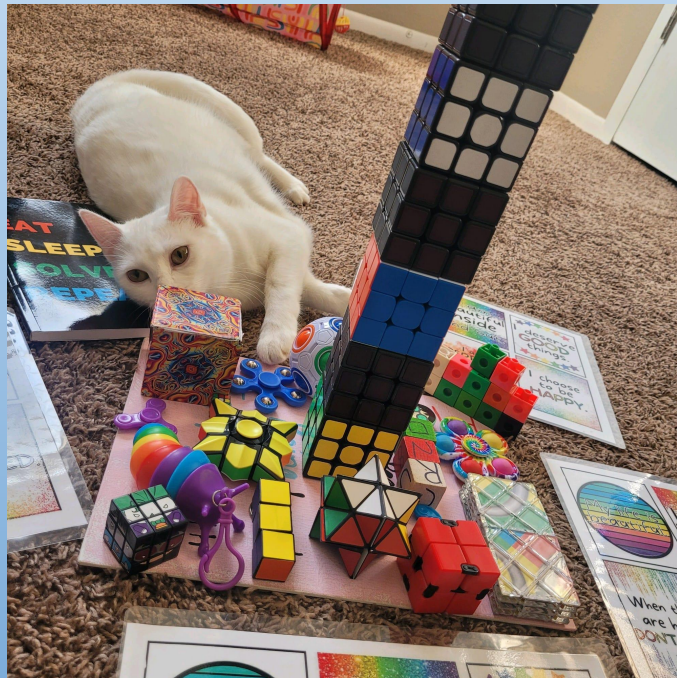




Mental Health, I/DD, and What's Possible

Whit Downing







KCDD
Kansas Council on
Developmental Disabilities

Diagnosed With:

Autism

Depression

Anxiety

PTSD



Different \neq Less

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.

Who I am and What I do

- Vice President of Policy & Programming, Kansas Council on Developmental Disabilities (KCDD)
- Advocate for inclusive mental health policy and support systems
- Leader of KCDD's Behavioral Health Workgroup
- Creator of plain language mental health tools
- Founder of We All Matter, a support group for people with I/DD

Getting here has been a journey, one that includes surviving a suicide attempt, navigating systems, and discovering the power of self-advocacy





Advocating for a better future:



- Washington DC
- Virginia
- Utah
- Nebraska
- Kansas



PREVALENCE OF IDD & MENTAL HEALTH CONDITIONS

As of 2019



**7.39 Million
People**

Had an IDD



**4.37 Million
People w/ IDD**

Had a mental
health condition

Autistic adults are 5.2 times more likely to have a least one psychiatric diagnosis compared to individuals without a developmental disability.



Sources:

- **Resources for Integrated Care Webinar**
- **NIH National Library of Medicine Research Study- 2019**



Before the Systems Saw Me

Stories Like Mine Are Everywhere

My story isn't clean or easy to summarize. It's layered. It's messy.

And for a long time, I didn't think anyone would want to hear it.





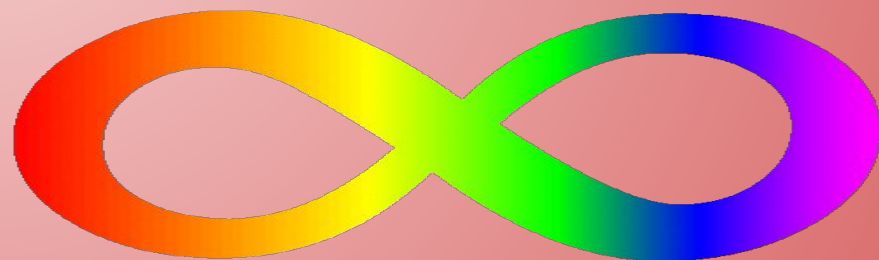
I've struggled with my mental health since I was really young.

All of my behaviors and mannerisms screamed that I needed help, but I wasn't met with understanding.



**I was on the IDD waiver
waitlist in Kansas for 8
years.**

- **I wasn't "just" autistic. I wasn't "just" someone with mental health needs.**
- **But because I didn't fit neatly into one system, I feel like I was often left out of all of them.**
- **I fell between the cracks of behavioral health and disability services.**
- **And for a long time, I believed the problem was that there's something majorly wrong with ME**





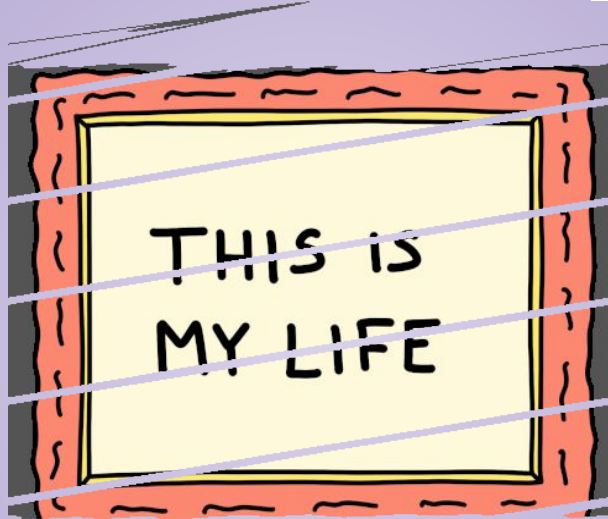
Eventually, I realized I wasn't the problem. The system was never designed with someone like me in mind.

