The Johnson Foundation AT WINGSPREAD

Conferences that Inspire Solutions

DRAFT

Issues in Children's Mental Health

Exploring national, state and local perspectives

April 2012

Prepared by
The Johnson Foundation at Wingspread,
Ashley Staeck, Community Program Associate

33 East Four Mile Road
Racine, Wisconsin 53402

262 | 639.3211 main
262 | 681.3327 fax
info@johnsonfdn.org

www.johnsonfdn.org

Table of Contents

The Johnson Foundation AT WINGSPREAD

Conferences that Inspire Solutions

33 East Four Mile Road
Racine, Wisconsin 53402

262 | 639.3211 main
262 | 681.3327 fax
info@johnsonfdn.org

www.johnsonfdn.org

Issues in Children's Mental Health

A Look at Wisconsin and the Nation

The Johnson Foundation AT WINGSPREAD

Conferences that Inspire Solutions

April 2012

BACKGROUND

Positive mental health, from early childhood to old age, is an essential component of a healthy, fulfilling and productive life. Unfortunately, mental health problems occur commonly and at an early age. Because of limited availability and access, most children do not receive the mental health care they need.[i] [ii] Access to quality services varies greatly; leaving many of the most marginalized children with an even smaller chance of receiving necessary services. [iii] [iv] If left unaddressed, there are major consequences that can compromise a child's future and the health and vitality of a community. [v] By increasing the availability of and access to high quality mental health interventions, children in Racine will lead healthier, more productive lives.

Defining mental health

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."[vi] Positive mental health can be defined both as the absence of illness or problems, but also as the optimizing of mental functioning. There is a tendency to overlook the importance of mental health until problems arise. Yet, the Surgeon General notes, "[f]rom early childhood until death, mental health is the springboard of thinking and communication skills, learning, emotional growth, resilience, and self-esteem."[vii]

The term "mental illness" refers to diagnosable mental disorders. Mental disorders and conditions are "characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or impaired functioning."[viii]

33 East Four Mile Road
Racine, Wisconsin 53402

262 | 639.3211 main
262 | 681.3327 fax
info@johnsonfdn.org

www.johnsonfdn.org

The term "mental health problems" expands beyond diagnosable issues and includes signs and symptoms of a mental health issue that don't necessarily meet the criteria for a diagnosable disorder. 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."[ix]

Childhood trauma offers an example of the distinction between mental health problems and diagnosable disorders. Trauma symptoms may not qualify as a mental disorder, according to the Diagnostic and Statistical Manual of Mental Disorders Handbook. Nevertheless, trauma symptoms can be debilitating if left unattended. They place children at risk for depression, which, in turn, is linked to death from suicide, acts of violence toward others, school incompletion, and incarceration.[x] Interventions are available – from formal treatment to support group participation – that can curb the symptoms and avoid the consequences of trauma. In this instance, early intervention would help address this *mental health problem* before it becomes a disorder.

Mental health and the developing child

Understanding mental health in childhood and adolescence involves a blended perspective that combines both the study of development with the study of mental disorders. The U.S Surgeon General confirms, "[b]oth perspectives are useful. Each alone has its limitations, but together they may constitute a more fully informed approach that spans mental health and illness and allows one to design developmentally informed strategies for prevention and treatment."[xi]

The U.S. Surgeon general explains the following about the role of mental health in childhood:

> Mental health in childhood and adolescence is defined by the achievement of expected developmental cognitive, social, and emotional milestones and by secure attachments, satisfying social relationships, and effective coping skills. Mentally healthy children and adolescents enjoy a positive quality of life: function well at home, in school, and in their communities; and are free of disabling symptoms of psychopathology (Hoagwood et al., 1996)[xii]

Mental health problems in childhood begin at a young age[xiii] 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."[xiv]

Various factors put children at risk for developing a mental disorder or experiencing issues in social-emotional development. These risk factors include internal and external aspects such as:

- Prenatal damage from exposure to alcohol, illegal drugs, and tobacco;
- Low birth weight;
- Difficult temperament;
- Poverty;
- Deprivation;
- Abuse and neglect;
- Parental mental health disorder; and
- Exposure to traumatic events. [xv]

In the absence of stable, nurturing relationships in a young child's life, these external risk factors can cause toxic stress and damage the developing brain architecture of a young child.[xvi]

Prevalence

Mental health disorders are common among today's children and youth. The most common mental health disorders among children and youth include: mood disorders (e.g. depression, bi-polar), disruptive disorders (e.g. attention deficit), and anxiety disorders. It is estimated that one in five (20%) children ages 5 to 17 have a diagnosable mental health disorder[xvii] and 11 percent have a disorder that seriously limits their functioning[xviii]. For children ages 0 to 4, about eight percent are estimated to have significant behavioral problems.[xix]

