TE ADVISORY COUNCIL ON MENTAL HEALTH
and Subcommittee on Children's Mental Health

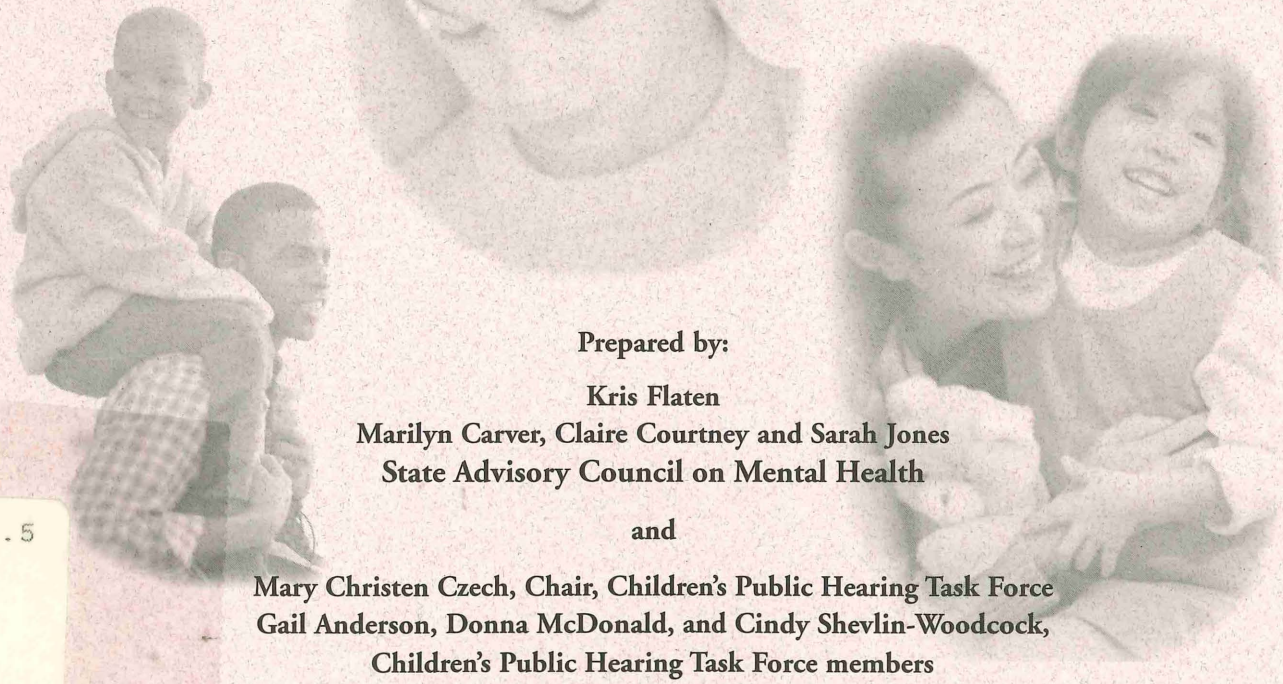
2000 Report to the Governor and Legislature

A Report on the 1999 Public Hearings on Adult and Children's Mental Health

Sarah Jones
Chair, State Advisory Council on Mental Health

Kris Flaten
Vice Chair, State Advisory Council on Mental Health

Sandy Holmstoen and David Sayler
Co-Chairs, Subcommittee on Children's Mental Health



Prepared by:

Kris Flaten
Marilyn Carver, Claire Courtney and Sarah Jones
State Advisory Council on Mental Health

and

Mary Christen Czech, Chair, Children's Public Hearing Task Force
Gail Anderson, Donna McDonald, and Cindy Shevlin-Woodcock,
Children's Public Hearing Task Force members

This information is available in other forms to people with disabilities by calling 651-582-1816 or contact us through the Minnesota Relay Service at 1-800-627-3529 (TTY).

Table of Contents

Executive Summary

In addition to its other ongoing activities, the State Advisory Council on Mental Health and the Children's Subcommittee on Mental Health hosted seven public hearings across the state of Minnesota in 1999. The purpose of the hearings was to hear how well Minnesotan's mental health needs are being met, particularly in light of the 10th anniversary of the passage of the Children's Mental Health Act of 1989. (The Comprehensive Adult Mental Health Act was passed in 1987). This report is a summary of the findings of those hearings. Members of local advisory councils and children's collaboratives were included as hosts. Members of the State Advisory Council on Mental Health and the Children's Subcommittee attended each hearing. The hearings were held on:

September 18 in Bemidji
September 25 in Duluth
October 2 in Alexandria
October 9 in Marshall
October 23 in Owatonna
October 30 in Rosemount
November 6 in Minneapolis

Consumers, advocates, family members, providers and the general public were invited to testify on any topic concerning mental health services and needs. They were also invited to submit written testimony and /or fill out a survey that was distributed at the hearings or available from the Department of Human Services. A range of participants from lay persons to professionals, gave testimony. They included: consumers, parents, family members, foster parents, members of children's collaboratives, local advisory council (LAC) members, mental health professionals, social workers, case managers, Department of Human Services personnel, county commissioners, social services directors, corrections personnel, teachers, school nurses and a school counselor.

The written materials and oral testimony were analyzed. The following general themes emerged for adults and children, respectively:

Both Adult and Children's Mental Health:

- Access to Mental Health and Related Services
- Lack of funding, lack of services and lack of providers
- Fragmentation of the Mental Health System
- Managed care, health insurance and Minnesota health care programs (Medical Assistance, Prepaid Medical Assistance, Minnesota Care, General Assistance Medical Care)
- Public Education/Anti-Stigma/Consumer Empowerment
- Prevention and Early Intervention
- Family Support
- Suicide Awareness, Education and Prevention

Adult Mental Health:

- Legal and Human Rights: Civil Commitment, Treatment Issues, Discrimination, Reporting of Abuse
- Housing
- Transportation
- Employment

Children's Mental Health:

- Crisis/emergency services
- Respite care
- Collaboration and coordination of care
- Disparity between mental and physical health care
- Special concerns in rural areas
- School issues
- Need for training of parents and professionals
- Transition issues

While attendance at the hearings was lower than anticipated, the information obtained from those who did participate was compelling and valuable. Many people spoke with great courage, conviction and passion in describing the pain, suffering and grief they were experiencing or had experienced; the

inadequacies of the services they had received; the ways in which they had been well served by the current system and; the hopes and dreams they had for better services, treatment, and recovery.

