

**A FAMILY GUIDE**

*Integrating Mental Health and  
Pediatric Primary Care*





**National Alliance on Mental Illness**

*Find Help. Find Hope.*

*A Family Guide: Integrating Mental Health and Pediatric Primary Care*

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NAMI, the National Alliance on Mental Illness, is the nation's largest grassroots mental health organization dedicated to building better lives for the millions of Americans affected by mental illness. NAMI advocates for access to services, treatment, supports and research and is steadfast in its commitment to raising awareness and building a community of hope for all of those in need.

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## A FAMILY GUIDE

# *Integrating Mental Health and Pediatric Primary Care*



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## INTRODUCTION

“Integration is in response to the fragmentation of health care. As individuals we are not fragmented, we are whole people. The current health care system does not recognize this. Integration is trying to fix a big problem, which is that we have two separate systems that take care of our health. Integration is a game changer for health care.”

- Benjamin Miller, Psy.D., assistant professor, Department of Family Medicine, University of Colorado School of Medicine

We know physical health impacts mental health and mental health impacts physical health. Yet, the health care system has historically treated mental and physical health separately. You may experience this when you visit a primary care provider with your child and then are sent elsewhere for mental health care. This fragmentation is often costly, frustrating and does not lead to the best outcomes for families.

When it comes to the health and well-being of your child, it is important to understand that mental health is part of overall health. A healthy child is one with a healthy body and a healthy mind. You cannot have one without the other.

Addressing the whole person by integrating care is one way to begin to address the fragmentation that often exists in our health care system. Integrated care is designed to treat mental health conditions like any other health conditions that children experience.

There is widespread support to improve our nation’s health care system by effectively integrating mental health and pediatric primary care.

- ▶ “The need for primary care clinicians to manage children with mental health concerns only will continue to increase in the future... Primary care clinicians are, and will continue to be, an important first resource for parents who are worried about their child’s behavioral problems.” – American Academy of Pediatrics Task Force on Mental Health<sup>1</sup>
- ▶ “One of the best indicators of risk for emergence of mental illness in the future is the presence of parental or caretaker concern about a particular child’s behavior. Primary care offices can screen for risk by routinely inquiring about parental concern. The prevention of mental



illness and physical disorders and the promotion of mental health and physical health are inseparable.” – National Research Council and Institute of Medicine<sup>2</sup>

- ▶ “Mass screening in primary care could help clinicians identify missed cases and increase the proportion of depressed children and adolescents who initiate appropriate treatment. It could also help clinicians to identify cases earlier in the course of disease.” – U.S. Preventive Services Task Force<sup>3</sup>
- ▶ “This report calls on the nation—its leaders, its mental health research and service provision agencies, its schools, its primary care medical systems, its community-based organizations, its child welfare and criminal justice systems—to make prevention of mental, emotional and behavioral disorders and the promotion of mental health of young people a very high priority.” – National Research Council and Institute of Medicine<sup>4</sup>

Interest in mental health and primary care integration is growing. Many communities have developed innovative approaches to improve the quality of care provided to youth and families. These communities have seen the benefits of addressing mental and physical health conditions in a coordinated, collaborative manner to ensure that children receive comprehensive and high quality care and reach their optimal health.

Integrated care presents you and your child with opportunities to actively participate with both primary care and mental health providers in care delivery. It is important to understand what integrated care means, what it looks like in practice and how it impacts you and your child.

So, what exactly is integrated care and what does it mean for your child? How might this change your role in seeking mental health care for your child? What questions should you be asking in an integrated care setting and what should you expect?

This guide is designed for families to provide you with a roadmap to navigate the integrated care landscape. It offers families help and hope in finding the best comprehensive care for their child. This guide will help you better understand what integrated care is and what it can mean for your child's improved health. Reading this guide may help you think differently about the kind of help you may want to seek for your child

and questions to ask your primary care provider. Asking the right questions can get you and your child more effective care. This guide also provides you with information on how to become more involved in the integrated care movement to improve the quality of care that your child receives.

While integration of mental and physical health care applies across the life span, this guide highlights the impact of integration on children and youth and what you need to know about mental health care in the pediatric primary care setting.

### **INTEGRATED CARE: WHAT IS IT?**

There is no one definition or approach to integrated care. Rather there are principles and concepts that help to define what it means. Here are two definitions that capture the principles and concepts of integrated care:

- ▶ “Integrated health care is the systematic coordination of physical and behavioral health care. The idea is that physical and behavioral health problems occur at the same time. Integrating services to treat both will yield the best results and be the most acceptable and effective approach for those being served.” – The Hogg Foundation for Mental Health<sup>5</sup>
- ▶ “Integrated primary care combines medical and behavioral health services to more fully address the spectrum of problems that patients bring to their primary medical care providers. It allows patients to feel that, for almost any problem, they have come to the right place.” – Alexander Blount, Ed.D., director, Center for Integrated Primary Care<sup>6</sup>





Simply put, integrated care refers to the practice of incorporating mental health care into primary care settings *and* primary care into mental health care settings for the purpose of improving the quality of care.

