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Integrating Public Health, Mental Health, and Special Education Perspectives to Address the Mental Health Needs of CYSHCN

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Children and youth with special health care needs (CYSHCN) include a broad, diverse population needing a vast array of services. In addition to private sector service providers, multiple public agencies share responsibility for identifying and meeting the needs of this population, including public health, mental health (within the Department of Human Services in Minnesota), and special education.

The 1998 Maternal and Child Health Bureau (MCHB) definition of this population¹ (see box) is the broadest and most inclusive definition in that all children receiving special education and all children with mental disorders are included in the group of CYSHCN. However, not all CYSHCN receive or need special education services, nor do all children with mental disorders receive special education services. However, all CYSHCN, regardless of the nature of their condition, either have or are at increased risk for, mental health problems.² (See article by Patterson on risk and protective factors.) The focus of this article is the mental health needs of CYSHCN,

Children and youth with special health care needs (CYSHCN) have a chronic physical, developmental, behavioral, or emotional condition that requires health and related services of a type or amount beyond that required by children generally.

Maternal and Child Health Bureau definition¹

and specifically, the complexity and the promise of bringing together the approaches of public health, special education, and mental health in identifying and meeting children's mental health needs.

The Public Health Perspective

The mission of public health is to "fulfill society's interest in assuring conditions in which people can be healthy." Its mission is achieved, in part, through monitoring the health status of a population in order to identify health problems. In 2001, MCHB and the National Center for Health Statistics conducted the first national survey of

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Historically, the Maternal and Child Health Bureau focused their attention primarily on children with physical disabilities, as reflected in earlier names for the Title V programs — "Crippled Children's Services" and later, "Services for Children with Handicaps." Today, the CYSHCN population includes children and youth with disabilities of all kinds, some of whom are also eligible for special education services when their learning is affected by the disability. It also includes children with chronic illnesses who may have no disability or special education needs. Finally, it includes children whose primary diagnosis is a mental disorder, such as a severe emotional disorder.

The focus of this issue of *Healthy Generations* is the mental health needs of all children and youth meeting the MCHB definition. In the lead article, Edwall, Shevlin-Woodcock and Thorson provide an integration of public health, mental health, and special education perspectives about defining and meeting the needs of this population. Patterson focuses on risk and protective factors, with a particular emphasis on how we might understand the meaning of co-morbidity and secondary conditions for this population. Wright and Garwick emphasize a program targeting the mental health needs of Head Start children, and Quesnell describes an innovative effort in St. Cloud, Minnesota to better address the mental health needs of children in the schools. Finally, Hurley and Leonard describe a policy initiative in Minnesota, the Individual Interagency Intervention Plan, designed to integrate the service needs of children with disabilities.

We thank our authors for sharing their insights about the growing, and often under recognized mental health needs of CYSHCN.

Joän Patterson, Barbara Leonard, Ann Garwick, Co-Editors

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CYSHCN, based on the 1998 MCHB definition, to estimate the size of this population. Nationally, 12.8% of the U.S. population under the age of 18 years (an estimated 9,360,356 children) has a special health care need that has lasted or is expected to last at least 12 months.³ (The estimated percentage in Minnesota is 12.4%.) Of this group, 28.7% have a condition that is emotional, developmental, or behavioral in nature. Furthermore, of all CYSHCN who were 3 years and older, 28% nationally and 31% in Minnesota were receiving special education services. [This may be an underestimate, however, because it is based on parent report and question wording may have contributed to underreporting.⁴] Of all the CYSHCN identified in the survey who were receiving special education services, 48% nationally and 58% in Minnesota had an emotional, developmental, or behavioral condition. Stated in another way, 54% of CYSHCN receiving special education services in Minnesota were reported to *need* mental health care by their parents; this is in contrast to CYSHCN who were *not* in special education where only 19% needed mental health care.³

In addition to the 2001 survey just described, several other national population-based surveys demonstrate the mental health needs of CYSHCN very clearly:

- 35% of children and adolescents with disabilities ages 4 to 17 were reported to be unhappy, sad or depressed.⁵
- Only 40% of CYSHCN with disabilities with poor psychosocial adjustment had received mental health treatment.²
- While 1–3% of adolescents in the general population are diagnosed with depression, 15% of adolescents with asthma and 25% of adolescents with inflammatory bowel disease have this diagnosis.⁶

In the 2001 Minnesota Student Survey of 6th, 9th and 12th graders, more than 20% of youth identified as having a special health need reported a history of suicide attempts; and depending on age and gender, 1/3 to 2/3 of students with special needs reported having thought about committing suicide.⁷

Both state and national studies note that CYSHCN status does not necessarily mean that mental health needs are identified or treated. Physicians, regardless of specialty, rarely discuss behavioral health issues with children or adolescents with chronic illnesses.

The Mental Health Perspective

Beginning in the mid-1980s, Minnesota, like most states, began to operationalize a national vision for systems of care for children with mental health needs. This vision, defined by the Child and Adolescent Service System Principles (CASSP),⁸ grew from the dual awareness that children with mental health needs often received services from multiple, uncoordinated systems and also that children in all service systems had mental health needs—whether

or not those needs were identified and treated. “Systems of care” presumably brought all child-serving systems, including public health, health care, social services, education, and corrections, to a common table to jointly plan ways to meet the needs of children and their families at all levels—from individual care plans to systems transformation.

