



Mood Disorders Society of Canada
Société pour **les troubles de l'humeur** du Canada

www.mooddisorderscanada.ca

Mood Disorders Society of Canada

Pan-Canadian Opinion Survey

November 2011

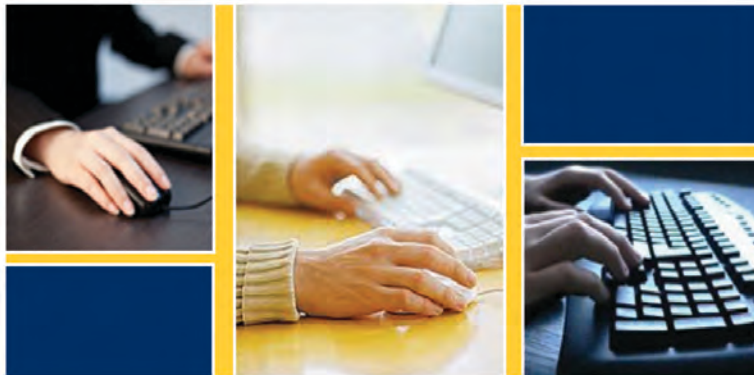


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Executive Summary

The Canadian health care system continues to come up short for individuals with mental illnesses according to the findings of the September 2011 pan-Canadian opinion survey of the mental health community by Mood Disorders Society of Canada (MDSC).

The Canadian mental health community spoke up and expressed serious concerns over shortages in many aspects of the mental health system causing significant problems for individuals with mental illnesses, their families and caregivers.

The survey identified the following key shortages for individuals with mental illnesses:

- The number of health care professionals available to treat individuals with mental illnesses causing lengthy delays for a diagnosis and proper treatment;
- Covered insured services forcing individuals with mental illnesses to incur debts or go without treatment;
- Health care professionals able to treat individuals with mental illnesses in the ER forcing these individuals to wait dangerously long periods of time;
- Hospital beds and follow up thereby forcing individuals with mental illnesses back out to the community with little or no support;
- The level of respect and dignity from front line workers leaving individuals with mental illnesses feeling frustrated and unworthy; and
- Community support leaving individuals with mental illnesses nowhere to turn.

The survey did point out some positive aspects of services in Canada. For example, 91% of respondents with a mental illness had a family doctor, 52% saw their family doctor for their mental illness and 46% were very to extremely satisfied with their family doctor for treating their mental illness



Background

In order to collect opinion about the experiences and concerns of the health care system among the Canadian mental health community, Mood Disorders Society of Canada conducted an online survey in September 2011.

The survey was circulated to approximately 10,000 people within the MDSC network and was subsequently circulated to their networks, thus the total distribution was not known. The survey received 3,125 responses. In some cases, over 500 individuals provided additional written comments to questions in the survey. In our experience, this is a significant response rate and reflects the level of engagement and eagerness of the community to express and share their concerns about the Canadian mental health care system.

What we learned through this process is that significant gaps in the mental health care system continue to be ignored by our health policy makers.

Key findings

- Our survey indicated that 35% of the respondents with a mental illness waited more than 12 months for a diagnosis. It is unacceptable to us that individuals who seek medical attention for their mental illness continue to wait lengthy periods of time before they receive a diagnosis.
- Fifty-nine percent (59%) of respondents reported that uninsured services prevented them from seeking the type of support they would have liked such as health care services from a therapist, psychologist, alternative health care, or other. The lack of insured services prevented the majority of individuals with mental illnesses from seeking the support they needed.
- Fifty-two percent (52%) of respondents reported visiting a hospital emergency room because of their mental illness, and of those respondents 50% indicated that they were moderately to extremely dissatisfied with the care they received at the emergency room; 24% alone were extremely dissatisfied. Wait times in emergency rooms continued to be very long and negative attitudes towards people with mental health issues from front line workers persisted.



- Sixty-five percent (65%) of respondents indicated that their local hospital did not provide adequate care for patients with mental illness. The number one reason selected was that the hospital “does not seem to prioritize mental illness”. Respondents to the survey were so passionate about the level of care provided by their local hospital that 27% shared a written comment in addition to selecting their response from the list provided. We were dismayed to learn that the level of care provided to individuals with mental illnesses in hospitals across Canada remained very poor.
- The highest percentage of respondents, 41%, indicated that “increase funding for mental health services” was the issue that government must act upon immediately followed by 22% who selected “develop more safe affordable housing.”
- When asked directly, the majority of respondents, 56%, reported that their number one funding priority was to shorten wait times to get mental health services (from patient request to time of receipt of services).