There is no single, right way to integrate services and supports. There are a number of steps that primary care practices can take in moving toward integrated care. These steps include everything from distributing information to families about mental health care in primary care practices to co-locating mental health care in primary care practices to fully integrated collaborative care. These steps aim to improve communication, collaboration and coordination among health care providers, families and youth and emphasize a care team approach to addressing mental and physical health concerns. The table, *At a Glance: Steps to Integrated Care*, captures the different ways in which primary care practices can move toward fully integrated care.

For most youth, the pediatric primary care setting is the most practical location for integrated care because most families and youth access care in primary care offices. The primary care office is a place where families have often established a trusting relationship with a primary care provider. It is also a place that youth are familiar with and are comfortable visiting. However, youth with serious mental health conditions who require ongoing, regular care from mental health providers *may* benefit from coordinated care in a mental health care setting that also has the capacity to provide essential primary care.

## AT A GLANCE: STEPS TO INTEGRATED CARE

Steps	Description	Benefits	Limitations
Share mental health information, supports and resources with youth and families.	Primary care office displays posters, brochures and fact sheets that emphasize the importance of mental health and share information with youth and families.	<ul style="list-style-type: none"> <li>Raises public awareness about mental health.</li> <li>Makes a statement that mental health matters.</li> <li>Connects families to valuable information.</li> <li>Helps to normalize mental health issues.</li> <li>Creates a welcoming environment for conversations about children's mental health.</li> </ul>	<ul style="list-style-type: none"> <li>Resource distribution is a small step.</li> <li>It does not lead to care for a child in need.</li> <li>Primary care practices may have limited capacity to help ensure that families understand the information being shared.</li> </ul>
Provider education and training.	Primary care and mental health care providers are educated and trained to address both mental health and other physical health concerns.	<ul style="list-style-type: none"> <li>Helps providers confidently address both mental and physical health issues.</li> <li>Increases providers' knowledge, expertise and capacity.</li> <li>Promotes understanding across health care fields.</li> </ul>	<ul style="list-style-type: none"> <li>Follow-up and ongoing coaching and mentoring are needed but rarely provided.</li> <li>Training provides time-limited impact without other supports.</li> <li>Training and education can be costly.</li> </ul>

## AT A GLANCE: STEPS TO INTEGRATED CARE (continued)

Steps	Description	Benefits	Limitations
<p>Planning for changes in the primary care office to deliver mental health care.</p>	<p>Primary care office develops a plan to begin to provide mental health care. This can include:</p> <ul style="list-style-type: none"> <li>Identifying staff who will provide youth and families with behavior rating scales and collect information from schools and other child-serving agencies to better understand the child's needs.</li> <li>Adjusting primary care provider schedules to allow for longer appointments.</li> <li>Identifying billing codes to seek reimbursement for mental health care.</li> <li>Reviewing technology needs related to electronic health records.</li> </ul>	<ul style="list-style-type: none"> <li>Organized office systems support primary care providers in providing comprehensive and coordinated care.</li> </ul>	<ul style="list-style-type: none"> <li>Primary care offices are busy and longer visits with children and families may be challenging for practices.</li> <li>The dissemination, collection and review of screening tools and outside records is often time-consuming.</li> </ul>
<p>Mental health screening.</p>	<p>Primary care providers use checklists or questionnaires to ask children, youth and families about their feelings, behaviors and functioning in order to identify mental health concerns early.</p>	<ul style="list-style-type: none"> <li>Identifies mental health concerns early and alerts the care team about concerns.</li> <li>Links youth to services and supports before mental health concerns become more serious.</li> </ul>	<ul style="list-style-type: none"> <li>Screening without follow-up and a link to effective services does not improve outcomes.</li> <li>Children and youth may not be comfortable with screening if they have concerns about confidentiality.</li> </ul>

## AT A GLANCE: STEPS TO INTEGRATED CARE (continued)

Steps	Description	Benefits	Limitations
Primary care referral with collaboration.	Primary care office provides referrals to families for mental health providers that take into account the family's treatment preferences and barriers to accessing mental health care. This enhanced referral system also encourages follow-up, feedback and coordination between the primary care providers and mental health care providers.	<ul style="list-style-type: none"> <li>Encourages follow-through with referrals.</li> <li>Facilitates communication, collaboration and treatment coordination between primary care and mental health providers.</li> <li>Allows primary care providers to remain involved and to effectively coordinate care.</li> </ul>	<ul style="list-style-type: none"> <li>A national shortage of child and adolescent mental health providers has led to limited referral options and long waiting times for families seeking mental health care for their child.</li> </ul>
Supportive counseling and treatment with consultation.	Primary care providers provide supportive counseling, family education and treatment within the primary care setting for mild to moderate issues rather than referring families out. Mental health providers are available in-person, by phone or by video conference to provide consultation on cases.	<ul style="list-style-type: none"> <li>Improves the primary care provider's ability to effectively treat a child with mental health needs.</li> <li>Allows the primary care provider to draw upon the expertise of a trained mental health provider and to become more comfortable in addressing the needs of children with mental health conditions.</li> </ul>	<ul style="list-style-type: none"> <li>Primary care providers may not be able to provide long-term psychotherapy or evidence-based treatments.</li> <li>They may be uncomfortable or unwilling to provide any level of mental health care in their primary care offices.</li> </ul>

