### Addressing Complex Behavioral Needs with Youth

Elizabeth Manley Senior Advisor for Health & Behavioral Health Policy November 4, 2024



What works best is anything that increases the quality and number of relationships in a child's life. People, not programs, change people.

Dr. Bruce Perry, Mind and Heart Foundation

" It is thought that families who receive consistent support will not only achieve higher community integration and wellbeing but will also become less entangled and dependent upon formal services."

Focal Point, Winter 2006

Strengthening Social Support Research Implications for Interventions in Children's Behavioral Health

#### Timeline of the Family Movement in Children's Behavioral Health

In 1982, Jane Knitzer published Unclaimed Children: The Failure of Public Responsibility to Children and Adolescents in Need of Mental Health Services thus setting in motion the children's mental health movement and the rise of the family and youth movements.

1988 - 89

1992 - 93

CASSP 1984 In 1984, Congress funded the Child & Adolescent Service System Program (CASSP). Initially, the program did not address family issues. By year two an additional goal was added to develop family input into the planning and development of service systems, treatment options and individual service options.

#### First Federal Funding for Family-Run Organizations

Hawaii, Minnesota, Montana, Virginia and Wisconsin were the first states to receive \$20,000 for their family organizations. Indiana, Kentucky and New Jersey were awarded grants the following year.

#### SAMHSA Authorized by Congress

The Substance Abuse and Mental Health Services Administration (SAMHSA) was created by Congress in 1992 to improve the quality and availability of substance abuse prevention, addiction treatment and mental health services.

> National Youth Development Board Formed 2003 - 04

Youth MOVE National Established 2006

Certification Commission Formed for Parent Peer Support Providers 2011

#### SAMHSA/CMS Joint Bulletin

SAMHSA and Centers for Medicare and Medicaid issue a joint bulketin in May 2013 identifying parent peer support as a key service that can enable children with complex needs to live at home and participate fully in family and community opening the door for Medicaid billing for parent peer support.

#### **Research and Training Center**

CASSP and the National Institute on Disability and Rehabilitation Research (NIDRR), established the first Research and Training Center on Family Support and Children's Mental Health at Portland State University.

#### 1986-87 Families as Allies Conferences

Portland State University hosted five regional Families as Allies Conferences for families.

#### **Next Steps Conference**

Portland State University and NIDRR co-hosted at the Next Steps Conference in Arlington, Virginia in December 1988 to create an agenda for children's mental health.

#### Federation of Families Started

In February 1989, a 20 person Steering Committee of families voted to form a national family organization. The Federation of Families for Children's Mental Health was incorporated in Maryland in September 1989.

#### Children's Mental Health Initiative (CMHI)

SAMHSA funds the first four Systems of Care grants to communities for children's mental health

#### **President's New Freedom Commission**

Term 'family driven care' defined.

2008 First Youth MOVE Chapter

#### Youth MOVE National Incorporated

Family-Run Executive Director Leadership Association Established

Executive Directors of 16 family-run organizations form an organization dedicated to building leadership and organizational capacity of family-run organizations. FREDLA becomes a partner in the TA Network as part of the National Technical Assistance and Training Center for Children's Behavioral Health.

Family-Run and Youth Organizations Looking Ahead

Thanks to the pioneers in the family movement: Jane Knitzer, Barbara Huff, Barbara Friesen, Ira Lourie, Jane Adams, Jane Wolker, Sue and Norma Smith, Trina and David Osher, Richard Donner, Marge Samels, Al Duchnowski, Scott Bryant- Comstock, Spbil Goldman, Judy Katz-Levy, Chris Koyanagi, Dixie Jordon, Gail Dariels, Marion Mealing, Naomi Karp, Shannon Crossbear, Glenda Fine, May Telesford, Velva Sprigg, Robert Friedman, Beth Stroul, Karl Dennia,

