

Mayview Regional Service Area Plan (MRSAP) Summary Report: Phase 2 Consumer and Family Assessment Results

Executive Summary

In partnership with the Department of Public Welfare (DPW), Allegheny, Beaver, Greene, Lawrence and Washington Counties are working together to strengthen their community behavioral health systems. This planning process includes consumers, family members, providers and other stakeholders. The primary goal of this effort, called the Mayview Regional Service Area Plan (MRSAP), is to help individuals with mental illness live in their home communities, not Mayview State Hospital. From the beginning, the planning group has been committed to following recovery principles.

In 2005-2006, the Assessment and Discharge Planning Committee, part of the regional planning group, began the development of the assessment and community support plan (CSP) process. This Committee includes consumers, hospital staff, community provider liaisons, state employees, and county representatives. The Committee developed the assessment and CSP process based on the belief that understanding people's preferences and interests, not only for treatment and housing but for daily activities and supports, is essential in a recovery-focused process.

The assessments include three separate tools: a peer assessment, family assessment, and clinical team assessment. All counties have a Consumer and Family Satisfaction Team (CFST), a group of consumers and family members trained in interviewing. A consumer working for a CFST conducted a face-to-face interview with each person at Mayview and did phone interviews with any family members that consumers gave the CFST permission to contact.

This report summarizes the peer and family assessment responses for the 52 Mayview residents selected to participate in Phase 2 of this project. Of these 52 residents, 46 chose to complete a peer assessment; 17 family members completed a family assessment. These assessments, completed between September and November 2006, describe what people want and need when they transition to the community.¹

Age, Gender, Race, County and Length of Stay

Of the people selected for Phase 2, the majority are from Allegheny County (38 people, 73%), followed by Beaver and Washington Counties (6 people, 12% each) and Lawrence County (2 people, 4%). About half of the people are male, and about 60% are white, 21% are African American, and 10% said they were of an "other" race or ethnicity. The majority of people have had long lengths of stay at Mayview:

- 15 people (29%) had stays longer than 10 years
- 14 people (27%) had stays between five and 10 years
- 22 people (42%) had stays between two and five years
- Only one person had been in Mayview less than two years

¹ This report does not include results of the clinical assessments for two reasons. First, the clinical assessment includes different questions than the peer assessment, making comparisons between the two difficult. After the first phase of the project, the Office of Mental Health and Substance Abuse Services (OMHSAS) asked the CFSTs to complete peer assessments with all state hospital residents with stays over two years. As part of this project, the state-wide CFST organization made some changes to the MRSAP assessment that were adopted locally. The clinical assessment questions were not changed, although some sections on residential history, physical health and psychiatric health were added. Second, not all of the clinical assessments had been completed at the time of this report. Clinical assessments are completed just prior to the consumer's first community support plan meeting.

Housing

People have strong preferences about where they live, and the amount of support they need.

- 41% of consumers strongly prefer living alone independently, and 52% strongly prefer living with family. (Note: In completing the assessments, consumers could choose “strongly prefer” for more than one housing type.)
- A significant minority strongly prefer transitional (33%) or permanent group (24%) settings, although an even larger number do not want to live in these settings at all.
- No matter what housing people prefer, most still want support staff, whether it is daily, weekly or monthly. Some (22%) were not sure how much support they might need.
- A majority of people would prefer being able to walk to some places to meet their daily needs – including grocery stores, bus stops, parks, the pharmacy, and church.

The counties need a variety of housing options for consumers, from independent settings to transitional or permanent group settings. When helping people find community housing, paying attention to what resources are nearby is important.

Life Skills

People need help with life skills – including meeting their daily needs, money management, transportation, and finding a job – not just with finding housing and getting to treatment.

- *Living skills.* About half the consumers stated they could cook, use appliances, and go some places on their own, while closer to 40% thought they could grocery shop without help.
- *Money management.* The great majority of consumers feel they need help with, or need to learn, skills like balancing a checkbook, paying bills, banking, and budgeting.
- *Self-care and safety.* More consumers stated they can manage these tasks than tasks in any other category. More than 70% can do laundry, keep a clean living space, recognize dangerous situations, contact someone in an emergency, and take care of their personal appearance. *However, 70% to 75% need help or need to learn how to find a job and a place to live.*
- *Mental health needs.* The majority of consumers stated they need some help or need to learn how to meet their mental health needs in the community, from following a medication schedule to making appointments.
- *Transportation.* The majority of consumers also stated they need help taking public transportation. Even more consumers indicated they would need help in getting a driver’s license or having access to a car.

Needs and skills vary from person to person. Community providers need to help teach these skills, and plans need to be individualized.

Education and Work

Two-thirds of consumers expressed wanting to work full-time, part-time, or volunteer in the community, 65% would like to learn to use a computer, and 52% would like to pursue some education in the community. Clearly, many people find work or school fulfilling. Community providers need to help consumers who have an interest in working or attending school find work or educational opportunities.

Social and Communication Skills, and Community Involvement

About half of consumers indicated they want help finding things to do, learning about their neighborhood, structuring their free time, and communicating with others in social situations. A significant number (more than one third) also want help with getting a driver’s license, dealing with authority figures, family relationships, meeting people, and paying attention to time.

A majority (61%) would like to use spiritual supports in their recovery, and more than half would like to speak to someone who has been in the hospital and is now living in the community. Only 37% know who to contact if they need an advocate in the community. Paying attention to these needs and goals is essential for helping consumers move toward recovery.

Relapse Prevention and Clinical Needs

The majority of consumers recognize they need some tools and treatments for their mental wellness. The most commonly preferred treatments are individual therapy (78%), followed by individual visits with a psychiatrist (63%). Group therapy (54%) and talk therapy (52%) are also common needs. Many consumers also think non-clinical tools will be helpful. For example:

- 58% think they will need relaxation techniques
- 58% think they will need music therapy
- 52% think they will need a drop-in center
- 46% think they will need spirituality activities
- 41% would like to own a pet

In order to meet the diverse individual needs and preferences, systems should offer a variety of clinical and non-clinical tools and treatments.

Family Supports

While a minority of the 52 residents had family members complete assessments, families play an essential role in many consumers' lives. In the family assessments, families tended to recommend structured living settings rather than independent settings. Family respondents also thought their family members would need help with or need to learn many living skills. Family respondents think their family members will need clinical treatment and other tools for wellness, and would benefit from help in learning about their communities and finding meaningful activities.

