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"To empower individuals with I/DD and their families to lead systems change, build capacity, and advocate for inclusive, integrated, accessible communities where everyone belongs and thrives."

**2021 SPECIAL COMMITTEE ON HOME AND COMMUNITY BASED SERVICES
INTELLECTUAL AND DEVELOPMENTAL DISABILITY WAIVER
October 21, 2021**

Chairman Hilderbrand and Members of the Committee,

Thank you for the opportunity to speak to you today. My name is Craig Knutson, Policy Analyst for the Kansas Council on Developmental Disabilities (KCDD). The Council is made up of self-advocates, family members, state agencies, and our partners identified in the Federal Developmental Disabilities Act.

Federal and state laws created the Council to advise policymakers on issues that impact people with disabilities and their families as well as carryout activities that increase Self-Advocacy, Systems Change, and Capacity Building.

Today we are gathered here to discuss the Waiting List for the I/DD Waiver services in Kansas. Kansas was once seen as a shining example of how to deliver state of the art, individualized, person centered supports and services. For a historical perspective on Kansas' leadership role in supporting Kansans and their families with I/DD, I would offer our Appendix 1: A Brief History of Supports and Services in Kansas, adapted from the Dec. 6, 2019 Becky Ross presentation at the Kansas Health Institute on the History of Kansas IDD Waiver Program.

If there is one thing I hope you take away from the Brief History of Supports and Services it is that Kansas has a rich tradition of creative solutions for the problems of the day. Today, we need to explore solutions to an evergrowing waiting list for supports and services for the I/DD and other waiver services. The Council, which was originally created to help states navigate solutions so that people with I/DD and their families can live more independently in the community proposes the following three step plan to reduce and ultimately eliminate the waiting list in Kansas:

- 1) We need to implement a comprehensive state wide study to better understand the needs of people who are currently on the waiting list and those who enter services because of crisis exception.
- 2) We need to expand our offerings of individual and family supports.
- 3) We need to build current systems capacity.



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Implementing a waiting list study

In order to implement effective, data driven interventions to reduce the waiting list, we need to first have reliable data on not only who is on the waiting list, but also what are the current needs of the Kansans who are waiting for supports and services.

A system for monitoring the needs of people on the Waiting List and understanding their current and future support needs is critical for the state to effectively serve people with intellectual and developmental disabilities. Particularly as people are on the waiting list for multiple years, and their needs change, sometimes extensively, during this time. The intent of this initial study and subsequent monitoring would be to enable the State to make data-driven decisions about effectively and efficiently serving people on the Waiting List, leading to better outcomes for Kansans with disabilities and their communities. We believe this would also assist us the State with implementing the Employment First law by identifying how many people with I/DD want to work, and the supports needed to do so.

This study can support the State to address two issues that can cause added costs and contribute to ineffective services for people: (1) the data can be used to better understand and predict people who will enter services through a crisis exception, and (2) CDDOs and MCOs will have robust information to plan for future services and respond to changes in people's needs.

A significant number of people are currently entering services because of a crisis exception, not because their spot came up on the waiting list. Examples of reasons a person may qualify for a crisis exception include: (1) an aging caregiver to a person with I/DD suddenly dies, (2) a person has a significant mental health condition that makes living with current caregivers impossible, or (3) a person's medical condition changes such that they need more support than caregivers or natural supports can provide. The Olmstead decision and its implementation in Kansas necessitates that community supports be engaged when a person who qualifies for the HCBS Waiver and is on a waiting list experiences a crisis exception.

Coming into the service system in crisis means providers must scramble to provide services without a clear understanding of the person's current needs. The number of crisis exemptions per year makes it difficult for the state of Kansas and its provider networks to effectively plan and mobilize to provide individualized supports when a person comes into the system. This creates risk for the person and great expense for the responding systems. Given the large number of people who come into the service system through crisis exceptions, this highlights the need to understand the support needs of people on the waiting list to promote better outcomes and a more efficient delivery of services. A better understanding of the needs of people on the waiting list would assist the State in delivering services people need before they reach crisis.

Further, a crisis for a person with I/DD does not just impact the I/DD provider system. Multiple other community health systems and other State and community resources are often impacted, including the foster care system.