## AT A GLANCE: STEPS TO INTEGRATED CARE (continued)

Steps	Description	Benefits	Limitations
Co-location of services.	Primary care providers and mental health care providers are housed in the same setting.	<ul style="list-style-type: none"> <li>Increases the opportunity for primary care providers and mental health providers to communicate, collaborate and coordinate care.</li> <li>Makes it easier for families to follow-through with referrals.</li> </ul>	<ul style="list-style-type: none"> <li>Does not guarantee collaborative, coordinated or integrated care.</li> <li>May encourage a hand-off without coordinated care.</li> </ul>
Collaborative care or coordinated team care.	A comprehensive, team-based approach to integrated care in which mental health providers are on staff and work with primary care providers as a care team on an ongoing basis to address the mental and physical health needs of youth. This approach often entails regular care team meetings, training, close collaboration on treatment plans and shared electronic health records.	<ul style="list-style-type: none"> <li>Allows families and youth to access a full array of integrated mental and physical health services and supports in an integrated setting.</li> <li>Improves family satisfaction with services and treatment outcomes.</li> </ul>	<ul style="list-style-type: none"> <li>There may be sustainability issues because it can be difficult to secure funding to cover the cost of time spent on collaboration and consultation with the care team.</li> </ul>



## WHY INTEGRATED CARE MAKES SENSE FOR FAMILIES

“When families are so caught up in trying to take care of their child’s mental health needs, regular health care needs—such as vision, weight, blood pressure, allergies—fall to the wayside. When care is integrated, parents only have to go through one door, not multiple doors, to make sure their child is healthy.”

– Sue Abderholden, parent and executive director, NAMI Minnesota

The integration of mental health and primary health care makes sense for several reasons. Most families value their relationship with their primary care providers and are comfortable openly discussing concerns about their child. Primary care providers are often the first point of contact when a child is born. Primary care providers, typically pediatricians, are also the trusted professionals that families most often turn to with concerns about the health and well-being of their child. This places primary care providers in a key position to improve the early identification of mental health concerns and to link families with effective services and supports.

Most families initially seek help for mental health concerns in the primary care setting. This is especially true for families from culturally, economically, racially and ethnically diverse communities.<sup>7</sup> Up to 70 percent of primary care medical appointments are for issues related to psychosocial concerns.<sup>8</sup> More than half of all care for common mental health conditions—including anxiety, depression, attention-deficit/hyperactivity disorder (ADHD) and related conditions—is provided in the primary care setting.<sup>9</sup>

There are several reasons to seek help from the primary care setting:

- ▶ Easier access to care because of a critical shortage of mental health providers, especially in rural communities.
- ▶ Care provided in a primary care setting may be covered by insurance policies that do not include mental health care coverage.
- ▶ Families may feel more comfortable in a primary care setting because of stigma associated with seeking care in a mental health care setting.

Many families have long-standing, trusting relationships with primary care providers and these providers understand how to work effectively with youth and families. You and your child may want to ask your primary care provider to use his or her experience in coordinating care with specialists on a broad range of health issues to help ensure that your child gets the help that he or she needs from mental health providers.



## HOW INTEGRATED CARE CAN BENEFIT YOUR FAMILY

“When my family physician spoke with my daughter’s therapist everyone finally was on the same page. I felt like my daughter’s treatment moved forward and all of her health needs were being addressed... Finally, everyone—my daughter, my family and I—had hope that treatment was on the right track and things would be better.”

- Parent

Integrated care is re-envisioning the way your child receives and participates in health care. There are many ways in which you can benefit from integrated care.

### Families, health care providers and program leaders who have experience with integrated care have reported the following benefits for families:<sup>10, 11</sup>

Improved access to care.	Reduced stigma.
Avoidance of treatment errors and duplicative tests and lab work that are costly.	Reduced treatment errors by using an integrated medical chart.
Increased consultation, referral and collaboration because of regular contact between mental health and primary care providers.	Encouraged the development of individualized care plans and established clear lines of responsibility for follow up.
Improved adherence to treatment.	Greater convenience and satisfaction for families.
Increased likelihood that families follow through with referral for mental health services and supports.	Decreased wait times between mental health referrals and initial appointments.
Decreased use of unneeded medical and emergency services.	Increased attention to the treatment preferences of families.



Ultimately, integrated care promises to improve the quality of care provided to children, youth and families. It helps to establish ongoing, close relationships between youth, families and health care providers that help to produce better outcomes and greater satisfaction with care for everyone.

## THE MEDICAL HOME AND INTEGRATED CARE

“The medical home is built on a trusting, collaborative, working partnership between the child, family and primary care provider in cooperation with specialty care practitioners and the community network of medical and non-medical resources.”