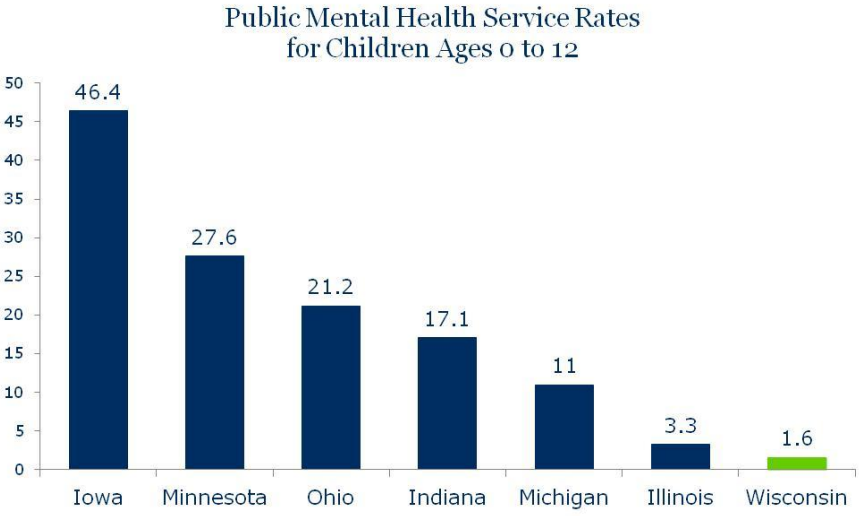
PREVALENCE ESTIMATE	CHILDREN WITH A DISORDER*	TOTAL CHILD POPULATION[xx]
United States	14,819,786	74,098,929
Wisconsin	268,426	1,342,129
		*Assuming 20% prevalence estimate

MAJOR CHALLENGES FOR WISCONSIN CHILDREN

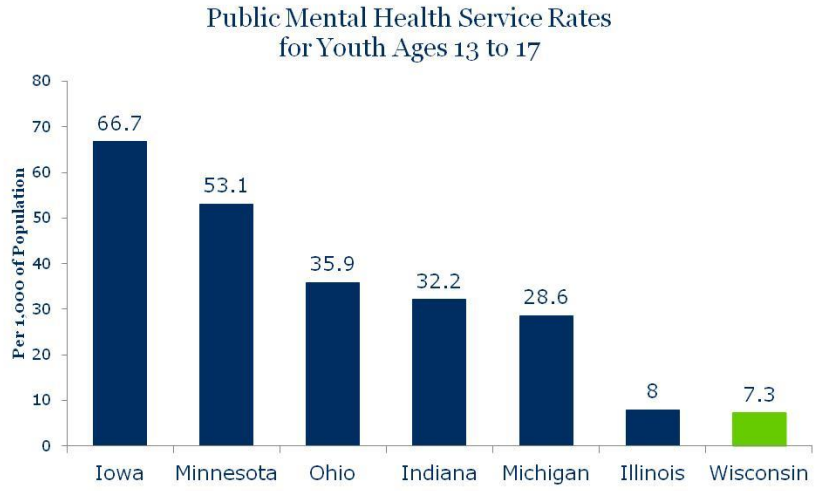
National estimates suggest 80% of children ages 6 to 17 do not receive the treatment they need.[xxi] In addition, many children ages 5 and younger also do not receive the services needed to optimize their social-emotional development.[xxii] Children face major challenges in two areas:

1. Accessing necessary services, and
2. Receiving a quality of care that will improve their mental health outcomes.

In Wisconsin, public mental health system service rates for children and youth are the lowest of any state in the upper Midwest.[xxiii]

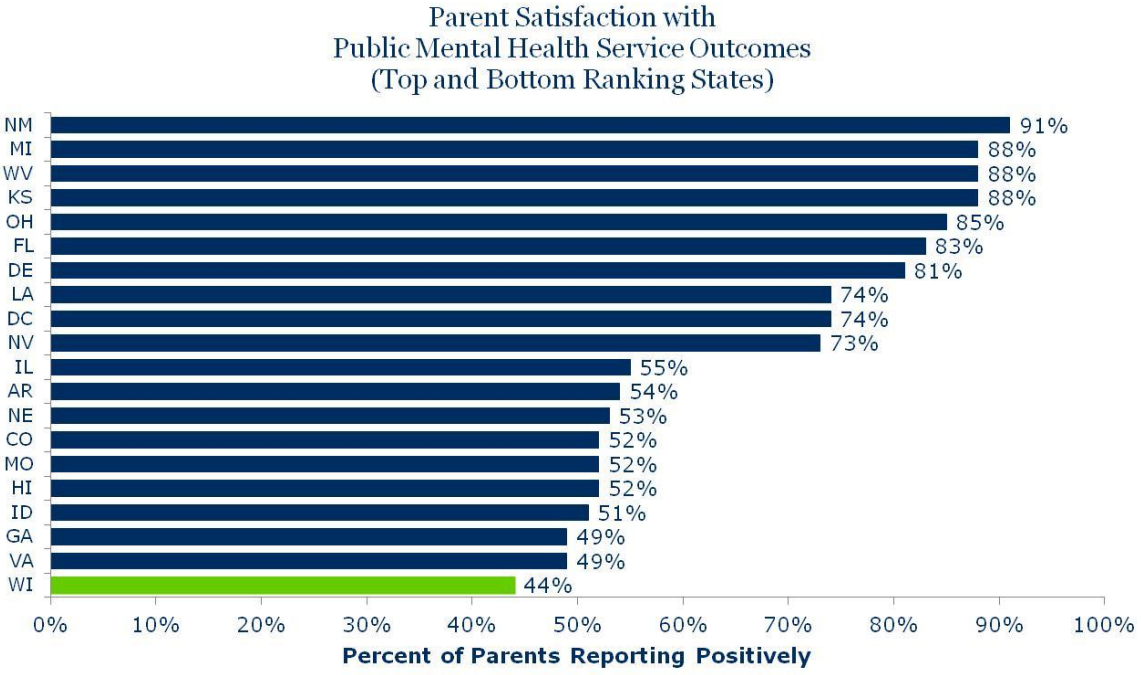


Source: Center for Mental Health Services Reporting System (2009); Wisconsin Family Ties[xxiv]