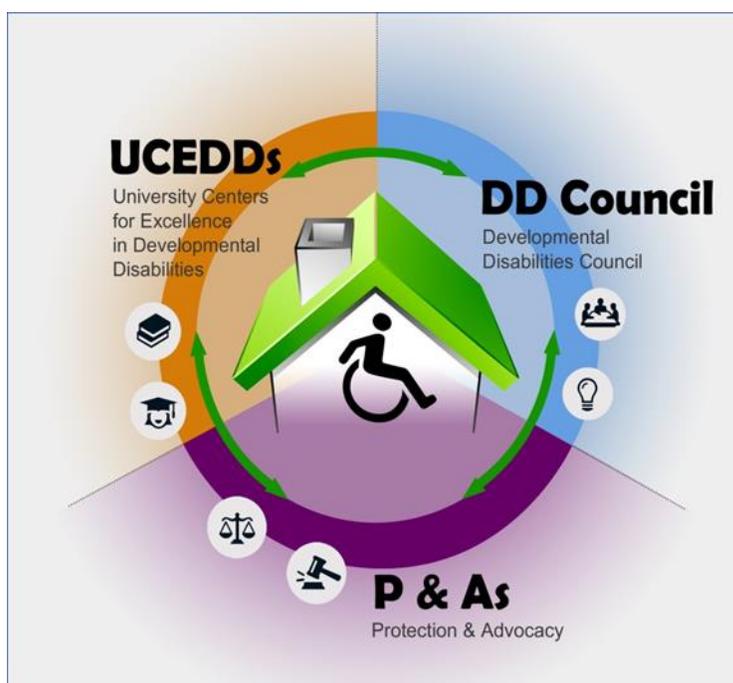


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Fortunately, Kansas has a natural and logical solution to conduct the waiting list study: the Kansas University Center for Excellence on Developmental Disabilities (UCEDD). UCEDDs were created by the same federal legislation as the DD Council, and like the Council, every state has a UCEDD. Whereas Councils were created to advise policymakers, empower advocacy, lead systems change, and build capacity, UCEDDs were created to serve as an interdisciplinary pre-service prep and continuing education, community training and technical assistance, model & demonstration services, research, evaluation, and information dissemination – to inform policy and community practice.

Below is a graphic explaining the relationship between the three IDD Network Partners (Councils, UCEDDs, and P&As) created by the DD Act.



When we have a greater understanding of people’s actual needs, we can better predict the service and support needs to prevent a crisis in the first place, and it will allow us to predict services needs at both a systemic and local/CDDO level so that appropriate services can be made available when needed.



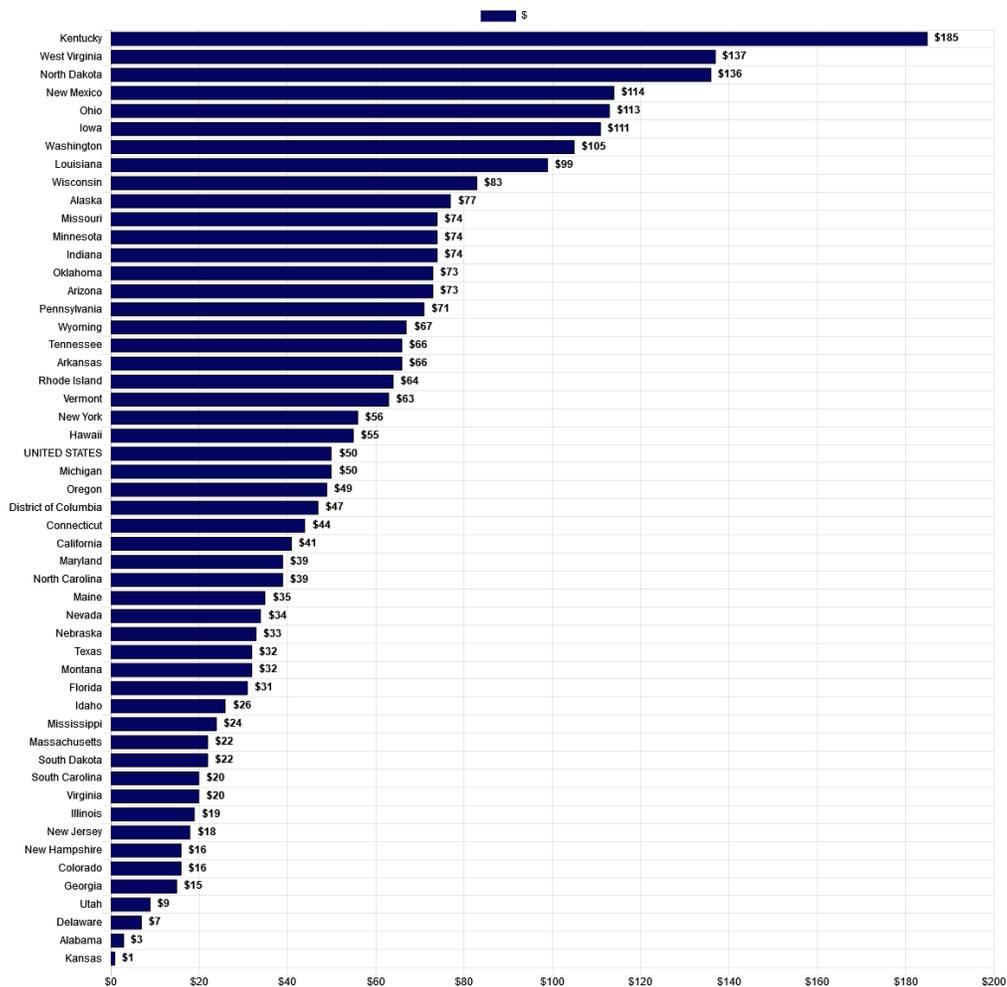
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Expanding our offering of individual and family supports

