

MARCH 2021

COMPLEX NEEDS WORK GROUP REPORT

*Kansas Department for Aging and Disability Services
&
Community Developmental Disability Organizations*

PREPARED BY:

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Developmental
Disability Organization

WORK GROUP OVERVIEW

The KDADS/CDDO Complex Needs Work Group was created in compliance with the SFY'20 Participating CDDO Agreement in section X. "Statewide Group Meetings, Business Meetings and Stakeholder Meetings". Specifically subsection, A. "Statewide Group Meetings," item 1. e. "Complex Needs" defined the work group's tasks as "CDDOs and KDADS will work in partnership to address system challenges including but not limited to gaps in services and supports to individuals experiencing co-occurring IDD and behavioral health needs or interfering behavior creating barriers to successful community integration" (pg. 19). Russell Bowles, KDADS ICF-IDD Program Manager and Dee E. Nighswonger, Director for the Sedgwick County Developmental Disability Organization were appointed to be co-chairs of this new work group.

Work group members began meeting on September 25, 2019. The work of the group occurred through face-to-face meetings in Wichita and virtual meeting platforms consistently throughout 2020 culminating in this report offered for consideration by KDADS leadership, all CDDO's and system stakeholders. The work group created a charter, developed a shared purpose, completed a gap analysis with significant stakeholder input, reviewed existing research studies and reports, identified strategic focus areas and recommended strategies for progress. What is clear from the work undertaken by this group, the challenges are significant, adaptive and imperative to address with a strategic, comprehensive and consistent approach. The current system of services inadequately meets the needs for persons with intellectual/developmental disabilities and co-occurring behavioral health conditions, trauma and significant complex needs or behavior that interferes with quality of life and full community inclusion.

The work group committed to the following shared purpose: “Members of the work group will strive to develop strategies that promote effective collaboration among systems; proactively eliminate gaps in services and achieve attainable outcomes for people with IDD.”

Through a comprehensive and in-depth gap analysis the following Keys for Change were identified and became foundational to the group’s work:

- Training and education
- Workforce shortages
- Access to behavioral health services
- Access to crisis services
- Services between institutional care and community based supports
- Provider rates

The work group believes these Keys for Change align with the KDADS long-term and short-term strategic goals.

KDADS Long-Term Goals for 2020-2024:

- Revitalize self-direction offerings/Support self-direction and self-determination through programming and policies.
- Improve workforce development across the state.
- Movement toward data-informed continuous quality improvement.
- Adopt strategic prevention framework.



KDADS' SHORT TERM GOALS (2020-2022)

- Identify and address gaps in the continuum of care for children and adults
- Redefine the role of state hospitals-provide education, build trust, serves as a resource for communities
- Adopt strategic prevention framework

KDADS/CDDO COMPLEX NEEDS WORK GROUP'S KEYS FOR CHANGE

- Access to behavioral health services
- Access to crisis services
- Services between institutional care and community based supports

- Work with partners to provide staff training and capacity building
- Assess current service delivery workforce status
- Value direct care providers more highly
- Partner with community colleges/secondary educational institutions to recruit and develop workforce

- Workforce shortages
- Training/education for staff and stakeholders
- Provider rates/increased wages

- Develop meaningful measurement metrics, then identify data to support them
- Inventory current data collection resources
- Take advantage of opportunities to capture new data
- Establish targets for key measures

- Workforce shortages
- Training/education for staff and stakeholders
- Provider rates/increased wages
- Access to behavioral health services
- Access to crisis services
- Services between institutional care and community based supports

- Strengthen discharge planning process and implement prevention strategies into the discharge planning method
- Pilot the sequential intercept model with a targeted population; potentially with the populations of KDADS consumers interfacing with the criminal justice system

- Access to behavioral health services
- Access to crisis services
- Services between institutional care and community based supports

UNDERSTANDING THE CHALLENGES FROM THE NATIONAL PERSPECTIVE

Members of the work group reviewed a number of resources to inform our collective understanding of the needs and challenges facing the population. Those resources are referenced at the end of this document. What follows are the highlights of what we learned.

