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Mental Illness

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Mental Illness

– Cheryl Asmus

Mental illness is a general term that refers to a group of illnesses, much like heart disease refers to a group of illnesses affecting the heart. Mental illness can come and go, or it can last for the life of the individual. Among the causes are substance abuse, chemical or hormonal imbalance, genetic predisposition, environment, and psychological or social factors.

For many of our nation's families, serious mental illness is real and can result in family dissolution, financial bankruptcy, wrongful imprisonment, or giving up custody of children just to get them treatment. A bill currently in Congress would give states the option of allowing families of disabled children to purchase Medicaid coverage for them.

The first article is a mother's story that describes the powerful impact a child's mental illness can have on a family and community. Marty Dwyer is a relentless advocate and leader for families living with mental illness, from advocacy in courts to starting and directing a local chapter of the Federation of Families.

Mental illness is not just a problem facing children and adolescents. Adults typically are stigmatized (negatively labeled) and isolated, in addition to facing the difficulties of day-to-day life with mental illness. The clubhouse model, featured in the second article, helps adults with mental illness live productive and satisfying lives. Colorado clubhouses are located in Boulder, Fort Collins, Greeley, Littleton, and Wheat Ridge.

The next article details the wide range of direct and indirect costs of mental illness both nationally and in Colorado. Direct costs include treatment and rehabilitation , and indirect costs include lost productivity at work, school, or home due to disability or death. Other serious outcomes include loss of employment, homelessness, substance abuse, involvement in the criminal justice system, and suicide.

We chose to present as a possible model to others, the Larimer County Community-wide Mental Health and Substance Abuse project, an effort by an entire county to make a difference in mental health and substance abuse services in their community. Other Colorado counties have developed similar collaborations, such as the Summit Prevention Alliance.

– Cheryl Asmus, Ph.D., is coordinator of the Family and Youth Institute at Colorado State University.

Family View

– Marty Dwyer

There comes a moment when a parent fully understands there is something wrong – really, truly, wrong – with my child; that this behavior, this thought process, is over the line of normal. My child has a mental illness. So begins the journey.

We search for answers. Will the schools be supportive? Maybe the pediatrician can sort this out. How about the hospital? What is the difference between a psychologist and a psychiatrist, anyway? What is the cap for mental health services on our insurance policy? How do I apply

for Medicaid for a child? What do you mean, Social Services is coming to speak to us? Surely our families will understand. Substance abuse? Not my Susie or Johnny! Juvenile justice, residential treatment, out-of-community placement, individual educational plans, blame assessment, psychotropic medications, biological brain disorders …we need expertise that we probably do not possess.

So where can we turn for help? A limited array of services is available, but not a way to access them in a comprehensive manner. Parents must identify the problem, find the solution and make it happen. Answers can come late or in a piecemeal manner. The children are often ostracized, disciplined for their disorders, and told in many different ways that they can't be helped.

Often, criteria for entrance into a program are limited by standards that the child or family may be unable to meet. Age, insurance, income, diagnosis, co-occurring disorders, or availability of space can be reasons for rejection. Ejection from a program often is done on the basis of behavior due to the youth's mental illness issues. For instance, a child just admitted to a substance abuse treatment program may be ejected for using non-prescribed drugs.

Parents and siblings are embarrassed by this child's behaviors, too. The constant need for interventions on the child's behalf, time away from work, stigma, inexperience of caregivers, limited funding of school programming and need for around-the-clock care wear on us. We have little left over for our other children or partners. The family may break down under the stress of a child or youth who is terribly sad, delusional, violent, compulsive, or enraged. No respite care exists for families whose youth have emotional, behavioral or mental disorders. Indeed, there is little support or understanding for the families. There is no coordination of care for our youth. They may be sucked into a downward spiral that all too often ends in the juvenile justice system.

The good news is that families, consumers (people who receive mental health services) and providers have identified components of an effective, helpful system. We suggest that people in the system:

- Understand that we, as parents, love our children. We recognize that many emotional, behavioral and mental disorders are biological in origin and that environmental factors may be involved.
- Focus on individual and family strengths rather than the detrimental deficits model.
- Respect family values, cultures and faiths.
- Understand that families need a voice and a vote on every decision-making team.
- Provide a single entry process where we are helped to identify and access needed services.
- Use a team approach. That means everyone involved with the care of this child (family, schools, treatment professionals, doctors, legal system) develops a plan of care that is comprehensive, inclusive, strengths-based, and unconditional.
- Be flexible, creative and caring. If strategies don't work, change them.
- Do what it takes to find the most effective medications, treatments, programs and education plans.
- Do not let this child fall through the gaps in our system.
- Do not give up on this child or the family. Be there, no matter what.
- Help families connect with one another to learn how others found solutions. Parents who have been there speak our language and understand our pain. They guide us through the grief process and help us gain perspective.
- Recognize the value of family advocates. They acquire a national view of needs, learn best practices, attain skills in plan development, help navigate the system, support families and help develop policy. They help us share information and experiences, and develop coping skills.
- Eliminate the stigma of mental illness. Most beliefs about mental illness are based in ignorance. Mental illnesses are treatable and sometimes curable. They are as deserving of funding, compassion and treatment as any other medical disorder.

