"IN MY OPINION, OUR HEALTH CARE SYSTEM HAS FAILED WHEN A DOCTOR FAILS TO TREAT AN ILLNESS THAT IS TREATABLE."

— KEVIN ALAN LEE

THE SPLIT MIND: SCHIZOPHRENIA FROM AN INSIDER'S POINT OF VIEW
What matters most is how you see yourself
ISSUE: LACK OF ANY ORGANIZED SUPPORT FOR FAMILIES WITH CHILDREN WITH MENTAL HEALTH ISSUES

By Kelly Walker, Larry Lutton, Kelley Maginnis, Autumn Henley, Liz Stevens and Cabrinni Kulish.
A woman living in senior housing who is convinced that the Government is poisoning her water and spying on her through her windows and heating vents, and therefore barricades herself in her home for self protection. Riverbend’s nurse case manager is the only person she allows into her apartment. By filling her pill planner and managing her social security funds as representative payee, the staff is able to monitor whether the woman’s physical health is in jeopardy from not eating or blocking the heat in order to protect herself from the malevolent forces she fears. If imminent risk of harm is seen, an intervention is arranged.
BY SHOW OF HANDS WHO THINKS THIS IS A SUCCESS STORY?

How many think it is not? Why?
INTRODUCTION TO OUR ISSUE AND A DESCRIPTION OF CURRENT SERVICES

- Mental Health System VS. Developmental Disabilities System
<table>
<thead>
<tr>
<th>Regulations</th>
<th>Enabling Legislation – RSA 135-C &amp; He-M 400s &amp; 1000s</th>
<th>He-M 500 &amp; 1000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding Sources</td>
<td>Medicaid, state funds, some private insurance, some self-pay.</td>
<td>Medicaid Waiver, state funds, some self-pay</td>
</tr>
<tr>
<td>Funding Distribution</td>
<td>Fee for Service</td>
<td>Individual budgets for bundled services</td>
</tr>
<tr>
<td>Eligibility</td>
<td>Complex criteria including diagnoses, symptoms and functional impairments determined through rigorous and thorough intake process. Services prescribed by psychiatrist and based on medical necessity.</td>
<td>Relatively broad categories with informal intake interview. Eligibility based on outside obtained evaluations. Level of need impacts type/amount of service, not agency eligibility. In Home Supports are provided on a limited basis determined by number of risk factors.</td>
</tr>
<tr>
<td>Organization of services in NH</td>
<td>10 Regions served through Community Mental Health Centers with single State Psychiatric Hospital</td>
<td>10 Regions served through Area Agencies</td>
</tr>
<tr>
<td>Nature of Services</td>
<td>Treatment-focused</td>
<td>Focus is on quality of life</td>
</tr>
<tr>
<td></td>
<td>Children and Families Programs: through age 18</td>
<td>Early Supports and Services 0 – 3 (direct therapeutic interventions)</td>
</tr>
<tr>
<td></td>
<td>Adult Community Support Programs: 18+</td>
<td>Family Support and In Home Supports 3 through 18 or through 21 if still in school</td>
</tr>
<tr>
<td></td>
<td>Some centers have separate programs for 60+</td>
<td>Adult funded services 21 through end of life.</td>
</tr>
<tr>
<td>Service Population</td>
<td>Adults are typically self-guardians. Large numbers of individuals who are court ordered to treatment through conditional discharges.</td>
<td>Adults usually have Guardians. Individuals and Guardians invested in outcomes</td>
</tr>
<tr>
<td>Political Advocacy</td>
<td>Statewide Behavioral Health Association engages in systemic advocacy efforts representing all CMHCs. No CMHC formalized activity engaging families or consumers. Limited center by Center work.</td>
<td>Statewide coordinated effort. Legislative liaisons at each agency. Grass root involvement by individuals and families</td>
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</tbody>
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### Who Does the New Hampshire Public Mental Health System Serve?

