

Report from Listening Session on Accessing Ramsey County Mental Health Services May 2022

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Greetings!

On behalf of the National Alliance on Mental Illness (NAMI) Ramsey County, I am pleased to present this report which summarizes the findings and recommendations from our Listening Session on Accessing Mental Health Services in Ramsey County. Our report is intended to be a springboard for discussion and action to improve access to vital mental health services for those with serious mental illnesses. With timely, effective treatment and supports, we know that they can lead productive and meaningful lives.

We have heard from those experiencing mental illnesses and their family members that Ramsey County must improve its services to those most in need in order to promote recovery; assist with employment; and prevent crises, homelessness, and incarceration. We have also heard that programs need to include family members as supportive partners.

We highly recommend the development of an accredited clubhouse in Ramsey County through Clubhouse International. This will require partnership and investment by the public, private and nonprofit sectors. We look forward to working with county commissioners, officials, advocates, foundations, mental health professionals, people living with mental illnesses and other stakeholders to lay the groundwork for this successful model that is found in over 300 communities in 30 countries around the world.

I would like to thank the following individuals who contributed to our February 10, 2022 Listening Session and to this report:

- Tom Berkas chair of the Ramsey County Adult Mental Health Advisory Council who co-hosted this program
- Sophia Thompson, Director of Mental Health and Adult Support for Ramsey County who provided an overview of county services and supports
- NAMI Ramsey County Listening Session Planning Committee including Joan Cleary, Michele Gran, Kayla Murphy, Colleen Oftedahl and Marly Yang and our NAMI Ramsey staff Katy Jo Turner
- NAMI Ramsey County members Kathy Jackson, Jennifer LaForgia and Joan Cleary who drafted and edited this report
- County residents who shared their experiences with accessing mental health services for themselves, for their loved ones or for those they serve.

NAMI Ramsey County supports, educates and advocates for those in our community living with mental illnesses as well as for their family and friends. Please join us and help make a difference. or more information, visit: https://www.namiramseycounty.org/

Sincerely,

Mindy Greiling, President

NAMI Ramsey County Report from Listening Session on Accessing Ramsey County Mental Health Services May 2022

PURPOSE

In an effort to better understand the accessibility of Ramsey County Mental Health Services, NAMI (National Alliance on Mental Illness) Ramsey County held a listening session on February 10, 2022 for people who have experience accessing such services. The goal was to gather information regarding the effectiveness as well as current shortcomings of this system through first hand accounts from clients and family caregivers. Forty-two individuals attended the program.

NAMI Ramsey County is sharing this summary of our findings and recommendations with county commissioners, pertinent county administrators, lawmakers, and other stakeholders in the hope that the personal stories will inform future decisions to improve mental health service accessibility – particularly for those who need it most.

OVERVIEW

NAMI Ramsey County planned and co-hosted the Zoom session with the Ramsey County Adult Mental Health Advisory Council. Sophia Thompson, Director of Mental Health and Adult Support for Ramsey County, presented a 30-minute description of Ramsey County Mental Health Supports and Services, which included demographic information on clients served. She also provided specific data on four programs: mental health courts, adult targeted case management (TCM), crisis teams and the new voluntary engagement program (designed in Minnesota statute to help avoid the need for civil commitment by engaging proposed patients voluntarily in needed treatment). Ramsey County is currently serving 20 individuals in mental health court and their grant allows for 40 people. The graduation rate is 45 percent. The voluntary engagement program designed to address the pressing need to help individuals who have anosognosia so do not recognize their illness is currently limited to 15 individuals.

Following Ms. Thompson's presentation, the 40 minute listening session began, moderated by NAMI Ramsey County members Kayla Murphy and Marly Yang. In total, during and after the listening session, thirteen people shared their stories.

- Two people with mental illnesses and two mental health workers relayed their
 positive experiences with the now defunct Apollo Center and emphasized the
 importance of establishing a similar community meeting place, e.g, an International
 Clubhouse, in Ramsey County. (Clubhouses offer people living with mental illnesses
 opportunities for such things as friendship, employment, housing and education).
- Another health care worker, a targeted case manager, detailed grave inadequacies within the system and commended families who help their loved ones navigate a complicated system.
- One parent reported frustration with getting help for her son who is living with an alcohol use disorder.
- The remaining seven stories were recounted by parents of adult children with severe mental illnesses. Their stories had astounding similarities with regard to challenges in accessing services for this high-level need population.