Our children deserve an all-out effort to improve the delivery of services and reduce the stigma associated with their disorders. The return on the community investment in the care of our children can be measured in the growth of the spirit that is nurtured, treated and encouraged.

– Marty Dwyer is a family advocate, a consumer and a parent of children with special needs. She and her husband Jim have five birth sons, a foster son and an extended family of six Vietnamese refugees. Their diverse family has been featured on the Today Show three times. Marty serves on boards, committees and coalitions concerning the mental health community. She directs the Northern Colorado Chapter of the Federation of Families for Children's Mental Health, a national, parent-run organization that works to provide information and referral, set policy, influence legislative change, and support families whose children and youth have emotional, behavioral or mental disorders.

For more informaton on the Federation of Families for Children's Mental Health, see: http://www.ffcmh.org/

Clubhouse Model: A Community-building Approach for Adults with Serious Mental Illness

– Robert Jackson

Mentally ill adults, for the most part, feel themselves unneeded and marginalized in our society. The United States Department of Health and Human Services now estimates their numbers to be as high as 10 million. Often impoverished and isolated by both psychological symptoms and social stigma, many of them spend their days attempting to manage their illnesses on their own, seeking and sometimes rejecting psychiatric treatment, and looking for food, shelter and other necessities of life.

One hopeful development for mentally ill adults, the clubhouse model, is an approach that has its roots in New York City in the late 1940s, at a place on West 47th Street called Fountain House (Beard, Propst, and Malamud, 1982). At Fountain House and other clubhouse model programs, members find the chance to discover their competencies and strengths. In these communities, members are workers and contributors, not simply clients or patients. Here they can take advantage of opportunities to meet and form natural ties with others through shared work. Everyone, regardless of limitations or disabilities, is needed and has something to contribute.

At the center of the clubhouse model is the work-ordered day, organized and scheduled according to *collective* needs, rather than *individual treatment* goals. Members serve meals, write and publish newsletters, maintain the clubhouse and grounds, plan social and recreational events, and develop educational programs. Members also help each other access needed services outside the clubhouse and participate in a variety of social, recreational, and educational activities. In the clubhouse model, professional staff do not *treat* or explicitly *rehabilitate* members. Rather, they *collaborate with members* in leading group work activities, managing daily affairs of the clubhouse, encouraging friendships, and discovering new and meaningful roles for members within and outside the clubhouse (Jackson, 2001).

"This practical approach is helping me cope with reality because I'm expected to use my abilities. I'm finding my abilities because other people need my help," said a clubhouse member. (Jackson, 2001, p. 2.)

Work is understood by sociologists and psychologists to be a fundamental aspect of personal identity development. In a vibrant clubhouse community, members find opportunities for competitive, part-time, entry-level employment positions that introduce or reintroduce them to the skills and aptitudes necessary for more permanent positions. In seizing these opportunities, they gain the reward of earning a paycheck and the satisfying feeling of a job well done. Although some members may choose to work primarily within the clubhouse, transitional employment opportunities maintained by the clubhouse in shops, schools, community organizations and businesses often serve as steps to more permanent employment.

The clubhouse philosophy is reflective of universal human needs for social connection and meaningful work. Like others, people with mental illnesses have the core human needs to feel "wanted, needed and expected." In this regard, the clubhouse model may hold promise for other disabled, excluded, and disempowered populations. Elderly people, youth separated from their families, immigrants, cultural outsiders, ex-prisoners and others might also benefit from evolving clubhouse-model program approaches. At least one clubhouse for head-injured adults has been developed in the United States.

The philosophy and approach of the clubhouse model has been shown to be an effective approach for helping mentally ill adults. Such clubhouses can be found in more than 350 locations in the United States and 16 other countries. Five clubhouses operate in Colorado, all organizational members of a statewide clubhouse association. Clubhouses everywhere develop and maintain their own standards of performance and make frequent contact through regional meetings and international seminars.

More information on clubhouses and the clubhouse model can be obtained by contacting the International Center for Clubhouse Development (ICCD) in New York or through accessing the ICCD web page at http//www.iccd.org.

