The Johnson Foundation AT WINGSPREAD

Conferences that Inspire Solutions

Top of Mind:
Children's Mental Health in Racine

Highlighting facts and uncovering urgent needs

June 2012

Published by
The Johnson Foundation at Wingspread

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Top of Mind: Children's Mental Health in Racine

Part 1: Highlighting national, state and local facts

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BACKGROUND: RECOGNIZING THE REALITY

Good mental health is essential to a fulfilling, productive life. Yet mental health problems commonly occur at an early age—and unfortunately, many children do not receive the care they need.[1] [2] Access to high-quality prevention and intervention services varies greatly; the most marginalized children have an even smaller chance of receiving vital services.[3] [4] The consequences of untreated mental health issues can compromise not only a child's future but also the community's vitality.[5] On the other hand, increasing access to high-quality mental health prevention and intervention services can help our children lead healthier, more productive lives.

Defining mental health

Good mental health is both the absence of illness or problems, and the optimizing of mental functioning. The U.S. Surgeon General defines mental health as "a state of successful performance of mental function, resulting in productive activities, fulfilling relationships with other people, and the ability to adapt to change and to cope with adversity."[6]

Children's mental health is defined by the achievement of cognitive, social, and emotional developmental milestones. Mentally healthy children are highly functional, with satisfying relationships and positive coping skills. Serious deviations from these developmental milestones are considered "mental disorders."[7]

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"Mental illness" is an umbrella term that refers to *diagnosable* disorders and conditions "characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or impaired functioning."[8] Official diagnoses can be made by board certified psychiatrists or clinical psychologists using the classification system in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM).

"Mental health problems" go beyond "mental illness" to include conditions that don't necessarily meet the DSM's criteria for a diagnosable disorder. As the Surgeon General explains, "[a]lmost everyone has experienced mental health problems in which the distress one feels matches some of the signs and symptoms of mental disorders."[9]

"Emotional behavior disability (EBD)" (formerly "emotional disturbance") is the term schools use to identify students with significant social, emotional, or behavioral challenges that impede their ability to learn. To be identified as EBD and receive appropriate services, students must meet defined criteria that include exhibiting abnormal, severe, and chronic behaviors in school and in at least one other setting (at home or in the community).

"Serious emotional disturbance" (SED) is often used by government agencies. An SED is defined generally as "a diagnosable mental disorder found in persons from birth to age 18 years that is so severe and long-lasting that it seriously interferes with functioning in family, school, community, or other major life activities."[10]

Mental health and the developing child

Childhood mental health problems can begin at a young age[11] and arise from "the complex, multilayered interactions of specific characteristics of the child, his or her environment, and the specific manner in which these factors interact with and shape each other over the course of development."[12]

Research shows that various factors can increase the risk for developing mental health problems in childhood. In the absence of stable, nurturing relationships in a child's life, these risk factors can

cause toxic stress and damage the child's developing brain architecture.[13] Such risk factors include:

- Prenatal damage from exposure to alcohol, illegal drugs, and tobacco;
- Low birth weight;
- Poverty;
- Deprivation;
- Abuse and neglect; and
- Exposure to traumatic events.

Additional risk factors include:

- Parental mental health disorder; and
- Difficult temperament. [14]

Prevalence

It is estimated that anywhere from one in eight[15] (12%) to one in five (20%) children ages 5 to 17 have a diagnosable mental health disorder[16], and 11 percent have a disorder that seriously limits their functioning[17]. Among children ages 0 to 4, about eight percent are estimated to have significant behavioral problems.[18] The most common mental health disorders among children and youth include attention deficit disorders (ADD or ADHD), mood disorders (e.g. depression, bi-polar), and conduct disorders.

Prevalence differs by race, poverty, and gender. Boys have higher rates of mental disorders (largely driven by the higher diagnosis of ADHD in boys) than girls. Mood disorders are more prevalent in girls.[19] According to SAMHSA's *Mental Health, United States, 2010,* black children show higher rates of minor and severe emotional and behavioral difficulties than Hispanic, white and other races/ethnicities. Children at or near the poverty level also had higher rates of reported mental health problems.

PERCENTAGE OF CHILDREN WITH REPORTED DIFFICULTIES	SEVERE OR MINOR DIFFICULTIES	NO DIFFICULTIES
Hispanic origin and race		
White-alone, non-Hispanic	19.4	80.7
Black-alone, non-Hispanic	24.6	75.4
Hispanic	16.1	83.9
Other, non-Hispanic and multiple races	10.9	89.0
Poverty status		
Poor (<100% FPL*)	26.3	73.7
Near poor (< 200% FPL)	21.1	79.0
Not poor	15.7	84.4

*FPL = Federal Poverty Level
Source: SAMHSA, *Mental Health, United States, 2010*[20]

