

Chapter Three Civil Rights and Social Justice



Figure 1 Ricky Wyatt (Martin, 2011)

The holocaust was inspired by eugenics social movements in the United Kingdom and United States that rationalized social controls governing marriage, reproduction, immigration and the institutionalization of people thought to be feebleminded. The eugenics movement lives on today and reveals itself in racist policies, practices and social actions affecting refugees, immigrants, people of color, those with disabilities, and others perceived as being different.

For some of us, the practices of eugenics seem so distant that they appear as insignificant events in our history. In our daily living, we see African American men hand in hand with Caucasian women, Asian women with Hispanic men, African American men with Caucasian men, Hispanic women with Asian women, and men and women with disabilities loving men and women with and without disabilities. Furthermore, these observations we make during our daily living do not alarm us as threats to the human species as they did others in the early twentieth century. Instead, they confirm our loving nature and that we all are created equal and live in a democracy where we are free to love and live with those we choose to love and live with.

For others of us, the eugenics movement of social control lives on as we seek to repudiate and deny others as having the same civil rights as ours. We see those different than us as a threat to our wellbeing and believe that through a divine appropriation, the riches of the world we live in belong to our particular race of people. Eugenics and racism expand during economic transitions where one race suffers financial setbacks and believes the conservation of their style of living is threatened by other races of people and those who appear to be different.

During these times of fear, some lash out, condemning anything and everything they suspect threatens their wellbeing. Victimization feeds on blame. We rationalize the way we treat those we are blaming and lose our sense of coherence with our social nature. If these social movements of racism, fear, hate and violence go unchecked, our fellow citizens lose their civil rights and liberties. This is what happened to those with developmental disabilities during the eugenics era in the early twentieth century.

We live in networks of networks of conversations uniting us in our collective social actions that I will call our social networks. Social networks are closed whenever the relations amongst those in the networks of conversations are hidden from those outside of the network of conversations. Abuse and neglect continue on within the family, while those being abused keep the secret from others outside the family. Some deny the holocaust ever happened. They keep the understanding of the mass genocide from their children and young adults, who, without an adequate understanding, may relive the horrors of their ancestors.

Social networks are open whenever the relations amongst those in the networks of conversations invite others outside the network to the conversation. Outsiders are welcome to join and contribute to a shared and common purpose, while conserving the social networks' openness. Emotions of love, happiness, joy, and feelings of excitement, optimism, and wellbeing expand both the number of people engaged in the network of conversations and the intensity of relational emotions that grow with time. Love expands intelligent action, conserves freedom, and generates wellbeing in our lives (Maturana & Bunnell, 1998).

By the 1960s, the social movement of eugenics was almost invisible, as if it had become a permanent, secret, weave in the cultural fabric of society. It wasn't secret because government was not transparent; it was secret because over decades of not seeing those separated from society in institutions, we lost them in our memories. If a brother or sister of a brother or sister held in a state hospital asked their parents about them, they were told to not ask about them again. As if their brotherhood or sisterhood never happened.

Large-scale social change in dictatorships occurs closed networks and in abrupt culture changes. It is founded in the cultural revolution brought forth by the tyrant; whereas, large-

scale social change in democracy occurs in open networks and is founded on the conservation and expansion of freedom. Large-scale social change in democracy is easy to underestimate. It is gentle and slow, emerging as a social movement of social caring for the wellbeing of oneself and others. It's easy to miss in the torrent of news of social ills and destruction. Thankfully, we need to look no farther than our daily living to find ourselves in relationships where we care about ourselves, our family, friends, coworkers, neighbors, and others we may not even know, regardless of their appearance or capabilities.

How do we do what we do when we are living well together?

When we do take the time to stop and reflect upon our daily living by asking, "*How do we do what we do in our network of conversations that conserves and expands living well together*", we find ourselves outside of eugenics theory and argument and in realizing how large-scale social change occurs in networks of conversations that bring forth grace, love, wellbeing, collaboration, and understanding.

Many are the moments that contributed to society's change from eugenics' horrors to community-based services and many are those who inspired others to contribute to the social change. Out of those many, I see Ricky Wyatt as one who activated the liberation movement of people with developmental disabilities, or, the aforementioned idiots, imbeciles, morons and feeble-minded. You've met Ricky before. At least his persona, Jimmy who barely lived at Eastern Oregon State Hospital and loved wild ponies.

I suppose both Ricky and Jimmy could be thought of as those feeble-minded who concerned Elizabeth Kite. They lived on the borderline with others who were not feeble-minded

but lived in much the same ways, making it difficult to tell them apart from “normal” people. I invented Jimmy as a fictitious character, but Ricky was a living, human being who sued Bryce Hospital in Alabama for its eugenics practices.

Ricky Wyatt – raising hell inside and outside Bryce Hospital

“Besides my mom and me, I have had 56 members of my immediate family who have worked here at Bryce between 1927 and 1982. Many of them were very close to me. My grandmother retired as the dietician of the Women’s Receiving Building. My Aunt Mildred, who was also my guardian and who helped me file the lawsuit, was a nurse’s aide. My cousin Jackie worked in the psychiatric department. Way back when, my great-great grandfather even made ice out here in the first ice house they ever had. A dozen of my aunts worked as nurses or aides or in food services. It’s like my whole family history is tied up here. I just never knew how tied up I myself would become with this place.”