This report summarizes, as faithfully as possible, the full range issues and concerns brought forward by the citizens who either attended the public hearings or submitted written testimony, expressing multiple perspectives and sometimes divergent views. This report does not comment on the accuracy of any of the statements made in testimony, or on the prevalence of the experiences of the respondents. Additionally, it is not possible, in a report on public testimony, to convey adequately the depth of feeling, the honesty and the courage with which people shared their stories and experiences. Members of the State Advisory Council on Mental Health and Children's Subcommittee on Mental Health were honored by the opportunity to hear citizens' perspectives and left the hearings with a renewed commitment towards bettering mental health in Minnesota.

Response

In response to the public hearings, the State Advisory Council on Mental Health and Subcommittee on Children's Mental Health

- formed a joint task force on Prevention and Early Intervention which has made recommendations to the Departments of Children, Families and Learning; Commerce, Corrections; Health, Human Services and to the Children's Cabinet
- formed a supportive housing work group which made recommendations to the Department of Human Services and Minnesota Housing Finance Agency for more supportive housing programs;
- recommended an increase in support for coordinated employability programs
- requested a study by the Legislative Auditor's office on managed care in Minnesota
- formed respite care and crisis/emergency services work groups. The Respite Care group is working with the Department of Human Services, Children's Mental Health Division, to survey counties on the need for respite services, to fulfill the goal of obtaining funding for respite care services for families with severely emotionally disturbed children, while the Crisis/Emergency group is finalizing recommendations for county guidelines on crisis services.
- are participating with the Minnesota Department of Health, in collaboration with the Department of Human Services and Department of Children, Families and Learning, other agencies, and community representatives, in developing a state strategy for suicide prevention. Additionally, a public information campaign is being launched to raise awareness about suicide and its prevention.

The State Advisory Council on Mental Health and the Children's Subcommittee on Mental Health thank each person who participated in the hearings.

Introduction

In January 1999, members from the State Advisory Council (SAC) and the Children's Subcommittee on Mental Health formed a Public Hearings Committee to plan the fall hearings on mental health. The first public hearings had been held in 1987 and resulted in the formation of the State Advisory Committee that year and the Children's Subcommittee two years later.

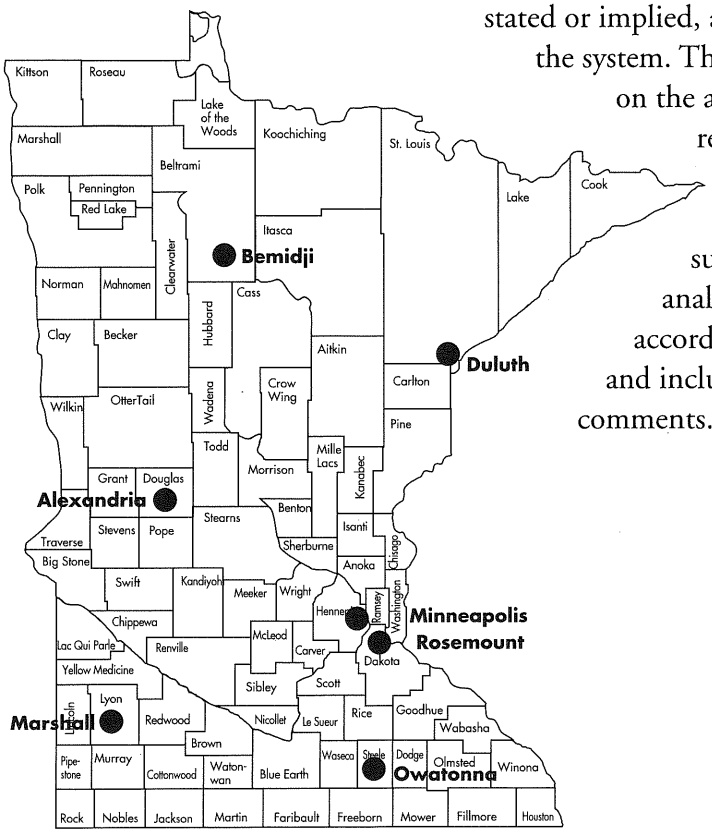
The Public Hearings Committee invited testimony from consumers, family members, mental health care providers, social services agencies and other interested parties to get a sense of where Minnesota's mental health system should be headed. Separate sessions for adult and children's mental health were held to ensure adequate time on the issues for testimony from consumers, their families and other stakeholders. Children's sessions were held in the mornings, while adults were held in the afternoons. Hearings were held on Saturdays so that they would be accessible to working families.

People who were unable to appear at the hearings were given the opportunity to testify by facsimile, email, voice mail, letter or telephone. Mental health surveys were available at the hearings to allow people the chance to offer input if time constraints did not allow them to testify. Surveys were also made available through the Department of Human Services, Local Advisory Councils and other agencies.

To create the opportunity for statewide participation, seven sites were selected to accommodate the metro and greater Minnesota areas and serve the widest geographical area possible. Bemidji and Duluth sites were chosen in Northern Minnesota, while Owatonna and Marshall sites served persons living in Southern Minnesota. Central Minnesotans could testify at the Alexandria or metro sites in Minneapolis and Rosemount. The hearings were held at colleges, a church, a community center and a county administration center.

Panelists heard not only from people who were frustrated with Minnesota's mental health system but also those who have had positive, successful experiences. Testimonials indicated what was working and what was not. Many people had recommendations, whether stated or implied, about how to improve the system. These findings are based on the analysis of the tape-recorded public hearings, and the synopses of letters received and surveys returned. The analysis was organized according to subject matter and includes participants' comments.

Public Hearings Sites



Findings from the 1999 Adult Mental Health Public Hearings

Access to Mental Health and Related Services

The concerns about difficulties accessing services fall into three categories: lack of appropriate services to meet the individual's needs, shortage of providers and difficulties with other medical services.

Lack of appropriate services to meet individual's needs.

There was a lot of testimony concerning difficulties accessing the care appropriate to the individual's needs. The line demarcating those with "serious and persistent mental illness" (SPMI) as defined in the Comprehensive Adult Mental Health Act of 1987 was seen as artificial and burdensome, often preventing people from getting adequate medical/psychiatric services with first onset of symptoms of a mental illness. The hope of many families and consumers of mental health services was that early intervention might prevent an episode of mental illness from becoming long term and chronic. Or, if such prevention was not possible, early intervention might inhibit the disease process and minimize the effects of the illness on the person's life, including his/her natural support system, family relationships, school and vocational achievements. Additionally, the use of diagnostic criteria to determine those who have SPMI does not adequately cover all conditions including PTSD (post-traumatic stress disorder), DID (dissociative identity disorder), OCD (obsessive compulsive disorder) and others.

