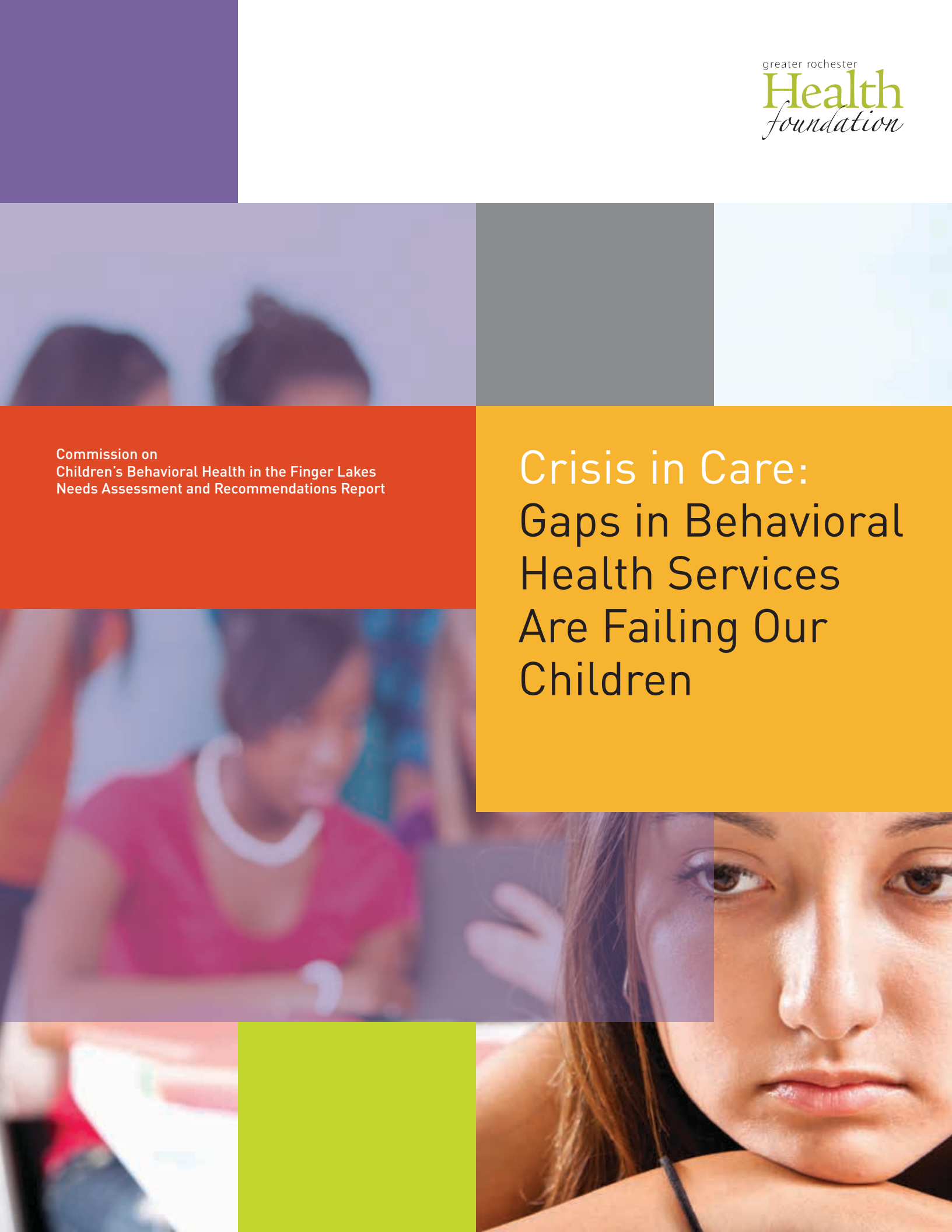


Commission on
Children's Behavioral Health in the Finger Lakes
Needs Assessment and Recommendations Report

Crisis in Care: Gaps in Behavioral Health Services Are Failing Our Children



Children's Behavioral Health in the Finger Lakes

“We would never treat children suffering from cancer the way we treat children suffering from mental illness. It is a travesty to ignore, overmedicate or throw kids into the court system before we provide proven therapeutic solutions. There is a better way.”

— Bonnie DeVinney
Chief Operating Officer
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Executive Summary

The Greater Rochester Health Foundation convened the Commission on Children's Behavioral Health in the Finger Lakes in spring 2015, in response to concerns from parents, child care providers, schools, pediatricians and children's mental health clinicians. They consistently raised alarms about the shortfalls of our region's children's behavioral health system: the demands placed on it, its capacity, and in some cases, its quality.



The Commission is comprised of 25 regional experts from diverse backgrounds including business, law, healthcare, social services, advocacy, government, and research. The group worked more than nine months to outline recommended policy, practice, and funding changes to improve the state of children's behavioral health services in a nine-county region (Genesee, Livingston, Monroe, Ontario, Orleans, Seneca, Wayne, Wyoming, and Yates).

As part of this effort, the Health Foundation commissioned a study by the Division of Child and Adolescent Psychiatry at the University of Rochester Medical Center (URMC)¹, engaging researchers and clinical practitioners to examine the state of children's behavioral health care throughout the region. The study assessed systems that reach children (families, schools, courts, and community organizations) and conducted interviews, focus groups and data analysis. Their findings were presented regularly to the Commission for review and assessment and the Commission then worked to develop meaningful recommendations for change.

The URMC white paper¹ served as the basis of selected content for this report, including some quotes, data points, and topical discussion throughout.

KEY FINDINGS INCLUDE:

- In any given year, 13%-20% of children between the ages of two and 18 experience a mental disorder, and the prevalence of these illnesses appears to be increasing.
- Of those children with a diagnosable behavioral health issue, only one in five will see a mental health provider. Of those who do, many will not receive treatment soon enough.
- Low-cost, evidence-based prevention interventions exist and have been proven to reduce behavioral health issues. We just need to implement them. Today, prevention efforts are virtually non-existent in regional child care settings, elementary and secondary schools, or community resource settings.¹
- Access to care is highly problematic. Families seeking assistance for children in need are unable to find quality care that is readily available.
- Finding culturally appropriate care is nearly impossible for people of color.
- Quality of care is inconsistent, and evidence-based interventions are not a routine part of clinical training or continuing education.
- The shortage of practitioners trained to address the needs of children and adolescents is staggering. Although several issues feed this shortage, inadequate reimbursement is a key contributor.

- An overwhelming number of children in our region experience or witness trauma-inducing events. Left unaddressed, trauma has a high probability of prompting serious mental health and behavioral issues, yet resources that can recognize and address signs of trauma are few and inconsistently available.
- Active coordination between the multiple organizations that serve children and adolescents – pediatricians, schools, families, churches, youth groups, and even the court system is critical. Today, however, there is no established process for this coordination to occur. The issue is particularly acute for children who are involved in family court and demonstrate behavioral issues in school.

The Commission agrees: our region is facing an urgent need to address these issues. And meaningful improvements are within reach. With focused, concerted effort across multiple systems, our children could begin to receive prevention and treatment interventions that will address their struggles.

WHAT'S NEXT

After its assessment, the Commission has identified three overarching recommendations that should take top priority:

- An Implementation Task Force should be formed to systematically address these issues. This Task Force should consist of educators, human service providers, court personnel, major health care providers, payors and foundations, and others committed to addressing the gaps in children's behavioral health.
- The initial priorities of the Implementation Task Force should center on prevention, starting from preschool through age 10, and address the recognition of and response to trauma for all children and adolescents.
- Resources should be aligned to support ongoing advocacy efforts, mobilizing parents and professionals to work together to address policies and practices, including legal and regulatory barriers in New York State.

Additional recommendations that address specific challenges and gaps are highlighted throughout this report.

The Commission recognizes that our region faces a variety of challenges, from economic stagnation and overwhelming rates of poverty to structural racism and a disintegration of family stability. Add this to the wide range of environments in which families live – from densely populated urban areas to rural areas bereft of service, and we realize the charge is not small.


However, the price of ignoring our inadequate and ineffective behavioral health system will be paid over generations. Change is possible, but the Commission believes we cannot afford to wait any longer to focus attention and resources on this significant issue.

Comments included in this report are direct quotes from interviewees and members of focus groups conducted by URMC. Because their participation in the project was anonymous, their quotes are attributed as such.¹

Homeless and foster-care youth, and those with diagnoses like autism spectrum disorder have growing and specialized needs for behavioral health services and special concerns around access and quality. This report does not address these populations, although the Commission recommends that future studies consider the specific needs of children facing extenuating circumstances that make access to care exceedingly difficult.

While we understand the term behavioral health is inclusive of both mental illness and substance use disorders, substance abuse is its own health concern and the full scope of substance abuse treatment is not included in this report. Substance abuse is only included in this paper relative to necessary prevention programming and as it pertains to those who also suffer mental illness because this further complicates a person's ability to find effective, timely treatment.

¹ Scharf, M. A., Alpert-Gillis, L. J., Wyman, P. A., White, A. M., Cerulli, C., Nichols-Hadeed, C., Thompson Stone, J., Wallace, J., Malcolm, K. T., Thomas, K. K., Washington, M., Petrova, M., Thon, E. P., Funchess, M., Lily, T., Wilson, J. (2015). Promoting Children's Behavioral Health: Examining Needs, Resources and Implementation of Best-Practices for Children and Youth in the Greater Rochester Area of New York State.



“In the U.S., 7 million kids under the age of 18 have asthma, 7 million have peanut allergy, and 200,000 under the age of 20 have diabetes. But 17.1 million children under the age of 18 have or have had a diagnosable psychiatric illness, so the common disorders of childhood and adolescence are mental illness.”

– Dr. Koplewicz
Founder and President
Child Mind Institute

A Wide Gap

In any given year, about one in five children in the United States suffers from a diagnosable mental illness, yet only about 20 percent of these children receive mental health care (American Academy of Pediatrics, 2013).

