PEDiatric Mental Health Care: Needs Assessment for Illinois
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Background
About Illinois Pediatric Mental Health Care Access Expansion Project

ICAAP and the University of Illinois Chicago’s (UIC) DocAssist are the two grantees in a federally funded project with the Illinois Department of Public Health (IDPH), the Department of Healthcare and Family Services (HFS), and the Department of Human Services (DHS). This collaborative effort is known as the Illinois Pediatric Mental Health Care Access Expansion project (PMHCA). The PMHCA is funded by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services’ (HHS) through two programs authorized by Congress: the American Rescue Plan and the Bipartisan Safer Communities Act.

About the Children’s Mental Health Crisis in Illinois

Health systems, health care providers, and families in Illinois are struggling to effectively address children’s mental health due to limited resources, lack of access to mental health care, and the high volume of patients in crisis with limited support available for providers. As the mental health needs of children and families in Illinois continue to increase, our state’s pediatricians and other pediatric healthcare providers find themselves on the frontlines, conducting key screenings and interventions, to support children and families. In fact, pediatric primary care settings are often the first place parents seek help when they have issues, concerns, or questions regarding the mental health and development of their child.

About Illinois Chapter, American Academy of Pediatrics

The Illinois Chapter of the American Academy of Pediatrics (ICAAP) is a membership organization of approximately 2,000 pediatricians throughout Illinois. ICAAP is dedicated to improving the health and well-being of infants, children, and adolescents throughout Illinois. ICAAP advocates on behalf of children, families, and health professionals; develops and provides continuing medical education and resources for pediatric professionals; and collaborates with other organizations on programs and projects that improve the health and well-being of children.
Proposed ICAAP Tasks & Goals

We recognize that pediatricians and other pediatric health care providers have key insights into patient well-being because of their opportunity and ability to develop relationships and build trust with parents and caregivers in order to support children. ICAAP seeks to help build capacity and confidence in mental health screening, diagnosis, care, and outreach for pediatric health care providers throughout Illinois.

At ICAAP, we are eager to leverage our network and resources to complete the following tasks as a part of our work on the Illinois PMHC:

- Develop educational interventions to support best practices in mental health care for children and adolescents
- Share streamlined methods for connecting families to new resources in the mental health care system
- Increase the number of pediatric care providers adapting the principles of trauma-informed care into their practice
- Link pediatricians and pediatric offices to expand efforts in their communities
- Promote the American Academy of Pediatrics (AAP) guidelines on mental health services and policies throughout Illinois

*The Illinois Pediatric Mental Health Care Access Expansion is funded by the U.S. Department of Health and Human Services’ (HHS) Health Resources and Services Administration (HRSA) through two programs authorized by Congress, the American Rescue Plan and the Bipartisan Safer Communities Act.

Setting State-Wide Direction on Children’s Mental Health Care Services

Although health care providers in Illinois have access to general mental health trainings, there is no statewide direction or Illinois-specific education for pediatric health care providers. We believe an education program tailored to the needs of Illinois pediatric health care providers will help to create a network of support that expands capacity, builds confidence, and facilitates the application of skills and knowledge in pediatric settings. In order to foster the successful transformation of the children’s mental health care in Illinois, pediatricians and other pediatric care providers must be included as first-line providers in mental health care and support.

In March 2022, Governor JB Pritzker launched the Children’s Behavioral Health Transformation Initiative to evaluate and redesign the delivery of behavioral health services for children and adolescents in Illinois. As Illinois embarks on transformational change in the delivery of behavioral health services, it is vital that pediatricians be informed of these new opportunities and included in the development of these systems to ensure a seamless connection of physical and behavioral health services.
Introduction
Introduction

The ICAAP team has taken steps to assess the needs of pediatric health care providers in Illinois around mental health services by conducting a needs assessment survey and coordinating key focus groups to better determine a successful plan of action. These activities took place between April 2023 and July 2023.

To facilitate an effective needs assessment, ICAAP assembled an advisory group made up of subject matter experts and leaders in pediatric health care in Illinois. In partnership with ICAAP staff, this group provided vital input on the development of the assessment tools used in this initiative.

Members of this advisory group include:

- **Frank Belmonte, DO, MPH, FAAP**: Chief Medical Officer, Advocate Children’s Hospital
- **Mary Dobbins, MD, FAAP**: Director of Integrated Care, SIU Springfield
- **Nidhi Kukreja, MD, FAAP**: Pediatrician, Esperanza Health Centers
- **Jennifer Thomas, MD**: Family Medicine (Primary Care), IAFP/Pathways/Morris Hospital
- **Anna Volerman, MD, FAAP**: Associate Professor of Pediatrics, University of Chicago

ICAAP also partnered with sr4 Partners, a consultancy firm based in Chicago, to conduct all necessary needs assessment activities.

About this Report

This report summarizes the information uncovered during the needs assessment process. ICAAP will use this information to develop and execute appropriate training and education activities to enhance pediatric health care providers’ capacity and confidence around screening, diagnosis, and treatment of children’s mental health within their practice. The aforementioned advisory group will be responsible for guiding the development of the curriculum and implementation of future activities.

For this report, the term mental health care encompasses behavioral health and emotional health.
NEEDS ASSESSMENT:
Survey Methodology
Survey Content and Structure

sr4 conducted an online survey using Typeform software which allowed ICAAP to better reach health care providers throughout the state. The survey questions were broken out by topic following this order:

- **Patient Population**: Questions exploring the extent of mental health concerns in patient populations and how this may be associated with adverse social determinants of health or developmental concerns.
- **Professional Development**: Questions to better determine interests and areas of need.
- **Mental Health Screening**: Questions to identify what screening tools are being used, how practices are implementing these tools, etc.
- **Practice Readiness**: Questions requesting information on frequency of screening activities, the establishment and use of crisis clinical protocols, etc.
- **Resources and Referrals**: Questions seeking greater details on provider awareness and use of referrals, types of referrals, etc.
- **Skills and Knowledge**: Questions requesting details on health care provider activities, skills, and comfort with mental health care delivery.
- **Demographics**: Questions requesting basic demographic information like profession, area of specialty, type of practice, and location.
- **Barriers to Providing Care**: Questions to identify the support and resources currently available to providers and those still needed for providers and clinics to implement best practices in mental health care.