In Minnesota, the public system for meeting children’s mental health needs was established by the 1989 Children’s Mental Health Act, followed in the early 1990s by enabling legislation for Children’s Mental Health Collaboratives and broader-based Family Service Collaboratives. Recently, there were a series of changes in Minnesota Health Care Programs (publicly subsidized health care assistance programs for low-income individuals), and now most of the mandated services of the Children’s Mental Health Act are part of Minnesota’s Medicaid state plan. Case management for children and adolescents with serious emotional disturbances (SED) continues to be a county responsibility.

The children’s mental health service system in Minnesota has grown dramatically in both the public and private arenas in the past 20 years. Nevertheless, it is clear that there continue to be unmet needs, service disparities, and fragmentation in the coordination of specialty mental health services within both health care and education. In 2002, the Minnesota Department of Human Services

convened a task force that created a blueprint for addressing these issues; in particular, it called for:

- Early identification of mental health problems and early, effective intervention;
- Increasing access to services—from primary care to crisis services and inpatient psychiatric hospital beds; and
- Development of quality standards, monitoring processes, and introduction of evidence-based practices into children’s mental health care.

Developing strategies to implement the changes required the

creation of new public-private partnerships. At present, this effort is being advanced by the Minnesota Mental Health Action Group (MMHAG), an initiative launched by the Minnesota Department of Human Services and all of Minnesota’s major health plans and facilitated by the Citizens League.

Although the needs of CYSHCN have not been an historical focus of the children’s mental health system, MMHAG is calling attention to the co-occurrence of mental and physical disorders; the need for coordinated care; the need to work more closely with pediatrics, primary care and public health nursing to address mental health issues; the opportunities created by the medical home movement for better connections between primary care and community resources; and the care enhancement created by co-location and other models of integrated care. It is truly an opportune time to foster rapprochement among public health, specialty mental health care, and primary care.



The Special Education Perspective

In Minnesota, 11.4% of students, ages 5 to 18, are receiving special education and related services.⁹ All of the children receiving special education, by the MCHB definition, are children with special health care needs, and some of the students in special education have diagnosed mental disorders.

The special education, public health and mental health systems concur that children who have physical problems, intellectual disabilities, low birth weight, a family history of mental and addictive disorders, multi-generational poverty, caregiver separation, abuse or neglect are at greater risk for experiencing mental health problems than those without such conditions.

The results of a 2003 study found that children 6–17 years with disabilities are at increased risk for poor psychosocial adjustment and have an elevated need for mental health services. The odds of receiving mental health or counseling if a child also received special education services was four times greater for those with poor psychosocial adjustment compared to those with good adjustment. Older age, male gender, and public insurance also increased the odds of receiving mental health services for those in special education, and race/ethnicity was not a barrier to receiving mental health or counseling. Most importantly, the likelihood of mental health service use was twice as likely if the child's care was coordinated by a health professional and 2.5 times as likely when coordinated by a health professional *and* the child's family.²

In an effort to bring the public systems that serve children with disabilities together, the Minnesota legislature passed The Minnesota System of Interagency Coordination Act (MnSIC) (Minn. Stat. §125A.023 and Minn. Stat. §125A.027) in 1998.¹⁰ This Act requires that county boards and school boards develop and implement a coordinated, multidisciplinary, interagency service system for children and youth with disabilities, ages birth through 21. In Minnesota, this includes the Departments of Education, Human Services, Corrections, Human Rights, Employment and Economic Development (Rehabilitation Services and State Services for the Blind), Commerce, and Public Health. This legislation requires that interagency agreements be developed to ensure that services and programs required by state and federal law are coordinated to meet the needs of eligible children and youth and their families, identify barriers to coordinated services, and reduce service fragmentation.

The Mental Health Leadership in Special Education Committee, developed under the auspices of the Minnesota Department of Education, Special Education Policy Section, recommended the development of a process for interagency teaming and coordination to enable access to school and community mental health services as needed for children and youth with disabilities, ages birth to 21.¹¹ This effort dovetails with the interagency process for coordinating services in the document called the Individualized Interagency Intervention Plan (IIIP), which is described in this issue by Hurley and Leonard. The State Interagency Committee attached to that process is currently undertaking a closer look at the coordination of services for children with mental health needs.

A Framework for Integration

What is needed at this point is not a singular model—arguably what the system of care has become—but a defined process that can help us determine whether we are making progress toward a coherent and functional system for children with multiple needs and

their families. The Substance Abuse and Mental Health Services Administration (SAMHSA) of the federal Department of Health and Human Services has suggested a model for bringing a public health approach to mental health service delivery that appears adaptable to this process. The process involves these steps:

- Profile population needs, resources, and readiness to address problems and gaps in services;
- Develop a comprehensive strategic plan;
- Mobilize and/or build capacity to address needs;
- Implement evidence-based, resilience-building prevention and intervention programs;
- Monitor process, evaluate effectiveness, sustain effective approaches and programs, and improve or replace those that fail.

Attention should be given to two remarkable local initiatives described later in this newsletter, one in a Head Start community program and the other a Safe Schools/Healthy Students project. These are projects in which integration has taken hold, with tremendous synergistic effects for the participating systems and the children and families they serve.