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

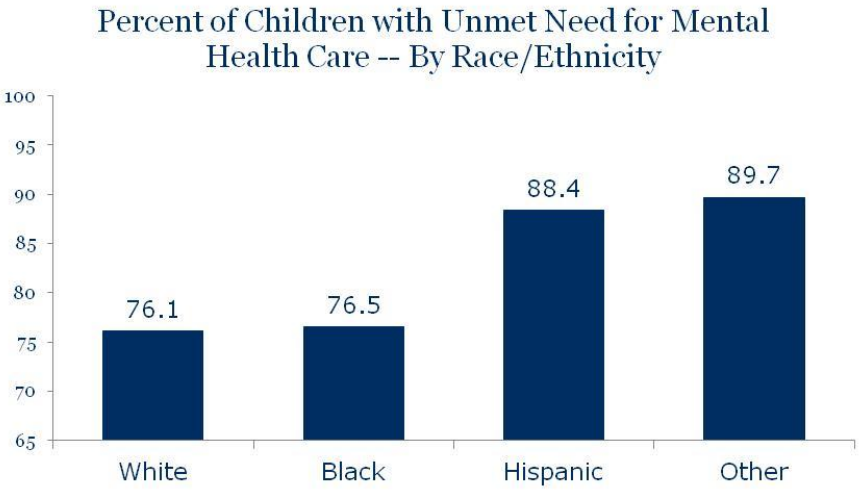
In terms of quality, using parental satisfaction as an indicator, Wisconsin falls at the bottom of the rankings for public mental health services. [xxvi]



Source: Mental Health Statistical Improvement Program. As cited in: Wisconsin Family Ties[xxvii]

VARIANCE IN SERVICE UTILIZATION AND ACCESS

National studies have shown children from minority racial/ethnic backgrounds to be more likely to have unmet mental health care needs.[xxviii] 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.

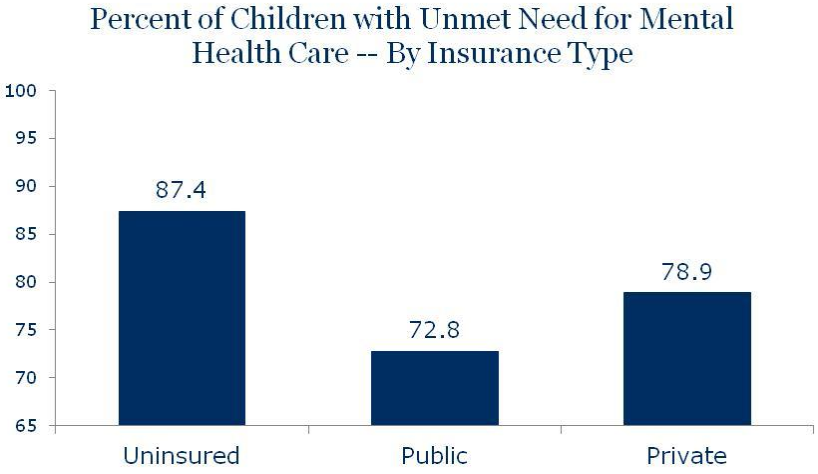


Source: Katoka, Zhang, and Wells (2002). Am J Psychiatry 159:9[xxix]

Similar racial/ethnic disparities hold true for even younger children who are still developing social-emotional skills. Instead of receiving appropriate services and interventions in preschool, African-American preschoolers are expelled at a rate 3 to 5 times higher than their peers of other racial/ethnic backgrounds.[xxx]

Children living in households with incomes below the poverty level are more likely to experience shorter lengths of treatment or drop out of treatment. [xxxi] [xxxii] Children living in poverty are also more likely to receive community mental health services or services paid for by public insurance, which brings additional challenges to accessing services. [xxxiii]

Children covered by public and 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."[xxxiv]



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

Another study showed that children with public insurance have limited treatment options and wait longer to receive treatment. 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."[xxxvi] 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." For the outpatient specialty care area of psychiatry, only 17 percent of clinics scheduled appointments for children with public insurance and only 50 percent for children with private insurance.

Children covered by private insurance plans face additional challenges because of gaps in coverage that prevent them from getting the services they need. For example, "private health plans sets limits on mental health coverage, such as on the number of visits or types of medications that can be prescribed."[xxxvii]

SERIOUS CONSEQUENCES

National research shows the social costs and consequences of unaddressed and unprevented children's mental health problems to vary widely depending on the severity of the problem and the developmental stage of the child. Equally, communities suffer a loss and incur high costs when the social emotional development of young children is not enhanced and mental health in all children is not optimized. If a child's mental health is not fully optimized and problems are not prevented or successfully treated at early stages, they can lead to a significantly reduced quality of life and receipt of services in the most expensive care settings.

Research compiled by the U.S. Surgeon General summarizes:

> "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."[xxxviii]

Nationally, suicide is the third leading cause of death for youth, while in Wisconsin it is the second leading cause of death for children and youth ages 10 to 24.[xxxix] The 2007 youth suicide rate in Wisconsin was 9.23 (per 100,000 of the population), much higher than the national rate of 6.85.[xl] In 2009, 20 percent of Wisconsin high school students reported symptoms of depression, 11 percent reportedly made a plan about how they would attempt suicide, 13 percent seriously considered attempting suicide, and 6 percent actually attempted suicide one or more times that year.[xli]

Wisconsin's mental health hospitalization rate (number of children per 1,000 who have been or are hospitalized in a given year for mental health issues) was 5.6 in 2008.[xlii]