“It’s really just a family tradition. I have more memories of family members coming here to pick up paychecks than I do of my time here as a patient. My mom played here and I did, too. What she liked to do and what we all liked to do was slide down the big banister inside the main building.” (Alabama Department of Mental Health, 2009)

Ricky was born in 1954 into poverty and hard living. This always seemed to be the case in the eugenics field work created by Elizabeth Kite. If you want to find those living on the mental

borderlines, start by befriending those living on the edge of society and documenting their social deviances.

“My mom was unable to take care of me because she got in trouble. We have always been close and we still are, but she just couldn’t be here for me when I was young. When my great-grandmother got too old to care for me I was taken in by my aunt, Mildred Rawlins.”

“I got in trouble and got sent away to the Industrial School in Birmingham. Eventually they sent me back to Tuscaloosa but I stayed in trouble and got sent away again. Nothing real bad, I was just a hell-raiser like a lot of young boys. I mean, I broke some windows or something. But anyway I got sent to the Methodist Children’s Home in Selma.” (Alabama Department of Mental Health, 2009)

Ricky didn’t stay in Selma long. After a brief meeting with his parole officer he was sent to Bryce Hospital in Tuscaloosa. Bryce opened in 1861 as the Alabama State Hospital for the Insane.

“I was good at sports, especially basketball. I could get in there and play with those older boys. That Methodist Home was a great place, looking back on it. I just didn’t realize it at the time. Unfortunately, I kept getting in trouble and they decided to let the state take me so I came back to Tuscaloosa. My Aunt Mildred already had her hands full so she decided the best thing she could do was to put me into Bryce.”

Ricky wasn't insane and he was not developmentally disabled. He was a troublemaker. Being locked up at Bryce was not the result of a scientific diagnosis but the social action of eugenics incarcerating Ricky and many like him. His poverty, family struggles and trouble making behaviors were the diagnosis leading to imprisonment in the institution his family had grown up with. Ricky was 14 years old when they locked him up at Bryce.

“I was the youngest person in there by far. I’d say the next person was maybe ten years older than I was. I never had a diagnosis or anything. I didn’t have mental illness. I was even a pretty good student. I was just a little wild and didn’t have much supervision.”

“I didn’t like it, but it wasn’t a totally new environment I mean, I’d been around here all my life and my family was still all around. But that first night in there with all those people I was scared to death. After a couple of weeks it got better and I wasn’t so scared.”

Because Ricky was not insane, he did not need therapy, and, because he was not developmentally disabled he did not need special education. What Bryce decided Ricky needed was Thorazine. Their hypothesis was that troublemakers make less trouble if they are sedated. Of course, this was “all for Ricky’s own good” (according to the theory).

“They just did it because it was simple and easy. That was the easiest way to take care of all those people, just zone them out on meds. But I was really young and I didn’t even have a diagnosis.

I knew what was happening and I at least had my family around. They would come see me and I always said the same thing to every one of them: 'Get me out of here!'"

Like Jimmy had at Eastern Oregon State Hospital, Ricky also witnessed the abuses of the "back" wards.

"The nurses and aides and sometimes even the supervisors would make people fight so they could bet on the winners. Or they might just lock us all up so they could have a good card game without being disturbed. To get us up in the morning they might come in there and poke us with a broom, or throw hot water on us. Of course to me the worst thing was that I knew there was nothing wrong with me. They couldn't tell; they just assumed I was sick. But I knew."

With help from his Aunt Mildred, Ricky made his case for being released from Bryce. He was placed into a perverse social conveyor belt moving his way "up" from ward to ward. Bryce was trying to quiet Ricky by distracting him by moving him to more and more pleasant wards, but Ricky held his ground and his grace shows in his understanding of the eugenics social institution and those who worked there as he looked back at the success of his lawsuit that became the Bill of Rights Act for people with developmental disabilities.

"I had a genuine feeling that these people, these patients who were basically helpless, were tortured in their minds and they still had to put up with these horrible conditions. I didn't know of course that it would turn into such a big thing. I just wanted relief for myself and for all these people I saw who needed relief."

“Bryce Hospital and the preservation of its grounds and buildings are important to me. This has all been a big part of my life. I grew up here. It hasn’t all been good. Being a patient here certainly wasn’t. But it’s my family heritage. It’s part of who I am.”

“This is about the patients I was here with and who were here before me. I want Bryce preserved and remembered for the patients who spent their lives here and all the people who worked their whole lives and retired here. The time that I was in here I didn’t care a thing about preserving that history.” (Alabama Department of Mental Health, 2009)

In 1970, the Alabama state legislature cut cigarette taxes that were used to fund mental health services, causing Bryce to layoff over 100 employees. Psychologists, social workers, nurses and physicians were among those who lost their jobs as even the appearance of ethical care and treatment disappeared. The University of Alabama Department of Psychology filed a federal lawsuit against the State and demanded reinstatement of those who had been laid off. Presiding over the lawsuit, federal Judge Frank Johnson ruled that Alabama’s Department of Mental Health and Mental Retardation had the authority to hire and fire who they pleased. However, Judge Johnson believed that there was a federal question concerning the minimum standard of treatment for people who were involuntarily committed to state institutions.

