



Kansas Health Equity & Outcomes Coalition





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Our Mission: Empower individuals with intellectual and developmental disabilities (I/DD), families and caregivers to lead systems change, build capacity, and advocate for inclusive, integrated, accessible communities where everyone belongs and thrives throughout Kansas.

Our Vision: We envision a state where all people with intellectual and developmental disabilities live, learn, work, play, belong, and thrive in the community they choose.

Our Purpose: The purpose of KCDD is to support people of all ages with developmental disabilities so they have the opportunity to make choices regarding both their participation in society and their quality of life.

AdventHealth Medical Group Primary Care at Shawnee Mission is providing comprehensive, patient-focused care for adults with a chronic condition through the Special Pediatric-to-Adult Need (SPAN) program. The first and only program of its kind in Greater Kansas City, SPAN provides a consistent, reliable medical home for patients with special needs, including Down syndrome, autism, cerebral palsy and genetic disorders.

Located on the AdventHealth Shawnee Mission campus, the SPAN program allows patients with special needs to receive primary care in the same location as their family members. Led by [Laura Gaffney, MD](#), the SPAN team includes a nurse practitioner, a social worker and other clinical associates who make up a patient-focused team with expertise in the care of adults with special needs.

This project is funded by the Administration on Community Living (ACL) Public Health Workforce grant. Under the Biden Administration, ACL was awarded \$150 million to support the public health workforces through the aging and disability communities with 11 grantee networks across the US.

The Administration for Community Living was created around the fundamental principle that older adults and people of all ages with disabilities should be able to live where they choose, with the people they choose, and with the ability to participate fully in their communities. By funding services and supports provided primarily by networks of community-based organizations, and with investments in research, education, and innovation, ACL helps make this principle a reality for millions of Americans.



ABSTRACT

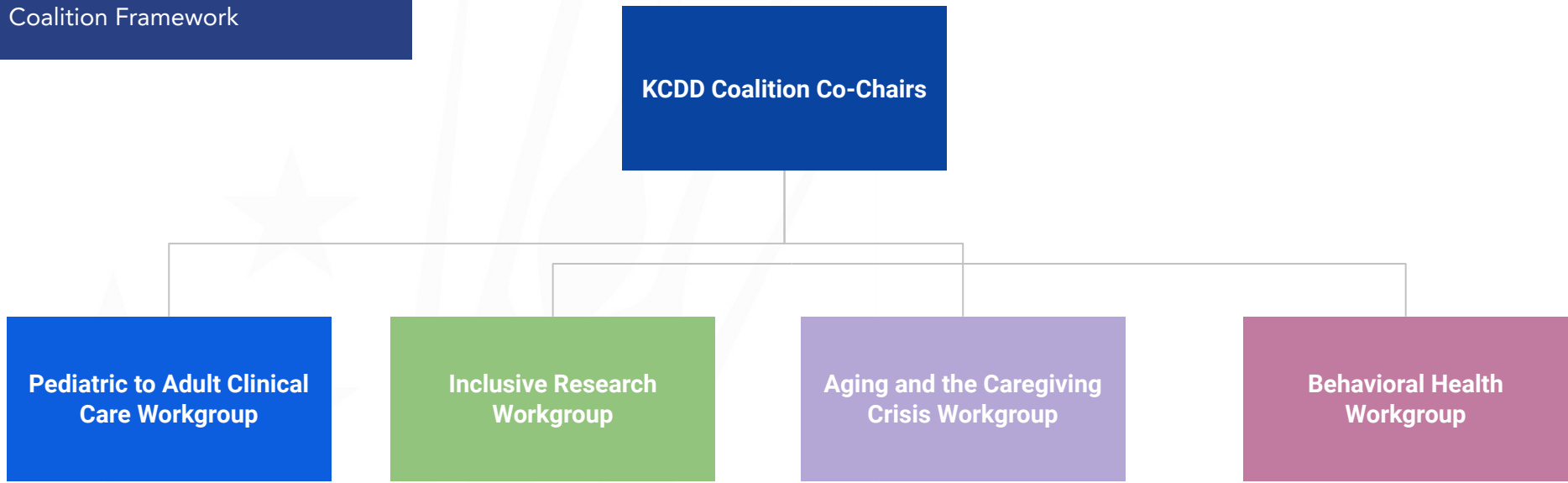
In the fall of 2023, the Kansas Council on Developmental Disabilities launched a first of its kind statewide Intellectual & Developmental Disabilities (I/DD) Health Equity & Outcomes Coalition, with the goal of convening self-advocates, families, and caregivers, as well as Kansas state agencies and departments, healthcare professionals, researchers and providers from across Kansas.

