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.
Acknowledgments

- Dean T. Collins
- Kansas State Library
- Kansas State Historical Society
- David Skinner
- Louann Gebhards
- Carol Arace
Political Beginnings

- 1881 – Major J.B. Abbott sponsors legislation to establish State Asylum for Idiotic and Imbecile Youth in Lawrence
- Only eleven other states had similar institutions
- Capacity set at 30
- Major Abbott’s daughter, Belle, is first patient
- Reverend H.M. Greene named first superintendent and repeatedly recommends name change to Kansas Institution for the Education of the Feeble-Minded

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.
Henry H. Goddard proposed classification system

- Feeble-minded: IQ of 50-70
- (Moron: IQ of 50-70)
- Imbecile: IQ of 25-50
- Idiot: IQ of less than 25

Goddard was a psychologist and eugenicist – more on that later. He avidly sought to apply Binet’s intelligence testing to classify the feeble-minded.
“With increasing vehemence and moral judgment, state officials in the nineteenth century viewed mentally retarded people as burdensome, dangerous, or both. Whether to protect them or restrain them, the reasoning went, idiots and imbeciles should be removed from society.”

Philip M. Ferguson

Abandoned to Their Fate

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

► 1887 – The Asylum and its inhabitants are moved just outside Winfield
► Governed by the Board of Trustees of State Charitable Institutions
► 1888 Rev. Greene “resigns,” but actually is fired by the Board for introducing dances to the Asylum inmates
► 1888 -1892 – Dr. C. K. Wiles is Superintendent and concerned about stamping out masturbation

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.
STATE ASYLUM FOR IDIOTIC AND IMbecile YOUTH.
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
Dealing with “Sin”

► 1892 – Dr. F. Hoyt Pilcher, a Populist, is named the third Superintendent
► Eleven boys are castrated that year
► Public furor arises – largely politically, rather than ethically, based
► 1894 – Pilcher replaced by Dr. C. S. Newlon

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.
Efficient Factories

- Facility self-contained:
  - Farm, including dairy cattle, hogs, etc.
  - Own electrical plant
  - Many staff lived on grounds
  - Own fire department
  - Own security

“(To this day, when a visitor travels to small towns where many...asylums were built, the simplest strategy for locating the facilities is to look for the smokestack towering over the landscape.)”

Philip M. Ferguson
Abandoned to Their Fate

Even by the time I worked in institutions, employees could still live on the grounds and there were separate staff dining rooms.
Many enlightened professionals in the field saw a responsibility to train asylum inmates; others saw this as a way to obtain free labor. Male students worked on the farm or at other chores around the institution. Female students were taught to sew, do laundry and perform housework. Higher functioning students cared for “low grades.”

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.
Political Change

- 1898 – An election results in the Board returning Dr. Pilcher to the Superintendent’s job
- He continues his castration policy and, in his biennial report to the Legislature, writes:
  “… forty-seven operations have been performed, a great majority of which operations were made at the special request of parents who had visited the institution and witnessed for themselves the good results arising therefrom.”
1900 – Another election and C. S. Newlon is returned to Superintendent.

His views of those in his care are expressed in his 1902 report to the Legislature:

“Very few live to a greater age than twenty-one – undoubtedly a providential provision. The blighted tree and injured fruit in like manner die early. ...Hard work in the open air prolongs life and keeps down the inherent viciousness.”
Another Institution

- 1903 – State Hospital for Epileptics established in Parsons
- Most patients come from the two state insane asylums at Topeka and Osawatomie
- Winfield transfers some, as well, to prevent its inmates imitating what they see when someone has a seizure

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.
More Changes

► 1905 – The Board of Trustees is replaced by a “non-political” Board of Control of the State Charitable institutions
► 1909 – Upper age limit of 15 for admission to Winfield is removed and institution is renamed State Home for the Feeble-Minded
► Dr. I. W. Clark advocates for higher salaries for attendants working at Winfield

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.
A Big Step Backward

- 1911 – Dr. F. C. Cave becomes superintendent and hires T. E. Hinshaw as his medical officer
- 1913 – Kansas passes a law to allow legal sterilizations to prevent “defective or feeble-minded children”
- 1916 – Dr. Cave reports that 75% of Winfield’s residents are unable to benefit from any schooling:
  “Trying to teach a feeble-minded child anything from books, and expecting him to retain sufficient amount of such knowledge for any practical purpose in life, seems to me about as discouraging a proposition and as fruitless of results as anything could be.”