2016

2013

## **Children's Behavioral Health in the U.S.**

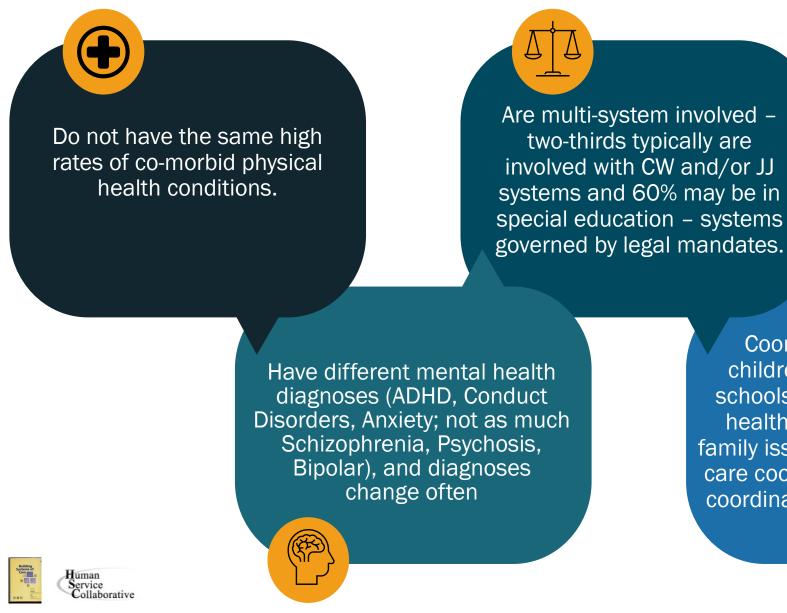
- Nearly 20% of children and young people ages 3-17 in the United States have a mental, emotional, developmental, or behavioral disorder
- ➤Over 10% have a Serious Emotional Disorder (SED)
- Suicidal behaviors among high school students increased more than 40% from 2010-2019
- Rates of emergency department visits for MH increased by 25% for children between 2016 and 2018

> Rates for older age groups showed no statistically significant change.

- In 2020, only 44% of adolescents ages 12-17 with a major depressive episode in the last 12 months reported receiving treatment.
  - 2022 National Healthcare Quality and Disparities Report. Rockville, MD: Agency for Healthcare Research and Quality; October 2022. AHRQ Pub. No. 22(23)-0030.



Children & Youth with Serious Behavioral Health Conditions are a Distinct Population from Adults with Serious and Persistent Mental Illness



Coordination with other children's systems (CW, JJ, schools), between behavioral health providers, as well as family issues, consumes most of care coordination activities, not coordination with primary care.



Pires, S. March 2013 Customizing Health Homes for Children with Serious Behavioral Health Challenges. Human Service Collaborative.

To improve cost and quality

of care, focus must be on

whole family - takes time -

implies lower staffing ratios

and higher rates

### PYRAMID OF CHILDREN AND SERVICE NEEDS

Public Health Approach

Most Complex Needs

#### Intensive Behavioral Health Supports

Intensive care coordination utilizing a Wraparound approach; intensive services & supports

#### Intermediate Behavioral Health Supports

Targeted interventions; service & support access; intermediate care coordination

Less Complex Needs

#### Universal Health Promotion

Early identification & screening; universal health & behavioral health care promotion & prevention

8-12%

30%



60%

### The Challenge:

- 50% of all adult mental health challenges begin by the age of 14
- 75% of all adult mental health challenges begin by the age of 24



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Kessler RC, Berglund P, Demler O, Jin R, Merikangas KR, Walters EE. (2005). Lifetime Prevalence and Age-of-Onset Distributions of DSM-IV Disorders in the National Comorbidity Survey Replication. Archives of General Psychiatry, 62 (6) pp. 593-602. doi:10.1001/archpsyc.62.6.593.

<u>Children MH Facts 9-21-16 rev (nami.org)</u>

### A Word About Language:

NO Case NO Client NO Kiddo NO Placement

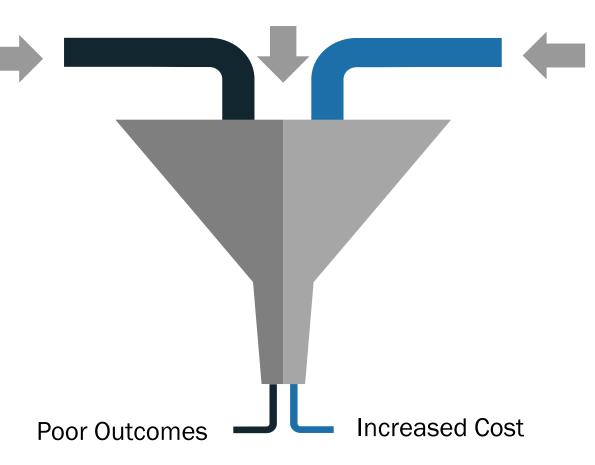




### HISTORIC/CURRENT SYSTEM PROBLEMS

Deficit-based/medical models; Racial/ethnic disproportionality and disparities; Knowledge, skills and attitudes of key stakeholders