In other words, in an average suburban or rural classroom, four children likely have a diagnosable mental illness. In larger urban classrooms, there are likely more – and it is likely that only one of these children in each room is receiving professional mental health care.

In the Greater Rochester area, regional studies have shown children in need in our nine-county region may be on a long waiting list, parents may not be able to find care appropriate to their child's needs and their budget, or they may not be able to rearrange school and work schedules to accommodate that care. Meanwhile, those four or more children in class are being taught and cared for by a teacher whose training has focused appropriately on education and not how to screen for, treat, or work with children with an array of behavioral health needs.

Courts throughout the region are rife with children whose parents are engaged in the criminal justice system. The courts

also manage cases in which children with diagnosable mental illness have broken the law or are at risk of hurting themselves as a result of their illness. Deciding their needs and/or punishments are legal experts with little to no training in mental health. These legal experts may not even recognize children who need mental health treatment, let alone have the ability to provide or mandate it.

Primary care doctors who have sworn their professional lives to preventing and treating chronic and acute illness in children are struggling to treat the mental health illnesses that bring many of their patients to them. Unable to obtain timely treatment for these patients through referrals to therapy, doctors often prescribe medicines as their only option, while preferred, evidence-based, first-line interventions for many of these disorders are actually psychotherapies.

Professionals across education, medicine, and the justice system are frustrated, concerned and heartbroken working day in and day out with children who need help and whom they cannot adequately serve.

Heartbroken, too, are the families who know their children are not “bad” or “spoiled” but in need of help. They feel isolated and helpless watching life get increasingly more difficult for their children as they suffer from poor school performance, difficulty in social relationships, and punishment or scorn in academic and/or child care settings.

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As much as parents want to help, they are faced with the realization that helping their sons or daughters likely means criticism of them as a caregiver. They fear society will label them as a bad parent for raising a misbehaving child, or will blame their genetics and/or parenting skills for having a child with a mental illness.

This is not just a problem for those who live and work with children. Everyone in the region pays taxes for education, covers the costs of law enforcement and courts to intervene, and ultimately invests in the next generations of community members. Whether urban, suburban or rural, rich or poor, unmarried or married, with children or without, we are all affected by the children who live here.

GROWING CHILD MENTAL HEALTH DIAGNOSES

The number of children being diagnosed with a mental illness is rising – locally and nationally. Across all income groups in the Rochester region, there was a more than a 35 percent increase in mental health diagnoses among children seen as outpatients (2010 through 2014). At the same time, there was a 40 percent increase in prescriptions to treat behavioral health illnesses. By 2014, 11 percent of all pediatric claims included a behavioral health diagnosis.

"We're never going to treat our way out of this problem," says Jeff Kaczorowski, M.D., The Children's Agenda. "The depth and prevalence of mental health issues – and severity of illnesses – in the United States has increased dramatically. This indicates there is something going on earlier in children's development that needs to be addressed earlier, and at the population level, in order to get to the root of this."

Behavioral and emotional illnesses that go unrecognized or unaddressed in childhood can progress with debilitating consequences in adolescence and adulthood. For example, anxiety disorders (generalized anxiety, social anxiety, panic disorder, post-traumatic stress disorder, separation anxiety disorder, or specific phobias) are the most prevalent psychiatric illnesses among children. These disorders in particular help prime the brain for depression in the teen years – which in turn puts individuals at a 50 percent higher risk for depression as an adult.

Often families are unaware their children are struggling with suicidal thoughts or plans until a threat or attempt is made. Nearly a third of students surveyed in Monroe County reported feeling so sad and hopeless almost every day for two or more weeks in the past year that they stopped their usual activities. Twelve percent had seriously considered attempting suicide within the past year, while seven percent had actually attempted it (Centers for Disease Control and Prevention behavioral risk study conducted by the Monroe County Department of Health).

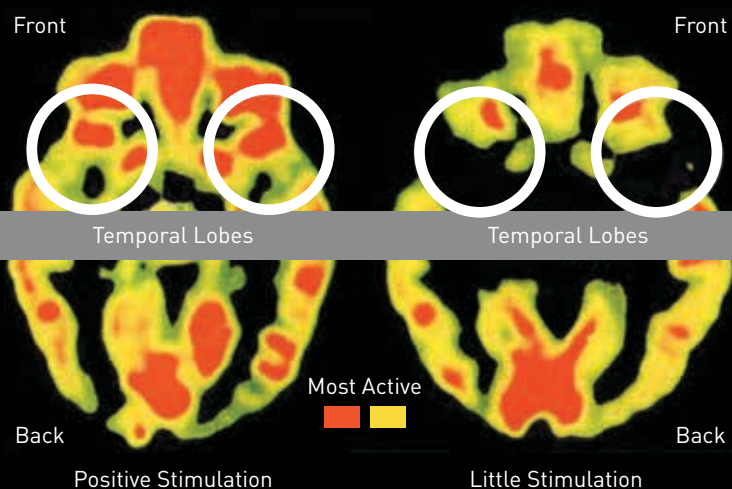
SUICIDE

In East Rochester, on July 29, 2015, 12-year-old Kennis Cady committed suicide in the five minute span her parents Dan and Michaela were on the phone with each other trying to figure out how to get her help. Her father told a *Democrat and Chronicle* reporter about his reaction to an alarming incident with Kennis shortly before her death:

"At that point, for the first time, I really saw there was something troubling her different from regular childhood stuff," Dan Cady is quoted. "She started crying and said she was sad, and I said, 'Why are you sad?' and she said, 'I don't know.' Michaela and I had a talk that night about getting her help. ... We didn't realize that within 48 hours we'd lose our daughter."

STIMULATION

Brain scans comparing two different three-year-olds.



SOURCE: CDC



Contributing Factors in Common

While the nine-county region is made up of a very diverse set of communities representing different social, economic, and geographic compositions, some common experiences throughout the region negatively impact children's mental health and their ability to get help.

Among these, trauma, poverty, and family dysfunction are particularly insidious because they interfere with children's healthy brain development and their ability to become resilient to stressors.

TRAUMA

By the time most children turn 18, they have experienced some form of traumatic experience. Those living in poverty experience sustained trauma and have a lower resiliency, or ability to manage these experiences and emotionally bounce back. Among the forms of trauma most damaging to children's ability to bounce back are domestic violence and other ongoing violence witnessed or endured daily.

Some regional studies, particularly in Monroe County, found that children as young as five or six have witnessed violence in their neighborhood or home. Many also have a parent who is depressed, which hinders his or her ability to provide adequate emotional support to the child in response to trauma. One quarter of children in the Rochester City School District in grades K-3 – children no older than 10 years old – were found to be at risk for school adjustment problems, with behaviors that included carrying weapons, and getting into physical fights (2011 Monroe County Youth Risk Behavior Survey Report).

Mental health professionals seek to promote resiliency among children that will help them deal with trauma in a way that positively impacts their development – to respond in a healthy way to the difficulties and adversities life hands them.

To understand the need for resiliency, it's important to realize that some forms of stress are worse than others and require a different level of coping skills. Not all stress is "bad"; some amount of stress or conflict is necessary in life as it inspires, motivates and teaches. There's also "tolerable" stress which has no positive outcome but doesn't cause permanent harm.

Many factors related to trauma impact a child's development and functioning. These include: the type and severity of trauma the child experiences and its duration, his or her age at the time, the perpetrator, and amount of support available. Also critical to the child's ability to deal with trauma is the

“All children, even the most fortunate, suffer emotional injuries. At home, in school and on the playground, all children experience disappointment, frustration and failure; criticism and disapproval; and exclusion by peers. In every family, there will be moments of anger and misunderstanding.

In healthy development, children recover from these moments. Whether on their own or with our support, most children bounce back. Emotional injuries are, in many respects, analogous to physical injuries. Just as our cells must repair physical injuries, emotional injuries also must be healed. Without this healing, the injurious process will spread.”

– Kenneth Barish, Ph.D.
“How to Raise an Emotionally Resilient Child”
PBSParents.com

subsequent cascade of events (e.g., foster care, etc.), and the child's individual coping skills and resources.

"Toxic stress, however, overwhelms the person system and often we see mental and physical effects that can last a lifetime," says Michael Scharf, M.D., Associate Professor of Psychiatry and Pediatrics and Chief of the Division of Child and Adolescent Psychiatry, University of Rochester Medical Center. "With resiliency, when stress comes along it is tolerable rather than toxic."

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– Michael Scharf, M.D.

TRAUMA RECOMMENDATIONS

- Provide universal education regarding trauma-informed care, including historical trauma, for all who work with youth;
- Provide ongoing training – including role-specific mental health training, culturally-specific trauma-informed training, and referral training – for emergency responders, court staff, attorneys, educators, primary care providers, hospital staff, medical transport staff, and community members and leaders;
- Professionals working with children must develop standards for accurately interpreting early signals of mental health problems to avoid criminalization-oriented interventions because of implicit biases.

POVERTY

There is broad recognition of the issue of poverty in the City of Rochester. In fact, it is reported that approximately half of the children living in the city are in families that live well below the poverty line. But the issue affects people throughout our area. While children represented one third of the total number of people living in poverty in the nine-county region, they account for only a little more than 20 percent of its population.

Perhaps surprisingly, the suburbs outrank the City of Rochester in terms of number of people in poverty and the rate at which poverty is increasing. According to the Children's Agenda, 40 percent of Monroe County families living in poverty are in the suburbs. A 2014 report from the Metropolitan Policy Program at Brookings Institution ("The Growth and Spread of Concentrated Poverty, 2000 to 2008-2012") noted Rochester's suburbs experienced a 43 percent rate of growth in the poverty rate between 2010 and 2012. All rural counties in the region have roughly a 10 percent rate of child poverty, which combined with lack of local treatment options makes acquiring services even more daunting.