In the wake of the COVID-19 pandemic and related economic crisis and longstanding racial ethnic inequalities, a committee of state Medicaid executives and behavioral health experts met to provide a framework for addressing the growing crisis facing our communities due to increasing demands for access to appropriate behavioral health services. The framework developed by this group recognizes the unique needs of those with IDD and offers strategies and action items to better address current unmet needs. Kansas's very own, Melissa Warfield, Director of Policy Research for KDHE's Division of Health Care Finance participated in the development of this report. The report acknowledges that those with IDD are 10% more likely than the general population to have a co-occurring mental health condition.

STRATEGIC OPTIONS	ACTION ITEMS
Understand the needs of the population	<ul style="list-style-type: none">• Leverage data from providers, plans, and other state agencies• Engage stakeholders to identify challenges and potential solutions
Ensure primary supports for stability	<ul style="list-style-type: none">• Enhance direct care workforce capacity• Expand respite care coverage• Enhance case management• Engage stakeholders to identify challenges and potential solutions
Enhance behavioral health treatment for individuals with ID/DD	<ul style="list-style-type: none">• Incentivize collaboration between ID/DD and behavioral health providers• Support specialized crisis services that can be tailored to those with ID/DD• Engage stakeholders to identify challenges and potential solutions

The NADD, an association for persons with dual diagnosis, has consistently estimated that approximately 1/3 of individuals with IDD also have a qualifying mental health diagnosis. Local research in Sedgwick County identified that 45% of their IDD program eligible individuals have one or more co-occurring conditions. Additionally, between 80-90% of the IDD population has experienced some form of trauma further adding to the complexity of their needs. Not surprisingly, the work of our group identified many of the same strategic priorities and recommended strategies as The National Association of Medicaid Directors.

In March, 2020 the University of Alaska Anchorage's Center for Human Development published the results of a national needs assessment completed to help identify current gaps and needs in mental health services for those living with intellectual and developmental disabilities across the U.S. An online survey was distributed through 29 national organizations representing disability and mental health professionals, policymakers and advocates. There were 877 responses from 48 states. In summary here is what the study found:

- A person with IDD or their family members will go to their primary care physician or health center for mental health services
- Community Mental Health Centers are likely places for people with IDD needs to go
- There is a shortage of knowledgeable providers and services
- Mental health needs of people with IDD are severely underserved
- Existing services are less accessible for those with higher IDD needs or who are non-verbal
- The current workforce needs professional development opportunities
- A local or on-line directory with sufficient details is needed to help identify available services
- Policy changes and cross-system collaboration are needed



The National Association for County Behavioral Health and Developmental Disability Directors (NACBHDD) represents local county behavioral health and developmental disability issues in Washington D.C. Through education, policy analysis, and advocacy, NACBHDD promotes national policies that recognize and support the critical role counties play in caring for people affected by mental illness, addiction, and developmental disabilities. During 2020, the IDD sub-committee of the organization completed a survey of the membership to better understand the current approaches to services, challenges and barriers to such service delivery and identification of any unique or effective approaches as well as gaps in capacity and expertise. The Complex Needs Work Group gleaned the following findings from the “NACBHDD Occasional Paper”:

- There appears to be inconsistent tracking of prevalence data among members
- Outcomes are not consistently tracked across members of the organization
- Services rely heavily on medication management, crisis services and case management/care coordination
- System challenges are consistent with those identified by the KDADS/CDDO workgroup

The NADD: an association for persons with intellectual disabilities and mental health needs, was founded by Dr. Robert J Fletcher in 1988 in response to the growing need for a forum to educate the professional community regarding the realities and unique needs of those with dual diagnoses and to address the absence of research, information, and access to effective services for people experiencing co-occurring intellectual/developmental disabilities and behavioral health needs. NADD is considered to be the leader in education, consultation, and training related to the IDD/MI dual diagnosis. NADD publishes the Journal of Mental Health Research in Intellectual Disabilities. The organization has issued public policy priorities identifying the following two priorities as essential for improved outcomes for persons with IDD and co-occurring mental health needs:

- State Inter-System Collaboration
 - Establish agreement regarding significant need to support the population
 - Collaboration related to policy, infrastructure and service/support changes is priority
 - Cross-agency data collection is important in decision making;
 - Collaborative work has benefits for states
- State Managed Care Organizations (MCO) Contract Specifications
 - Specific collaboration with MCO's is needed to ensure those charged with funding services/supports are engaged in efforts to improve access to needed services
 - Agreement is needed on data collection to demonstrate system improvement progress
 - Pilot initiatives are needed.



