). Most recently, the KU research team has focused research on using the SDLMI as a Tier 1 intervention in multi-tiered systems of supports to enable all learners, with and without disabilities, to become more self-determined (Shogren, Wehmeyer, & Lane, 2016). This has involved the development, validation, and implementation of a new online measure of self-determination normed with youth and young adults across disability categories and without disabilities (Shogren, Little et al., 2020).

This focus on all students leads to the final section of this paper, focusing on where I believe we need to go as we move forward in the 21<sup>st</sup> century.

## 21<sup>ST</sup> CENTURY EDUCATION

In the education of students with disabilities, we will have to respond to the same changes in the educational landscape as will all schools. The Partnership for 21st Century Learning, or P21 (<https://www.battelleforkids.org/networks/p21>), was established just after the turn of the century to examine and make recommendations for education in the 21st Century. A report issued by the coalition framed the issues as such:

“...education was built for an economy and a society that no longer exists. In the manufacturing and agrarian economies that existed 50 years ago, it was enough to master the “Three Rs” (reading, writing, and arithmetic). In the modern “flat world,” the “Three Rs” simply aren’t enough. If today’s students want to compete in this global society, however, they must also be proficient communicators, creators, critical thinkers, and collaborators (the “Four Cs”)

In *Deep Learning: Engage the World Change the World*, Michael Fullan, a thought leader in how education is transforming, and colleagues (Fullan, Quinn, & McEachen, 2018) argued that we need to cultivate rich learning environments for children that are driven by learner’s curiosity, teach students to be problem designers, pose problems in which students can be actively involved, and structure schools where learning is about taking risks and a lifelong venture. Note that Fullan and colleagues say that these rich learning environments are *driven* by student curiosity, not just ‘take advantage of’ student curiosity.

I have had the chance to collaborate with Yong Zhao, a foundations distinguished professor in the KU School of Education’s Department of Educational Leadership and Policy Studies, to think about how the work we’ve

done can align with and contribute to the kinds of changes that Fullan describes. In *Reach for Greatness: Personalizable Education for All Children* (Zhao, 2018), Yong makes a series of arguments that help us understand how we need to structure education for the 21st century for all learners.

First, Yong argues that the educational status quo is based upon two basic, but flawed assumptions: (1) “there is a set of skills and knowledge everyone must have in order to live a successful life in the world,” and (2) “all children are capable of and interested in acquiring the skills and knowledge at a similar pace” (p. 8). Think back to the P21 consortium’s argument that education was built for an economy and a society that no longer exists.

Instead, Yong pointed out that changes in society always redefine the value of knowledge and skills. Changes brought about by technology have made traditionally valued skills and knowledge obsolete, requiring the need to consider new human qualities; that understandings of human nature and learning suggest that human beings are differently talented, have different desires and interests, and have different experiences that interact with their natural talents and interests to give each person a unique profile of abilities and desires, stronger in some areas and weaker in others; and that in a world in which technology has and will continue to replace humans in routine tasks, we need human beings to be unique, creative, and entrepreneurial and an education system that helps every student become uniquely creative and entrepreneurial.

We, as a field, talk a lot about the importance of individualization. And yet, far too often, the educational programs that students with disabilities receive are based primarily upon their disability diagnosis and the low expectations associated with deficits models of disability (Wehmeyer, 2019). General education has not done much better: Zhao (2018) argued that “the education system rarely cares about children’s individual passions or talents” and emphasizes primarily the “talents” of being a good student, following rules, doing homework, getting good grades, and passing tests” (p. 17)

Zhao suggested that in the 21st Century, we can shed the burden of determining who will succeed and who will not, and we can embrace the idea that every student has their own unique profile of strengths and limitations and that when everyone is unique, there is no utility whatsoever to the notion of average. Every student can be great in their own way. Second, we can approach the education of all learners with the belief that all talents are worth developing and all passions worth pursuing.