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

1916 – Dr. T. E. Hinshaw, Medical Officer, begins a eugenics diatribe that will continue throughout his career:

“In view of the constantly increasing number of defectives, the insane, the feeble-minded and epileptic, it would seem timely to suggest, even to urge, that a campaign of publicity be carried forward … till the general public is sufficiently enlightened that it will favor the movement to render absolutely, by surgical means, the above-mentioned classes incapable of reproducing their kind.”

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 20th 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.
Growth – In Size and in Support for Eugenics

- The Hospital for Epileptics begins to become over-crowded
- 1917 – The State Board of Administration replaces the State Board of Control and will govern all charitable and educational institutions
- 1917 – New sterilization law passes that will remain on the books until 1965
- 1918 – The institution at Winfield receives three new buildings
- Winfield Superintendent Cave advocates for a law to sterilize all “defectives”; he sees them as a “menace”

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.
1920’s: Eugenics and Institutional Image

- 1920 – State Home for the Feeble-minded becomes the State Training School
- Fitter Families contests begin at Kansas State Free Fair
- In the 1920’s both the Winfield and Parsons institutions presented themselves as quality institutions – economically efficient, scientifically advanced, well-respected
  - Baseball teams
  - Bands
  - Award-winning livestock
  - Sterilizations continued

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.
Boys’ Band, School for Feeble-minded Youth.
Death and Murder

- From the beginning of these institutions, death was treated lightly
- Deceased residents were buried on campus with only a number to mark their grave
- 1922 – One patient murders three others who were sleeping at Parsons
- 1924 – Four patients attack and kill another Parsons patient

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.
MAIN BUILDING, STATE HOSPITAL FOR EPILEPTICS, PARSONS, KANS.
Families and Institutions

- Families were not encouraged to visit or correspond with their loved ones
- Superintendents were even rude to parents in their correspondence with them
- Supt. Cook wrote one parent:
  "I have repeatedly told you and I wish I could make you understand once and for all that you must not write letters to (the patient) in which I can find any encouragement for a parole. It seems to me, after being cautioned so many times, you would...decide that your efforts...would be futile."

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.
Both institutions used shame as a way to punish patients.

Supt. Cook boasted of making boys wear denim dresses and cutting girls’ hair very short, making them go barefoot and work with “low-grades”

His Medical Officer, T. E. Hinshaw wrote:

“It has been said that a feebleminded pretty girl is a dangerous member of society.”

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.”
State Hospital, Parsons, Kansas.
Economics of Institutions

- For about 70 years, institutions were expected to help pay much of their own costs through farm production.
- Winfield per diem costs:
  - 1915 - $0.43
  - 1948 - $0.82
  - 1958 - $4.00
  - 1981 - $67.36
  - 1991 - $226.00
  - 1997 - $312.00

For many years, operating an institution at the lowest cost possible was a goal.
Duplicate  AUG 3  1915  491

Received of Mrs. Anna Skvor  
Thirty-nine $39.00    00  Dollars
For Care and Maintenance of Carrie Skvor 
from 7-22-1915 to 10-22-1915

$39.00  

F.C. Cane, Agent  
By Nellie N. W. Steward.
Dietary Double Standard

- Meals prepared for staff at Parsons and Winfield were much better than those for residents—both in terms of quality and quantity.
- 1919 – Typical day’s menu for patients:
  - Breakfast: Stewed raisins, rolled oats, gravy, bread, coffee
  - Dinner: Bread, oleo, peas, and corn
  - Supper: Vegetable soup (tomatoes, peas, corn), bread, tea

There were double standards even when I worked at Larned State Hospital in the mid-seventies and Norton State Hospital in the early 1980’s. There was a separate staff dining room and separate menus for staff and residents.
A New Day?