The survey included 44 questions delivered in a variety of styles to ensure accurate and comprehensive data that reflects the needs, feedback, and mental health practices of each region. Styles included:

- Multiple Choice
- Likert Scale
- Open Ended
- Yes/No
- True/False
- Rating/Satisfaction
- Frequency

Respondents were required to answer all questions. The survey also included skip logic and conditional design to ensure respondents only answered applicable questions.

The ICAAP team and advisory board reviewed the survey and provided feedback for the most effective strategy. The survey was estimated to take respondents 15 minutes to complete, however, the average completion time was 26 minutes.
**Provider Location Categorization for Survey Analysis**

ICAAP used the following regional map, developed by the Division of Mental Health of the Illinois Department of Health and Human Services, as a guide to effectively group survey respondents by location.

**Respondents were broken out by the following regions:**

- **Region 1** covering Cook County, including Chicago
- **Region 4** covering Hancock, Adams, Schuyler, Brown, Cass, Menard, Logan, DeWitt, Macon, Piatt, Douglas, Edgar, Clark, Coles, Cumberland, Effingham, Shelby, Moultrie, Christian, Montgomery, Sangamon, Morgan, Macoupin, Green, Jersey, Calhoun, Scott, and Pike counties
Survey Launch and Distribution Information

Once approved, the survey was opened for participation on Wednesday, June 14, 2023, and closed on Tuesday, July 4, 2023. The survey was open to all primary pediatric health care providers and subspecialists in Illinois.

The ICAAP team conducted large scale and targeted outreach activities to drive reach and engagement across all regions.

These distribution outreach efforts included:

- Email Blasts
- Mentions in ICAAP’s Weekly Newsletters
- Social Media Posts
- Printed Fliers
- QR Codes for Digital Access

To get a comprehensive analysis of the needs of pediatric health care providers, ICAAP engaged valued partners to share the survey with their networks. These partners include:

- University of Illinois at Chicago and Illinois DocAssist
- ICAAP Membership, Executive Board members, and friends
- Chicago Department of Public Health
- Local Health Department leadership from throughout the state
- Illinois Academy of Family Physicians (IAFP)
- Illinois Association of School Nurses (IASN)
- Illinois Critical Access Hospital Network (ICAHN)
- Illinois Rural Health Association (IRHA)
- Illinois Vaccinates Against COVID-19 (I-VAC) network
- Leadership from Illinois pediatric academic medical centers

Ethical Considerations

Ethical considerations included confidentiality, informed consent, anonymity, free participation, language to minimize bias, and sponsor disclosure. Participant demographics were collected confidentially, with no personal identifying information being asked or shared. The needs assessment clarified the sponsor’s interest, purpose, and intended outcomes only. Participant anonymity and data security were maintained throughout the collection, review, and reporting process. All survey respondents voluntarily contributed insights without coercion or compensation.

Challenges

Eliciting the participation of busy providers was expected to be a challenge. In the pursuit of more inclusive and diverse perspectives, the survey was distributed through a number of organizations in addition to ICAAP. Subsequently, the number of potential respondents (and the subsequent response rate) is unknown. In general, however, the response rate was consistent with prior ICAAP surveys, and the demographics representative of the target audience.
NEEDS ASSESSMENT:
Survey Findings
Respondent Demographics

176 pediatric health care professionals completed this needs assessment survey.

Profession & Specialization

77% of respondents self-identified as pediatric physicians. Respondents identified as:

- 77% Physicians
- 10% Nurses
- 7% Nurse Practitioners
- 2% Physician Assistants
- 4% Other (Social Workers, Childcare Providers, Therapists, Community Health Workers, Professional Administrators)

Self-identified specializations include:

- 70% Pediatrics
- 11% Family Medicine
- 6% Internal Medicine
- 1% Psychiatry/Developmental Pediatrics
- 12% Other
**Location**

More than half of the health care providers who responded practice in Cook County:

- **53%** Region 1
- **21%** Region 2
- **17%** Region 3
- **5%** Region 4
- **4%** Region 5

This directly reflects the density of pediatricians across the state:

- **Region 1 (Cook County & Chicago):** 56.43%
- **Region 2:** 27.87%
- **Region 3:** 7.62%
- **Region 4:** 4.6%
- **Region 5:** 0.42%

Source: The American Board of Pediatrics, General Pediatricians US State and County Maps
Mental Health Needs Among Pediatric Populations

Mental Health Concerns

Pediatric health care providers reported that many of their patients are struggling with mental health concerns.

Almost all (93.7%) of respondents reported that more than a quarter of their patients struggled with mood, behavior, or other symptoms related to mental health.

Only a very small number of health care providers (6.3%) estimate that less than 25% of their patients struggle with mood, behavior, or other symptoms related to mental health.

Mental Health Concerns + Adverse Social Determinants of Health

A majority of providers (66%) reported that at least half of their patients with mental health concerns also struggle with adverse social determinants of health. This data varies by region. See page 16 for more information on the regional breakout.
Mental Health Concerns + Adverse Social Determinants of Health

Percentage, by region, of healthcare providers that estimate 50% or more of patients struggle with mood, behavior, or other symptoms related to mental health and face adverse social determinants of health

<table>
<thead>
<tr>
<th>Region</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Region 1</td>
<td>41.49%</td>
</tr>
<tr>
<td>Region 2</td>
<td>25%</td>
</tr>
<tr>
<td>Region 3</td>
<td>56.67%</td>
</tr>
<tr>
<td>Region 4</td>
<td>66.67%</td>
</tr>
<tr>
<td>Region 5</td>
<td>0%</td>
</tr>
</tbody>
</table>

Mental Health Concerns + Developmental Delays or Differences

Half of the pediatric health care providers estimate that less than 25% of their patients with mental health concerns also have developmental delays or differences.

This data indicates:

- That children and families in Illinois are facing unprecedented mental health challenges
- That children and families are turning to their pediatric health care providers seeking support

“We need more education on handling anxiety at all ages.”

—Pediatric Physician, Primary Care, Region 2
Practice Mental Health Readiness

Our survey data strongly indicates the need for additional resources and capacity-building materials to improve pediatric health care provider confidence in screening, treatment, and outreach for patient mental health needs.