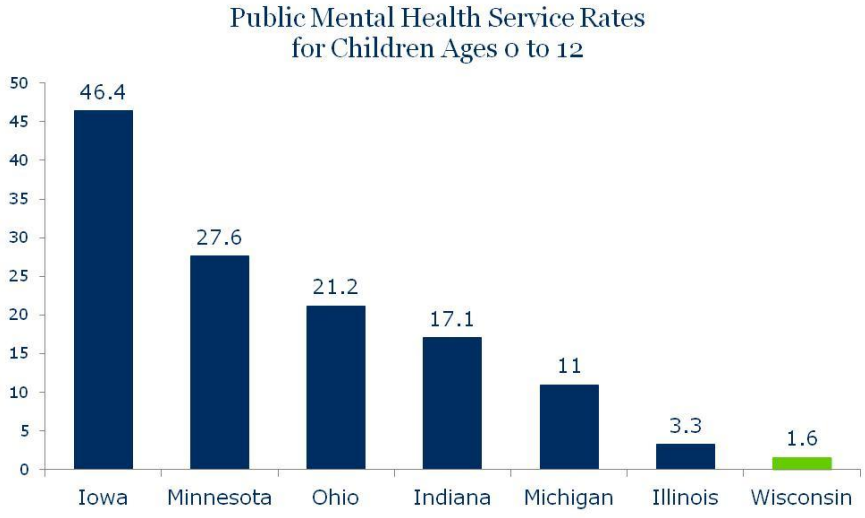
MAJOR CHALLENGES FOR WISCONSIN CHILDREN

Children face major challenges in two areas:

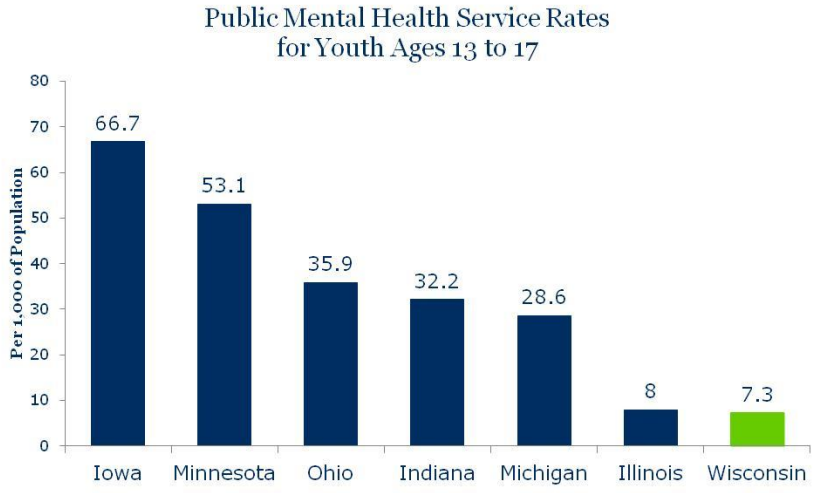
1. Accessing services
2. Receiving high-quality interventions

Nationwide, estimates suggest 80 percent of children ages 6 to 17 do not receive the treatment they need for their mental health problems.[21] In addition, many children ages 5 and younger do not receive the services they need to optimize their social-emotional development and prevent future disorders.[22]

Wisconsin's public mental health system service rates for children and youth are the lowest of any state in the upper Midwest.[23] Only 1.6 percent of Wisconsin children ages 0 to 12 with a Severe Emotional Disability (SED) are served by the state mental health authority (the Division of Mental Health and Substance Abuse Services in the Department of Health Services). Similarly, service rates for children ages 13 to 17 are the lowest in the Midwest; the public system serves 7.3 percent of those with an SED.