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Risk and Protective Factors for Mental Health Problems among CYSHCN

Joän M. Patterson, PhD, LP

Epidemiologic data reveal that CYSHCN are at a two-fold or greater increased risk for experiencing mental health problems.¹⁻⁴ Having “mental health problems” does not always constitute a full-blown mental disorder as defined by clinical criteria. More often, the evidence is based on increased symptoms of disorder. This increased risk is usually attributed to the added stress experienced by youth with chronic conditions and by their families. Furthermore, many stages of the life course are affected, since most of these health conditions continue for lengthy periods, often indefinitely. This added time factor also increases the risk.

Generally, the onset of a mental health problem in the context of adapting to a physical health condition is considered a *secondary* condition (with the physical health condition being viewed as primary). Under these circumstances, knowledge of risk and protective factors can inform intervention programs to prevent mental health problems in this population. However, when the special health care need is primarily an emotional or behavioral disorder, then the mental health condition would be considered the primary condition, although another mental health problem may emerge secondary to the primary diagnosis. Here too, risk and protective factors are relevant to intervention strategies, which may slow the progression of the condition and minimize disability and adverse effects on a child’s overall development. It is also possible that a mental health condition can emerge independently and not as secondary to having a physical disorder. In all of these scenarios, the presence of two or more conditions concurrently implies *co-existing* or *co-occurring* conditions and is referred to as *comorbidity*.

CYSHCN experience the same risks and protective factors that affect developmental outcomes for all children. However, having a special health need heightens a child’s vulnerability to these other risks—creating a kind of synergistic effect. Risk and protective factors related to the mental health of children in general were reviewed in the January 2002 issue of *Healthy Generations*;⁵ they are summarized in the sidebar on the next page.

Electronic Guide Available on Mental Health in Children and Adolescents

An electronic guide on recent, high-quality resources for staying abreast of new developments in child and adolescent mental health and for conducting further research has been produced by the MCH Library. This knowledge path addresses the goals outlined in the Report of the Surgeon General’s Conference on Children’s Mental Health: A National Action Agenda, and taps into the health, education, social services, and juvenile justice literature. The knowledge path includes information on (and links to) websites and electronic publications, journal articles, databases, and electronic newsletters. It is intended for use by health professionals, program administrators, policymakers, educators, and families who are interested in tracking timely information on this topic. The knowledge path is available at http://www.mchlibrary.info/KnowledgePaths/kp_mentalhealth.html

Additional Risk Factors for CYSHCN

There are some risks that are specifically related to having a special health need. Contrary to expectations, severity of the condition has not been shown to affect psychological adjustment.⁶ However, there are other characteristics of chronic conditions that do vary in their impact on a child’s risk for psychological maladjustment:

➤ **Activity or functional limitations** intrinsic to some chronic conditions can increase the risk for mental health problems.⁷ National surveys show that children and youth who are limited in their ability to perform activities normally expected at a given age (such as mobility, self-care, communication, learning) experience more emotional problems than children with chronic illnesses only.^{1,2}

➤ **Type of physical impairment** may increase the risk for mental health problems. There is some evidence that youth with sensory or neurologic impairments⁴ or intellectual disabilities⁸ have more emotional problems than youth with other chronic conditions.

➤ **Uncertainty** is a characteristic of many chronic conditions, which may increase the risk of mental health problems because it creates added distress. Uncertainty may be related to life expectancy, course of the condition, symptom unpredictability, and even invisibility of the condition. Invisible conditions contribute to uncertainty in terms of whether to disclose its presence and because of others’ misattributions about a child’s inability to do or accomplish certain activities.⁹

➤ **Painful medical procedures and recurrent hospitalizations** may have a traumatic and long-lasting impact on psychological functioning leading to post-traumatic stress disorder, anxiety, and compromised functioning.¹⁰

➤ **Interference with normative life tasks** is likely to occur because of limitations in full participation, fear of parents/caregivers about consequences of participation in normative activities, illness exacerbations leading to school absences, malaise, etc.

➤ **Social stigma and isolation** are general risk factors for emotional problems, which are experienced more often by youth with disabilities. Despite Americans with Disabilities Act guarantees of access and accommodations in public settings, subtle and not-so-subtle barriers remain to full inclusion. The Individuals with Disabilities Education Act requires that children with disabilities be educated in regular classrooms to the greatest extent possible while receiving needed supports. However in practice, there is considerable variability in the degree and spirit of inclusion provided by schools. CYSHCN are more likely to be teased and bullied by their peers.¹¹ In the 2001 Minnesota Student Survey of 6th, 9th, and 12th graders, twice as many students with special needs reported chronic truancy compared to their healthy peers, and 12.3% skipped because they felt unsafe compared to 5.5% of their healthy peers who felt unsafe.¹²

➤ **Maltreatment** is 3.4 times more likely among children with disabilities compared to healthy children.¹³ The perpetrator is more likely to be a family member or someone known to the child.



chronic condition, and advocates effectively for their child in both formal and informal settings, there is less likelihood that the child will experience mental health problems due to the chronic physical condition.

