Accessing Infant and Early Childhood Mental Health Services

Snapshot of Community Feedback on Systemic Barriers and Opportunities

December 2022

Abstract

This report summarizes the perspectives shared by a few community members involved in Illinois' publicly funded programs that support infant and early childhood mental health (IECMH), including parents/guardians and service providers. It is intended to encourage and begin to guide State and community leaders' conversations on improving access to mental health services in Illinois for children under the age of six.

Governor's Office of Early Childhood Development

Executive Summary

There is a growing need for infant and early childhood mental health (IECMH) support for children under the age of six, exacerbated by the COVID-19 pandemic. While Illinois has a number of publicly funded programs to support this, families and the service providers that help them are struggling to access mental health services for young children. Based on national survey, in 2018-2019 just over half (53.2%) of children ages 3-17 years with a current mental or behavioral health condition received treatment or counseling from a mental health professional in the past year, and 42.8% took medication for an emotional, concentration, or behavioral condition.[1]

To better understand how State leaders could help address this problem in Illinois, an independent consultant was hired to talk to a few community members*, including parents/guardians and service providers, to begin to gather their perspectives on systemic barriers and opportunities. While these community members shared a number of strengths of IECMH systems, many were concerned that the mental health needs of young children in Illinois are not being met due to the following reasons:

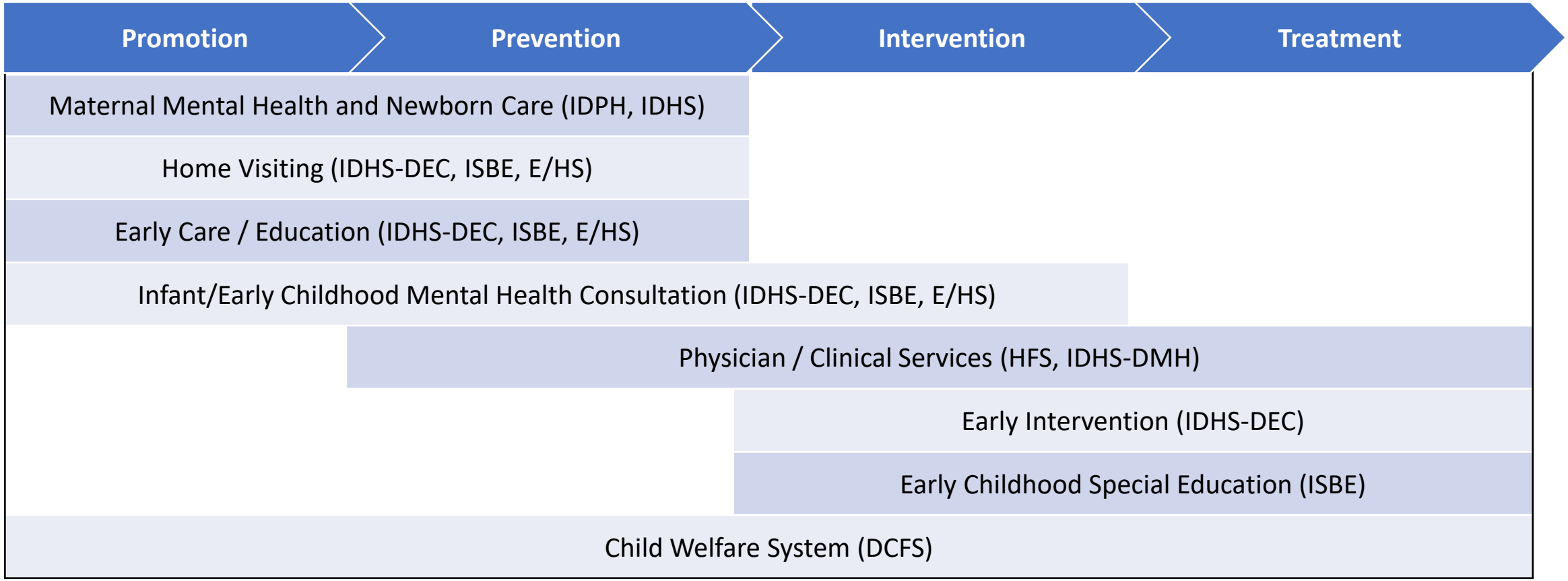
1. Most adults don't know how to identify mental health needs at this young age, or are hesitant to do so; caregivers feel like they have to advocate strongly to get early care/education and healthcare professionals to take action.
2. There is a shortage in clinicians that serve children under six, especially with state insurance (Medicaid); families are significantly burdened by the search effort to find one when not supported by a service provider.
3. Assessments and eligibility requirements are perceived to limit serving children early enough (before a crisis), between age 3-5 (when there isn't a medical condition), and providing holistic family support.
4. Treatment/therapy can be hard to receive when outside the family's community or routine, especially in rural areas; more local, non-clinical environments would help support children's development.

