THE GILMORE RESEARCH GROUP
FIFTY YEARS OF STRAIGHT ANSWERS

# --Mental Health Transformation-- A Research Project for Social Marketing Development

**Prepared for:**

Washington Department of Health
Olympia, Washington

**by:**

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**&**

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# EXECUTIVE SUMMARY

## Overview, Purpose and Methodology

The overall purpose of this research was to gather information that will be used to develop a marketing plan to support Mental Health Transformation in Washington State. A "social marketing" approach will be used, relying on the utilization of traditional marketing principles and techniques to influence target audiences to voluntarily accept, reject, modify or abandon a behavior for the benefit of individuals, groups or society as a whole. The long-term goal of this social marketing effort will be to change attitudes and behaviors around mental health in the State of Washington. The first year focus for this plan is on eliminating stigma and promoting the use of the Recovery Model.

Based on a review of the literature and discussions with the Social Marketing Task Group, three major audience segments were identified as key sources for planning input. These segments were selected based on their perceived ability to have the biggest impact on the elimination of stigma as well as to promote the Recovery Model. One segment had three sub-groups, identifying a total of five audiences to be targeted for research:

- Mental Health Providers.
- Consumers of Mental Health Services.
- Policy Makers:
    - Local Elected Officials.
    - Transformation Workgroup.
    - Legislative Task Force Members and Staff, and other key legislators.

Using both structured and free-flowing instruments developed by Gilmore and the DOH Office of Health Promotion, with input from the Social Marketing Task Group, a total of 62 Providers, 32 Consumers and 48 Policy Makers (13 Local Elected Officials, 10 Legislative Task Force members and staff, 25 Transformation Workgroup members) were interviewed by telephone.

# Mental Health Providers.

Providers were drawn from lists provided by DOH as well as from Internet sources located by Gilmore Research Group. All were professionals licensed by the State of Washington and currently practicing or in clinic management in the state. Most reported having some type of counselor or social work license and had been practicing an average of 12 years or in administration an average of 19 years. A small percentage (8%) reported having an all private practice, but most had a practice that uses at least some public funding. Respondents represented both sides of the state and both urban and rural settings.

These providers were asked about several behaviors key to eliminating stigma and adopting the Recovery Model: 1) attending consumer discussions or workshops; 2) partnering with consumers; 3) using person-centered language; and 4) encouraging peers to use these practices. In addition, they were asked about current behaviors in relation to: 5) adopting the Recovery Model.

The 62 providers interviewed—51 practitioners and 11 administrators—were in close agreement on nearly all the topics included in the survey. Unless otherwise noted, the findings in this summary combine the two groups.

## 1. 0 DESIRED BEHAVIOR: ATTEND DISCUSSION GROUPS OR WORKSHOPS WITH CONSUMERS

### 1.1 Current Behavior

- Just over half indicated they have attended such a session.
- Those who have attended reported doing so about twice in the past year.
- Many have discussed with peers the benefits of attending such sessions.
- Most have encouraged consumers to attend such sessions.

### 1.2 Current Knowledge/Beliefs

- All administrators reported they are aware that other administrators attend such sessions.
- While most of the providers know that at least a few of their peers attend such sessions, some are not aware that any of their peers attend.

### 1.3 Perceived Barriers

- Time constraints; too many other demands on time.
- Already have a heavy load of tasks and responsibilities.
- Do not know that such sessions exist.
- Know that there are sessions but do not know the time or location of sessions.
- No sessions in the area (rural settings), or in reasonably convenient location.

### 1.4 Perceived Motivators

- Encouragement from their practice management and from practitioner/administrator peers.
- Having successful consumers from their own practice and others taking part in the sessions.
- Learning in advance about timing and location of sessions (a week or more).
- Grants or other incentives provided by government.
- Academic research findings (administrators, in particular).

## 2.0 DESIRED BEHAVIOR: MAKE CONSUMERS PARTNERS

### 2.1 Current Practice

- Many providers currently partner with all consumers.
- A few, however, partner only sometimes or not at all.
- All administrators encourage this practice at their clinics.

### 2.2 Current Knowledge/Beliefs

- A majority of providers and near majority of administrators agree completely that successful recovery is how the consumer, not the practitioner, defines it.
- Most believe that consumers need to learn from their own mistakes.
- Most also believe that when you share power with the consumer, you also share responsibility.

### 2.3 Perceived Barriers

- Some consumers are not ready for partnering; it may not yet be appropriate, based on their level of illness.

### 2.4 Perceived Motivators

- Knowing more about the standards for partnering.
- Having more training in the steps and techniques.

## 3. 0 DESIRED BEHAVIOR: USE LANGUAGE OF RESPECT

### 3.1 Current Practice

- Almost everyone, especially administrators, make a point to use person-centered language.
- No one reported not using such language at least some of the time.

### 3.2 Current Knowledge/Beliefs

- Most providers sampled believe that outcomes improve when language changes and stereotypes are abandoned.

### 3.3 Perceived Barriers

- Old habits, people forget about using the language or are not aware of their misuse.
- Providers use the old terms for verbal "shorthand" with peers, feeling that is acceptable.
- Practitioners, in particular, are not comfortable reminding peers to use respectful language; they feel it is professionally demeaning.

### 3.4 Perceived Motivators

- Having practice/clinic make person-centered language a priority, a conscious goal.
- An agreement among peers to remind one another to use such language.
- Adopting and using Recovery Model practices.
- Peers speaking more publicly within the mental health community that this is the desired norm.

## 4.0 DESIRED BEHAVIOR: ENCOURAGE PEERS/CO-WORKERS TO USE GOOD PRACTICES (WORKSHOPS, PARTNERING, PERSON-CENTERED LANGUAGE)

### 4.1 Current Practice

- A majority of providers make a point of always offering encouragement to their peers to engage in these practices, and others do so sometimes, but 1 provider in 5 does not offer encouragement very often or does not do so at all.

### 4.2 Current Knowledge/Beliefs

- Half of the providers and almost all of the administrators agree completely that mental illness is a condition that people can manage and live with.
- A majority believe that evidence-based practices are available and effective.