KEY FINDINGS

Ramsey County Mental Health Services fall short in serving those most in need, people with serious and persistent mental illnesses (SPMI). Those diagnosed with illnesses including schizophrenia, bipolar disorder, schizoaffective disorder and other mood disorders have the greatest need. They often have an accompanying chemical dependency dual diagnosis.

Accessing available resources is hindered greatly by: bureaucratic red tape; lack of effective and preventative wraparound services; anosognosia (lack of insight, which means the ill person cannot request services themselves or many times even accept them) and navigating the criminal justice and/or civil commitment court system. In addition to those qualifying for civil commitments, many others never reach the level for civil commitment, but nonetheless have many unaddressed, urgent needs. While their situations are extremely complicated, efforts should be made to streamline and simplify the process to access services. Ramsey County espouses the availability of such services, but major roadblocks exist. Additionally, classic hallmarks of certain severe mental illnesses prevent access.

The revolving door of crisis/hospitalization/restabilization for this population is unhealthy, expensive, and far less effective than establishing proactive mental health supports and wraparound services up front. The difficulty in getting help before, during and after a crisis

was a common thread throughout the testimonies. Services for voluntary clients seem adequate. However, the extreme challenges discussed below exist for those with diagnoses that often include anosognosia. Seven of the eight family stories below are shockingly similar and heart-wrenching.

This report highlights major **service shortcomings** for those most in need:

- 1. Accessibility for Involuntary Clients
- 2. Civil Commitment and Outpatient Treatment
- 3. Cycle of Crime/Incarceration/Mental Health Court
- 4. System Navigation/Paperwork Difficulty for People with SPMI
- 5. Lack of Wraparound Services
- 6. Emergency Services
- 7. What Happens When There is No Family to Do Everything?
- 8. Lack of Clubhouse Services

The report calls for recommended improvements for consideration and action by Ramsey County Commissioners and county agency officials in partnership with foundations, hospitals and mental health providers, those living with mental illnesses and their family members as well as other stakeholders. NAMI Ramsey County highly recommends that Ramsey County establish a local clubhouse through <u>Clubhouse International</u>.

Through over 300 local Clubhouses in more than 30 countries around the world, Clubhouse International offers people living with mental illness opportunities for friendship, employment, housing, education and access to medical and psychiatric services in a single caring and safe environment. This social and economic inclusion reverses the alarming trends of higher suicide, hospitalization and incarceration rates associated with mental illness.

MAJOR SHORTCOMINGS

1. Accessibility for Involuntary Clients

Ramsey County must recognize, appreciate, address and prioritize the needs of those experiencing *anosognosia* and those with the most *serious and persistent mental illnesses* (*SPMI*), who, by nature of their illness, cannot recognize they are ill and consequently cannot *voluntarily* seek services.

Anecdotal Listening Session Feedback:

• The system is hardest for those who need it most. It's too complicated for people with SPMI. That's why 911 gets called.

- For those with anosognosia, navigating the bureaucracy is impossible. They don't seek help on their own because they don't believe they are ill.
- Son has anosognosia. Homeless for three years, in and out of hospital, IRTS, overdosed.
- There is such a lack of recognition of anosognosia diagnosis and too much focus on autonomy for a very sick person who can't know it.
- Patients with physical disabilities receive prioritized assistance relative to the severity of their disability. Why is this not the case with serious and persistent mental illnesses?
- Targeted Case Management advocates for clients having choice, but too much choice for people who aren't cognizant can be counter-productive.
- Son no longer has anosognosia but when he uses crack he stops cooperating. Mental health workers say it's his choice and their hands are tied. How can this be when he is very ill and a vulnerable adult?
- The system is geared for voluntary people who aren't as sick as those with anosognosia/and/or Mental Illness Chemical Dependence (MICD). People like my son would never volunteer for help when he's at his worst and needs it most.
- Parents aren't empowered to be listened to when they have adult children who are very ill but not terribly willing to accept help.
- There is minimal recognition of serious and persistent mental illness as a condition akin to other severe health problems rendering individuals in need of long-term support.
- Please let's do things without waiting for a crisis.
- Mom wants to change the system to make it more easily accessible before the person is on the streets or in jail.
- Family was advised to seek guardianship for earlier help but the process took so long and the son no longer qualified by the time the court date arrived.
- Improve the voluntary engagement program (see above). Increase opportunities for people to participate in the program. Limiting it to 15 clients will not meet the need.