Respondent confidence in existing mental health care practices

<table>
<thead>
<tr>
<th>Survey Item</th>
<th>Strongly disagree/disagree</th>
<th>Strongly agree/agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I can recognize warning signs that may require crisis intervention.</td>
<td>2.8%</td>
<td>84.1%</td>
</tr>
<tr>
<td>I routinely screen my patients for mental health concerns.</td>
<td>7.4%</td>
<td>84.5%</td>
</tr>
<tr>
<td>I routinely screen my patients for developmental delays/differences.</td>
<td>9.1%</td>
<td>86.0%</td>
</tr>
<tr>
<td>I can appropriately support patients with emotional, behavioral, or other mental health needs.</td>
<td>9.1%</td>
<td>65.9%</td>
</tr>
<tr>
<td>My clinic actively promotes an emotionally healthy workplace environment.</td>
<td>9.7%</td>
<td>65.3%</td>
</tr>
<tr>
<td>Patients/Families in my practice are routinely screened for social determinants of health (SDOH).</td>
<td>18.2%</td>
<td>61.0%</td>
</tr>
<tr>
<td>My office staff and I do not become overly distressed when working with individuals who have emotional/behavioral/mental health concerns.</td>
<td>19.3%</td>
<td>50.1%</td>
</tr>
<tr>
<td>Someone in my office is knowledgeable regarding community resources and is able to assist families in their navigation.</td>
<td>20.5%</td>
<td>64.0%</td>
</tr>
<tr>
<td>My office staff and I have the resources to take action when my patients have warning signs that may require crisis intervention.</td>
<td>21.6%</td>
<td>51.7%</td>
</tr>
<tr>
<td>My office staff and I can appropriately manage patients/families who are emotionally distressed.</td>
<td>22.2%</td>
<td>47.2%</td>
</tr>
<tr>
<td>My clinic has protocols to manage patients in crisis.</td>
<td>29.0%</td>
<td>71.0%</td>
</tr>
<tr>
<td>My clinic actively promotes trauma-informed care (TIC) practices.</td>
<td>40.9%</td>
<td>31.3%</td>
</tr>
<tr>
<td>My practice routinely utilizes Community Health Workers.</td>
<td>68.2%</td>
<td>31.2%</td>
</tr>
</tbody>
</table>

Identified areas where pediatric health care providers require additional support:

- Assisting patients in navigating community resources
- Promoting trauma-informed care practices
- Resources for implementing protocols to manage patients in crisis
- Managing patients/families who are emotionally distressed
- Supporting patients who require crisis intervention
- Building knowledge of community resources
- Resources for clinic staff working with individuals who have emotional/behavioral/mental health concerns
- Routine screening for social determinants of health (SDOH)
**Practice Strengths: Mental Health Screening & Assessment**

Respondents indicated that they are comfortable screening for mental health needs and recognizing situations where a patient may be in crisis, but feel under prepared to offer referrals or additional support once certain mental health needs are identified through the screening process.

- **85.8% strongly agree/agree** that they routinely assess their patients for developmental delays or differences.
- **84.6% strongly agree/agree** that they routinely conduct screenings for mental health concerns in their patients.
- **84.1% strongly agree/agree** that they can identify warning signs that might require immediate crisis intervention.
- **65.9% strongly agree/agree** that they can appropriately provide support to patients with emotional, behavioral, or other mental health needs.

**Confidence in Assessment and Intervention by Mental Health Concern**

Survey data suggests that while pediatric health care providers are more confident in screening for common mental health concerns, they do not have the same confidence in their ability to provide referrals and resources to their patients and families.

<table>
<thead>
<tr>
<th>Percent respondents reporting ability to appropriately conduct an interview to assess:</th>
<th>Percent respondents reporting inability to appropriately provide education and resources regarding:</th>
</tr>
</thead>
<tbody>
<tr>
<td>General emotional/behavioral/mental health concerns</td>
<td>93.2%</td>
</tr>
<tr>
<td>Anxiety and depression</td>
<td>90.3%</td>
</tr>
<tr>
<td>Suicidal ideation and self-harm</td>
<td>90.0%</td>
</tr>
<tr>
<td>Substance use</td>
<td>73.3%</td>
</tr>
<tr>
<td>Aggressive behavior</td>
<td>58.0%</td>
</tr>
<tr>
<td>Gender identity and sexuality</td>
<td>58.0%</td>
</tr>
<tr>
<td>Eating disorders</td>
<td>57.4%</td>
</tr>
<tr>
<td>Trauma</td>
<td>51.1%</td>
</tr>
</tbody>
</table>
Screening Process

When reporting screening practices for mental health within their clinics, respondents offered specific insights. They described a process in which:

- Pediatric patients are screened using appropriate tools before meeting with a provider.
- Once the physician assesses the patient, these screenings are reviewed.
- If needed, additional questions are posed to the patient, and their answers are thoroughly discussed.

Clinicians’ assessment highlighted that most of these screenings involve patients completing paper questionnaires themselves.

This standardized approach is integrated into various types of visits, including:
- Wellness Check-ups
- Sick Visits
- Annual Appointments

This decision-making process is based on the provider’s judgment and can be influenced by time limitations.

Use of Screening Tools

The Patient Health Questionnaire (PHQ-9) screening tool is utilized by 73.9% of respondents, while 63.6% use the Ages and Stages Questionnaire (ASQ-3).

Moreover, 61.4% of respondents incorporate the Modified Checklist for Autism in Toddlers (M-CHAT-R/F) into their practices. Other screening tools being utilized by respondents include:

- Psc17: Pediatric Symptom Checklist (ages 4–17 years)
- SWYC: The Survey of Well-being of Young Children
- SCARED: Screen for Child Anxiety Related Disorders
- Vanderbilts Assessment Scales for ADHD
- C-SSRS: Columbia Suicide Severity Rating Scale
- CAST: Childhood Autism Spectrum Test
- Suicide screening questions
- Pediatric symptom check-list (ages 5 and up)
- CRAFFT: Car, Relax, Alone, Forget, Friends, Trouble – Substance Abuse Screening Tool
- SDH: Social Determinants of Health
- ACEs: Adverse Childhood Experiences
- Beck: Depression Inventory
- CRBS: Conners Comprehensive Behavior Rating Scales
- ASQ: Suicide Questionnaire: Ask Suicide-Screening Questions

“It is part of our regular workflow, especially for certain age groups/annual physicals. We have the recommended screenings in a chart format that all providers have access to and review prior to visits.”