The following slides include more detail on the feedback shared by these community members and opportunities to expand on the work that State agencies are currently leading to increase access to infant and early childhood mental health.

*Based on conversations with 26 community members involved in State IECMH programs; This snapshot may not represent the entire population. Details in appendix.

The Infant and Early Childhood Mental Health (IECMH) system operates as a mixed delivery system, which 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*)



*Glossary of acronyms located in appendix.

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.[2]
- 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.[3]
- 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.[4]

"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 appendix.

How do children under six access mental health services?

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

Typical actions	• Parent or friend recognizes a concerning behavior / difference from other children; or
	• Early childhood professional (e.g., home visitor, teacher, Infant/Early Childhood Mental Health Consultant, DCFS) identifies concern; or,
	• Concern is identified via preventative screening in pediatric well-child visit.
		• Parent searches for service provider on their own, using search engines, Medicaid Managed Care Coordinator, or word-of-mouth; or,
		• Early childhood professional refers child to a mental health program or provider directly; or,
		• Parent takes child to primary care provider (PCP) who verifies concern and refers family to a program or service provider
			• Child completes an assessment to determine level of delay or diagnosis to qualify for services:
			• Early Intervention (EI): children age 0-3 with 30%+ delay, medical condition, or risk factors
			• Special education: children age 3-5 with social-emotional disabilities that adversely affect educational performance
			• Clinician: children age 0-5 that meet or are at risk of a DC:0-5 diagnosis
				• Service location varies by provider:
				  • EI: provider goes to the child's location during the day
				  • Special education: as determined by the IEP team, often a school district location
				  • Clinician: typically at a clinic
				• If child doesn't qualify, provider may recommend alternative supports (e.g., play groups, preschools)

While there are a number of pathways to mental health services for young children, families struggle to find and receive services.

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/Guardian

"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*

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

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
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
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

"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

"If I hadn't gotten the therapist's name from WIC, I don't know how I would have found someone." – Parent/Guardian

"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

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

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/Guardian* *"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*

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

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
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
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
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 need to integrate mental health professionals to where children are already going." – EC service provider

"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/Guardian

"We try to work on behaviors in-house since it's so hard to get mental health services." – EC service provider

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

Additionally, community members recognized a number of strengths in IECMH systems that could be built upon

- All community members recognized the value of early childhood services to support the child and family – such as home visiting, preschools, Early Head Start, and wish all families could access these.
- Families highlighted the effectiveness of models that come to them, such as Early Intervention (EI), home visiting, and some individual clinicians.
- Referrals or hand-offs between service providers were extremely helpful and appreciated (e.g., referrals to therapists that serve young children, EI transition to special education).
- The recent introduction of the DC:0-5 is helping clinicians diagnose mental health needs in young children.
- There is a growing trend for doctor's to have mental health specialists associated with their office.