Lack of home and community-based services and supports; limited types of interventions; patterns of utilization



Administrative inefficiencies; fragmentation; rigid financing structures





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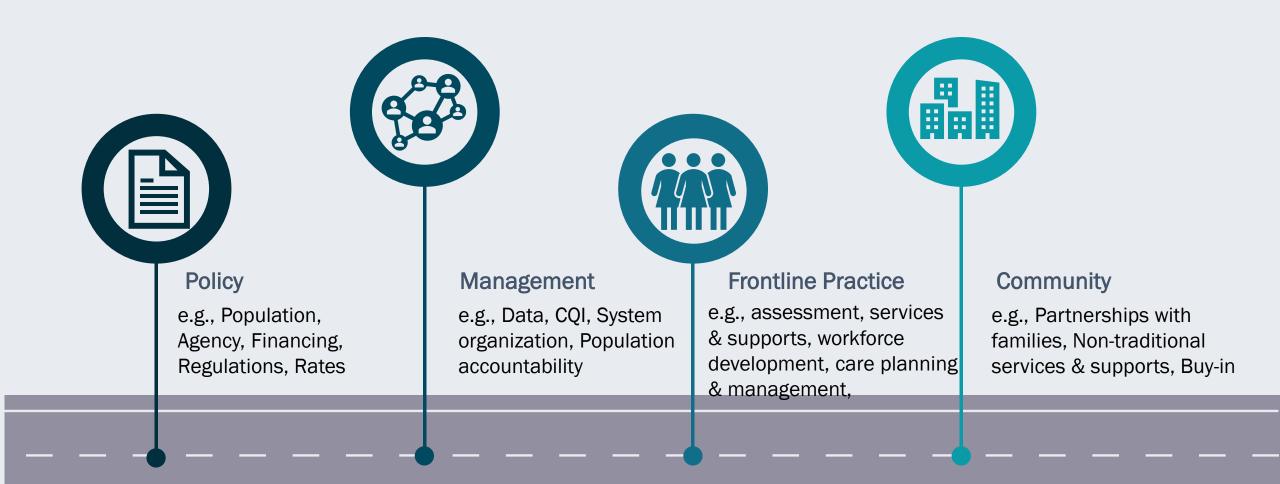
### Getting help can be hard and confusing...

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### SYSTEM CHANGE/TRANSFORMATION FOCUS