Children's basic needs – food, clothing, and shelter – must be met first before parents and caregivers can begin to address their mental health needs. These significant details of people's daily lives – if they have enough money in their wallet for bus fare, where the bus stop is (if there is one), the condition of their home, the safety of their school (and their walk to school), the food they've eaten in a given day – cannot be underestimated in relation to their mental wellness and accomplishing the difficult task of seeking care.

FOCUS ON CHILDREN AND FAMILIES

Human development and brain research have clearly pointed out what parents already feel and know – environment influences the emotional wellbeing of our children. Healthy functioning does not occur in isolation; it occurs within the context of a home, a family, a peer group, a school, a neighborhood, a community. Therefore, healthy social-emotional development is either enhanced or inhibited by the context in which our children live and grow.

As a society, we have raised our awareness, interventions, and treatments to address the unique symptoms and issues for children but have lagged behind in systematically supporting the most influential environment in a child's life – the family. Where there is a child in need, there is a family in need, and where there is a family in need, there is a need for an integrated family-based approach that addresses the interplay between the child, his/her family, and their environment. "Family-centered approaches lead to better health outcomes and wiser allocation of resources as well as greater patient and family satisfaction." (ACP)

In addition to family-centered care and treatment, families need coordinated and integrated health-promotion services and approaches, to build resiliency and prevent further development of challenging emotional, behavioral, and familial problems.

It is a subtle but essential shift. The heart of the matter is our families. With an intention to integrate and coordinate systems to systematically hold the family as the focal point, we influence the environment in which those families seek care and support, and thus influence the development, restoration, healing and emotional wellbeing of our children.

AMERICAN ACADEMY OF PEDIATRICS
Committee on Hospital Care INSTITUTE FOR
FAMILY-CENTERED CARE POLICY STATEMENT
Organizational Principles to Guide and Define
the Child Health Care System and/or Improve the
Health of All Children Family-Centered Care and
the Pediatrician's Role. PEDIATRICS Vol. 112 No. 3
September 2003 6

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WHEN CHALLENGES STACK ON CHALLENGES

Michael admits: he is not living the life he wants. He strives for something better but just doesn't know how to suppress his demons.

Michael has been diagnosed with ADHD, depression, schizophrenia, and bipolar disorder. He's also never had a consistent, caring adult presence for more than a short period of time.

"I've literally never had anyone stay in my life. I had to learn everything on my own and at times was homeless, sleeping in the rain or in a shed," he explains. "I'm still stressed, still grieving and I don't know how to express it the right way."

Not knowing how to express his feelings led him to violence and substance abuse, behaviors that kept him from earning a high school diploma and earned him a police record instead.

When Michael was sent to jail for burglary and assault, he was without medication for two weeks until the system could process a request for a doctor and the doctor was able to visit and evaluate him. But the consistency of prison got him thinking about his future, and he began working toward his GED, with the hopes of getting his life on track.

Then his brother died of an enlarged heart and his mother died a month later. This new grief again derailed his sobriety and his plans.

Michael has now been meeting a psychiatrist regularly for nearly three years and goes to individual and group therapy weekly for his chemical dependency. And although this court-appointed treatment provides some welcome consistency, Michael struggles with mixed messages and advice coming from the different systems with which he's involved.

"One person will tell me one thing and the other says something else," he says of the mental health and addiction specialists, adding, "The judge wants me to do something else. It makes me crazy. My needs aren't being met and I have no connection with the therapist. I get into my own thoughts and shut down and want the pain to go away fast. That's when I want to use [drugs] again to make it all go away."

Michael's greatest wish is to successfully move past drug court, "be successful and get a real decent job." The reality, he says, is that it may not happen. "Every chance I get, when I know I'm going to cross the finish line, something holds me back."



“In the African American community we don't acknowledge mental health problems, so it was hard for me. I didn't want to acknowledge my daughter was suffering from mental health issues and it took me time to accept it.”

– Erick Stephens
Father of a child with mental illness
Parent Engagement Specialist
Healthi Kids/ Finger Lakes Health System Agency
Member of the Commission on Children's Behavioral Health in the Finger Lakes

STIGMA

Parents are afraid of what others will think about their child's illness, and it is preventing them from getting care soon enough. Worrying about being blamed for their child's illness or related actions keeps them from admitting their child needs help and seeking treatment (with average treatment delays of up to eight years). In some cases, families only attend one appointment with a mental health professional and do not return.

A community member shared, "I think the thing that happens is by the time the [obvious] need [for treatment] arises, the child is already labeled as 'bad.' The parents already know they've failed. Somehow it's their fault and everyone is kind of reactive instead of being responsive to the need."

In some cultures, particularly in African American and Hispanic communities, families fear criticism for seeking treatment because mental illness is taboo and family concerns should not be made public.

"I thought there was a stigma...for the kids as well because...in the African American community, you know, we're kind of raised, 'you don't put stuff outside the house,'" says one mother.

Erick Stephens, the father of a child with mental illness, struggled to accept his daughter's problems were related to her mental health. Stephens is a parent engagement specialist with Healthi Kids/ Finger Lakes Health System Agency and is a member of the Commission on Children's Behavioral Health in the Finger Lakes. Despite his experience working with children and families, Stephens says he had trouble facing his daughter's struggles with mental illness because of his cultural perceptions as an African American.

"In the African American community we don't acknowledge mental health problems, so it was hard for me. I didn't want to acknowledge my daughter was suffering from mental health issues and it took me time to accept it," he explains, noting his wife who is Asian American was much more ready to address the issue and seek help. "She was

firm in getting me to accept my daughter was struggling, and yet it still took me a long time to even feel comfortable talking about it."

He notes stigma is intensified when it is multi-generational. "I know [adult] members of my immediate family struggle with mental illness but we ignore it or make excuses for their behavior or struggles. We say they're having a bad day or are just stressed out. My daughter has taught me that's not the case; I've learned a lot from her."

In addition to concerns about how their child's mental health would be reflected on them, parents want to protect their child. They know there is disparity in how medical illness and mental illness are perceived by society and don't want their child labeled. An individual of any age with a medical disease or congenital condition is referred to as suffering from the disease: "diabetic," "anemic," or with the disease "has a heart condition," "battling cancer," etc. In the case of mental health diagnoses, however, society has created such non-clinical labels such as "crazy" and "nuts."

"My daughter felt ashamed that she had to go to a mental health provider," agrees Stephens. "If someone had a broken leg and went to the doctor there wouldn't be a reason for them to feel ashamed, but there's still such a stigma attached to mental illness."

While families and children themselves face negative perceptions, so too does the mental health profession as a whole. Stories of treatments that didn't work, medications that made patients listless, and horrible experiences scare some families away from treatment until the illness has progressed to the point of crisis. Families who have negative experiences with stigma, blame or with treatment itself in the past are even less willing to seek services for their children.

Among all barriers to children's behavioral health care identified in the Commission's analysis, stigma is one of the most difficult to counter as it will require changing perceptions across all areas of society.

Parents are afraid of what others will think about their child's illness, and it is preventing them from getting care soon enough.

Prevention and Screening

How the brain develops, and whether cognitive and emotional abilities reach their full potential, is determined by “a complex interplay between genetics, development and environment,” explains Kaczorowski.

“While genetics help determine development, the environment influences what genetic factors turn on and off.”

Someone with a genetic predisposition to cancer, then, will likely develop cancer if he or she introduces environmental factors such as smoking. Similarly, a child who is predisposed to a mental illness will be more likely to develop the illness if he or she experiences environmental factors such as toxic stress, trauma, or lack of necessary support.


Since approximately 80 to 90 percent of critical brain development takes place between birth and age five, this is a critical window. Whether the brain's architecture forms correctly is determined by this interplay between genetics, development, and environment. Without responsive, reliable and appropriate caregiving, the brain will not physically form as it should, which can lead to learning and behavioral difficulties.

“Biologically it makes sense to focus on prevention. We have the ability to focus on developmental needs and improve the environment while children are young,” urges Kaczorowski.

He recalls working in preschools: “We could tell the difference between children from nurturing, stable environments and those struggling because the environment was not quite right. The great thing about development at the early stage is that small changes can have a huge impact. Children get tremendous, lifelong benefits from appropriate bonding and a stable home environment.”

“Because of the critical window of development in infancy, if mom has depression it can really impact a young child,” says Kaczorowski. “If mom and dad are working and the child is in an environment without much stimulation or nurturing, that also can be a problem.”

He notes helping mothers with postpartum depression, creating high-quality child care settings for working families, and providing family leave so parents can create strong bonds with their children are all proven to be effective at creating the type of environment children's brains need to develop. Additionally, for families where neither parent received good parenting themselves, creating a parenting support program to give them the skills that were not modeled for them will help them break the cycle in their new families.



“It is easier to build strong children than to repair broken men.”

– Frederick Douglass

Lack of resources is a major barrier to providing adequate preventive strategies.

For example, in "Nurse Family Partnership," a national evidence-based program developed in Rochester and reintroduced here by The Children's Agenda, registered nurses visit first-time, low-income families at home on a weekly to monthly basis. The visits begin when the mother is in her second trimester and continue until the child is two years old. Nurses help parents learn how to care for their child, as well as create parenting goals and problem-solving skills. Since its inception in 2006, the Nurse Family Partnership has helped more than 1,200 local mothers and children.

As we know is the case with many medical conditions, prevention and early detection/treatment is often less costly than waiting until an illness arises and providing treatment. According to the Centers for Disease Control and Prevention (CDC), treatment of children with mental illness is

among the most costly of health and medical conditions, with an estimated annual cost of \$247 billion. Additionally, evidence that such specific prevention programs reduce the severity or occurrence of childhood mental, emotional, and behavioral problems (e.g., depression, substance use problems, violence) has increased significantly in recent decades.

Lack of resources is a major barrier to providing adequate preventive strategies, and to early detection and treatment of mental health issues at healthcare entry points, such as pediatric offices. This resource imbalance sometimes leads to extremely adverse consequences.

