

While we are looking ahead to a day when people with intellectual and developmental disabilities will all live the kind of lives they want to live – lives like yours and mine – we can get caught up in the belief that every decision we make is the right one. If we spend a moment to look back, we can see that not every decision was right or good, even though there were many at the time who believed it to be.

This is the story of the Kansas institutions for people with IDD. It is depressing, at times disturbing, at times contradictory.

Much of the information comes from published biennial reports to the Legislature – spanning 1881-1958 – along with newsletters of the State Department of Social Welfare from the State Library and the Kansas State Historical Society. I also relied on a 1965 article in the *Bulletin of the History of Medicine* written by Dean T. Collins, who trained as a psychiatrist at Menninger's and actually served as Acting Superintendent at Winfield for 3 months in 1962.

Please note there will be terms used that are, today, offensive. These terms are used in the historical context in which they occurred.





Rev. Greene believed the purpose of the institution was to try to educate the children living there. From the beginning, he struggled with the number of "custodial cases" sent to the asylum.



Goddard was a psychologist and eugenicist – more on that later. He avidly sought to apply Binet's intelligence testing to classify the feeble-minded.



Abandoned to Their Fate, published in 1994, is a very good history of American policy toward people with IDD from 1820-1920.



Lawrence legislators were lobbying for more money for KU and Haskell, and the new asylum was requiring more investment, as well. So, Cowley County legislators lobbied hard to move the asylum to Winfield.





## **Sin and Intellect**

"Mental retardation has a long association with sin and immorality. For most of the nineteenth century, the official view was that idiots were either the result of bad behavior (as by the parents), or the perpetrators of it."

> Philip M. Ferguson Abandoned to Their Fate



During this period of Kansas history, the serious opposition party for the Republicans, was not the Democratic Party, but Populists. The 1892 election resulted in Populist members of the Kansas House of Representatives locking themselves in the Kansas House Chamber. Republicans broke down the door.





Even by the time I worked in institutions, employees could still live on the grounds and there were separate staff dining rooms.





Keep in mind that in the early years, there was no objective screening process for admission to the asylum. County judges could order youth to be admitted and children were often abandoned on the doorstep. This meant that many youth in the asylum would not really meet the standard of IDD we have today, so there were always some very capable youth in the asylum.









Early reports from the two state insane asylums complained about the number of patients who had epilepsy, but no mental illness. Both these facilities were overcrowded, so this was a way to relive that overcrowding and provide care to epileptics – for whom there was no real treatment at the time.





This is the beginning of the end for the Asylum to serve only youth and opened the door to adult admissions.



This is a parlor at Parsons. Notice the throw pillows at various points in the room and at the corners of the pillars of the entrance. These were likely placed to help cushion the head when a patient fell to floor with a grand mal seizure.



In all, over 3,000 people were legally sterilized in Kansas. 58% were male. Over 2,000 were people reported to have some sort of mental illness. 856 were sterilized due to "mental deficiency."





Eugenics was a pseudo-scientific field launched by Sir Francis Galton, a famous statistician cousin of Charles Darwin. During the first 40 years of the 20<sup>th</sup> century, eugenics was very popular in the U.S. Much of the work of its proponents helped to influence Hitler and the Nazis. The concept of gassing the "unfit" came from an American eugenicist. The vasectomy was actually pioneered by a physician eugenics enthusiast who was looking for a better method than castration to sterilize "unfit" males.

Many famous Americans were, at one time, proponents of eugenics, including Theodore Roosevelt, Woodrow Wilson, Helen Keller, Charles Lindbergh, H. G. Wells, Alexander Graham Bell, and John Harvey Kellogg – of corn flakes fame.



Kansas also had a marriage law at the time that allowed for fines if someone married someone who was "unfit" – alcoholic, feeble-minded, insane, etc.

The new sterilization law removed the requirement for a judge to sign off on the sterilization order.









Fitter Families contests were created by Florence Sherborn, who was at KU at the time. The concept was used to teach eugenics and encourage fit families – who were examined and scored at these contests – to reproduce and "unfit" families not to.









To this day, most of the graves at the IDD state hospitals and the state mental health hospitals – whether still operational or closed – have only small markers with numbers and no names on them. An exception is Winfield, whose last chaplain worked very hard to locate and establish stone markers for as many graves as possible.







In the early days of these institutions, the families were believed to be to blame for their child's disability, so separating them from their child made sense to those who worked in the institutions.


I worked at Winfield State Hospital from 1983 to 1989. There were residents there at the time, who still spoke of low-grades. One woman, in particular, used to get upset and plead not to be "sent to the low-grades."