Frustration was expressed with the current criteria used to authorize hospitalization or more intensive outpatient treatment when a person experiences an increase in symptoms or difficulty managing his/her illness. These stringent and high criteria (in many cases, the "commitment standard" of "dangerousness to self or others") actually discourage a person from recognizing and seeking treatment early on in the episode of illness or intensification of symptoms. In the long run, this is detrimental to the individual with the illness and more costly to the system as a whole. For most people, access to longer term treatment (more than 5-21 days) has been limited to the state Regional Treatment Centers (RTCs) which usually require that a person be under a civil commitment order. Citizens repeatedly expressed the need for longer term inpatient care-both in community hospitals and as voluntary patients in the regional treatment centers.

A recurrent theme in the hearings across the state was the need for mental health services to be tailored to the individual's needs. Many people expressed frustration with the need for the individual to fit into a program rather than have the services designed to fit the person's needs. Examples include the need for integrated treatment for those with both mental illness and chemical dependency issues; specialized treatment (including DBT training) for those with borderline personality disorder, dissociative identity disorder and post-traumatic stress disorder; longer lengths of stay for inpatient treatment; long term supports for housing, community living and employment; additional adult foster care options; integrated recreational opportunities; and mental health supports in post-secondary educational programs. Citizens identified outreach needs including crisis services and services to persons who are homeless and have mental illnesses. Throughout, people were asking for services to be centered on the individual so that people would have easy access to mental health professionals and would be able to make choices about their care, e.g., changing their case manager if they so desired.

A big issue concerning access revolves around those people who have mental illnesses and are in correctional facilities. Too often, there are concerns that they are not getting appropriate treatment and medications for their mental illnesses. This makes it even more difficult for many of them-especially those who are particularly vulnerable-to manage within the correctional institution.

Shortage of providers.

There is a statewide shortage of professionals trained to work with persons with mental illnesses in both rural and metro areas. Individuals testified to waiting 6-8 weeks for an initial appointment with a psychiatrist or clinical nurse specialist. One of the reasons listed for the shortage was the relatively low pay for all levels of professionals working with people with psychiatric needs. In part, medical students may not be training in psychiatry because they can expect to earn significantly less than they would in other specialties. The shortage of psychiatrists is most acute in rural areas, with people traveling great distances to access needed care. Other direct service staff-working in group homes or as case managers-may earn the same or less than a fast food restaurant manager. Low reimbursement rates for medical assistance claims were cited as a major problem, with reports of several community mental health centers being forced to close their doors, shorten their hours, increase wait times for appointments or close satellite offices because the payments they receive don't cover the costs of operating their centers. Citizens also testified that 15 minutes with their psychiatrist every 2-3 months does not constitute good care and treatment; both the shortage of psychiatrists and the way(s) health plans are authorizing care were blamed for the short and infrequent visits. Additionally, with the move towards community integration (fewer bed days at RTCs), professionals working in the community are treating persons with more complex needs, including, for example, mental illness and chemical dependency. This requires additional training and funding for staff to provide good, competent service.

Access to medical care.

The third category concerns the difficulties experienced by persons with mental illnesses in accessing appropriate medical care which treats multiple issues cohesively and supportively. One example is sleep apnea which may not be detected in someone with a mental illness but which can greatly affect the efficacy of treatment for the mental illness. Concerns were raised about elderly persons with mental illness in one county not receiving adequate medical care, about difficulties accessing dental care (primarily due to low reimbursement rates), and the need for mental health programs and services to be handicapped accessible.

Legal and Human Rights: Civil Commitment, Treatment Issues, Discrimination, Reporting of Abuse

Family members and consumers of mental health services provided the bulk of testimony under this heading. Concerns were voiced passionately and with great conviction. Consumers of mental health services cited many occasions where they did not receive respectful treatment at the hands of mental health professionals and law enforcement officers. They spoke of many negative experiences with both the use of seclusion and restraints and the non-enforcement of current regulations governing such use. There were also reports of physical and sexual abuse in treatment settings and a desire for better reporting mechanisms when such abuse occurs. There was a strong sense of being victimized by the system that was supposed to help them. There was a request for the regulation of ECT (electroconvulsive therapy) treatments being performed in the community-both inpatient and outpatient. There was also a report of code violations which were ignored in a group residential housing facility. Additionally, there was a request for a mechanism by which consumers of mental health services could resolve disagreements about treatment decisions with their psychiatrists.

Negative experiences with the treatment system lead consumers of mental health services to fear treatment and to not ask for help even when they may know that they need it.

Family members expressed concern that they were not able to help their loved one access care in a timely manner when the individual's self-awareness or willingness to recognize that they had an illness was impaired. Family members clearly want to have a credible voice in treatment decisions and in the civil commitment process. Frustration was expressed that their loved one could "fake it" or "pull it together" for the court appearance, then continue to be very ill and exhibit symptoms at home or in the community. Family members spoke eloquently about the effects of untreated or under-treated mental illness on the family as a whole, including children and spouses.

Fragmentation of the Mental Health System

Many people testified that they have experienced fragmentation within the mental health system particularly in terms of differences between various counties and the way that they provide services: a "county operated mental health system results in significant inequities from county to county". Some testified to an inequity in services and resources available between rural and metro areas. Some spoke with frustration at how difficult it is for someone receiving public mental health services to move from one county to another. The new county may refuse to provide services until residency is established, thus leaving a person without services. Also expressed was a concern that the needs of elderly persons with mental illnesses are not being met. There is a perceived lack of accountability and a sense that services are poorly coordinated in publicly funded mental health programs. Examples include the "monopoly" some mental health centers have on services in some areas and a lack of continuity of providers and care for persons with mental illnesses. Suggestions were made for regionally based evaluations of the effectiveness of mental health services.

At the same time, there was a call for increased funding for community mental health services including case management and community support programs. A recurrent suggestion was that funding for services follow the individual with mental illness-wherever that person resides, whatever services that person receives-rather than programs or institutions. People also spoke to the disparities in funding between the system for persons with developmental disabilities and the mental health system, urging greater funding of the mental health system.

Health Coverage

Many concerns were expressed under the general topic of health insurance coverage. Private insurance plans limit or do not cover necessary services for persons with mental illnesses. As a result, costs are shifted to the public system and/or services provided are uncompensated. Within the public system, Medicare does not pay for prescriptions; neither Medicare nor Medical Assistance (MA) pays for some needed services like long term community supports or even weight management programs; and Medicare/MA reimbursement rates for mental health services are not adequate. There was the suggestion that Minnesota adopt the "Rehab. Option" under Medical Assistance and that Medicare should pay for prescriptions. Additionally, court ordered services should be paid for by health plans/health insurance wherever applicable. There was also a general call for affordable health insurance.