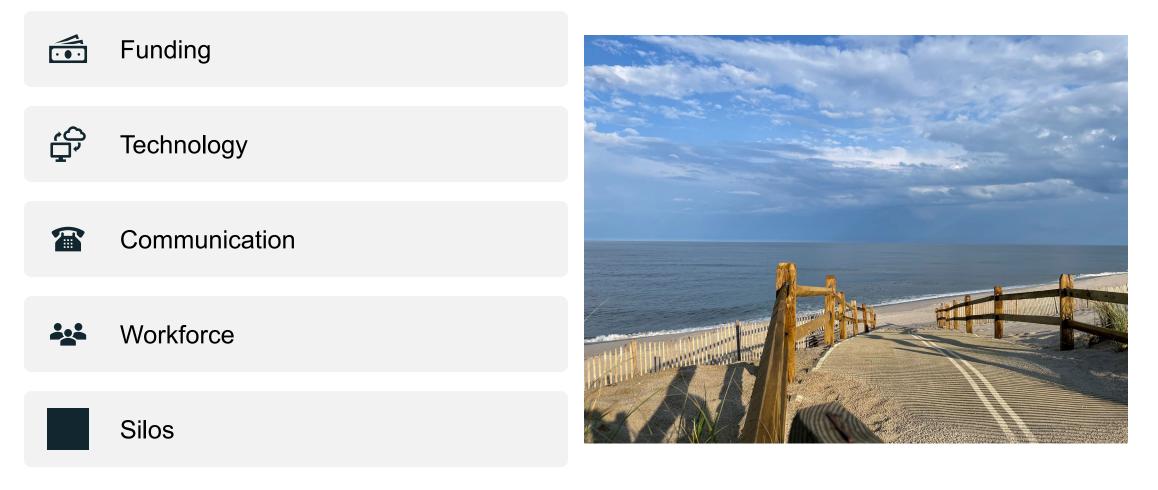
**ACROSS ALL LEVELS** 

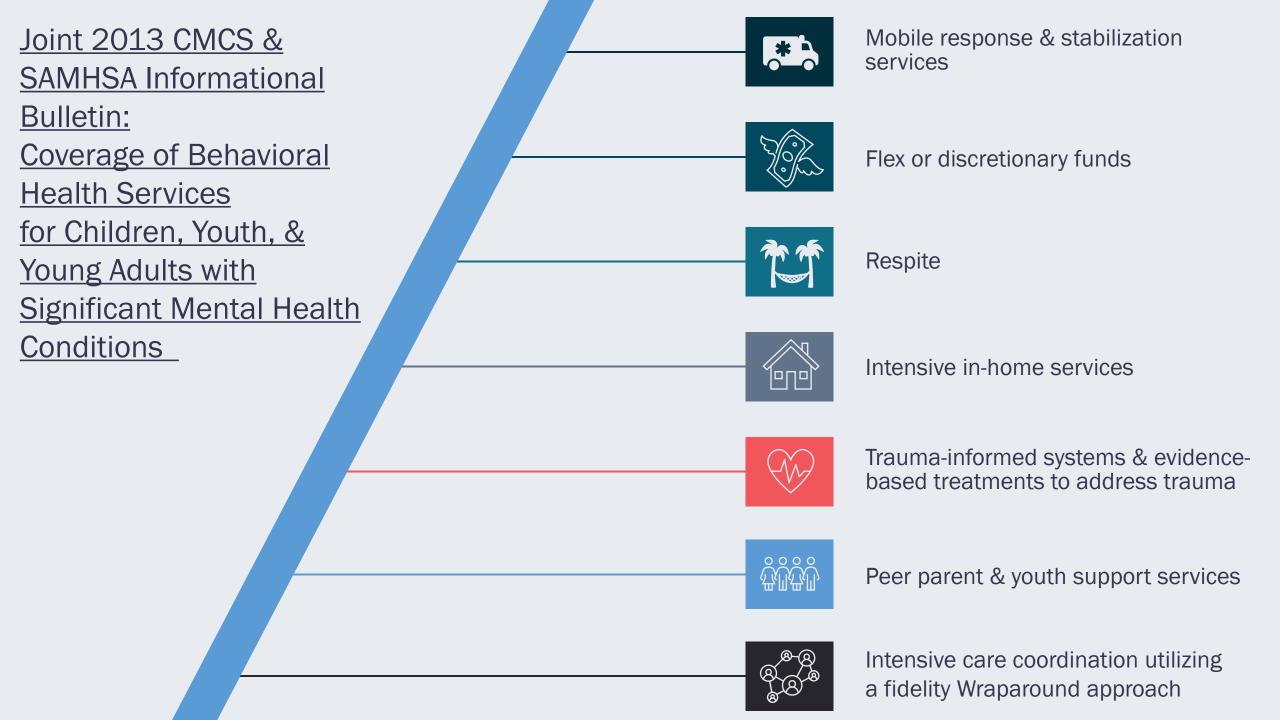


Pires, S. (2010) COPYRIGHT 2023 INNOVATIONS INSTITUTE AT UCONN

SCHOOL OF SOCIAL

### **Challenges to Transformation**

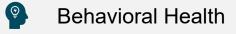


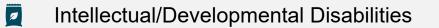


### **The Silos**



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Substance Use