[Judge Frank Johnson- social justice and civil rights](#)

Frank Johnson was a veteran serving as an infantry lieutenant in Patton’s third army. He was shot during the invasion of Normandy and his surgeons left the bullet in him so he could

quickly return to the battlefield. After coming home from the war, he followed his passion for law and in the 1960s and 70s, Johnson's judicial decisions shaped the civil rights of Americans.

In 1956, Judge Johnson ruled that segregation of public transportation—brought to the nation's consciousness by Rosa Parks and Dr. Martin Luther King Jr—was unconstitutional. The Supreme Court upheld his ruling. When John Lewis and others were beaten in the Montgomery, Alabama, Greyhound Station without protection from the local police, Judge Johnson enjoined the police and the Ku Klux Klan from future actions against protesters. In 1961 and 1962, Johnson ruled against attempts to keep African Americans from voting. In 1963, Judge Johnson ruled in favor of statewide desegregation affecting all public agencies including education, libraries, and agriculture. When Governor George Wallace denied permission for Dr. Martin Luther King Jr's call for a march from Selma to Montgomery, Judge Johnson ruled that the road be open to the marchers. Days after the march, a young white woman was killed by the Ku Klux Klan. An all white jury acquitted the killers, but the federal courts prosecuted them under the Civil Rights Act of 1964 and they were found guilty. Judge Johnson gave the murderers the maximum sentence in 1965. In 1966, he ruled that the state of Alabama must let African Americans serve on juries.

Judge Johnson's decisions placed himself and his family in grave danger. He was a republican and his family had opposed the Ku Klux Klan for a hundred years. The Klan could not intimidate him or his family. When high school students burned a cross on Johnson's lawn, he recused himself from the case and advised the presiding judge, "Judge Rives, you ought to put those boys on probation. Don't send those high school students to the penitentiary. All they

were doing was implementing what they hear at their breakfast table.” A Klansman bombed Johnson’s mother’s house while she was upstairs, but the Johnson family refused to be intimidated. Johnson was appointed to become the director of the FBI but had to withdraw when it was found he had a life-threatening aneurysm. He was awarded the Presidential Medal of Freedom by President Clinton.

Judge Johnson issued an order in favor of Ricky Wyatt and the other plaintiffs, suing Bryce Hospital and the State of Alabama based on the right to treatment.

The patients at Bryce Hospital, for the most part, were involuntarily committed through noncriminal procedures and without the constitutional protections that are afforded defendants in criminal proceedings. When patients are so committed for treatment purposes they unquestionably have a constitutional right to receive such individual treatment as will give each of them a realistic opportunity to be cured or to improve his or her mental condition. (Johnson, 1971)

Morton Birnbaum – the right to treatment

Morton Birnbaum joined Ricky Wyatt’s law team and had a huge impact on Judge Johnson’s ruling. In the late 1950s, Birnbaum was a research fellow at the Department of Social Relations at Harvard and a postdoctoral fellow in the Training Program for Social Scientists in Medicine. In 1960 he published “The Right to Treatment” in the *American Bar Association Journal* (M. M. Birnbaum, 1960). Although Birnbaum believed “our society undoubtedly

recognizes the moral right to treatment” (M. M. Birnbaum, 1960), federal law did not recognize the right to treatment as a civil right of those involuntarily locked away in state run institutions housing people with presumed mental illness.

Birnbaum saw the implications of the absence of a right to treatment. States making the case for institutionalizing the mentally ill for care and treatment did not appropriate sufficient funds for the institutions to provide therapeutic care. This led to a human crisis. Because state legislators appropriated insufficient funds for institutions, what happened in state run institutions was decided upon by legislative fiat. Dr. Birnbaum was action oriented. He wrote that if the right to treatment was recognized and enforced, the standard of treatment in institutions would be raised.

Birnbaum made his claim for the right to treatment with reinforcing data. In 1958, 545,000 people were institutionalized in nonfederal institutions that only had the capacity for 520,000. Out of the 545,000, conditions were unacceptable for 85,000 due to fire and safety reasons. He cited findings from a University of Texas Sociology Department study of one state mental institution. The study showed that understaffing due to overcrowding resulted in custodial vs therapeutic care, thereby hindering proper treatment and planning for improvement, and placed the control of care in the hands of ward attendants instead of psychiatrists.

“The Right to Treatment” described an institutional system spinning out of control. Year by year, admissions increased, and year by year, state resources for care decreased. This led Birnbaum to his legal solution.

If the right to treatment were to be recognized, our substantive constitutional law would then include the concepts that if a person is involuntarily institutionalized in a mental institution because he is sufficiently mentally ill to require institutionalization for care and treatment, he needs, and is entitled to, adequate medical treatment; that being mentally ill is not a crime; that an institution that involuntarily institutionalizes the mentally ill without giving them adequate medical treatment for their mental illness is a mental prison and not a mental hospital; and, that substantive due process of law does not allow a mentally ill person who has committed no crime to be deprived of his liberty by indefinitely institutionalizing him in a mental prison. (M. M. Birnbaum, 1960)

Dr. Birnbaum invoked the United States Declaration of Independence by basing the right to treatment on the unalienable rights shared by all—the right to life, liberty, and the pursuit of happiness.