—Pediatric Physician of Region 1
Medication Management

A significant percentage of participants (67.1%) reported routinely prescribing medications like selective serotonin reuptake inhibitors (SSRIs) for anxiety and depression. Additionally, 63.1% routinely prescribe stimulant medications.

Summary table of medication prescription practices:

<table>
<thead>
<tr>
<th>Medication Practices</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stimulant medications</td>
<td>93.2%</td>
</tr>
<tr>
<td>Alpha - 2 agonists (e.g. clonidine and guanfacine)</td>
<td>90.3%</td>
</tr>
<tr>
<td>Medications for anxiety and depression (e.g. SSRIs)</td>
<td>90.0%</td>
</tr>
<tr>
<td>Neuroleptics (antipsychotics)</td>
<td>73.3%</td>
</tr>
<tr>
<td>Medications to assist with sleep</td>
<td>58.0%</td>
</tr>
<tr>
<td>Mood stabilizers</td>
<td>51.1%</td>
</tr>
</tbody>
</table>

Confidence and Capacity for Mental Health Treatment & Referral

Our survey data strongly indicates the need for additional resources and capacity-building materials to increase pediatric health care provider confidence in mental health treatment and outreach for patient mental health needs.

79.5% of respondents reported they can appropriately offer self-management strategies

77.8% of respondents reported they can appropriately connect patients and families to mental health services

Respondents Highlight the Need for Referrals and Resources:

To enhance their quality-of-care delivery, respondents emphasized the usefulness of referrals and resources including:

- Social Workers
- Counselors
- Illinois DocAssist or IDA

Having greater access to these referrals and resources contribute to a more comprehensive approach to patient care.

“I have been practicing since 1996. Over the last 5-10 years something has shift in pediatric populations. On average I spend 20-30% of my time actively managing children/teens with significant mental health problems: anger/aggression/severe depression/severe anxiety/self-harm/suicidal thoughts…I routinely call Illinois DocAssist for help; they know me by name!”

—Pediatric Physician of Region 1
Identified Barriers to Providing Pediatric Mental Health Care

In providing care for most emotional, behavioral, mental health concerns, the survey findings indicate several barriers including:

- **Network for Referral:** 81.25% of respondents find challenges in establishing a network for referrals to other specialized care providers.

- **Amount of Time:** 80.7% highlight time constraints as a significant barrier to providing comprehensive care.

- **Office Support Structures:** 52.3% identify issues with inadequate support structures within the office environment that hinder effective care delivery.

- **Resource Materials:** 43.8% face difficulties due to the lack of sufficient resource materials for treatment and education.

- **Payment:** 42.6% note that financial concerns and payment issues impact their ability to offer care.

- **Skills and Knowledge:** 41.5% acknowledge the need for ongoing professional development to enhance their skills and knowledge in addressing complex mental health concerns.

- **Comfort Level/Stress Tolerance:** 40.3% acknowledge the challenges of managing their personal level of distress while providing care.

- **13.1%** report that they encounter all of the mentioned barriers in their clinic’s care provision.

- **1.7%** state that none of the listed barriers are applicable in their clinic’s context.

> “It is obvious to everyone in primary care involving all ages that mental health care access and support is appalling here. There is no reliable and affordable psychiatry, psychology, social work, therapy, or counseling…Families deserve better.

We can only do so much here.”

—Family Medicine Physician of Region 3
Identified Barriers to Providing Pediatric Mental Health Care  

**Limited Network of Referral**

Many survey respondents noted that difficulty in referral and limited access to specialists pose significant barriers in mental health care delivery for their patients.

Percentage of health care providers in each region reporting limited network of referral as a barrier:

<table>
<thead>
<tr>
<th>Region</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Region 1</td>
<td>73.4%</td>
</tr>
<tr>
<td>Region 2</td>
<td>66.7%</td>
</tr>
<tr>
<td>Region 3</td>
<td>76.7%</td>
</tr>
<tr>
<td>Region 4</td>
<td>77.8%</td>
</tr>
<tr>
<td>Region 5</td>
<td>85.7%</td>
</tr>
</tbody>
</table>

* Please refer to page 10 for regional coverage details

More than 80% of respondents reported an insufficient network of referrals and amount of time as a challenge in their ability to provide adequate mental health care.

81.25% of respondents reported that **network referral** is a barrier in providing care for the majority emotional/behavioral/mental health concerns.

80.7% of respondents identified **time constraints** as a major barrier to providing care for the majority emotional/behavioral/mental health concerns.

**Limited Amount of Time**

Many survey respondents noted that having a limited amount of time with patients hindered their ability to provide mental health care to their patients.

Percentage of health care providers in each region reporting limited amount of time as a barrier:

<table>
<thead>
<tr>
<th>Region</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Region 1</td>
<td>70.2%</td>
</tr>
<tr>
<td>Region 2</td>
<td>77.8%</td>
</tr>
<tr>
<td>Region 3</td>
<td>73.3%</td>
</tr>
<tr>
<td>Region 4</td>
<td>55.6%</td>
</tr>
<tr>
<td>Region 5</td>
<td>85.7%</td>
</tr>
</tbody>
</table>

* Please refer to page 10 for regional coverage details
Additional Barriers to Providing Pediatric Mental Health Care

Many respondents provided further insight regarding barriers in providing mental health care in the open-ended portion of the survey, including:

- **Insurance:** There is limited availability of child psychiatrists that accept Medicaid patients. This, along with insufficient reimbursement or reimbursement challenges for providers, impacts the accessibility of mental health care for children and families.

- **Time:** Long waitlists for pediatric mental health care can delay or completely inhibit a patients’ access to care. Furthermore, the full schedules of pediatric health care providers might hinder their availability to offer timely patient support.