DIAGNOSING THE PROBLEM IN KANSAS

While understanding the challenges as identified by national research and stakeholder organizations is helpful, the members of the workgroup wanted to dig deeper into the current circumstances in our own state. Members were asked to identify the important stakeholder groups in their respective communities and circles of influence. The names and contact information for those identified stakeholders were included in the distribution of a survey drafted by sub-committee members. The survey was distributed to over 12,732 stakeholders representing the following groups:

- Community Service Providers
- Legislators
- Kansas Department for Aging and Disability Services
- Department for Children and Families
- Child Welfare Contractors
- Law Enforcement
- School Districts
- Behavioral Sciences Regulatory Board Licensed Professionals
- Council of Community Members

This is not an exhaustive list of all stakeholder groups represented. Responses were received from 1,300 stakeholders from across the state for a 10.2% return rate. Respondents represented a diverse geographic area across Kansas. Work Group members culled through over 1,100 comments to identify themes for the most urgent priorities. Results are summarized below:

Andover Fall River Winfield Tonganoxie Derby Abilene Mission

Beloit **Prairie Village** Wichita Kansas Junction City

Haysville **Atchison** Osawatomie Garden City Wamego

Parsons McPherson **Pittsburg** ARKANSAS CITY

Hutchinson Chanute **Newton** City MO

Olathe Bel Aire **Overland Park** Kansas

Topeka Wellington **Wichita** Leawood

Kansas City Columbus Lawrence

Leavenworth **Salina** Ottawa **Lenexa** Shawnee Mission

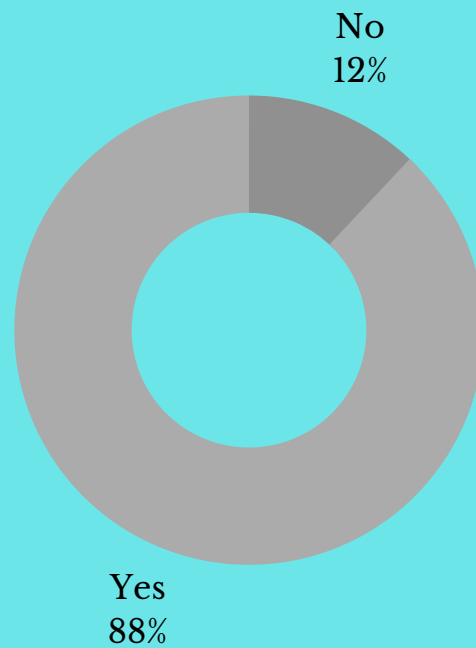
Manhattan Liberal **Shawnee** Augusta **Dorado**