The coalition, through a series of workgroups, is developing an action-oriented blueprint aimed at ensuring our healthcare systems and partners throughout Kansas realize health equity for our I/DD population in our urban, rural and suburban communities. This coalition, which serves as a new national model, provides an innovative platform of stakeholder engagement and collaboration, advocacy and systems change to:

- Improve the quality of life and increase life expectancy of all Kansans with I/DD
- Address issues related to access to improving medical care access, expertise and training across all healthcare professionals and speciality areas
- Address access issues as well as supports, services and disability-related benefits across Kansas' rural, urban and suburban communities
- Address disparities in health and healthcare delivery across our state for the entire IDD population
- Enhance the workforce and establish a formal career ladder for direct support providers (DSP), healthcare providers, etc. who support and work with the IDD community

Better the quality of life for individuals with intellectual and developmental disabilities (IDDs) in Kansas by:

- Improving Overall Health Outcomes Across the Lifespan
- Increasing Research Participation, Innovation and Outcomes
- Expanding Resources for the Aging Population and their Caregivers
- Increasing Diagnoses and Treatments for Behavioral and Mental Health Conditions



FRAMEWORK

1. Create working groups focused on each of the stated goals.
2. Within each group, undertake an assessment of progress, gaps, and opportunities for advancing health equity for people with IDD in Kansas.
3. Develop an outreach, education, advocacy and public policy strategy that seeks to address the recommended outcomes in a meaningful way.

COALITION MEMBERS

Advent Health
Aetna Better Health
Alliance Rehab and Medical Equipment
Amgen
Assured Trust Company
Autism Society - The Heartland
Black Nurses Association of Kansas
Bert Nash Center
CareSource
Catholic Charities KC-SJ
Children's Mercy Hospital Kansas City
Community Health Council of Wyandotte
Developmental Services of Northwest Kansas, Inc. (DSNWK)
Down Syndrome Innovations
The Golden Scoop
Hunter Health Kansas
Institute for Advancing Medical Innovation
InterHab
Johnson County Developmental Supports
Kansas Center for Autism Research and Training
Kansas City Hospice & Palliative Care
Kansas City Indian Center
Kansas Dept for Aging and Disability Services (KDADS)
Kansas Department for Children and Families
Kansas Department for Health and Environment (KDHE)
Kansas Family Support Center
Kansas LEND, University of Kansas Medical Center

Kansas State Nurses Association
Kansas State Physician Assistant Program
KU Center on Developmental Disabilities
KUMC Girls Night Out Program
L'Arche Heartland
NAMI Kansas
New Hope Therapy Services
Onward Kansans
Optum Care
Oral Health Kansas, Inc.
Raise Health Innovations
Rush University Dept of Community, Systems and Mental Health Nursing and PATHPWIDD
Sedgwick County Department of Aging and Disabilities
Sedgwick County Developmental Disability Organization
Special Needs Assured
Special Olympics Kansas
Sunflower health plan
UnitedHealthcare Community Plan of Kansas
University of Kansas Medical Center (UKMC)
University of Kansas School of Nursing
We Care and Connect
Whole Story Planning

Pediatric to Adult Clinical Care Workgroup

Barriers to Address/Goals for the Workgroup:

- Improve Care Coordination for self-advocates, families & caregivers
- Transition from Pediatric to Adult Clinical Care & Health Insurance Systems
- Standardizing Medical Forms
- Lack of primary care physicians who take Medicaid - where is the next generation of specialists to serve the IDD population?
- Coordination between clinical care institutions regardless of community (suburban, urban and rural communities)
- Heightened focus on Women's health (mammograms, cancer screenings, regular OBGYN care) with a Women's Health Guide in plain language to be published this fall

Women's Health Guide

The purpose of this guide is to support women with Intellectual and Developmental Disabilities (IDD) as they navigate their healthcare, including nutrition, reproductive health, cancer screenings, and more! This guide was written and developed by the Kansas Council on Developmental Disabilities in collaboration with female self-advocates, Girls Night Out (KU), providers that care for individuals with IDD, and the Kansas State Nurses Association (KSNA).

Studies show that women with disabilities are less likely to receive Pap smears (as low as 66.1 percent) compared with nondisabled women (81.4 percent). Disabled women were also much less likely to have a mammogram (as low as 61.2 percent) when compared with nondisabled women (72.8 percent)¹. It is important for women with IDD to understand their options when it comes to cancer screenings and prevention methods. Women with disabilities are more likely to be diagnosed with breast cancer at later stages and have higher breast cancer mortality rates compared with their nondisabled peers.

¹C. Brooke Steele and others, "Prevalence of Cancer Screening Among Adults With Disabilities, United States, 2013," *Prevention of Chronic Disabilities* 26 (9) (2017), available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5268742/>.