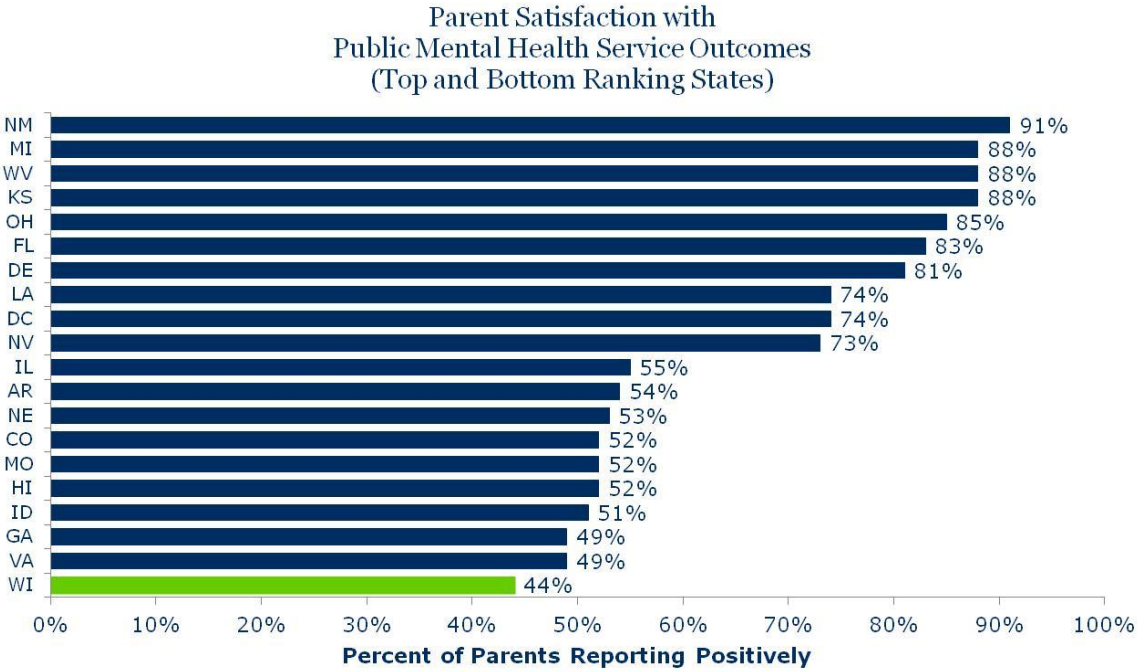


Source: Center for Mental Health Services Reporting System (2009); Wisconsin Family Ties[24]



Source: Center for Mental Health Services Reporting System (2009); Wisconsin Family Ties[25]

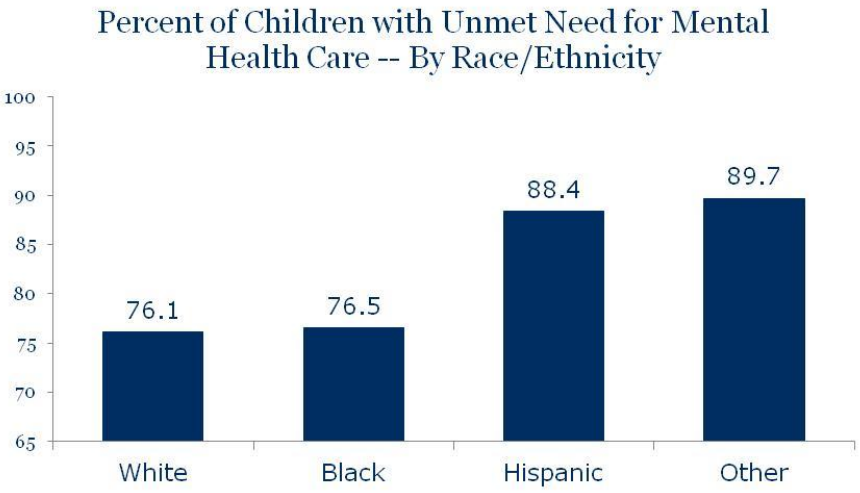
What about the quality of care Wisconsin children receive? Parental satisfaction ratings, an indicator of quality, fall at the bottom of the rankings for public mental health services. [26]



Source: Mental Health Statistical Improvement Program Survey, 2009, as cited in Wisconsin Family Ties[27]

VARIANCE IN SERVICE USE AND ACCESS

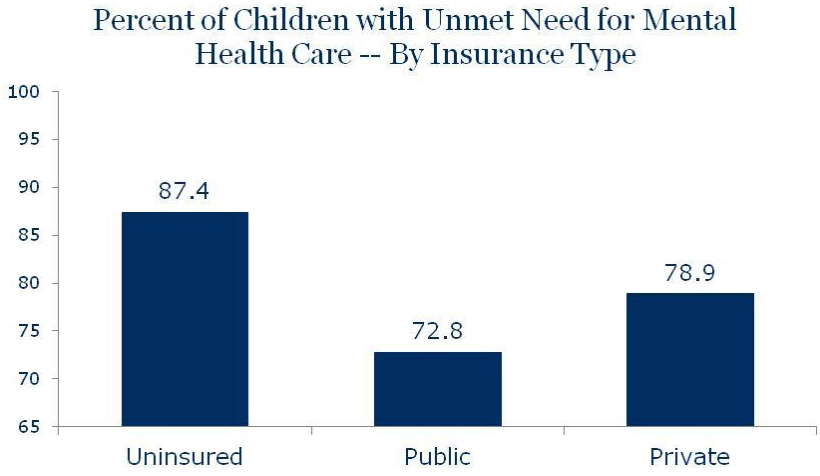
National studies show children from racial/ethnic minority groups are more likely to have unmet mental health care needs.[28] In a study published in the *American Journal of Psychiatry*, almost 90 percent of Hispanic/Latino children ages 6 to 17 had unmet mental health needs. Seventy-six percent of white and black children also had unmet needs.