The National Center for Children in Poverty states that children and youth with mental health problems "are more likely to be unhappy at school, be absent, or be suspended or expelled. [For elementary aged-children with mental health problems], they may miss as many as 18 to 22 days, in the course of the school year. Nationally, their rates of suspension and expulsion are three times higher than their peers."[xliii] In Wisconsin, school-aged children with emotional or behavioral disabilities are suspended from school at a rate nearly eight times that of non-disabled students.[xliv]

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[xlv]

According to a study done by Yale University Child Study Center, even preschool aged children with unaddressed social-emotional needs "face expulsion rates three times higher than children in kindergarten through 12th grade."[xlvi] Expulsion in preschool can be significantly disruptive to the caregiver-child relationship and can increase stress in the family and parental workplace. 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 had asked a family to leave their program.[xlvii]

Left untreated, children with disorders and other emotional-behavioral problems are likely to drop out of school, making it harder to find a job and more likely to live in poverty as adults. National estimates reveal almost half of students aged 14 and older with a mental health disorder drop out of high school.[xlviii] In Wisconsin, students categorized with an Emotional Behavioral Disability (EBD) graduate at a much lower rate than other disability groups. In fact, in the 2009-10 school year, only 65 percent of students with an EBD diagnosis graduated.[xlix]

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[l]

Children and youth with untreated mental health disorders are also at increased risk of criminal justice involvement. Some studies have shown children with unaddressed mental health problems to be more likely to commit acts that land them in court.[li] In fact, one study found "an alarming 65 percent of boys and 75 percent of girls in juvenile detention have at least one mental illness."[lii]

Children who have untreated mental disorders also use health care services at higher rates and incur higher costs compared to other adults. In addition, there is evidence that mental health problems during childhood increase the risk of certain physical health problems like asthma and obesity in adulthood.[liii]

Beyond the social costs, treatment for unprevented and unaddressed mental health disorders is incredibly expensive. A report released by the Agency for Healthcare Research and Quality revealed 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."[liv] Healthcare costs for children's mental disorders are more expensive than other conditions like asthma, acute bronchitis, and infectious diseases. In addition, these costs are rising, as spending grew by 37 percent on children's mental health disorders in a three year period (from 2006 to 2008). In 2008, total 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

To avoid years of unnecessary suffering and the loss of growth during critical developmental years, intervention is necessary.[lv] Through promotion, prevention, early identification, and treatment, it is possible to:

1. Reduce mental health problems among children for whom a problem has been identified
2. Help all children optimize their mental health

Effectively improving the mental health of children involves multiple strategies and activities. Types of interventions commonly found in communities are listed in the following table.

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

Positive mental health can be defined not only as the absence of illness or problems, but also as the optimization of mental functioning. Across the country and in Wisconsin, mental health challenges are negatively impacting the lives of children, their families, and communities (as a whole). Increased availability of interventions for those in need as well as supportive social emotional development for all children can not only reduce lifetime costs (both economic and social) for individuals, but also increase the quality of life for all.

References

[i] Kataoka, S.H., Zhang, M.S., & Wells, K.B. (2002). Unmet need for mental health care among U.S. children: Variation by ethnicity and insurance status. *American Journal of Psychiatry,* 159:9, 1548-1555.

[ii] Mental Health Statistics Improvement Program Survey. (as cited in Wisconsin Family Ties [2011] Data show children's mental health is being neglected in Wisconsin.)

[iii] Hoberman, H. M. (1992). Ethnic and minority status and adolescent mental health services utilization. *Journal of Mental Health Administration, 19*, 246-267.

[iv] Kataoka, et al. (2002).

[v] Multiple sources (as cited in Masi, R. & Cooper, J. (2006). Children's mental health: Facts for policymakers. National Center for Children in Poverty. Columbia University.)

[vi] U.S. Department of Health and Human Services. (1999). *Mental Health: A Report of the Surgeon General.* Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health.

[vii] Ibid.

[viii] Ibid.

[ix] Ibid.

[x] Multiple sources (as cited in Masi, R. & Cooper, J. (2006). Children's mental health: Facts for policymakers. National Center for Children in Poverty. Columbia University.)

[xi] USDHHS. (1999). *Mental Health: A Report of the Surgeon General*.

[xii] Ibid.

[xiii] New Freedom Commission on Mental Health. (2003). *Achieving the promise: Transforming mental health care in America. Final report* (DHHS Pub. No. SMA-03-3832). Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration.

[xiv] USDHHS. (1999). *Mental Health: A Report of the Surgeon General*.

[xv] Ibid.

[xvi] Child Development Fact Sheet. Center on the Developing Child. Harvard University. National Scientific Council on the Developing Child. National Forum on Early Childhood Program Evaluation.

[xvii] New Freedom Commission on Mental Health. (2003). Achieving the promise.

[xviii] Shaffer, D., Fisher, P., Dulcan, M.K., Davies, M., Piacentini, J., Schwab-Stone, M.E., Lahey, B.B., Bourdon, L, Jensen, P.S., Bird, H.R., Canino, G., & Regier, D. A. (1996a). The NIMH Diagnostic Interview Schedule for Children Version 2.3 (DISC-2.3): Description, acceptability, prevalence rates, and performance in the MECA Study. Methods for the epidemiology of Child and Adolescent Mental Disorders Study. *Journal of the American Academy of Child and Adolescent Psychiatry, 35*, 865-877.

[xix] Lavigne JV, Gibbons RD, Chirstofeel KK, et al (1996). *Prevalence Rates and Correlates of Psychiatric Disorder among Preschool Children*. J Am Acad Child Adolesc Psychiatry, 35:2, 204-214.

[xx] U.S. Census

[xxi] Katoaka, et al. (2002). *Am J Psych*

[xxii] Gilliam, W.W. (2005). Prekindergartens left behind: Expulsion rates in state prekindergarten programs (FCD Policy Brief Series 3). New York, NY: Foundation for Child Development.