2. Civil Commitment and Outpatient Treatment

Civil Commitment is difficult to obtain. Those without strong family support to help navigate the complicated system will not obtain commitment and will likely be homeless. If/when commitment is finally achieved, the patient has already demonstrated substantial need and now deserves stabilization support, sustained and adequate wraparound services, and appropriate housing.

- Civil commitment helps but only begins when a person is a danger to themselves or others.
- Those who are civilly committed need the most help. They should "go to the front of the line." The commitment designation ought to be enough to demonstrate the great need for more services, including housing and wrap-around services.
- Son's parents know without commitment he would be on the streets and homeless.
- After civil commitment, monthly injectable medications help.
- Hennepin County Medical Center (HCMC, now Hennepin Health) recommended commitment for son. Ramsey County petitioned for commitment, until they found out he was homeless and in a Hennepin hospital. (Police took him from Ramsey to HCMC when there was no bed in Ramsey.) Hennepin referred the son back to Ramsey and when nothing happened there, the hospital discharged the son on foot.
- It's difficult to achieve civil commitment.
- After three years of struggle, son was finally committed to Anoka Regional Treatment Center and now resides in a traumatic brain injury facility in Duluth where he's safe. He is taking meds and no longer paranoid.
- What does it take to get someone committed? Her son is a wonderful man with severe alcoholism, depression and anxiety. He's unemployed and not allowed to see his children. He calls 911 once or twice per week. She's tried fruitlessly for civil commitment without success. Mom believes commitment would break son's cycle.
- Even with a MICD civil commitment in place and court-ordered treatment, son has been turned down by eight treatment centers. Still waiting for placement.

3. Cycle of Crime/Incarceration/ Mental Health Court

- Son was arrested, jailed many times, admitted to ER, in and out of court. "He was caught in the criminal justice system and it was a nightmare to get him out."
- Son couldn't be diverted to Mental Health Court because he had no mental health diagnosis yet.
- Son did well in Mental Health Court.
- Son was not diverted to Mental Health Court so sent to District/Felony Court. Family wouldn't have pressed charges for their home being burglarized had they known that would happen. Ramsey County needs to serve more people in Mental Health Court and not criminalize people who are very sick.

4. System Navigation/Paperwork Difficulty for People with SPMI

Anecdotal Listening Session Feedback:

- Daughter witnessed her mother struggle on the phone for 90 minutes, then said, "The system only works for my brother if my mom can help him access it."
- Son isn't able to get services on his own. He could never deal with the phone calls that pass the caller from person to person.
- Son can't fill out paperwork for TCM on own so doesn't have one. Mom tried to help but faxes got lost. It was a nightmare.
- Son's Supplemental Nutrition Assistance Program (SNAP) benefits lapsed for two months. TCM hadn't helped with this or even noticed the son wasn't receiving funds. When mom noticed, TCM blamed it on the county financial worker. That person didn't answer the phone. Mom has never had a good experience with any of the financial workers. Mom fed son during lapsed paperwork for SNAP and now has marked her calendar and does the paperwork. Shouldn't the county worker be doing this?
- One mother tried relentlessly to contact and speak with the listed county financial worker. To no avail.
- Paper work is overwhelming and mom feels insecure with this level of help.
- What happens to the poor kids without families to help with all this?
- Processes are so complicated that only those clients with professional parent advocates stand a chance of getting and retaining services.

5. Lack of Wraparound Services

SPMI patients require a much higher case management approach than those with less severe mental illnesses. As such, they require improved and more frequent case management. This management should include a *comprehensive and sustained* plan which coordinates *all* aspects of the case and patient needs - past, present and future anticipated needs.