Housing

At nearly every hearing, the need for affordable, safe housing was raised. The housing market is very tight; people are having trouble finding adequate places to live. Some persons with mental illnesses are homeless. In a tight housing market, landlords can choose their tenants so people with unlawful detainers, criminal histories or other difficulties may have difficulty getting accepted into housing units. There is a need for additional rent subsidies. There is a need for permanent housing with long term, increased, expanded, supportive services.

Transportation

The need for safe, affordable and accessible transportation also continues to be a recurrent theme both in rural areas (where often there isn't any public transportation) and in metro areas (where public transportation is often very time consuming and difficult for some persons with mental illnesses to use). Access to transportation is essential to a person's sense of independence as well as necessary to access needed services and activities including employment.

Employment

There is an increased awareness that persons with mental illnesses can be employed successfully. This has created an increased demand for services to assist persons in securing and maintaining community based employment, often including long term support. Employers and consumers of mental health services need to be educated about the pros and cons of self disclosure (including possible discrimination) concerning disabling conditions, reasonable accommodations and how they may apply to persons with psychiatric disabilities. The disincentives to employment in public assistance, health coverage and housing programs should be eliminated. Work is a very important part of the recovery process for persons with mental illnesses.

Public Education/Anti-Stigma/Consumer Empowerment

Persons with mental illnesses want and need to be treated with dignity and respect. Suggestions were made for educational, public health campaign efforts targeted towards the general public, policy makers, legislators, providers and families to increase awareness and sensitivity towards the experiences of persons with mental illnesses. There was also a call for an increased number of peer support groups, self-help, mentors, consumer empowerment training and programs in addition to a suggestion for an easily accessible directory of available services.

Suicide Awareness, Education and Prevention

The general public, providers, family members and consumers of mental health services need education regarding the warning signs for suicide, symptoms of depression and other mental illnesses, and the need for early intervention and treatment to prevent suicides. Lack of awareness, lack of access to services and appropriate treatment has resulted in deaths-consistently nearly 500 per year in Minnesota.

Family Supports

Families clearly testified about their need for information and education about the resources available to their loved ones. Families need assistance in getting treatment for their loved ones when they're in crisis and when they may lack self-awareness about their illness. Families also need support services to help them cope with and support their loved one who has a mental illness. Additionally, some families experience a loss of income/financial support or an increase in expenses when their loved one becomes ill-for example if the mother in the family is not able to care for the children, the family may not be able to afford necessary child care. Many times community property law and the rules concerning public assistance provide incentives for families to break up, for spouses to divorce, in order to afford necessary treatment or to provide for children. Such break ups erode the individual's natural support system and make recovery more difficult.

Findings from the 1999 Children's Mental Health Public Hearings

Introduction

Many issues impact children and adolescents with mental health needs and their families. Three areas have been selected as priority issues for the year 2000 as a result of the testimony provided at the Public Hearings. They include: Crisis and Emergency Services, Respite Care and Early Intervention and Prevention. The remaining issues identified in the report will provide a basis for continued work and selection of future priority areas by the Subcommittee on Children's Mental Health. We thank the family members, advocates, providers, county and state agency representatives who generously gave of their time and testimony at the Public Hearings. Together, through understanding and respect of each others' perspectives, we gain a recognition of how we can work together to improve mental health services in Minnesota.

Attitudes towards Parents and Children

Generally parents expressed concerns about the mental health system letting families and children down. A call for a more effective, consumer-based, family-friendly integrated system which shares responsibility with schools, juvenile justice, health care providers and insurers was echoed throughout the state. Parents expressed the need for information and guidance in navigating the complexities of the mental health system to improve access and timeliness of help for their children. Testimony indicated the system is under funded, overloaded and under stress from the increasing demands for more services. As the system identifies more children in need, it creates more demand for services while lacking the funding to provide those services.

Families need to be involved with treatment if children are to succeed. This sentiment was voiced repeatedly at the hearings, in the letters received and the returned surveys.

> "There is good evidence through the federal grant that, when parents are involved in the treatment of their child, things go better for the child: Truancy levels go down, symptoms improve, and there are fewer out-of-home placements." *Parent Liaison, Minnesota Department of Human Services*

Parents. While family involvement makes a difference, it takes a lot of energy. Parents want to be involved, but parents testified they are sometimes so overwhelmed with the responsibilities of parenting a child with mental illness, there is little time or energy for anything else. Parents said they need to feel valued as part of the educational and medical process for their children. Many felt there was little collaboration between the professionals or with the family, and the burden was on parents to communicate with and between all the parties involved in their child's care.

Balancing all the needs of the family while juggling job, school, and other responsibilities may leave little time for effective advocacy on behalf of a child with mental illness. Parents may become frustrated and stressed. Parent support groups, where they can be found, have proved invaluable.

Beyond parent support groups, parents expressed the need for support from the professional advocates and caregivers involved with their children. Parents asked for child and family-friendly services, more collaboration with others, validation, and attention to all aspects of the lives of their families.

Parents throughout the state reported feeling blamed by professionals for their children's problems. The problems were often seen as a result of poor parenting and not their children's mental illness. Staff was seen as judgmental towards parents, which made communication between families and service care providers difficult. Parents often felt their feedback was invalidated. They were not always included as partners in the design and delivery of services to their children but treated rather, as if they were in the way of treatment.

Parents were also labeled "difficult" when they fought or pushed for services. If they were unable to follow through with county or provider directives due to work, transportation or other problems, they were viewed as uncooperative.

> "(For parents of children with mental illness,) the problems of keeping a job are very real? When we have children who are having really big struggles, there are just endless meetings. All those meetings take place during working hours for professionals. And if we have to choose staying at work (rather than attend meetings,) then we're labeled non-compliant or resistive." *Metro Minnesota parent.*

A parent from Greater Minnesota stated that it was more helpful when *"professionals realize parents are doing the best they can and don't blame (them.)"*

Children. Parents and providers commented on the negative attitudes towards children with mental health issues. Children were viewed as "being bad," or labeled as defiant, attention-seeking, or with typical adolescent behavior instead of as severely emotionally disturbed. Without a diagnosis, children may be denied services by counties or coverage by insurance plans. A Greater Minnesota parent said one of the main problems is that, *"Children seem to have no value in society—they don't vote and they don't own property."*

The chair of a Coordinating Council of Children's Collaborative expressed similar concerns about negative societal attitudes: *"These (children with mental health needs) aren't poster children. These are children who are frequently treated like the toxic waste of our human societies."*

Stigma has prevented parents from seeking help for their children and families for many reasons including shame, labeling, name calling and social isolation, all of which is not associated with seeking services for physical health conditions.