[xxiii] Center for Mental Health Services Reporting System (2009) U.S. Department of Health and Human Services (as cited in, Wisconsin Family Ties [2011] Data show children's mental health is being neglected in Wisconsin.)

[xxiv] Ibid.

[xxv] Ibid.

[xxvi] MHSIP. (as cited in Wisconsin Family Ties [2011] Data show children's mental health is being neglected in Wisconsin.)

[xxvii] Ibid.

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

[xxix] Ibid.

[xxx] Gilliam (2005). Pre-kindergartens left behind.

[xxxi] Hoberman, H. M. (1992). Ethnic and minority status and adolescent mental health services utilization. *Journal of Mental Health Administration, 19*, 246-267.

[xxxii] USDHHS. (1999). *Mental Health: A Report of the Surgeon General*.

[xxxiii] Canino et al., 1986; Costello & Janiszewski, 1990 (as cited in USDHHS. (1999). *Mental Health: A Report of the Surgeon General*.)

[xxxiv] Katoaka, et al. (2002). *Am J Psych*

[xxxv] Ibid.

[xxxvi] Bisagaier, J. & Rhodes, K.V. (2011) Auditing access to specialty care for children with public insurance. *The New England Journal of Medicine 364*: 2324-33.

[xxxvii] Center on Aging Society (2003). Child and adolescent mental health services. Washington, DC: Georgetown University (as cited in Bazelon Center for Mental Health Law. Facts on Children's Mental Health. www.bazelon.org.)

[xxxviii] USDHHS. (1999). *Mental Health: A Report of the Surgeon General*.

[xxxix] Mental Health America. Section A: Statement of Need. www.mhawisconsin.org/Data/Sites/1/media/.../gs11-narrative-final.pdf.

[xl] Ibid.

[xli] 2009 Wisconsin Youth Risk Behavior Survey: Part V: Suicide. Wisconsin Department of Public Instruction.

[xlii] Wisconsin Interactive Statistics on Health (WISH).

[xliii] Blackorby, J. & Camero, R. (2004). Changes in school engagement and academic performance of students with disabilities. In *Wave 1 Wave 2 Overview* (SEELS) 8.1 – 8.23. Menlo Park, CA: SRI International

[xliv] Wisconsin Department of Public Instruction. (as cited in, Wisconsin Family Ties [2011] Data show children's mental health is being neglected in Wisconsin.)

[xlv] Ibid.

[xlvi] Gilliam, W. S. (2005). Prekindergartens left behind.

[xlvii] Supporting Families Together Association. (2011). Child Retention in Wisconsin Child Care Settings: Understanding the Attitutdes, Beliefs, and Behaviors that Impact Expulsion and Retention in Early Care and Education.

[xlviii] Wagner, M. (2005). Youth with disabilities leaving secondary school. *Changes Over Time in the Early Post School Outcomes of Youth with Disabilities: A Report of Findings from the National Longitudinal Transition Study (NTLS) and the National Longitudinal Transition Study-2 (NTLS2)* 2.1–2.6. Menlo Park, CA: SRI International.

[xlix] Wisconsin Department of Public Instruction. (as cited in, Wisconsin Family Ties [2011] Data show children's mental health is being neglected in Wisconsin.)

[l] Ibid.

[li] Nimmo, Margaret L. (2000). Action Alliance for Virginia's Children and Youth, Special Report: Issues in Children's Mental Health.

[lii] Skowyra, K. R. & Cocozza, J. J. (2006). *Blueprint for change: A comprehensive model for the identification and treatment of youth with mental health needs in contact with the juvenile justice system.*. Delmar, NY: The National Center for Mental Health and Juvenile Justice (NCMHJJ) and Policy Research Associates, Inc.

[liii] Goodwin, R.D. et al. (2009) Do mental health problems in childhood predict chronic physical conditions among males in early adulthood? Evidence from a community-based prospective study." Psychological Medicine; Feb 2009. Vol 39. Issue 2. P301-311.

[liv] Spending on children's mental health disorders grew by 37% over 3-year period. (2012, January 23). *OPEN MINDS Weekly News Wire.*

[lv] The National Advisory Mental Health Council Workgroup on Child and Adolescent Mental Health Intervention Development and Deployment. (2001). Blueprint for change: Research on child and adolescent mental health." Washington, D.C. (As cited in Facts on Children's Mental Health in America. (2012) National Alliance on Mental Illness.)

Issues in Children's Mental Health

Examining Racine Systems and Services through Key Informant Interviews

The Johnson Foundation AT WINGSPREAD

Conferences that Inspire Solutions

April 2012

BACKGROUND

An estimated one in five children, nationally, has a diagnosable mental health disorder.[i] Many of these children (and their families) do not receive the care they need.[ii] Without appropriate services, many problems escalate and may eventually lead to school failure, hospitalization, and criminal justice involvement. [iii] [iv]

Racine Statistics

If Racine County is consistent with the national and state prevalence rates, then approximately 7,150 children, ages 5 to 17 have a diagnosable mental health disorder, 4,000 have a serious emotional disability and more than 800 children younger than five years have significant internalizing or externalizing behavior problems. [v] [vi] [vii] [Note: Utilizing national prevalence estimates may be too conservative of an approach for estimating prevalence in Racine. Given Racine's unique challenges (e.g. high child poverty rates) and the known risk factors associated with mental health problems, the prevalence of mental health problems may be much greater in Racine.]