### 4.3 Perceived Barriers

- Practitioners are not comfortable in "pushing" peers, feeling it is professionally inappropriate.
- Some peers lack the awareness, time, or access to resources that would allow them to follow these practices.
- Practitioners say that their peers report the educational and/or language level of some consumers would keep them from partnering or being in workshops, regardless of the practitioners' encouragement.
- Administrators say that operational and other priorities direct their time and focus elsewhere, suggesting that this perception exists for many providers and their peers across the state.

### 4.4 Perceived Motivators

- Raise awareness within the mental health community through education and training.
- Provide the resources needed to get the word out; for example, workshops need more/better advertising and advance communications.
- Make more time available; relieve providers of some current tasks, such as paperwork.
- Make this behavior a priority, a specific goal for the practice/clinic; management support will be important.

# 5.0 DESIRED BEHAVIOR: ADOPTION OF THE RECOVERY MODEL

## 5.1 Current Practice

- All providers in this study were aware of the Recovery Model.
- Most providers said they are "very" knowledgeable about the Model.
- Most said they have worked to reduce stigma in some way:

  - Helped consumers understand they can get better.
  - Treated consumer as individual, not "diagnosis".
  - Got consumers involved in recovery, encouraged them to advocate for themselves.

## 5.2 Current Knowledge/Beliefs

- Most providers believe that the Recovery Model works.
- Even more believe that outcomes will improve using the model.
- Most providers believe outcomes improve when consumers are involved in treatment decisions.
- Most believe that their practice will benefit by using the Model.
- Most believe that recovery requires person-centered treatment.
- A wide majority of providers believe that people with mental illness are not more violent than any other people.
- A wide majority also believe that more emphasis on recovery will mean less crisis intervention.
- Just over half believe that evidence-based practices that promote the Recovery Model are available and effective.
- Half of the practitioners and most administrators agree completely that mental illness is a condition that people can manage and live with.

## 5.3 Perceived Barriers

- Recovery Model goals are not clear to everyone.
- Too much emphasis on measurement; not enough room for individual variation within the Recovery Model.
- The process of implementing the Recovery Model will take a long time and require big societal changes; change comes slowly.
- There is not enough funding for wide-spread implementation.
- Want management support to move forward on the Recovery Model, and less bureaucracy.
- Other issues have higher priority, for example, not everyone who needs it even has access to mental health care.

## 5.4 Perceived Motivators

- Evidence that the Model works, that outcomes improve and that mental health practices will benefit.
- Evidence that outcomes improve when consumers are involved in treatment decisions.
- Evidence that people with mental illness are not more violent than any other people.
- Evidence that more emphasis on recovery means less crisis intervention.
- Personal experience of the providers themselves, or in seeing success of a co-worker who has gone through the Recovery Model process.

It is noteworthy that discussion of financial implications behind adopting the Recovery Model will need more detailed explanation and as much factual information as is available. The two statements below were not seen by providers to be at all persuasive in moving them toward the Model:

- It won't cost more for the provider/clinic to move to the Recovery Model.
- Funding to move to the Model won't be a problem.

Overall, the results of the research with these providers indicate that the goals of eliminating stigma and moving toward adoption of the Recovery Model are good ones.

- All providers but one feel that elimination of stigma is very or somewhat urgent.
- Most of the providers in this research reported themselves to be very knowledgeable about and are currently using the Model. Barriers to full use still exist, and not everyone has embraced the beliefs behind the Model.

There is guarded optimism among these providers that the Transformation initiative can be successful in Washington.

# Consumers of Mental Health Services

Consumers successful in their recovery from serious mental illness were the focus of this phase of the study investigating how best to promote the goals of the Transformation. A total of 32 consumers were reachable, available and willing to be interviewed. A list of people successful in their recovery was provided by DOH, Transformation Grant staff and Social Marketing Task Group members. All of the interviews were conducted by telephone, with some in a small group discussion format and some as individual discussions. Those interviewed included adults, youth in transition, and parents of children and youth.

All of the consumers in this sample reported engaging in the specific behaviors designated as important in the Transformation process. These behavioral goals include: 1) advocate/tell your story/participate and encourage the same from others and 2) take responsibility in your recovery, including being a partner in treatment. In addition, because the consumers in this sample are already in recovery and are engaging in advocacy, it was often desirable to employ retroactive interviewing techniques such as *before you were doing these things, what prevented you* or *what convinced or motivated you to do these things* in addition to the current *what gets in your way* or *what motivates you to keep doing these things*. These findings are included in the barriers and motivators section of the report.

## 1.0 DESIRED BEHAVIOR: ADVOCATE, TELL YOUR STORY, PARTICIPATE AND ENCOURAGE THE SAME FROM OTHERS.

### 1.1 Current Behavior

- Among the consumers in the sample, a wide range of participation and advocacy was reported, including:
    - Speaking and sharing at forums where providers were present.
    - Speaking at school assemblies.
    - Sharing experiences in small groups with other consumers.
    - Writing articles for newsletters or newspapers or being interviewed for television.
- Others have attended workshops, including peer education workshops, but have not yet shared publicly.

## 1.2 Current Knowledge/Beliefs

- It is important to feel you have a place at the table and feel comfortable in order to be involved. Feeling that they will be heard, that they have a story to tell and that others will listen was important for several consumers as they began advocating for themselves and others.
- By sharing publicly you encourage others to seek treatment. This is a huge motivation for the consumers in this sample to engage in the dialogues and workshops.
- By sharing publicly you reduce stigma. This belief, too, influenced the consumers to share publicly.
- Sharing experiences is an important part of your own recovery. Believing this was also important for many of the consumers in order to share publicly.

## 1.3 Perceived Barriers

- Basic shyness, insecurity with speaking skills.
- Feeling that they don't have enough to offer or say or that anyone would want to listen to.
- Stigma – a fear that if they publicly share or disclose, others will think less of them, stigmatize them, stereotype them or discriminate against them.
- Not knowing what kinds of opportunities exist for public sharing.

## 1.4 Perceived Motivators

- Wanting to let others know they are not alone.
- Encouraging others to seek treatments.
- Educating the public about mental illness in hopes of eliminating stigma.
- Having a need to tell their story.
- Feeling public sharing helps with their own recovery.
- Knowing their stories will be heard, that they will be listened to.
- Encouragement from others to share publicly might be motivating, depending on the perceived credibility of the source. Encouragement from other consumer advocates and providers would probably be more influential than from family.
- More training in public speaking and presentation skills would encourage some to speak publicly.