Source: Katoka, Zhang, and Wells (2002). Am J Psychiatry 159:9[29]

Children living in households with incomes below the poverty level are more likely to experience shorter treatments or to drop out of treatment. [30] [31] Children living in poverty are also more likely to have public insurance, which has been tied to a greater likelihood of having unmet needs. [32]

Children covered by public (and even private) insurance face real challenges in receiving adequate services. One national study found that "79% of children with private health insurance and 73% with public health insurance have unmet mental health needs."[33]



Source: Katoka, Zhang, and Wells (2002). Am J Psychiatry 159:9[34]

Another study showed that children with public insurance wait longer to receive treatment and have limited options. A 2011 study published in *The New England Journal of Medicine* found "significant disparities in children's access to needed outpatient specialty care, attributable to specialists' reluctance to accept public health insurance."[35] The same study also found that "even when children with Medicaid-CHIP were not denied appointments outright, the appointments were, on average, 22 days later than those obtained for privately insured children with identical health conditions." In outpatient specialty psychiatric care, only 17 percent of clinics scheduled appointments for children with public insurance and only 50 percent for children with private insurance.

Even with private insurance, children may face coverage gaps that prevent them from getting services. For example, "private health plans set limits on mental health coverage, such as on the number of visits or types of medications that can be prescribed."[36]

SERIOUS CONSEQUENCES

Failure to optimize a child's mental health and prevent or successfully treat problems early on can significantly reduce that child's quality of life. The cost to families and society is high, though national research shows those costs vary depending on the problem's severity.

The U.S. Surgeon General summarizes the research:

> Unaddressed mental health problems are associated with personal distress. If problems are recurring or long-lasting, they can lead to compromised relationships resulting in fewer friends and social supports (Klein et al, 1997). On the more severe end of the spectrum: mental health disorders also substantially increase the risk of suicide and self-harm. Over 90 percent of children and youth who commit suicide had a diagnosable mental disorder. (Shaffer & Craft, 1999). Suicide attempts throughout the lifecourse reaches a peak during adolescence.[37]

Suicide

Nationally, suicide is the third leading cause of death for youth; in Wisconsin, it is the second leading cause of death for children and youth ages 10 to 24.[38] The 2007 youth suicide rate in Wisconsin was 9.23 (per 100,000 of the population), significantly higher than the national rate of 6.85.[39]

The 2009 Risk Behavior Survey of Wisconsin high school students found 11 percent reportedly planned a way to commit suicide, 13 percent seriously considered suicide, and 6 percent attempted suicide one or more times that year.[40]

Suspensions and Expulsions

Children and youth with mental health problems are less likely to function and succeed at school. They have higher rates of absences, suspensions, and expulsions—even though they most need adult supervision.

Elementary students identified as having mental health problems miss an estimated 18 to 22 days (about a month) each school year. National suspension and expulsion rates for children with mental health problems are three times higher than for their peers.[41] In Wisconsin, the suspension rates are eight times higher for children identified as having mental health problems.[42]

SCHOOL DISABILITY CATEGORY	% STUDENTS SUSPENDED*
Non-Disabled Students	5.05%
Autism	4.94%
Cognitive Disability	12.86%
Deaf/Blind	0.00%
Emotional Behavioral Disability	**39.13%**
Hearing Impairment	5.69%
Specific Learning Disability	13.53%
Other Health Impairment	**28.12%**
Significant Developmental Delay	1.29%
	*Wisconsin, 2008-09

Source: Wisconsin Department of Public Instruction[43]

Early Development Roadblocks

The Yale University Child Study Center found preschool children are expelled at a rate three times higher than children in kindergarten through 12th grade.[44] A survey of licensed early care and education providers in Wisconsin, conducted by the Supporting Families Together Association (SFTA), found that within the last two years, 52 percent of providers asked a family to leave their program.[45]

The reasons for expulsion are often rooted in behavioral, social and emotional difficulties that could be mitigated by mental health consultation. Expulsion in preschool can significantly disrupt the child's development and increase family and parental workplace stress.

Dropping Out

Left untreated, children with disorders and other emotional-behavioral problems are likely to drop out of school, making it harder for them to find a job and more likely that they'll live in poverty as adults.

Nationwide, it's estimated almost half of students ages 14 and older with a mental health disorder drop out of high school.[46] In Wisconsin, students identified with an Emotional Behavioral Disability (EBD) graduate at a much lower rate than that of other disability groups. In the 2009-10 school year, 65 percent of Wisconsin students with an EBD diagnosis graduated, versus 80 percent of students with other disabilities and 91 percent of students without disabilities.[47]

SCHOOL DISABILITY CATEGORY	GRADUATION RATE*
Autism	92%
Cognitive Disability	73%
Emotional Behavioral Disability	**65%**
Hearing Impairment	95%
Specific Learning Disability	85%
Other Health Impairment	80%
Students with Disabilities	**80%**
Students without Disabilities	**91%**

*Wisconsin, 2009-10

Source: Wisconsin Department of Public Instruction[48]

Crime

Children with unaddressed mental health problems are more likely to be involved with the criminal justice system; studies show they are more likely to commit acts that land them in court.[49] One study found "an alarming 65 percent of boys and 75 percent of girls in juvenile detention have at least one mental [disorder]."[50]

Higher Healthcare Costs

Children with untreated mental disorders become adults who use health care services at higher rates and incur higher costs than do other adults. There is also evidence that mental health problems during childhood increase the risk of physical health problems such as asthma and obesity in adulthood.[51]

Untreated mental health problems can become costly mental health disorders. The Agency for Healthcare Research and Quality reports mental health disorders to be the most costly condition for children in

2006 and 2008, "both in overall spending and in average spending per child."[52] These costs are rising; spending on children's mental health disorders grew 37 percent over three years (2006 to 2008). In 2008, spending on children's mental disorders in the U.S. totaled $12.2 billion.