<table>
<thead>
<tr>
<th>Setting</th>
<th>Eligibility</th>
<th>Services</th>
<th>Funding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Mental Health Centers</td>
<td>Meets State eligibility for Serious Mental Illness (SMI) or Serious Emotional Disturbance (SED) and is Medicaid eligible</td>
<td>All services available to SMI or SED population plus intake &amp; Emergency Services</td>
<td>Medicaid; State funds; insurance; self-pay</td>
</tr>
<tr>
<td>Community Mental Health Centers</td>
<td>Meets State eligibility for SMI or SED but is not Medicaid eligible</td>
<td>All services available to SMI or SED population</td>
<td>CMHC; Medicare; insurance; self-pay</td>
</tr>
<tr>
<td>Community Mental Health Centers</td>
<td>Does not meet State eligibility for SMI or SED</td>
<td>Full array of Outpatient Services</td>
<td>Insurance; self-pay; may be limited charity support in some communities</td>
</tr>
<tr>
<td>Peer Support Agencies</td>
<td>Self-report of mental illness</td>
<td>All services of the Peer Support Agency</td>
<td>Mental Health Block Grant; State funds</td>
</tr>
<tr>
<td>Family Mutual Support (community-based)</td>
<td>Families of youth with SED to age 18</td>
<td>Individual and group family-to family support and education</td>
<td>State funds</td>
</tr>
<tr>
<td>Emergency Services</td>
<td>Psychiatric Crises</td>
<td>Assessment; consultation; intervention; crisis counseling (6 sessions)</td>
<td>CMHC; insurance</td>
</tr>
<tr>
<td>New Hampshire Hospital (includes the Anna Philbrook Center for children)</td>
<td>Hospital level of care</td>
<td>Service array for acute inpatient care</td>
<td>State funds; some Medicare/insurance; some Medicaid under age 22 or over age 65</td>
</tr>
</tbody>
</table>
A ROAD MAP OF DIFFERENT JOURNEYS THROUGH THE NEW HAMPSHIRE MENTAL HEALTH SYSTEM
Welcome to Service Quest, your fast and friendly computerized program directing you to the supports and services you need for your family. Busy families like you often don’t have the time to search for the right services, but now, with ServiceQuest, you won’t have to. Your route has been preprogrammed to save you time and energy. In order for Service Quest to work properly and ensure your satisfaction, please follow the directions exactly. If you make a wrong turn, ServiceQuest will simply recalculate the route, but unfortunately this means you will need to go back to the beginning of the map as you may not retrace your steps on the map. Please note that as you move through the map, the directions are given as if you were in a car driving the route. You may find it helpful to turn the map as you go to make sure you are following the directions exactly. In addition, while you are adjusting to the program, the instructions will go slowly, then as you get more familiar with the program, the instructions will go faster. If you get lost, please follow the demonstration at the front of the room. We hope that Service Quest meets your expectations and needs. Enjoy.
This activity was not to see how good you are at mazes, or how high your frustration tolerance is with computer programs that give the wrong directions, but to show you how it can feel to have the services your family needs out of reach. For families with mental health concerns, sometimes finding the appropriate help can seem like a maze leading to dead ends without solutions. However, dealing with these issues in reality is not a simple activity or frustrating maze for families to complete, it is their life. Now, we will show you what the quest for services can look like in real life with two stories from members of our group who have been face to face with the roadblocks they faced and the consequences of the lack of services for families with mental health concerns.
LARRY’S STORY
THE KEEP SOUND MINDS VIDEO
**Strengths** - Comprehensive services for children, adolescents, adults, and seniors. There are psychiatrists on staff, as well as nurses and therapists. Quality of care is generally considered excellent. There is a choice of how therapy and services are administered. Individual, as well as group therapy. Family counseling is also available. If need be, the counseling can take place at the consumer's home. Case Managers can also meet at the consumer's home.

Medication is monitored and adjusted by the psychiatrist as needed. A consumer does not just have one person that they work with. There is a team which consists of the therapist, psychiatrist, case manager, and a vocational specialist.
One added strength with Region 8, Seacoast Mental Health, is the close proximity to Exeter Hospital. It is literally within walking distance. If a crisis requires a consumer to go there, the psychiatrist can easily get to the hospital quickly. A favorable experience was reported because of this. There was a consumer in crisis and needed to be brought to the Exeter Hospital Emergency Room. The consumer's parents had been in touch with SMH, and when they arrived the psychiatrist met them, and was in control of the situation. The consumer and parents were treated with dignity, and given options for treatment. The consumer's parents were also given helpful information on how to care for their child at home.