Dr. Birnbaum dropped out of high school and became a Navy veteran. After attending a night high school, he earned his law degree from Columbia University and his medical degree from New York Medical College. His daughter, Dr Rebecca Birnbaum described her father as a dreamer and a fighter, who sometimes seemed discouraged and isolated. His seminal article, “The Right to Treatment,” was rejected by 50 different publications. Little changed after its publication, so Birnbaum spent his own money litigating the right to treatment. In 1971, Dr. Birnbaum served as co-counsel for plaintiffs in a class action suit, *Wyatt v. Stickney*, brought about by 5,000 inmates of Bryce Hospital in Alabama. The case centered on inmate Ricky Wyatt’s right to treatment (R. M. Birnbaum, 2010).

Ira Dement and Jack Drake – investigative field workers

Ira Dement was a U.S. attorney who worked on Ricky's case and described the how Bryce had become an institution incarcerating people labelled as mentally ill.

“Anybody who was unwanted was put in Bryce. They had a geriatric ward where people like your and my parents and grandparents were just warehoused because their children did not care to take care of them in the outside world, and probate judges would admit them and commit them to Bryce on a phone call, on a letter from a physician saying that they could not take care of themselves. They were not mentally ill. Bryce had become a mere dumping ground for socially undesirables, for severely mentally ill, profoundly mentally ill people, and for geriatrics.”

There was one ward with nothing on it but old people. Beds were touching one another and they were simply warehoused. There was a cemetery in the back, but no records. Someone would die — they would merely dump them in an unmarked grave and that was the end of it and no accountability, supervision, no investigation to determine the cause of death — nothing.” (Alabama Disabilities Advocacy Program, 2004)

Jack Drake was also on Ricky's team and began investigating deaths at the Partlow institution also in Tuscaloosa. Partlow opened in 1923 as the Alabama Home for Mental Defectives.

“I remember one of the things I did before the hearing was to review the accidental deaths of people who died at Partlow for a two-year-period and the extreme examples

were residents who would get up in the middle of the night — go to one ward, maybe leave the door open and go into another ward, get into an unlocked medicine cabinet and eat the contents of 40 bottles and die.” (Alabama Disabilities Advocacy Program, 2004)

Four short years before I saw similar abuse and neglect at Eastern State Hospital in Washington, Drake discovered one resident who had been scalded to death and another who had been restrained in a straight jacket for nine years so he wouldn't suck his fingers. Drake discovered Partlow had no fire safety equipment and that the fire department could not be contacted after 5pm because the Partlow switchboard had shut down.

[March 1971 Judge Johnsons' ruling that the State of Alabama could not justify the absence of treatment at Bryce.](#)

There can be no legal (or moral) justification for the State of Alabama's failing to afford treatment and adequate treatment from a medical standpoint to the several thousand patients who have been civilly committed to Bryce's for treatment purposes. To deprive any citizen of his or her liberty upon the altruistic theory that the confinement is for humane therapeutic reasons and then fail to provide adequate treatment violates the very fundamentals of due process. (Johnson, 1972)

Representing the plaintiffs on Wyatt v Stickney, Ricky had won his case. In August of 1971 the plaintiffs requested that the plaintiff class be expanded to include those involuntarily

committed to Partlow State School and Hospital, originally named the Alabama Home for Mental Defectives.

This litigation originally pertained only to Alabama's mentally ill, but by motion to amend granted August 12, 1971, plaintiffs have expanded their class to include residents of Partlow State School and Hospital, a public institution located in Tuscaloosa, Alabama, designed to habilitate the mentally retarded. In their amended complaint, plaintiffs have alleged that Partlow is being operated in a constitutionally impermissible fashion and that, as a result, its residents are denied the right to adequate habilitation. (Johnson, 1971)

Alabama's position on those who at the time Judge Johnson referred to as mentally retarded, may have been argued along the eugenics logic that their heredity had rendered them without the capacity to learn if not for the psychologist, Murray Sidman.

[Murray Sidman- the advent of the scientist-practitioner](#)

Sidman is a behavioral psychologist, who received his PhD from Columbia University. He is a pioneer in the field of applied behavior analysis and served as a research scientist at Walter Reed Army Institute of Research and as director of the Behavioral Sciences Department at the EK Shriver Center for Mental Retardation and Developmental Disabilities. Sidman is a scientist-practitioner and introduced the notion of single-subject research in 1960 (M. Sidman, 1960). He believed that basic research could provide solutions to intractable problems and began applying B. F. Skinner's behavioral research at Walter E. Fernald State School and

Hospital, opening in 1887 as the Massachusetts School for the Feeble-Minded. Sidman described working with “boys” with severe behavioral deficiencies:

When we first became acquainted with them, they were lined up naked around a large bare room, unattended to except when they had to be cleaned up after urinating or defecating on the floor. (At that time, such a scene was common in state residential facilities for people with severe behavioral deficiencies. It was easier for the largely untrained staff to respond to emergencies than to take preventive measures.) When we started by providing candy as reinforcers, we quickly found that the boys were capable of much more behavior than they ever had displayed before. Within a few months we had them dressed, playing games, and taking part in various learning programs that we instituted. We accomplished much with just candy and food as reinforcers. (M. Sidman, 2011)

Sidman also described the feeling of wellbeing that arose from his teams discovery that repudiated the deductive theory of eugenics.