One community member reflected, "Well I think often times nothing happens until crises happen...our whole system, whether its medical or mental health doesn't activate until someone is going to get thrown in jail."

“If we really get prevention strategies right for young families we would see a decrease in the severity and commonality of mental illness in children.”

– Jeff Kaczorowski, M.D.

"Getting things right prevents a cascade of problems," says Kaczorowski. "If we really get prevention strategies right for young families we would see a decrease in the severity and commonality of mental illness in children."

Similarly, there is overwhelming consensus that not enough screening exists and therefore children are not identified early enough. Significant needs are "band-aided over" until the bandage breaks. To improve prevention and access to care, it is necessary to increase and improve screening programs. While there are numerous childhood screening points for hearing, speech, vision, motor development, and academic achievement, children are not regularly screened for behavioral and emotional wellness milestones. There are programs around the region that do offer screening either on a small scale or with support from grants, but these do not meet the needs of the region as a whole.

PREVENTION AND SCREENING IN SCHOOLS

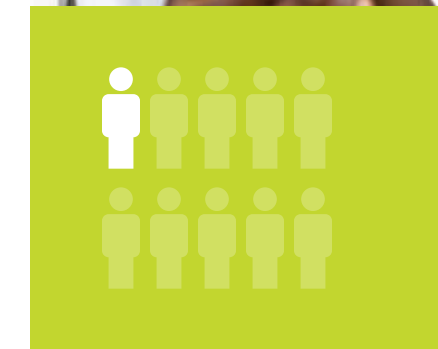
Across regions and districts, children with unmet needs are struggling in school, and schools are having trouble managing the behavioral, emotional, and social problems that adversely affect students' functioning. For example, more than half of schools surveyed report that one in 10 (or more) students display disruptive behaviors that interfere with learning (this proportion is highest in younger grades and in urban vs. suburban schools), and less than half of schools view themselves as managing these problems "well."¹

As noted earlier, students living in poverty face more trauma. This can threaten learning fundamental academic skills and increase the likelihood of disengagement. In Monroe County, suburban school students are presenting increasing rates of anxiety symptoms, drug and alcohol use, and social media exposure that disrupt the learning environment and can serve as a catalyst for self-harm.¹

Not surprisingly, schools are potentially the most common point of entry for children's mental health services. They are also the most viable venue for consistent prevention programming. School-based mental health services can have a major impact on reducing both the burden of mental health problems in our community and poor educational outcomes. According to a review by the Robert Wood Johnson Foundation, investment in effective school-based or school-partnered prevention programs result in savings, both in direct and indirect costs.

Preventive interventions are more effective and sustainable when they align and integrate with core educational needs, such as the requirement for effective classroom management, and provide a set of skills and concepts used by students, parents, and staff over time (O'Connell et al., 2009). An example is the effective Good Behavior Game program, which provides tools for 1st-3rd grade teachers in classroom management, and reduces a range of behavioral problems in students by late adolescence, including delinquency and substance use problems (Kellam et al., 2008).¹

Currently, however, there is great variability among services available in schools and the quality of those programs across urban, suburban, and rural districts and across age groups. While schools struggle for resources to create or maintain such programs, schools within a district or region rarely "pool resources" for training or evaluation of programs. In some cases, prevention programs only are present due to an individual "champion" who advocates and devotes time, rather than through a systematic approach. One administrator from an urban elementary school explains, "We had a classroom behavior program but lost it



1 in 10
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with
learning.

after a year...the vice-principal who founded the program left the building.”

Only half of schools surveyed have a committee that reviews prevention needs, and fewer evaluate their prevention activities or are sustaining prevention programs. The most common preventive interventions currently used are social skills/resilience programs and bullying prevention (nearly half of secondary schools also have some form of drug prevention program). However, only one-third of schools implementing a prevention program are using programs with the highest level of evidence.¹

On a positive note, some districts in the region currently use doctoral-level mental health providers (psychiatrists or clinical psychologists) on a part-time consultation basis for evaluations and to develop plans for students. In these cases, pupil personnel

services (PPS) staff are usually highly motivated to expand them.¹

A PPS staff member from a rural school shared some insight about a program in which a child psychiatrist works with primary care physicians in their community: "...he comes out once a month, he's been just a godsend. There are no childhood adolescent psychiatrists in our community and hardly any in Rochester... he works with our primary care physicians and that has been a huge help...We've had really good luck in terms of getting families in to meet with him...the communication loop has been pretty good.”¹

While screening and prevention services in schools vary across the region, motivation is high and the majority of schools would devote more time and resources to it if they had the opportunity.¹



Only half of schools surveyed have a committee that reviews prevention needs, and fewer evaluate their prevention activities or are sustaining prevention programs.

PREVENTION RECOMMENDATIONS

- Implement evidence-based strategies for mental health prevention programs in schools, including:
 - Collaboration across school districts to pool resources and provide training and ongoing support;
 - Establish a clearinghouse of effective programs and assessment tools to discover student risks and protections;
 - Align prevention programs with children's educational needs and system priorities;
- Mental health prevention screening in schools and primary care settings should be standard practice. In support of this practice, primary care physicians' (PCPs) capacity for screening, assessment and referrals through the use of on-site social workers, psychiatric nurses, etc., should be developed and supported through reimbursement;
- Establish "severity thresholds" for service eligibility at licensed facilities and reimbursement criteria, so early intervention and secondary prevention can be received in the early stages of symptom onset;
- New York State should provide ongoing support for continuing education for educators and primary care physicians in the prevention and early identification of mental health disorders in children;
- Link reimbursement funding to the use of evidence-based prevention interventions.

Treatment

Effective screening and prevention programs are half of the children's behavioral health equation.

There needs to be evidence-based treatment available to those children who are in need of mental health care, but mental health professionals are inconsistently taught these practices in graduate school. Evidence-based treatments are those for which scientific evidence exists showing they reduce symptoms and/or improve the functioning of the individual. These are specific treatments (i.e., cognitive-behavioral therapy) used to treat specific diagnoses (i.e., depression or obsessive-compulsive disorder).

Few mental health clinicians surveyed believe they are up-to-date on evidence-based treatments for common mental illnesses. This is in part because ongoing education is necessary to stay current with advancing mental health strategies and to become adept at working with special populations such as preschoolers. Such continuing education programs can be costly, and offer little incentive for practitioners who must give up clinical time to attend, do not receive reimbursement for related fees, and see little follow-up support for using new skills.

There is also not enough training in stages of development and evidence-based

treatments among professionals outside the mental health arena who work with children, such as primary care providers, and school and judicial staff. Were these individuals sufficiently trained, they could provide much-needed early referral, intervention, and treatment. And among the providers available, there is limited to no racial diversity.

TOO FEW MENTAL HEALTH PROVIDERS

Even if training in evidence-based practices were made immediately available to every provider in the nine-county region, there are simply not enough providers to serve the number of children who need treatment.

There seem to be several reasons for this shortage of qualified behavioral health providers. Focus groups indicated: 1) fewer people seem to be choosing to become mental health providers (or continue to be mental health providers) due to relatively low salaries; 2) there is a high level of education required and the relative cost of that education is significant; 3) providers who treat children tend to drift toward providing more adult services over time due to issues with reimbursement; and 4) recent graduates and practicing professionals tend to be ill-prepared to provide evidence-based treatment for children and youth.

Inconvenient office hours, scheduling problems and waiting lists are very real hurdles for families. Most families are unable to find a mental health provider who is

HOPING TO GET BETTER

By the time she was 10 years old, DeMaurice had experienced enough trauma to set the tone for her teenage years. Her mother died when she was eight, she had already spent four years in the foster care system in New York City, and she was brought to Rochester into a household of constant conflict. In fourth grade, she was suspended for a week for fighting in school.

"I blamed myself," she says. "Because my mom died when I was little, I don't know how to express my feelings. I get angry too fast – sometimes about things that I shouldn't be angry about at all."

She was sent to in-school counseling for the remainder of the school year and saw a counselor outside of school as well. "Counseling helped. I became much calmer," she reflects. "I still have anger issues now, but not to the point I would go off."

After four years in a hostile home environment, she moved in with an aunt with whom she has a much healthier relationship.

While self-aware and with a much-improved disposition these days, 16-year-old DeMaurice still has an Individualized Education Plan that states she is "emotionally disturbed." She is placed in smaller classes, which she likes, and explains she is still working on her anger and other emotions like trust. She has friends now, but says the worst part of being unable to control her anger is, "I've lost a lot of people because of my attitude."

When asked what she hopes for the future, she pauses and then says simply, "I don't know. To get better."

accepting new child or adolescent patients. If they are able to connect with one who is, the wait time is usually 12 weeks. It's also difficult – and many caregivers are unwilling – to remove a child from school to attend appointments, but the shortage of providers results in few available appointment times to choose from. Most do not include evenings and weekends. The difficulty is compounded for parents and caregivers who may not be able to take time away from work, especially if they can't find affordable treatment nearby.

When parents cannot access a provider for necessary outpatient services, their child's mental illness progresses to the point of requiring inpatient care. This challenge is even more daunting for urban and rural youth. In fact, a Finger Lakes Health Systems Agency analysis discovered that, among patients with private health insurance, suburban youth more often used outpatient services, while urban and rural youth more heavily utilized inpatient services.

"Families struggle to find appropriate outpatient services. They may try multiple sources or be reluctant to seek mental health care initially. Some may go to their primary care provider and receive treatment that may work for a time or may not work at all. In the meantime, the condition of the child worsens. It finally hits crisis and the

child needs to be admitted for an inpatient level of care," explains Scharf. "We see things going from a problem, to a lot of suffering, chaos and a lot of problems, and then to a safety crisis. Sufficient community outpatient services would allow intervention earlier and keep things from getting to the point of a child having an inpatient-level mental health need."