- **Resource Limitations:** Insufficient knowledge and ability to follow up on resources, especially in challenging cases that require specialized care beyond a provider’s capabilities, can lead to gaps in treatment. Some areas, particularly rural ones, lack the necessary resources. Additionally, understanding how to manage medication for mental health concerns poses difficulties.

- **Staffing:** Shortages of mental health professionals, including psychiatrists, can exacerbate the challenges of ensuring children and families are connected to providing timely and effective care.

- **Affordability:** This remains an issue for families seeking mental health care, as costs might prevent them from accessing the necessary services.

- **Parental Denial:** Some parents might be unaware of or unwilling to admit their child has a mental health concern. This delays intervention and proper care.

These barriers underscore the need for comprehensive solutions that address not only the clinical aspects of care, but also the systemic, financial, and educational challenges that impact the effective management of emotional, behavioral, and mental health concerns among pediatric patients.
Utilization of Existing Resources & Referrals

Respondents reported varying levels of awareness and utilization of mental health care resources and services. The survey findings reflected that more than 50% of respondents are aware of resources such as school-based services, UptoDate, and Illinois DocAssist. There are 76.1% utilizing care coordination, however, this varies greatly by location.

Use of care coordination by region:

Region 1: 80.9%
Region 2: 66.7%
Region 3: 76.7%
Region 4: 88.9%
Region 5: 42.9%

* Please refer to page 10 for regional coverage details

The Potential of Illinois DocAssist

The role of Illinois DocAssist is to help primary care clinicians screen, diagnose, and treat the mental health and substance use problems of children, adolescents, and perinatal women through consultation, training, and referral assistance.

While this program can help to provide much-needed support, there are currently barriers to awareness and administration that need to be addressed to fully leverage the program’s potential.

Of the respondents who have utilized Illinois DocAssist, the average overall rating of their experience was a 4.1 on a scale of 1 to 5 with 43.1% of respondents rating their experience a 5.

* Please refer to page 40 for our plan to better support and build awareness for this program

“[Illinois DocAssist is] very good about providing targeted/focused advice on the issue. Have always been available within 24 hours of my call.”

—Pediatric Physician, FQHC, Region 1
NEEDS ASSESSMENT: Focus Group Methodology
Needs Assessment: Focus Group Methodology

In addition to the online survey, sr4 Partners conducted six virtual focus groups on behalf of ICAAP. Focus groups provided additional details from participants and helped to better identify the areas of opportunity and support pediatric health care providers need in Illinois.

We worked with sr4 Partners to develop focus group questions stemming from the online survey data and results, allowing us to concentrate on the areas where more information was needed or could be gathered.

Focus Group Survey Content and Structure

Questions:

1. Which mental health conditions are you seeing most in the patients you serve?
   1.1 What support and resources would equip you to better meet those needs?

2. How is care coordination provided at your clinic?
   2.1 Is care coordination provided internally or externally through a referral process?

3. How are you conducting your mental health screenings?
   3.1 Who conducts screening?
   3.2 How is the screening process conducted?
   3.3 What barriers, if any, currently exist for you when screening patients?
   3.4 Based on your experience, what practices are working best for your clinic when screening patients?

4. How often do you use Illinois DocAssist?
   4.1 How can Illinois DocAssist be more helpful to you?

5. Based on the survey data collected, providers reported that more than 50% of patients live with adverse determinants of health (SDOH). What resources would make you feel adequately equipped to address SDOH with patients and their families?

6. Have you adopted trauma-informed practices or education in your clinic?
   6.1 What kind of support is needed to consistently apply trauma-informed care practices?

7. Based on the survey results, the top 5 barriers providers are facing include: network for referral, amount of time, office support structures, resource materials, and payment. Share details about how these barriers are impacting your clinic.
   7.1 What support will empower you to navigate the barriers you may be experiencing?

8. According to the survey, 60% of providers shared that they or their clinic staff do not have a method of tracking patients for assertive follow-up. What support would help providers develop and consistently use a tracking process for screening and assertive follow-up?

9. What resources are needed for you to consistently and most efficiently provide mental health care? (i.e. certifications/certificates, in person/online educational training options, emails, handouts, etc.)
   9.1 What resources do you use most to provide education and mental health support to patients and caregivers?
   9.2 What additional resources do you feel you need to be more successful in providing mental health support to patients and caregivers?

10. What are the unique challenges of your provider group?
Focus Group Survey Content and Structure  

**Structure:**

The focus group introduction included a brief overview of ICAAP’s interest, purpose of the focus groups, and the intended outcomes.

Each session was recorded with moderators present to ensure:

- Psychological Safety
- Overall Production
- Accuracy of Data Collection

Not all questions listed above were asked of the focus group participants. Moderators asked participants 6–7 questions from the questions list and allowed for organic conversation related to the themes of the needs assessment including:

- Patient Population
- Practice Readiness
- Personal Skills and Knowledge
- Barriers to Providing Care
- Resources & Referrals
- Professional Development

Participants answered questions verbally as well as shared their thoughts using the chat feature.

**Scheduling:**

We actively worked to ensure diverse and wide representation in these focus groups. Participants did not have to complete the online survey to participate in the focus groups. We offered several timeslots to participants, including:

- Tuesday, July 11th 2023 (8:00 – 9:00 AM) – ADVISORY GROUP ONLY
- Tuesday, July 18th 2023 (8:00 – 9:00 AM)
- Wednesday, July 19th 2023 (12:00 – 1:00 PM)
- Wednesday, July 26th 2023 (8:00 – 9:00 AM)
- Wednesday, July 26th 2023 (5:30 – 6:30 PM)
- Monday, July 31st 2023 (8:00 – 9:00 AM)
Focus Group Survey Content and Structure Continued

Participation Outreach and Engagement:

To encourage deeper and more practical discussion, ICAAP encouraged participants to attend with the most appropriate peer group. However, participants were allowed to utilize the time slot of their choice.

- Rural Areas Focus Group: Tuesday, July 18th 2023 (8:00 – 9:00 AM)
- School Health Focus Group: Wednesday, July 19th 2023 (12:00 – 1:00 PM)
- FQHC Focus Group: Wednesday, July 26th 2023 (8:00 – 9:00 AM)
- Private Practice Focus Group: Wednesday, July 26th 2023 (5:30 – 6:30 PM)
- Mental Health Care Focus Group: Monday, July 31st 2023 (8:00 – 9:00 AM)

Illinois pediatric primary care providers and subspecialists were invited to participate in the focus groups. To publicize the opportunity, the same outreach activities were completed as for the online survey.