## 2.0 DESIRED BEHAVIOR: TAKE RESPONSIBILITY IN YOUR RECOVERY, INCLUDING BEING A PARTNER IN TREATMENT AND FOLLOWING TREATMENT GUIDELINES

### 2.1 Current Practice

- Because each consumer defines what recovery looks like for himself/herself, life goals, exercising independence and actively managing their illness appear different for each.
- All respondents, however, view recovery as a process and not necessarily an end result, even those who are in resiliency. In addition, all seek treatment as necessary, follow treatment guidelines and share in the decisions affecting their treatment.
- All report being involved in treatment decisions with their providers.
- All report seeking treatment as perceived necessary.

### 2.2 Current Knowledge/Beliefs

Perhaps not surprisingly, all of these respondents believe that recovery is possible. This belief motivates them to continue seeking treatment and following treatment guidelines, constantly working toward recovery. They also feel it is important to let others (consumers, providers, family, community) know this.

- Several remarked that it was important that recovery and treatment are individualized and recovery is defined by the consumer--what recovery is and what it means to you.
- Many of the consumers in this sample reported not always knowing what and where to find the appropriate treatment and services or in finding ways to pay for it.
- *I can get better*. All reported that this belief is essential in recovery; they had to believe there is hope, and they spread this message to others, as well.
- Some, but not all believe that evidence-based practices work or believe this to be true or that believing this would convince them to engage in recovery.
- Some, but not all believe, "*I will still be unique*." Most who did not understand or agree with this belief felt that for them, recovery and treatment should lead them to *fit in better and not be so different from everybody else.*
- Consumers reported working in partnership with their providers or working to find a provider that encouraged consumer involvement in the treatment decisions, thus not feeling coerced.
- It was very important for the consumers in this study to know or hope that there is something (a treatment, service or organization) out there that will work for them. Indeed, this was considered a key motivator in moving toward recovery. There was less agreement, however, that it would be affordable.

- For some consumers believing, "*If I get help and change my behaviors, it will be worthwhile and I will be met half-way,"* would definitely motivate them to move toward recovery. For others, this belief appeared as demeaning and *talking down to them.*
- Believing that mental illness is a condition that many people can learn to live with was also a central belief for the consumers in this study.

## 2.3 Perceived Barriers

- Knowing what treatment is available, where it is available, and the options for payment presents one of the bigger challenges for the consumer. Many report frustration in finding appropriate treatment or services as well as in how to pay for them.
- Lack of knowledge about choices and options:
    - Difficulty in obtaining.
    - Conflicting and confusing information.
    - No centralized clearing-house of information about services available.
- Lack of access to appropriate treatment:
    - Geographic (remote areas sometimes poorly served).
    - Financial.
    - Long waiting lists and difficulty in getting first appointment.
    - Service not available or discontinued.
- Poor communication and coordination between agencies and systems prevent seamless delivery of services, especially for youth in transition.
- Not all of the consumers in this study agree that evidence-based practices work. There is a feeling that it could de-individualize treatment; that it could lead to a cookie-cutter approach.
- Too few resources and services specifically geared to youth.
- Lack of knowledge about illness.
- Feelings of hopelessness, believing you are alone, believing you can't get better.
- Stigma, including family, community, self:
    - Creates denial, hiding, and obstacle in seeking treatment. Creates feelings of shame.
    - There is stigma about even entering a building labeled "Mental Health".

- The illness, itself: (May be too ill to advocate for self or seek appropriate treatment.)
- A perception that some providers are resistant to including consumers in treatment decisions or that some are inclined to rely too heavily on medication.
- Negative effects/side effects from some medications prescribed, such as huge weight gains.
- Finding affordable treatment presents a tremendous challenge:

    - Those with insurance perceived to have access to better care, seeing fewer treatment choices for those receiving public services.
    - Lack of insurance parity. Physical illness benefits much better and more inclusive than for mental illness. Benefits are exhausted before year's end and consumers have to pay out-of pocket – a huge gap.
    - Difficult to find affordable treatment for the poor who do not qualify for Medicaid or SSI.

## 2.4 Perceived Motivators

- Believing there is hope; that they can get better. This is promoted by:

    - Education about mental illness and their illness(es) in particular. Empowers them to make better choices, as well.
    - Believing mental illness is a disease like diabetes or asthma that many people manage and learn to live with, that they can live successful lives.
    - Learning about recovery and what it means for them.
    - Believing that if they don't seek treatment, they may die. *"The choice is simple…"*

- Knowing they are not alone:

    - Support groups such as Safe-WA, NAMI perceived as very helpful in recovery process.
    - Hearing personal stories from other consumers.
    - Community resources such as clubhouses.

- Support or help in navigating through the system to access the appropriate services. This is important in the beginning of recovery as well as throughout. WRAP programs are considered very helpful by many of these consumers.
- Reducing the stigma of mental illness removes barriers to people seeking treatment and not hiding in shame for fear of being discriminated against such as in employment or being stigmatized in other ways.
- Support and coordination of services for youth in transition.
- Encouragement from providers to take an active role in treatment decisions.
- Feeling they are entitled to get better, that they are worthwhile human beings.

- Being seen as people and not their illness.
- Help with access to affordable treatment and services or help paying for them.
- Believing *you have the right to fail and the dignity of risk.*

# Policy Makers

## *Transformation Workgroup*

From this group information was gathered about funding legislation and support for key transformation initiatives including elimination of stigma, advancing recovery and increasing the understanding of the populace of this state that people with mental illness can and do recover. The first two desired behavior goals for this group are to eliminate stigmatizing language and to adopt processes that promote recovery; the third behavior is to champion legislation for funding to accomplish the first two goals. Some members of the Transformation Workgroup represent special populations such as older adults, Native Americans, youth, NAMI and mental health providers; thus, information was also gathered about the Transformation initiatives pursuant to these special interest groups.

