Snapshot: Community Feedback on Accessing Infant and Early Childhood Mental Health Services

Presentation to Early Learning Council

February 27, 2023

Governor's Office of
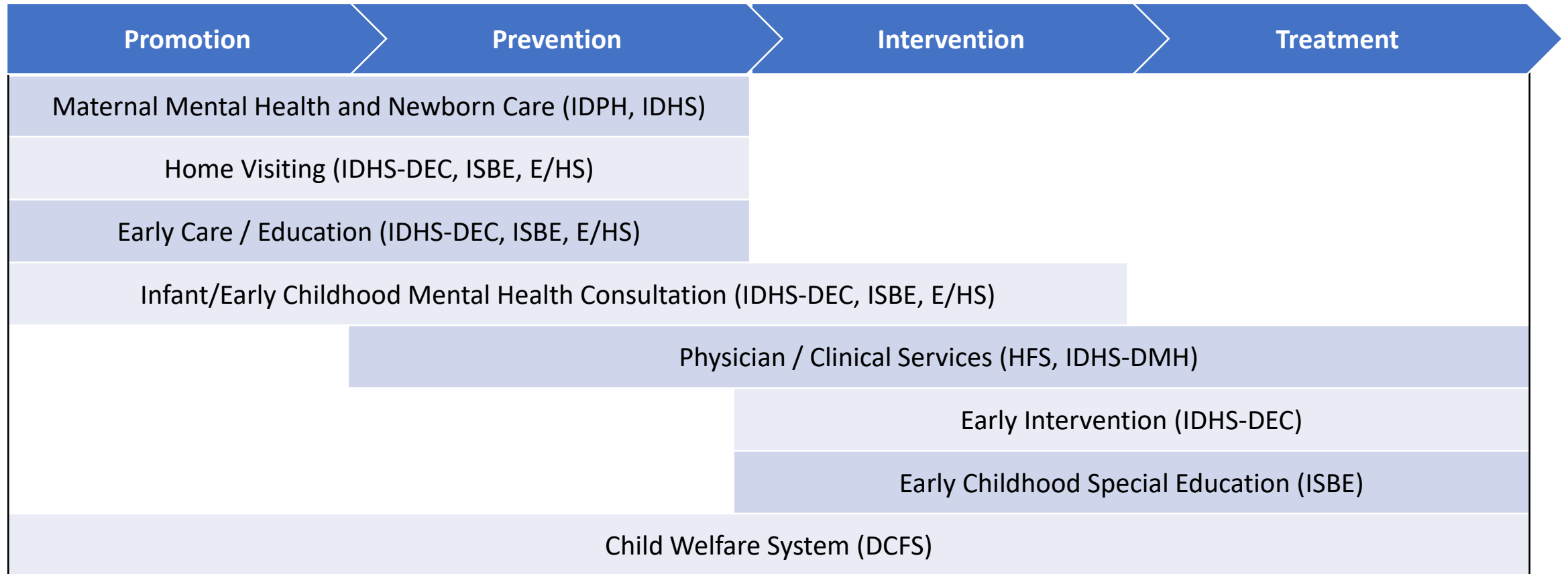Early Childhood Development

Introduction

Background

- There is a growing need for infant and early childhood mental health (IECMH) services for children under the age of six

- While Illinois has several publicly funded programs to support IECMH, families are struggling to find and access these services

- To inform how State leaders can help, an independent consultant spoke to a few community members* to begin to understand their perspectives on systemic barriers and opportunities

Objectives for today

- Share this snapshot of community members' feedback on Illinois IECMH systems to encourage and guide conversations on improving access to mental health support for young children

*Based on conversations with 26 community members involved in State IECMH programs, including families and service providers; may not represent entire population.

The Infant and Early Childhood Mental Health (IECMH) system includes various State agencies and services that span the mental health continuum

Publicly funded mental health service areas for children under the age of six (agencies)

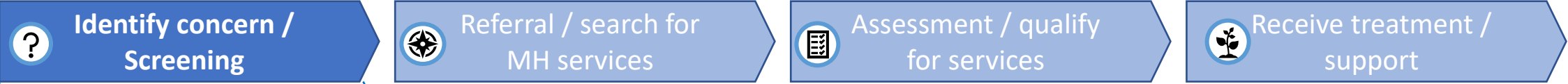| Promotion	Prevention	Intervention	Treatment
Maternal Mental Health and Newborn Care (IDPH, IDHS)			
Home Visiting (IDHS-DEC, ISBE, E/HS)			
Early Care / Education (IDHS-DEC, ISBE, E/HS)			
Infant/Early Childhood Mental Health Consultation (IDHS-DEC, ISBE, E/HS)			
	Physician / Clinical Services (HFS, IDHS-DMH)		
		Early Intervention (IDHS-DEC)	
		Early Childhood Special Education (ISBE)	
Child Welfare System (DCFS)			

Why should we strengthen the IECMH system?