These outreach efforts included:

Email Blasts     Mentions in ICAAP’s Weekly Newsletters     Social Media Posts     Printed Fliers     QR Codes for Digital Access

ICAAP asked valued partners to share information about the focus groups as well.

Sample outreach marketing materials:
Engagement and Incentives:

Data security was monitored and maintained throughout each session. Participants voluntarily contributed insight without coercion. Participants were issued $25 gift cards upon successful completion of the focus groups. Advisory group members were not compensated for their focus group participation.

Ethical Considerations:

Ethical considerations encompassed confidentiality, informed consent, free participation, language, and sponsor disclosure. No personal identifying information was asked during the focus groups although names, emails, and demographic information (including profession, specialty, practice setting, and practice region) was required for focus group registration.

Challenges:

The focus groups experience major challenges and limitations which impacted execution and outcomes, including:

- **External Hacking:** The focus groups were facilitated virtually via Zoom software. The registration process was also administered via Zoom software and available publicly through ICAAP’s website. During the focus group timeframe, ICAAP’s virtual events were targeted by external digital disruptors. There were hundreds of bots and/or users from around the world registering for events and attending, potentially disrupting participation and engagement. We enlisted our information technology security to address this problem, and then updated Zoom settings so registrants for the focus groups had to be manually approved and monitored at all times throughout the registration and event process. ICAAP and sr4 did not want to inadvertently exclude any real participants from the focus groups, but there was no evidence that allowed us to be completely sure.

- **Low Registrations:** Participants were given ten times/dates to choose from, that were scheduled for morning, midday, and evening timeslots. Despite promotional efforts, the number of participants was lower than the anticipated and desired number.

- **Time Constraints:** The virtual focus groups were conducted over a 1-month period during the summer month of July, which included a holiday. This short time frame could have limited the participation of potential respondents who were unavailable or occupied. Additionally, it was back-to-school season for pediatricians, which is often the busiest time for clinics, and this may have contributed to a provider’s inability to take an hour to participate.

- **Accessibility:** The virtual focus groups were limited to providers who have access to Zoom software. This could have excluded providers who lacked the necessary resources to participate.
Mental Health Needs Among Pediatric Populations

In relation to patient population, the focus groups identified the following as the most prevalent mental health conditions among their patient population:

- Anxiety
- Depression
- Attention Deficit Hyperactivity Disorder (ADHD)

It was acknowledged that these conditions are well-known in pediatrics and can have a profound impact on the child’s well-being.

Participants, including school health providers and private practitioners, also highlighted the need to address other mental health concerns such as:

- Trauma
- Body Dysmorphia

These issues were indicated as leading contributors to self-harming behaviors and make it challenging for young individuals to develop healthy coping mechanisms.

The Role of Social Determinants of Health

It was evident from the focus groups’ discourse that social determinants of health play a significant role in the rise of mental health concerns among pediatric patients. Identified social determinants of health include:

- Neighborhood and Built Environment
- Economic Stability
- Social and Community Context
- Poverty
- Domestic Violence

Social Determinants of Health - Healthy People 2030 | health.gov

Focus group participants strongly agreed that these external factors can create stressful and challenging environments for children which can negatively impact their mental health.

Participants noted that addressing concerns related to these social determinants of health requires a holistic approach to mitigate the impact of these issues on young individuals’ mental wellbeing including:

- Early Intervention
- Trauma-Informed Care
- Community-Based Support Systems
Practice Readiness

According to focus group participants, screening processes for pediatric patients are typically routine and tailored to the patient’s age and developmental stage. Providers commonly follow up with patients and families to discuss screening results and address any emerging mental health concerns.

In rural areas, providers often rely on parents’ observations of their children’s sleeping patterns and eating habits as indicators of potential mental health concerns. School health providers similarly assess students’ eating habits and hygiene as potential signs of mental health needs.

“A lot of our families are illiterate…lack of continuity is a problem due to turnover… screenings are not done or there is a lack of follow up due to lack of ownership.”

—Pediatric Physician of Region 1

Barriers to Mental Health Screening:

**High Turnover:** One major obstacle discussed was the high turnover rate of medical assistants, this leading to missed screenings when newer staff members are unfamiliar with the timing for administering questionnaires or screenings to patients and their families.

**Poor Integration of School Health Care Providers:** School health providers shared facing difficulties when suggesting the need to screen younger children. School health providers further spoke to often feeling excluded from mental health conversations within the school setting and believe their role is perceived as solely focused on physical health. As a result, this leads to a further disconnect in coordinating mental health care for young individuals.
Practice Mental Health Readiness  Continued

**Barriers to Mental Health Treatment:**

1. **Limited Specialists/Outside Referrals:** Many providers strongly expressed frustration in connecting patients and families to resources after identifying mental health concerns during screening.

2. **Screening Hesitancy:** Some spoke to hesitancy they feel in screening for certain conditions such as social determinants of health when they don’t feel adequately prepared to address these concerns.

3. **Need for Training:** Multiple focus group participants shared the desperate need for additional training related to trauma as it relates to patient care and workplace well-being.

4. **Support in Follow Up:** It was also discussed that overall support is needed in providing adequate follow-up and connecting patients and their families to mental health care.

In highlighting this issue, providers spoke to the need for a comprehensive approach that includes training and better integration of mental health support.

“Once we do the screening there is just nowhere for these kids…there is nowhere to refer them to after the screening process.”

—Pediatric Physician of Region 5

“I don’t screen for ACES because I don’t know what to do, I don’t have resources and it doesn’t make sense for me to screen and I’m sorry…I feel totally helpless…having any answers would be great.”

—Pediatric Physician of Region 1
External Barriers to Treatment

In discussing barriers to provide care, multiple focus groups identified several key challenges, including:

- **Care Coordination**: Participants emphasized the importance of establishing care coordination in every clinic to connect patients and families with necessary mental health care beyond primary care visits. This was seen as crucial to prevent patients and families from getting lost in the follow-up process, especially when social determinants of health (SDOH) such as access to food or housing were factors.