Anecdotal Listening Session Feedback:

Targeted Case Management (TCM)

Mom has been asking for a TCM for son since September. Her son was given
paperwork but couldn't complete it. Bureaucratic red tape prevented her son from
being assigned a Targeted Case Manager (promised by December, 2021), but still
nothing and currently her son is homeless.

- A Targeted Case Manager spoke: would like to see clients get more services, e.g., in a hub where people can connect. Allocate funds there for better service coordination.
- Targeted Case Management says when families partner with a TCM it helps individuals better. It's hard for moms to get connected.
- Son had a very good crisis case manager, but when no longer in crisis he got passed around to TCMs who are pretty good to not very good. One always set appointments for mornings when the son was comatose from his boatload of meds and failed to understand why. She questions their training and real life experience.
- MICD There's a lack of recognition of the CD (chemical dependency) part and a lack of MICD services.
- There needs to be less piecemeal services and one person who is really responsible for each SPMI person.
- There are funds for the opioid crisis. Use some of this money for wraparound services for people with MICD and other chemical dependencies.

Intensive Residential Treatment Services (IRTS)

- The IRTS facilities are limited to a maximum stay of 90 days and then you time out before you're on your feet. They are better for less sick, voluntary patients. But for her son not so much: it was easy for him to run away and he did several times; there was no follow up.
- Mom called repeatedly to get son into an IRTS. Once in, he escaped and took a plane to Duluth.
- IRTS has counseling and classes for voluntary participation. This counseling should be required for patients who are SPMI and experience anosognosia so they can receive much-needed education into their illness/situation.

Homelessness/Housing

Lack of supportive housing options is a fundamental problem.

- My psychiatrist told me to stay in a homeless shelter for at least one night to get housing. It took a while but worked.
- Housing is available for those with cognitive and physical disabilities. Why is it not a priority for those with SPMI (severe and persistent mental illnesses)?

Employment

Employment services are sorely lacking for SPMI.

- Vocational Rehabilitation services offered through the Minnesota Department of Employment and Education are not geared to them.
- Individual Placement and Support (IPS) services, designed specifically for this
 population and that evidence shows work, aren't typically offered to them. •
 Clubhouse International helps with employment.

Other Support Service Needs

- CADI Funding improvements: CADI funding can help with housing costs. Licensed social worker who is also the parent of an adult child living with mental illness sees significant limitations of CADI funding.
- Personal Care Assistants (PCA): Would help support SMI clients.
- Peer Counselors: Son had a positive experience with an excellent peer counselor but after two visits, the person disappeared. Mom almost would have rather they hadn't met at all since it built up failed expectations.
- Assertive Community Treatment (ACT) Team: Difficult to obtain for my SPMI son who has been committed twice in three years.
- Priority Access to Support Services: Are people who haven't been committed getting ahead of him? If so, why?

6. Emergency Services

While families generally appreciated the emergency services, they expressed frustration in the following areas:

Crisis Teams

- Didn't show up for 1½ hours and by then my son had taken off.
- Son goes to the hospital voluntarily via crisis team once or twice a week but is released in one to two days at most and sometimes not admitted. They are great but we're all throwing up our hands.
- I don't call them anymore because our son isn't voluntary and doesn't meet their criteria until we don't have time to wait for them.
- They are caring people, but their hands are tied by: "must be a threat to themselves or others" law. There needs to be exceptions: the law needs to consider those with anosognosia who lack insight into their condition and have very serious mental illnesses and are often delusional.

Law Enforcement

- After the crisis team didn't show up until son had taken off, mom called the police who took him to the hospital.
- Happy to hear about embedded social workers. Huge progress in the last 10 years.
- Ramsey County Sheriff's Department was great when they finally picked him up due
 to an apprehension warrant after civil commitment revocation due to meth use.
 Came in an unmarked car/plain clothes. But this was only after several days of
 coordination via telephone with mom, caseworker and the sheriff's department. Use
 of specialized units and police with MI training should continue to improve.

Hospital Beds

- Son waited in the ER for over 24 hours without a bed; when admitted he was barely there before being released.
- Huge problem with not enough beds.
- Police had to take the son from Ramsey to Hennepin Health (formerly called Hennepin County Medical Center) for a bed.