Child Protection

🔆 Juvenile Justice

Section Education

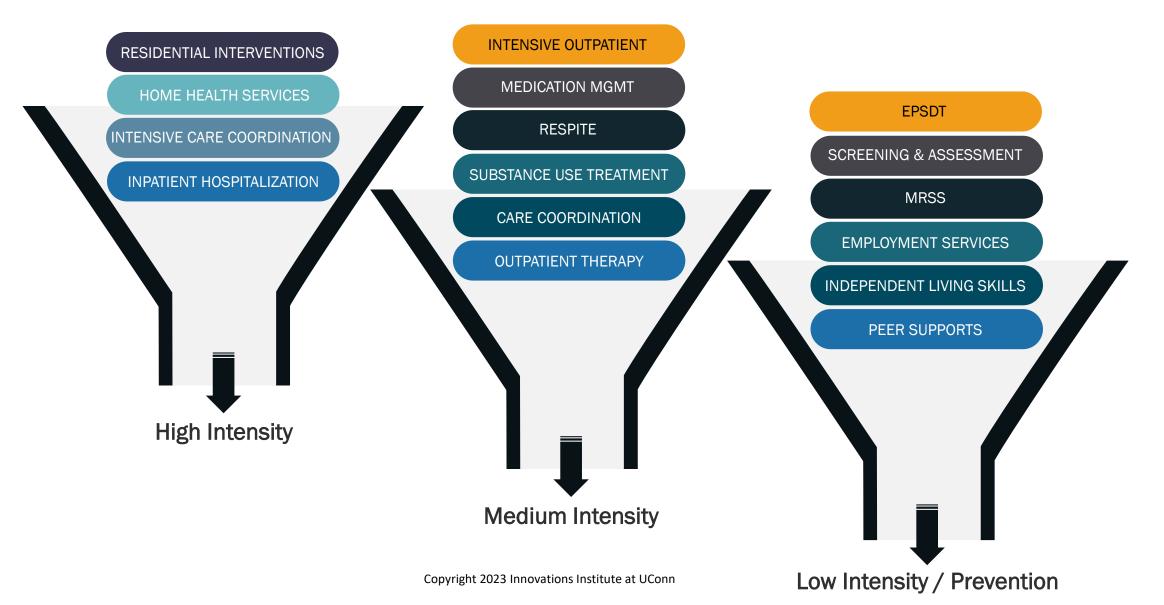
Pediatricians

X Vocational

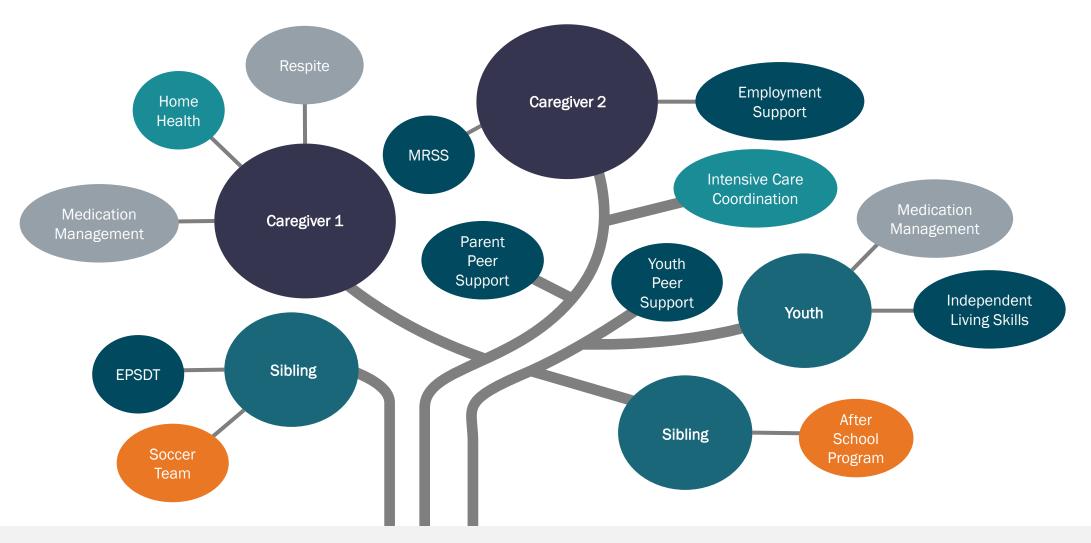
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### CURRENT STRUCTURES OF SERVICE ARRAY BY INTENSITY OF CRITERIA

BUT... How do we ensure families can get what they need regardless of level of intensity of service or need?