EXAMPLES

"Thankfully, I always had someone in the house to help us – 'This is what we do next.'" – Parent/Guardian

"We try to maximize the supports we have available to help the family as broadly as possible." – EC service provider

"The DC:0-5 helps by adding the signs for mental health needs in young children to the IM+CANS, which used to be a barrier." – CMHC

"The EI model was great! And they made the transition to special education so easy." – Parent/Guardian

How can we improve access to services that support IECMH?

Recommendations from these 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)

*Snapshot of community feedback; may not represent entire population. Additional details located in appendix.

Program leaders are focusing on some of these opportunities already

	Focus areas	Example IECMH State-led initiatives in progress or planned for FY2023 (agency*)
Increasing number of MH providers	Expanding capabilities of current EI and clinical professionals to provide mental health services for young children	• Offering EI service provider training on mental health (e.g., pyramid principle, trauma informed) (DEC-EI) • Expanding CMHC service delivery by providing training on treatments for common diagnoses in DC:0-5, based on data collection (DMH, HFS) • Expanding access/providers of more intensive services for young children (HFS)
Expanding eligibility	Broadening SE diagnoses for EI and building CMHC capacity for clinical assessments	• Expanding EI eligible social-emotional diagnoses (DEC-EI) • Offering CMHCs training on how to use DC:0-5 to make a diagnosis for age 0-5 (DMH)
Promoting programs	Disseminating, or better communicating, information on accessing available services	• Disseminating program info to increase community awareness / enrollment (DEC-C&P) • Developing community reference sheet on IECMH programs (GOECD) • Improving website and communications on children's behavioral health services (HFS) • Improving EI service coordinator communication with families (DEC-EI)
Supporting role of pediatrician/PCP	Enabling pediatricians/ PCPs to screen for MH needs and better refer to services	• Forming PCP work group to improve screening tools and promote referral process (HFS) • Expanding DocAssist program (DPH-MCH)
Improving access to I/ECMHC	Increasing opportunities for early childhood workforce to utilize I/ECMHC	• Increasing Caregiver Connections workforce (DEC-C&P) • Expanding EI providers' use of I/ECMHC (DEC-EI) • Requiring HV programs to contract with consultant from I/ECMHC Registry (DEC-HV) • Hiring I/ECMHC Coordinator to support I/ECMHC's use of FAN framework (DEC-HV) • Making I/ECMHC an allowable expense within the ECBG budgets (ISBE)
Supporting Early Childhood workforce and system	Offering professional development and other supports for early childhood system	• Providing teacher professional development on mental health through ECPL and STAR NET projects that focus on SE skills and implementing the Pyramid Model (ISBE) • Address workforce shortage to open more E/HS classrooms (Office of HS) • Exploring therapeutic classrooms and smaller groups to help influx of MH needs (E/HS)

*Glossary of acronyms located in appendix

Opportunities for State, program and community leaders to further respond to the concerns raised by these community members

	Identify concern / Screening	Referral / search for MH services	Assessment / qualify for services	Receive treatment / support
Potential strategic focus areas	• Increase access to IECMH training for all professionals that work with young children; consider cross collaboration on PD programs or content • Accelerate efforts to encourage and enable pediatricians and teachers to more readily screen and refer to EI/clinical mental health assessments • Launch a public campaign on IECMH to increase awareness and foster early action when needed	• Promote IECMH careers and education to strengthen the pipeline to early childhood MH professions (pre-service) • Further scale training on DC:0-5 and treatment models to all clinicians that accept Medicaid (in-service) • Disseminate more cross-system program information (e.g., flyers, websites, outreach) • Enhance fiscal stability to treat IECMH (e.g., Medicaid reimbursement rates, subsidize training) • Improve data systems and search tools to include more (and accurate) details to find MH providers of 0-5	• Continue to strengthen eligibility and assessment for the social-emotional domains in EI and special education to allow flexibility and more contextual identification of early needs • Rapidly scale up training and communications to increase clinician awareness of DC:0-5 diagnosis and ability to serve children “at risk” of a diagnosis • Identify strategies to close the service gap for age 3-5 (e.g., expand eligibility categories or age limits, double down on growing number of clinicians for age 3-5)	• Increase awareness and enrollment in Medicaid/ All Kids to help more families afford mental health services • Expand programs/funding in service deserts (e.g., rural areas) • Provide more funding to support community-based alternatives to therapy (e.g., access to ECE, play groups, parent cafes, I/ECMHC) • Expand eligibility and/or service models to provide holistic support to families through age 6 (e.g., therapy, coaching, referrals)