- **Accessing Mental Health Care**: Participants highlighted specific barriers faced by patients and their families in accessing mental health care including affordability, transportation, and internet connection for telehealth services. These barriers are particularly challenging for Medicaid patients.

- **Payment for Behavioral Health**: Many participants stressed the need to develop more practical and equitable payment options for behavioral health services, especially for Medicaid-covered pediatric and adolescent patients. The disproportionately low payment from Medicaid is a major barrier to both referring to specialty services and allotting the appropriate amount of time in pediatric offices.

- **Broadband Access in Rural Areas**: Rural providers pointed out that while broadband access is expanding, it often reaches only the center of towns, leaving more rural areas underserved. Expanding broadband access was seen as important to ensure all patients, including those in the most rural areas, have access to telehealth services.

- **Trauma-Informed Care**: The focus groups emphasized the importance of incorporating the concepts of trauma-informed care into clinical practices (which includes the engagement of the professionals and clinic-wide education). Lack of understanding in this regard was shared as something that greatly affected patient engagement and overall efficiency of medical care provided to patients and families.

Focus group discussions clearly indicate that these barriers must be addressed in order for pediatric health care providers to offer more effective and impactful mental health care to their patients and families.
Utilizing Existing Resources & Referrals

Using Illinois DocAssist

In comparison to the survey respondents, focus group participants articulated a drastically different understanding of potential resources, including specialty providers to which they can refer. Many of focus group participants shared how helpful Illinois DocAssist is, primarily because it connects them to a psychiatric perspective for patient cases and provides medicine management guidance.

Some participants felt that Illinois DocAssist is underused because many pediatric health care providers are unaware that the resource exists and/or are uncertain how to best leverage the service as a provider.

Participants who shared that the did not use Illinois DocAssist did express a strong desire to learn more about how to access and use the program.

ICAAP Support

Focus group participants shared how helpful and consistent the support has been from ICAAP in better managing pediatric mental health care needs. Participants noted the availability of patient and parent handouts, citing these as great resources and sharing that more of these kinds of resources are needed.
Professional Development Opportunities

Focus group participants cited the importance of professional development for providers, emphasizing the benefits of webinars and online training opportunities. Participants found webinars and online training valuable in providing specific knowledge about mental health conditions.

Areas of Opportunity to Improve Professional Development

Focus group participants shared a wide range of improvements that they believe will help drive more effective professional development, including:

- Training on best practices for engaging patients and their families when discussing different mental health conditions.
- Case studies shared by pediatric providers as part of their professional development.
- A combination of professional development formats, including in-person training sessions, webinars, handouts, and certificate programs to cater to different learning preferences and availability.
- Encouraging medical practices to sponsor a certain number of their pediatric providers to participate in these opportunities.
- Providing information about professional development opportunities months in advance to allow providers to plan their participation.
- Targeting areas with less focus on mental health care and identifying barriers to providing such care to gain a deeper understanding on what specific professional development may be needed.
NEEDS ASSESSMENT SUMMARY:

Key Insights
**Needs Assessment Summary: Key Insights**

The following key insights capture the collective feedback, viewpoints, and considerations as defined by pediatric health care providers who participated in the online survey and virtual focus groups.

**Integrating Trauma-Informed Care**

27.7% of respondents of the survey indicated that they are unsure about their clinic’s promotion of trauma-informed care, while 33% of respondents would like further assistance on trauma-informed care practices. Focus group participants revealed that there is a varying level of understanding in how trauma-informed practices are relevant to mental health care.

Many participants emphasized the urgent need for training on implementing seamless trauma-informed practices within clinics.

**Providing Treatment Post Diagnosis**

Although many health care providers expressed feeling confident in their mental health screening processes, they also shared they felt ill-equipped to handle the next steps after making a diagnosis.

48.3% of survey respondents would like further assistance on incorporating basic therapy techniques (de-escalation, self-management, motivational interviewing).

**Medication Management**

46.6% of survey respondents and multiple focus group participants identified significant need for greater support in managing medications.

This support could involve gaining a better understanding of medication management for specific mental health conditions and/or understanding how to utilize Illinois DocAssist for further assistance.
Barriers to Providing Care
Survey respondents and focus group participants identified a number of barriers hindering proper delivery of mental health care to pediatric patients, including:

- Limited access to psychiatric services and support for pediatric patients
- Limited knowledge of community resources
- Long wait lists for mental health care for those with private insurance
- Inability to connect patients on Medicaid with appropriate psychiatric care

As a result, providers are placed in a position to provide long-term support that may require medication management, without the appropriate resources and support to do so effectively.

Addressing Social Determinants of Health
Pediatric health care providers further highlighted that many patients with mental health conditions are also greatly impacted by social determinants of health. While some pediatric health care providers have care coordination workflows in place, others do not and find it extremely challenging to address the immediate needs of patients and families, negatively impacting their ability to provide mental health care.

Resources & Referrals
Survey respondents denote that pediatric health care providers need greater access to resources and referrals to provide better care for their patients. Respondents suggested a wide range of needed resource mediums including:

- Patient handouts related to specific mental health conditions
- Patient handouts related to substance use and abuse
- Resources on best practices for medication management
- How to use Illinois DocAssist

Focus group participants also suggested a wide range of needed resource mediums including:

- Webinars addressing best practices for follow up care
- Establishing collaborative care models
- Resources on specific mental health conditions

Participants also shared a desire to connect and learn from other providers across the state and requested more information about Illinois DocAssist and how to best leverage the resource.
Addressing the Role of Illinois DocAssist

Of those who have utilized IDA, 73.8% of respondents reported a positive overall experience with using it. Users liked the convenience and availability of this free telephonic consultation service. The collaborative model of care allowed respondents to be easily connected to professional psychiatrists that could offer advice for specific patients and could help with medication questions. Respondents reported that calls were usually returned within 24hrs with targeted advice on the issue and additional follow-up material provided by email. The trauma-informed advice offered by the mental health consultants helped to actively treat patients with complicated needs.