### **Comprehensive Service Array**



## Families accessing what they need regardless of identified level of intensity of need

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## Interruption of Care Pathways

### Children's Crisis Systems Are Different

### Crisis System Core Elements

- Crisis is defined by the family/young adult recognizing family/young adult's sense of urgency
- ✓ Single point of access with a youth specific triage and connection to mobile teams
- ✓ Available 24/7/365 with face-to-face response
- ✓ 100% immediate mobile response by teams trained to work with youth, young adults, and families
- Response does not include law enforcement unless deemed necessary after risk/safety screening and parent/caregiver agrees
- ✓ Developmentally appropriate assessment
- Focuses on shifting care pathways from high intensity services recognizing natural intervention points
- Recognizes that the exposure to higher intensity services can be trauma inducing
- ✓ Recognizes and supports the natural support system
- $\checkmark$  Recognizes the healing potential within communities



### Mobile Response and Stabilization

#### ....

#### **MRSS Core Services**

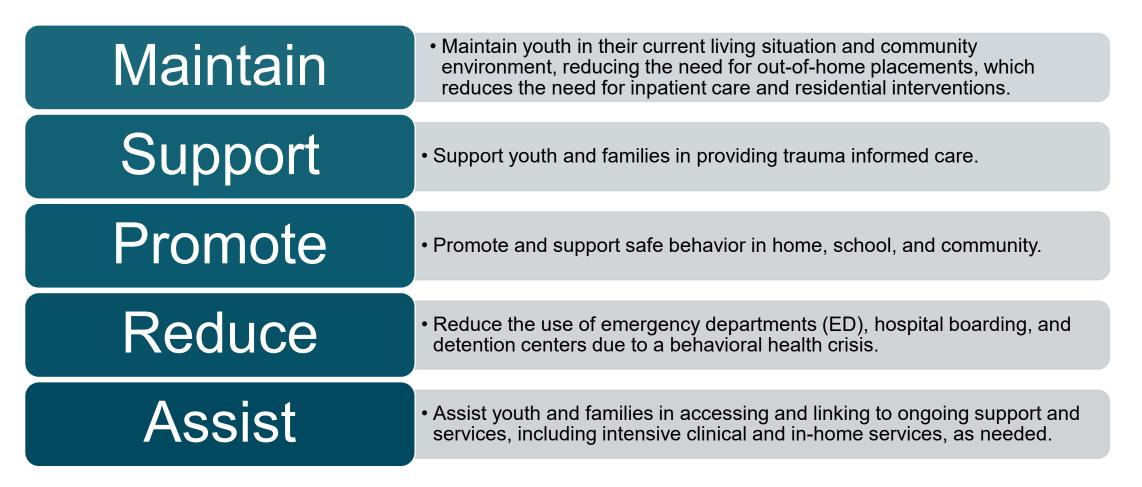
At any point throughout MRSS there should be immediate access to clinical and psychiatric consultation. Services should also include use of standardized and validated suicide screening, youth and family-specific assessment tools, and written crisis and safety plans developed collaboratively with the parent/caregiver and youth.

- 1. Someone to Contact Access Point
  - Uses single point of access that is or includes 988.
  - If the access point is a lifespan service, the triage processes for youth and their families are customized with mobile responses being the standard rather than the exception.
  - Screens and assesses for risk of self-harm at all points of engagement.
  - Screens for general safety that informs response decisions inclusive of where to meet.
  - If parent/caregiver and/or youth is not available for immediate responses, deferred in person response is offered and scheduled at their convenience within 24 hours.
  - Has established protocols for mobile response, engagement, and knowledge of community resources.
  - Provides warm hand-off to mobile response team.
  - Has the ability to remain on the line with callers until the mobile response team arrives, if needed.
- 2. Someone to Respond Mobile Response
  - Has capacity to respond with two person teams based on established protocols with consideration to safety as well as the needs of both responders and youth and families.
  - Responds without law enforcement, unless essential for safety reasons and as a last resort. Must
    include youth and family's input in the decision to use law enforcement and ensure youth/family
    is aware of use of law enforcement prior to arrival.
  - Allows for multiple 24/7/365 in-person responses for up to 72 hours, as needed.
  - Conducts essential operational functions:
    - + Provides initial de-escalation.
    - Performs a safety assessment and administers a child- and family-specific assessment tool with developmentally appropriate suicide screening protocol.
    - + Assesses immediate basic needs the family may have such as food, income, stable housing, medical care, and facilitates access to community services.
    - + Develops and implements an initial crisis and safety plan.
    - + Honors and aligns with the family and youth/young adult's culture and facilitates connection to natural/informal supports.



