A Project of National Significance funded by Administration for Community Living aimed at improving access to mental health services for people with I/DD, Brain Injury and other Neurodevelopmental Disabilities

National Dialogues on Behavioral Health
November 2024

A Much Needed Project of National Significance

- Nation struggles to provide community mental health services for individuals with I/DD, brain injury, and other cognitive disabilities – causing significant trauma and adverse outcomes for people on a daily basis
- People with complex needs stretching systems of care
- Lawsuits relating to care occurring in multiple states
- Lack of expertise, resources and capacity to best support people with a dual diagnosis
- Siloed systems responsible for different elements of care
- Lack of trained medical, law enforcement, and crisis care providers

The Link Center Partner Organizations

Leading Partners

- NASDDDS
- NADD
- NASMHPD
- NASHIA

Diversity, Equity, Inclusion

- Green Mountain Self Advocates
- Autistic Self Advocacy Network
- CommunicationFIRST

Continuous Quality

- National Center for START Services
- Sonoran Center at Univ of Arizona
- Nisonger Center at OSU

NASDDDS – NASMHPD – NADD -NASHIA An Increasingly Necessary Partnership

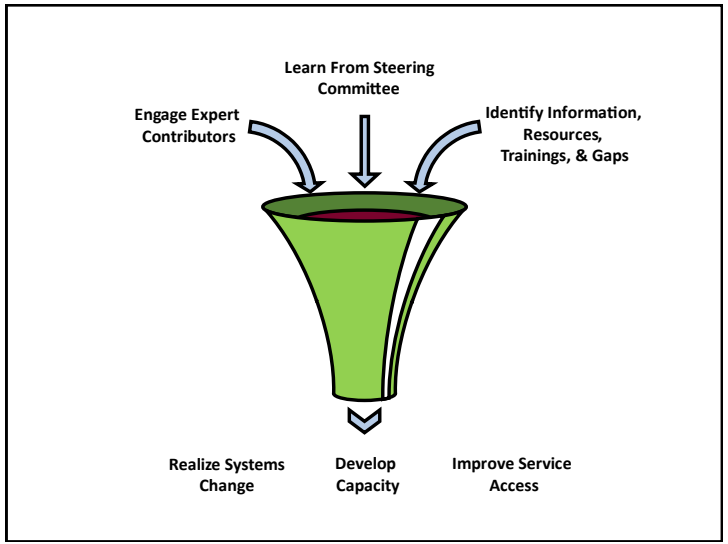
- While our associations have long recognized the importance of working together on shared issues, our partnership was renewed with vigor in recent years, when our collective memberships report increases in situations requiring a cross-system collaborative approach
- Despite the fact that we know that many individuals have multi-system involvement, our state structures have often impeded truly whole-person support
- We have partnered on several other initiatives - like the Dual Diagnosis Capacity Building Institute - bringing those learnings to The Link Center

Key Goals of The Link Center

Systems Change	DSW & Clinical Capacity	Service Access
Improvements in policies, service design, and service coordination	Build a diverse workforce to support individuals with I/DD, brain injury and other cognitive disabilities who also have MH support needs	Improve access to person-centered, culturally and linguistically appropriate MH services and community supports

Key Project Activities & Outputs

- Curated resource library for a wide array of audiences
- Identification of best practices and strategies for scalability
- Model policies and protocols for state systems and clinicians
- Training curricula to support workforce competencies in trauma-informed supports for people with ID/DD/MH
- Toolkits and resources for meaningful engagement and adaptive approaches to treatment for people with ID/DD/MH
- Accessible website as the hub for all TA center activities