1933 - Growing concerns about conditions in the institutions led to the creation of the Public Welfare Temporary Commission, which made several recommendations:

- Work training for patients
- Revision of the commitment practice
- Creation of a central psychological service
- A parole system at Winfield
- Abandonment of policy of low operating cost
- Development of special classes in public schools
- Reserving Winfield for custodial cases and creation of a new training school

Most of these recommendations were not implemented.
Overcrowding - Again

- 1937 – Winfield’s census is around 900
- 1944 – Census at Parsons reaches an all-time high – 1,006; Winfield’s drops to 731
- Also in 1944, Winfield gets a new Superintendent, L.C. Tune
  - His tenure results in no census reductions and horrible conditions for the residents
  - He also submits no biennial reports and ignores much correspondence from families
- 1947 – Division of Institutional Management, under the State Department of Social Welfare, replaces Board of Administration

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.
Bunk beds increase hazards of patient welfare.
Glimmers of Hope

1948 – Winfield’s per diem almost doubles from 1943
1952 – Winfield’s staffing ratio is 121 to 1,494
Winfield’s new Superintendent, Colonel John Smith, begins making changes:
- Improving residents’ diets
- Reaching out to the community
- Advocating for, and receiving, more staff
- Recommending working with teacher training programs to help them prepare to teach severely disabled children

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.
More Changes

- 1953 – State Hospital for Epileptics becomes Parsons State Training School
- It will become well known for research, including the use of electro-convulsive therapy and using Thorazine to control hyperactivity
- 1955 – Consultants from the Menninger Clinic survey the State Training School at Winfield
  - Conditions have improved since L.C. Tune’s time, but residents on custodial wards live in “snake pit” conditions

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.
More Changes (cont.)

- 1956 – State Training School at Winfield and Parsons State Training School become State Hospitals & Training Centers
- 1958 – Winfield discontinues its farm and dairy operations
- 1958 - The Parsons Research Project begins with a grant from the National Institute of Mental Health
- 1959 – Legislature authorizes creation of Kansas Neurological Institute
- 1960 – KNI officially opens and Parsons discontinues its farm and livestock operation

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.
Reducing Overcrowding

- Overall census of residents in the early 1950’s is almost 2,400 – in two institutions
- Opening KNI helped reduce census at Winfield, but not Parsons
- 1963 – State Sanitorium for Tuberculosis at Norton (established in 1913) authorized to serve residents from Parsons and Winfield in empty buildings
- 1967 – Census at all four institutions peaks 2,979
- 1968 – Remaining TB patients at Norton are transferred to Chanute; institution at Norton renamed Norton State Hospital

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.
National Changes

- 1971 – Medicaid funds authorized for intermediate care facilities for persons with mental retardation (ICF/MR)
  - Will slow de-institutionalization by allowing states to use funding to invest in bricks and mortar
- 1972 – First of many court rulings: Wyatt v. Stickney, concerning Partlow State School in Alabama; introduces concepts of “least restrictive environment” and habilitation
  - 70 court cases between 1971 and 1996

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.
State and National Changes

- 1973 – Kansas Department of Social and Rehabilitation Services created to replace Department of Social Welfare
- 1974 – Kansas begins spending state funds for community services
- 1975 – Education for all Handicapped Children Act passed
- 1981 - Congress passes legislation authorizing Home and Community Based Services (HCBS); takes effect in 1982
- 1982 – Kansas one of first states to apply for an HCBS waiver; Special Purpose Grants also initiated by SRS to support community services
- KNI becomes recognized as a Regional Resource Center

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

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

► 1985 – First of several federal “look-behind” surveys conducted at Winfield
  ❖ Institution given 5 days to correct serious protection from harm deficiencies
  ❖ Similar reviews, with different troubling findings, will occur again at Winfield and other institutions several times over the next five years

► 1988 – Legislature orders Norton State Hospital closed and buildings converted to a prison

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.
Re-focusing Efforts

- 1990 - New, separate HCBS waiver approved for people with IDD
- 1991 – Community Integration Project begins to bring people out of the three institutions
- 1992 – Legislature authorizes funding for Family Subsidy Program
- 1994 – Kansas Developmental Disability Reform Act passed
- 1997 – Nationally, almost twice as many people are served with HCBS as live in ICFs/MR

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.
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.
End of an Era

- 1998 – 117 years after it opened as the State Asylum for Idiotic and Imbecile Youth, Winfield State Hospital & Training Center closes
- 2018 – KNI and Parsons combined average census is just over 300
- 2018 – More than 9,000 people served on the HCBS/IDD waiver; more than 3,000 waiting for such services

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.
Questions?