- Marie Mann, M.D., medical officer, Maternal and Child Health Bureau, Health Resources and Services Administration

A “medical home” is an approach to delivering comprehensive and coordinated primary health care. The medical home approach provides a “go to” care team to help families and youth access needed resources and to coordinate care across all practice settings. There is no single definition for a “medical home,” but there are key elements that help to define this approach to care. The American Academy of Pediatrics (AAP), which has helped to define the concept of “medical home,” has stated that the medical home approach to care includes:

- ▶ **Accessible care** 24 hours a day and seven days a week for clinical support, questions and concerns.
- ▶ **Continuous care** to allow youth and families to see a member of the care team who is familiar with their unique needs.
- ▶ **Child and family-centered** care to ensure youth and families develop an effective partnership with the treating provider and care team who respects them as experts, encourages their participation in care delivery and ensures that care is always provided based on family needs and preferences.
- ▶ **Coordinated** care between youth and families, primary care and any specialty care when needed by developing effective care plans, securing referrals to specialty care, maintaining health records and providing youth and families with connections to other community resources.

- 
- ▶ **Comprehensive** care by ensuring that the child receives appropriate screenings, necessary evaluations, preventive care, specialty care and effective management of all health conditions to help the child reach his or her full potential.
  - ▶ **Compassionate** care by providing the youth and family with a supportive, safe and comfortable place to share concerns and ask questions.
  - ▶ **Culturally effective** care by acknowledging and addressing the cultural and religious beliefs and values of the youth and family in service delivery and outcome goals. Health care providers should be aware of the cultures in their communities and should respect the values and beliefs of those cultures in all aspects of care.

The medical home should include the capacity to address mental and physical health concerns together. Youth, families and primary care providers should work as a team to determine the resources that are needed for the child to be mentally and physically well and to reach his or her full potential.

The medical home emphasizes the importance of treating the whole child from the top of the head to the tip of the toes. The medical home provides a framework for thinking about and implementing integrated care because it focuses on team work, collaboration, developing effective partnerships with youth and families, coordinating care and improving the overall quality of care.

The Patient Protection and Affordable Care Act, the federal health care reform law, includes a new Medicaid Health Home option. This option expands on the traditional medical home model and provides Medicaid funding for comprehensive care management, care coordination and collaboration, individual and family support and more for children, youth and adults with serious mental health conditions.<sup>12</sup> This state Medicaid option is designed to improve the quality of care that is delivered to children and adults with a number of chronic health conditions, including serious mental health conditions, and promises to increase the state-level focus on integrated care.



## HOW FAMILIES CAN BECOME MORE INVOLVED IN THE INTEGRATED CARE MOVEMENT

“Primary care providers need families and youth to help them lead this effort in making integration programs available for all.”

– Brenda Reiss-Brennan, M.S., mental health integration director, Intermountain Healthcare

The integrated care movement is still in its infancy, so there are many opportunities for youth, families and family organizations to become more involved in helping to shape the development of integrated care approaches. Much of the work that has been done to date has been initiated by providers, with little involvement of the family voice. If families are involved, it is more likely that the integrated care models that are developed will work better for you and your child.

There are many ways to get involved. You can learn more about how care is delivered in your child’s primary care practice, talk about your needs in an integrated care setting with your primary care provider and determine how you can help to bring more integrated care into the practice. You can also work with other youth, families and organizations to reach out to other stakeholders involved with integrated care to help design and promote effective integrated care models in your state and community. These proactive steps are all summarized, starting on page 19.

For starters, learn all that you can about integrated care. This guide is a start, but the more you understand about medical homes, co-location models, collaborative care and related issues, the more you can weigh in on the subject. Knowledge is power. A full array of family friendly resources on integrated care is available at [www.nami.org/primarycare](http://www.nami.org/primarycare).

## LEARN MORE

### ASK QUESTIONS ABOUT INTEGRATED CARE

► Start a conversation with your child's primary care provider about integrated care and ask whether comprehensive and integrated care is available in the office.

#### Questions that you may wish to ask your child's primary care provider about aspects of integrated care:

Do you provide integrated care in your practice that includes providing care for all of my child's health care needs, including mental health care?

What do you do if you think a child may have a mental health concern? Do you assess for mental health issues regularly with the children you see in your practice?

Will my child's mental and physical health conditions be considered together? Will they be treated as equally important components of my child's overall health? If so, how?

Will you and my child's mental health and other health care providers work together with our family as a care team?

How will you remain involved with my child's care if he or she primarily accesses services and supports within the mental health care system? What ongoing care will you provide?

Do you have a case manager or care coordinator on staff in your office? Case managers or care coordinators are nurses, social workers or other staff members in the primary care office who can help families connect with outside services and supports.

Do you have a mental health provider within your office and on staff? If so, how do you coordinate care with the mental health provider and our family?



► Understand how medical information will be shared and addressed in the practice. Mental health and substance abuse treatment medical records have a higher level of protection under federal and state laws. However, this should not stand in the way of integrated and collaborative care.

### Questions that families may wish to ask related to their child's medical records:

What consent forms must be filled out so that you can closely collaborate with my child's mental health provider and our family?