Family respondents also need support themselves. A majority want to learn about their family member's medical needs, their medications and illness, and resources like hotlines.

Generally, the peer and family assessment results are similar to those from Phase 1 of the project. In both groups, more consumers preferred independent living arrangements, with some resources for daily needs in walking distance. Many consumers were interested in working or volunteering. Consumers in both phases require varying amounts of help with meeting their daily needs, including money management, transportation, and finding a job, in addition to finding housing and getting to treatment.

In conclusion, the peer and family assessments provide important information for planning in two ways:

1. The answers describe what is important to an individual (and their family, in some cases) for services and supports in the community. These answers become the basis for developing a community support plan to help an individual transition from Mayview to the community.
2. The answers describe what the MRSAP planners, and all others involved in the behavioral health systems in these five counties, need to pay attention to when they develop services and supports in the community.

Most importantly, these assessment answers show the variety of needs and interests for people with serious mental illness. To be successful in supporting consumers in recovery, the systems in the Mayview service area need to offer individualized planning and develop flexible, responsive services and supports that can meet people's needs over time.

Introduction

Allegheny, Beaver, Greene, Lawrence and Washington Counties, in partnership with Mayview State Hospital and the Pennsylvania Department of Public Welfare (DPW), are working together to strengthen the behavioral health systems in these five counties. This regional planning group includes consumers, family members, providers, staff from the state mental hospital and a representative of the DPW field office, policy-makers, payers and advocates. The primary goal of this effort, called the Mayview Regional Service Area Plan (MRSAP), is to help individuals with mental illness to live in their home communities. From the beginning, the planning group has been committed to following recovery principles. AHCI acts as the project manager for this planning process.

In 2005-2006, the Assessment and Discharge Planning Committee, part of the regional planning group, began the development of the assessment and community support plan (CSP) process. This Committee includes consumers, hospital staff, community provider liaisons, state employees, and county representatives. The Committee developed the assessment and CSP process based on the belief that understanding people's preferences and interests, not only for treatment and housing but for daily activities and supports, is essential in a recovery-focused process.

The assessments include three separate tools: a peer assessment, family assessment, and clinical team assessment. All counties have a Consumer and Family Satisfaction Team (CFST), a group of consumers and family members trained in interviewing. A consumer working for a CFST conducted a face-to-face interview with each person at Mayview and did phone interviews with any family members that consumers gave the CFST permission to contact.

The Committee has also created a facilitated process for developing a CSP for each consumer. The CSP is informed by the peer, family and clinical team assessments. These plans will guide the transition and support of consumers moving from Mayview to the community. This process is modeled on the one used at Harrisburg State Hospital.

Over the first phase (July 2005 – July 2006), 30 individuals were discharged from Mayview and one unit was closed. The counties selected 52 individuals for Phase 2 (July 2006 – June 2007), with the goal of discharging at least 30 individuals before June 30, 2007.

This report includes results of the peer assessments and family assessments from people in Phase 2. Family members and Mayview residents were asked the same questions. All interviews were completed between September and November of 2006.

This report does not include results of the clinical team assessments for two reasons. First, the clinical assessment includes different questions than the peer assessment, making comparisons between the two difficult.² Second, the treatment team completes the assessment right before the first CSP meeting, to insure that the most recent clinical information is included. Because these meetings have started gradually since December, not all the clinical assessments have been completed.

Of the 52 people from Allegheny, Beaver, Lawrence, and Washington counties selected for Phase 2, six chose not to participate in the peer assessment process. Some people did not answer all of the questions.³ This report also includes answers from 17 family assessments, for 15 different consumers. Most assessments were completed by the consumer's mother (7 people) or sibling (7 people), while two people had their children complete the assessment.⁴ Because only 26% of consumers with a peer assessment had a family assessment for analysis, these results are presented separately.

This report includes:

- Answers from 46 peer assessments
- Answers from 17 family assessments

Comparing the two groups of answers is difficult because of differences in group size.

Age, Gender, Race, and County

Of the people selected for Phase 2, the majority are from Allegheny County (38 people, 73%), followed by Beaver and Washington counties (6 people, 12% each), and Lawrence County (2 people, 4%).

- **Gender:** 52% are male, and 48% are female
- **Race/Ethnicity:** 60% are white, 21% are African-American, 10% said they were of an “other” race or ethnicity, and 10% did not answer
- **Age:** One person is 25 years or younger and 4 people are over 65 years. Most people are between 25 and 35 years (14%), 36 and 50 years (31%), or 51 and 65 years (37%).
- **Length of Stay at Mayview:** Only one person has been in Mayview less than two years. Twenty-two people (42%) have stays lasting between two and five years, 14 people (27%) had stays between five and 10 years, and 15 people (29%) had stays longer than 10 years.

² During Phase 1 of the project, all three assessment tools contained the same questions. After Phase 1, the Office of Mental Health and Substance Abuse Services (OMHSAS) asked the CFSTs to complete peer assessments with all state hospital residents with stays over two years. As part of this project, the state-wide CFST organization decided to make some changes to the MRSAP assessment. To be consistent with this state project, MRSAP adopted the same assessment tool and changed the family assessment to match.

Based on feedback from Phase 1 participants, the clinical team assessment was expanded to include sections on treatment, past housing placement, and physical health. Other questions from the original assessment were not changed.

³ People who completed the assessment but did not answer specific questions are shown in the “no answer” category. The six people who did not participate in the assessment are not included.

⁴ Twenty-two family members completed interviews for 19 different people. One person had three different family members complete assessments; one person had two family members complete assessments. Two of the six people who did not complete the peer assessment had family members who completed an assessment. Six family members chose not to complete an assessment when contacted by a CFST.

One county used the family assessment tool from Phase 1. While these assessments will still be used in the individual CSP meetings, they are not included in this report because the questions are different.

Disabilities

People were asked if they had any disabilities. Many people (39%, 20 people) reported a visual impairment, which could include wearing glasses or a more serious problem. A small number of people (4%, 2 people) reported a hearing problem, and 15% (8 people) reported a problem with getting around (mobility impairment).

Housing Preferences

Table 1 shows people's preferences for housing. For each housing category, consumers were asked how much they wanted to live in this setting (very much, a little, or not at all). People could strongly prefer more than one housing type.