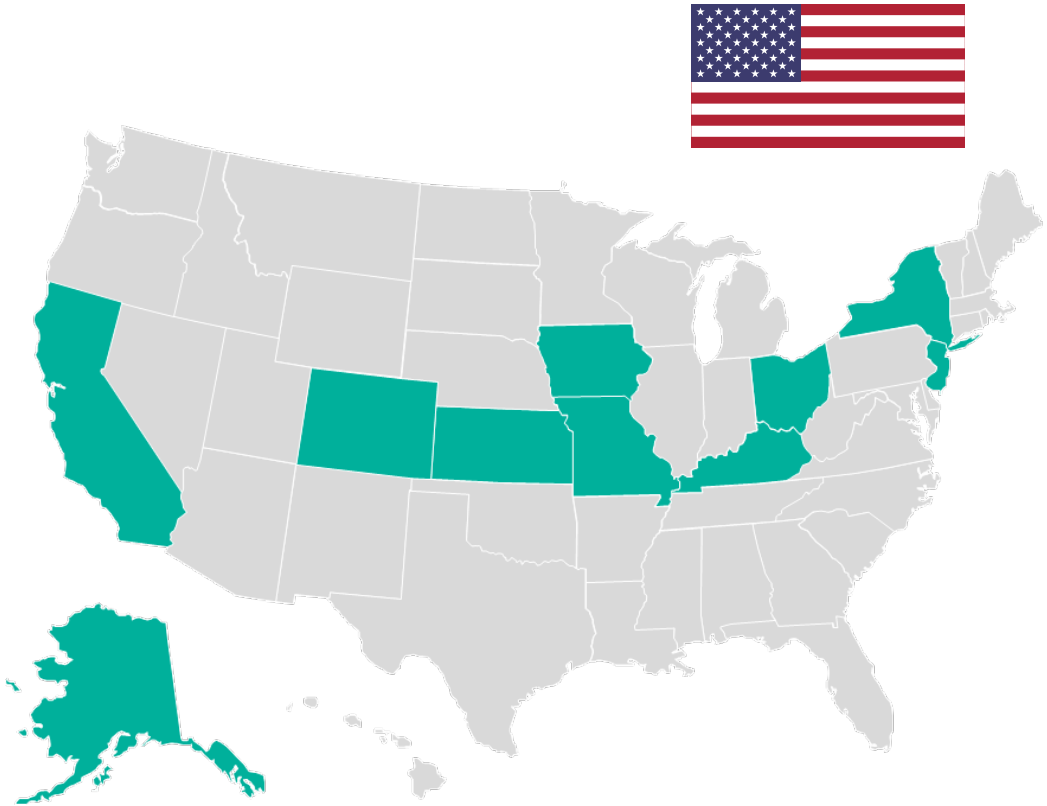
THE LINK CENTER
Bridging I/DD and Mental Health Systems

Lived Experience Driving the Work: The Link Center Steering Committee

- Over **100** applications submitted
- Selection focused on diversity, specifically related to the person's area of residence, race, culture, ethnicity, age, communication strategy, and lived experience
- To date, feedback on topics including a) language use, b) engaging families and persons with lived experience in other grant activities, and c) priority areas for resource identification and development
- Steering Committee actively shaping the work of The Link Center

Steering Committee Member States

- Alaska
- California
- Colorado
- Iowa
- Kansas
- Kentucky
- Missouri
- New Jersey
- New York
- Ohio
- Washington, DC



THE LINK CENTER
Shared Learning Groups

YEAR 1

OCTOBER 2023	JANUARY 2024	APRIL 2024	AUG 27 & 28 2024
Supporting Someone in Crisis	Supports for Trauma	Supporting Someone through a Transition	Supporting the Whole Person

YEAR 2

OCT 22 & 23 2024	JAN 21 & 22 2025	APRIL 22 & 23 2025	JULY 22 & 23 2025
Navigating Risky Situations	Moving through the Justice System	Developing Regulation and Coping Skills	Building Systems Partnerships

Partnership with SAMHSA

988 Suicide and Crisis Lifeline

988
SUICIDE
& CRISIS
LIFELINE

Six-State Policy Academy to Build Inclusive 988/Crisis Lifeline Supports

- Aimed at building strong, collaborative systems of support that enable states to effectively support individuals in crisis regardless of disability and/or communication differences – ***State teams include Mental Health, I/DD, 988, Medicaid, Child Welfare and others***
- GA, MD, KS, OH, WV, VA
  - ✓Survey and Public Listening Sessions
  - ✓State tailored interventions and workplans
  - ✓Virtual, peer learning opportunities
  - ✓In person academy