Who will have access to my child's mental health and medical treatment records?

Who will have primary responsibility for maintaining and managing my child's mental health and medical treatment records?

What is the process for sharing my child's mental health and medical records to coordinate, collaborate and communicate with our family, other health care providers and with others involved in my child's care?

What are the legal requirements and rules related to sharing mental health and other physical health information across primary care, mental health care and other settings?

#### **Tip:**

Sometimes concerns about privacy laws can act as a barrier to providers sharing information. That is why it is important for your family to address this issue head-on with the primary care provider and to gain a better understanding of the privacy laws and what consent forms are necessary to allow effective collaboration across mental health and primary care.

- ▶ Determine how information about your child's treatment plan will be shared. Communication is key in the delivery of integrated care because there are often multiple members of the care team and it is important to understand how they will communicate with each other.

### Questions that you may wish to ask about communication:

How will you communicate with our family as members of the care team about the health care and mental health care that our child is receiving?

How will you communicate with mental health providers to help ensure effective collaboration and true integrated care?

Of the providers on our child's care team, who will take the lead for the care that is provided and who will most often communicate with our family?

Who should we communicate directly with if we have ongoing concerns about our child's care or health conditions?

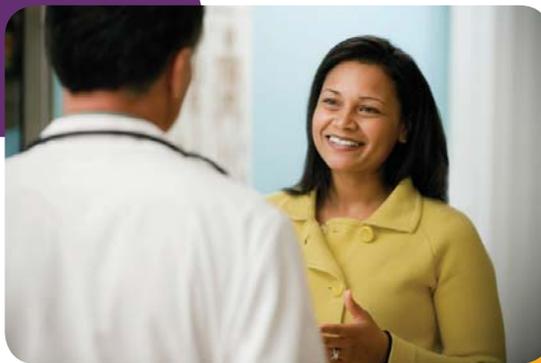
#### Tip:

The questions you ask are going to depend on how integrated care is being delivered in the practice. If the primary care provider has been trained to effectively deliver mental health care, then you may not wish to ask many of these questions. However, if mental health referrals are made or a mental health provider is co-located in a primary care office or if collaborative care is being delivered by a care team, then these questions become important in how collaborative care is delivered.

- ▶ If your child is prescribed medication for a mental health condition, it is important to ask who will be responsible for managing the medication, for closely monitoring and tracking side effects and for taking into account medication interactions if your child is taking other medications.

## **SPEAK UP** COMMUNICATE YOUR NEEDS

- ▶ Share with your primary care provider the importance of integrated care and the issues that are important to your family in the delivery of integrated care. This information will help to develop an integrated care approach and a comprehensive treatment plan that works for you and your child.
  
- ▶ Start a conversation with your primary care provider about the importance of the family and the child (if age appropriate) as members of the care team. Drive decisions about your child's care and his or her treatment plan. You may wish to share the following information related to mental health care with your child's primary care provider:
  - Treatment preferences and how you would like to see integrated care work across the treatment team;
  - Community resources that the primary care provider may not be aware of that are important to families; and
  - Cultural perspectives that will help the primary care provider better understand your child and family.
  
- ▶ Remember that primary care providers are there to help with all the health conditions that your child may develop and to provide you with a link to effective care. Mental health care is no exception. Feel comfortable sharing concerns and requesting the care your child needs to lead a fulfilling life at home, in school and in the community.





## **SHARE RESOURCES**

### **HELP YOUR PRIMARY CARE OFFICE**

- ▶ Share resources with primary care providers about the importance and value of integrated care. Visit [www.nami.org/primarycare](http://www.nami.org/primarycare) to find resources to bring to your primary care office about the importance of mental health in primary care settings.
- ▶ Work with primary care and mental health providers to develop forms to use in coordinating care and feedback forms that establish clear lines of communication between families, primary care providers and mental health providers. These forms will communicate information about the treatment plan, the expectations and timelines for anticipated outcomes, progress in implementing the treatment plan and more.

## **RAISE YOUR VOICE**

### **GATHER FAMILIES TO GET INVOLVED**

- ▶ Form a group of interested families and family organizations that want to work with you to help ensure that effective integrated care is delivered in your community. Connect with your NAMI State Organization and NAMI Affiliates. To find their contact information, visit [www.nami.org/local](http://www.nami.org/local).
- ▶ Bring your group of families together to brainstorm about the elements of integrated care and integrated care models that you would like to have available in your community.
- ▶ Take the challenges to integrated care identified on page 25 and strategize on how these can be overcome. Youth and families are natural partners to work with both primary care and mental health provider organizations to help overcome these challenges.

## **BUILD SUPPORT**

### **REACH OUT TO STAKEHOLDERS IN YOUR COMMUNITY**

- ▶ Start a dialogue about integrated care with leaders from your state or community's organizations of pediatricians, social workers, psychologists, psychiatrists, school psychologists, school counselors, family physicians and other provider groups. You may find that these groups are also interested in bringing integrated care to the community or are working on doing so. Contact information for these organizations is listed on NAMI's online resource list available at [www.nami.org/primarycare](http://www.nami.org/primarycare).