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**Identified Areas of Improvement for IDA**

Although users of IDA reported favorably to its use, they did comment that the system is limited by the resources available within the caller’s community, so it can be challenging or even impossible to get patients referrals for resources or specialist appointments close to their home. They also reported that the system could be improved with increased capacity and longer hours that would allow for quicker real-time responses. Respondents note that an option for rapid response is needed. Additionally, video access, text for consultation and live chat functionality would also improve the service offered by Illinois DocAssist.

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**Respondent Concerns Regarding IDA:**

- “Show which places have openings rather than just names of places.” —Pediatrician, Region 1
- “I don’t always get a response when I request a consultation.” —Pediatrician, Region 2
- “Increase capacity.” —Pediatrician, Region 1
- “The psychiatrists were very helpful and kind. They help with medication management and called back when they said they would.” —Pediatrician, Region 3
- “[Illinois DocAssist is] professional, caring, and very responsive to my needs.” —Pediatrician, Region 1
Recommendations
Recommendations

Based on the comprehensive analysis captured by our needs assessment, ICAAP makes the following recommendations for improved training, education, and advocacy. These recommendations aim to support the needs of pediatric health care providers and to better address the current mental health crisis among children and adolescents in Illinois.

Enhanced Training & Education for Pediatric Care Providers

Training and education can enhance pediatric health care provider’s ability to deliver high-quality care to children and adolescents. Based on the needs identified in this assessment, new training and education materials must address the following topics in order to help build confidence, refine skills, and expand knowledge for pediatric health care providers to better address pediatric mental health care.

Training & Education on Diverse Mental Health Conditions:

Pediatric providers who are trained in diverse mental health conditions can offer a more holistic approach to overall care by addressing both physical and emotional needs. Many mental health conditions in children can go undetected or misdiagnosed without proper training. Pediatric providers need to be able to recognize early signs and symptoms of a wide range of mental health conditions to intervene and provide timely support.

Training & Education on Medication Management:

Given the increasing prevalence of mental health concerns among children and adolescents, it is crucial for pediatric care providers to receive comprehensive training in medication management to ensure safe and effective treatment. These training and education opportunities should provide foundational knowledge, medication selection and initiation, and best practices for monitoring and addressing adverse effects.

Integration of Trauma Informed Practice:

Pediatric health care providers need support and training around best practices for integrating trauma-informed care in their clinical workflows. These training and education opportunities must cover topics like:

- Recognizing signs of trauma
- Understanding the impact of trauma on mental health
- Utilizing trauma-sensitive communication techniques

This opportunity can enhance providers’ ability to identify and address mental health concerns stemming from traumatic experiences, ultimately improving the quality care and support provided to young patients.
ICAAP Plan of Action to Address These Needs

While there is no single solution to address the systemic, administrative, and capacity barriers that our pediatric health care providers and patients are facing, there are concrete changes we can make to improve outcomes.

ICAAP proposes the following initiatives:

- Develop training and education modules and materials for primary health care providers on common mental health issues and conditions in children and adolescents that incorporate social determinants of health and health equity.
- Offer Continuing Medical Education (CME)/Continuing Education Unit (CEU) for the aforementioned training modules.
- Create clinical support materials to aide pediatric health care providers in integrating mental health care services into clinical workflows.
- Create and distribute outreach materials for families that help to educate them on relevant mental health issues and the support opportunities available to them.
- Increase knowledge and understanding of the role of Illinois DocAssist (IDA) in supporting health care providers in providing mental health treatment and support to youth in Illinois through outreach and awareness building.
- Develop a messaging plan for pediatric health care professionals including primary care, emergency physicians/staff, pediatric nurse practitioners, and school-based personnel that highlight the benefits of Illinois DocAssist and the new training materials as delivered by this initiative.
Working Together to Advocate for Children’s Health

Advocacy in pediatric care involves being a voice for children’s needs and rights, both within the health care system, and in broader social and policy contexts. Based on the findings of this needs assessment, we believe cross-institutional advocacy is necessary to ensure the well-being of children and to protect their rights within the health care system. The deliverables outlined above are tangible action items designed to address immediate need and to create a bridge for stronger pediatric mental health care in Illinois. But there is more work to be done. ICAAP calls on all pediatric advocates, institutions, and health systems to work together in advocating for the following:

**Improving Medicaid/Insurance Coverage for Mental Health Care:**

Ensuring that all children have access to affordable healthcare through Medicaid or other insurance programs is crucial. Removing barriers to access, such as financial constraints, can contribute to early intervention, better management of chronic conditions, and improved overall health outcomes for children.

> “The reason I chose to complete this survey is to say how incredibly disheartening and difficult it is to have essentially no meaningful mental health services for Medicaid patients. Even privately insured patients have a long wait time, but public aid patients are so, so challenging to support when payment for mental health providers is inadequate.”

—Pediatric Physician, Region 2

**Increase Payor Reimbursement:**

More reasonable payment rates from insurance companies or payers for pediatric services can incentivize healthcare providers to offer high quality care for children and support mental health. Proper reimbursement processes can help sustain pediatric practices, attract skilled professionals, and ensure that children receive the necessary medical attention and support.

**Building the Social Work and Child Psychiatry Workforce:**

Adequate mental health support is vital for children’s overall well-being. Increasing the number of psychiatrists and social workers trained to provide care for children can help to:

- Address the growing mental health needs of pediatric patients
- Lead to better access to mental health services
- Improve the quality of care for children in Illinois
We, The Illinois Chapter, American Academy of Pediatrics, would like to extend our heartfelt gratitude to all pediatric health care providers working to support children’s mental health. We also want to thank the following individuals and organizations who played a significant role in the successful completion of this needs assessment:

Respondents and Participants
We extend our appreciation to the participants who graciously devoted their time and shared their valuable insights, making this report of research findings possible. Their willingness to be honest and open when completing the needs assessment and engagement in meaningful discussions throughout the focus group sessions was instrumental in shaping our findings.

Subject Matter Expert Work Group
We are immensely thankful for the unwavering guidance, insightful feedback, and continuous support throughout the research process. The expertise and dedication greatly enriched the quality of the research process.

We thank our community, IDPH, and the Governor’s Office for their continued support and efforts to promote child, youth, and family well-being and better access to quality healthcare in Illinois!

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