Although national and state mental health service rates are incredibly low, children's public mental health service rates are even lower in Racine County. [viii] [ix] In 2010, The Racine County Human Services Department served only 10 of the 4,010 children ages 5 to 17 estimated to have a severe emotional disturbance (SED).[x] That means the treated prevalence rate in Racine County is 0.2 percent for those children with the most severe mental health problems (far below the state rate of 3.1 percent). Racine County ranks 54th of the 67 Wisconsin counties in terms of treated prevalence rates.

33 East Four Mile Road
Racine, Wisconsin 53402

262 | 639.3211 main
262 | 681.3327 fax
info@johnsonfdn.org

www.johnsonfdn.org

The local consequences for leaving mental health problems unadressed are difficult to measure as there is very limited data available. Although, the hospitalization rate for Racine County children's mental health services (number of children per 1,000 who have been or are hospitalized in a given year for mental health issues) is available. 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.[xi] That means it cost roughly $4,728,940 to hospitalize children in Racine in 2009.

Gaining an Improved Understanding of Racine's Unique Challenges

Knowing the negative impact unaddressed and unprevented children's mental health problems have on a community, the Johnson Foundation at Wingspread sought to better understand how these issues manifest themselves in Racine. In order to obtain a deeper understanding of the challenges locally, the Foundation called upon the expertise of community stakeholders.

Foundation staff interviewed representatives from various children's mental health stakeholder groups in order to get a well-rounded view of the issues. Interviews were conducted with consumers, parents, advocates, child welfare workers, counselors, psychologists, psychiatrists, doctors, public health workers, special education workers, social workers, researchers, and hospital administrators.

Stakeholders were asked a variety of questions with the goal of understanding the challenges and barriers children, families, providers, and communities face when trying to:

1. Reduce mental health problems among children for whom a problem has been identified; as well as
2. Help all children optimize their mental health[xii]

Thirty-five interviews were conducted August through December 2011 via phone or in-person with individuals representing private and public sector perspectives at local, state and national levels. The methods used for selecting stakeholders to interview were theoretical and snowball sampling until the point of saturation was reached. At this point, many

of the same issues and themes were continuously identified and no new information was uncovered.

This summary captures the key themes and trends that the interviewed stakeholders identified. Although many challenges and concerns were identified, it is possible not all of the issues were captured through the interviews. Through the key informant interviews, four key challenges to improving the mental health of children in Racine were identified. The challenges include:

1. Limited access and underutilization of existing services
2. Poor coordination among programs
3. High costs and limited funding
4. Shortage of quality services

LIMITED ACCESS AND UNDERUTILIZATION OF EXISTING SERVICES

In line with national, state, and local statistics, almost all key informants stated access as one of the major challenges facing Racine children and youth. The services that are available in Racine are underutilized and difficult to access. Interviewees identified many barriers and challenges that make it difficult for children and their families to access and utilize the services they need.

Long Waiting Lists – Interviewees said waiting lists for psychological and psychiatric services can range from six weeks to six months, depending on demand, service type and insurance type. Although demand for counseling and medical services fluctuates throughout the year, there are consistent waiting lists for many services. In some cases, organizations serving low-income clients had seventy people on their waitlist. In fact, waiting lists for child psychiatry services can be up to six months long.

Refusal by Providers to Take Publically Insured Patients –. Many providers do not accept any (or accept only a small proportion of) children with public insurance. Almost every interviewee noted the challenges that children with public insurance face when trying to access mental health services. Refusal by some providers to take children with public insurance also drives the waiting lists up. One stakeholder stated, "There are a fair number of good child therapists in town, but they don't take Title 19" (a form of Medicaid).

Individual Does Not Meet Behavioral Criteria for Programs – One interviewee noted that "tough" clients are not served and that "most places just want to treat the ideal client." In addition, a few interviewees noted that some children or adolescents are hospitalized when they may be better served in an outpatient setting; implying hospitals sometimes set their criteria too low.

Lack of Transportation and Child Care – Families have a hard time utilizing available services because getting to scheduled appointments is a major challenge. Interviewees said that many families struggle to get to scheduled appointments due to a lack of transportation and child care for other children in the family. Children who are unable to make it to scheduled appointments are often doubly penalized. First, they are unable to benefit from the services they hoped to receive that day. Secondly, they may be prohibited to receive any future services from that particular provider. 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."

In addition, some children have needs that cannot be addressed locally, and must travel to Milwaukee or farther for treatment. If they do not have available transportation, they will not be able to access the appropriate treatment.

Overwhelming Caregiver Demands – Families face many other demands in their day-to-day lives that can affect their ability to make time for their child's mental health care needs. Because of work or other life demands, parents are unable to get their child to scheduled appointments or address their child's mental health needs at all. 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 – Navigating a mental health system in another language can be very challenging for non-English speaking families. There is a huge deficit in Spanish–speaking clinicians and outreach services.

Unclear Access Points – Even if they could, many parents do not know where to take their children for care. One interviewee noted, "the way [the system has] been designed…hasn't been designed for 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?"

In addition, families also don't know the specialty areas of different providers. 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. Because of this, many children in need of services do not get the help they need.

POOR COORDINATION AMONG PROGRAMS

Within Racine county, there are some great services, but these services are not well coordinated or collaborative. Providers do not work together and have limited knowledge of one another. This can be very confusing for families and children with mental health needs, who are often asked to navigate a fragmented system alone. One interviewee stated, "the system doesn't flow together. [It's] disconnected."