Our subject in this experiment was a severely retarded boy with whom we had been working for several years in the context of an intensive teaching project at the Walter E. Fernald State School. . . We had taught him step by step – agonizingly slowly – to dress himself, to feed himself, to make his bed, to help with chores, to draw simple figures with pencil and crayon, to name pictures, objects, and features of objects like colors, sizes, and quantities, and to speak some of his needs instead of using violence to draw our attention. We had not yet

been able to teach him to read with comprehension. In the experiment, it took us more than 15 hours of instruction over a four week period to teach him to match 20 spoken to printed three-letter words. And then, at the end of that month, we watched him suddenly matching the 20 printed words to pictures and vice versa without having been directly taught to do so.

During the final test session, the excitement in the laboratory was palpable. We were all outside the experimental cubicle, jumping up and down with glee as we watched correct choice after correct choice registering on the recorder. My son, who was helping in the lab that summer, said to me, “Dad, I never saw you lose your cool like that before.” Looking inside the cubicle through a one-way mirror, we could see Os Cresson, good lab technician that he was, sitting quietly behind the subject, hands folded in his lap, not moving – hardly breathing, saying nothing, only his eyes, wide open and unblinking, betraying his tension. But when the boy had completed the tests, Os could contain himself no longer. He grabbed the ... boy in a bear hug and cried out, “Goddammit, Kent, you can read!”

(Critchfield, Barnes-Holmes, & Dougher, 2018)

Between 1900 and 1975, social scientists and policy makers defended institutionalization of “mental defectives” by claiming they were beyond remediation. The statistics of intelligence were used to convince others that human intelligence was static and those with developmental delays could not learn basic skills. When Sidman and his colleagues realized that those with severe behavioral deficiencies could learn, eugenics suffered an irreversible setback. Any perceived link between science and the eugenics social movement was

broken when social scientists following Sidman began documenting new procedures for effective treatment. Once this evidence was available, the question of access to treatment and habilitation began to grow. If those with most serious developmental delays can learn, how can custodial care in institutions be defended?

Sidman was an innovator in the social and behavioral sciences. In a retrospective, he wrote that the behavior analyst should insist on data before endorsing any theory, treatment, or evaluation procedure. He also believed that the behavior analyst focused more on a criteria of reliability than of validity. His practice of inductive science became an alternative to the deductive theoretical approach used in eugenics and logic theory.

Sidman also questioned what many scientists had not become aware of. As was the case for eugenics, the laws for social and behavioral experimentation were left to philosophers and logisticians, “many of whom have never performed an experiment and would probably be horrified if they saw what experimental scientists actually do” (M. Sidman, 2002). He broke one of the cardinal rules set by those very philosophers—the separation of the observer from the observed. Sidman thought that good experimentation was a social process, a going back and forth through a continuing exchange between the subject and experimenter. He also wrote of the importance of experiment in the validation of social theories.

One must judge theories on grounds of parsimony (precision, neatness, and simplicity), coherence, and consistency in their explanations of existing data, and productivity in their predictions of phenomena that have not yet been observed (see Sidman, 1997. particularly pp. 138

Finally, a theory must be capable of disproof. The methodology of theory construction is just as demanding as is the methodology of experimentation. Further more, do not go into theory construction under the illusion that you can escape from the technological constraints of rigorous experimentation. Failure to attend to the subtleties of experimental methodology will make one unable to evaluate rigorously the data that must inevitably be produced to test any theory. (M. Sidman, 2009)

Sidman's simple demonstration proving that those abandoned in institutions could lean tipped the apple cart of eugenics. Treatment was proving to be effective, bringing into question the rights of those incarcerated in institutions.

Minimal Constitutional Standards for Adequate Habilitation of the Mentally Retarded

The State of Alabama was not responding to Judge Johnson's demands for reforming the management of Bryce and Partlow. In Appendix A of his decision on Wyatt v Stickney Johnson articulated the minimum constitutional standards for habilitation, or adequate treatment for people with developmental disabilities.

The ruling represented a significant societal shift by guaranteeing the right to treatment for those who had been denied their constitutional rights for almost a century.

1. Residents shall have a right to habilitation, including medical treatment, education and care, suited to their needs, regardless of age, degree of retardation or handicapping condition.

2. Each resident has a right to a habilitation program which will maximize his human abilities and enhance his ability to cope with his environment.
3. c. Residents shall have a right to the least restrictive conditions necessary to achieve the purposes of habilitation. To this end, the institution shall make every attempt to move residents from (1) more to less structured living; (2) larger to smaller facilities; (3) larger to smaller living units; (4) group to individual residence; (5) segregated from the community to integrated into the community living; (6) dependent to independent living.
4. No borderline or mildly mentally retarded person shall be a resident of the institution.
5. Residents shall have a right to receive suitable educational services regardless of chronological age, degree of retardation or accompanying disabilities or handicaps.
7. Prior to his admission to the institution, each resident shall have a comprehensive social, psychological, educational, and medical diagnosis and evaluation by appropriate specialists to determine if admission is appropriate.
8. Within 14 days of his admission to the institution, each resident shall have an evaluation by appropriate specialists for programming purposes.
9. Each resident shall have an individualized habilitation plan formulated by the institution. [Including:]
 - a. a statement of the nature of the specific limitations and specific needs of the resident;

- b. a description of intermediate and long-range habilitation goals with a projected timetable for their attainment;
- c. a statement of, and an explanation for, the plan of habilitation for achieving these intermediate and long-range goals;
- d. a statement of the least restrictive setting for habilitation necessary to achieve the habilitation goals of the resident;
- e. a specification of the professionals and other staff members who are responsible for the particular resident's attaining these habilitation goals;
- f. criteria for release to less restrictive settings for habilitation, including criteria for discharge and a projected date for discharge.