Cumulative Risk and Cascade Effects

In general, exposure to a single risk factor, even a chronic health condition, may not result in more emotional or behavioral problems,

particularly if a child has a well functioning family and has access to good health and education services. However, children with chronic conditions who live in families with limited economic or social resources and who experience multiple stressors are expectably more at risk. Families lacking adequate income or health insurance, living where schools are poor quality, facing unstable employment, experiencing substandard housing and/or residential mobility will have a harder time managing their child's chronic condition. In turn, their child is more likely to experience mental health problems. Frequently, the dynamic nature of adapting to a chronic health condition is associated with one risk leading to new risks, which can beget more risks, resulting in a cascade of risks.¹⁹

Conversely, families who have some critical resources at the outset are more likely to be able to acquire additional resources, and their children are more likely to experience success. Success begets success and can lead to a cascade of protective factors.

A cascade of risks or conversely, protective factors, is associated with a continuous developmental trajectory. The goal is to set in motion a positive developmental trajectory where protective factors are present and grow and where risk factors are minimal or eliminated. This is the fundamental way that mental health problems as secondary conditions in CYSHCN can be prevented.

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This higher prevalence may be related to the child's long-term dependency needs, inability to communicate preferences, challenging behavior, and poor social skills, as well as to caregiver exhaustion, emotional stress, lack of respite, lack of knowledge about the child's condition and unrealistic expectations.

➤ **Poor parent and family adaptation to the chronic condition** can be viewed as a risk factor for children's mental health problems, particularly when there are family financial problems,^{3,7,14} parental conflict, single parent status,¹⁴ parent exhaustion, or depression.^{7,15} In other words, when general risk factors are present (see sidebar), both the child and parent(s) have an increased risk for psychological problems. When parents' health is compromised, the child with special needs is less likely to get the physical and emotional nurturance needed and may even feel responsible for family problems.

Protective Factors & Resilience

Even though there is a greater risk for mental health problems among CYSHCN, it remains that the *majority* of these children adapt and do well. Paradoxically, some may function even better than their peers without chronic conditions.¹⁶ This has been attributed to the inoculation effect where exposure to a stressor can actually strengthen a person.¹⁷ The latter is more likely when there are sufficient resources in the family and community to meet the child's special needs—resources such as high-quality, accessible health care services, good schools and special education services, adequate private insurance and publicly funded programs, and an accepting, supportive community.¹⁸ Furthermore, when a child's family becomes more cohesive from facing the challenge together, develops a perspective about life that *accepts* the presence of the

Risk and Protective Factors Related to Children's Mental Health⁵

Individual Risk Factors

- Genetic inheritance
- Exposure to injury, infection, toxicants, nutritional deficiencies (in-utero or after)
- Difficult temperament

Family Risk Factors

- Parental depression/psychopathology
- Parental substance abuse
- Unresolved family conflict or domestic violence
- Physical or sexual abuse
- Psychological maltreatment
- Parental criticism and contempt
- Prolonged family stress due to death, divorce, extreme economic hardship etc.
- Chronic poverty

Community Risk Factors

- Living in neighborhoods characterized by
 - Concentrated poverty
 - Violence
 - Social disorder
 - Gangs
 - High residential mobility
- Sustained fear of crime
- Social isolation
- Discrimination and racism
- Aggressive, anti-social peer groups
- Peer bullying, teasing, harassment
- Poor quality schools

Individual Protective Factors

- Outgoing temperament
- Social skills
- Self efficacy
- Innate intelligence

Family Protective Factors

- Stable two-parent family structure
- Positive extended family connections
- High quality parent-child relationships
- Family closeness, warmth, trust, open communication
- Authoritative parenting

Community Protective Factors

- Competent, achievement-oriented peers
- Social capital—neighborhood cohesion and collective efficacy
- Support from adults in school & community
- Age-relevant resources (childcare, libraries, parks, recreation)
- High quality health care
- Good schools

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Seamless Mental Health Services in a School Setting

Michael Quesnell, PhD

Your 12-year-old is struggling. As you watch him fade inward, you think back to earlier days when his school-work and friends all came so much easier. His spontaneous laugh was contagious. He was easy to be with, curious about life, and had plans for the future. His shallow eyes now seem lost as he drifts in and out of an awareness of life around him. His sense of emptiness creates a heavy ache in your own chest as you try to understand and help your son.

This difficult scenario unfortunately is played out every day in schools in our communities. Howard Adelman and Linda Taylor, from UCLA's School Mental Health Project, believe that most school-based services, where they exist, are focused on the most severe problems and responding to crisis.¹ They acknowledge that early intervention, soon after the onset of symptoms, is rare; prevention often remains an unfulfilled dream. In St. Cloud, Minnesota, a new collaborative has been formed to address these challenges. The St. Cloud Area Schools, together with Safe Schools/Healthy Students, and the St. Cloud Hospital are pioneering an innovative partnership to specifically address the issue of seamless mental health services in the public school setting.

The idea for a Mobile Wellness Center (MWC) started with a grassroots effort of parents, school staff, and mental health

providers who were concerned about the barriers to receiving mental health care for children. These barriers included:

- lack of insurance coverage for mental health care;
- long waiting lists to see providers; and
- the need for improved understanding of mental health conditions among family members, school staff, and the community.