Limited Communication Among Providers- "There are pieces to a good mental health system here. We don't do a good job of working together well on things" said one interviewee. Another interviewee gave a specific example of a deficit in service collaboration and communication, "doctors need to communicate with therapists. [Without this], doctors and clinicians can only rely on what the patients tell them." Another interviewee stated "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." Currently, consultation and coordination happens informally with some providers. One provider said, "I try to talk to school…we correspond with letters. I send teachers [forms] to answer and fill out. Sometimes [I talk to] school counselors"

Limited Knowledge Within the Field - Part of the reason services and systems do not coordinate with one another is because they are not aware of the services available in the community. 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…"

System Challenges to Coordination–Poor coordination, at the state level, has impacts on 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 departments at the state level that have a stake in improving the mental health of children: the Department of Health Services, the Department of Child and Family Services, the Department of Justice, and the Department of Public Instruction, don't address children's mental health issues well. One interviewer said, "All four departments are fragmented; none do a very good job." Poor collaboration and communication sends mixed messages to families that have children with 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."

HIGH COSTS AND LIMITED FUNDING

Many children do not receive treatment because services are unaffordable. In addition, insufficient funding for children's mental health services severely limits the variety and availability of key services. Limited funding also forces some providers to serve only the clients that can pay to participate in treatment or programming.

Lack of Insurance - There are instances where children cannot access services because they have no health insurance and their families are unable to pay the out-of-pocket costs associated with care. Interviewees mentioned instances when a child was unable to receive care because their family earned too much to qualify for BadgerCare, but couldn't afford private insurance. Another stakeholder noted an instance when a parent of a child with mental health problems suddenly lost their job and, subsequently, their employer-based health insurance. Before private or public insurance was figured out, that child lost coverage for their regular therapy sessions and prescriptions.

Families Cannot Afford Co-Pay –Co-pays for therapy, psychiatry, and medication can be more than families can afford. With high co-pays, families are often forced to choose between necessary treatments and going into debt. 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 Insurance Coverage –Some private insurance networks limit the coverage they will provide for the duration, location, and type of treatment for children's mental health services. This, in-turn limits the treatment that the child is likely to receive, as most families are unable to pay large, 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." One parent noted, "Last year, our insurance limited us to 20 [counseling] visits. [That means my child] can't go every week [like he needs] then." Another way coverage is limited is if a certain provider is not on a client's insurance panel, then the service is considered "out of network." This limits the choice of provider for a child, forcing some families to travel long distances to see a provider "in network." Finally, medication seems to be better covered than therapy or counseling, even though both are necessary for effective treatment.

Inadequate Reimbursements and Funding for Children's Mental Health Services- As stated earlier, many children are unable to access important services because of providers' refusal to accept public insurance. Medicaid reimbursement rates for treatment are unrealistically low and do not cover the costs related to services. In many cases, Medicaid-only or "straight Medicaid" reimbursement can pay a third of a typically 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 affects the quality of services provided to children. Budget cuts at the state and federal levels have affected services in our local community. In schools, the number teacher's aids available in classrooms have dramatically decreased. Teacher's aids often provide classroom support to children with behavioral and emotional needs.

SHORTAGE OF QUALITY SERVICES

Interviewees identified major shortages in key service areas. There are shortages in the workforce, in the types of services (ranging from prevention to treatment) available, as well as in programs that provide high quality, client-focused services. The identified gaps to promoting and improving the mental health of children in our community include:

Workforce Shortages

Psychiatry – There is a major community shortage of outpatient psychiatry services for children and adolescents. Many interviewees could only think of four to five child psychiatrists in the area. Many interviewees also noted that non-traditional modes for delivering psychiatric services were not utilized in the community. Primary care physicians and nurses specializing in psychiatry are underutilized.

Shortages of child and adolescent psychiatrists are prevalent throughout the country. Part of the reason is because it is not as desirable as other medical fields. One interviewee stated, "All of the glamour in medical school is in surgery, etc… not child psychiatry." In

addition, specializing in child psychiatry requires additional training. 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 fatigue factor.”

Culturally Competent Providers- In addition, it has been hard for our community to attract culturally-sensitive providers.[1] 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.”

Shortages in Types of Services

Prevention and Early Identification– Overall, there are limited children’s mental health prevention and early identification services in Racine. Prevention can range from promoting healthy socio-emotional development in young children, to teaching school-age children healthy coping skills and behaviors. In addition, many children have mental health issues that are not caught early, and are manifested in unhealthy ways. Interviewees stated a need for more preventative programs, health promotion, and early identification supports in our community.

[1] Note: For many reasons, clinics, schools, and other providers have a hard time attracting trained providers to Racine, let alone those that are fully licensed. Organizations struggle to attract providers due to: 1) the proximity of universities and schools where professionals are trained and 2) the size and location of our community. There are a limited number of training programs nearby. Students or residents often develop ties to the community where they receive their training, making them less likely to relocate. Also, there are fewer opportunities for professionals in training to connect to local organizations through internships or residency. In terms of psychiatry, the Wisconsin medical schools are located in Milwaukee and Madison. “The closest specialty program for [psychiatric nursing] is at Rush (in Illinois). Finally, it is hard to attract providers to Racine, in general. One interviewee said, “It's hard to compete from the city of Racine. [Providers] have many options. Big cities are more attractive.”

Community Education – Families and stakeholders are not adequately educated about: consumer rights, provider responsibilities and changes to statutes/laws. Privacy statutes are very confusing for parents and providers. In terms of school information, 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 (or limited understanding of laws) hinder communication between providers, impacting the quality of services delivered to children. "Collaboration is difficult because of laws." One interviewee noted, "doctors often prescribe quickly, not contacting schools because or releases of information." Recent and consistent changes to BadgerCare, without adequate education around the changes, also confuse families and providers.