AVERAGE SPENDING PER CHILD	2006	2008
Mental disorders	$1,931	$2,483
Asthma	$621	$796
Trauma-related disorders	$910	$1,029
Acute bronchitis	$242	$226
Medical Expenditure Panel Survey (MEPS-HC)		

INTERVENTIONS

Intervention can prevent years of suffering and inhibited growth during critical developmental years.[53] Through prevention, early identification, and treatment, children can live healthy and productive lives. Strategies to improve children's mental health depend on the level of care necessary. Here are typical community interventions.

STRATEGY	ACTIVITIES
Prevention	Activities that: • Reduce risk • Prevent onset
Early Identification	Assessment, Diagnosis and Evaluation

Treatment	• Treatment interventions
	  ○ Outpatient
	  ○ Partial hospitalization/Day
	  ○ Residential
	  ○ Inpatient
	  ○ Medication
	• Community-based interventions
	  ○ Case management
	  ○ Home-based services
	  ○ School-based services
	  ○ Therapeutic foster care
	  ○ Therapeutic group homes
	• Crisis services

CONCLUSION

Across the country and in Wisconsin, mental health challenges are hurting children, families, and communities. Increased availability of interventions for those in need as well as supportive social emotional development for all children can not only reduce lifetime costs for individuals, but also increase the quality of life for all.

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Top of Mind: Children's Mental Health in Racine

Part 2: Uncovering urgent needs

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STARTING POINT: ESCALATING ISSUES

Children in Racine are suffering because they are not receiving the services they need to address their mental health problems.[1] Public mental health service delivery rates in Racine are among the state's lowest. Waiting lists and no-show rates for key services are growing. Without appropriate services, thousands of Racine's children may face hospitalization, school failure, juvenile justice involvement, and even death. [2] [3]

Racine Statistics

National prevalence estimates say up to 20 percent of children ages 5 to 17 have a diagnosable mental health disorder. In Racine, that translates to about 7,000 children, of whom 4,000 would have a disorder that severely limits their functioning and some 800 would show significant behavior problems before age 5. [4] [5] [6]

But using national numbers may be too conservative. Given Racine's unique challenges (e.g., high rates of low birth weight and child poverty) and the known risk factors associated with mental health problems, the problem here may be even bigger. Let's look at some other measures.

In-School Medication vs. Support

In the 2010-11 school year, Racine Unified School District served roughly 21,000 students. In that same year, school nurses administered 49,000 doses of medication, 70 percent of which were behavior modifying/psychotropic medications. Yet only 30 percent of those

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doses went to special education students; the rest were given to students not receiving any additional supportive services.

Public Service Delivery Rates

National and state public mental health service rates are low—as low as 1.6 percent. In Racine County, they're even lower.[7] [8] A 2012 Wisconsin Mental Health Federal Block Grant application shows Racine County Human Services Department serving only 10 of the 4,010 children ages 5 to 17 estimated to have a severe emotional disturbance (SED).[9] Racine County was listed as having a treated prevalence rate of 0.2 percent, ranking 54th of Wisconsin's 67 counties. [This estimate does not include the number of children receiving mental health services in foster care and in residential treatment settings. But those numbers are not included in other counties' totals, either.]

Waiting lists for psychological and psychiatric services range from six weeks to six *months*, depending on demand, service type, and insurance. While demand for counseling and medical services fluctuates, there are consistent waiting lists for many services. Some organizations serving low-income clients have waitlisted as many as 70 people.

Psychiatric and psychological service "no-show" rates are also high in Racine. One local organization schedules overlapping appointments, in hopes of seeing just one client during that time.

Costs

Limited data make it difficult to specify the costs of leaving children's mental health problems unaddressed. We do know the hospitalization rate for Racine County children's mental health services (number of children per 1,000 hospitalized per year for mental health issues). In 2008, Racine's rate was 8.6, higher than the state's rate of 5.6. We also know that in 2009 there were 410 psychiatric hospitalizations of children. The average stay was 8.8 days, with an average charge of $11,534 per hospitalization.[10]

INTERVIEWS: UNCOVERING THE CHALLENGES

The Johnson Foundation at Wingspread sought to better understand how children's unaddressed and unprevented mental health problems affect Racine.

We interviewed a wide range of children's mental health stakeholders: consumers, parents, advocates, child welfare workers, counselors, psychologists, psychiatrists, doctors, public health workers, special education workers, social workers, researchers, public policy experts and hospital administrators. Through these interviews, we sought to understand the challenges children, families, providers, and communities face when trying to:

1. Help children identified as having a mental health problem
2. Help all children optimize their mental health[11]

Thirty-five in-person and phone interviews were conducted August through December 2011, with participants chosen through snowball sampling. We interviewed until we reached the point of saturation, when the same issues and themes recurred and no new information arose.