Limitations of the survey – the survey was designed to gather opinions from the mental health community about its concerns and experiences with the Canadian mental health care system. The information is qualitative and meant to inform the work of the Mood Disorders Society of Canada regarding its position statements on various mental health policies. MDSC believes the opinion survey results accurately illustrate the respondents’ experiences and provides a fair reflection of the mental health care system from the viewpoint of the user, family member and other stakeholders. In our opinion, it does not necessarily reflect the attitudes of individuals who are not currently using and/or do not have access to mental health services.

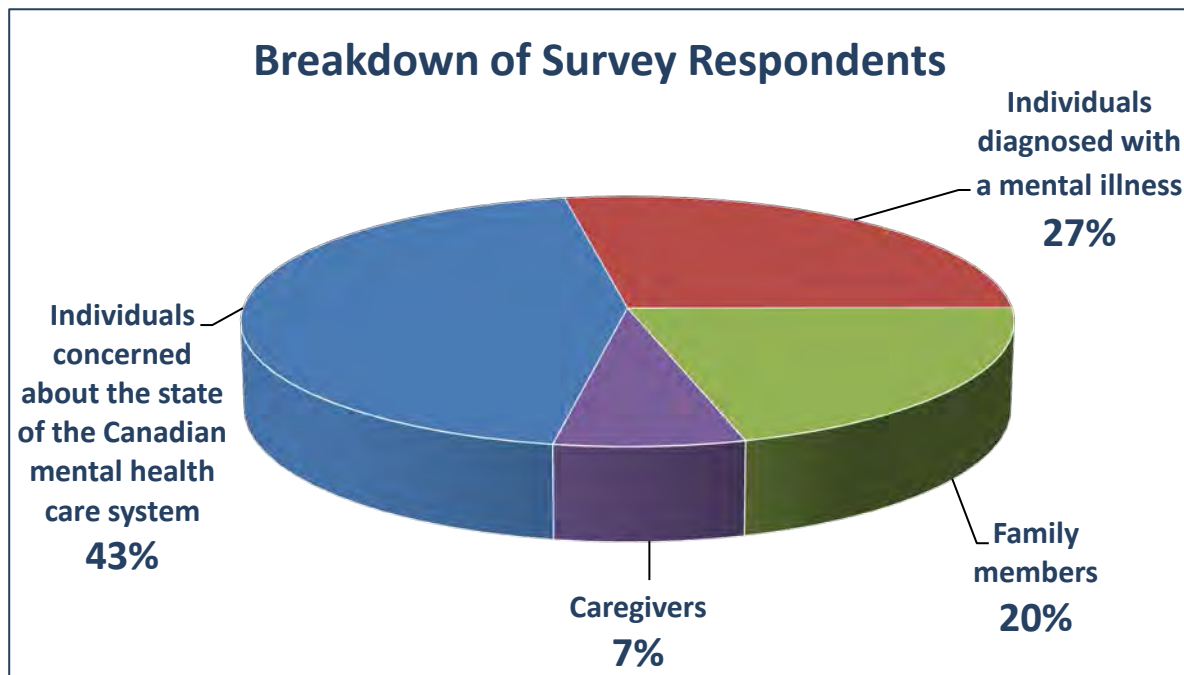


Introduction

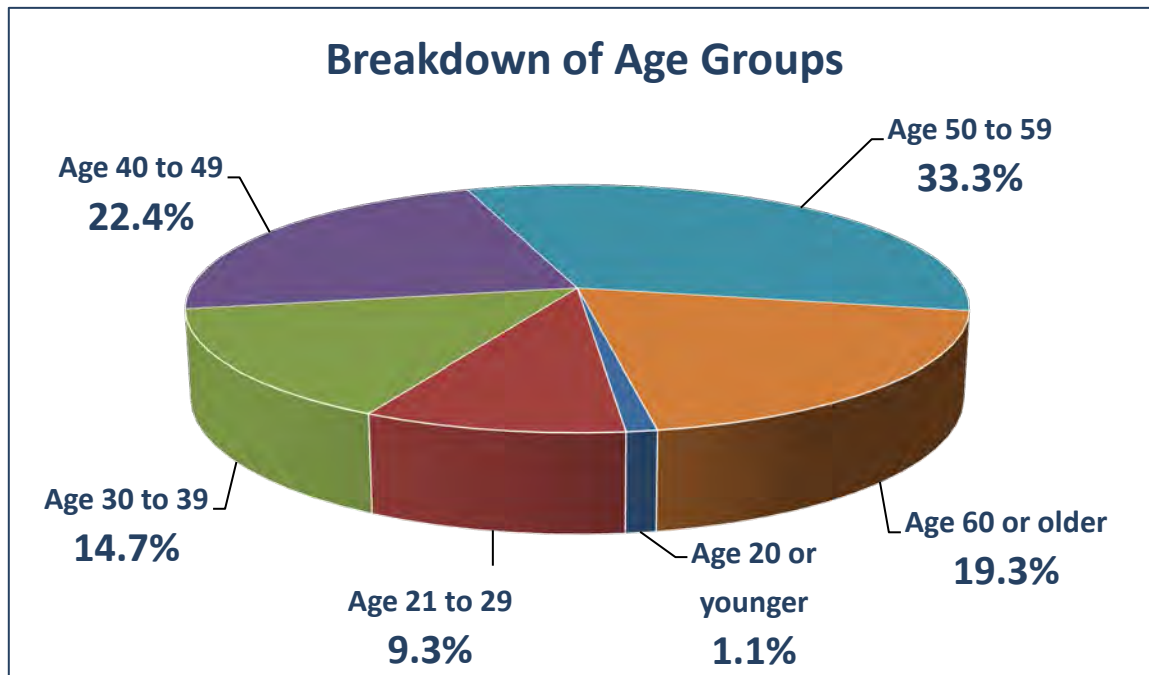
This report is an analysis of the results of Mood Disorders Society of Canada (MDSC) pan-Canadian opinion survey conducted in September 2011. The purpose of the survey was to help MDSC to better understand the experiences and concerns of the Canadian mental health community with the mental health care system and to be able to express those concerns to Provincial, Territorial and Federal levels of government.

Who responded

A link to the survey was circulated to approximately 10,000 people within the Mood Disorders Society of Canada network and was subsequently circulated to their networks, the total distribution was not known. It was also placed on the MDSC website. Individuals were given four weeks to respond. The survey received an impressive 3,125 responses from individuals with a diagnosed mental illness, undiagnosed mental illness, family members and caregivers, as well as individuals concerned about the mental health care system. While respondents were not specifically asked to identify themselves as a health care professional, we know from the written responses and verbal comments received, that health care professionals were included among the respondents. The following chart provides the survey respondent breakdown.



The majority of respondents, 77%, were female and the age breakdown was as follows:



Key findings among individuals with a mental illness both diagnosed and undiagnosed

Length of time to diagnosis