In Monroe County, use of emergency and crisis services exceeds the state average. Youth on Medicaid and Managed Care Medicaid seem particularly vulnerable to the lack of available outpatient services. In the nine-county region as a whole, there was a drop in outpatient visits among children and adolescents with Medicaid over the course of those three years. In addition, during that time, 11 organizations primarily located in rural counties stopped providing child services altogether and 11 reduced their child services by half or more.

"I think that smaller counties have a real challenge [with access] and honestly, [this issue has] a history of being overlooked. It's very easy to ramp up in an urban setting but when you come out here and you have to transport a kid an hour and a half away to get a particular service, how is that helpful? So the smaller counties, the rural counties have some special challenges," shared a clinician from a rural county.

In addition to a lack of child psychotherapists available to see patients directly, there also is a lack of child psychiatrists available to provide medication consultation, medication treatment, and to sign treatment plans. The impact of this can be seen in one local county, where the resignation of their child psychiatrist resulted in discontinued care of all child and adolescent patients because New York State Office of Mental Health (OMH) requires that all treatment plans developed in OMH-licensed facilities be signed off by an M.D.



SHORTAGE OF PRESCHOOL AGE RESOURCES

There is a particular shortage of providers with adequate training and expertise to work with early childhood groups (i.e., infants, toddlers, and preschoolers) with mental and behavioral health concerns.

The shortage of professionals trained to evaluate and provide treatment for preschool children is acute, especially given the proportion of children in these classrooms with social and emotional problems. As noted earlier, given the significant amount of critical brain development that takes place in these early years, the lack of adequate care at this age can begin a downward spiral toward a lifetime of problems.

School professionals often see children who exhibit behavioral issues within the preschool and kindergarten setting go undiagnosed and without intervention for years. This is in part because specialized training in recognizing emotional and behavioral problems and working with these children and their parents is not common for many preschool teachers and staff.

"It helps to have an experienced child care staff who have multiple strategies, but day cares typically do not have experienced staff due to high turnover," explains a director of a child care facility that serves ages birth through early school years.

She notes her facility rarely "kicks out" a child from day care, but admits, "It's typically a moral dilemma of the other children's experience being disrupted in order to focus on one child's needs, or even worse when other children's safety is at risk due to a child's behavior."

The lack of adequate care in early childhood can begin a downward spiral toward a lifetime of problems.

RECRUITMENT AND RETENTION RECOMMENDATIONS

- Work with the New York State Legislature to allow the retention of foreign medical graduates in child psychiatry in the region;
- Offer loan forgiveness programs for needed mental health providers who work with children and underserved families in both schools and community settings.

RACE AND CULTURE CLASH

Several oft-cited reports detail the sheer lack of diversity in the mental health workforce. From the landmark 2001 report "Mental Health: Culture, Race, and Ethnicity – A Supplement to Mental Health: A Report of the Surgeon General," to Suman Fernando's "Mental Health, Race, and Culture" (2010), the lack of access to, poor quality of, and dearth of diverse practitioners in mental health care for minorities is well-documented.

It is no surprise that the Rochester region's child and adolescent behavioral health workforce also reflects low cultural and language diversity. Ultimately, parents and caregivers have few options when it comes to finding a provider with whom a child can really connect. And this connection is a critical component of effective treatment.

"We struggled to find a provider our daughter feels comfortable with – and still haven't found someone she can relate to culturally," explains Stephens. Of African American and Asian American descent, his daughter most closely relates to her African American identity and has expressed a desire to find an African American mental health provider. "I could never understand why we couldn't find someone who could relate to us culturally. It was only after I started working with the Commission and looking at the

research that I realized it's because there's a big gaping hole in brown-skinned providers nationwide."

Stephens' daughter eventually dropped out of therapy because she wasn't comfortable with it, but when the symptoms came back she told her parents she needed therapy again. "She's still not with someone she's 100 percent comfortable with, but we didn't want that to be the reason she didn't receive therapy," says Stephens.

He had one rare opportunity to see firsthand what a difference a cultural connection can make for a child in crisis. Once when his daughter needed immediate help, a friend of the family who is African American and a psychologist came to their house to talk to her. The friend is not an adolescent practitioner so couldn't treat her, but Stephens saw that his daughter related better to that person just talking with her than she did to any of the Caucasian mental health providers who have treated her.

Compounding the lack of diversity among providers is a lack of training in cultural attitudes about mental illness and treatment. Few clinicians are attuned to these unique aspects of experience and identity. One clinician explained to URMC researchers how essential such recognition is for the child: "When a professional deals

with a child without acknowledging that a child is bicultural/bilingual, they fail the child because they don't really know the experience."

However, the majority of clinicians perceived language and culture as minimal barriers for patients to receive care – illustrating a disconnect between the wants and needs of patients and the current skill set and understanding of those who are meant to serve them.

REIMBURSEMENT PROHIBITIVE TO EXPANSION OF SERVICES

The current reimbursement model of both public and commercial insurers creates another obstacle to providing children with evidence-based treatment programs since reimbursement is not linked to use of this particular type of treatment. Organizations and practitioners also have little incentive to expand their scope of services to include pediatric and adolescent patients because it is not cost-effective to do so. For example, the reimbursement for a 60-minute mental health visit is approximately the same as most eight-minute primary care medical appointments. Additionally, child mental health services are reimbursed at the same or similar rates to adult services, yet it usually takes more time to provide child services because providers need to work with and engage others in the process, such as families, schools or the courts.

With organizations and individual providers finding it difficult to "break even" when providing child mental health services, it is no wonder few choose to enter or expand in the field.

DIVERSITY RECOMMENDATIONS

- Efforts to improve the diversity of the mental health workforce should include:
 - Attract a culturally diverse workforce by coordinating local educational pipelines for mental health professional development and leadership;
 - Strengthen recruitment, education, and retention of diverse providers through monetary and social incentives;
 - Require provider preparation programs and professional development opportunities on diversity, community engagement, cultural competency, and health literacy training;
 - Create training and coaching programs to increase understanding of and address the implicit biases among providers that impacts disparities.



REIMBURSEMENT RECOMMENDATIONS

- Financially incentivize child psychiatrists and psychologists to live and practice in our region;
- Negotiate with commercial insurers to:
 - Improve reimbursement rates for mental health services including collaborative care activities (e.g. phone consultation);
 - Provide enhanced reimbursement for increasing urgent, outpatient and intensive outpatient services;
- Link reimbursement to the population being served (children vs. adults) and to the use of evidence-based assessment and treatment (e.g., value-based reimbursement);
- Create one or more regional, outpatient-based, urgent care/crisis services to improve immediate access for short-term care.

LIMITED TRAINING AMONG OTHER PROFESSIONALS

Other professionals who regularly come into contact with children outside the mental health community – such as primary care physicians (PCPs), teachers and legal professionals – receive limited to no training in basic mental and behavioral health strategies. Were there more competency among these individuals, they could provide early intervention, compensating for the limited number of available mental health clinicians.

Primary care physicians (PCPs)

Anecdotally, almost half of PCPs' child and adolescent patients come to them with mental health issues, yet very little of their training is in mental health. Most who participated in the URMC research review have participated in some training on children's mental health in the last five years, and are willing to participate in innovative consulting services to better their practice.

However, they lament that they generally do not feel prepared to handle their patients' mental health concerns and psychiatric medication needs. Logically, this leads them to seek consultation from or referrals to mental health providers, but the vast majority of primary care practitioners are unable to find such help. This reality results in an increase in psychiatric medications being prescribed by pediatricians before the patient can receive psychotherapeutic interventions.

Mental health clinicians agree they are not able to meet growing needs. Only one-third of mental health clinicians are almost always able to see urgent referrals in five days and routine referrals within two weeks.

Training in schools

As discussed earlier, schools serve as the one de-facto entry point into the mental health system, yet teachers and administrators have inadequate resources, training, and preparation for that role.

Although nearly all schools employ at least one full-time staff member whose primary role is addressing students' mental health needs, this individual is usually focused on special education needs. The majority of schools consulted expressed concern for general education students, noting half or fewer are having their mental health needs met.

An unintended consequence of having insufficient resources for general education students can be a delayed response to a student's needs until his or her academic functioning has become adversely affected enough to warrant an Individualized Education Program (IEP). To address this, a few schools are implementing comprehensive strategies that allow other personnel to follow an evidence-based program guide or curriculum. Most services tend to be in small groups or brief individual counseling.

TRAINING RECOMMENDATIONS

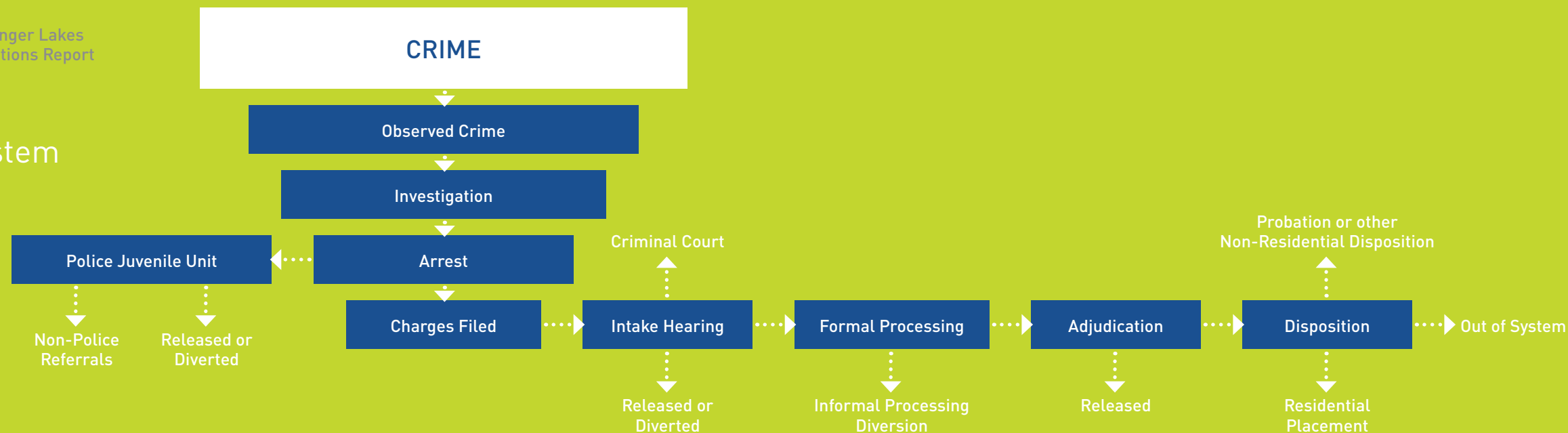
- New York State Department of Education, as the licensing and accrediting entity for all educators and mental health professions, should:
 - Require all training programs in mental health professions to include training in evidence-based approaches to assessment and treatment, and require continuing education in these areas;
 - Require that teachers receive training in typical development, mental health, and the social-emotional development of children, and document competencies in these areas;
- An interdisciplinary group of graduate training programs in the mental health disciplines should be organized in the region to discuss training capacity and community needs as they relate to the workforce. Provide recommendations on training to meet workforce needs;
- Graduate medical education programs in psychiatry should include increased opportunities for child and adolescent training, with enhanced goals for evaluation and treatment of adolescents;
- New York State should provide ongoing support for continuing education and case-based consultation for primary care physicians (e.g., CAP-PC) and educators.