This grassroots effort led to the vision of a MWC—a partnership between families, schools, and mental health providers. One purpose of the MWC is to increase public awareness of the mental health needs of young people.

Mental health disorders in children are more widespread than many adults believe. The Department of Health and Human Services indicates that 1 in 5 children and adolescents may have a diagnosable disorder;² yet 70% to 80% receive little or no help.³ We now know that some long-term, untreated mental health disorders actually lead to changes in the brain,⁴ which increases the likelihood of life long mental health problems. Early intervention is essential.

Mental health problems contribute to educational failure. Among children with serious emotional disturbances, half drop out of high school compared to 30% of all students with disabilities.⁵ These mental health problems can stem from restricted opportunities associated with poverty, difficult and diverse family circumstances, lack of English language skills, violent neighborhoods, and inadequate health care.

The MWC is a traveling clinic, built on an Airstream chassis. The interdisciplinary team consists of a public health nurse, social worker, psychologist and psychiatrist. The MWC provides mental health screening, assessment, and referrals for students at all schools in the St. Cloud School District and in private schools. The purpose of the MWC is to provide children access to caregivers for early, appropriate treatment, and services. Two unique aspects of the MWC are its multidisciplinary team and access to comprehensive assessment. Assets of the MWC include:

- Parents can access timely consultation for their children through the MWC.
- Students will not have to miss as much school for their appointments, since the service comes to them. In addition, it is easier for school staff and care providers to work together.
- Parents, whether or not they have insurance, will not have to pay for the comprehensive assessment provided through the MWC.
- Consulting psychiatrists and psychologists can assess and initiate a treatment plan working together with school social workers and nurses.
- School staff can access education and consultation so that they can help children with mental health problems succeed in school.

Teachers are in a pivotal place to identify and help children who may be experiencing mental health problems. Teachers are not mental health professionals, but they can recognize signs and symptoms in their students, know how to access help for them, and know how to support their needs in the classroom. They also can initiate adaptations and different classroom strategies to help students be successful.

The Minnesota state legislature, recognizing the importance of teachers taking the responsibility to learn more about children's mental health, passed a bill in 2002 requiring that teachers obtain education in the signs and symptoms of early onset mental health conditions.

Evaluation

The Wellness team provides comprehensive, multidisciplinary assessments as well as professional development to school and community staff and family life educators. In its first six months of operation, the MWC staff held 80 education events, which were attended by 1,030 school staff and community members. Evaluations indicated high satisfaction with the services and increased understanding of mental health problems and the importance of early intervention.

In the first six months, the MWC saw 387 students, with 161 receiving a comprehensive mental health assessment. Waiting time for services has decreased. With a sample of 65 students, waiting time from triage to first

appointment was 17 days, compared to previous waiting times of 56 to 70 days. MWC staff made 322 referrals to school and community resources. Based on parent interviews, approximately 67% of referred services were used.

In focus groups with teachers and staff, those who have referred students reported excellent services by the staff, and marked improvement in the children as a result of the MWC's services and follow-up referrals and supports. In a focus group with parents whose children have received assessment and services, all participants expressed relief at accessing high-quality, thorough

mental health assessment services for their child conveniently and quickly when compared to past experiences. Parents found staff to be professional, empathetic, supportive and skilled. Parents believe the MWC—with so many resources in one place—has improved early access and mental health care for children in the community.

Beyond improved access to mental health services, the MWC seeks to increase the mental health capabilities of its clients, while creating a lasting change in how this community views the importance of mental health for youth and families. For parents and their children, a new pathway toward health is now available.

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Early Childhood Mental Health Initiatives within Minnesota Head Start

Catherine Wright, MS
Ann W. Garwick, RN, PhD, LP



In May 2004, the Minnesota Head Start Association, the Children’s Mental Health Partnership, the Minnesota Department of Education, and the Children’s Mental Health Division of the Minnesota Department of Human Services conducted a statewide event entitled “Strengthening Mental Health Services for Head Start Children and Families.” A

broad range of stakeholders informed the development of a Mental Health Action Plan for Minnesota Head Start. The proposed plan challenges all Minnesota Head Start agencies to define and enhance their activities around mental health prevention and early intervention for low-income families with children birth to 5 years. The plan also calls for Head Start, in partnership with state agencies and other existing groups, to challenge the mental health system to respond to the needs of Minnesota’s youngest children. The comprehensive plan addresses screening and referral, program design, and training and support related to early childhood mental health for all Minnesota Head Start agencies. The following description of early childhood mental health initiatives sponsored by the Ramsey Action Program (RAP), Inc. Head Start illustrates how one Head Start agency is implementing this plan in collaboration with community partners.

For four years, RAP Head Start, which serves 1500 children in Ramsey County, has focused on early childhood mental health. An estimated 1000 children under the age of 5 living in Ramsey County experience significant mental health problems, but do not receive any treatment. The need for mental health services is also illustrated by the fact that over 50 children per year are expelled from their childcare placements in Ramsey County because of behavioral and mental health concerns. In a

Ramsey County survey initiated by the local Interagency Early Intervention Committee and the Children’s Mental Health Collaborative in 2000, parents identified early childhood special education and child protection services as the leading mental health services in Ramsey County. These findings were quite concerning as neither service was designed to fully treat a child’s mental health problems. In response, RAP Head Start created a comprehensive early childhood mental health system of care in partnership with local foundations, government agencies, parents, school districts, mental health professionals, health care professionals, the University of Minnesota, and early childhood professionals.