Preliminary Learnings: There is Much Work Ahead

- Cross agency collaboration is essential
- Myths and misperceptions about people with disabilities persist
- Call center staff require ongoing support and coaching on supporting individuals who may not use spoken word alone to communicate
- 988 partnerships with community leaders are key
- What happens after the call – important to have services to meet needs (and to overcome exclusions related to I/DD)
- Understanding role of family in supporting individual is important
- Trust and safety is paramount
- First responders need support and training, and mobile crisis teams need support and on-demand expertise
- Strategies for communication, in all of its forms, is necessary

The Biggest Challenges

Smashing the Myths and Changing the Paradigms the Myths Have Produced

Myths that Obstruct Access to Mental Health Treatment

MYTHS	
People with I/DD, Brain Injury and/or other neurodevelopmental disabilities cannot experience mental illness.	**FALSE**
People with I/DD, Brain Injury and/or other neurodevelopmental disabilities don't experience trauma because of cognitive challenges	**FALSE**
People with I/DD, Brain Injury and/or other neurodevelopmental disabilities cannot benefit from evidence-based mental health treatments	**FALSE**
All behavior exhibited by people with I/DD, Brain Injury and/or other neurodevelopmental disabilities is bad behavior, not symptoms of mental health diagnoses or trauma.	**FALSE**

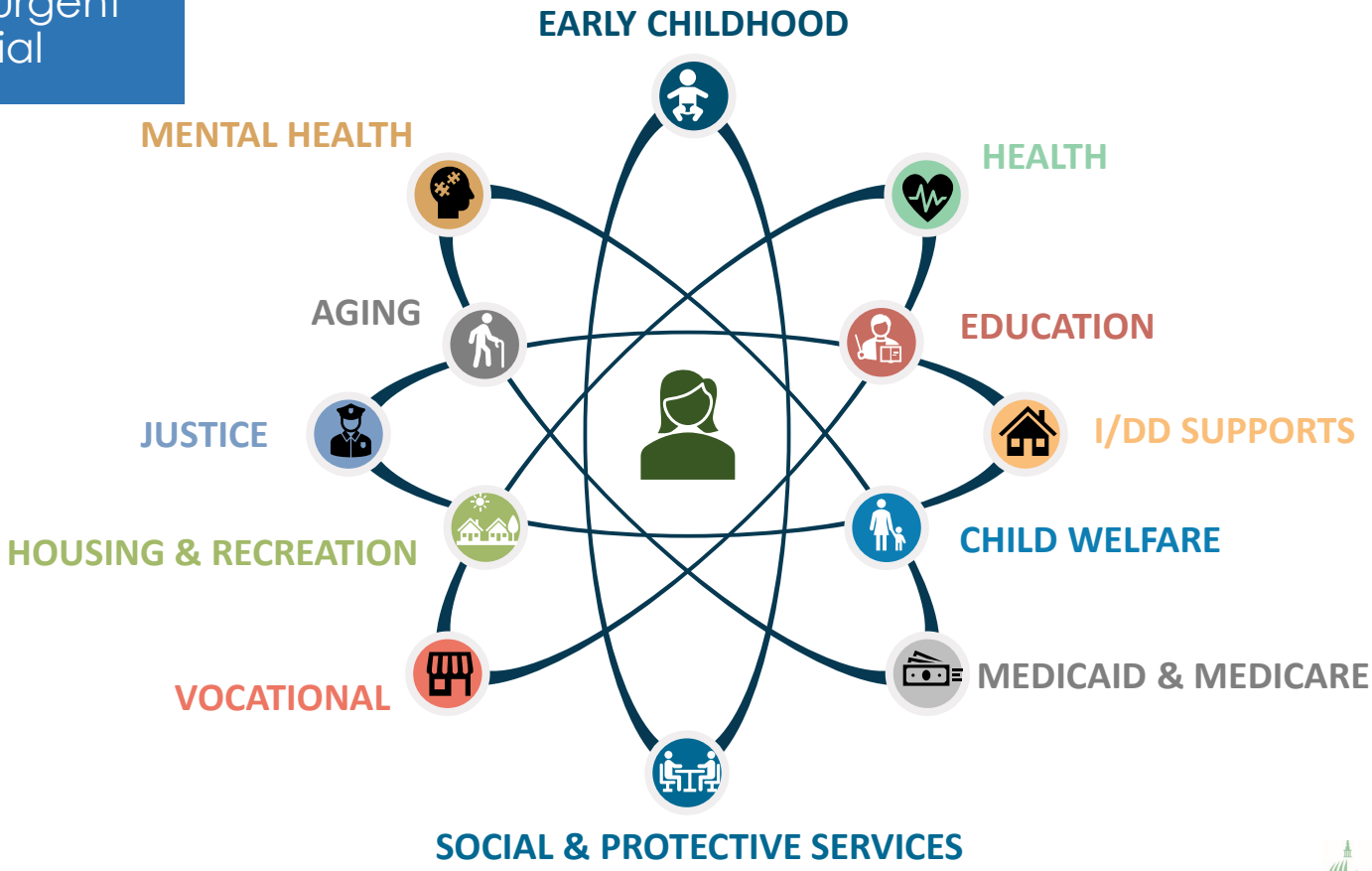
The Truth About Individuals with Disabilities and Mental Health