### 1.0 DESIRED BEHAVIOR: ELIMINATE STIGMATIZING LANGUAGE

### 1.1 Current Behavior

- Transformation Workgroup members clearly understand the goals of the Transformation and demonstrate support for the elimination of stigma.
- Members avoid stigmatizing language as evidenced during interviews and exhibited a degree of comfort and familiarity in using "person first" language.
- Workgroup members are functioning in many roles to effect a reduction of stigma. They are advocating, serving on committees, training others, heading state agencies, engaged at grass-roots levels such as peer-to-peer counseling, developing IEP's, and seeking housing and employment opportunities for people with mental illness.
- Funding for mental health services is seen as a medium to high priority for the state by a majority of the Workgroup interviewed (19 of 25).

## 1.2 Current Knowledge/Beliefs

- Workgroup members understand that stigma is a huge issue for people with mental illness in general, and also see its additional impact on specific sub-segments of the population whom they may represent.
- Employment and housing for people with mental illness are seen as necessities if stigma reduction is to take place.
- The current mental health system in Washington State needs to be transformed.
- People with mental illness can and do recover.
- Believe community based programs and non-traditional methods such as clubhouses are effective in helping people with mental illness recover.

## 1.3 Perceived Barriers

- People are uncomfortable discussing mental illness.
- Fear: People are afraid of people with mental illness and stereotype them as being dangerous or non-treatable.
- A feeling, among consumers as well as general public, that mental health issues should be kept private.
- A lack of employment for consumers – average employment is at 15%.
- Stigma reduces employment opportunities.
- Lack of education on part of employers – don't know how to employ people with mental illness.
- Lack of clear understanding about stigma and recovery from mental illness community wide and amongst some legislators.
- Labeling someone as having a mental illness is stigmatizing.
- A need for housing for consumers.
- A widely held perception that some diseases are not treatable.
- Mental illness not viewed as a mainstream issue.
- Attention seems to be on illness or aberrance rather than on wellness or normalcy. Too few examples showcased of people with mental illness in recovery and functioning.
- People needing public mental health services are often placed in a subservient position such as in having to go where the state pays.
- Communication perceived as sometimes slow or inefficient by a couple of Workgroup members (Logistics – sometimes hard to get or disseminate information in a timely way among members of the Transformation Workgroup – being east of the mountains seen as presenting some difficulty in disseminating information).

### 1.4 Perceived Motivators

- Funding for programs designed to increase employment and housing opportunities for people with mental illness – training, education.
- More clubhouses and peer-to-peer counseling opportunities.
- Increased parity.
- Legislation making it easier to access care, especially as it relates to underserved populations.
- Consider mental illness as a health issue; include mental health treatment in health treatment.
- Find opportunities to showcase people in recovery.
- Work with schools/start educating about stigma at a very young age.
- Believe community based programs and non-traditional methods such as clubhouses are effective in helping people with mental illness recover

## 2.0 DESIRED BEHAVIOR: PROMOTE RECOVERY

### 2.1 Current Behavior

- Same as current behaviors shown in 1.1, with the addition that these respondents show strong support for community efforts, such as the Clubhouse Model.

### 2.2 Current Knowledge/Beliefs

- Same as the Current Knowledge/Beliefs shown in 1.2 with the additions shown below.
- Workgroup members understand that stigma is a huge issue for people with mental illness and also understand the magnitude of its impact on recovery.
- They believe the Recovery Model works and that recovery looks different for each person.
- They believe mental health should be a mainstream health issue.
- They believe mental health should be on the same "level" as physical health.
- The concept of *Recovery* is not always well understood.

## 2.3 Perceived Barriers

- Funding - For developing programs, expanding access to care, taking successful programs statewide, education and training, generating awareness, etc. (Note: A number of Workgroup members see funding as "high" or "improved," and cite the large influx of funding in the last couple of years. Even amongst some of these members, however, there was a perception that more funding might be needed or that it needed to be reallocated or shifted.)
- Budget issues - budget priorities shift or change, often perceived as a response to the "loudest voices at the time" or to crises.
- The mental health system is an adult oriented system not always well suited to children and families.
- There is not enough early intervention or assessment.
- A lack of a secure environment for people to go or be placed – incarcerating people with mental illness rather than placement where they can be treated.
- A lack of geriatrics training among medical professionals. (Depression in older adults often goes undiagnosed because practitioner is unaware of what to look for.)
- Lack of transition programs as kids age out of system – transition a weak area.
- Lack of enough-evidence based programs for kids.
- Lack of access to mental health services/lack of access to medical services (long term mental health consumers have a problem accessing health care services).
- More people needing services than resources available to serve them.
- Lack of parity (insurance).
- Lack of consistency and lack of common data systems and common guidelines in system. There are 13 RSN's and there is a perception that there is little accountability and few parameters.
- A perceived difference in health care system between physical and mental health.
- Current regulations that may restrict or reduce services and reimbursement such as Medicaid regulations.
- Lack of access to mental health services amongst specific groups – i.e., Tribal groups.
- MHS run as an adult model. Services are approved and funded for adults and are not a good fit for children and families.
- Easier to count adult consumers so numbers for children appear low because basically only count chronically mentally ill. (Much of child illness is short term trauma or behavioral related.)
- Educators not trained in mental illness or have many other priorities.
- People with mental illness face lack of access to health care services.
- Other popular issues take priority.
- Many special interest groups need to find common voice to promote change.
- Need for more consumer empowerment and state supported media access.
- Recovery not always understood – doesn't always follow everyone's expectations.
- People don't accept mental illness as a real problem.

## 2.4 Perceived Motivators

- Abandon the thinking that separates physical and mental health.
- More funding to support Consumer/Family run groups and organizations/peer support.
- Showcase real people and real success stories.
- Consider older adults separately by tailoring messages for them that focus on their special needs and understanding.
- Fund programs to increase employment for the people with mental illness.
- Develop a centralized system with links and phone numbers to help people access services.
- Fund programs ensuring adequate housing for people with mental illness.
- Promote consumer and family member involvement …more consumer representatives everywhere including governing boards.
- Funding for peer support positions.
- Change policy and contract wording to reflect goals of transformation.
- Training and policy discussion supporting premise that recovery works.
- Educate about mental health and illness at earliest possible age; make it a part of the health curriculum.
- Improve access to services.
- Become less crisis driven and more pro-active.
- Implement community-based recovery oriented programs.