Readiness for Discharge

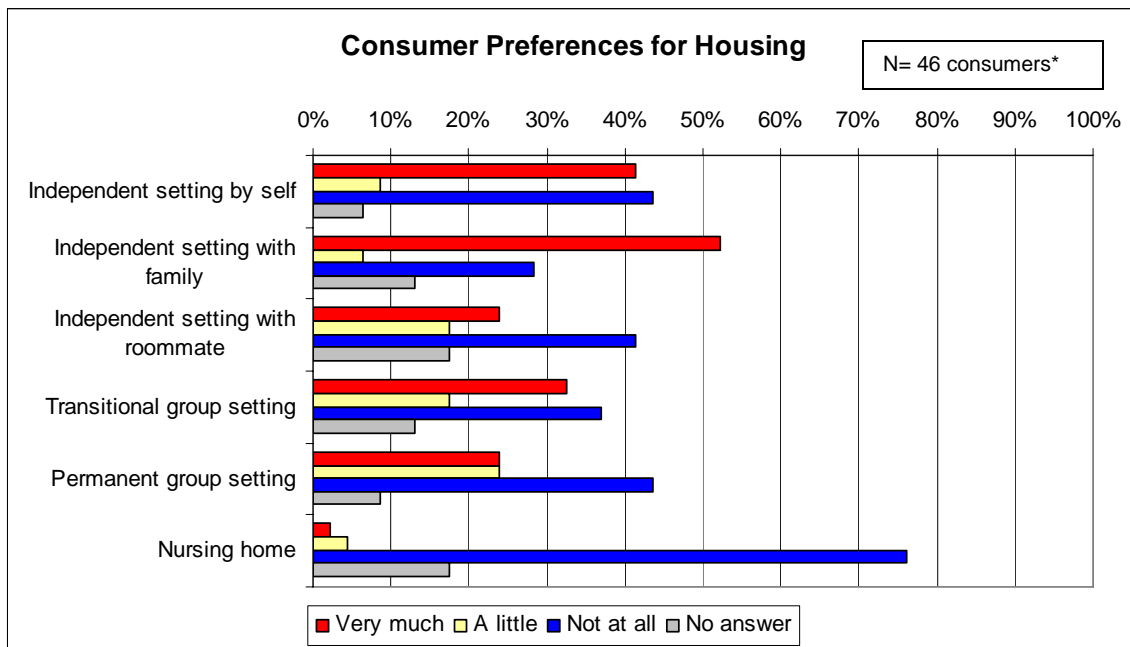
When consumers were asked "how ready do you feel to live outside of the hospital..."

- 35 people (76%) said they were ready
- 7 people (15%) said they weren't ready
- 4 people (9%) said they were a little ready

Most family members did not feel consumers were ready for discharge.

- 2 people (12%) said their family member was ready
- 11 people (65%) said their family member was not ready
- 4 people (24%) said they were a little ready

Table 1



* N = how many people's responses are included in the chart.

Independent settings alone (41%, 19 people) or with family (52%, 24 people) are preferred the most. A significant minority strongly prefer transitional (33%, 15 people) or permanent group (24%, 11 people) settings, although an even larger number do not want to live in these settings at all.

Roommates and Housemates

Most people (78%, 35 people) want to share a house with a small group of people (6 or fewer). Regardless of their housing preference, most people want their own room (24%, 11 people) or only one roommate (37%, 17 people).

Smoking Preferences

Some people also have preferences on whether they live with smokers. Forty percent (18 people) prefer living with smokers, 31% (14 people) prefer living with non-smokers, and 29% (13 people) have no preference.

Housing Support Staff

No matter what housing people prefer, most still want support staff.

- 33% (15 people) want daily support staff
- 20% (9 people) want weekly support staff
- 11% (5 people) want monthly support staff
- 12% (6 people) do not want any support staff
- 22% (10 people) were not sure

People have strong preferences for where they live, and the amount of support they need. The counties need a variety of housing options for consumers, from independent settings to transitional or permanent group settings.

Family Perspectives on Housing

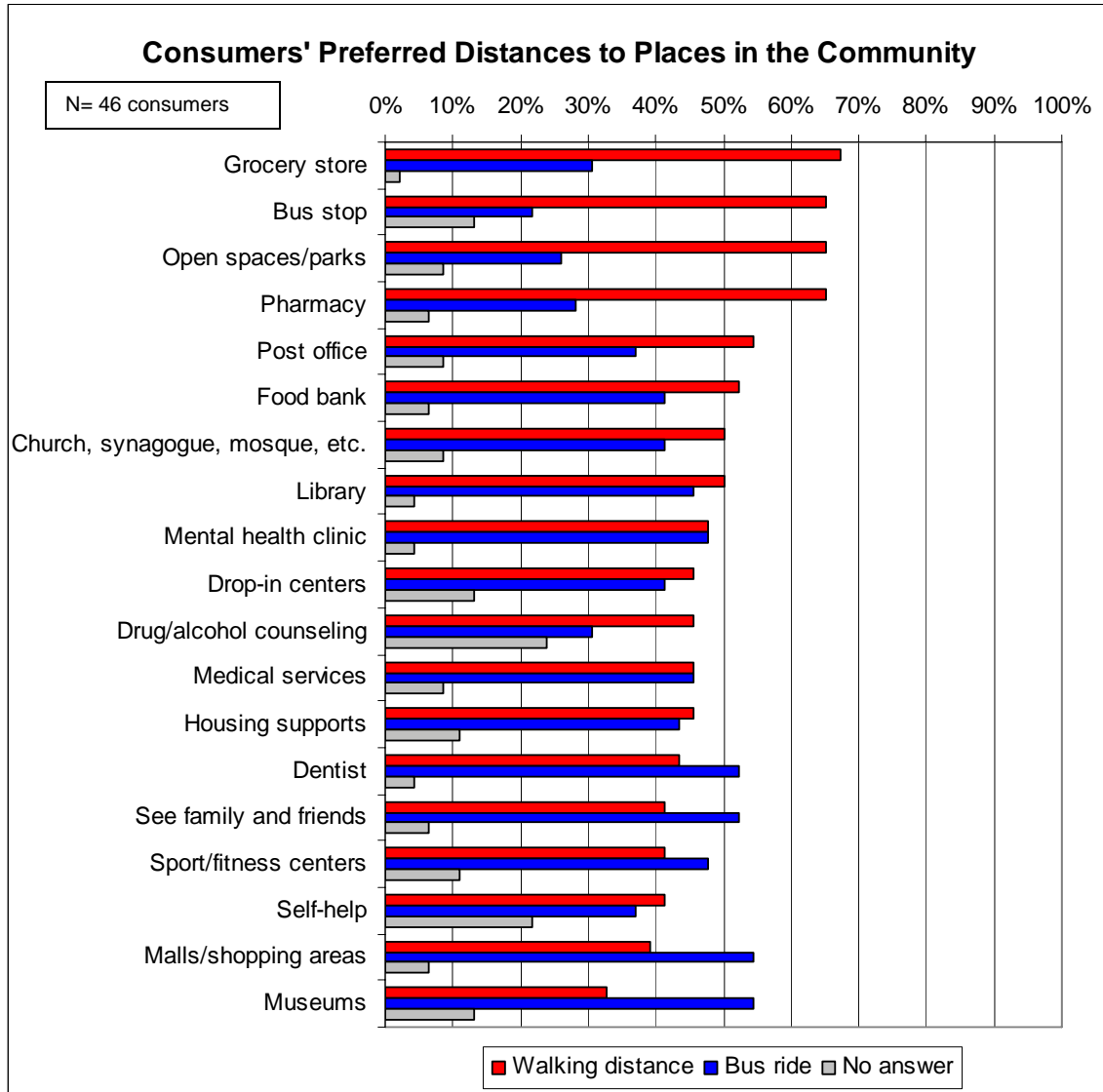
Family respondents tended to recommend structured living settings rather than independent settings:

- No one recommended an independent setting alone and one person recommended an independent setting with a roommate
- 12% (two people) strongly recommended a family setting
- 35% (six people) strongly recommended a transitional group setting
- 53% (nine people) strongly recommended a permanent group setting
- Nearly all family members (15 people, 88%) recommended daily support staff

Housing Location

Table 2 shows people’s preferences for the resources or places people want to live near. For each resource, people were asked if they would prefer to be within walking distance or if they would not mind taking a bus to get there.

Table 2



A majority of people are concerned about being able to walk to places to meet their daily needs – including grocery stores, bus stops, parks, the pharmacy, post office, and church. While a large number of people still want to be able to walk to treatment and support services, they are more equally divided between preferring walking distance or a bus ride.⁵

When helping people find community housing, paying attention to what resources are nearby is important.

⁵ Many family members did not answer these questions, so a family perspective is not included.

Life Skills:

What consumers know, what they need help with, and what they need to learn

Consumers were asked how well they could perform life skills in different areas: living skills, money management, self-care and safety, mental health needs, and transportation. Consumers could respond “completely on my own,” “with some help,” or “don’t know how.” Tables 3 – 7 show how consumers answered these questions.

Table 3

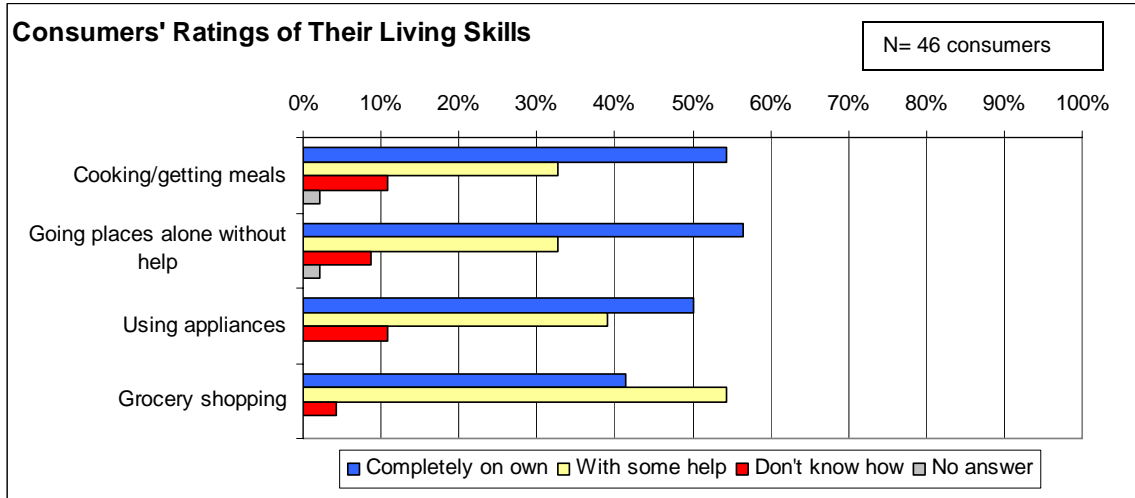


Table 4

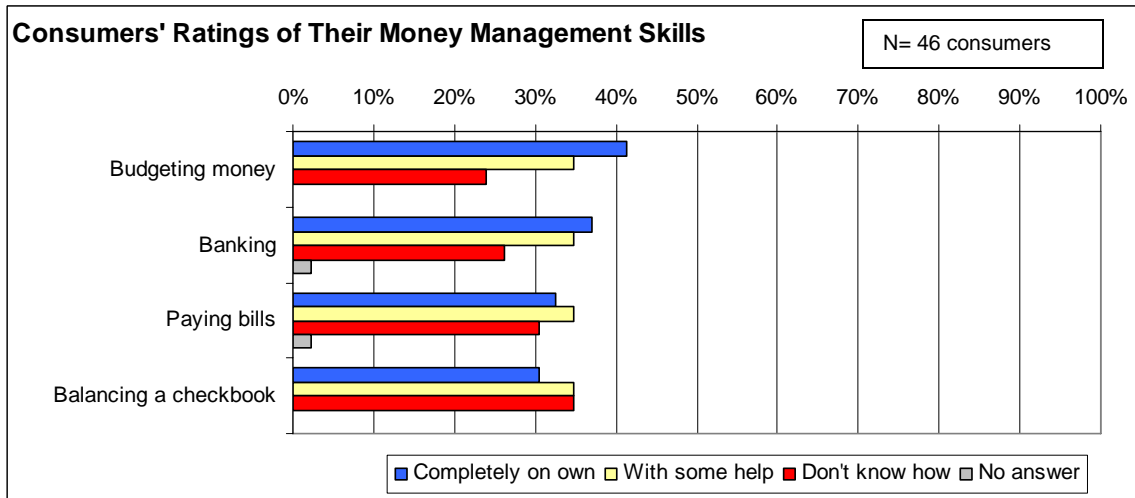


Table 5

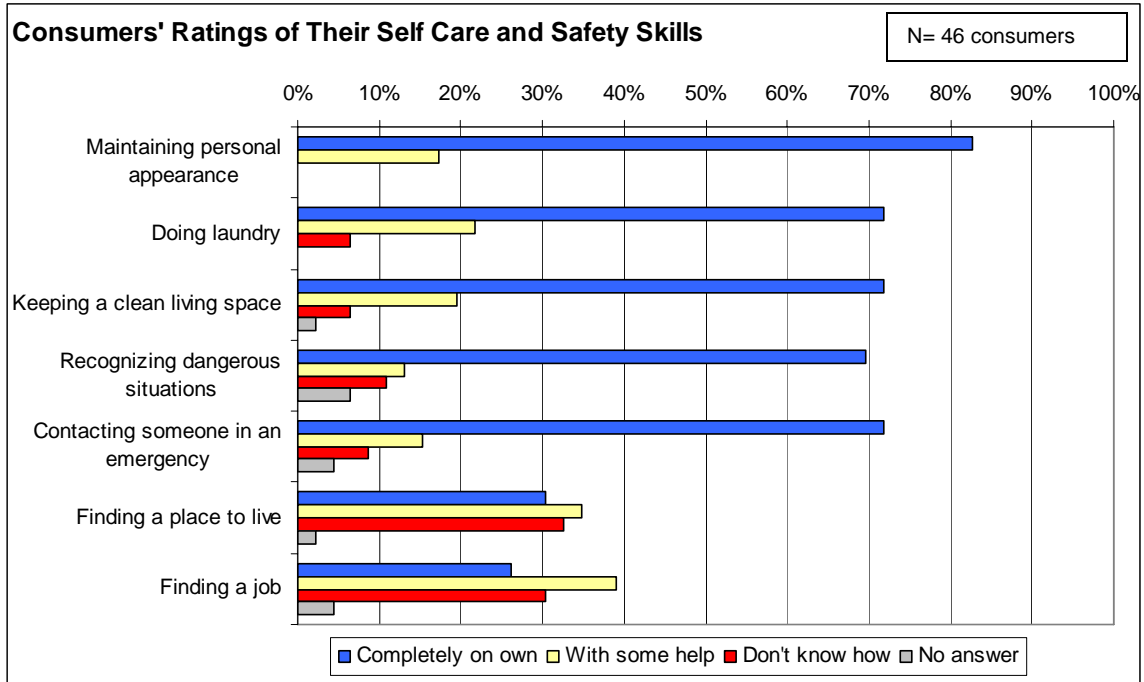


Table 6

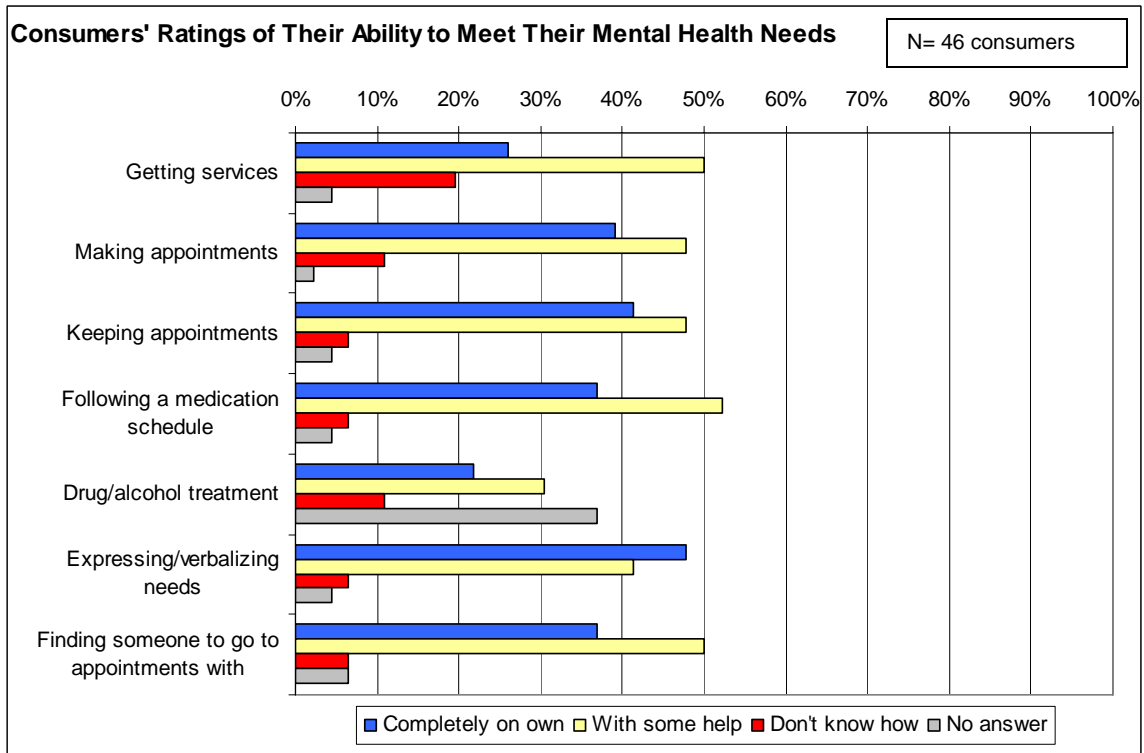
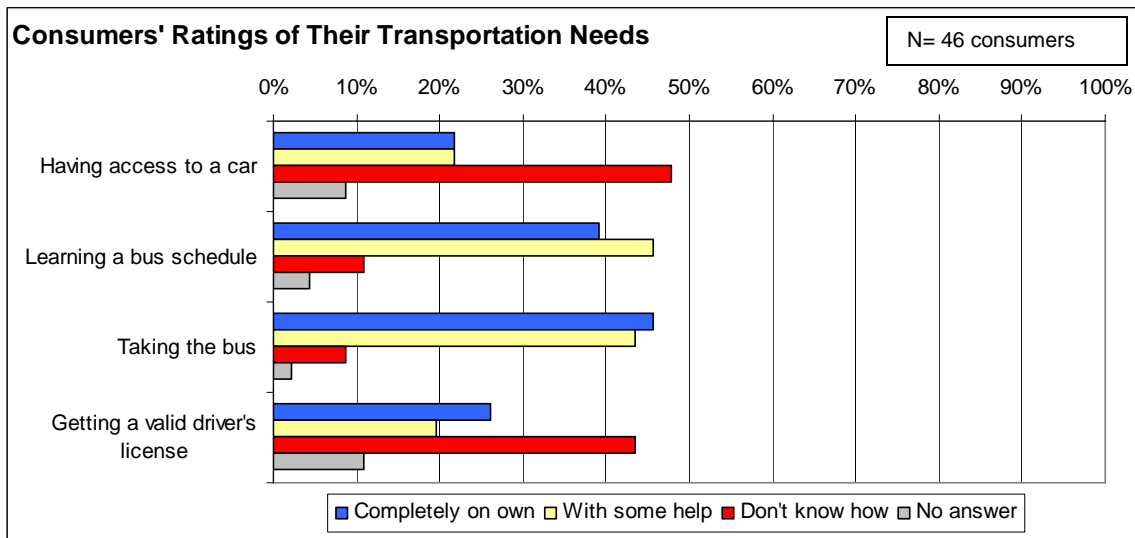