MYTHS	
People with I/DD, Brain Injury and/or other neurodevelopmental disabilities experience mental health conditions at rates higher than the general population – a meta study estimates prevalence at or above 33% incidence.	**TRUE**
People with I/DD, Brain Injury and/or other neurodevelopmental disabilities have life experiences that increase likelihood of trauma: • Higher rates of abuse, neglect and exploitation, including higher victimization rates of sexual abuse • Social isolation and bullying • Extensive and invasive medical procedures (with or without consent) • For some, separation from family, love and support	**TRUE**
People with I/DD, Brain Injury and/or other neurodevelopmental disabilities can benefit from evidence-based mental health treatments – sometimes with necessary but simple accommodations	**TRUE**
Behavior supports can be important to support people with disabilities, but they should be used alongside mental health treatments to ensure that the person is supported holistically	**TRUE**

Myths Led to Policy and Practices that Impede Progress Today

- Because of the presumption that individuals with disabilities, especially those with I/DD, could not experience mental health conditions, there was a presumption that they could not benefit from rehabilitative or restorative treatments.
- This led to Medicaid in many states excluding individuals from rehabilitative benefits if they had a "primary diagnosis of intellectual disability"
- This manifested in both coverage and medical necessity policies where they continue to exist today
- This had far reaching ramifications on clinical availability as payment was out of reach for services and/or training/accommodations
- This contributed to a generation of clinical providers unwilling to provide mental health treatment – and a perpetuation of bias regarding the capacity of people with disabilities.

Removing Siloed Approaches to Support is Urgent and Essential



NASDDDS

An Emerging Service Paradigm for Individuals with Disabilities and Mental Health Conditions is Evolving ….but it Requires Recognition and Active Support

Restorative Environment – HCBS Essential Element of the Solution

- A place to live that is safe, trauma informed
- Stable staff
- Develop trusting relationship with others
- A life worth living – a person-centered approach
  - People can see people important to them as frequently as possible – this is the basis for resiliency
  - People doing things important to him/her as frequently as possible
  - Being in the community
  - Having a pet
  - People making choices and decisions
- Focus on brain health
  - Good diet/attractive food – reduce caffeine and sugar; critical nutrients (brain/gut connection)
  - Exercise – increase oxygen flow –biking, swimming, walking running, sports
  - Sleep – building good habits
- Implementing meaningful routines – predictable and reliable
- Mental and physical health treatments integrated into the program