Additional resources

This study created additional resources which are available on the GOECD website:

1. IECMH Cross-Systems Guide to Accessing Illinois Services

   - This guide aims to explain the various parts of Illinois' publicly funded infant and early childhood mental health (IECMH) systems and how to access the services within them. It is intended for early childhood and mental health professionals to help them facilitate connections to services for families that seek mental health support for children under the age of six. It is available at: https://oecd.illinois.gov/content/dam/soi/en/web/oecd/events/event-documents/02-27-2023-iecmhcrosssystemsguidetoaccessingillinoisservices-final.pdf

2. Illinois IECMH Community Reference Sheet (multiple languages)

   - This reference sheet was designed to introduce State-funded IECMH programs and services to community members and provide service providers a tool to share these supports, and a first step to accessing them, with families that have concerns about their young child's mental health and social-emotional development. It is available in multiple languages. The English version is available at: https://oecd.illinois.gov/content/dam/soi/en/web/oecd/documents/resources-reference-parents-families-iecmhc-eng.pdf

Acknowledgements

This community needs snapshot was made possible by the PDG B-5 Renewal Grant, Supplemental Fund Project Grant. Per a promise of confidentiality, we cannot list the 26 community members that shared their experiences, but we deeply appreciate their time and perspectives.

The recruitment of community members and summarization of their feedback was guided by a project leadership team that included program leaders from agencies that support infant and early childhood mental health in Illinois. A few community partners also guided our approach and supported the recruitment of community members to speak to.

We thank all of these contributors for their time and assistance!

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APPENDIX

Overview of approach

Objectives

Begin to explore community perspectives on improving access to mental health support for children under the age of six by gathering feedback from a few parents/guardians and service providers currently involved in the State's IECMH programs.

Purpose

To inform how State and community leaders can help improve pathways to services for young children. This report was created within a broader cross-systems study focused on helping families connect to state-wide programs that support mental health.

Timeline: June 2022 – December 2022

Participation: 26 community members

- 6 Parents/Guardians
- 5 Community Mental Health Center clinicians
- 8 Early Intervention, Home Visiting, I/ECMHC professionals
- 3 Physicians or Medicaid representatives
- 4 individuals from Advocacy Organizations
- From counties: Adams, Carroll, Cook, DeKalb, DuPage, Lee, Madison, McHenry, Ogle, St. Clair, Whiteside

Example questions

1. How are mental health concerns identified for children under the age of 6?
2. How do families find a program and service provider to help their child with a mental health need?
3. How do they qualify for these services?
4. Where do they go to receive the therapy / treatment needed?
5. How can we make it easier for families to access mental health services, and for providers to help them?

Community members' ideas to improve access to IECMH support (additional details)