Access

Many of the parents who testified said when they first experienced problems with their children, they were confused about how and where to get help. There may have been many resources available, but parents did not know how to access them. Providers might not know of all the services available to families. There may be many points of access to the children's mental health system, and the treatment or services received depends on which point is accessed-whether through the school system, pediatrician, county, LAC, statewide agency or other service entryway.

It was not uncommon for families to be unaware of available help, treatment programs, LACs, collaboratives, or wraparound services. Many parents said they were uninformed about the Children's Mental Health Act and their rights. They often had to learn on their own and find their own resources.

Funding.

Without proper funding, services cannot be provided. The majority of people who testified in person or in writing mentioned the lack of funding-whether for implementation of the Children's Mental Health Act and mandated services, training and education, special programs, transportation, reimbursement rates to health care providers, schools systems, support for LACs and families, etc. Parents and providers both said that unfunded mandates are unrealistic, and full funding of the Children's Mental Health Act is needed to achieve a responsive, viable children's mental health system in Minnesota.

Availability.

The availability of mental health services varies throughout the state. Not all counties are able to provide the same services due to lack of staff or funding and other restrictions. Some parents found social services staff were not helpful or were told that programs and services were not available to their families. Even when armed with the appropriate information, parents still reported difficulty accessing services. They cited many barriers put before them, and they talked of having to struggle for services mandated by the Children's Mental Health Act.

"A parent should not have to fight to get help." *Parent, Greater Minnesota*

Some of the parents who testified worked in or with the mental health field, and even they cited difficulty accessing mandated services.

"There should be more help out there. I figure if I'm having this much trouble, and I know something about what's going on, how can the normal lay person handle these systems?" *Parent and Elementary School Nurse, Metro Minnesota*

Much of the negative commentary had to do with the lack of services or the inability to access them, but when services were provided, they were appreciated:

"When we finally received services, it was fabulous. We found a wonderful therapist and our daughter had a dramatic turnaround." *Parent, Greater Minnesota*

A Greater Minnesota parent made this observation about the help that she received from her county and mental health care providers: *"Restrictive services helped my son, allowing him to stay until he was stabilized. There was exhaustive transition planning and it was implemented exactly as planned, with a slow transition home, mentoring services and continuity of care with his former child psychologist."*

Continuum of Care.

There is fragmentation of services and lack of continuity between systems of care which causes a disconnect when a child goes from one system to another. Services provided may not be the same and benefits lost. Little cooperation between the mental health, juvenile justice, and school systems was cited by several parents and health care providers, often leading to serious gaps in service. Counties also do not often share resources or information. Some parents stated the Data Privacy Act prevented counties and agencies from sharing more information. Both parents and mental health stakeholders decried the policy of "dollars following the program and not the consumer," when providing services to children.

"My blue sky idea [is] that every child has an endowment that follows them. [If] the money follows the child, then we'd have providers all over the place chasing kids to give them service. Right now the money follows the institution." *Psychologist and nurse, Greater Minnesota*

County/Government Barriers.

The perception that some counties are unfriendly, unresponsive or distrustful deterred families from seeking help or continuing treatment. Some parents felt counties waited to provide services only after their child was out of control or the parents were desperate, causing undue stress on the family and loss of valuable treatment time. Several parents reported that the county waited until there was a court action before giving them services. Others said they were told the only way they could access services was through a CHIPS petition.

"(The family with whom I am working) can't really hook into all the county services yet because they don't quite fit (their) guidelines... The longer I'm in business, the more confusing it gets as to how to provide services." *Licensed Psychologist, Greater Minnesota*

Some restrictions required families to exhaust all other options before getting residential care. Parents statewide reported how the least restrictive setting mandate actually delayed their child getting the necessary help and caused undo stress on the family and child. Requirements placed on the county by the state also can be barriers to services. Counties may lack funding, staff, or needed resources to

provide the desired mental health services to families. Sometimes if the funding was in place, there was not staff to administer the programs.

Often, families were only able to access services through the court system after their child broke the law. Many parents said they were told that their child "needed to do more" to qualify for services. If the child broke the law, then the family would get some help. Parents talked of the pain of waiting for their child to do something serious enough to warrant the intervention of the juvenile justice system in order to get services.

Managed Care and Insurance.

There were many complaints about managed care, Health Maintenance Organizations (HMOs), and Prepaid Medical Assistance Plans (PMAPs) by both parents and service providers. They reported more restrictions and less flexibility in service provisions under managed care, and the belief that care was driven by dollars.

> "Treatment is based on actuarial rather than medical decisions." *Greater Minnesota County Commissioner*

The financial burden created by mental health services is very real and has an impact on families. A child with a serious mental illness can quickly deplete family and insurance resources. Families may be limited to only the treatment they can afford. Often families forego seeking treatment due to financial constraints. Many families cannot afford the high insurance rates, deductibles or co-pays, nor are they able to pay for treatment not covered under their insurance plans. Families might not qualify for medical assistance plans due to income ineligibility and thus find treatment costs prohibitive.

Insurance plans may not pay for treatment unless a child fits into certain categories. Under managed care plans, approval may be required before a child can get services. Caps on service cause many problems for families seeking help for a child with mental illness. Authorized sessions with a service provider may be unrealistically limited.

> "Why does treatment have to be so controlled-all to fit cost guidelines?" *Parent, Greater Minnesota*

PMAPs/HMOs threaten some community-based providers. If a specialist is outside the HMO/PMAP provider network, insurance will not pay. Loss of local health care providers in HMO/PMAP provider networks may mean long drives for families to access care, making follow-up difficult. Health care contracts may differ in what they cover, creating barriers to providing the best services to children. Families can lose services if forced to switch insurers. Insurers do not cover holistic, environmental or innovative medicine. Problems were reported getting private insurers to pay for agreed upon services unless the family made extensive appeals. Clients would have to cancel appointments because insurers refused to pay the provider. Families may find the efforts to appeal denials of service cumbersome, with lots of paperwork, phone calls and time invested.

Counties also reported difficulties with the insurance process. Under managed care, more county funds get expended when insurers refuse to pick up the costs of services. As more county funds are expended, the county cannot expand services to other families. Complicated billing systems are also stressful for counties. One county hired a person full time just to work with insurance policy issues. Many social workers, frustrated with the complex billing system, were giving up and not getting service reimbursements.