Inclusive Research Workgroup

Barriers to Address/Goals for the Workgroup:

- Ensuring “Disability” is included in DEI policies and strategies in healthcare and research
- Collaboration across Kansas-based institutions for research and research participation
- Building a pipeline for people with IDD to participate as co-researchers at all institutions
- Increase research participation across all IDD diagnosis – creating a newsletter with research opportunities for healthcare professionals to share with their patients

Barriers to Address/Goals for the Workgroup:

- Increase access to behavioral health services for IDD community in Kansas – working with our state partners to improve the quality of care in mental health / behavioral health centers for individuals with IDD
- 988 Crisis Hotline Training for callers with IDD (in partnership with KDADS)
- Development of IDD Behavioral Health Toolkit, including nonverbal training materials
- Increase mental health supports for individuals with IDD
- Support healthcare providers and mental health professionals – increase training and workforce
 - Medicaid rates
 - Capacity to serve patients with complex health issues
 - Need for formalized state training

What to Expect When Calling 988

You are not alone. Help is available 24/7.

What is 988?

The 988 Suicide & Crisis Lifeline is a number you can call, text, or chat with when you are struggling emotionally. The person who answers the phone is trained to help you.

What happens when I call?

Dial 988	When you are struggling with your emotions or wanting to hurt yourself, you can pick up the phone and dial 988.
Wait for a counselor	<p>You will hear a message saying that you have reached the 988 Suicide and Crisis Lifeline. After that, music will play as they connect you with a counselor.</p> <p>You may have to wait up to 3 minutes- don't be discouraged. They want to help you.</p> <p>You can try to focus on your breathing or do deep-breathing to help you stay calm while waiting.</p>
Starting the conversation	There is no right or wrong way to start the conversation. You can start the conversation by just saying "hi, I am struggling right now."
Talking to the counselor	<p>This is where you share about what you are struggling with.</p> <p>The counselor will listen to you. The counselor may ask you questions to understand your situation. You can also ask the counselor questions.</p> <p>The counselor is there to listen and help you understand your feelings.</p>
After the call	Sometimes, the counselor may offer to call you back the next day to check in on you.

Questions you may have:

Can I call 988 even if I am not suicidal?	Yes. You can call 988 for support for ANY emotional stress you are experiencing.
Can I text or chat with a counselor instead of calling?	Yes. You can send a text to the number 988 to be connected with a counselor. You can also chat online by going to https://988lifeline.org/chat/
Will anyone know that I called 988?	Your call will be private and YOU get to decide who knows that you called 988. Your counselor will only contact emergency services if they think that your life is in immediate danger. You deserve support.
What if I struggle to find words for how I am feeling?	Your counselor is trained and will be patient with you. You will have time to think about what you would like to say.

A Guide Created by Whit Downing, Self-Advocate (KCDD)



WHAT IS A SAFETY PLAN?

MAY 2024 | BY WHIT DOWNING

Safety plans include what you would do and who may be able to help support you during a mental health crisis, or if you are having thoughts of suicide. In order to be prepared, it is best to make a safety plan BEFORE you reach a crisis point.

Before we get into how to actually make your safety plan, there are a few things we wanted to mention:

- It is okay to ask someone to help you write your plan. You don't have to do it alone, and you deserve support.
- Even if someone is helping, you get to decide what goes into your plan and what you think would work best for you.
- It may help to share your plan with family members, friends, your therapist, or anyone else who helps support you. Sharing your plan with others can help them know how to help you during your time of crisis.



On your safety plan, you should include your **warning signs** which are signs that let you know you're not feeling safe.

A warning sign may be that you are crying a lot more than usual. Another example of a warning sign could be that you are having thoughts of wanting to hurt yourself.

WHAT IS A SAFETY PLAN?

After you list out your warning signs, many people make a list of their **coping skills**. Coping skills are things that you can do to improve your mood and distract yourself. On your plan, you can include coping skills that you do by yourself, or even ones that include other people.

A few examples of coping skills are

- coloring,
- listening to music,
- going on a walk,
- or even talking on the phone with a friend.

If your coping skills are not helping you feel safer, it is good to know **who to reach out to for support**. Your list should include the people you trust and feel safe to talk to about how you are feeling.

Sometimes, you may need to reach out for professional support in order to stay safe. It is okay to need help. A few examples of professional support include calling 988, reaching out to a therapist or doctor, calling 911, or going to the hospital.



Finally, you want your safety plan to include **your reasons to stay alive**. When you feel overwhelmed by your emotions, it is important to have a reminder of why you want to stay alive.



Aging & the Caregiving Crisis Workgroup

Barriers to Address/Goals for the Workgroup:

- Enhancing resources for caregivers and guardians to navigate the system
- Opportunities for aging in place, equity in retirements and quality/new housing solutions
- Increasing capacity, flexibility in the I/DD workforce and service offerings
- Training for Direct Support Providers (DSPs), family caregivers, etc.
- Ability to meet the I/DD community where they are, need healthcare, live and work:
 - In-Home Care
 - Dementia/Alz & I/DD
 - Paying Family Caregivers
 - Supportive Living & Residential Care for individuals with I/DD who require 24/7 care and those who can live independently