The survey revealed that the length of time to receive a diagnosis was still far too long. It took more than 12 months for the greatest number of respondents (35%) with a mental illness to receive a diagnosis from the time they first sought medical attention. On a positive note, 26% responded that they received a diagnosis immediately.

Key Findings

Individuals
with a
mental illness



Level of satisfaction with family physicians

The majority of individuals with a mental illness, 91%, had a family physician and 52% saw their family physician for their mental illness. While 45% reported being very to extremely satisfied with their family physician, 15% were moderately to extremely dissatisfied with the manner in which their family physician was treating their mental illness. Many who provided comments site general lack of knowledge and limited time for mental illness as the key reasons for their dissatisfaction with their family physician.

“Family doctors do not have the time to diagnose properly. They are not experts with mental illness. It wasn't until I was in emergency at the (city name removed) General Hospital that someone took me seriously that I had mental illness.”

Level of satisfaction with health care professionals (including family physician)

The majority of the respondents with a diagnosis, 73%, continued to see or have seen a psychiatrist for their mental illness. While 51% reported being very to extremely satisfied with their health care professional, a total of 16% reported being moderately to extremely dissatisfied with their health care professional for treating their mental illness. Those dissatisfied with their health care professional sited misdiagnosis, no diagnosis, stigma, lack of understanding, lack of funding, shortage of health care professionals, and shortage of time with a health care professional as key reasons for being dissatisfied with the care they received.

One in five respondents indicated that their health care professional responded only “slightly quickly” or “not quickly at all” when they needed help, and 6% responded that their health care professional did not listen to them at all. Twenty-one percent (21%) reported that it was not at all easy to schedule an urgent appointment with their health care professional.