10. As part of his habilitation plan, each resident shall have an individualized post-institutionalization plan.

11. In the interests of continuity of care, one Qualified Mental Retardation Professional shall be responsible for supervising the implementation of the habilitation plan, integrating the various aspects of the habilitation program, and recording the resident's progress as measured by objective indicators.

12. The habilitation plan shall be continuously reviewed by the Qualified Mental Retardation Professional responsible for supervising the implementation of the plan and shall be modified if necessary.

13. In addition to habilitation for mental disorders, people confined at mental health institutions also are entitled to and shall receive appropriate treatment for physical illnesses such as tuberculosis.

14. Complete records for each resident shall be maintained and shall be readily available to Qualified Mental Retardation Professionals and to the resident care workers who are directly involved with the particular resident.

15. Residents shall have a right to dignity, privacy and humane care. (Johnson, 1972)

In this 1972 supplemental ruling, Judge Johnson also ordered that those in Partlow State School and Hospital had the right to worship, communicate with those outside of the institution, be free from unnecessary excessive medication, be free from medications used for punishment purposes, and be free from seclusion in locked rooms. He also prohibited electric shock treatment, physical restraint, mistreatment, abuse, and neglect. Finally, he ordered that those being held at Partlow had the right to exercise, spend time outdoors, receive nourishing, well-balanced diets, and to clothing and dental services (Johnson, 1972).

The Developmentally Disabled Assistance and Bill of Rights Act

At the time Judge Johnson wrote the supplement that prescribed treatment for those at Partlow, people with developmental disabilities had no rights. The eugenics social movement deduced they were less than human. Even still, a civil rights movement for them was building since Senator Robert Kennedy's tour in 1965 of Willowbrook State School in New York brought attention to the atrocities.

“I think that at the state institution for the mentally retarded, and I think that particularly at Willowbrook, we have a situation that borders on a snake pit, and that the children live in filth, that many of our fellow citizens are suffering tremendously because [of] lack of attention, lack of imagination, lack of adequate manpower.

There is very little future for these children, for those who are in these institutions. Both need a tremendous overhauling. I'm not saying that those who are the attendants there, or who run the institutions, are at fault—I think all of us are at fault and I think it's just long overdue that something be done about it. (Kennedy, 1965)

“This was my first real experience with news manipulation,” wrote Geraldo Rivera when he prolonged his daily coverage of Willowbrook so he could sustain maximum interest in his television special on the institution (Rivera, 1972). Burton Blatt, a Syracuse University professor of special education and rehabilitation, wrote of the influence of Robert Kennedy’s visit to Willowbrook in 1965 on his decision to tour five state institutions with a friend to photograph the institutions during the Christmas holidays. Two institution superintendents gave them access, and in 1974, they published their photo essay (Blatt & Kaplan, 1974).

On September 24, 1974, Judge Johnson’s supplemental order involving Partlow State School and Hospital became the blueprint for a national referendum on the rights of people with developmental disabilities in a senate report titled “Developmentally Disabled Assistance

and Bill of Rights Act” (J. Randolph, 1974). The report kept the atrocity of the eugenics social movement in the public spotlight with riveting testimony.

The institutionalized mentally retarded are the most neglected of all persons in our society. They have been subjected to ethical and legal abuses, with loss of rights, both civil and personal, frequently occurring without even a semblance of due process. Such abuses have recently been recognized by class action suits through the courts and some change can be expected. Some of the dehumanizing aspects result from gross inadequacies of institutional facilities, programs and personnel, and are not a necessary consequence of residential care.

The Senate report detailed conditions on the back wards of Partlow during mealtime.

Ground food was brought to the dayroom in a very large aluminum bowl along with nine metal plates and nine metal spoons. Nine working residents were sent in to feed these 54 young boys from this one bowl of food with nine plates and nine spoons. The feeding was accomplished in a total state of confusion. Since there was no accommodations to even sit down to eat, it was impossible to tell which residents had been fed and which had not been fed with this system. (J. Randolph, 1974)

The report went on to present the minimum constitutional standards for adequate treatment established by Judge Johnson’s 1972 Supplemental Order to *Wyatt v. Stickney*. It also

reflected Judge Johnson's matter-of-fact approach to evidence-based social justice, which in turn became evidence-based social caring. It began with formula grants to the states for planning, providing services, and operating facilities for people with developmental disabilities. This was an entirely different system than the eugenics system. It wasn't going to be a matter of changing parts of the eugenics social movement. It was a new social movement of liberation. This was the brilliance of Judge Johnson. His decisions were evidence-based and ethical. They were about establishing and improving social care for people who had been abandoned.