# 3.0 DESIRED BEHAVIOR: CHAMPION LEGISLATION

## 3.1 Current Behavior

- Same as Current Barriers shown in 1.1 and 2.1 with the addition that these respondents champion a number of legislative actions that would result in a decreased need for crisis intervention.

## 3.2 Current Knowledge/Beliefs

- Same as Current Knowledge/Beliefs as shown in 1.2 and 2.2 with the additions shown below:
- Employment and housing for people with mental illness are seen as the building blocks for Recovery.
- Investing in mental health can save money.

## 3.3 Perceived Barriers

- Some members believe legislators do not understand the need for pro-active legislation and the need to fund services and programs that will reduce the need for crisis services.
- There are existing regulations that place limits or deny services and reimbursements for those served by public mental health.
- A couple of members perceive a lack of consistency and accountability throughout the system and the 13 RSNs.
- There are many special interest groups with their own sets of "priorities," and they don't always speak with one voice.
- Mental health is not accepted by the population or by insurance carriers as being as important as physical health.
- There are many competing demands that need attention by the legislature.

## 3.4 Perceived Motivators

- Arrive at an agreement among the various advocates and interests as to where the greatest needs or barriers are, set 2 or 3 measurable goals and focus on those. Become less fragmented and more focused and united.
- Expand (*pepper*) the Clubhouse Model around the state.
- Show how everyone can be better served through Transformation, including groups that are currently underserved.
- The governor supports the legislation.

## *Legislative Taskforce*

Members of this Taskforce were contacted by mail, e-mail and telephone and invited to participate in this study. Ten people agreed to be interviewed, representing people who are in the legislature as well as legislative staff and agency advisors.

Five desired behaviors were identified for this segment of policy makers: 1) They should draft legislation that funds Transformation; 2) They should reallocate current funding so that the elements of Transformation can be supported; 3) They should ensure adequate funding for Transformation; 4) They should re-interpret current regulations; and 5) They should support development of employment opportunities.

Because the first three desired behaviors, in particular, are similar many of the Current Behaviors and Beliefs, as well as Perceived Barriers and Motivators are the same.

### 1.0 DESIRED BEHAVIOR: DRAFT LEGISLATION THAT FUNDS TRANSFORMATION

#### 1.1 Current Behavior

- These respondents understand Transformation well and support its implementation. Some expect that state agencies already have sufficient funds to implement it.
- A Mental Health Parity bill has been passed, making mental health equivalent to physical health in insurance coverage and subject to the equal co-pays and limitations.
- They have determined that state funding and delivery systems are not working particularly well for people who need and use mental health services.
- Funding for mental health services is seen as a medium to low priority for the state, although there has been some improvement over the past few years.
- These respondents admit that job opportunities for people with mental illness are not very good.
- There is strong support for community efforts, such as the Clubhouse Model, which can be an excellent source for help on needs such as employment and job training.

#### 1.2 Current Knowledge/Beliefs

- These respondents hold key beliefs that would allow them to support drafting legislation for Transformation funding.
- The only areas related to recovery where these respondents have some question are 1) they do not totally agree that success is how the consumer defines it and 2) they do not agree that people with mental illness pose no greater violence risk to the community than people without mental illness.

### 1.3 Perceived Barriers

- Outside of this Taskforce, many legislators are not aware of the rationale for Transformation. They do not hear enough from people who have been successful with mental health treatment and do not have evidence of how Transformation can save costs over time.
- Not enough effort goes into prevention or early intervention, while too much attention and too many resources go to handling crises.
- Mental health is seen as a funding "black hole" by some legislators and they resist putting more funds at risk. Mental health funding, while never the highest priority, is often not even high in the second tier of funding.
- Mental health is not accepted by the population or by insurance carriers as being as important as physical health.

### 1.5 Perceived Motivators

- Replicate and expand the Clubhouse Model around the state.
- Prepare a strategic plan to show how the current system can be changed to a more recovery-based system with measurable outcomes.
- Demonstrate that Transformation can save the state money in the long run.
- Listen to successful constituents who have experienced mental illness. Hear their stories about what works.
- Show how everyone can be better served through Transformation, including groups that are currently underserved.

## 2.0 DESIRED BEHAVIOR: REALLOCATE CURRENT FUNDING IN SUPPORT OF TRANSFORMATION ELEMENTS

### 2.1 Current Behavior

- Same as the Current Behaviors shown in 1.1.

### 2.2 Current Knowledge/Beliefs

- Same as the Knowledge/Beliefs shown in 1.2, with the addition that these respondents' beliefs would allow them to support an effort to reallocate funding for Transformation.

## 2.3 Perceived Barriers

- Same as the Perceived Barriers shown in 1.3, with the additions shown below.
- Funds are categorized too much, not allowing flexibility and efficiency in how funds are used at the local level.
- Legislators are not aware of the rationale for Transformation. They do not hear enough from people who have been successful with mental health treatment and do not have evidence of how Transformation can save costs over time.

## 2.4 Perceived Motivators

- Same as the Perceived Motivators shown in 1.4, with this addition: In the strategic planning process, to the extent possible, show how current funds can be reallocated to achieve goals.

# 3.0 DESIRED BEHAVIOR: ENSURE ADEQUATE FUNDING FOR TRANSFORMATION

## 3.1 Current Behavior

- Same as the Current Behaviors shown in 1.1.

## 3.2 Current Knowledge/Beliefs

- Same as Current Knowledge/Beliefs shown in 1.2, with the addition that these respondents' beliefs would allow them to support adequate funding for Transformation.

## 3.3 Perceived Barriers

- Same as Perceived Barriers shown in 1.3 with this addition: There may be lack of agreement on funding levels that are appropriate for various services and segments of the population.

## 3.4 Perceived Motivators

- Same as Perceived Motivators shown in 1.4, with this addition: Hammer out agreement among the various advocates as to where the greatest needs are in order to get Transformation started.

## 4.0 DESIRED BEHAVIOR: REINTERPRET CURRENT REGULATIONS.

### 4.1 Current Behavior

- These respondents understand Transformation well and support its implementation. If current regulations exist that could be made more effective for Transformation, reinterpretation would likely be a welcome approach.