This coalition of community partners, known as the Ramsey County Early Childhood Mental Health Committee, works together to develop and offer the following services:

➤ **RAP Head Start preschool day treatment program.** This classroom-based program serves preschoolers who have a mental health diagnosis and who have difficulty functioning at home or in the community. Many of the children enrolled in the RAP Head Start day treatment program have been previously expelled from numerous childcare programs because of their behavior and mental health issues.

➤ **Mental health screening for children birth to 5 years in Ramsey County.** A standardized mental health screening tool will be used to annually screen 10,000 children under the age of 5 years in Ramsey County. A coalition of community partners, including RAP Head Start, school districts and medical clinics have agreed to use the same tool so that comprehensive screening can be done. The tool will be available in English, Spanish, Hmong and Somali.

➤ **Child therapeutic support services.** RAP Head Start works with the Minnesota and Ramsey County Departments of Human Services to become a certified provider of Child Therapeutic Support Services. This service would enable the RAP Head Start program to provide individual, group, and family skill training for Head Start children who are experiencing mental health issues—a critical need in Ramsey County, which has very few early childhood mental health providers available.

➤ **Infant-toddler mental health based home visiting services.** RAP Head Start works with a local non-profit agency to provide infant-toddler mental health-based home visiting services. These services focus on attachment-based relationships between the infant/toddler and his or her parents.

➤ **Training, consultation and mental health services for childcare centers.** The coalition is working with two non-profits to provide training for Ramsey County Early Childhood programs around a best-practice mental health curriculum and to provide childcare center-based consultation as well as on-site mental health services to pre-school children in local childcare centers. These services are designed to

increase the skills and training of the community’s childcare staff, while providing needed services to children with mental health issues in their childcare center. The on-site services are designed to prevent young children from being expelled from their childcare centers.

➤ **Coordinating funding streams to support comprehensive mental health services.** RAP Head Start works with community partners, foundations, and the government to sustain these initiatives through billing insurance and combining various funding sources to more effectively serve children birth to 5 years with mental health problems.



Interested in making a difference?

Consider a Master's in Public Health (MPH) Degree in Maternal and Child Health (MCH)



Debra Waldron, MD, is a student in the accelerated, one-year MCH program. She combines an active pediatric practice at the Indian Health Board of Minneapolis with her course work at the School of Public Health.

"I chose to pursue a MPH at the University of Minnesota to acquire the knowledge and skills to administer programs and to develop policies that will promote and preserve the health of Native American youth and their families,"

said Debra. "The course in Foundations of Maternal Child Health Leadership especially provided insight into these issues."

Debra has an interest in ensuring that all pediatric patients have a "medical home" that incorporates the American Academy of Pediatrics' definition that child health care should be "accessible, continuous, comprehensive, family centered, coordinated, compassionate, culturally effective and delivered or directed by well-trained physicians who provide primary care and help to manage and facilitate all aspects of pediatric care." She is currently using information learned in her course work to plan a community-based initiative for a medical home model that fits the Native American community.

For her field experience, she is working with the staff of Minnesota Children with Special Health Needs at the MN Department of Health on a project to assess the feasibility of integrating mental health screening for CYSHCN in the medical home setting. "Our field experience provides an opportunity to become involved with public health agencies, to observe and to participate in their activities," Debra reports. "We network not only with our fellow students and professors, but also with our mentors and professionals in public health practice."

Community-based, comprehensive mental health training and services will provide needed access to care that young children with mental health issues require and support the children's parents by eliminating barriers to care and decreasing the stigma around children's mental health problems. Furthermore, the services described above will provide children with tools they need to become ready for school by kindergarten. The Ramsey County Early Childhood Mental Health Initiatives underscore how much can be accomplished when a community comes together to support a cause such as early childhood mental health.

Catherine Wright, MS, is the Special Services Coordinator for Ramsey Action Programs, Inc. Head Start in St. Paul, Minnesota. She has a masters' degree in counseling psychology and has extensive experience managing, coordinating, and providing prevention, early intervention and therapeutic intervention services to young children and families.

Ann Garwick, PhD, is the Director of the Center for Child and Family Health Promotion Research and is an Associate Professor in the School of Nursing at the University of Minnesota. Ann serves on the RAP Head Start Health, Special Education and Mental Health Advisory Committee.

What is the Maternal and Child Health Program? It is a training program for MPH students who are interested in promoting and preserving the health of families, including women, children, and adolescents, including those with special health care needs. The Program is in the Division of Epidemiology and Community Health in the School of Public Health at the University of Minnesota.

Who are the faculty? The MCH faculty is multidisciplinary with expertise in epidemiology, medicine, nursing, psychology, sociology, nutrition, family studies, health education, and program administration. MCH faculty focus their research, teaching, and community service on children with chronic health conditions; reproductive health and family planning; pregnancy outcomes; social inequities in health; women's health; infectious diseases; substance use; and child, adolescent, family, and community health promotion, risk reduction, and resiliency.