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### **MRSS Goals**





### WHY EFFECTIVE CARE COORDINATION IS NEEDED

#### FAMILY NEEDS ARE COMPLEX

- Youth with complex behavioral health challenges have multiple & overlapping areas of need
- Families often have unmet basic needs
- Traditional services do not attend to health, mental health, substance use, & basic needs holistically
- Prioritization of what to work on is hard to figure out

#### FAMILIES OFTEN ARE NOT FULLY ENGAGED

- Child-serving systems are complex & difficult to navigate, & families often do not know how or where to access services.
- Families & youth often feel that the system is not working for them
- Limited engagement leads to treatment dropouts & missed opportunities

## Systems do not work together well for individual families

SYSTEMS ARE IN SILOS

- unless there is a way to bring them together
- Youth get passed from one system to another as problems get worse
- Families relinquish custody to get help
- Youth are placed out of home

## Locus of Accountability: Intensive Care Coordination

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### **Residential Interventions within a System of Care**



Home Like Environment



**Trauma Responsive** 



 $\bigcirc$ 

**Non-Coercive** 



Goal is for the youth to feel better



No breaks for the team when the youth is in an out of treatment intervention Prioritize Family Engagement and Community Engagement

## Family

### Connections

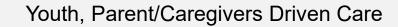
## School

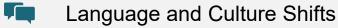
## Community



## Workforce Development

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Workforce Development: Training, Coaching and Mentoring



Care Planning with a Focus on Teaming



Non-Traditional Supports and Informal Support



Community Engagement and Resource Development is Prioritized

Data and Continuous Quality Improvement

# **Practice Shifts:**

A Center of Excellence (COE) is an organized center or partnership that supports state and/or local child- and family-serving agencies in designing, implementing, and sustaining services, practices, and frameworks that have been shown to be effective with specific populations of children, youth, young adults, or families.

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### Inside the COE

Education on system reform, EBPs, & implementation

TA on design, implementation, & selection of effective approaches & system design

Advocacy for best practice approaches

Research & evaluation related to design, installation, & implementation efforts A Center of Excellence (COE) is an organized center or partnership that supports state and/or local child- and family-serving agencies in designing, implementing, and sustaining services, practices, and frameworks Policy Development

Grant writing

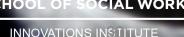
Continuous Quality Improvement (CQI) including fidelity & outcomes

Educate & teach next generation

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# We can't forget to check ourselves...

- Regular review of system utilization including referrals and eligibility criteria
  - Are we partnering with families at the right time and place?
  - Is anyone left out?
  - Service & support gaps?
- Workforce quality
  - Skill development
  - Fidelity to implemented models
  - Access to expert coaching and support
- Policy and procedure review
  - Have barriers been identified
  - Is there a need for more specificity or clarity
- As systems evolve, don't forget to check in around what is working to ensure it continues working amidst any future reform



### **Outcomes are important – quality assurance must be routine & overt across all system levels**

System rebalanced with more diversion & financing going to prevention & home & community-based supports	Behavioral health access & treatment to address disparities	Emergency room visits for behavioral health needs	Police response due to behavioral health needs
<b>Residential intervention</b>	Inpatient hospital stays	School attendance, graduation, suspension & expulsion rates	Juvenile justice involvement, detention & commitment rates
Child welfare involvement, out of home stays, incident reports with child protection & placement disruptions	Expulsions & suspensions from childcare settings due to behavioral concerns	Engagement in primary care early childhood visits	Suicide rates