### 4.2 Current Knowledge/Beliefs

- Same as Current Knowledge/Beliefs shown in 1.2, with the addition that these respondents' beliefs would allow them to support reinterpretation of existing regulations.

### 4.3 Perceived Barriers

- Same as Perceived Barriers as in 1.3, with this addition: There is no comprehensive search of existing regulations to identify which ones could be reviewed for potential Transformation support.

### 4.4 Perceived Motivators

- Prepare a plan for a comprehensive review of mental health related regulations and identify those that can be reinterpreted to support Transformation. An example might be state and federal statutes that ban discrimination in the state, which might be useful in encouraging landlords and employers to eliminate stigmatization when dealing with people who have a mental illness.
- Review and fund laws passed in 1991 requiring state agency coordination and delivery of service.
- Review regulations for Medicaid eligibility and access to services under Medicaid provisions.

## 5.0 DESIRED BEHAVIOR: SUPPORT DEVELOPMENT OF EMPLOYMENT OPPORTUNITIES

### 5.1 Current Behavior

- Same as Current Behavior shown in 1.1.

### 5.2 Current Knowledge/Beliefs

- Same as Current Knowledge/Beliefs shown in 1.2, with the addition that these respondents' beliefs would allow them to support the development of employment opportunities.

## 5.3 Perceived Barriers

- Same as Perceived Barriers shown in 1.3.

## 5.4 Perceived Motivators

- Same as Perceived Motivators shown in 1.4, with the additions shown below.
- Demonstrate that when people who have mental illness can be employed and contributing to the tax rolls.
- Listen to successful constituents who have experienced mental illness and what occurred in their searches for employment and job training.

## *Local Elected Officials*

A sample of elected officials was randomly drawn from public records of counties and cities across the state. They were screened to be people with responsibility for, or at least an interest in, mental health funding for their jurisdictions. A total of 13 officials were interviewed by telephone.

There were three desired behaviors identified for this segment of policy makers: 1) They should approve local budgets that allows for Transformation; 2) They should reallocate current funding so that the elements of Transformation can be supported; and 3) They should support employment opportunities at the local level.

Because these desired behaviors have similarities, many of the Current Behaviors and Beliefs, as well as the Perceived Barriers and Motivators are the same.

## 1.0 DESIRED BEHAVIOR: APPROVE LOCAL BUDGETS THAT ALLOWS FOR TRANFORMATION

### 1.1 Current Behavior

- At this time, few officials have had any introduction to budgeting for Transformation, and indeed, few have even heard of the effort.
- Most agreed that mental health services in their areas are not adequate, and felt that funding is insufficient. They look primarily to the state and federal sources to help with funding.

### 1.2 Current Knowledge/Beliefs

- These officials embrace most of the beliefs that would be needed in order for them to create budgets to support Transformation.
- However, they doubt that people with mental illness can recover completely, and they believe that people with mental illness pose more risk to their communities than do people without mental illness.

### 1.3 Perceived Barriers

- Lack of information about the Mental Health Transformation effort in Washington.
- Lack of knowledge and understanding of mental health issues, particularly that people can recover.
- Budget priority for mental health is not high in their communities.
- Funding is seen as a state or federal responsibility.

- Mental health services are not always effective in their communities, due to lack of access/insurance coverage, transportation, knowledge on how to navigate the system.

### 1.4. Perceived Motivators

- More funds from state or federal sources and/or help in budgeting to include Transformation priorities.
- Legislative support for making mental health a priority, dedicated to Transformation.
- Better information for officials and the public regarding Recovery Model and stigma principles.
- Empirical evidence that Transformation works; data and examples.
- Provide leadership in changing old habits, assure outreach and help at the grassroots level of the community.

## 2.0 DESIRED BEHAVIOR: REALLOCATE CURRENT FUNDING TO SUPPORT ELEMENTS OF TRANFORMATION

### 2.1 Current Behavior

- Same as Current Behavior shown in 1.1, with the addition that officials have not addressed how current funding can be reallocated to support Transformation.

### 2.2 Current Knowledge/Beliefs

- Same as Current Knowledge/Beliefs shown in 1.2, with the addition that these officials' beliefs would allow them to reallocate funds to support Transformation.

### 2.3 Perceived Barriers

- Same as Perceived Barriers in 1.3.

### 2.4 Perceived Motivators

- Same as Perceived Motivators shown in 1.4.

# 3.0 DESIRED BEHAVIOR: SUPPORT EMPLOYMENT OPPORTUNITIES AT THE LOCAL LEVEL

## 3.1 Current Behavior

- Same as Current Behavior shown in 1.1, with the addition that these officials have not addressed employment opportunities as part of Transformation.
- Also, about half of these officials felt that job opportunities for people with mental illness were reasonable in their areas. The others said that such programs are not available.

## 3.2 Current Knowledge/Beliefs

- Same as Current Knowledge/Beliefs shown in 1.2, with the addition that these officials' beliefs would allow them to create and support job opportunities for people with mental illness.
- They also hold two key beliefs, however, that could stand in the way of funding effective job opportunities: they doubt that people with mental illness can recover completely and they believe that people with mental illness pose more risk to their communities and do people without mental illness.

## 3.3 Perceived Barriers

- Same as Perceived Barriers shown in 1.3.

## 3.4 Perceived Motivators

- Same as Perceived Motivators shown in 1.4.

# Recommendations

## PROVIDERS
### Recommendations

Using the traditional social marketing model, the following "4P" strategies are recommended for *consideration*, based solely on barriers and motivators the target audience evidently perceives for the desired behaviors.

***Product***

- Develop and offer additional trainings, presentations and workshops where providers learn in detail about the Recovery Model as well as best practices.
- Make available publications and articles substantiating best practices.

***Price***

- Provide more financial support for best practices.
- Provide financial incentives for implementing best practices.
- Influence administrators to provide "time off" for workshops and trainings.

***Place***

- Provide convenient locations for trainings, presentations and workshops.
- Provide advance notice of trainings, presentations and workshops.
- Distribute articles at ongoing conferences as well as these additional trainings.

***Promotion***

- Key Messages:
  - Best practices are evidence-based.
  - Use social norming techniques.