Evidence based evaluation

Evidence is evidence and it creates its own recursive learning cycles. These are circular evidence-based systems by design. Therein lies their brilliance. As a good example of this circularity is in the design of evaluation as a relationship between the federal and state governments and their mutual responsibilities.

The evaluation system linked the federal and state governments in an annual cycle of learning and continuous improvement. Federal and state governments both shared a responsibility for evaluating all of the states' plans. The Developmentally Disabled Assistance and Bill of Rights Act characterized evaluation as "1) assessing the effectiveness of an ongoing program in achieving its objectives, 2) relies on the principles of research design to distinguish a program's efforts from those of other forces working in a situation, and, 3) aims at program improvement through a modification of current operations" (J. Randolph, 1974).

The report warned against evaluation being a numbers game, only concerned with the number of people being served. It specified four simple outcomes related to evaluation, as relevant today as they were in 1974.

1. Who is being served, who is providing service, how is the program being carried out?
2. Are programs, or projects pursuing appropriate objectives or goals?
3. Do the programs and projects achieve or lead to beneficial results for the consumer?
4. Which of the available program alternatives is most effective and efficient? (J. Randolph, 1974).

Perhaps the simplicity of the evaluation system came out of the Committee on Labor and Public Welfare's concern "about the lack of adequate methods to evaluate services and service systems in a way which truly reflects the impact of such services in meeting the needs of developmentally disabled persons, and assesses the impact of such services on the developmental progress made by an individual in the ability to perform more complicated tasks and to develop the skills to live in a more normalized environment in society" (Randolph, 1974).

The keystone of the model evaluation system was the measurement of progress made by people with developmental disabilities. The law required person-centered *habilitation plans* that were developed after a service provider had collected baseline data on the individual needs and then established long- and short-term goals including measures of progress to care for those needs. Another brilliant design element of evaluation was to base agency

performance on the measured progress of every person with developmental disabilities being served.

It is the Committee's intent that the end result of the development of such a system shall be criteria on which to base the evaluation of the performance of an agency in delivering services to an individual, and that such criteria shall measure that performance of an agency on the basis of the progress made by an individual in mastering complicated tasks and developing the ability to live more normally in society. (Randolph, 1974)

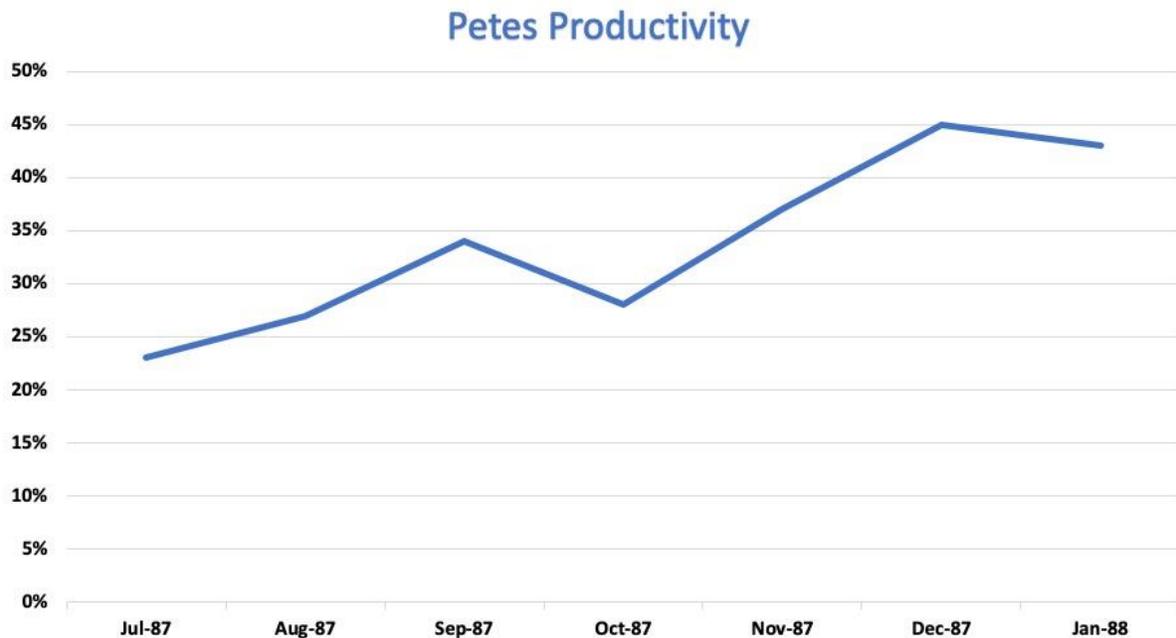
This was an early innovation of using continuous quality improvement in the domain of evaluating social impact. Data was continuously collected during the teaching or training process to measure effectiveness and efficiency. This was the data to be used to report progress at the person level, agency level, state level, and federal level and as Sidman pointed out – to contribute to the wellbeing of everyone involved. The entire evaluation system began with a simple learning cycle.

After evaluating the child, the teacher established a plan of care including goals and measures of progress. This was taught and data was collected on the child's response to the teaching. Every day the teacher examined the data and improved upon her teaching plans.