Table 7



At an individual level, people’s responses varied. Some people stated they could do many of these tasks on their own, while some people stated they did not know how to do many of the tasks. Most people had a range of answers – while comfortable with some tasks, they recognize they will need help in some areas, and will need to learn some new skills in the community.

- **Living skills:** About half the consumers stated they could cook, use appliances, and get some places on their own, while closer to 40% thought they could grocery shop without help.
- **Money management:** The great majority of consumers need help with, or need to learn, skills like balancing a checkbook, paying bills, banking, and budgeting.
- **Self-care and safety:** More consumers stated they can manage these tasks than tasks in any other category. More than 70% can do laundry, keep a clean living space, recognize dangerous situations, contact someone in an emergency, and take care of their personal appearance. **However, 70% to 75% need help or need to learn how to find a job and a place to live.**
- **Mental health needs:** The majority of consumers need some help or need to learn how to meet their mental health needs in the community, from following a medication schedule to making appointments. Many people did not answer how much help they would need with getting drug and alcohol treatment. (This could mean they do not believe they will need these services in the community or they do not have a history of drug or alcohol abuse.)
- **Transportation:** The majority of consumers also need help taking public transportation. Even more consumers indicated they would need help in getting a driver’s license or having access to a car.

People have different skills and needs. Community support plans should reflect the individual’s strengths and needs. People need help with life skills – including money management, transportation, finding a job, grocery shopping – in addition to finding housing and getting to treatment. Community providers need to help teach these skills.

Family Perspectives on Life Skills

Families generally thought that their family members need a lot of help with living skills.

- In comparison to consumers' ratings of their own skills, very few family respondents thought their family members could complete tasks on their own and would require at least some help.
- Money management and meeting mental health needs are the two areas where family respondents thought their family members need the most help.
- Family respondents were most confident in some of their family members' self-care and safety skills, including maintaining personal appearance and doing laundry. Nearly all family respondents thought consumers would need help finding a job and a place to live.
- Many family respondents did not answer some of the questions, which may indicate that they are not sure of their family members' skills since they have been in the hospital.

Literacy, Education and Employment

While most consumers say they know how to read, many are interested in pursuing education:

- 91% of consumers (42 people) stated they can read
- 39% (18 people) have trouble reading, or understanding what they are reading
- 65% (30 people) would like to learn to use a computer
- 52% (24 people) would like to pursue some education in the community

A majority of consumers are interested in working or volunteering, and would like job training.

- 74% (34 people) are aware that they can work and keep their benefits
- 17% (8 people) would like to work full-time
- 41% (19 people) would like to work part-time
- 9% (4 people) are interested in volunteering
- 33% (15 people) are not interested in working
- 57% (26 people) would like training for a job

Working

Two-thirds of consumers want to work full-time, part-time, or volunteer in the community.

Family Perspectives on Education and Employment

Family respondents did recommend education and work for their family members when they are discharged:

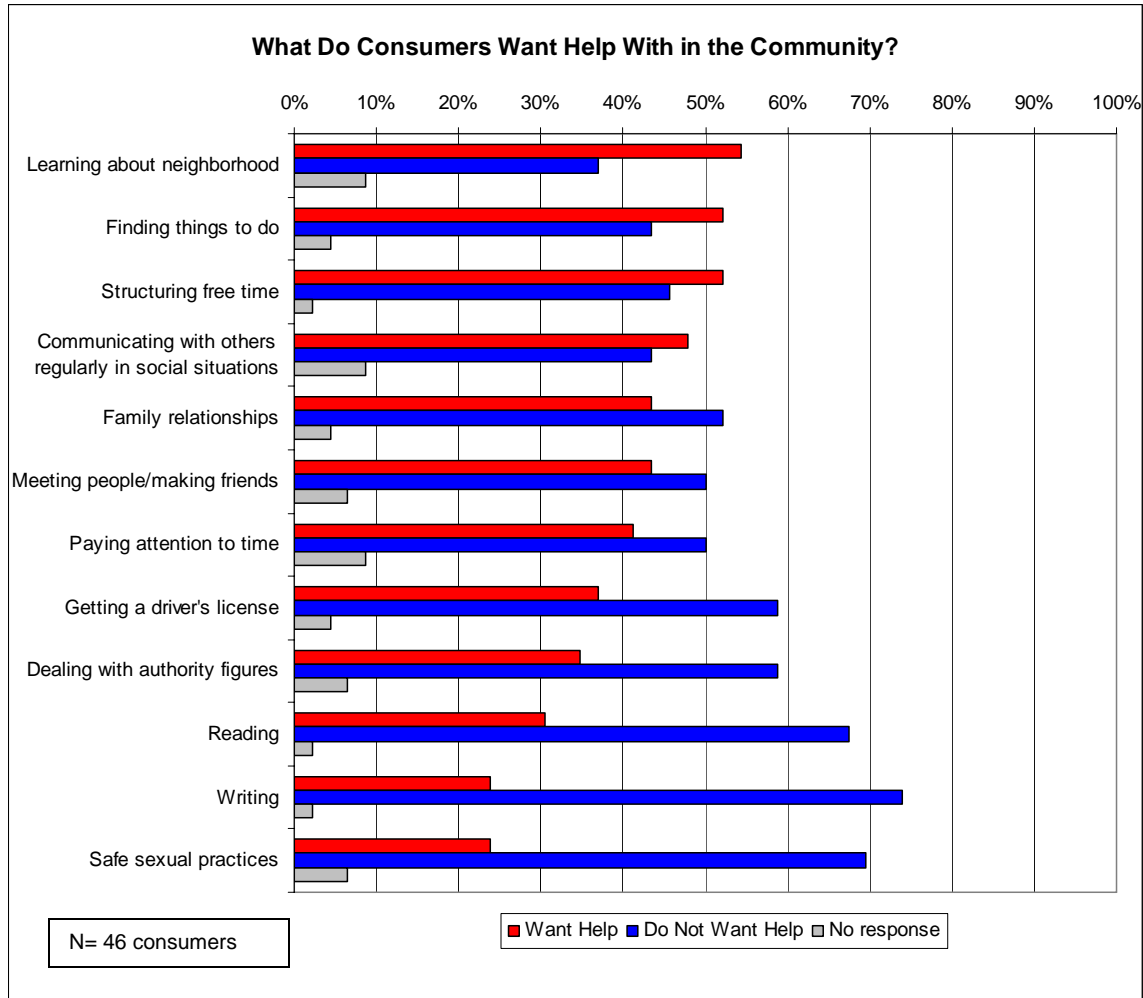
- 71% (12 people) recommended their family member learn to use a computer
- 47% (8 people) recommended their family member receive some kind of education
- 47% (8 people) recommended their family member work part-time
- 29% (5 people) recommended their family member volunteer
- 18% (3 people) recommended their family member not work
- 82% (14 people) recommended job training