- Key Messengers:
  - Administrators establishing these best practices as a goal and priority.
  - Consumer testimonials and success stories.
  - Peer testimonials and success stories.

- Key Communication Channels:
  - Notices in newsletters announcing trainings, presentations and workshops.
  - Are there provider lists so you could do a mailing?
  - Any popular web sites that would include announcements?

# PROVIDERS
## Summary of Barriers and Motivators

| DESIRED BEHAVIORS | Attend Discussion Groups or Workshops With Consumers | Partner With Consumers | Use Language of Respect | Adopt the Recovery Model | Encourage Peers/CoWorkers to Adapt These Same Best Practices |
|---|---|---|---|---|---|
| **BARRIERS** | Time constraints<br><br>Already have heavy load<br><br>Not aware sessions existed<br><br>Don't know time and locations<br><br>No sessions in my area (rural) | Some consumers not ready<br><br>Not appropriate for some consumers | Old habits<br><br>Seems acceptable when just with peers<br><br>Not comfortable correcting peers | Goals not clear to everyone<br><br>Too much emphasis for us currently on using measurable objectives perceived as limiting treatment options<br><br>Not enough room for individual variation<br><br>Implementation process is lengthy<br><br>Requires big societal change<br><br>Lack funding for wide-spread implementation<br><br>Not enough management support<br><br>Other consumer priorities like access to mental health care | Not comfortable pushing peers<br><br>Believing my peers have similar barriers in terms of awareness, time, access to resources and management support<br><br>Concern among some peers that consumers aren't ready |
| **MOTIVATORS** | Management and peer support and encouragement<br><br>Awareness of related consumer success stories<br><br>Advance notice<br><br>Financial support or incentives<br><br>Substantiating academic findings | Knowing more about the components of and standards for partnering<br><br>Having more training in steps and techniques | Having clinic or practice make this a priority standard/goal<br><br>Peer agreement<br><br>Adopting Recovery Model practices<br><br>Peers speaking publicly that this is the desired norm | Evidence that it works for consumers and providers<br><br>Evidence that people with mental illness are not more violent than other people<br><br>Evidence will reduce crisis intervention<br><br>Testimonials and success stories | Increased awareness of good practices through education/ training<br><br>More promotion of workshops<br><br>Management support for extra time and effort needed<br><br>Having clinic or practice make this a priority standard/goal |

## CONSUMERS
### Recommendations

Using the traditional social marketing model, the following "4P" strategies are recommended for *consideration*, based solely on barriers and motivators the target audience evidently perceives for the desired behaviors.

***Product***

- Consider forming a special consumer speakers bureau.
- Create training for members of the speakers bureau.
- Work with members to help schedule speaking opportunities.
- Work with members to provide opportunities at policy making advisory councils.
- Increase peer support activities, especially for youth.
- Enhance interagency communication systems.
- Provide durable/long-lasting materials (e.g., booklets, web sites) on mental illness, resources and financial options.

***Price***

- For consumer advocates:
  - Provide annual advocacy awards.
  - Provide financial support for travel-related expenses.
  - Consider providing an honorarium for speaking/advising.
- Increase consumer awareness of financial options.

***Place***

- For consumer advocates, provide speaking opportunities at convenient times and locations.
- Increase consumer awareness of locations and means of access to care.

***Promotion***

- Key Messages:
  - Success stories.
  - What does recovery look like.
  - Financial support is available.

- Key Messengers:
  - Providers.
  - Consumer advocates.
  - Advocacy groups.

- Key Communication Channels:
  - Provider offices.
  - News articles and stories (helping to reduce stigma and create norms).
  - Web sites.
  - Adult and family networks.

# CONSUMERS
## Summary of Barriers and Motivators

| DESIRED BEHAVIORS | Advocate, Tell Your Story, Participate and Encourage the Same from Others | Take Responsibility In Your Recovery, Including Being a Partner in Treatment and Following Your Treatment Plan |
|---|---|---|
| **BARRIERS** | Basic shyness, insecurity with speaking skills<br><br>Feeling don't have enough to offer or say<br><br>Concern whether anyone would want to listen<br><br>Stigma – fear will be thought less of and/or discriminated against<br><br>Not knowing what opportunities for speaking are available | Not knowing what treatment is available, where it is available and options for payment<br><br>Lack of knowledge about options and best choices due to difficulty in obtaining information as well as conflicting and confusing information<br><br>Lack of access to appropriate treatment; long waiting lists and difficulty getting first appointment<br><br>Poor communication and coordination between agencies and systems preventing seamless delivery of services, especially for youth in transition<br><br>Lack of confidence among consumers that evidence-based practices work, that they represent a cookie-cutter approach when their situation is individual<br><br>Too few resources specifically geared for youth<br><br>Lack of knowledge about illness<br><br>Feelings of hopelessness, believing you are all alone<br><br>Stigma and feelings of shame<br><br>The illness itself can interfere with seeking appropriate treatment<br><br>Perception that some providers aren't interested in partnering model<br><br>Negative side effects from some medications<br><br>Affordability |
| **MOTIVATORS** | Training in public speaking and presentation skills<br><br>Wanting to let others know they are not alone<br><br>Getting others to seek treatment<br><br>Eliminating stigma<br><br>Believing the public sharing will help my own recovery<br><br>Believing my story will be listened to and heard<br><br>Encouragement from others to share publicly, especially consumer advocates and providers | Believing there is hope, that they can get better, that they are worthy<br><br>Knowing they are not alone<br><br>Support in navigating through the system<br><br>Reducing the stigma; being seen as people not an illness<br><br>Support and coordination of services for youth<br><br>Encouragement from providers to take an active role<br><br>Access to affordable treatment<br><br>Believing okay to risk and fail |

## POLICY MAKERS: TRANSFORMATION WORKGROUP

### Recommendations

This group's input relates primarily to recommended strategies for other target markets versus strategies that would be used to influence them as a group. They can be combined with other product, price, place and promotional ideas. In addition, perhaps not surprisingly, many of their recommendations fall in the "Policy" category, one some consider a 5th "P".