Who should apply? People who care about vulnerable populations and want careers in program planning and development, evaluation, surveillance, assessment, teaching, or research. The program offers a special emphasis on MCH epidemiology for interested students. Clinical professionals, and others with advanced degrees who are interested in administering MCH-related health programs or conducting research projects are also encouraged to apply. Individuals with advanced degrees may have the option of completing the two-year MPH Program in one year.

For further information about the MCH Program, call 612-626-8802 or 1-800-774-8636; e-mail gradstudies@epi.umn.edu; or visit www.epi.umn.edu/mch/academic/ or www.sph.umn.edu



The Minnesota Individual Interagency Intervention Plan (IIIP)

John Hurley, MHA
Barbara Leonard, RN, PhD, FAAN

As a result of advocacy by families of children with disabilities, the 1998 Minnesota legislature passed the Interagency Services for Children with Disabilities Act. This legislation expanded the federally mandated birth to 3 coordinated interagency system to include all children up to 21 years. The purpose of this new system, “The Minnesota System of Interagency Coordination” (MnSIC) is to develop and implement a coordinated, multidisciplinary, interagency intervention service system for children ages birth to 21 with disabilities. The target population are children who are first eligible for special education AND receiving services from at least one other public agency.

MnSIC requires that the state interagency committee, comprised of representatives from education, public health, and human services, do the following:

- Identify and assist in removing state and federal barriers to local coordination of services provided to children with disabilities.
- Identify adequate, equitable and flexible use of funding by local agencies for these services.
- Develop guidelines for implementing policies that ensure a comprehensive and coordinated system of all state and local agency services.
- Develop, consistent with federal law, a standardized written plan (see box).
- Identify how current dispute resolution systems can be coordinated and develop guidelines for that coordination.
- Develop an evaluation process to measure the success of state and local interagency efforts to improve the quality and coordination of services for children with disabilities.

In addition to the above, local school boards and county boards (social services and public health) are required to:

- Implement policies that ensure a comprehensive and coordinated system of all state and local agency services.
- Use a standardized written plan (IIIP) for providing services. (see box)
- Access the coordinated dispute resolution system and incorporate the guidelines for coordinating services at the local level.
- Use the state-developed evaluation process to measure the success of the local interagency system.
- Develop a transitional plan for children receiving services from Part C of the Individuals with Disabilities Education Act (IDEA).
- Coordinate services and facilitate payment for services from public and private institutions, agencies, and health plan companies.
- Share needed information consistent with state and federal data practices requirements.

Local programs have asked the state for training and technical assistance on the following topics: team facilitation and mediation skills, best practices in service coordination, funding strategies, design of local systems, governance, data practices, etc. Experience with Part C demonstrated the need for and the value of state leadership and assistance to local programs.

Minnesota local public health agencies have had long-standing relationships and experience with coordinated interagency systems through their participation with IDEA—Part C and the local Interagency Early Intervention Committees (IEIC). Public health has played a significant role in the design of the Part C system that supports children, birth to 3, as well as

The Individual Interagency Intervention Plan (IIIP) is a standardized written plan for addressing the needs of children with disabilities, birth to 21 years. Its purpose is to identify and organize formal and informal supports in a way that addresses the child’s and family’s strengths and concerns. The IIIP also serves as a framework for interagency teams to document, describe, and coordinate services as well as payment arrangements for each child and family.

The impact of the IIIP is illustrated by Carolyn, Bob and their children. Married for 23 years, they became foster parents in 1990, adding to their family of four birth children, an adopted daughter and two permanent foster children. In 1994, when one of their foster daughters was showing signs of developmental delays, they began their journey into the world of special services. At 6 years, their daughter had two diagnoses, Attention Deficit Hyperactivity Disorder (ADHD) and Fetal Alcohol Syndrome (FAS). Later she was diagnosed with Reactive Attachment Disorder and Bipolar Disorder. Carolyn reflects, “We faced many challenges and received many different services. At first we were working with a special education team and an Individual Education Plan (IEP) that included occupational therapy, adaptive physical education, special education, a support paraprofessional in the classroom, and a pediatrician to identify and coordinate her medication needs. As our daughter moved into the K–12 education system, the need for home, community, and educational supports increased.

“When I became involved with our local Interagency Early Intervention Committee (IEIC), one of the first things I heard about was the IIIP,” Carolyn continues. “As I learned more about the IIIP, I knew this was exactly what our daughter needed.” By the time their daughter was in the third grade her mental health and learning disability issues were overwhelming the family’s resources. Her mother says, “It became my full-time job to coordinate communication between agencies, educate staff regarding her mental health issues and coordinate five care plans: Individual Service Plan (ISP), Rule 40/Behavior Intervention Plan, IEP, Crisis Plan, and a manic plan. My husband and I were the only ones who had a complete, comprehensive understanding of her needs. Just getting through the week was exhausting, leaving us with very little time or energy to focus on the needs of our other children.” After learning about the IIIP at a state meeting, Carolyn and her husband sat down with 15 professionals and wrote an IIIP for their daughter in two hours. “After years of hearing what she couldn’t do, we finally had a document that not only addressed her needs and concerns, but also acknowledged her many strengths!” “We remain forever grateful for the effort the team put forth that day.” Carolyn says her daughter’s progress during the first year on her IIIP was remarkable. Coordinating care through an IIIP has meant fewer meetings, fewer phone calls, and the development of a cooperative working relationship among staff to help her develop her full potential in all environments. “Most importantly, the IIIP has allowed me to be a Mom again to her and our other children.”



providing service coordination and child find activities. Some public health agencies also are involved in Children's Mental Health and/or Family Service Collaboratives and are already involved with the Interagency System for Children with Disabilities birth to 21 years.