Yong calls a personalizable education comprised of

four features: agency, shared ownership, flexibility, and value creation (Zhao, 2018). Agency emphasizes what Fullan and Zhao both discussed for 21st Century education, that “for students to explore, identify and enhance their strengths and follow their passions, they must become owners of their own learning . . . They must have agency in designing their own learning” (Zhao, 2018, p. 58). Shared Ownership emphasizes that students and adults (teachers, administrators, cafeteria workers, para-educators, etc.) are co-owners of what happens in the school. Flexibility is first and foremost a mindset that “believes in the value of change and that plans, no matter how carefully thought out, will always have unexpected disruptions and/or outcomes that require change” (Zhao, 2018, p. 64). Finally, value creation involves supporting students to harness their passions and strengths to create something of worth, something valuable to themselves and others, a process that makes learning meaningful and gives it purpose.

Everything I hear from leaders in 21<sup>st</sup> Century learning like Zhao and Fullan and others convinces me that the work we’ve done in self-determination is critical for all students, and that we move beyond special education by putting aside outdated systems based upon diagnoses and labels and provide every student the opportunity to have agency and shared ownership over their learning by becoming self-determined learners. And that represents what I see the next challenge in our own work. How do we move from student-directed learning to truly self-determined learning?

Some of the work I did with a colleague, Dennis Mithaug, on self-determined learning theory and, more recently, with Yong Zhao on teaching students to be self-determined learners provides at least a glimpse of what I think self-determined learning looks like:

- Teachers teach students to teach themselves.
- Students learn how to set and achieve goals and make plans.
- Teachers relinquish ownership for learning to the student by:
  - Creating learning communities that are autonomy supportive and using teaching methods that emphasize students’ curiosity and experiences;
  - Ensuring that learning is tied to activities that are intrinsically motivating or lead to the attainment of goals that are valued and based upon student preferences, interests, values.
- Teachers emphasize mastery experiences, using assessment (both teacher-directed and student-directed) to provide supportive feedback, and aligning instruction with students’ strengths and abilities.

- Teachers provide choice opportunities, supporting volition, and emphasizing the goal process and not just goal outcomes.
- Students take initiative in learning because learning is meaningful and of personal value to them.
- Students act volitionally because they are provided choices that are meaningful, meaningfully different, and autonomy-supportive (Wehmeyer & Zhao, 2020).

## CONCLUSION

My Ross and Marianna Beach Distinguished Professor of Special Education Inaugural Lecture ended with the above list of actions to promote self-determined learning, but that seemed an insufficient conclusion to this article. Instead, I want to return to where I began, with Tom Gilhool. Tom was a key player in writing P.L. 94-142. *PARC v. Commonwealth Pennsylvania* was, really, a trial balloon with regard to legislation to ensure a free, appropriate public education for students with disabilities. During the 1990s, as I have mentioned, I conducted research at The Arc of the United States. The Arc was founded in the early 1950s by pioneers in the parent movement like Elizabeth Boggs. While there, I had the privilege of getting to know parent and professional advocates like Elizabeth, Gunnar Dybwad, and Robert Guthrie (whose test for phenylketonuria significantly altered the life trajectory for many children), as well as pioneers in the self-advocacy movement like Bernard Carabello, Nancy Ward, Tia Nelis, and others. I also had the privilege of working with and getting to know professionals who authored P.L. 94-142 like Tom Gilhool, Alan Abeson, and KU's own, Rud Turnbull (Figure 24).