In order to impact the waiting list, we need to provide Kansans new and different options for supports and services; options that are person centered and focused on the family, options that are focused on independence and employment. Unfortunately, Kansas currently lags behind the rest of the nation in how much we invest in individual and family support spending per capita (please refer to IDD Comparison Chart #1). Kansas spends 1/50th of the national average on individual and family supports. Alabama, the second worst state in the nation, spends three times as much per capita as Kansas on individual and family supports.

INDIVIDUAL AND FAMILY SUPPORT SPENDING PER CAPITA (CITIZEN OF GENERAL POPULATION): 2017





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What constitutes individual and family supports, and why is it important in our conversations about the waiting list? Individual and family supports comprise three basic types of supports and services:

- 1) Supported living and Personal Assistance; this is supports for housing in which individual choose where and with whom they live, in which ownership is by someone other than the support provider (such as the individual, family, landlord or a housing cooperative), and in which the individual has a personalized support plan.
- 2) Supported Employment; these are individualized job placements and I/DD state agency financed programs for long-term employment supports, with the goal of developing independent work skills and maintaining competitive employment alongside co-workers without disabilities.
- 3) Family Support; this is support for children and adults with I/DD living in the family home.

Time and again we have families that come before the Bob Bethell KanCare Oversight Committee and testify that they don't feel supported by the state. Unfortunately, their stories are not isolated incidents, but are reflective of the fact, as a state, we simply do not support families of people with disabilities. In order to meet the needs of Kansas families we need to invest in a Family Supports and/or Community Supports waiver that allows individuals and their families to access supports and services that meet their individual needs—needs that may not be covered by the current IDD waiver.

We also need to make sure that Kansans with IDD have access to Supported Employment supports and services. If a person attains competitive, integrated employment, they become more independent and less reliant on more costly comprehensive supports and services. Unfortunately, as the national data shows, Kansas hasn't made competitive, integrated employment a priority—despite the fact that Kansas was the first state in the nation to enact Employment First legislation. It is time for Kansas to turn the dream of employment into reality for people with disabilities.

Supported employment supports is the one service that people on the waiting list can access if they gain competitive, integrated employment while on the waiting list. Unfortunately, there is a lack of providers to provide those supports because Kansas has the lowest reimbursement rate for supported employment in the nation.

Kansas, being the solution focused state that it is, has taken measures to increase competitive, integrated employment opportunities through the implementation of the Supports and Training for Employing People Successfully (STEPS) program. The STEPS program provides employment and independent living supports, enabling them to increase their income while gradually decreasing their reliance on Social Security and other public benefits.



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STEPS is a pilot program that launched July 1 and is facilitated by a Community Services Coordinator who helps participants prepare for employment, increase independence, receive and maintain health care coverage, and provide on-going supports to help maintain employment. STEPS services are provided by community agencies with the experience to successfully support people with disabilities to reach and maintain their employment goals. The program is scheduled to run through 2023 and if successful, may be extended. It should be noted that the STEPS program was initially proposed in the KCDD Roadmap to Employment.

We need to make sure that individuals on the waiting list and their families are aware of the STEPS program and potential opportunities for ongoing supported employment supports as well as many untapped community and natural resources. KCDD advocates for the creation and implementation of a statewide Waiting List Navigator position to help individuals and families connect with resources to help prevent potential crisis situations while people wait for services.

Building Current Systems Capacity

I think it is important to point out that our network of service providers do an outstanding job of supporting people with IDD within the confines in which they are allowed to operate under the waiver. Many providers have been very creative in the types of services and supports they offer, and there are many pockets of excellence. There are providers who are looking to shut down their sheltered workshops and ensure that their consumers have opportunities for competitive, integrated employment, and there are providers who are exploring how enabling technology can foster independence for their consumers while at the same time offer opportunities for reallocation of their workforce to meet individual needs, for example.

While there are areas of innovation, we need to make it easier for the provider network to offer more individualized supports and services—this means allowing providers-and potentially families and individuals- to bill for services that are not allowed under the current IDD waiver. This is why we need a Family Supports/Community Supports waiver.

We need to make sure that this new waiver, and current waiver services are adequately funded. The current IDD waiver services are in desperate need of increased funding, and we need to ensure that wages for direct support professionals are commensurate with the duties they perform and competitive with the current job market. If we can't find enough workers for the people who are already on the waiver, how can we expect to find enough workers to provide the types of supports and services the 4,500 Kansans on the waiting list need?