This history reinforces the important role of public health in interagency systems. This interagency role emerged with the advent of health care reform and the emphasis in public health to enact the core public health functions (assessment, policy development and assurance) and be less involved in providing direct health care services.

John Hurley, MHA, is Section Manager for the Minnesota Children with Special Health Needs (MCSHN) program in the Division of Community and Family Health, Minnesota Department of Health. Barbara Leonard, RN, PhD, FAAN, is a Professor and Director of the Center for Children with Special Health Care Needs in the School of Nursing at the University of Minnesota.

On-line Data Resources

The CYSHCN homepage of the Data Resource Center for Child and Adolescent Health contains an easy to use, interactive data query feature that allows users to view and compare state, regional and nationwide findings from the National Survey of Children with Special Health Care Needs. State profiles on key performance indicators for CYSHCN are also available and can be found at www.cshcndata.org.

Data Moment

Evaluating Program Satisfaction

Evaluating the effects of a program is difficult, which is why evaluation is the subject of many books and graduate courses. For this "Data Moment" we will consider a very specific matter in evaluation: the common practice of asking participants about their satisfaction with a program. While it is important to know if participants liked a program, there are many things to consider in attempting such evaluation. First, evaluators should be careful to select a relevant time frame for the program evaluation, as program components (e.g., staff, services) can change over time. The time frame for evaluation should represent a period of time during which the program elements were consistent and it should be a current time frame so the evaluation data can be used to inform current practices. Second, evaluators should consider how many people were served by the program during the evaluation time frame in order to identify a representative group for evaluation, in terms of numbers and distribution of key demographic or other variables. For example, if a program served 1000 people during a specific time period and 20 people were surveyed, the findings about "satisfaction" (or any question) would be dubious because it is unlikely that the 20 respondents would be representative of program participants. Further, if 100 people were queried and only 20 responded, the findings would also be questionable. Not only would those 20 participants represent a small number of participants, but they also may represent a biased group because they (unlike most of the potential participants) chose to respond—and their opinions may not reflect the majority opinion. Evaluators should also be sure that the participants in evaluation surveys are aware of the program: people cannot always identify the name of programs that serve them and thus they may not be able to answer questions that refer to the program by name. In addition, evaluators may want to be sure that participants have had a sufficient "dose" of the program: an individual with only one exposure to a program may have a different perspective than one with multiple exposures. Evaluators will either want to screen survey participants to be sure that they have had a minimum level of program exposure. If they do not screen participants, they will want to ask participants about exposure level, in order to adjust analysis. Evaluators must also be careful to assure participant confidentiality and anonymity. Participants may be reluctant to have their identities attached to their responses, for fear of jeopardizing their relationship with the program. Also, "social desirability" may influence responses and must always be considered in the interpretation of survey data. Social desirability refers to the natural desire on the part of survey participants to please evaluators and say things they think the evaluators want to hear. Finally, general satisfaction with a program may be less important than satisfaction with specific components of the program. Evaluators should try to ask detailed questions about satisfaction with key program components because they could be most useful for generating ideas about program development or modification. In sum, questions about program satisfaction are frequently asked in program evaluations, but they may not always be answered or interpreted carefully. One of many useful resources for evaluation is The American Evaluators Association, which has some useful links to on-line evaluation handbooks and text at www.eval.org.

Healthy Generations Videoconference

Mental Health of
 Children and Youth with Special Health Care Needs
 Thursday November 18, 2004
 1-3 pm

Blue Earth County
 Voyager Room
 410 S. 5th St.
 Mankato

Clay County
 Family Services Center
 1st Floor
 715 11th St. N
 Moorhead

Crow Wing County
 Courthouse
 Multimedia Room
 326 Laurel Street
 Brainerd

Itasca County
 Room J135
 123 NE 4th St.
 Grand Rapids

Nobles County
 Commissioners Room
 315 10th Street
 Worthington

Olmsted County
 VC Room 07
 2116 Campus Drive SE
 Rochester

Ramsey County
 MDH Distance Learning
 Center
 3rd Floor, Metro Annex
 130 E. 7th Street
 St. Paul

St. Louis County
 Government Services Center
 Room 709
 320 West 2nd St.
 Duluth

Stearns County
 Human Services, ITV Room
 705 Courthouse Square
 St. Cloud

Registration is free and limited by site. To register online, please go to www.epi.umn.edu/mch/events/videoconference.shtm and complete the registration form. For additional information, please email mch@epi.umn.edu. Certificates of Attendance will be provided. Please visit: www.epi.umn.edu/mch/events/index.shtm for any changes to these conference sites.

**UPCOMING
 EVENTS**

Proceedings from the 2004 MCH Summer Institute: Presenter information, PowerPoint slides, and audio records can be found at <http://www.epi.umn.edu/mch/summer/2004.shtm>

Next Issue of Healthy Generations:
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