References

Anderson, S. B. (1998). *We are not alone: Fountain House and the development of clubhouse culture*. New York: Fountain House.

Beard, J., Propst, R.N., & Malamud, T.J. (1982). The Fountain House model of psychiatric rehabilitation. *Psychosocial Rehabilitation Journal, 5* (1), 47-53.

Jackson, R. (2001). *The clubhouse model: Empowering applications of theory to generalist practice*. Belmont, CA: Brooks/Cole Thomson Learning.

– Robert Jackson, Ph.D., is an associate professor in the Department of Social Work at Colorado State University and author of The clubhouse model: Empowering applications of theory to generalist practice, *2001*.

Costs of Mental Illness

– Elizabeth Hornbrook Garner

About one in five Americans ages 18 and older suffers from a diagnosable mental disorder in a given year. In 1998, this estimate was over 44 million people. Four of the 10 leading causes of disability in the U.S. and other developed countries are mental disorders: major depression, bipolar disorder, schizophrenia, and obsessive-compulsive disorder. However, the treatment success rate for a first episode of schizophrenia is 60 percent, 65 to 70 percent for major depression, and 80 percent for bipolar disorder.[1]

The burden of mental illness on health and productivity has long been underestimated. Data developed by the massive Global Burden of Disease study reveal that mental illness, including suicide, accounts for over 15 percent of the burden of disease in established market economies, such as the United States–more than the burden caused by all cancers.

The study also measured the burden of all diseases. Major depression ranked second only to ischemic heart disease in magnitude of disease burden in established market economies. Schizophrenia, bipolar disorder, obsessive-compulsive disorder, panic disorder, and post-traumatic stress disorder contributed significantly to the total illness burden attributable to mental disorders.[2]

A range of effective treatments exists for most mental disorders, yet nearly half of Americans who have a severe mental illness fail to seek treatment, according to the first-ever Surgeon General's report on mental health (1999). The report focuses on the connection between mental health and physical health, barriers to receiving mental health treatment, and specific mental health issues of children, adults and elderly people.[3]

Direct costs (spending for treatment and rehabilitation) of mental health services in the United States in 1996 totaled $69 billion – over 7 percent of total health spending. Indirect costs of mental illness, such as lost productivity at the workplace, school, and home, were estimated in 1990 at over $78 billion. An additional $17.7 billion was spent on Alzheimer's disease and $12.6 billion on substance abuse treatment.[2]

In 1997, Colorado's total and per capita mental health expenditures were $219 million and $57 respectively, which ranks it 24th (total) and 25th (per capita) in the nation.[4]

Suicide

Research shows that almost all people who kill themselves have a diagnosable mental or substance abuse disorder or both, and that the majority have depressive illness.[5]

Colorado has one of the highest suicide rates in the country. Its rate has exceeded the national average since suicide data were first collected in 1910. Although Colorado's rank decreased from 7th in 1996 to 12th in 1998, suicide is the second leading cause of death in every age group from 10 to 34. The governor appointed the Suicide Prevention Advisory Commission in 1998 and opened the Office of Suicide Prevention and Intervention in November 2000. The Colorado plan is available on the Web.[6]

Substance Abuse

Substance abuse often co-occurs with mental illness. The national costs of alcohol and drug abuse were estimated to be over $276 billion in 1995, according to a study by the National Institute on Drug Abuse and National Institute on Alcohol Abuse and Alcoholism. The largest impact was on lost productivity due to premature death, illness and victimization. The health care costs for alcohol abuse were about twice that for drug abuse.

A 1998 study by the National Center on Addiction and Substance Abuse at Columbia University indicates the heaviest burden of substance abuse and addiction on public spending falls on states and local programs, including prisons, Medicaid programs, and child welfare systems. At least 70 percent of abuse and neglect cases stem from alcohol- and drug-abusing parents. The most significant opportunity to reduce the burden on public programs is through targeted prevention programs. However, this study shows:

??States spend over 100 times as much to clean up the result substance abuse and addiction makes on children as they do to prevent and treat it. Colorado spends over 1,500 times as much.

??On average, over $95 of every $100 states spend on substance abuse goes to the burden on public programs and less than $4 for prevention, treatment and research. Colorado spent 6 cents of every $100 on prevention, treatment and research.