Many of the individuals surveyed have given up on the system, since they have found that it does not work for them. Here are some quotes that expressed the sentiment of many.



“Currently not seeing a professional. The system doesn't have enough resources, quite frankly, I've given up and I'm just managing as best I can on my own, going to a practitioner only if a specific symptom becomes overwhelming (ie, I need a script for treating acute insomnia).”

“Upon referral to the mental health system in (city name removed) I was informed that since I wasn't in crisis the system had no place for me due to its strained resources.”

“...overall I am still disappointed with the lack of accurate knowledge and stigma that still exists in the medical community (particularly among family doctors).”

“I have had problems since I was a teen, treated when I was in late 30's saw many health care professionals, only found one who could help, have no mental health support currently.”

“I'm disappointed that referrals take too long, it could be hazardous to someone in a crisis situation.”

“The wait times for psychiatric care in (province name removed) is beyond unacceptable. If it weren't for private practitioners (very expensive) I might be dead”

Uninsured services

Fifty-nine percent (59%) of respondents reported that uninsured services prevented them from seeking the type of support they would have liked such as health care services from a therapist or psychologist, alternative health care, or other. Uninsured services continued to be a major barrier for the majority of respondents seeking help for their mental illness.

“I need a LOT more support than two hours a month. I've attended (name of location removed) twice and it helped a lot, but I'm still suicidal after almost five years and there's no other help available to me. I'm getting worse with only seeing my therapist twice a month and that's all the time she has.”



“What the government supplies, I now consider worse than useless. There is no use in giving me 3 months of therapy and then having the government decide that I have reached a limit. It is dehumanizing!!!!”

“I would continue with therapeutic treatment but simply can't afford it. Have found it very helpful in the past when covered by insurance, I no longer have insurance.”

“It took me 13 years to find good qualified psychologist and she is the only one in the community but paying for long term counseling has put me in debt because government doesn't fund psychologists.”

“I pay out of pocket any time for the pain or die.”

“In the past, sessions with the therapist have been limited to 6 or 10 maximum which caused more hardship than help.”

Clinics and emergency rooms

Clinics and emergency rooms continued to be used by a majority of individuals with mental illness. Fifty percent (50%) of the respondents with a mental illness reported using a clinic because of their mental health issues and 25% indicated that they were moderately to extremely dissatisfied with the care they received at the clinic; 14% alone were extremely dissatisfied.

Fifty-two percent (52%) of respondents reported visiting a hospital emergency room because of their mental illness, and of those respondents 50% indicated that they were moderately to extremely dissatisfied with the care they received at the emergency room; 24% alone were extremely dissatisfied. Twenty-two percent (22%) of respondents provided comments to express their concerns with the level of care at hospital emergency rooms.

Respondents reported using the emergency room as a last resort when they have suicidal thoughts. It is very concerning that in these cases, individuals were left to wait extremely lengthy periods of time and in many cases were not treated with the sensitivity required.



Survey respondents indicated that stigma associated with mental illness continued to be prevalent in emergency rooms; 43% reported that it was not easy at all to talk to hospital staff about their mental health issues and 19% indicated that the staff was not all responsive to their questions.

“48 hours waiting, 10 min rushed consultation”

“I would never go back. They treated me with total lack of respect...laughed about me to another staff and I am not being paranoid but you see the problem...I cannot complain as they think I am "Paranoid". Anyone else would be taken seriously. People with mental illness are treated like we do not matter by most hospital workers with the few exceptions. I am willing to go speak to try and change this.”

“When I've been suicidal it's been excruciatingly painful to wait in the emergency room for hours. A few years ago my local hospital built a little alcove, which helped a bit, but still didn't seem safe or private. When I've been taken in as an emergency rather than self presenting I believe it was faster, but I can't remember those times very well.”

“It's very hard to go to an emergency for mental health emergency. The system is now designed not to keep you there because of budget restrictions(no of beds, staff, etc..) it's not easy to be turned away when you need help and feel you cannot stay alone because you are afraid of yourself and your actions.”

“Mental health care in the ER tends to leave me feeling even more crazy when I leave than when I arrived.”

Access to medications

Eighty percent (80%) of respondents were able to access the medications they needed. Seven percent (7%) were not able to access the medications they needed, and 11% responded that they did not need medications. Even though many respondents indicated that they could access the medications they needed, many expressed that it was financially difficult to do so and that they had to make sacrifices to pay for their medications.