Psychotherapy – There is a need for 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– Comprehensive and quality psychological evaluation services were identified as a service gap in Racine. In order to gain an understanding of each child's unique issues and needs, intelligence testing, neuropsychological testing and other types of testing is often needed. This information helps providers know more about the diagnoses.

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

Mobile Crisis– Although Racine County does offer mobile crises services, interviewees noted that a youth-focused approach needs further development.

Advocacy – Although there are some state and local mental health advocacy groups with a presence locally, the current groups have not adequately addressed some of the key challenges facing children with mental health needs. One parent explained, "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 parent 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. [I had] no [help]."

One interviewee noted, "Children with Title 19 insurance have little or no voice." Another noted, "Organizations don't take on a lot of advocacy roles because they receive funding from [organizations that they may be challenging] and they don't want to jeopardize that [relationship.]"

Peer Support– Peer support services are lacking for families and children with mental health needs. Although there may have been in the past, there are currently no regularly functioning peer support groups for parents of children with mental health needs. One interviewee noted, "support groups are needed for parents of 'troubled teens." There is, currently, a support group for children of sexual violence, but it only meets once a year and is targeted to 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 child mental health system players 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 other school staff have limited knowledge of community resources available to students who need additional support or intervention. One interviewee stated, "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 an 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 specialized areas including: infant mental health and trauma-informed care.

Language/Cultural Responsiveness – There is a huge deficit in Spanish–speaking and culturally competent clinicians. Because of the lack of Spanish-speaking psychiatrists and child therapists in Racine, many children serve as translators between their service provider and parents. This is problematic as the children are often unable to serve as reliable translators of medical terminology. Until recently, there were no Spanish speaking psychiatrists in Racine. Now there is one. There are one or two Spanish speaking therapists in the community, but not enough to meet the demand. Some of the interviewees also noted a deficit in culturally-appropriate providers.

CONCLUSIONS: MOVING FORWARD

All of the children in our community have mental health needs, some needing more intervention than others. In fact, children in Racine need intervention now, more than ever. Multiple interviewees noted a recent change in mental health needs of children in Racine, in terms of severity and age. One interviewee said that there are "much younger children with much higher needs." Another interview noted that “more kids at younger ages (than normal) have issues." Another said, “We've seen a lot higher acuity -- violent behaviors; children not having a lot of coping strategies”

In order to avoid the consequences associated with unaddressed mental health problems, it is important that the Racine community address issues early and effectively. In order to provide quality services and meet the mental health needs of children in our community, the identified service gaps, barriers, and challenges must be addressed.

Based on the common themes and issues identified throughout the stakeholder interviews, it is clear that improvements are needed in the children’s mental health service continuum in Racine. Children, their families, providers, and communities face many, complex challenges as they try to reduce mental health problems and improve the mental health of all Racine County children. Although many issues and concerns were identified, it is possible not all of the issues were captured through the interviews.

It is our hope that this summary be used as a resource and as a starting point for future discussions focused on improving the current children's mental health system in Racine. Identifying the key issues and increasing understanding of them, will hopefully lay the foundation for identifying and implementing appropriate solutions.

References

[i] U.S. Department of Health and Human Services. *Mental Health: A Report of the Surgeon General*. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health, 1999.

[ii] Katoaka, S.H., Zhang, L., & Wells, K.B. (2002) Unmet need for mental health care among U.S. children; Variation by ethnicity and insurance status. American Journal of Psychiatry, 159, 1548-1555.

[iii] Wagner, M. (2005). Youth with disabilities leaving secondary school. *Changes Over Time in the Early Post School Outcomes of Youth with Disabilities: A Report of Findings from the National Longitudinal Transition Study (NTLS) and the National Longitudinal Transition Study-2 (NTLS2)* 2.1–2.6. Menlo Park, CA: SRI International.

[iv] Skowyra, K. R. & Cocozza, J. J. (2006). *Blueprint for change: A comprehensive model for the identification and treatment of youth with mental health needs in contact with the juvenile justice system.*. Delmar, NY: The National Center for Mental Health and Juvenile Justice (NCMHJJ) and Policy Research Associates, Inc.

[v] New Freedom Commission on Mental Health. (2003). Achieving the promise.

[vi] Shaffer, D., Fisher, P., Dulcan, M.K., Davies, M., Piacentini, J., Schwab-Stone, M.E., Lahey, B.B., Bourdon, L, Jensen, P.S., Bird, H.R., Canino, G., & Regier, D. A. (1996a). The NIMH Diagnostic Interview Schedule for Children Version 2.3 (DISC-2.3): Description, acceptability, prevalence rates, and performance in the MECA Study. Methods for the epidemiology of Child and Adolescent Mental Disorders Study. *Journal of the American Academy of Child and Adolescent Psychiatry, 35*, 865-877.

[vii] Lavigne JV, Gibbons RD, Chirstofeel KK, et al (1996). *Prevalence Rates and Correlates of Psychiatric Disorder among Preschool Children*. J Am Acad Child Adolesc Psychiatry, 35:2, 204-214.

[viii] Katoaka, et al. (2002). *Am J Psych*

[ix] Center for Mental Health Services Reporting System (2009) U.S. Department of Health and Human Services (as cited in, Wisconsin Family Ties [2011] Data show children's mental health is being neglected in Wisconsin.)

[x] Wisconsin Council on Mental Health. (2011). Wisconsin's Community Health Block Grant Plan for Adults and Children FFYi 2012-13: Draft: Estimate of Prevalence.

[xi] Wisconsin Interactive Statistics on Health (WISH).

[xii] 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