Many people find work or school fulfilling. Community support plans should help people who have an interest in working or attending school find work or educational opportunities. Community providers should help consumers meet these goals.

Social and Communication Skills, and Community Involvement

Consumers were also asked if they would like help with different social and communication skills. Table 8 shows consumers' answers.

Table 8



- About half of consumers want help finding things to do, learning about their neighborhood, structuring their free time, and communicating with others in social situations.
- A significant number (more than one third) also want help with getting a driver's license, dealing with authority figures, family relationships, meeting people/making friends, and paying attention to time.
- A minority of people want help with reading, writing, or learning safe sexual practices.

Spiritual Supports

61% of consumers (28 people) would like to use spiritual supports or connections in their recovery process.

Many consumers are also interested in connecting with other consumers in the community.

- 35% (16 people) are interested in becoming active in the consumer movement
- 53% (24 people) would like to speak to someone who has been in the hospital and is now living in the community

Many consumers are not sure where to call or go if they need an advocate to help with insurance issues, treatment concerns, housing concerns, or civil rights. Only 52% know who to contact at the hospital, and 37% know who to contact in the community.

Many consumers would like help with social skills and becoming involved in the community – from finding things to do, to learning about their neighborhood. Paying attention to these goals is essential for helping consumers move toward recovery.

Family Perspectives on Social Skills and Community Involvement

Family respondents also recommended help with social skills and community involvement, including:

- 88% (15 people) recommended spiritual supports for their family member
- 88% (15 people) recommended help in finding things to do and structuring free time
- 77% (13 people) recommended their family member speak to someone who has been in the hospital and is now living in the community
- 77% (13 people) recommended their family member have help learning about the neighborhood and learning to communicate with others in social situations

Clinical Needs and Relapse Prevention

When consumers are asked about unsafe behaviors and mental or emotional problems, some state they have some awareness and ability to take care of their symptoms. While some believe they have learned relapse prevention skills, very few have worked on an advance directive.⁶

- 30% (14 people) stated they have behaviors that make them feel unsafe
- When asked how often they can tell when mental or emotional problems are about to occur, 13% (6 people) said never, 11% (5 people) said rarely, 37% (17 people) said sometimes, 13% (6 people) said often, and 22% (10 people) said always
- When asked how often they can take care of these problems before they get worse, 4% (2 people) said never, 4% (2 people) said rarely, 30% (14 people) said sometimes, 22% (10 people) said often and 28% (13 people) said always
- 43% (20 people) said they have been given relapse prevention tools to use when they return to the community
- 9% (4 people) said someone had worked with them to create an advance directive

Tables 9 and 10 show that people are interested in a variety of different tools and treatments for their mental wellness in the community. All consumers selected at least one tool or treatment and some consumers selected many or most of the treatments listed. The most commonly needed treatments are individual therapy (78%, 36 people), followed by individual visits with a psychiatrist (63%, 29 people). Group therapy (54%, 25 people) and talk therapy (52%, 24 people) were also common needs.

From these responses, it is clear that many consumers are interested in non-clinical tools to stay well. For example:

- 58% (27 people) think they will need relaxation techniques and exercise
- 58% (27 people) think they will need music therapy
- 52% (24 people) think they will need a drop-in center

⁶ A psychiatric advance directive is a plan, or a set of instructions or preferences, for mental health treatment. It is a legal document for providers, relatives, significant others, and/or friends to use in situations when the person is acutely ill and unable to make treatment decisions or give informed consent.

- 46% (21 people) think they will need spirituality activities
- 41% (17 people) would like to own a pet