A strength for all of the Community Health Centers is that they are mandated by the State to provide the same quality and level of care at each center. No matter which center a consumer goes to, the services will be the same. Payment for services is covered by most insurances, including Medicaid. For those uninsured or underinsured, a sliding scale is used.
Weaknesses - Consumers report that one of the biggest weaknesses was not enough male therapists. Frequent staff turnovers was another. Beaurocracy in terms of obtaining services, is the biggest weakness. Consumers and their families can have a difficult time in knowing where to turn, as well as being pointed in the right direction. There are also not enough Child Psychiatrists on staff, and consumers would like there to be more.

Emergency Rooms don't always have a clearly established protocol when it comes to dealing with a consumer who may have both mental health issues as well as a developmental disability issue. Each medical professional needs to be trained in both areas, and informed of protocol, to avoid someone not knowing what to do, and cause confusion, when it can be clearly avoided. When a consumer is brought to the ER, and is identified as someone in crisis, no matter who is approached, there should be immediate knowledge on the next step.
Opportunities –
Resolving the weaknesses will make all the CMC’s more effective. Hiring more male therapists and Child Psychiatrists, keeping the staff turnover to a minimum. See what the common denominator for the occurrence is, and address those issues. Educate families and the public about mental illness, through public service announcements, and other media outlets, visiting schools, holding more seminars. The purpose being to attempt to reduce the enormous stigma associated with mental illness, and to address the ignorance, misconceptions, and misinformation that currently exists.
Threats –

The biggest threat tends to be an ongoing one: Budget cuts and insurance cuts. When this occurs, services become more limited and more difficult to obtain. The other biggest threat is the system itself. Consumers have found difficulty in navigating through the system, which tends to resemble a maze. There are instances where even professionals are prevented from giving referrals, or being prohibited by the HIPPA law, to obtain a full history of the consumer, to better serve them. It becomes difficult and frustrating for both families and professionals trying to help the families, in obtaining services, or even finding the services. The services tend to exist, but with the difficulty in getting to them, they are not widely known about, so families seeking help aren't getting it.
WHAT WE NEED TO DO NOW

- Address the Stigma of Mental Illness
- Education
- Funding
- Resources
National Alliance on Mental Illness - NH

Do:
1. BE CALM and GIVE FIRM, CLEAR INSTRUCTIONS
2. ASSESS THE SITUATION for safety
3. MAINTAIN ADEQUATE SPACE between you and the person
4. INVOLVE and SUPPORT FAMILY if possible
5. BE HELPFUL respond to basic needs
6. GIVE FIRM, CLEAR DIRECTIONS; one person should talk to the subject.
7. RESPOND TO FEELINGS, rather than content.

Avoid:
1. TOUCHING THE PERSON it may cause fear and lead to violence
2. CONFUSING the subject
3. WHISPERING, JOKING OR LAUGHING
4. GIVING MULTIPLE CHOICES this increases confusion
5. STARING AT THE PERSON this may be interpreted as a threat
6. DECEIVING THE SUBJECT, dishonesty increases fear and suspicion; subject will likely remember it in any subsequent contacts.
Someone with a psychiatric illness might... **So you need to...**

- have trouble with reality → be simple, truthful
- be fearful → stay calm
- be insecure → be accepting
- have trouble concentrating → be brief, repeat
- be over stimulated → limit input
- easily become agitated → recognize agitation
- have poor judgment → not expect rational discussion
- be preoccupied → get attention first
- be withdrawn → initiate relevant conversation
- have changing emotions → disregard
- have little empathy for you → recognize as a symptom
- believe delusions → don’t personalize or validate
- have no motivation → stay positive
- have been traumatized → avoid touching

**NAMI NH 1-800-242-6264**
Resources

President's New Freedom Commission on Mental Health

National Institute of Mental Health
www.naminh.org

New
www.nhpolicy.org

http://www.mentalhealthcommission.gov/reports/reports.htm

www.dhhs.state.nh.us