But I started speaking up. I started advocating. And slowly, I found my voice.

That's where everything started to change for me... and that's where we'll go next.



- **Self-determination isn't just a buzzword. It means having control over your own life... your supports, your goals, your future.**
- **To me, it meant I could say: "This is who I am. This is what I need. This is what I want."**
- **And that those things actually mattered.**



In the past year and a half, I've started making decisions I've never been trusted with before.

SEE ME
HEAR ME

- **That shift... toward voice, dignity, and choice... was just the beginning.**
- **I didn't stop at finding my voice.**
- **I've started using it to create change. Not just for me, but for others like me who are still trying to be seen.**



**What would systems look like if
they were actually built by people
who live in them?**

That question shapes what I do at my job.

We're designing resources with people with I/DD at the center.



“NOTHING ABOUT US
WITHOUT US”



WE ALL MATTER

a mental health support group for
people with IDD





**You've heard my story, and now I'm
excited to bring in some of the
people I get to work with every day.
People who believe deeply in
advocacy and systemic change!**



KCDD's State and National Advocacy Efforts: A Panel Discussion



Sara Hart Weir
Executive
Director



Allyson McCain
Deputy
Director/Director
Health Equity &
Outcomes Coalition



Whit Downing
Vice President of
Programs



Lola Kernell
Advocacy
Coordinator

Let's talk about how KCDD is making sure people with I/DD are not just invited to the conversation, but leading it.

What are some examples of how we're doing that in Kansas right now?





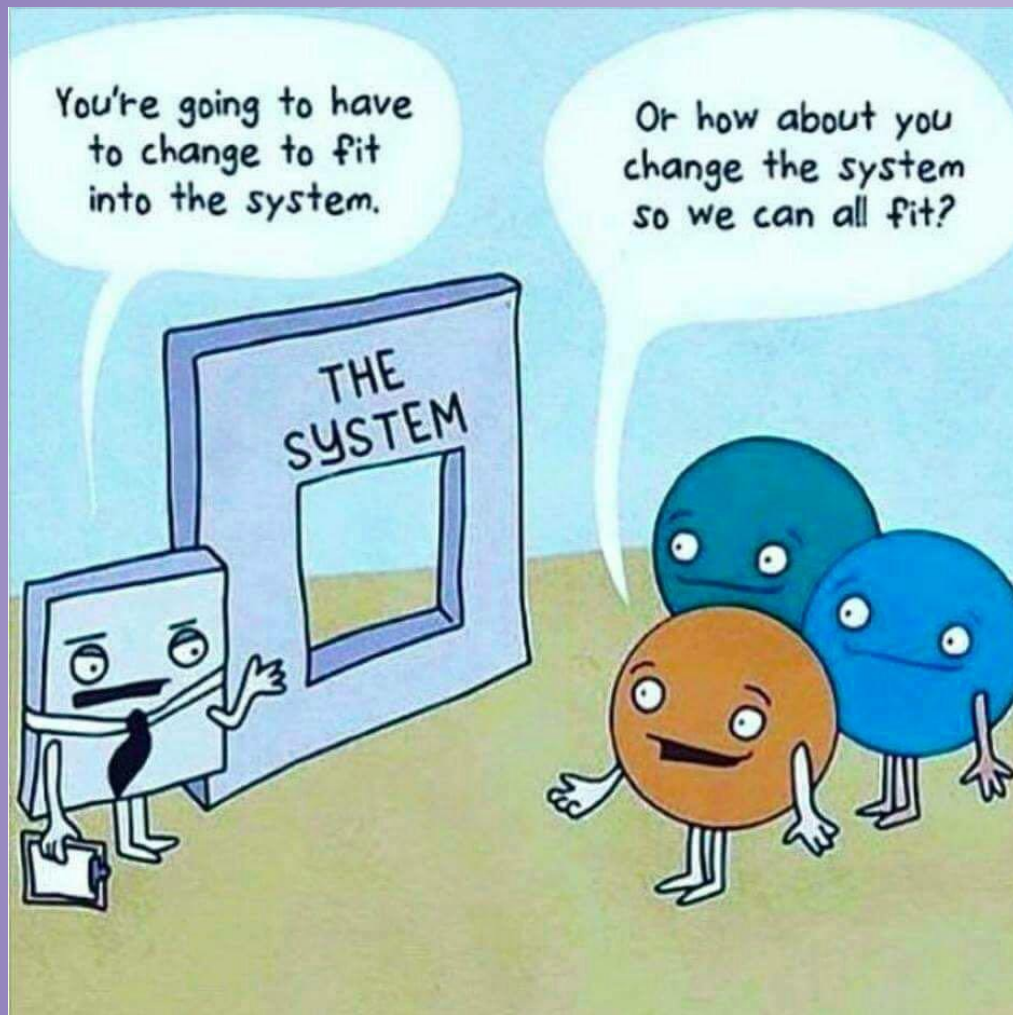
What we're doing here in Kansas is influencing national conversations, too.

What are examples of how our Kansas work has helped shape or influence national systems?



Many groups say they center lived experience.

What do you think actually sets KCDD apart?



**What's your
biggest hope for
how systems will
evolve over the
next few years?**



**It's not just about
systems, it's about
people.**

Now, I want to leave you with a few closing reflections.



**You've heard parts of my story
today...**

My story is one of many. And every single day, people with developmental disabilities and mental health needs are still trying to navigate systems that weren't built with them in mind.



Let's keep bridging forward.. together.