For many years, operating an institution at the lowest cost possible was a goal.

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There were double standards even when I worked at Larned State Hospital in the midseventies and Norton State Hospital in the early 1980's. There was a separate staff dining room and separate menus for staff and residents.





Most of these recommendations were not implemented.





From the beginning, these institutions illustrated the "If you build it, they will come" principle. Once there was a place to put people who were seen as needing care or as a drain on county resources, it quickly became over-crowded.

Superintendent Tune was to become infamous, following his ouster in 1951. Under his watch, residents had teeth pulled because they were biters, no meat was served to residents except a pork chop on Thanksgiving and fried chicken on Christmas. Masses of mail were unopened, there were blackjacks, whips, leg irons, and handcuffs found. A number of higher-functioning residents had built huts on the grounds to escape overcrowding in the dormitories. At this point, a psychiatric resident training at Menninger's was appointed as acting Superintendent.





Col. Smith's tenure saw many needed improvements, including his advocating for community and educational services for people with intellectual and developmental disabilities. Staff to resident ratios improved, but were still high.





Parsons began a decades-long association with the University of Kansas to do research at the institution, using the residents there, to try to improve treatment and training for people with IDD.

Although conditions had improved at Winfield, there were still units where residents who were very low-functioning were not provided any treatment or training opportunities.



The state acquired land from the VA hospital in Topeka, with some older buildings on it to create KNI. From its inception, KNI provided evaluation and treatment. It was also charged with performing research into causes and prevention. This function was never really realized.

In 1959, the Governor appointed an eight-member committee to study mental retardation. Two observations were noted by this committee—the need for better data about prevalence of mental retardation and the need for public education.





Norton served both TB patients and residents with IDD for about five years. Throughout its history, Norton would never accept direct admissions.



KC, Wichita, Winfield, Parsons, Topeka, Norton









In the sixties, we begin to see community options becoming more common, with a recognition that people with intellectual and developmental disabilities could be trained to perform self-care and other tasks. Certainly, President Kennedy raised awareness with his Presidential Commission on Mental Retardation and the story of his own sister, Rosemary.









Although the addition of ICF/MR to the Medicaid program was intended to help support people with mental retardation, in reality, it helped many states hang onto institutions and even enlarge them, by providing federal funding. The funding did improve conditions by requiring active treatment.



In the beginning, SRS had only 3 Commissions: Vocational Rehabilitation, Social Services, and Mental Health and Retardation Services. Within 6 months, the Children and Youth Commission was created.

By 1980, the national number of ICF/MR residents had grown to over 129,000 from the roughly 69,000 in 1975.

State Mental Retardation Hospitals Census												
	1930	1944	1952	1960	1963	1964	1965	1966	1967	1974	1983	
WSH	952	731	1,494	1,420	1,229	1,180	1,152	1,162	1,124	775	509	
PSH	731	1,006	853	653	681	678	685	739	750	424	281	
KNI				99	375	396	405	413	414	500	385	
NSH						29	61	65	131	260	152	
Total	1,683	1,737	2,347	2,172	2,285	2,283	2,303	2,379	2,419	1,959	1,31	

You can see the effects of increased community programs, an education mandate, and increased public awareness in the census reductions after 1967.



Prior to this, the federal government left it up to designated state staff to perform annual reviews of ICFs/MR. Sen. Lowell Weicker heard of some concerns about institutions in his home state of Connecticut; he held hearings on the matter which led to the federal Health Care Finance Agency (HCFA, now CMS) to begin performing these surveys, using HCFA staff.

In 1987, a paper published in the *Health Care Finance Review*, indicated that 15% of facilities that had one of these surveys had been notified of a possible termination of FFP.



During this period, the state also had several large private ICFs/MR and numerous small 6-15 bed ones. The advent of the HCBS/IDD waiver helped to close the large ones and convert many of the small ones to residential group homes.

The DD Reform Act re-named CMRCs to CDDOs, made the CDDOs the gatekeepers into the IDD system, and required person-centered planning.

State IDD Hospitals Total Census										
YEAR	1930	1944	1952	1963	1967	1974	1933	1988	1991	1998
TOTAL	1,683	1,737	2,347	2,285	2,419	1,959	1,317	1,149	990	407
								68		

The more than 50% reduction in census between 1991 and 1998 was primarily the result of the HCBS waiver and severely restricting admissions to the IDD institutions.



Unlike Norton, which was ordered closed by the Legislature, Winfield was selected for closure, along with Topeka State Hospital, by a specially appointed commission. The commission's recommendations were then accepted by the Legislature.