Medical Assistance.

Panelists at the seven hearings repeatedly heard that Medical Assistance (MA) reimbursement rates are too low. Due to the low reimbursement rates, some child psychiatrists are not seeing MA clients. Some families experienced problems after losing eligibility from MA then being reinstated into the program. They had to miss psychiatrist appointments, and some had their cases closed. The families needed to have county intervention and fill out additional paperwork to get their cases reopened.

Other parents said MA spend down criteria had prevented their families from qualifying for MA. They were ineligible for other assistance as well and found paying for mental health services prohibitive.

Disparity Between Coverage for Physical and Mental Health.

Many parents and mental health care providers testified that despite parity laws, there are still issues between mental and physical health care coverage. Physical and mental illnesses were not treated the same or subjected to the same restrictions.

Transportation Issues.

There may be no public transportation in rural areas. Other transportation issues occur when needed services aren't available in the community, necessitating a long drive to a service provider. For parents who must work, who have no transportation or an unreliable means of transportation, this is often an insurmountable problem. It makes follow-up after an initial evaluation difficult. Transportation problems may also arise when children are suspended from school buses due to their behavior and no alternate form of transportation exists. Parents may work and be unable to bring their children back and forth to school or they may not have available transportation.

Service Areas

Crisis/Emergency Services.

> "The biggest unmet need in children's mental health is the lack of crisis services." *Parent, Collaborative member, Greater Minnesota*

Parents across the state related tragic accounts of not being able to find services during a crisis or emergency. There are no clear-cut guidelines on what they should do when a child is in crisis. There are no universal numbers for parents to call which will put them in touch with mental health care providers who can make the decisions which will resolve the crisis or defuse the situation. Parents who had no other options available often relied on law enforcement to help handle a child who is out of control.

Parents cited the need for more inpatient hospital care during crises. Hospitals will not admit a child unless the child meets certain criteria, such as the threat to harm him-or herself or others. Managed health care plans may require a prior crisis plan in place or a therapist's directive for hospitalization before authorizing care. Also, some crisis centers will not take severely out of control children, even with a crisis plan.

Sometimes county staff is the stumbling block to getting help. Parents testified of waiting three or more hours before getting a response to a call for help. Sometimes they did not receive a call back at all. Other times, county workers may set unrealistic criteria to access crisis services. One parent noted that in her county, families had to be on a social worker's list as a potential crisis family in order to access crisis services. Sometimes there are no local providers in the community and parents may have to travel great distances — with a child in crisis — to get help.

Respite Care.

One of the services identified as most needed was respite care. Parents, county personnel, and mental health care workers all identified the lack of respite care and shortage of providers as pressing concerns. County staff who spoke at the hearings said their counties lack the funding for respite care services.

Parents want, and need, respite care. Some parents said the only time they had time away from their children was when school was in session and their children were in attendance. Waiting lists were long, according to parents. Lack of funding for services and providers were the reasons they were most often given for not receiving respite care-if they qualified for the service. Shortage of providers was blamed on some counties' requirements that respite caregivers be licensed foster care providers. Some respondents suggested counties be creative in funding respite services, using family members as respite caregivers and then paying them. Low reimbursement rates were also cited as a reason for a provider shortage. Funding, training, and a concentrated effort to

recruit respite care providers are needed to meet the demand.

Some counties may offer respite care but it is not adequate to meet the individual family's needs. The county may offer only one model of respite care, such as taking children over the weekend while the family only wants respite a few hours in the afternoon. Some families reported they still could not access respite care except through Child Protection Services, which they found shaming or punitive. Burnout and low reimbursement rates contributed to a lack of respite care providers.

Families also may be put on waiting lists for respite or foster care, or other services, with no guarantee that they will ever be able to access these services.

Early Intervention and Prevention.

> "I would put an emphasis on early intervention and prevention with younger children. I would emphasize early child screenings, mental health checkups for kids—every kid that goes to school gets a checkup by a physician. ...I see kids at the Juvenile Center (who are age) seventeen, and they have very tragic stories because you think about what could have been, what (they) would've been like been like if (early intervention) had happened." *Psychologist and Nurse, Greater Minnesota*

Parents, educators and providers all mentioned the need for early intervention and prevention services. School personnel talked about the importance of early diagnosis and intervention before the child fails at school.

> "Early intervention is so important. It's a lot cheaper—and the bottom line is always about money—if we deal with these kids when they're younger than if we have to deal with them as adults. I have a sign up in my office... (that says,) 'It is easier to build a child than rebuild an adult.'" *Parent and Elementary School Nurse, Metro Minnesota*

Mental health professionals talked about the success seen in early intervention and prevention programs.

> "We are successful in intervening earlier in the lives of the children. As we look at the ages of the kids who are served by our Children's Mental Health case management, they are younger and younger, where as before they were teenagers. Now we have children as young as (age) three (receiving case management)... I can say this (program) is successful locally." *Clinical Supervisor, Children's Case Management; Greater Minnesota*

Success can bring new problems-more children to serve with existing resources and lack of funding. The Early and Periodic Screening, Diagnosis and Treatment (EPSDT) screen was seen as a useful, but little-used tool to screen children for mental health issues. (The EPSDT program in Minnesota is known as Child and Teen Checkups[1]).

Case Management.

Case managers were viewed as a positive or negative resource, depending on the experience of the respondent. Some parents saw their case managers struggling with large caseloads and scarce resources. Others said their case managers were unaware of alternate programs and services. Another problem seen by parents was a lack of proper training given to case managers. However, some families reported being very satisfied with their case manger and the help they received:

> "...But help did come in the form of our county mental health coordinator... She helped us to find a therapist, respite care, and... to apply for Medical Assistance. ...Without (her) help, I can't imagine where we'd be. ...Each county (should) have enough county mental health coordinators to work with parents and help them sort through crises." *Grandparent, Greater Minnesota*

[1]See Further, 1999 External Quality Review Study, Child & Teen Checkups Participation Rate Review, Final Report: August 2000. Prepared by FMAS, A DynaCorp Company, Reston, VA. For a copy of the report, call (651) 215-6260.

In-Home Services.

Providers and family members spoke highly of in-home services. In-home counseling is flexible; it can be a family based counseling service or a short-term mentoring program, and it can provide a link to early family services. These services are found to be very beneficial, empowering children and their families. In an in-home situation, people can open up because they felt more comfortable. In-home services, however, are limited due to lack of funding and care providers willing to go into people's homes. Service to diverse populations is also difficult due to lack of culturally competent in-home behavior specialists.