- Before the pandemic, **1 in 6 U.S. children aged 2–8** years (17.4%) had a diagnosed mental, behavioral, or developmental disorder.[1]

- For children with treatable mental health disorders, **about half do not receive adequate treatment**. Receipt of treatment or counseling also increases with age, from 36.1% of children ages 3-5 years to 60.2% of adolescents ages 12-17 years.[2]

- During the pandemic, **44% of parents** said their young child exhibited **more physical or behavioral symptoms** than before, in a survey by Ann & Robert H. Lurie Children's Hospital of Chicago.[3]

"Kids need help before they are in crisis."
– Parent/Guardian

"Families can't access services that do not exist, or do not have trained providers that can help them in locations that are convenient."
– Community Mental Health Center

"We need to do a better job acknowledging when a parent has concerns, believing them, and taking action"
– Early childhood service provider

*References located in the notes section of this slide

Barriers to accessing services: feedback from community members*

Identify concern / Screening	Referral / search for MH services	Assessment / qualify for services	Receive treatment / support

Key concern

Potential causes shared

1 Mental health need is not recognized

- Parent and EC service providers do not know signs of IECMH needs
- Service providers don't believe parent's concern
- Parent may have a mental health need of their own and doesn't recognize child's

2 No action is taken

- Pediatricians and other professionals are hesitant to act, or don't know how to, at this young age
- Adults are slow to leverage early, preventative actions; wait for a crisis event to respond
- Providers think parents are worried about stigma for their child or to be labeled as "a bad parent"

"Parents don't always have the knowledge to ask questions around mental health." – Community Mental Health Center (CMHC)

"It's like I had to prove to their teachers and pediatrician that something was wrong. That was really hard on me." – Parent

"Doctors are hesitant to confirm a need for children under five. They say, "Wait," but we know that makes it worse." – Early Childhood (EC) service provider

*Snapshot of community member perspectives; may not represent entire population.

Barriers to accessing services: feedback from community members*

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Key concern	**Potential causes shared**	
3 Few mental health professionals serve age 0-5, especially with Medicaid	• It's a niche field; obtaining the deeper expertise needed to treat 0-5 is costly • This field is not promoted enough in colleges • The "whole-systems" approach needed to serve young children is costly; Reimbursement rates and administrative processes deter providers from accepting Medicaid	*"It's an ongoing challenge to come up with ways that will allow for best practices while balancing the need to make the program fiscally sustainable." – CMHC*
4 Parents are burdened by the search for providers	• Families are calling MH professional one-by-one to find services, which is daunting • MCO and public systems do not have enough detail to help parents find a Medicaid provider, near them, who serves young children	*"If I hadn't gotten the therapist's name from WIC, I don't know how I would have found someone." – Parent*
5 People struggle to optimize services across systems	• Silos between agencies can make the system feel disjointed to families; stand-alone components • Providers don't know the whole system well enough to help parents access all programs	*"Families can be funneled into one system and get stuck there because providers don't know how to move them between systems in a fluid way." - CMHC*

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Barriers to accessing services: feedback from community members*

Identify concern / Screening	Referral / search for MH services	**Assessment / qualify for services**	Receive treatment / support

Key concern	**Potential causes shared**	
6 Eligibility requirements are too narrow; gap for age 3-5 in particular	• 30%+ delay can be hard to quantify for SE domain in EI; lack of awareness on other ways to qualify for EI • The age window for EI is really small; parents miss the deadline a lot • Special education is perceived to be for only medical conditions and disrupting behaviors • There are few alternatives for age 3-5 if don't qualify for special education since few clinicians serve children under 6	*"In my opinion, the 6 months we missed because she didn't qualify for EI by a smidge were crucial." – Parent* *"It is very hard to get mental health support because the definition and screening criteria are too narrow. We need to expand the list of what accounts for trauma." – EC service provider*
7 Providers lack awareness of tools / policies that expand services	• Common tools (IM+CANS) don't have early-age signs of MH; DC:0-5 helps but it's new • CMHCs may not be aware that they can, or how to, serve a child "at risk" of a diagnosis	*"There are emerging issues that haven't reached the level of diagnosis yet, and so we can't help them." – CMHC*

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Barriers to accessing services: feedback from community members*

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Key concern	Potential causes shared	
8 MH treatment is expensive and hard to get to	• Mental health services are not affordable without insurance; Medicaid copays can be hard to afford too • Families with Medicaid are traveling far, or using out-of-network services, or have long wait times, especially rural areas	*"We need to integrate mental health professionals to where children are already going." – EC service provider*
9 Families need more holistic support, and through age six	• Clinicians feel that diagnosis requirements limit how much they can support family members • Special edu is focused on the child only	*"There needs to be more support for the families. EI had it, but when a child goes into school that parental support is gone." – Parent*
10 There is a shortage in alternatives to therapy as well	• General workforce shortage in ECE limits alternatives for supporting 0-5 mental health • Not all early childhood service providers have the capability to help with mental health; need training	*"We try to work on behaviors in-house since it's so hard to get mental health services." – EC service provider*

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How can we improve access to services that support IECMH?

Recommendations from community members*

1	**Increase system capacity**	• Grow the number of MH professionals that serve children under 6, and clinicians that accept Medicaid • Broaden eligibility and assessment approach to allow for earlier intervention and to close the service gap for age 3-5 • Provide more equitable access to treatment (geography, language)
2	**Better connect families to services**	• Increase awareness of IECMH to all adults that work with young children (signs of MH needs and services) • Encourage taking action earlier, especially pediatricians • Improve search engines, data systems and support personnel to help families find MH professionals
3	**Broaden service model**	• Expand MH capabilities of ECE workforce • Provide holistic family support in all programs • Increase community-based opportunities for social-emotional development (sub-clinical support)

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Take-away: Please consider discussing IECMH in your committee meetings

Recommended Discussion Questions:

1. How well do these IECMH opportunities align with the work you are leading?

2. Are there opportunities to expand your work to better support IECMH?

3. Are there collaboration opportunities to accelerate improvement efforts for IECMH?

Additional resources available via GOECD:

1. IECMH Community Needs Snapshot - Full Report

2. IECMH Cross-Systems Guide to Accessing Illinois Services

3. Illinois IECMH Reference Sheet (multiple languages)