	Recommendations*	Examples
Grow number of MH professionals	Grow the number of MH professionals that serve 0-5, and accept Medicaid	• Fund or provide training on mental health treatment models for 0-5 • Increase university partnerships to market this field to new grads • Improve Medicaid reimbursement (fee, process) to incentivize services for children under 6
Expand eligibility	Expand eligibility to allow for earlier intervention and provide more services for age 3-5	• Enable service providers to treat children when child's need is not quite 30% delay or full diagnosis (e.g., increase awareness of new policies that allow for this) • Expand special education or clinical services to close gap for 3-5 year old's
Provide more equitable access	Make it easier for all to receive treatment (affordable, local)	• Bring more services to where the families are (e.g., integrated health centers, EI model, more clinical locations in rural or underserved communities) • Simplify Medicaid billing and make it more affordable (lower copays or payment plans) • Increase multi-lingual providers so treatment is in native language
Increase knowledge and action taking	Increase awareness of IECMH (signs, needs and services) to encourage taking action earlier	• Distribute information that helps service providers and families understand services available (e.g., program flyers at schools or hospitals, websites) • Offer more training to the EC workforce and healthcare professionals on the signs of mental health concerns in young children • Promote more actively screening and referrals for assessments, especially teachers and PCPs
Improve navigational tools and support	Improve search engines and family support to find MH professionals	• Include more detail in search tools to make referrals more useful (e.g., match mental health need, age, and Medicaid plan), including healthcare systems that MCOs use • Increase access to professionals who can assist families in searching for programs and providers (more and improved care coordination, centralized or single hubs/hotline) • Encourage and support all providers to refer families to other services (warm handoff)
Broaden MH service model	Expand holistic family support	• Extend the family coaching/support model from EI into services for ages 3-5 • Expand clinician service model to support family members more when helping child
Offer more sub-clinical support	Increase opportunities for social-emotional development	• Increase access to early care/education environments that can support mental health • Fund community activities that support SE development (play groups, parent groups)

*Snapshot of community feedback; may not represent entire population.

Glossary of Acronyms

CMHC	Community Mental Health Center
DCFS	Department of Child and Family Services
DEC-C&P	Division of Early Childhood-Community & Partnerships
DEI	Diversity, Equity, and Inclusion
EC	Early Childhood
E/HS	Early Head Start / Head Start
EI	Early Intervention
GOECD	Governor's Office of Early Childhood Development
HFS	Healthcare and Family Services
HV	Home Visiting
IDHS (DHS)	Illinois Department of Human Services
IDHS-DEC	Illinois Department of Human Services-Division of Early Childhood
IDHS-DMH	Illinois Department of Human Services-Division of Mental Health
IDPH (DPH)	Illinois Department of Public Health
IECMH	Infant and Early Childhood Mental Health
I/ECMHC	Infant/Early Childhood Mental Health Consultation
IM+CANS	Illinois Medicaid Comprehensive Assessment of Needs and Strengths
ISBE	Illinois State Board of Education
MCO	Managed Care Organization (Medicaid)
MH	Mental Health
PCP	Primary Care Provider
SE	Social Emotional
WIC	Women, Infants, and Children

Endnotes

1. In 2018-2019, just over half (53.2%) of children ages 3-17 years with a current mental or behavioral health condition received treatment or counseling from a mental health professional in the past year, and 42.8% took medication for an emotional, concentration, or behavioral condition. Source: HRSA National Children's Health Survey, Mental Health brief 2020; https://mchb.hrsa.gov/sites/default/files/mchb/data-research/nsch-data-brief-2019-mental-bh.pdf

2. From parent-reported data in 2016, 1 in 6 U.S. children aged 2–8 years (17.4%) had a diagnosed mental, behavioral, or developmental disorder. Source: https://www.cdc.gov/childrensmentalhealth/data.html. Based on article: Cree RA, Bitsko RH, Robinson LR, Holbrook JR, Danielson ML, Smith DS, Kaminski JW, Kenney MK, Peacock G. Health care, family, and community factors associated with mental, behavioral, and developmental disorders and poverty among children aged 2–8 years — United States, 2016. MMWR, 2018;67(5):1377-1383, available at https://www.cdc.gov/mmwr/volumes/67/wr/mm6750a1.htm

3. 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. Source: HRSA National Children's Health Survey, Mental Health brief 2020; https://mchb.hrsa.gov/sites/default/files/mchb/data-research/nsch-data-brief-2019-mental-bh.pdf

4. In a recent survey by Ann & Robert H. Lurie Children's Hospital of Chicago, 44 percent of parents said their young child exhibited more physical or behavioral symptoms during the pandemic than before. Source: https://www.luriechildrens.org/en/news-stories/pandemic-dramatically-increases-childrens-mental-health-difficulties/