**Figure 24:** Rud Turnbull and Alan Abeson at Rud's retirement party. Photo from author's collection.

Alan Abeson had worked with Fred Weintraub at the Council for Exceptional Children when P.L. 94-142 was being written and the two co-authored the first textbook on the then-new federal law (Weintraub & Abeson, 1976), which I had used as a graduate student in special education in 1978. When I began at The Arc of the United States in 1990, Al Abeson was the executive director. I distinctly remember a conversation with Al in late 1997 or early 1998 concerning the reauthorization of IDEA. The 1997 reauthorization was particularly contentious because both branches of the federal legislature were controlled by an increasingly conservative Republican party led by House Speaker Newt Gingrich. At one point, President Bill Clinton shut the government down for two weeks, in part to keep the Republican majority from eliminating the U.S. Department of Education. IDEA was attacked by conservatives as just another unfunded mandate, and it was only because there were disability advocates on both sides of the aisle like Democratic Senators Ted Kennedy and Tom Harkins and Republican Senators Bob Dole and George Mitchell, that the bill passed. In reflecting on that reauthorization process, Al expressed frustration with the degree to which the IEP process had become a litigious, bureaucratic, and paperwork driven process, and about how little progress had been made in achieving the vision he and the other framers had for a quality, inclusive education system. He wondered, ultimately, if it had been the right thing to do.

I assured Al then and would do so now that P.L. 94-142 was the right thing to do. I personally saw young people who had never had access to education come to school for the first time. The law opened the door to literally thousands and thousands of students. It was a significant civil rights accomplishment. But 2022 is not 1975. Incrementalism as a policy to achieve inclusive education has failed (Slee, 2001; Wehmeyer & Kurth, 2021). By incrementalism, I refer to public policy processes of creating change through small, discrete steps, as opposed to large jumps. When I was with The Arc, we issued annual report cards on the education of students with intellectual disability in inclusive settings. These were based upon the OSEP annual reports. Over the decade I was at The Arc, the percent of students with intellectual disability educated in general education environments increased from 5% to 7%. In the twenty years since, it has increased to only 17%. In the book upon which much of my inaugural lecture was based, I tracked changes in the percentage of students with intellectual disability educated in regular education environments from 1992 to 2015 and calculated that there was an annual increase of 0.42% per year. If that continued, I wrote, it would take until the

year 2129 for students with intellectual disability to be included at even the rate of all students with disabilities (62.7%) at that point (Wehmeyer, 2019).

Efforts to reform education and to include students with disabilities have been incremental: a pilot project here, changes in the language in existing laws there, implementing a federally funded initiative via a large project, and so on and so forth. And, I believe, the actual changes in the daily lives for students and their families have been minimal.

The fact is that incrementalism has failed, and this is not the time for tinkering around the edges of education. The field itself is undergoing significant and lasting changes. The worldwide COVID pandemic has altered education in ways that we can't currently understand. It is time to go beyond special education. A supports paradigm allows us to abandon systems that diagnose, classify, and segregate. A strengths-based approach that emphasizes self-determined learning will be important to all learners if they are to succeed in the 21<sup>st</sup> century. I believe we have the knowledge and skills needed to dramatically reform education. I believe strengths-based approaches provide a blueprint for educating all learners. What remains is the will to do so.

I want to close with another story from a self-advocate who I had the privilege of getting to know during my time with The Arc, T.J. Monroe. T.J. was an early self-advocacy leader in Louisiana. In his important book on the self-advocacy and disability rights movement, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (1993), Joe Shapiro, who is now National Public Radio's disability reporter, told a story about T.J. leading a self-advocacy meetings. I have sat in on numerous self-advocacy meetings and they are, by and large, raucous events with lots of noise and activity. In other words, very difficult for a leader to govern. Shapiro related that T.J., having banged his gavel to no avail many times, finally shouted above the din that people needed to be quiet because they had a revolution to act on. What T.J. meant was that they had a resolution to vote on, but I always thought that T.J.'s malapropism was what really mattered. The self-advocacy movement was a revolution. We need a revolution in education.

#### ENDNOTES

1. <http://www.temple.edu/instituteondisabilities/voices/detail-Video.html?media=006-01>
2. <https://www.fordlibrarymuseum.gov/library/speeches/750707.htm>
3. <https://www.youtube.com/watch?v=bpVEjzO6Dd0>
4. See <https://mn.gov/mnddc/parallels2/one/dybwad-parents/rosemaryGunnar02.html> for an interview with Gunnar.

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