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- ▶ Facilitate meetings or social events that bring together key primary care and mental health care providers so that they can begin to get to know each other better and network. This is an important first step in building coalitions and getting work on integrated care started.
  - ▶ Contact your state's Medicaid office, state mental health authority and private insurance companies to discuss the steps necessary to change billing and coding rules so health care providers can get paid for providing integrated care like screening, case management, consultation and related care. Talk about how integrated care can lead to improved quality of care, better outcomes and can lower overall health care costs. For more information on addressing the financial obstacles to implementing integrated care, visit NAMI's online resource list available at [www.nami.org/primarycare](http://www.nami.org/primarycare).
  - ▶ Educate your state legislators and other state officials about the benefits of integrated care and how this approach improves the quality of care, leads to better outcomes and will help to lower overall health care costs. Armed with good information, legislators may consider sponsoring legislation that requires insurance companies and the Medicaid program to pay for care management and care coordination.

## **BRING CHANGE**

### **WEIGH IN ON THE INTEGRATED CARE MOVEMENT**

- ▶ Develop a family coalition, with multiple stakeholder groups, to come together in support of bringing more widespread integrated care into your state and community. The coalition may start with family organizations, but may expand to include provider organizations, all working together to improve the quality of care and to produce better outcomes.
- ▶ Serve on advisory boards and councils that are developing integrated care programs in your state or community. Ensure that families are at the table to help shape these programs so that they ultimately meet the needs of families.
- ▶ Get involved in the work being done by your state in implementing the Affordable Care Act, enacted in 2010. Contact either the State Medicaid office or the state mental health authority to find out which committees or advisory groups are working on health homes and/or are focused on integrated care.



## OVERCOME CHALLENGES

### USE YOUR NETWORK TO FIND CREATIVE SOLUTIONS

Although it makes perfect sense to look at the overall health care needs of your child and to integrate care across all of his or her health care needs, the following are some of the challenges that may exist in bringing integrated care to practices in your community:

- ▶ Silos exist in how primary care and mental health care are delivered that impede effective communication and collaboration.
- ▶ Lack of training, education and comfort in addressing mental health issues in primary care and other health issues in mental health care settings.
- ▶ Limited time to effectively address mental health issues in primary care.
- ▶ Limited referral sources for mental health care that impact the willingness of primary care providers to screen and to raise concerns about a child's mental health.
- ▶ Concerns with strict confidentiality and privacy laws and the sharing of mental health information between providers.
- ▶ Reimbursement concerns, especially for primary care providers providing mental health care, and concerns that time spent on care collaboration and consultation is often not reimbursed.
- ▶ Lack of funding sources to create the infrastructure that is needed for integrated care, including training staff, electronic health record systems, finding the right integrated care model that fits the needs of the community and costs to get the care model up and running.

Despite these challenges, the interest in integrated care continues to grow and programs are being developed across the country. Your involvement with coalitions and stakeholders committed to improving the quality of health care delivered to youth and families is key to overcoming challenges and discovering creative solutions. Starting on page 27 of this guide, there are a few integrated care approaches featured that have been implemented around the country. These models have managed to overcome challenges to get their program off the ground. Much can be learned from their experiences.



## MAKING THE CASE FOR INTEGRATED CARE

There are compelling reasons to support the broader implementation of integrated care. These can help you make the case for integrated care with various stakeholders.

### Reasons that you may wish to use to get integrated care implemented in your community:

Primary care providers are uniquely positioned to identify mental health concerns early and to connect children and their families to services and supports either in their own practices or in specialty mental health care since most children visit their offices at least once each year.<sup>13</sup>

Primary care settings are where we identify most childhood onset health conditions and where care is coordinated for these health conditions. Mental health conditions should be no exception.

Integrated care promises to remove the silos that currently exist to create greater efficiencies in care delivery and to lower overall health care costs.

Integrated care allows providers to see the whole child and recognizes that mental health is an integral part of the overall health and well-being of all children.

Integrated and coordinated care, with families as members of the care team, alleviates the need for families to coordinate care across providers so they can focus on providing the support their child and family need.

Half of all lifetime cases of mental illness begin by age 14, and despite the availability of effective services and supports, there are average delays of eight to 10 years from the onset of symptoms to intervention—critical developmental years in the life of a child.<sup>14, 15, 16</sup> This gap can be closed if primary care providers are better trained to identify mental health concerns early and to either coordinate or provide mental health care.



Less than one-half of children with a diagnosable mental health condition receive mental health services and supports in a given year.<sup>17</sup> Approximately 40 to 50 percent terminate services prematurely because of a lack of access, transportation, finances or stigma.<sup>18</sup> When mental health services are provided or coordinated through a primary care office, these issues can be eliminated.

Much has been learned through the SAMHSA Systems of Care grant program about collaboration, working across child-serving systems, eliminating silos in the services provided to children and families and other aspects of systems reform. Families have helped to drive this work so can use their expertise in helping to see integrated care more broadly implemented.