Personal Care Attendant Services.

Some comments indicated there are shortages of properly trained and paid Personal Care Attendants, and one reason is the low reimbursement rates. Some providers no longer offer PCA services for children with mental illnesses because they could not break even financially with the low reimbursement rates they received for services.

Psychiatric Services.

Panelists heard much testimony about the problems families faced accessing psychiatric services. There is a lack of child psychiatrists throughout the state, especially in rural areas or smaller counties. This shortage limits the availability of appointments, and families might have to wait several months before they see someone. Follow-up visits may be several months apart. The lack of child psychiatrists also means that some families have to drive several hours for psychiatric service, again making follow-up difficult. High turnover rates in rural areas mean lack of continuity of care for children and their families. Building trust with a new provider takes time that families and providers often do not have.

> "A big issue in our community is we are really lacking in child psychiatry services. We are sending children and families all over Minnesota. It's such a barrier to have to send children to the (University of Minnesota.) It's not that they don't get good services when they get there (but) sometimes follow-up is difficult for families. Maybe they don't have transportation or a telephone." *Parent and School Social Worker, Greater Minnesota*

Many parents and professionals felt child psychiatry services should be expanded. Psychiatric consultations ideally would involve several parties: the child's parents, mental health case manager, and Special Ed representative. This situation would require the time, commitment and coordination of several professionals.

Managed care limitations on services is a continual source of frustration for parents and providers alike. Capitation on services is geared towards adult need. More time and sessions are needed with children than adults. Short sessions do not tell the full story when working with children, and it takes several sessions just for the provider to get to know the child and build a relationship. Under managed care, providers may be limited to only one or two sessions before pre-authorization is required for more sessions. Comments about the lack of child psychiatrists reflected the belief that low insurance and Medical Assistance reimbursements, combined with service restrictions, kept some psychiatrists from taking on children as patients.

Residential Treatment Facilities.

General concerns received about treatment facilities were:

- Regional Treatment Centers (RTCs) need better diagnostic personnel and facilities for children.
- Children are vulnerable and need better protection in RTCs.
- Children have no voice in RTCs.
- Behavior management was given, but no therapeutic help offered during a child's stay.

There were positive comments as well. A greater Minnesota grandmother told panelists about all the difficulties her family went through with her granddaughter and what changed for their family: *"The turning point was when she was sent to the Willmar Regional Treatment Center. New psychiatrist,*

new medication—she's a new girl. We love this one—she's a keeper."

Support and Self-Help.

Services and information provided by private, nonprofit support groups, like the Minnesota Association for Children's Mental Health (MACMH), National Alliance for the Mentally Ill of Minnesota (NAMI-MN), and Parent Advocacy Coalition for Educational Rights (PACER Center) were praised by hearing participants. Mentoring programs and student support groups were also cited.

Transition Services.

There were several areas of transition services that were addressed during the hearings, including transitioning back into the family and community when returning from out-of-home placements in residential or correctional facilities; school to work transition needs; and transitioning from the children's mental health system into the adult system.

Transition home. Parents wanted the needs of the whole family considered when children returned from out-of-home placements. They wanted time for the family to heal first and assurance that the family was ready to have the child back. Often the needs of the siblings were not taken into account when making decisions. Remaining connected to the mental health community after the return home was imperative in transitioning the child back home as the family adjusted.

> "Children (coming from detention centers) without mental illness have a hard enough time transitioning (back into the community) but children with mental illness don't stand a chance when transitioning without a continuum of care." *Parent and County Commissioner, Greater Minnesota*

Into the community. There is a lack of transition services into the community, whether from an RTC, residential home or correctional facility. Respondents cited the need for work and community supports.

School to work. Parents wanted job training for children with severe emotional disturbance and emotional or behavior disorders. Several parents cited the need for the process to start earlier (age 14 years) and to get children into the workforce to prepare them for adulthood.

Children to Adult Mental Health Systems. Many participants believed there were inadequate transition services between the child and adult systems, if any at all. It was observed that most children's case managers were not trained in providing children with transition supports and services were limited by funding. Parents and providers felt the transition period was a vulnerable time for young adults and might require mentoring. Again, they felt the process should start earlier, when the child was age 14-16 years. Other suggestions:

- Semi-independent living arrangements are needed for 18-22 year olds.
- Extend parental authority over a child's mental health to age 22 years.
- Provide a six-month overlap between adult and children's case management.
- Continue support services in the children's mental health system until the child is ready to transition into the adult system, rather than by chronological age.
- Fund services that help children learn the social and emotional skills they need to be successful in the community and at home.

Wraparound Services.

Comments received about wraparound services included the need for coordination, flexibility, immediacy, and having money attached if they are to work. All parties need to work together, based on the strengths and needs of the family and child.

Juvenile Justice/Corrections System

A former corrections officer talked about the enormous number of youth in the corrections system with learning disabilities and mental illnesses. While the juvenile justice system is often an access of care point for many of these children, many parents and mental health care providers felt there was a disconnect between the mental health and juvenile justice systems. They cited inadequate or no treatment in correctional facilities, undiagnosed children languishing in the system, and no adequate transition or follow-up once children leave the correctional system. Often, the high cost of caring for children with mental health problems is shifted onto the correctional system. Part of that cost is the loss of a child's future ability to earn a living and place in society.

Suicide Prevention

Parents and professionals expressed concerns about the numbers of children and adolescents thinking about and attempting suicide. In some instances, services had been initiated only after a suicide attempt. Early intervention, education and timely access to appropriate services are needed to address this issue.

Collaboration

Several hearing respondents noted a lack of collaboration. The Data Privacy Act was cited as one barrier. The reluctance to share information and resources also affected true collaboration. Many parents felt their presence "at the table" and input were important for true collaboration, but felt excluded.

Mixed comments were received about collaboratives. Some families said that collaboratives are not a point of access for services, and they can only make referrals. However, the advantage of collaboratives is that everyone brings a different level of expertise, which they can use to leverage insurance, and be creative using funds through schools or wraparound grants.

> "(I) appreciate the team support for (my) daughter. It (provided) beneficial resources and gave (my) daughter the chance to improve emotionally and academically. (The) child's really progressive." *Response from a returned survey.*

Families appreciated it when care providers collaborated to meet their needs or came up with creative, flexible plans to serve them. Some parents gave high marks to their collaborative or interagency review teams.

Local Advisory Councils

Some participants at the hearings said LACs did not always receive the financial support they needed to be effective, and at times, were seen as being restricted in deciding on how money was spent. Family and consumer participation on LACs was also seen as lacking.