If we don't act now, the waiting list will continue to grow. It is time we embrace our history as a solutions oriented state as we tackle this complex problem.



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Thank you for the opportunity to speak to you today. I will be open to questions at the appropriate time.

Respectfully,

Craig Knutson
Policy Analyst
Kansas Council on Developmental Disabilities

Attached: Appendix 1: A Brief History of Supports and Services in Kansas



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Appendix 1: A Brief History of Supports and Services in Kansas

Kansas Milestones

- 1881
 - Major J.B. Abbott sponsors legislation to establish State Asylum for Idiotic and Imbecile Youth in Lawrence
 - Only provided services to youth up to age 15
 - Only 11 other states had similar institutions
- 1887
 - The Asylum and its inhabitants were moved just outside of Winfield
 - Later named the Winfield State Hospital & Training Center
- 1903
 - State Hospital for Epileptics established in Parsons
 - Later named Parsons State Hospital & Training Center
- 1909
 - Upper age limit of 15 for admission to Winfield is removed which began the end to serve only youth and opened the door to adult admissions
- 1913
 - Kanas passes a law to allow legal sterilizations to prevent “defective or feeble-minded children”
 - 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.”
- 1958
 - Local family driven groups begin to organize and provide places for their children to have group activities.
- 1959
 - Legislature authorizes creation of Kansas Neurological Institute (KNI)
- 1960
 - KNI officially opens
 - From its inception, KNI provided evaluation and treatment. It was also charged with performing research in to causes and prevention. This function was never really realized.
- 1963
 - State Sanitorium for Tuberculosis at Norton (established in 1913) authorized to serve residents from Parsons and Winfield
- 1967
 - Census at all four institutions peaks at 2,979



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- **1968**
 - Remaining TB patients at Norton are transferred to Chanute; institution at Norton renamed Norton State Hospital
 - Kansas has 21 boarding homes, two private children's institutions, and nine adult day training programs
 - **Kansas mandates Special Education of children with mental retardation SEVEN years before federal law**
- **1970**
 - **County mill levy authorized to fund community mental retardation services**
 - KNI begins wheelchair modification program
- **1971**
 - Medicaid funds authorized for intermediate care facilities for persons with mental retardation (ICF/MR). 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 on to institutions and even enlarge them, by providing federal funding. The funding did improve conditions by requiring active treatment.
- **1974**
 - **Kansas begins spending state funds for community services**
- **1975**
 - State implements Title XX Program of the Social Security Act
 - **Social Services Block Grant (SSBG)**
 - A capped entitlement program. Thus, States are entitled to their share, according to a formula, of a nationwide funding ceiling or "cap," which is specified in statute. Block grant funds are given to States to help them achieve a wide range of social policy goals, which include:
 - Preventing child abuse;
 - Increasing the availability of child care;
 - **Providing community-based care for the elderly and disabled**
- **1978**
 - Licensing and Certification Standards – The recognition of abuse and neglect in institutions and community settings lead to increased regulation of service settings. First attempts to professionalize the caregivers and creating what we now know are the provider network.



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- 1981
 - Congress passes legislation authorizing Home and Community Based Services (HCBS); takes effect in 1982
- **1982**
 - **Kansas was one of the first states to apply for an HCBS waiver; Special Purpose Grants also initiated by SRS to support community services**
- **1984**
 - First year HCBS funds were used in Kansas
 - KARF establishes a **taskforce on Supported Employment Program (SEP)**
- 1988
 - Legislature orders Norton State Hospital closed
- **1990**
 - **ADA and HCBS expansion waiting list eliminated**
 - **New, separate HCBS waiver approved for people with I/DD**
- 1991
 - Community Integration Project begins to bring people out of the three Kansas institutions
- **1992**
 - **Legislature authorizes funding for Family Subsidy Program**
 - **Direct financial subsidy payments are made to the family as a reimbursement for the additional expenses associated with supporting a child who has a disability in the home**
- **1994**
 - **Kansas Developmental Disability Reform Act passed**
 - Established CDDO's the gatekeeper in to the I/DD system, and required person-centered planning
- **1998**
 - Winfield State Hospital closed
 - **DD waiting list was effectively zero**
 - More than 50% reduction in Kansas ICF/MR census between 1991 and 1998 was primarily the result of the HCBS waiver and severely restricting admissions to the I/DD institutions
- **2004**
 - **Waiting list was 515**
- **2010**
 - **Waiting list was more than 3,000**
- **2018**
 - KNI and Parsons combined average census is just over 300
 - More than 9,000 people are served on the HCBS/IDD waiver
 - **Waiting list average 3,735**
- **2021**
 - More than 9,000 people are served on the HCBS/IDD waiver
 - **Waiting list is more than 4,500**