“I am working in a toxic work environment only so I can afford my meds.”



“Yes, however it is a financial hardship.”

“Inappropriately expensive. I skip doses to make meds last longer.”

Information about medications

The majority of respondents reported that their health care professional provided information about side effects, length of time before the medication starts working, the choice of medications available. Only 17% reported that their health care professional provided information on alternatives to medications such as hypnotherapy, acupuncture, meditation, etc.

Key findings among family members and caregivers

The responses by family members and caregivers generally reflected the responses from the individuals with a mental illness. Family members and caregivers expressed a higher level of dissatisfaction with health care professionals as well as the care provided in clinics and hospital emergency rooms.

Key Findings

**Family
members
and caregivers**

Level of satisfaction with health care professionals

Thirty-five percent (35%) of family members and caregivers were moderately to extremely dissatisfied with health care professional for treating mental illness, 9% of these respondents were extremely dissatisfied.

“Schizoaffective disorder diagnosed plus addiction, only sees psychiatrist twice a year, he goes off his medication and becomes hospitalized several times a year, has been in jail and homeless and no counseling has ever been offered, seems no institution or system can help him and we are living in fear that he will die.”

Uninsured services

There was an even split among family members and caregivers that reported that uninsured services prevented and did not prevent their family member or person they provided care for from seeking the type of support he or she would have liked (42% each); such as health care services from a therapist, alternative health care or other. Sixteen percent (16%) did not know.



A number of respondents who provided written comments indicated that more services would have been sought if they were insured. Comments received made reference to psychologists, therapists, and alternative health care providers.

“We would seek more help if services were insured.”

“He did see a Psychologist in the past but the cost is prohibitive.”

“This family member died by suicide April 28, 2002.”

“Insured coverage for a therapist or clinical psychologist would be very beneficial.”

“I believe his problems would not have escalated to the point they are if rehab/and mental health help were available.”

Clinics and emergency rooms

Sixty-one percent (61%) of family members and caregivers indicated that the person they provided care for or their family member used a clinic. Twenty-five percent (25%) of these respondents were moderately to extremely dissatisfied with the care received at the clinic.

Seventy percent (70%) of family members and caregivers indicated that the person they provided care for or family member used a hospital emergency room. Thirty-nine percent (39%) of these respondents were moderately to extremely dissatisfied with the care received at the hospital emergency room; 26% were extremely dissatisfied.

Lack of resources, stigma, long wait time, denied access, disrespectful staff, lack of quiet space, no follow up were some of the key issues identified by family members and caregivers when they made references to their hospital emergency room experience.

“We went in at 11 pm because my daughter cut her wrist. We were not seen by a psychiatrist until 2 pm the next day while we watched many patients taken before us. Then doctor brushed her off and sent her to see her own doctor who was on vacation for a week. Useless service, demeaning, exacerbated her feelings of low self-esteem.”



“Not enough specialized training in the ER, no service available in remote area, need an emergency psychic person at all times”

“There was no consideration given to the family and the need for a continuum of care. The focus was on short term wellness.”

Key findings among all respondents

Key Findings

All
respondents

Hospital care

Sixty-five percent (65%) of respondents indicated that their local hospital did not provide adequate care for patients with mental illness. The number one reason selected was that the hospital did not “seem to prioritize mental illness” (19%), followed by the “wait to see a health professional was too long” (18%), followed by there was a “perceived lack of concern for patients with mental illness” (16%).

There was a lot of interest and concern expressed about hospital care for individuals with mental health issues. Twenty-seven percent (27%) of respondents provided written comments to this question. They cited lack of resources (beds), hospitals not properly equipped to help patients with mental illnesses, stigma added to problems with care provided, patients were released too soon with little to no follow up and gaps existed between the hospital and community.

This comment summarizes the statements of many of the written responses.

“The resources are not available in the hospital. Beds are limited, patients are discharged without follow up care in place, long wait lists for out patient care.”

Other relevant comments:

“There are not enough beds, so patients are triaged and many are not admitted when they should be. Patients are not kept long enough to stabilize on their meds. Therapy is not provided. Staff do not spend enough time with the patients, are not compassionate, and referrals to outside community supports are not made.”

“Facilities are inadequate and treatment time is too rushed.”



“If there is NO Canadian Mental Health Plan in Place how can we expect ANYONE to put it on the radar?”