1/3

Portion of mental health clinicians able to see urgent referrals in five days and routine referrals within two weeks.

Criminal Justice System



The complexity of the juvenile justice system makes it difficult for families to navigate under the best of circumstances.

Juvenile justice system

Similar to schools, the juvenile justice system works with a significant number of youth who have a mental illness, yet court staff do not receive adequate training or education in mental health and developmental stages for children.

The reality is that it is the behaviors spurred by some mental illnesses that often land adolescents in court. According to a study from the National Center for Mental Health and Juvenile Justice, 70 percent of youth in state and local juvenile justice systems have a mental illness, and at least three-quarters of those in the system have experienced traumatic victimization. [More than 60 percent of individuals with a mental health disorder also have a substance use disorder, so substance-related violations can also be the cause of their court appearances.]¹

Existing mental health issues can be exacerbated by procedures like mental hygiene arrests (being involuntarily admitted to the hospital because of mental illness), and mental health consequences can emerge from repeating and reliving traumatic experiences in public courtrooms.¹

Meservy & Skowrya (2015) found that children in juvenile correctional placement are three times more likely to die by suicide than those in the general population. Many court-involved children are living in homes rife with dysfunction, hardship, and family histories of mental health and substance abuse issues. They are mired in intergenerational cycles that are hard to break, limiting their chances of a positive outcome. Due to the prevalence of risk factors and lack of protective factors that court-involved youth face, their mental health problems often persist and worsen as they age.¹

Note: This chart gives a simplified view of caseload through the criminal justice system. Procedures vary among jurisdictions. The weights of the lines are not intended to show actual size of caseloads.

SOURCE: Adapted from **The challenge of crime in a free society**. President's Commission on Law Enforcement and Administration of Justice, 1967. This revision, a result of the Symposium on the 30th Anniversary of the President's Commission, was prepared by the Bureau of Justice Statistics in 1997.

COURTS RECOMMENDATIONS

- Create coordinated reporting and tracking within the court system to quantify and track the need for and utilization of mental health services;
- Develop and implement ongoing, role-specific training programs for court personnel about children's mental health, substance abuse, and the impact of trauma;
- Locate mental health liaisons at court/probation for education, referral, and linkages;
- Engage the entire family in the court proceedings process;
- Provide mental health assessments for youth when parents/caregivers are involved in the court system;
- Change adversarial court procedures to a research-informed, team model that is focused on what is best for the child;
- Consider the creation of a specialty youth mental health court.



Other Barriers to Care

DYSFUNCTION IN A FRAGMENTED SYSTEM

Children with mental illness are part of and operate within a variety of systems – a family system, the educational system, the health care system (including the primary care provider, psychologist, psychiatrist and others), and sometimes the law enforcement and legal system.

While the various entities deal with the same child and family, the way each interacts with that family is vastly different.

Currently, there is limited and ineffective collaboration and communication across these entities – a situation that frustrates and limits the effectiveness of all involved.

There are numerous built-in barriers to coordinating care between these multiple systems:¹

- Confusion and rigidity about how to legally share sensitive information and manage reasonable privacy guidelines (HIPAA, FERPA, etc.);
- Time constraints on all parties for communication, which is often about complex issues – most phone contact between agencies and providers involves an inefficient phone tree that often leads to wasted time and missed

connections, compounded by the lack of reimbursement for communication time;

- Lack of knowledge amongst all involved about who is providing services for the child and family (e.g., child's school counselor and teacher; primary care provider; agency or practitioner involved with therapy or medications; social services; court liaison or probation officer; etc.);
- Standard forms in all settings do not include information about other members of the care team.

All of the aforementioned barriers result in lack of coordination, redundancy and confusion. This can lead to disagreements about diagnoses and disjointed and even cross-purposed interventions.

One school official noted, "One of the issues that I see is when we can identify a child we know has some mental health issues and the only way we can get them help as a school district when it's severe is the court system – it's a mental health arrest. That is disturbing to me, especially when I look at a high school kid that I know with a little bit of support we could keep them from getting into the court system. From a school district point of view, that's that only avenue we have..."¹

Court personnel agree. "I know with the Person in Need of Supervision and Juvenile Delinquency and child welfare, a lot of times there were so many delays because they're constantly doing new assessments and new

WHEN "THE BEST INTERESTS OF YOUR CHILD" BECOME A MATTER OF DEBATE

A mother of a 16-year-old who has been diagnosed with recurrent anxiety and depression shared her story with Commission members. A physician's assistant with more than 20 years' experience, she "knows the system" and at first felt assured she would be able to navigate it to help her son. In fact, she has worked diligently to find him inpatient treatment – he's been hospitalized as far away as the Buffalo area for as long as two weeks up to seven months.

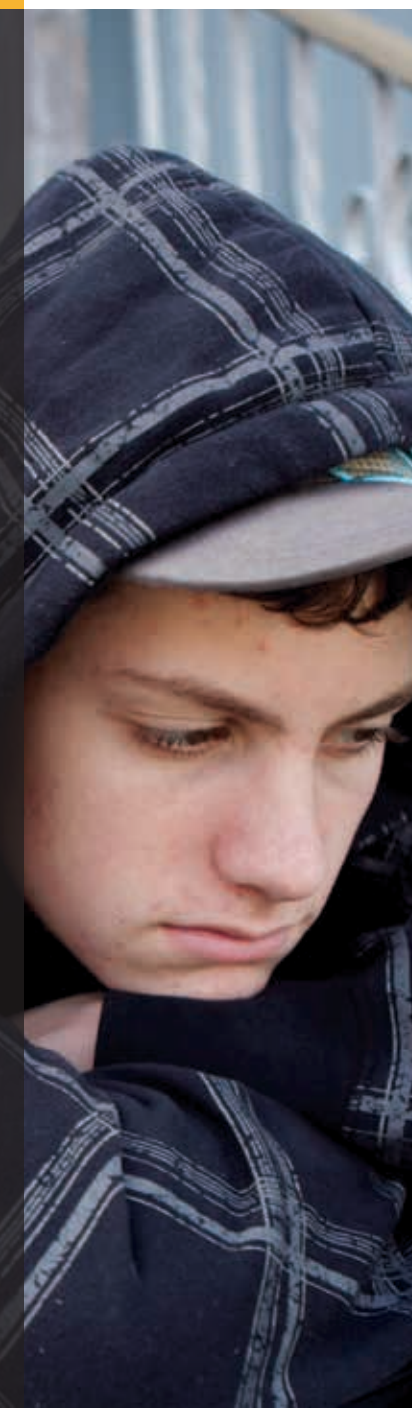
Although her experience has helped her son in the medical sense, she's been stymied by the educational system. Because when he suffers from acute symptoms – whether in inpatient treatment or not – he cannot attend school. That's when most parents discover how many people (and automated systems) believe they know what's best for a child with mental illness.

"A guidance counselor previously with the school district told me she would call Child Protective Services on me because I was 'letting him' stay home," she explained. "I asked her, 'He has a psychiatrist, medication, a therapist and all the resources we've been told to get – even a resource team at the school – what more do you want me to do?' Her response was to involve family court, have him declared a Person In Need of Supervision, then call the police every day to have them make him go to school."

She ignored the school counselor's recommendation, and her son has since rebounded. He's currently been doing well, trying to catch up on work from sophomore year while keeping up with junior year classes.

"The team at school now is remarkable, but there are still pockets of ignorance throughout the district, and I imagine all school districts, because there are rules they're trying to follow. They get stuck when kids can't go to school every day."

Even now, automated letters arrive at home whenever her son misses a certain number of school days, adding extra pressure to a family that's just working to get through each day. "Even though I know it's an administrative process thing, it's still hard to get this letter when we're doing all we can. Something needs to be done to distinguish between children who are truant because they're being manipulative and those medically in need."



evaluations instead of having a mechanism to see what's been done and then evaluate it," a court representative said. "...Now, of course, you have to update and do assessments, but sometimes it's just been done in another agency and if there was some way to have that information available [it would speed up the process]."¹

Currently, parents and caregivers must serve as the central communication point, gathering information from each organization, understanding what is relevant, and communicating back to others. This task can be herculean while managing mental health appointments, working, caring for the child at home, trying to pay for it all, and addressing their own emotions about their child's illness.

As one parent explained, "I need to have this person call me, I need to have that person call me, I need to have somebody do

a residential referral ASAP...as a parent, I am failing. My child needs help and whatever it has to take, I'm ready to go that step...I love you so much that I have to do whatever it takes to get you to the services you need to be a well person."