## **INTEGRATED CARE IN THE REAL WORLD MODEL PROGRAMS**

There are a number of innovative integrated care models that exist across the country. Starting on the next page are three programs that outline different approaches to integrating mental health and primary care.

These programs provide valuable examples of what integrated care can look like in different communities and how families can be actively involved. Families involved with the integrated care movement are encouraged to consider replicating models like these in their own communities. Families can also share the benefits and outcomes of these programs to help make the case for bringing integrated care to their communities.



## MASSACHUSETTS CHILD PSYCHIATRY ACCESS PROJECT

“Hopefully with our help, the primary care provider is much more welcoming and knowledgeable on how to respond to mental health issues and also proactive in terms of inquiring about mental health needs that may exist with a child. We have developed a kind of system of backing them up and being almost a virtual presence in their practice. From the standpoint of a family, this means they have a knowledgeable and interested pediatrician who, with the help of our program, is able to be more skillful and confident in terms of dealing with mental health issues.”

- Barry Sarvet, M.D., co-medical director, Massachusetts  
Child Psychiatry Access Project

**Description:** The Massachusetts Child Psychiatry Access Project (MCPAP) is a statewide system of regional children’s mental health consultation teams designed to help primary care providers meet the needs of children with mental health concerns in the pediatric care setting. The project includes six regional consultation teams with several child psychiatrists, one social worker/psychologist and one care coordinator. The child psychiatrists provide telephone consultations to primary care providers (often offering advice or answering questions) as well as face-to-face assessments and evaluations with children, adolescents and families. The psychotherapist also conducts evaluations and telephone consultations. The care coordinator helps youth and families find services and supports and provides resources and referral tracking. The care coordinator also helps keep primary care providers informed about who the youth are seeing for mental health care and when their appointments are scheduled so primary care providers can coordinate care and keep track of the care being provided.

The MCPAP program also trains primary care providers on how to respond to mental health needs and increases their competency to provide mental health care. Primary care providers are often able to address the needs of youth with mild to moderate mental health concerns while the consultation teams triage and reserve children with more complicated, serious mental health conditions for mental health providers.



**What Families Need to Know:** The message to families is that your pediatrician, at least in Massachusetts, is part of the mental health system and is connected to a network of resources that are there to help ensure that youth receive the mental health care they need, either directly through primary care or through a referral to a mental health provider. The program is designed to encourage families to feel free to openly communicate any worries or concerns they may have about their child with their primary care provider. The primary care provider should not only be waiting for the youth and/or family to share concerns, but should be asking directly about mental health concerns. Youth and families should know that their primary care provider not only wants to know about any mental health related worries or concerns, but is there to help.

**Benefits and Outcomes for Families:** The MCPAP program frequently encounters families who report that they really appreciate their primary care provider's role in helping with their child's mental health concern. They have a lot of families who are reporting that their kids are receiving all of the services their pediatrician recommended. Families are able to access services that they did not think they could get for their child with the help of the program's care coordinator. They also report that their child is improving because of their experience with the program.

Feedback for the program shows that it helps to reduce stigma because the youth involved in the program feel like the mental health symptoms they are experiencing are normal problems that are not shameful, mysterious or weird.

**Financing:** The program developers believe they are quite fortunate because the state of Massachusetts has been providing funding for the MCPAP program. Those who developed and operate the program do so because they are funded by the state, outside of the insurance reimbursement system. However, the program is trying to develop some ways to get more of a fair contribution from the private insurance system for the consultation work that they provide. Many of the families served by the program are privately insured so those involved with MCPAP are working to get private insurers to support the program. There is legislation pending in Massachusetts that would require insurance companies to pay for services provided by the MCPAP program.

**To learn more about MCPAP:** Visit [www.mcpap.com](http://www.mcpap.com).



## NORTH CAROLINA CENTER OF EXCELLENCE FOR INTEGRATED CARE

“Integration is a cultural shift for not only primary care practices but for families. We are used to going to doctors and having them tell us what to do. It is rare for people to push back and ask questions. We need to train ourselves.”

– Regina Dickens, Ed.D., program director, North Carolina Center of Excellence for Integrated Care

**Description:** The center, a program of the NC Foundation for Advanced Health Programs, is a statewide resource for medical and mental health providers. Its mission is to integrate medical and mental health services to provide better care and to improve health care outcomes. The center offers training and technical assistance to medical providers to help them integrate mental health services into their practices and facilities, and also prepares mental health providers to add medical screenings and referrals to medical services. The center helps providers develop strong, effective coordination and collaboration to better serve the needs of those receiving care through the program.

**What Families Need to Know:** Families need to understand the importance of scheduling regular well-child visits and physical exams for their children, especially when they move into adolescence. Early screenings and referral to treatment can reduce the impact of illness when caught early and treated appropriately. Families should also know why having a medical home and integrated care is important and how to work effectively and collaboratively with providers integrated into practices. Families facing issues around chronic medical and mental health conditions need to become informed partners in developing care plans that will work for them.