“It's not so much that the hospital's services are inadequate, but more that a hospital can only do so much. I think hospitals need to have better connections with community resources and help patients to get more adequate aftercare, and to help identify gaps they encounter in community services that lead to readmits.”

Mental health services

Respondents rated “access to a health care professional” as the most important service for those living with mental illness. This was followed in order by “counseling”, “psychiatric services”, “access to hospital”, “support services (such as peer support, online forums, etc.)” and “treatment with medications”. It is worth noting that each one of these services, with the exception of treatment with medications, were reported to be extremely important by more than 50% of respondents.

Mental health services in Canada versus other countries

The majority of respondents reported that in their opinion Canada is not doing well in all areas listed with respect to providing services for mental illness compared to other countries. The areas where Canada was rated to be furthest behind was in “providing adequate mental health services in rural communities”, followed by “providing safe affordable housing for persons with mental illness”. The area where Canada rated the highest when compared to other countries was in “providing training and support for family doctors”, however, 37% of respondents indicated that Canada was not doing well at all in this area.

Government action required

The highest percentage of respondents, 41%, reported that “increase funding for mental health services” was the most urgent issue for our government to act upon followed by the need to “create more community mental health services”, and “develop more safe affordable housing”. The item that ranked the least urgent among survey respondents was the need for “increased funding for mental health research”. Again, this question received a lot of attention; more than 16% of respondents provided a written comment rather than make a selection from the list provided.



Funding priority

“Shorten wait times to get mental health services (from patient request to receipt of services)” was the number one funding priority among the majority of survey respondents (56%). This is consistent with the responses to other questions where problems cited included lack of resources and shortages that exist across the Canadian mental health system.

Positive findings

While we firmly believe that there are tremendous shortages throughout the mental health system, the news was not all bad; there were some positive findings in the survey.

The survey reported that 35% of the respondents diagnosed with a mental illness waited more than 12 months to be diagnosed but 26% were diagnosed immediately.

Ninety-one percent (91%) of the survey respondents with a mental illness had a family doctor, 52% saw their family doctor for their mental illness and 46% were very to extremely satisfied with their family doctor for treating their mental illness. This was positive, but does not diminish our concerns for the 17% who were moderately to extremely dissatisfied with their family doctor for treating their mental illness.

The survey revealed that 73% of respondents with a mental illness saw a psychiatrist, 40% saw a psychologist, 22% saw a mental health worker. This tells us that individuals were reaching out and that the majority, 77%, were moderately to extremely satisfied. Once again, we remain concerned about the 16% who were moderately to extremely dissatisfied.

Eighty-two percent (82%) of respondents were able to access the medications they needed to treat their mental illness. However, some of the respondents wrote that this meant going into debt, rationing drugs, and staying in stressful situations to take advantage of benefits programs.

The majority of health care professionals provided extensive information on medications; only 17% provided information on alternatives to medications such as hypnotherapy, acupuncture, meditation, etc.



Summary

While we have made some gains in the mental health care system, there are still many areas where improvements are desperately needed. Clinics, but more importantly, hospital emergency rooms are not well equipped to deal with individuals presenting with a possible serious mental illness. In hospitals, individuals are left to wait unacceptably long periods of time, often in a state of psychosis with suicidal tendencies. Lack of personnel is not the only issue; we received many comments about the ongoing incidents of stigma, lack of knowledge, lack of respect and lack of appropriate waiting areas in hospital emergency rooms.

Local hospitals do not provide adequate care for mentally ill patients, according to 65% of the survey respondents. The number one reason cited is that the hospital does not seem to prioritize mental illness. The comments provided in the survey refer to lack of resources (beds), hospital not properly equipped to help patients with mental illnesses, stigma added to the problem with care provided, and gaps existed between the hospital and community,

Many individuals with mental illnesses continued to wait too long to receive a diagnosis. Thirty-five percent (35%) of survey respondents reported waiting 12 months or longer for a diagnosis. The comments we received cited the shortage of professionals across the board available to diagnosis and treat individuals with mental health issues.

The majority of respondents, 80%, indicated that they were able to access the medications they needed, however, 59% reported that uninsured services prevented them from seeking the type of support they would have liked such as that of a therapist, psychologist, or alternative health care provider.

“Increase funding for mental health services” was reported as the most urgent issue for our government to act upon by 41% of the respondents. “Shorten wait times to get mental health services, from patient request to receipt of services”, was the number one funding priority among 56% of survey respondents.





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