The interviews uncovered four challenges to improving the mental health of children in Racine, summarized in this report:

1. Poor system and service coordination
2. Multiple barriers to access
3. High service costs and limited funding
4. Workforce and service shortages

CHALLENGE 1: POOR SYSTEM AND SERVICE COORDINATION

Many services and systems within Racine County aim to improve children's mental health, but they do not coordinate their efforts. As one interviewee said, "The system doesn't flow together. [It's] disconnected." Fragmentation makes it difficult to identify available services, and families and children with mental health needs must often navigate the system on their own. These families don't know where to go for help, and providers don't know where to send them.

Limited Collaboration Between Providers- Providers do not communicate with one another, even when serving the same client. One interviewee said, "There are pieces to a good mental health system here. We don't do a good job of working together well on things." Another interviewee described frustration with limited information from other service providers: "Doctors need to communicate with therapists. [Without this], doctors and clinicians can only rely on what the patients tell them." Another said, "Outpatient therapists don't connect with public schools. Outpatient therapists don't know who to call, and teachers think they don't have a right to communicate."

Limited Knowledge of Available Services- One reason service providers don't work together is that they are not aware of other services available. One interviewee said, "It's hard…to know what's out there. There needs to be more networking." Another stakeholder explained, "There's not a great understanding of what each of us is able to do and what we are not able to do [in terms of] regulations, rules, etc."

Poor State-Level Coordination–Poor coordination at the state level affects county-based services. Mental health care funds and services are largely controlled at the local level. One interviewee said, "One of the problems we have in this state, [it's a strength and a weakness], are county-run governments. There are 72 different counties and 11 tribes [in Wisconsin and] all are fairly autonomous. [The differences] make it difficult for people moving from county to county to know how to access services." In addition, "most counties implement frameworks designed at the state level. [This creates] finger-pointing between counties and the state."

A couple of interviewees noted that the four state-controlled and county-implemented departments with a stake in improving children's mental health don't work together. The Department of Health Services, the Department of Child and Family Services, the Department of Justice, and the Department of Public Instruction work separately with children and their families. One interviewee said, "All four departments are fragmented; none does a very good job [of addressing children's mental health needs]." One interviewee gave this example: "Say there's a single mom with kids with mental health needs. The school says the kids need to be in residential treatment. The psychiatrist says the parent has to stay home to be available for kids. The Department of Workforce Development is pushing Mom to be gainfully employed."

CHALLENGE 2: MULTIPLE BARRIERS TO ACCESS

In line with national, state, and local statistics, almost all interviewees listed access as a major challenge for Racine children and youth, describing the following barriers to essential care:

Refusal by Providers to Take Publically Insured Patients –Almost every interviewee noted that many mental health service providers accept few children with public insurance—if they take any at all. That also drives up the waiting lists. One stakeholder said, "There are a fair number of child therapists in town, but they don't take Title 19" (a form of Medicaid).

Lack of Transportation and Child Care –Interviewees said that many families don't use available services because they struggle to get to appointments; they don't have transportation or child care for other children in the family. Children who miss their appointments are often doubly penalized. First, they lose the benefit of receiving the service. Second, the provider may refuse to continue serving the child. One interviewee stated, "If transportation [or child care] falls through at the last minute and families don't cancel their appointment in time, families often get 'banned' by the provider or clinic."

Some children's needs can't be addressed locally. If they can't travel to Milwaukee—or, in some cases, even farther—they can't access treatment.

Overwhelming Caregiver Demands –Other demands in families' day-to-day lives can affect their ability to address their child's mental health care needs. Work or other life demands may keep parents from getting their child to an appointment. These problems are exacerbated for low-income families. One interviewee noted, "Families face so many other stressors every day, like getting food on the table, that their appointment becomes less and less important."

Language – Non-English-speaking families face a significant challenge in navigating Racine's mental health system. There is a huge deficit in Spanish–speaking clinicians and outreach services.

Unclear Access Points – Many parents simply do not know where to take their children for care. One interviewee noted, "[The system] hasn't been designed with the 'end users' in mind. Families need to know all of the options and ask specifically for them. [They have] nowhere to go to say, 'I don't know where to go, what's out there?"

Families also don't know providers' specialty areas. For example, it is hard to know who works well with children, who works well with teenage girls, and who works well with children on the autism spectrum.

Stigma – Many interviewees noted that parents are often in denial about their child's mental health issues. Parents also have negative perceptions about mental health disorders and the effectiveness of treatment. As a result, their children don't get the help they need.

CHALLENGE 3: HIGH SERVICE COSTS AND LIMITED FUNDING

Many children do not receive treatment because the family can't afford it. In addition, insufficient funding for children's mental health services severely limits service variety and availability. Limited funding also forces some providers to serve only the clients who can pay to participate in treatment or programming.