Larned **Emporia** Valley Center **Hays** Colby

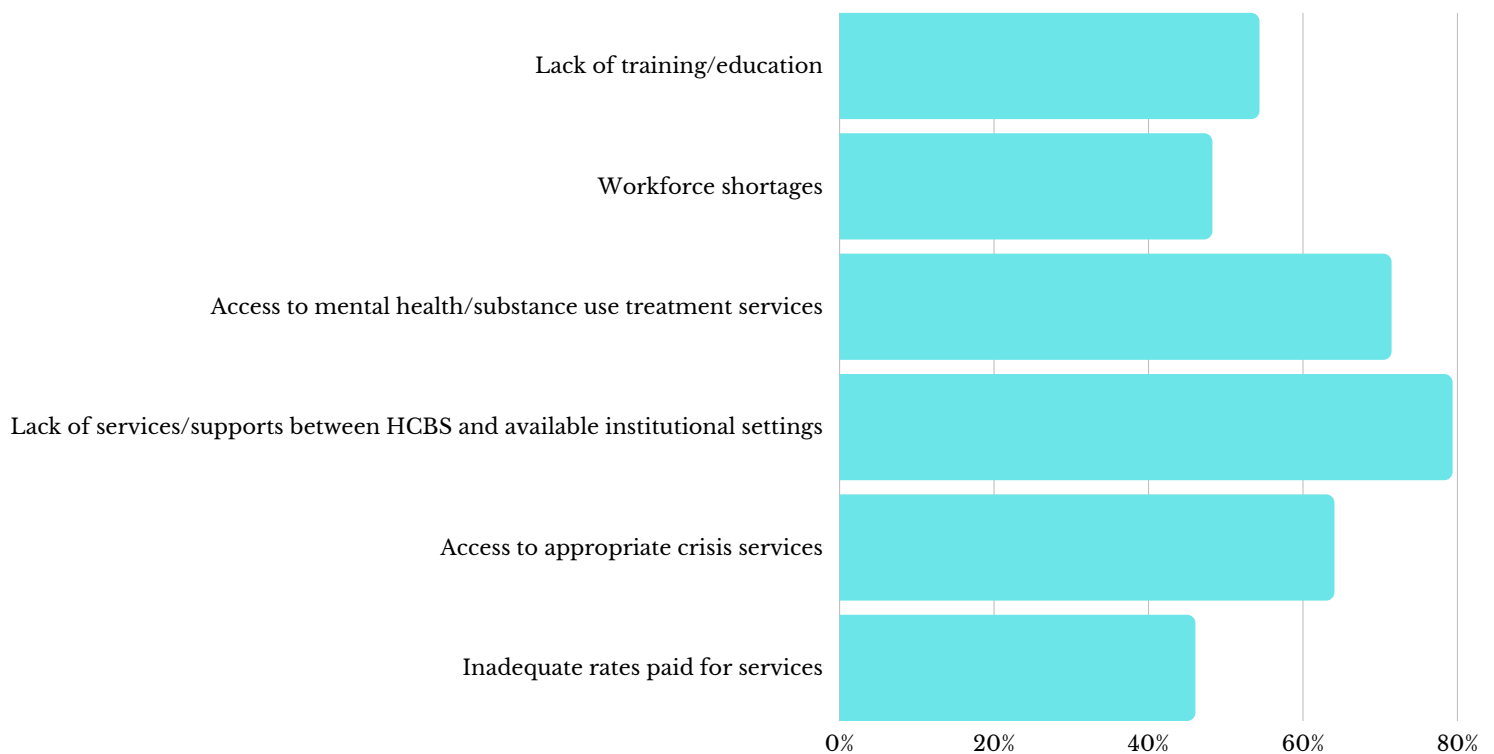
Independence Pratt **City** Merriam **Paola** Park **Dodge City**

Holton **Great Bend**

Do you perceive gaps in services/supports to individuals with IDD and a co-occurring mental health or substance use disorder?



**If yes to the previous question, what gaps have you identified?
Mark all that apply.**



How significant is your concern for challenges related to this population?

72



0

100

Not
Concerned

Extremely
Concerned

RECOMMENDATIONS

STRATEGIC FOCUS AREA 1: PROFESSIONAL WORKFORCE

1. Provide professional development & training
2. Address compensation inadequacy
3. Decrease workforce turnover

STRATEGIC FOCUS AREA 2: SERVICE CAPACITY

1. Fund development of needed supports
2. Develop integrated crisis supports
3. Develop Trauma-informed system of care

STRATEGIC FOCUS AREA 3: COMMUNICATION & COORDINATION

1. Increase transparency in communication through the IDD service system & ensure communication is accessible to all
2. Expand IDD service system stakeholders for broader, more comprehensive communication
3. Integration of services across systems

SUGGESTED NEXT STEPS

- Develop measurable outcomes for each of the Strategic Focus Areas
- Identify method for data collection to establish a statewide baseline for ongoing monitoring
- Prioritize Strategic Focus Area goals by impact/effort and urgency/importance
- Create an Annual Plan of Work for each State Fiscal Year
- Plans of Work should include specific, measurable objectives and tactics for each Strategic Focus Area goals
- First Plan of Work to be completed by State Fiscal Year 2022
- Select new CDDO Co-Chair
- Regularly review progress at scheduled KDADS/CDDO/Stakeholder meetings on-going

ACKNOWLEDGEMENTS

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