The Developmentally Disabled Assistance and Bill of Rights Act created a new system of social care with a person-centered approach to evaluation. Single subject research on positive behavior change was showing that a multiple baseline approach to evaluating social care was the most effective. It begins with a meeting between the student and the teacher. For those

most vulnerable and held in the back wards, the flow of the meeting moves in two directions. The teacher greets the student with love, respect, openness and optimism. After all the student may have a history of pain no one could really know. But, as the teacher greets them kindly and lovingly, the memory of intense physical and psychological pain might subside even for the briefest moment. The teacher explains in simple and age appropriate terms their responsibilities and how she would like to proceed to learn more about the student. This begins the second direction or flow. Now the teacher begins to collect data on the student's behavior. Do they move about independently? Is their language consensually coordinating social actions? Is their language conversational? How do they do what they do when they play? The teacher then commits to a plan to positively change painful behaviors into those of wellbeing, sets a target date for when this all will happen, and determines how she will measure the behavior to constantly improve wellbeing. In this way, the teacher is implementing the social care prescribed by the Developmentally Disabled Assistance and Bill of Rights Act (the Act).

The evaluation system was transformative. It was person centered, actionable, timely, valid, and accessible. Following Murray Sidman's approach, let's imagine a man who has been institutionalized most of his life. I'll call him Pete. The theory of eugenics justified Pete's institutionalization by claiming he could not lead a productive life. A community service provider has claimed that Pete can be a productive member of society. Maria, a teacher with the community service organization has established a goal that Pete's productivity would constantly improve from his baseline measure of 23%. The following is an evaluation of Pete's productivity during his first workweeks.



The trend line chart answers all four evaluation outcomes.

1. Who is being served (Pete) and by whom, Maria is self-evident.
2. Whether or not the objective is appropriate has been established between the teacher and the student.
3. Because Pete, usually with support from family and friends, agrees that productivity is beneficial, and because he is becoming healthier and happier, the trend line answers the question of whether or not the learning is beneficial.
4. Finally, the community's alternative social-care actions toward Pete's wellbeing can be compared because outcomes are transparent, open, and accessible to all.

When I said this evaluation system was brilliant, I understated its true brilliance. The whole arises from the loving social care captured in a single measure. The galaxy in a speck of dust frozen in time by a beam of pure light. Really, really brilliant. Data flowed from a single

instance and was aggregated as feedback for improving social care at all other levels of the interconnected system.

Ready for more brilliance? Got some.

University Affiliated Facilities – large scale systems change through inductive science

Under the Developmentally Disabled Assistance and Bill of Rights Act, the eugenics system of imprisonment, abuse and neglect had to be destroyed. With their civil rights now protected, the most vulnerable men, women, boys and girls needed *habilitation*. Habilitation was a new word to describe the processes that accomplished a manner of social caring that had never been accomplished before. *Rehabilitation* occurs when one regains a capacity they had before a traumatic event compromised their capacity. *Habilitation* is a process of social care that moves the most vulnerable closer and closer to a home of care and wellbeing. Practices of habilitation were discovered through inductive scientific practices and needed to be established and improvised on in order to be improved upon.

Having designed the evaluation system as a measure of continuous changes in wellbeing, the Act then funded University Affiliated Facilities (UAF) to do research leading to new discoveries in the caring for the most vulnerable people—those being held involuntarily whose lives were at risk in institutions. What made UAFs unique was because they weren't funded simply to publish research papers in peer-reviewed journals, but, to conduct research that could be used by communities to provide services for people who had not been served for generations.

Applying the circular evaluation processes to the UAF – a social learning system

The UAF conducted inductive behavioral research in positive behavior change experiments. The UAF functioned as a hub in the systems change network and connected to many communities by training and educating community service providers in new treatment practices. The community service providers collected person centered data and reported it to the UAF as an evaluation of the UAFs' efficacy.

Because the evaluation system was cyclic, with understanding wellbeing circulating through it, the relationship between the UAF and outlying communities became a system of continuous learning about societal transformation through liberation and love.

I was on either side of this beautiful system between 1976 and 1990 working as a community service provider and as a UAF researcher and in both cases, a scientist-practitioner.

The implementation of the Developmentally Disabled Assistance and Bill of Rights Act was an ethical movement led by a collective desire to liberate the most vulnerable, abandoned in the Holocaust-like system. It was a multiverse for me where very hard work, jubilation, policy making, and joyful, tearful, accountable, scientific happenings were spontaneously and congruently emerging.

I was among a new generation of young practitioner-scientists being mentored by young behavioral research scientists and cared for by those with wisdom in the communities we worked.

We were in the luminosity of the breaking dawn with young, open, and innocent minds. We had no theory and were guided by the accumulating evidence proving that the most

vulnerable could come home. We were making everything up and our competence more than made up for our deviances. We partied. We were having a blast.

Eugenics has it wrong. The young survive us all.

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Resources

[Biosphere, Homosphere and Robosphere.](#)

[Robert Kennedy Jr's visit to Willowbrook](#)

[Murray Sidman](#)

[Morton Birnbaum](#)

[Judge Frank Johnson](#)

[Wyatt v Stickney 1972 Supplement that includes Partlow School and State Hospital](#)

[Christmas in Purgatory](#)

[Developmentally Disabled and Bill of Rights Act 1974](#)

[Specialized Training Program](#)