High Service Costs for Families

Lack of Insurance – Some children can't access services because they have no health insurance, and their families can't pay for care on their own. Interviewees mentioned instances where a child's family earned too much to qualify for BadgerCare but couldn't afford private insurance. Another stakeholder described a child whose parent suddenly lost their job and, subsequently, their employer-based health insurance. While the family tried to qualify for public insurance or find affordable private insurance, that child lost coverage for regular therapy sessions and prescriptions.

Families Cannot Afford Co-Pay – High co-pays for therapy, psychiatry, and medication can force families to choose between going into debt or going without essential treatment. One parent stated, "[My] insurance is garbage. They've cut so many of my benefits. I end up paying out of pocket. [My insurance} doesn't cover my son's medication, [and they] don't pay for [his] whole visit anyways. I end up paying $75 a visit in co-pays."

Limited Financing and Funding

Limited Insurance Coverage –Some private insurance networks limit coverage for treatment type, duration, and location. This, in turn, limits the mental health care a child is likely to receive, as most families can't pay high out-of-pocket expenses. For example, one interviewee explained that "[one insurance company] only authorizes ten sessions. Once co-pay increases, people stop coming for services." A parent noted, "Last year, our insurance limited us to 20 [counseling] visits. [That means my child] can't go every week [like he needs]." Insurers may also limit coverage to specific providers, forcing some families to travel long distances to see a provider "in network." Finally, coverage seems to be better for medication than for therapy or counseling, even though professionals consider both necessary for effective treatment.

Inadequate Reimbursements and Funding for Children's Mental Health Services- As stated earlier, many children can't access important services because providers refuse to accept public insurance. Medicaid reimbursement rates for treatment are unrealistically low. In many cases, Medicaid-only or "straight Medicaid" reimbursement pays a third of a typical contracted rate. Many providers said that the Medicaid reimbursements do not even cover overhead costs associated with treatment.

Limited/Reduced Funding for Mental Health Services– Gradual and recent reductions in funding for community mental health services and support services in schools affect the quality of services for children. Federal and state budget cuts have affected services in our community. For example, schools have seen a dramatic decrease in the number of teacher's aids, who often provide classroom support to children with behavioral and emotional needs.

CHALLENGE 4: WORKFORCE AND SERVICE SHORTAGES

Interviewees identified major shortages in key service areas for promoting and improving children's mental health. There are shortages in the workforce, in available service types (from prevention to treatment), and in programs that provide high-quality, client-focused services. Here is a closer look at these gaps.

Workforce Shortages

Psychiatry – Racine has a major shortage of outpatient psychiatry services for children and adolescents. Many interviewees could think of only four or five local child psychiatrists and also noted that our community does not offer psychiatric services through non-traditional modes, such as telepsychiatry or pediatric-psychiatric consultation service networks.

This shortage is not unique to Racine; it's nationwide. Interviewees said one reason for the shortage is that child and adolescent psychiatry is not as attractive as other medical fields. As one interviewee said, "All of the glamour in medical school is in surgery, etc… not child psychiatry." The additional training required is another factor. One interviewee explained, "Child psychiatry is an extra year of training. Many people

don't want to do that. People just aren't going into the field." Another said, "Child psychiatry is a subspecialty. There's a [training] fatigue factor."

Culturally Competent Providers- It's also difficult for our community to attract culturally sensitive providers. One interviewee said, "A lot of the people who would be good therapists get weeded out. And really good business types who run psych agencies succeed and don't necessarily relate well to clients."

In fact, clinics, schools, and other providers have a hard time attracting any trained providers to Racine, let alone those who are culturally competent or even fully licensed. First, there are few universities or schools with professional training programs nearby. Wisconsin medical schools are in Milwaukee and Madison. One interviewee said, "The closest specialty program for [psychiatric nursing] is at Rush" (in Illinois). This is a problem because students or residents often develop ties to the community where they receive their training, making them less likely to relocate. Also, Racine offers fewer opportunities for those in training to connect to local organizations through internships or residency. Finally, Racine's size and location can be deterrents. One interviewee said, "It's hard to compete from the city of Racine. [Providers] have many options. Big cities are more attractive."

Service Type Shortages

Prevention and Early Identification– Interviewees said Racine needs more preventative, health promotion, and early identification programs. Prevention can range from promoting healthy socio-emotional development in young children to teaching school-age children healthy coping skills and behaviors. Without these services, children's mental health issues are not caught early and manifest in unhealthy ways.

Community Education – Families and stakeholders are not adequately educated about consumer rights, provider responsibilities, and changes in programs or laws. One stakeholder said, “Certain information can be gotten from schools. If you don't know what is out there, you don't know what to ask for." Privacy laws are especially confusing for parents and providers. Limited understanding hinders communication between providers, affecting quality of service; as one interviewee said, "Collaboration is difficult because of laws." Another noted, “Doctors often prescribe quickly, not contacting schools because they do not have a proper release of information of information." Changes to BadgerCare also regularly confuse families and providers.