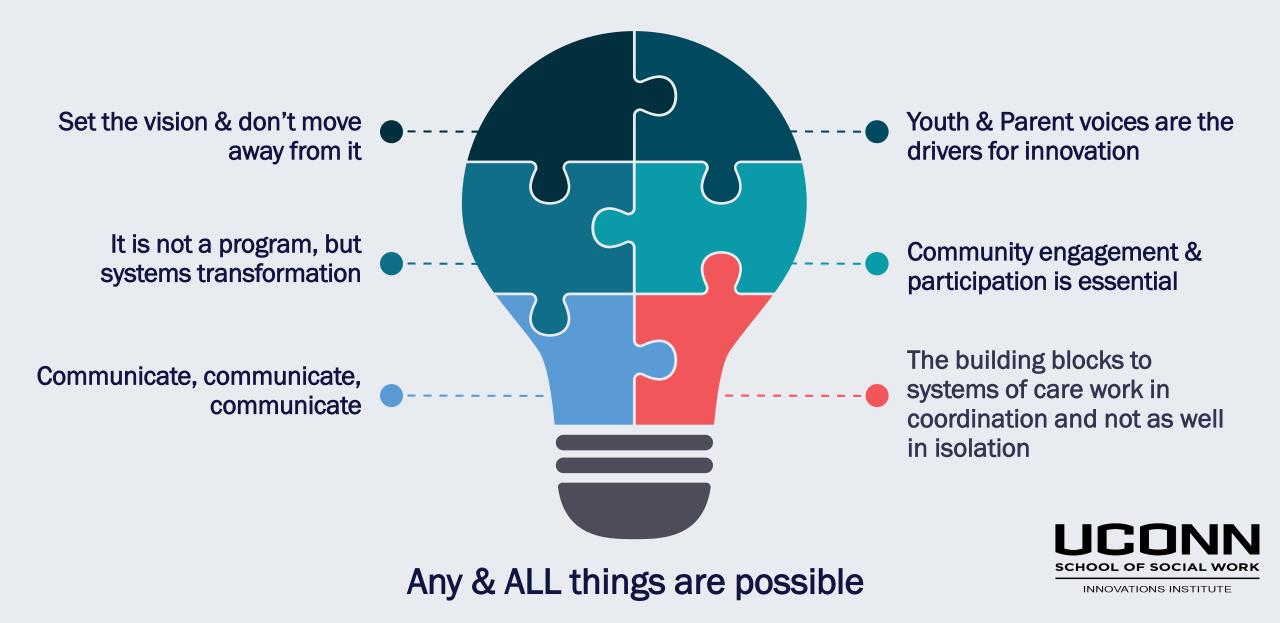


**Outcomes are important –** quality assurance must be routine & overt across all system levels

- Families report:
  - ✓ Ease of access to needed services & supports
  - ✓ Satisfaction with provided services & supports
  - ✓ They are better off because of the services & supports provided



### Best Advice & Lessons Learned from the Field





- Blau, Caldwell, Lieberman (2014). Residential Interventions for Children, Adolescents, and Families. Routledge, NY and London.
- Making the Case for a Comprehensive Children's Crisis Continuum of Care; NASMHPD 2018; <u>https://www.nasmhpd.org/sites/default/files/TACPaper8\_ChildrensCrisisContinuumofCare\_508C.pdf</u>
- Pires, Sheila; Building Systems of Care: A Primer; 2002; <u>https://gucchd.georgetown.edu/products/PRIMER\_CompleteBook.pdf</u>
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- Intensive Care Coordination Using High Quality Wraparound: Rates and Billing Structure; TA Network; 2015; <u>https://theinstitute.umaryland.edu/media/ssw/institute/national-center-documents/Intensive-Care-Coordination-Using-HQ-Wraparound-Rates-and-Billing-Structure.pdf</u>

• Stroul, B.A., & Blau, G.M. (Eds.). (2008). The system of care handbook: Transforming mental health services for children, youth and families, Baltimore, MD: Paul H. Brookes Publishing Co.





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- <u>https://www.cdc.gov/nchs/data/vsrr/vsrr034.pdf</u>
- <u>https://www.npr.org/sections/health-shots/2023/11/29/1215704543/suicide-rates-2022-teen-young-adults</u>
- <u>Children MH Facts 9-21-16\_rev (nami.org)</u>
- <u>Microsoft Word Mobile Response Best Practices.January</u> 2023.docx (uconn.edu)
- Home Building Bridges Initiative (buildingbridges4youth.org)
- trauma-informed-care.pdf (uppsala.se)





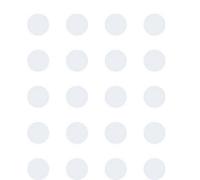
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