7. What Happens When There is No Family to Do Everything?

Parents expressed grave concern over who will care for their loved ones after they are gone. The system needs to provide a much, much higher level of care, care coordination and proactive wraparound services for those most vulnerable, specifically, those with an SPMI diagnosis or those on the path to such a diagnosis. There is also concern for such patients who currently lack supportive families. Who is caring for them?

Worry about future care for their loved ones with SPMI by aging/dying parents

Anecdotal Listening Session Feedback:

• Licensed social worker and mother of SPMI young adult: "Only those clients with a professional parent advocate stand a chance of getting and retaining services. While the costs are likely less to care for folks by providing: housing, PCAs, transportation and supportive employment than the cost of keeping folks stuck in the revolving door of homelessness, incarceration, hospitalization, discharge to short-term care, repeat, the will to establish permanent supports are lacking. Some of my clients have died in this cycle. I need to know that Ramsey County will step up so that when my advocacy fades with my aging, this will not be the fate of my son. He, by the way, has beaten the statistical odds by obtaining a two year degree and is working full time despite multiple disabilities."

- Son is better now but mom is worried about when she and husband die. Then she knows he will fall apart and be homeless or worse.
- Young woman with mental illness said her mom worries about what will happen to her when she dies.
- Parents in their seventies are worried about how SPMI son will cope after they can't take up slack for a mental health system that fails to meet his needs.
- Parents don't live forever and even when they are alive, they shouldn't have to also serve as full-time case managers. We should look at all we do for people with developmental disabilities or people with Alzheimer's and try to be more humane with people with SPMI.
- There is a thin level of support given to people with mental illnesses and their families.

8. Lack of Clubhouse Model

Not having a Clubhouse is a huge hole in Ramsey County's service model.

- Having a Clubhouse would help with Ramsey County's lack of employment services for SPMI. Clubhouses offer wraparound employment help and over the top help after a person gets a job.
- TCM says she's only required to contact her many clients once a month, but things can change in a day or two.
- Clubhouse needed in Ramsey County. Since Apollo closed, there isn't a safe place for SPMI to go.
- <u>Vail Place</u> (local clubhouse in Hennepin County) accepts people from Ramsey but clients would love to have a closer site in Ramsey.
- Vail Place attendee who lives in Ramsey takes a bus for 1½ hours to get there. She would love to see a Clubhouse International in St. Paul. She's happier there and participates in many activities and is kept from the hospital.
- Another Ramsey attendee in the Hennepin Clubhouse says drop-in places help her.
 She used to go to centers for homeless youth, but has aged out. She also must take the bus to get there.
- Vail Place has helped with socialization and employment.
- Worker with Ramsey County Crisis Center emphasized the importance/effectiveness
 of drop-in centers. Much needed in Ramsey. Without a Clubhouse there is no ability
 to refer clients, especially frequent clients, to a day-to-day program. People can make
 friends at a Clubhouse and have a place to go for holidays.

- Case manager says her clients need more connectness than she can provide.
- Mom wishes son had found friends at a Clubhouse instead of his crack-using ex-girlfriend who ruined his life for four years.

RECOMMENDATIONS

NAMI Ramsey County calls for a collaborative approach to "think outside the box" and effectively address these shortcomings by taking the following action steps:

- 1. Establish a Ramsey County Chapter of Clubhouse International.
- 2. Create a task force comprised of a variety of stakeholders to:
 - a. Audit, report and improve existing services and service accessibility for those most in need including but not limited to Voluntary Engagement Services, Mental Health Court and IPS.
 - b. Organize and provide services that give much higher priority to people with serious mental illnesses who are falling through the cracks. Create a classification system for identifying and serving those most in need.
 - c. Create proactive procedures to help identify and provide supports to the neediest during the period between stabilization and full blown crisis. This void is what needs and deserves the most attention.
 - d. Plan, launch and evaluate a series of creative pilot programs to help those most in need.

About NAMI Ramsey County

Governed by a voluntary board, NAMI Ramsey County supports, educates and advocates for those in our community who live with mental illnesses as well as for their families and friends. We are an affiliate of NAMI Minnesota and national NAMI. We are committed to diversity, equity and inclusion. For more information, visit: www.namiramseycounty.org