FAMILIES NAVIGATING WITHOUT A COMPASS

When a child suffers a mental illness, parents struggle to identify whom to call for help, and how to find the best mental health professional to meet their child's needs. Parents and caregivers desperately want to make the right decisions, but end up taking the only route that seems available to them, often times when in crisis.

"It was easier for me to get the police to respond to help my son than it was to find a psychologist when we needed one," explains one mother from a Monroe County suburb whose teenage son has anxiety and depression. "He was wielding a knife, threatening suicide and ran away from all of us, and the police had to chase him down the street and make a mental health arrest to get him help. As traumatic as it was, part of me said 'Finally!' because at least he was getting help."

The process is no easier for those working through the health care system. "In the referral process things may go haywire. No room, wrong match with provider, wrong insurance, a convoluted intake process that doesn't acknowledge what you know or have already done, etc.," explained one health official. By the time a link with care is made, it can feel off-putting to patients and their families.

Failed and traumatic encounters with a behavioral health professional or with the system can result in mistrust of that system and even further trauma for the child and family. At one point, when Stephens' daughter was about 13 years old, she was having a mental health crisis that necessitated a trip to the emergency room. While there, the family waited in the pediatric ER with families with physically sick and injured children. Eventually, a nurse

SYSTEM REDESIGN RECOMMENDATIONS

- Change New York State Office of Mental Health regulations to:
 - Allow systems flexibility in their structures for supervision and sign-off of treatment plans;
 - Modify state regulations so treatment can be provided more flexibly;
 - Allow for treatment of "family" as unit of care, instead of just the child;
- Promote a shift in care so the child's needs are not only viewed within the context of their environment but treatment consists of creating health promotion, wrap-around supports and streamlined communication for the parents, caregivers, and schools involved with the child;
- Promote efforts to co-locate services at universal points of contact (e.g., schools, PCP offices);
- Promote the funding of telemedicine initiatives;
- Advocate for adequately funded, county-based navigators to orient families to ever-changing local and regional services.

CROSS-SYSTEMS RECOMMENDATIONS

- Create a formal infrastructure for communication across all the systems that care for children;
- Advocate for modifications in federal and state regulations that interfere with communication between health providers and educators;
- Create a shift in care that includes the family as the focus in the wellbeing of the child;
- Establish a triage system (identifying, screening, referring, and funding) at the local, county, and state levels to provide services through community agencies at levels consistent with need;
- Facilitate partnerships between agencies, courts, schools, providers, and other systems to enhance family engagement and individualized care.



and security guard approached them and had their daughter remove her belt and her shoelaces on the spot.

"There she is, having lost all dignity and kids nearby asked their parents, 'What's the matter with her? Is she crazy?' My daughter had tears pouring down her face," recalls Stephens. "I was so angry because if she'd had the flu, they would have protected her privacy as a patient, but they didn't think twice about having her strip down right there in front of everyone as someone with a mental crisis."

The experience was so traumatic for his daughter that when she suffered other episodes, Stephens says she didn't want to go to the emergency room again: "One time I knew she was in a delicate state and really had to be seen; she wouldn't go so I had to physically carry her in to the ER."

He asserts, "One low-cost fix is to [treat] children with mental health issues with dignity. Take them to a room first. Treat them like they have a cold or broken bone."

Ultimately, facilitating the coordination of quality care from the start should be a priority. A child's needs are never in isolation of the needs of the family; the wellbeing of the child is linked to their family system. Empowering and enriching the family with resources and supports is essential. As one

health care worker explained, "The first time a child has a crisis, it is very important that a facility find a way to connect the parents to resources in the community so these parents learn and understand what the child is going through."

STRUCTURAL RACISM AND INHERENT BIASES

Many people of color and those struggling with poverty are particularly concerned about the implicit bias that makes it more likely that an African American, Latino/a or low-income child will be labeled as having "bad behavior" rather than as presenting early indicators of a developing mental health challenge. This lack of cultural competency can lead to missed opportunities for appropriate screening and early intervention and irrevocably change the life trajectories of children in need.

According to The Equity Project at Indiana University, African Americans are approximately 3.5 times as likely to be placed in out-of-school suspension as white students. The Project looked at data regarding connections between race, poverty, student behavior, and suspension/expulsion to determine if the rates of suspension/expulsion among African American students was due to differences in severity and types of behavior.

"It's all screwed up, from a monetary, economic perspective, as well, class perspective; I think the kids at the bottom get the worse quality care," says one community member. "Teenage boys don't want to go to therapy, period. They don't want to talk about their feelings. They don't want some woman to be asking them what's going on in your life and about personal things at home and about how they feel about things, and what's going on at school... If you're going to get the young men, and they're a challenging group, for lots of reasons, you have to go where they are... You've got to go to the basketball courts. You've got to do things in a non-traditional way."

WHEN SUBSTANCE ABUSE AND MENTAL ILLNESS COLLIDE

Substance abuse and mental illness have a complicated relationship. "People can have their first experience with a substance for a variety of reasons; sometimes this includes emotional distress. Depending on how and when they start using and their predispositions, they can develop a substance abuse disorder that takes on a life of its own," explains Scharf.

He adds, "It's important to recognize that specialized expertise is necessary to diagnose and treat substance abuse disorders that coexist with mental health disorders and both the substance abuse and mental health disorders need to be looked at and addressed directly."

Schools and courts can be on the front line of substance abuse screening and treatment among youth. Deficiencies in training and communication play a significant role here as well.

The Commission recognizes the importance of this topic, and of the coordination of care between providers; however, for the purposes of this report, we do not address the full scope of substance abuse treatment.

FINANCIAL CONSTRAINTS

More than three-quarters of youth with private insurance and nearly as many of those with public insurance have unmet mental health needs, often because of limited or nonexistent mental health coverage. Recently, the emergence of high deductible insurance for middle and low-income families has left many unable to afford services, especially combined with costs related to transportation and missed hours at work.

One professional who works in the court system expressed, "It's very tough for families, actually for the parents, to financially make it. They might work a couple of jobs and these are kids that are going to need a lot of supervision, so if there isn't somebody else there to help out, it's going to be really that much more challenging. Even

to take the kids to the appointments, because the appointments may only be available during the workday."

"Money. That has got to be number one on the access issue – for some of them that are Medicaid eligible, that's fine but you have a lot of people in this gray area and I have no idea if there's any money to pay for it. In this area you've got a lot of working poor," agreed another.

Given the scope of this issue and the complexity of the systems involved, the Commission recommends continued assessment of financial constraints to define actionable next steps.

“Specialized expertise is necessary to diagnose and treat substance abuse disorders that coexist with mental health disorders.”

– Michael Scharf, M.D.

Ultimately, facilitating the coordination of quality care from the start should be a priority.



The Solutions: Working Toward a Continuum of Care

Recommendations Summary

Mental illness is a disease, and those who suffer from it are entitled to a functioning system of care.

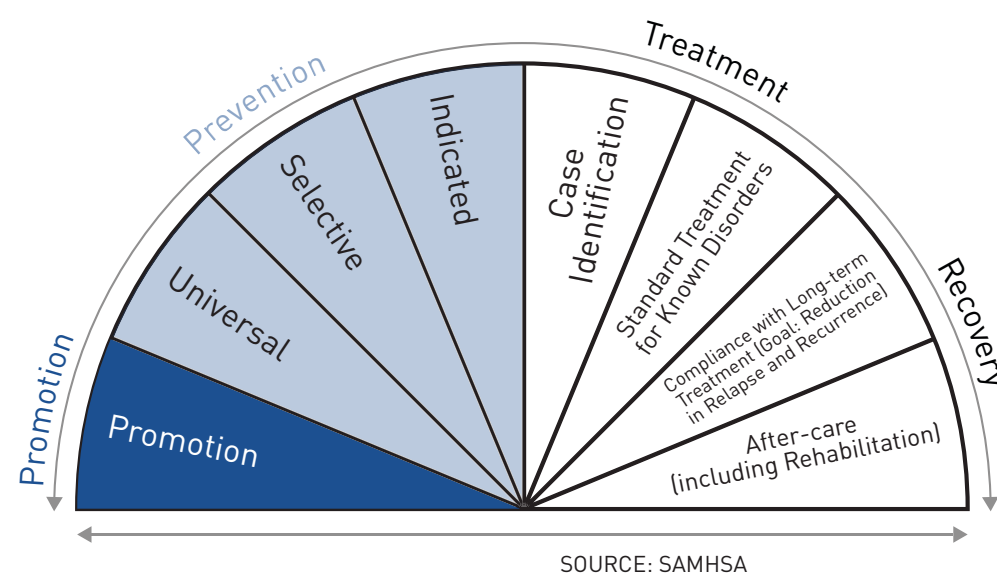
The Greater Rochester region prides itself on access to healthcare and world-class pediatric and adolescent medicine, yet we have failed to take collective action to address mental illness prevention and treatment in our children.

The Commission on Children's Behavioral Health in the Finger Lakes strongly emphasizes the recommendations defined within this report and summarized in the following pages.

We must commit to dedicating time and resources to our children's mental wellbeing

as much as we do to their physical health and prioritize the evidence-based preventive interventions and treatments that have been proven effective. It is time to stand with our children in the context of their environment – family, school, community – and create a web of wellness that enriches their development. Change across systems can be achieved. Affordable approaches exist that can be implemented right away. For those that take more time, actionable plans must be developed.

If we do not set about on a course of action to improve conditions for our region's children, we should expect to see an increasing number of adults with behavioral health issues and related physical comorbidities in the years to come – and then it indisputably will be society's problem.



TRAUMA RECOMMENDATIONS

- Provide universal education regarding trauma-informed care, including historical trauma, for all who work with youth.
- Provide ongoing training – including role-specific mental health training, culturally specific trauma-informed training, and referral training – for emergency responders, court staff, attorneys, educators, primary care providers, hospital staff, medical transport staff, and community members and leaders.
- Professionals working with children must develop standards for accurately interpreting early signals of mental health problems to avoid criminalization-oriented interventions because of implicit biases.