??Of the $620 billion total the states spent, $81.3 billion – 13.1 percent – was used to deal with substance abuse and addiction. Colorado ranked 9th in the country with 12.4 percent of state spending related to substance abuse.[4]

References

[1]National Institute for Mental Health – The Numbers Count: http://www.nimh.nih.gov/publicat/numbers.cfm

[2]The Impact of Mental Illness on Society: http://www.nimh.nih.gov/publicat/burden.cfm

[3]Mental Health: A Report of the Surgeon General, Chapter 1 and 2 – http://www.surgeon general.gov/Library/MentalHealth/home.html

[4]Substance Abuse and Mental Health Services Administration: http://www.samhsa.gov/oas/oas.html

[5]Harvard Medical School's Consumer Health Information: http://www.intelihealth.com/

[6]Colorado's suicide prevention and intervention plan: http://www.cdphe.state.co.us/pp/suicide.htm

– Elizabeth Garner is county information specialist for Colorado State University Cooperative Extension.

Community-wide Planning Project

– Beth Coughlan

For many years, both consumers and providers in Larimer County expressed frustration with the local mental health system, without much resolution of the problems. In Colorado, communities have no mandate to do comprehensive community mental health planning across sectors. Service providers planned their services in isolation from one another, and coordination was more the exception than the rule.

In 1998, a group of key mental health providers came together to discuss initiating a community-wide planning effort. Executive directors of the Larimer Center for Mental Health, Poudre Valley Hospital/Mountain Crest, and the Poudre Health Services District, and the president of the Mental Health Advisory Council made the commitment to work together to develop a planning process. A 15-member steering committee was formed comprising consumers and top officials from public and private agencies that serve those with mental illness and substance abuse issues.

When the group searched for models of community-wide mental health planning, they found none. In August of 1999, the steering committee launched a unique project with the goals of identifying important local issues and developing a structure to address them, prioritizing issues and potential system changes, and implementing the selected changes.

Phase 1: Gathering Information

An intense examination of the community's mental health system culminated in a report detailing the current status and challenges in providing adequate services. *Mental Illness and Substance Abuse in Larimer County: The Challenges We Face Today* was completed in February 2001. Included in the study are local, state and national trends; community perceptions of needed changes as identified by over 200 people in interviews, discussion groups and a public forum; profiles of most service organizations; funding sources and totals; and personal case studies illustrating key issues.

The report calls for a long-term commitment to community-wide planning to reduce fragmentation and improve coordination among providers. A series of community meetings in March gave residents an opportunity to learn more about the report and offer their reactions.

Phase 2: Prioritizing Issues and Selecting Strategies

The steering committee committed to a two-year pilot project that will establish an ongoing network of providers and consumers charged with creating changes in local mental health and substance abuse services. In this phase, subcommittees have begun to design specific plans in these four high-priority areas:

- improving information, referral and response systems;
- ensuring the overall continuum of care for those with and without insurance;
- developing a comprehensive education campaign for providers, consumers and the public; and
- advocating for policy changes, such as securing adequate state funding for Medicaid patients and those with low incomes who don't qualify for Medicaid.

Phase 3: Implementation

This phase will focus on implementation of the identified solutions. It is anticipated to begin later this year.

The commitment of top-level administration, to both personally participate in this process and commit funding to this project, has been a key factor in the success of addressing issues in mental health and substance abuse treatment on a community-wide level. This level of commitment has also fostered an evolving attitude among participants where problems and potential solutions are now seen as community-wide, and a shared interest and responsibility is carried outside the scope of individual agency concerns. Developing this sense of a community understanding for how inadequacies in the mental health and substance abuse system affect all those involved may be the most crucial aspect of creating effective changes.

– Beth Coughlan is community projects coordinator for Poudre Health Services District. For a copy of the report, contact Nancy Stirling, nstirling@healthdistrict.org, 120 Bristlecone Drive, Fort Collins, CO 80524, 970-224-520.

Additional Web Sites on Mental Illness

Alcohol and Drug Abuse Division of Colorado Department of Human Services: http://www.cdhs.state.co.us/ohr/adad/index.html

Colorado Behavioral Health Council (legislative issues pertaining to Colorado's mental health system): http://www.cbhc.org/issues.htm

Depression: Definitions, Facts and Statistics: http://www.coloradohealthnet.org/depression/depression_facts.htm

Fountain House: http://www.fountainhouse.org/

Mental Health Association of Colorado Inc: http://www.mhacolorado.org/research.htm

National Alliance for the Mentally Ill: http://www.nami.org/

National Institute of Mental Health: http://www.nimh.nih.gov

National Mental Health Association: http://www.nmha.org/

National Mental Health Consumers Self-Help Clearinghouse: http://www.mhselfhelp.org/techassist.html

Support services for people with mental illnesses and their families: http://www.cdhs.state.co.us/Text/ohr/mhs/cosups.html#seven

Invitation to dialogue

What issues and concerns would you like to see addressed?

Contact FYI at:

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Opinions expressed herein are not necessarily those of the Family and Youth Institute staff.

Coming next:
Fatherhood

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