Treatment for Trauma – Mental Health and HCBS

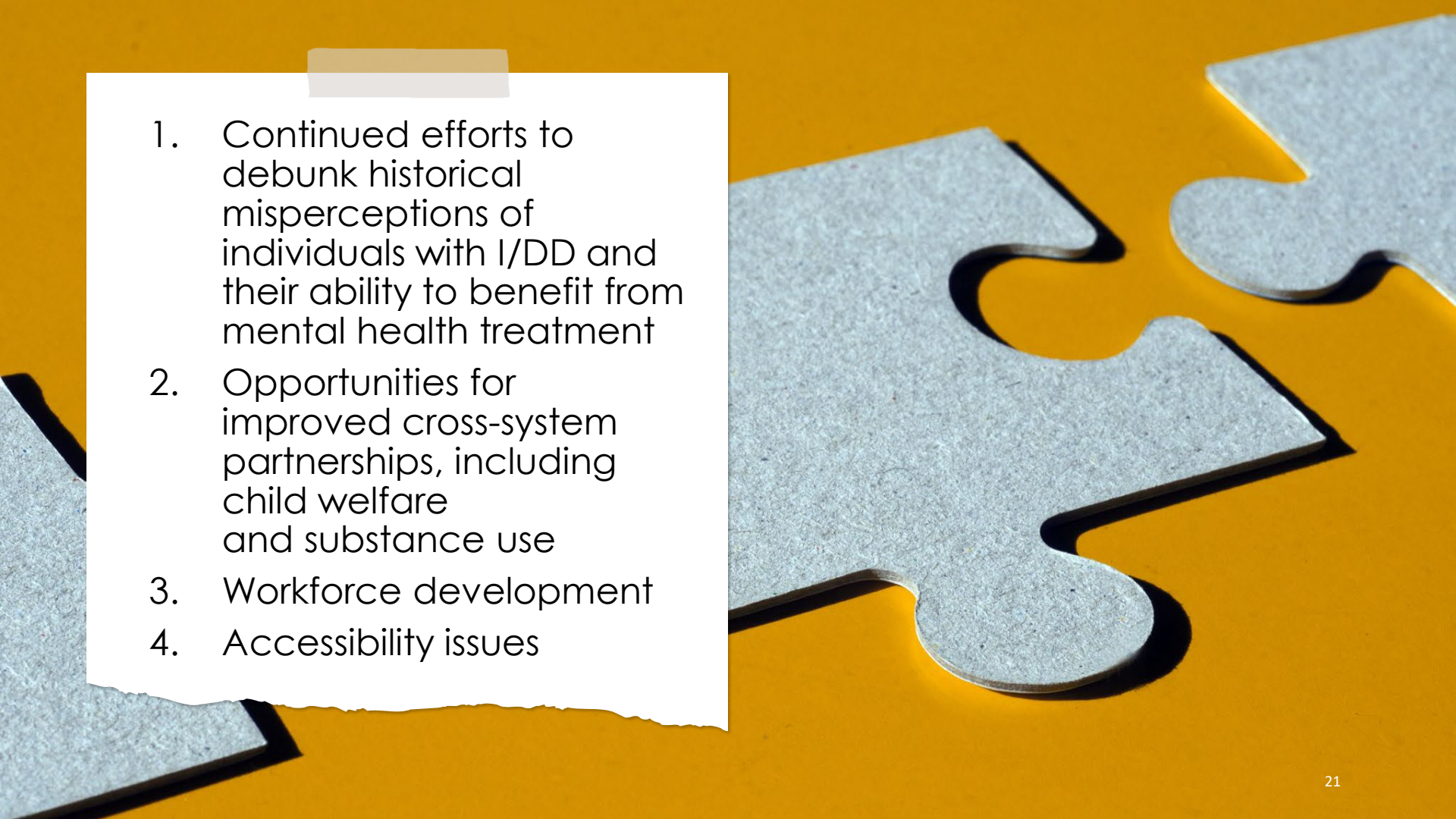
- Trauma Focused Cognitive Behavioral Therapy TF-CBT
- Individual therapy; group therapy
- Peer counseling
- Internal Family Systems Therapy (IFST)
- Intensive Systems Therapy (IST)
- Sex education and counseling
- Education about the mind and body
- Mindfulness training
- Neuro Affective Relational Model Therapy
- Dyadic Developmental Psychotherapy
- Sensory interventions that calm; breathing, weighted blankets, warm baths, swinging, etc.
- EMDR; Bio/Neurofeedback
- Neuro-Entrainment
- Play therapy, art therapy, music therapy, Psychodrama
- Animal therapy
- Movement therapy e.g., yoga, tai chi, exercise
- Group activities that involve movement with others – drumming, dancing, singing

Medical

- Psychiatry
- Physical Health

Challenges, Opportunities, and Next Steps

1. Continued efforts to debunk historical misperceptions of individuals with I/DD and their ability to benefit from mental health treatment
2. Opportunities for improved cross-system partnerships, including child welfare and substance use
3. Workforce development
4. Accessibility issues



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Questions