**Benefits and Outcomes for Families:** Families frequently report having reduced wait times for referrals and appointments in medical practices that have a mental health provider integrated into the practice. In these settings, wait times have been greatly reduced and families report better follow-up care. Families have also reported that their child experienced improvement in daily activities and a reduction in the number of days they did not feel well. Primary care providers reported greater satisfaction when they had access to mental health services and felt more confident in the care they can offer.



**Financing:** The center is funded through a contract with the State of North Carolina, Office of Rural Health and Community Care, to support selected primary care practices, community health centers and other providers as well as through a contract with the Governor’s Institute on Alcohol and Substance Abuse.

**To learn more about the NC Center of Excellence for Integrated Care:** Visit [www.icarenc.org](http://www.icarenc.org).

## **CHEROKEE HEALTH SYSTEMS**

“I had tried to get my doctor to see that something was wrong with my child and it was not until I came here that I was finally able to have someone listen and help. The combined efforts of the primary care and mental health providers helped identify my child’s problem. They offered understanding and helped us move forward.”

- Parent

**Description:** Cherokee Health Systems is a Federally Qualified Health Center (FQHC) and a Community Mental Health Center. FQHCs are community-based organizations that provide comprehensive health care, including mental health services, to persons of all ages, regardless of their ability to pay. Cherokee has a saying that there is “no wrong door.” Families come in through the mental health door with physical health needs and others come through the primary care door with serious mental health conditions. There are both primary care and mental health providers on staff who work closely together and collaborate on cases.

Cherokee has integrated health care records and coordinated treatment plans and holds weekly care team meetings to discuss cases. All of the providers on the care team know the medications individuals are taking, how they are doing in therapy, the resources they need and the lab work that has been done. This helps to avoid duplication of tests and provides enhanced services. Cherokee co-locates behavior therapists, clinical psychologists and social workers in primary care offices to provide mental health assessments, consultations and support.

**What Families Need to Know:** Youth and families should help to educate both their primary care and mental health care providers about all of their health and mental health care needs. It is important for

families to understand the significant impact that mental health conditions can have on a child's overall health care and vice versa. Families should ask what they can do to best positively impact their child's overall health care given that the child has a mental health condition.

**Benefits and Outcomes for Families:** Cherokee has seen a reduction in the use of emergency medical care since focusing on integrated care. Families report greater satisfaction with their child's health care and share how integrated care helps make their lives easier.

**Financing:** Financing is an ongoing challenge for Cherokee but there is a strong commitment to making the model work. Cherokee has figured out financing strategies to support integrated care and has negotiated some contracts with major payers to cover the important consultation, health promotion and coordination activities that are core components of integrated care.

**To learn more about Cherokee Health Systems:** Visit [www.cherokeetraining.com](http://www.cherokeetraining.com).





## CONCLUSION

“Everybody needs to think of themselves as a participant in the process. We want patients to be activated, involved and engaged. Be engaged in your own health care. Recognize that integration is not a model where someone tells you what to do. It is important for families to have a health care home and to have a team that is working together to address the whole spectrum of their needs, behavioral and physical. That is your right.”

– Parinda Khatri, Ph.D., director of integrated care, Cherokee Health Systems

Integrated care promises to improve the experience of families accessing health care for their child, whether it is accessing services for mental health or physical health concerns. However, in order for it to live up to its promise, families and youth must be involved in all aspects of integrated care. Work with other families and take time to envision the ideal health care system in which prevention, early identification and treatment for children’s mental health is given the same priority and urgency as all other health issues.

This family guide offers a starting point for thinking about how health care delivery can be more effective for you and your child and can be comprehensive, coordinated and collaborative. The integration of mental health and primary care offers real hope that we can improve the quality of care provided to children, youth and families. It is essential that families are part of the integrated care movement at every level.

## RESOURCES FOR FAMILIES

NAMI has developed a complete online resource list for families at [www.nami.org/primarycare](http://www.nami.org/primarycare).

These resources provide in-depth information about the different approaches to integrated care described in this guide and information about communication and information sharing, financing integrated care, the medical home, model programs and much more.

The website also includes NAMI’s comprehensive survey report on *The Family Experience with Primary Care Physicians and Staff*.



## **GLOSSARY OF TERMS**

**Care team:** A team of health care providers and other service providers involved with a child's care who work with the child and family to develop and implement a treatment plan. The plan takes into account the strengths, needs and treatment preferences of the child and family.

**Case managers and care coordinator:** This is typically a nurse, social worker or other staff member in primary care offices who helps families connect with outside services and supports.

**Primary care provider:** A health care provider who provides comprehensive care, including preventive care (well-child visits), acute care (treatment of illnesses and injuries) and chronic illness care. Primary care providers include pediatricians, family physicians, physician assistants, nurse practitioners and nurses.

**Mental health condition:** For purposes of this guide, reference to mental health conditions includes both mental health diagnoses and substance abuse disorders.

**Mental health provider:** A health care provider who provides mental health care. This person can be a psychiatrist, clinical psychologist, psychiatric nurse practitioner, clinical social worker or mental health counselor.

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