> "Consumers don't attend LAC (meetings) because most attention is given to maintaining the bureaucracy instead of mental health issues... Nothing comes of (our) efforts... There is no consumer empowerment." *Greater Minnesota Parent.*

In response to his comments, other participants at the hearing talked about their positive experiences with LACs. A discussion ensued about consumer empowerment and the need for more consumers on LACs. Currently, state law calls for at least one member of an LAC to be a consumer. The best practice model would call for more consumers on LACs.

Cultural Competency

Concerns were expressed about a lack of cultural competency among providers of services. For example, in one three-county area where there is a

diverse population, there were not any in-home behavior specialists who spoke Spanish, Somalian, or Hmong. More information needs to be gathered about the adequacy of culturally competent services.

Education/Training

The need for education and training for children, families, service care providers and the community was mentioned at all the hearings. Doctors, the faith community, and school personnel should have a basic understanding of mental health issues in order to help families. These are the persons children or parents might first turn to when in crisis.

Parents, providers, and advocates at the hearings said that *parents* need to know about their children's mental illnesses, treatment options, and their rights under the mental health system. They need to learn about available services and how to access and advocate for them.

Children also need to learn about their illness, how to access services and how to advocate on their own behalf. Educating themselves can make transitioning into the adult mental health system smoother. Several parents also said that *employers* need mental health education so that they will be more understanding when parents need leave time to attend their children's medical needs, school or counselor meetings, or to handle a crisis. They also said educated employers would help their children transition into the workplace.

Many individuals expressed the need for training and education for *law enforcement* personnel. Often law enforcement officers are the first responders to a crisis or emergency situation. Many parents said that law enforcement officers often did not know how to handle their children or their children were improperly treated.

Health care professionals also lack education, training and understanding of mental health issues. Parents cited hospital staff as being judgmental towards them and often blamed parents for their children's problems. Many parents want primary care physicians and their staff to learn more about mental health because the doctor was one of the few health care providers with whom their children had regular, ongoing contact. Often doctors are the persons who will make referrals to mental health care providers.

Many people who testified at the hearings thought *school personnel* should have more training on mental health issues and how to recognize mental health concerns in children. Teachers and other school staff need to be aware of a child's diagnosis and how to help achieve more successful academic outcomes. It was pointed out that teachers are required to receive training on children with developmental disabilities, but there were no similar training requirements for mental illnesses.

Other professionals who were in need of mental health education and training include *foster and respite care providers* and *social workers.*

Concerns of Rural Areas/Small Counties

County staff and parents were in general agreement about the lack of services and providers in smaller or more rural counties. These areas often lack psychiatrists, respite care and PCA services, and other mental health providers and services, and they experience high provider turnover.

Funding for crisis services is inadequate in rural areas, as crisis services are very specialized, very expensive and cannot be guaranteed to be cost effective. Families that are involved with farming may have special needs, especially during the harvest season. They may have difficulty getting to therapy sessions, taking time off from work or finding adequate transportation.

School System

When discussing the relationship between the mental health and school systems, public hearing respondents wanted more integration and a full continuum of services available. They saw the need for more school-based mental health services, which includes psychiatrists. Integrated, coordinated services minimize the time parents spend traveling to and sitting in meetings.

> "We're struggling in terms of getting mental health systems in the school in a way that's integrated. Sometime...what we do become(s) a program rather than a service...and services are placed in spots, off some place and don't get integrated (into the rest of the school.)" *County Social Services Supervisor*

Respondents saw the need to increase funding of school social workers, psychologists, emotional-behavior disorder specialists, paraprofessionals, and other mental health professionals. They noted the lack of funding for other school needs:

- More self-contained programs for children who cannot be mainstreamed
- Summer school programs for children with EBD or in Special Ed
- Early identification and prevention programs
- Alternate transportation for children suspended from riding the bus due to behavioral issues and
- More staff and teachers to reduce student-teacher ratios.

Parents want better training and education on mental health issues for teachers and other school personnel. Many times parents said they felt blamed for their children's mental health problems or behaviors. Parents want help in understanding their rights and the rights of their children in the school system. They also want communication in understandable terms. Often the language and acronyms used by educators confuse parents and their children.

Day Treatment. Parents and service providers both viewed day treatment as a successful program, however there was not enough funding to make the service available to all children who could benefit from it. Some parents wanted more involvement between day treatment and mainstream schools in order to lessen the impact on their children as they transitioned back into the mainstream setting.

Individualized Education Plans (IEPs). The parents who talked about IEPs did not always find them effective, helpful, or meeting the needs of their children or families. Often they did not understand their rights or realize that they could challenge the IEP. Some parents stated they were not involved in planning the IEP, or they found their input invalidated. Educators cited the lack of coordination between the IEP and a child's medical treatment. They found the IEP a limited tool in developing a broader interagency plan, which includes agencies outside the school system. It was also noted that the IEP had a narrow academic focus which did not look at the whole picture of the child. Some found IEPs ineffective because there was not enough parental involvement, flexibility or impetus for teacher involvement. They might also lack input from case managers or the collaborative when created, which, again, did not look at the child's life in whole.

Special Education. Not all children who need special education services received them. Many school mental health professionals are funded through Special Education funds. Not all students with mental illness have a diagnosis or meet special education criteria. Sometimes it is difficult to get an assessment because of insurance issues. The need to provide earlier services in school to prevent problems later on was mentioned by educators and parents. Some younger children might not qualify for Early Childhood Special Education because their behavior is harder to document, and the lack of documentation could disqualify them. Without a diagnosis, the child *might fall through the cracks.*

Conclusion

As noted in the Executive Summary, this is a report of the issues and concerns brought forward by the citizens who provided testimony at the 1999 public hearings on adult and children's mental health. Also noted in the Executive Summary, it is not possible here to convey adequately the depth of feeling, the honesty and the courage with which people shared their stories and experiences. Although the testimony expressed multiple perspectives and divergent views, on balance the findings reinforced the urgency given to the priorities and activities of the State Advisory Council and Children's Subcommittee, which are outlined in the Executive Summary. The Council has based its work for the past year on the findings from the public hearings outlined in this report. Members of the State Advisory Council on Mental Health and Subcommittee on Children's Mental Health were honored by the opportunity to hear citizens' perspectives and left the hearings with a renewed commitment towards bettering mental health in Minnesota.

For more information, contact Bruce Weinstock at :

444 Lafayette Road
St. Paul MN 55155-3828
PHONE: 651-582-1824
FAX: 651-582-1831
E-Mail: Bruce.Weinstock@state.mn.us