Psychotherapy – Racine needs quality youth- and family-focused psychotherapy treatment options. Many interviewees stated a need for more therapists and therapeutic interventions that specialize in children and youth. In addition, there is very little home- or school-based therapy available to children and their families.

Psychological Evaluation– Interviewees noted the lack in Racine of comprehensive and quality psychological evaluation services, which help identify a child’s needs and give providers more insight into the diagnosis. Such services include intelligence testing, neuropsychological testing, and other evaluations.

Alternatives to Hospitalization – One alternative to inpatient hospitalization is intensive outpatient or day treatment. Currently, these services are available only in Milwaukee.

Mobile Crisis– Although Racine County does offer mobile crisis services, interviewees noted a need to develop a youth-focused approach.

Advocacy – Although some state and local mental health advocacy groups have a Racine presence, they generally don’t speak up for children with mental health needs. One parent said, “I had no help! I was told nothing was wrong for years. I had to live with him for so many years…I thought about sending him [away].” Another said, “I had to do all of this [navigating and education] on my own. I was left high and dry that I had a child who was out of control.”

One interviewee said organizations avoid advocacy "because they receive funding from [organizations that they may be challenging] and they don't want to jeopardize that [relationship.]" Another interviewee summed it up: "Children with Title 19 insurance have little or no voice."

Peer Support– Peer support for families and children with mental health needs has disappeared; there are currently no regularly functioning peer support groups for parents of children with mental health needs. One interviewee said, "Support groups are needed for parents of 'troubled teens.'" There is a support group for children of sexual violence, but it meets only once a year and targets a very specific group of children.

Shortage of High-Quality Services

Lack of Appropriately Trained Staff – Providers receive limited training on mental health resources available throughout the community. Many stakeholders don't have complete knowledge of other system services. Doctors and outpatient therapists don't know who to call if they wanted to refer a family or coordinate services. School counselors and staff have limited knowledge of community resources available to students who need additional support or intervention. One interviewee said, "Schools don't have enough information. They have scattered knowledge, yet they should be the main referral source." Another person stated, "Social workers are unaware of the services that are available [to students with mental health needs]." One interviewed parent gave this example: "I'd get a call every single day from the school. [I thought], 'Why are you asking me for suggestions? Don't you know? Don't you have any recommendations?"

Interviewees also noted the lack of providers trained in infant mental health, trauma-informed care, and other specialized areas.

Language/Cultural Responsiveness – Until recently, Racine had one Spanish-speaking psychiatrist. Now there are none. The community has one or two Spanish-speaking therapists, not enough to meet demand. Some interviewees also noted a deficit in culturally-appropriate providers. As a result, children serve as translators between their service provider and parents—problematic because the children often cannot reliably translate medical terminology.

MOVING FORWARD: TIME FOR INTERVENTION

Children in Racine need mental health intervention, now more than ever. Multiple interviewees noted a recent change in the severity of our children's mental health problems and in the age at which problems begin. One interviewee said there are "much younger children with much higher needs." Another noted that "more kids at younger ages (than normal) have issues." Another said, "We've seen a lot higher acuity -- violent behaviors, [and] children not having a lot of coping strategies."

To avoid long-term negative consequences for individuals and our community as a whole, Racine must address children's mental health issues early and effectively. That means tackling the challenges identified again and again in stakeholder interviews, overcoming access barriers and service gaps to provide high-quality mental health services for our children.

Keep in mind that our interviews may not have captured all the challenges that children, their families, providers, and our community face in reducing mental health problems and improving mental health for all Racine County children. But we believe this summary offers a solid starting point for discussions on next steps.

We've identified key issues. Now it's time to increase understanding of these issues, identify solutions, and begin implementation.

Our children are waiting.

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[11] Georgetown University National Technical Assistance Center for Children's Mental Health

Attachment: Interviewed Stakeholder Organizations

Advocacy Groups

Wisconsin Council on Children and Families
Wisconsin Family Ties, Inc.
National Alliance for the Mentally Ill (NAMI) – Racine
The ARC of Racine
Disability Rights Wisconsin
Mental Health America – Wisconsin
Wisconsin Alliance for Infant Mental Health

Providers

Racine Psychological Services, Inc.
Children's Service Society of Wisconsin
Outpatient therapists and psychologists (Various private practices)
Zimmerman Consulting, Inc.
Professional Services Group, Inc.
Family Service of Racine
Lutheran Social Services of Wisconsin
Wheaton Franciscan Healthcare – All Saints
- Child psychiatry
- Pediatrics
- Administration

Schools

Prairie School
Racine Unified School District – Parent Involvement Center
Racine Unified School District – Instruction & Support
Racine Unified School District – Health Services

University Faculty

University of Wisconsin-Madison
University of Illinois-Chicago

Government

Wisconsin Council on Mental Health
SAMHSA – Division of Service and System Improvement
Racine County Human Services Department
Illinois Violence Prevention Authority
Fond du Lac County Department of Community Programs – Birth to Three Program

Mental Health Service Consumers