PREVENTION RECOMMENDATIONS

- Implement evidence-based strategies for mental health prevention programs in schools, including:
 - Collaboration across school districts to pool resources and provide training and ongoing support.
 - Establish a clearinghouse of effective programs and assessment tools to discover student risks and protections.
 - Align prevention programs with children's educational needs and system's priorities.
- Mental health prevention screening in schools and primary care settings should be standard practice. In support of this practice, PCPs' capacity for screening, assessment, and referrals through the use of on-site social workers, psychiatric nurses, etc., should be developed and supported through reimbursement.
- Establish "severity thresholds" for service eligibility at licensed facilities and reimbursement criteria, so early intervention and secondary prevention can be received in the early stages of symptom onset.
- New York State should provide ongoing support for continuing education for educators and primary care physicians in the prevention and early identification of mental health disorders in children.
- Link reimbursement funding to the use of evidence-based prevention interventions.

RECRUITMENT AND RETENTION RECOMMENDATIONS

- Work with the New York State Legislature to allow the retention of foreign medical graduates in child psychiatry in the region.
- Offer loan forgiveness programs for needed mental health providers who work with children and underserved families in both schools and community settings.

DIVERSITY RECOMMENDATIONS

- Efforts to improve the diversity of the mental health workforce should include:
 - Attract a culturally diverse workforce by coordinating local educational pipelines for mental health professional development and leadership.
 - Strengthen recruitment, education, and retention of diverse providers through monetary and social incentives.
 - Require provider preparation programs and professional development opportunities on diversity, community engagement, cultural competency, and health literacy training.
 - Create training and coaching programs to increase understanding of and address the implicit biases among providers that impacts disparities.

REIMBURSEMENT RECOMMENDATIONS

- Financially incentivize child psychiatrists and psychologists to live and practice in our region.
- Negotiate with commercial insurers to:
 - Improve reimbursement rates for mental health services including collaborative care activities (e.g. phone consultation).
 - Provide enhanced reimbursement for increasing urgent, outpatient, and intensive outpatient services.
- Link reimbursement to the population being served (children vs. adults) and to the use of evidence-based assessment and treatment (e.g., value-based reimbursement).
- Create one or more regional, outpatient-based, urgent care/crisis services to improve immediate access for short-term care.

TRAINING RECOMMENDATIONS

- New York State Department of Education, as the licensing and accrediting entity for all educators and mental health professions, should:
 - Require all training programs in mental health professions to include training in evidence-based approaches to assessment and treatment, and require continuing education in these areas.
 - Require that teachers receive training in typical development, mental health, and the social-emotional development of children, and document competencies in these areas.
- An interdisciplinary group of graduate training programs in the mental health disciplines should be organized in the region to discuss training capacity and community needs as they relate to the workforce. Provide recommendations on training to meet workforce needs.
- Graduate medical education programs in psychiatry should include increased opportunities for child and adolescent training, with enhanced goals for evaluation and treatment of adolescents.

- New York State should provide ongoing support for continuing education and case-based consultation for primary care physicians (e.g., CAP-PC) and educators.

COURTS RECOMMENDATIONS

- Create coordinated reporting and tracking within the court system to quantify and track the need for and utilization of mental health services.
- Develop and implement ongoing, role-specific training programs for court personnel about children's mental health, substance abuse, and the impact of trauma.
- Locate mental health liaisons at court/probation for education, referral, and linkages.
- Engage the entire family in the court proceedings process.
- Provide mental health assessments for youth when parents/caregivers are involved in the court system.
- Change adversarial court procedures to a research-informed, team model that is focused on what is best for the child.
- Consider the creation of a specialty youth mental health court.

SYSTEM REDESIGN RECOMMENDATIONS

- Change New York State Office of Mental Health regulations to:
 - Allow systems flexibility in their structures for supervision and sign-off of treatment plans.
 - Modify state regulations so treatment can be provided more flexibly.
 - Allow for treatment of "family" as unit of care, instead of just the child.
- Promote a shift in care so the child's needs are not only viewed within the context of their environment but treatment consists of creating health promotion, wrap-around supports and streamlined communication for the parents, caregivers, and schools involved with the child.
- Promote efforts to co-locate services at universal points of contact (e.g., schools, PCP offices).
- Promote the funding of telemedicine initiatives.
- Advocate for adequately funded, county-based navigators to orient families to ever-changing local and regional services.

CROSS-SYSTEMS RECOMMENDATIONS

- Create a formal infrastructure for communication across all the systems that care for children.
- Advocate for modifications in federal and state regulations that interfere with communication between health providers and educators.
- Create a shift in care that includes the family as the focus in the wellbeing of the child.
- Establish a triage system (identifying, screening, referring, and funding) at the local, county, and state levels to provide services through community agencies at levels consistent with need.
- Facilitate partnerships between agencies, courts, schools, providers, and other systems to enhance family engagement and individualized care.

Appendix:

URMC PROJECT FOCUS AND DESIGN

To inform the work of the Commission on Children's Behavioral Health in the Finger Lakes, the Greater Rochester Health Foundation commissioned a study by the Division of Child and Adolescent Psychiatry at the University of Rochester Medical Center¹.

As part of this effort, Michael Scharf, M.D., chief of the Division of Child and Adolescent Psychiatry at the University of Rochester Medical Center (URMC), assembled a team of experts from the Department of Psychiatry at URMC to gather information about the state of children's behavioral health care in our nine-county region. The team explored the quantity of available care/services relative to need in the area; the barriers to accessing what is already available; where gaps in services exist despite great need; what community strengths and assets there were; and some potential actionable recommendations for improvement. To ensure this examination was conducted in a comprehensive way, the team established four workgroups based on the primary domains where children can be assessed for, receive, or be linked with behavioral health care: clinical, education, community and court.

Clinics and hospitals are likely the first settings that come to mind when thinking about children's behavioral health care services, and trained practitioners (psychiatrists, psychologists, social workers, mental health counselors, substance abuse counselors, pediatricians, family medicine physicians and nurse practitioners) are concentrated in the clinical care domain. Thus, the clinical workgroup was tasked with providing a comprehensive picture of current clinical service delivery relative to need in all nine counties, including traditional mental health service delivery, integrated mental health service delivery in primary care, and telemedicine service delivery. This assessment naturally included identifying the particular access barriers and gaps in services, examining workforce spread and training issues, and learning about the specific difficulties that mental health trained practitioners and primary care practitioners experience with screening and care. This group was also particularly concerned with identifying service utilization differences between urban, suburban and rural locations in the region, Medicaid and privately insured families, and among underserved populations (e.g. preschoolers, children in foster care, homeless youth, traumatized children, and those with dual diagnoses).

Schools (including preschools and daycares) see the highest volume of children and have the most consistent long-term link with children and adolescents. The education system is the only setting where children are mandated to be, and where there is a legal responsibility to address social, emotional and behavioral needs for disabilities that affect learning. School has great potential as a familiar arena for children and their caregivers to address behavioral health care concerns, as the first place of early identification and intervention, and as the domain best suited for high-yield prevention programming. The education workgroup was tasked with examining how area schools currently address the behavioral health needs of their students, particularly in regard to the Positive Behavioral

Intervention System (PBIS) framework used by nearly all schools. They were also charged with assessing the specific behavioral health needs in the school setting, looking at rates and potential associations with educational outcomes, social-emotional wellbeing, substance use, and other health indicators. Finally, they investigated both the barriers and opportunities for reducing behavioral health problems and preventing new problems.

The community is the domain that children, youth and families call home – it is where they live, work and play and the space where they encounter their natural helpers and their social support networks. Community can encompass everything from recreation centers to church youth groups to 4H clubs in children's towns and neighborhoods, and is often deeply rooted in culture, race, ethnicity, religion, sexuality, age, geographical area, economics, and other aspects of personal and group identity. It is a deeply influential, but underappreciated domain for mental health intervention. The community workgroup was tasked with understanding what supportive youth community structures looked like throughout the nine-county region, recognizing the variance among and within counties. They sought to determine the strengths and gaps in community resources, as well as individual and family assets and needs related to optimal mental health and wellness for children and youth in our area.

The court system is the place of last resort for children with behavioral health problems. Of the many court-involved children and youth in the nine-county region, the majority have had traumatic experiences and suffer from mental health problems and/or substance use issues, yet court systems and processes are often not conducive to mental wellness. Court is not a therapeutic venue, but it is an immensely important setting through which at-risk children and youth can be linked with services and protections to help them improve their mental health and life trajectories. The court workgroup was tasked with understanding the severity of behavioral health problems among kids involved in the court system, whether at court for their own problems or involved in a parent or guardian's legal problems. They also wanted to determine how children's behavioral health issues are handled by the court, particularly because the health care and justice systems continue to operate in such distinct silos. They were also interested to learn what clinical, community, social services, and education system resources court professionals knew about and utilized.

Each workgroup identified pre-existing reports and publicly available data from which they could gather information for this effort, being attentive to overlap in domains. Workgroups also reached out to a variety of stakeholders within their domain to learn about their experiences with children's behavioral health care; some methods used were surveys, focus groups, and individual interviews. The workgroups all had an opportunity to present their preliminary findings from their specific research efforts to the Commission on Children's Behavioral Health in the Finger Lakes. These findings are reflected in the Commission's report.

Thank you

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¹ Scharf, M. A., Alpert-Gillis, L. J., Wyman, P. A., White, A. M., Cerulli, C., Nichols-Hadeed, C., Thompson Stone, J., Wallace, J., Malcolm, K. T., Thomas, K. K., Washington, M., Petrova, M., Thon, E. P., Funchess, M., Lily, T., Wilson, J. (2015). Promoting Children's Behavioral Health: Examining Needs, Resources and Implementation of Best-Practices for Children and Youth in the Greater Rochester Area of New York State.



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