Table 9

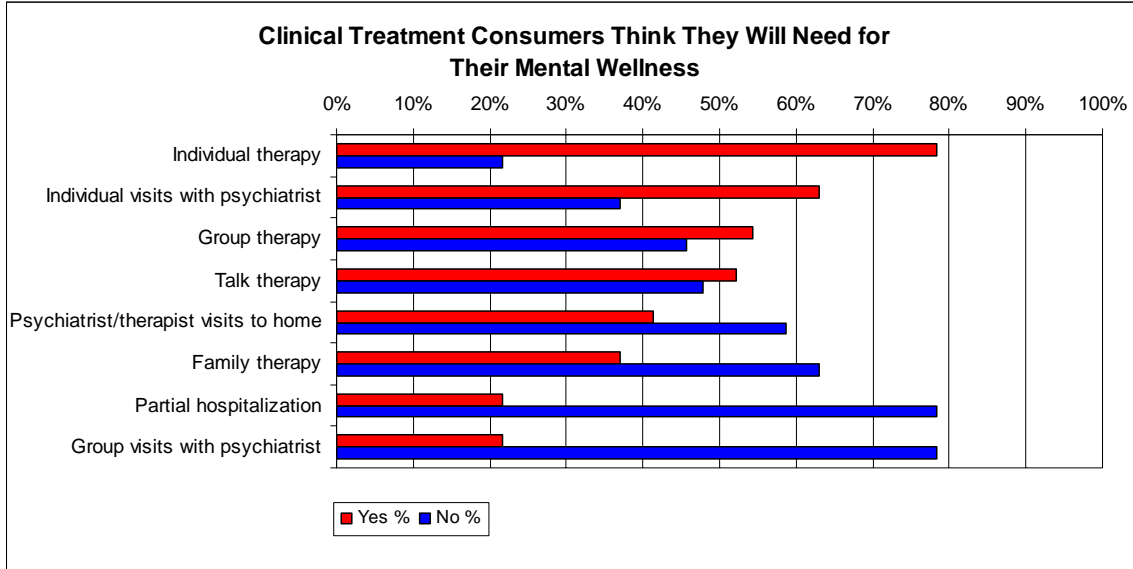
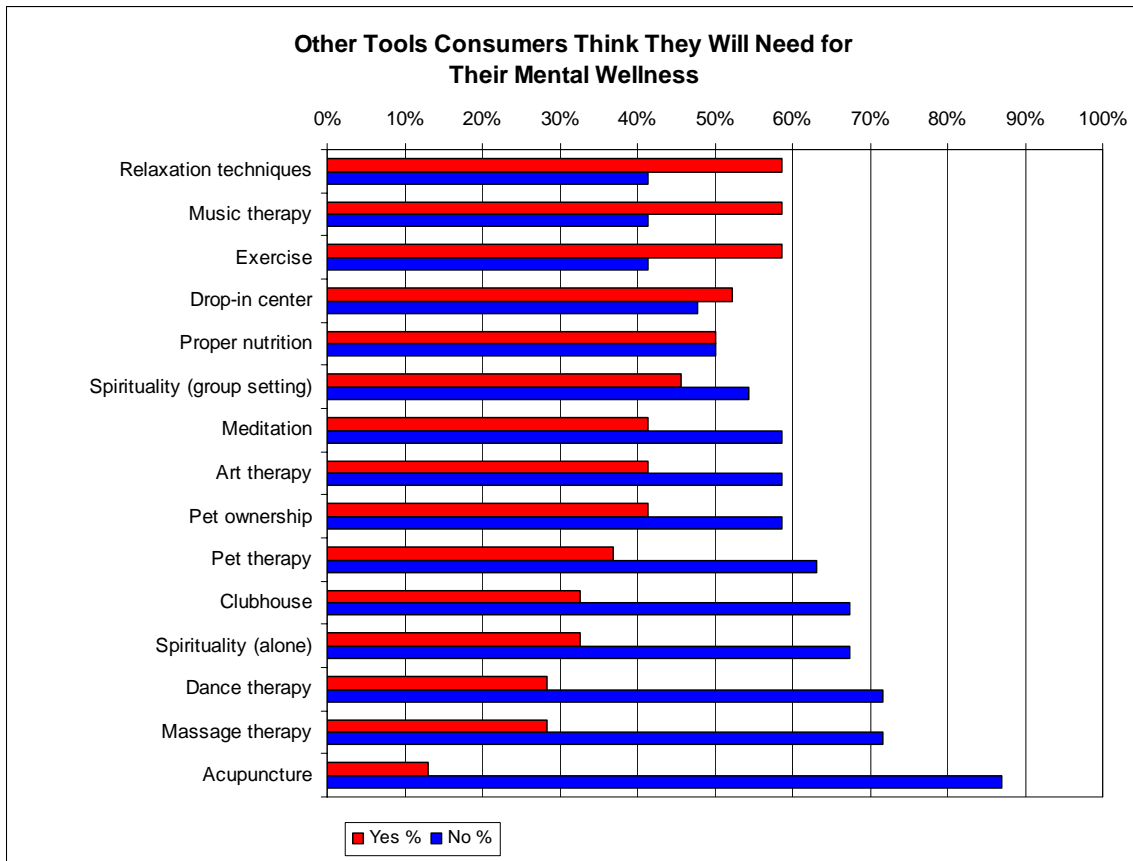


Table 10



The majority of consumers recognize they have a need for mental health treatment to stay well in the community. Many also think non-clinical tools, like relaxation techniques, will be helpful.

Family Perspectives on Clinical Needs

Family respondents recommended both traditional treatments and other non-clinical tools for their family member's mental wellness. For example:

- 71% (12 people) recommended individual therapy, and 58% (10 people) recommended individual visits with a psychiatrist
- 65% (11 people) recommended exercise, and 47% (8 people) recommended proper nutrition
- 41% (7 people) recommended dance therapy and art therapy
- 41% (7 people) recommended group therapy and psychiatrist or therapist visits to the home

Family respondents were asked what help *they* might need to make their family member's discharge successful. Many people wanted some help or support:

- 71% (12 people) would like help in understanding the medical care their family member needs
- 65% (11 people) would like to learn about dosage, side effects, and purpose of medications
- 53% (9 people) would like information on hotlines
- 47% (8 people) would like to link with other families and family psycho-education
- 41% (7 people) would like outpatient mental health care

Conclusion

The peer and family assessments provide important information for planning in two ways:

- The answers describe what is important to an individual (and their family, in some cases) for services and supports in the community. These answers become the basis for developing a community support plan to help an individual transition from Mayview to the community.
- The answers describe what the MRSAP planners, and all others involved in the behavioral health systems in these five counties, need to pay attention to when they develop services and supports in the community.

Key lessons for those involved in regional planning for the Mayview service area include:

- People have strong preferences for where they live, and the amount of support they need. The counties need a variety of housing options for consumers, from independent settings to transitional or permanent group settings.
- When locating community housing, paying attention to what resources are nearby is important.
- People need help with life skills – including money management, transportation, finding a job, grocery shopping – in addition to finding housing and getting to treatment. Community systems need to be responsive to these needs.
- Many people find work or school fulfilling. Individual plans should help people who have an interest in working or attending school find work or educational opportunities. Community providers need to help consumers meet these goals.
- Many consumers would like help with social skills and becoming involved in the community – from finding things to do, to learning about their neighborhood. Paying attention to these goals is essential for helping consumers move toward recovery.
- The majority of consumers recognize they have a need for some mental health treatment to stay well in the community. Many also think non-clinical tools, like relaxation techniques, will be helpful. Systems should offer access to a variety of clinical and non-clinical tools and treatments.

Most importantly, these assessment answers show the variety of needs and interests for people with serious mental illness. To be successful in supporting consumers in recovery, the systems in the Mayview service area need to offer individualized planning and develop flexible, responsive services and supports that can meet people's needs over time.