***Product***

- Develop agreements that focus and unify advocates and special interest groups, including measurable goals.
- Develop and offer school curricula that reach youth early.
- Improve data systems by creating a centralized system with links and phone numbers to help people access services.
- Support separate treatment for older adults.
- Host discussion groups on the recovery model.

***Place***

- Increase access to services.
- Increase clubhouses around the state.

***Promotion***

- Key Messages:
  - Showcase success stories.
  - Get the Governor's support and endorsement.
  - Mental illness is a health issue.

***Policy***

- Increased funding for consumer/family run groups, employment and access to housing, services and peer support positions.
- New legislation increasing access to care for underserved populations.

# POLICY MAKERS: TRANSFORMATION WORKGROUP
## Summary of Barriers and Motivators

| DESIRED BEHAVIORS | ACHIEVING THE ELIMINATION OF STIGMA | ADOPT PROCESSES THAT ADVANCE RECOVERY | CHAMPION LEGISLATION |
|---|---|---|---|
| **BARRIERS**<br><br>**(What's in the way?)** | Concern with others' perspectives:<br><br>Discomfort discussing mental illness; fear of people with mental illness; feeling this is a private issue, not a mainstream one; understanding of sigma; and belief that the disease is treatable.<br><br>Concern for consumers:<br><br>Employment opportunities, employer education, and housing opportunities<br><br>Concern with Workgroup<br><br>Timely and effective communications, given varied locations of members | Inadequate Funding:<br><br>Program development, access to care, education and training, public awareness<br><br>System is currently more adult than child or family-oriented<br><br>Inadequate<br><br>Early intervention, "outpatient" treatment, geriatrics training, transition programs for kids, access of mental health patients to medical care, insurance<br><br>Low public awareness and understanding | Not always seen as a Legislative Priority<br><br>Lack of understanding of value of pro-active versus crisis services<br><br>Existing regulations placing limits or denying services and reimbursements<br><br>Lack:<br><br>Consistency/one voice among special interest groups; acceptance by the population or by insurance carriers as important as physical health |
| **MOTIVATORS**<br><br>**(What would help?)** | Increased funding for:<br><br>Programs to increase employment; housing; more clubhouses<br><br>Showcase success stories<br><br>Legislation increasing access to care for underserved populations<br><br>Consider mental illness a health issue<br><br>Work with schools to educate kids at young age | Increased funding to:<br><br>Support consumer/family run groups and increase employment, access to housing, services and peer support positions<br><br>System changes:<br><br>Create a centralized system with links and phone numbers to help people access services; treat older adults separately; change policy and contract wording to reflect goals of transformation; proactive versus crisis driven<br><br>Communications and Education Solutions:<br><br>Educate kids at young ages, showcase success stories; host discussions that recovery works | Develop agreements that focus and unify advocates and special interest groups:<br><br>Agree on greatest needs, barriers, set 2-3 measurable goals<br><br>Expand (pepper) clubhouses around the state<br><br>Assure the Governor will support legislation |

## POLICY MAKERS: LEGISLATIVE TASKFORCE

### Recommendations

Using the traditional social marketing model, the following "4P" strategies are recommended for *consideration*, based solely on barriers and motivators the target audience evidently perceives for the desired behaviors.

***Product***

- Strategic plan delineating how current system can be changed to a more recovery-based system with measurable outcomes.
- Agreement among advocates as to where greatest needs are in order to get Transformation started.
- Comprehensive review of mental health related regulations and identification of those that can be reinterpreted to support Transformation.
- Review regulations for Medicaid eligibility and access to services under Medicaid provisions.

***Price***

- Review and fund laws passed in 1991 requiring state agency coordination an delivery of service.

***Place***

- Replicate and expand Clubhouse Model around the state.

***Promotion***

- Key Messages:
  - Transformation can save the state money.
  - Transformation can better serve the underserved.
  - Success stories.
  - Jobless rates.

# POLICY MAKERS: LEGISLATIVE TASKFORCE
## Summary of Barriers and Motivators

| DESIRED BEHAVIORS | DRAFT LEGISLATION THAT FUNDS TRANSFORMATION | REALLOCATE CURRENT FUNDING IN SUPPORT OF TRANSFORMATION ELEMENTS | ENSURE ADEQUATE FUNDING FOR TRANSFORMATION | REINTERPRET CURRENT REGULATIONS | SUPPORT DEVELOMENT OF EMPLOYMENT OPPORTUNITIES |
|---|---|---|---|---|---|
| **BARRIERS**<br><br>**What will make this hard?** | Concern with current awareness levels and attitudes of legislators regarding:<br><br>Rationale for Transformation<br><br>Consumer success stories not visible<br><br>Funding for mental health is seen as a "black hole"<br><br>Additional Taskforce concerns with need for:<br><br>Early intervention<br><br>Acceptance as important as physical health | Funds are categorized too much, not allowing flexibility<br><br>OTHERS SAME AS FOR "DRAFT LEGISLATION THAT FUNDS TRANSFORMATION | Lack of agreement on funding levels appropriate for various services and segments of the population<br><br>OTHERS SAME AS FOR "DRAFT LEGISLATION THAT FUNDS TRANSFORMATION | SAME AS FOR "DRAFT LEGISLATION THAT FUNDS TRANSFORMATION | SAME AS FOR "DRAFT LEGISLATION THAT FUNDS TRANSFORMATION |
| **MOTIVATORS**<br><br>**What would help?** | Replicate and expand Clubhouse Model around the state<br><br>Develop a strategic plan to show how current system can be changed to a more recovery-based system with measurable outcomes<br><br>Demonstrate that Transformation can save state money and better serve the underserved<br><br>Visibility for consumer success stories | SAME AS FOR "DRAFT LEGISLATION THAT FUNDS TRANSFORMATION" | Hammer out agreement among various advocates as to where greatest needs are in order to get Transformation started<br><br>OTHERS SAME AS FOR "DRAFT LEGISLATION THAT FUNDS TRANSFORMATION" | Prepare plan for a comprehensive review of mental health related regulations and identify those that can be reinterpreted to support Transformation<br><br>Review and fund laws passed in 1991 requiring state agency coordination and delivery of service<br><br>Review regulations for Medicaid eligibility and access to services under Medicaid provisions | Become informed about actual jobless rates among people with mental illness<br><br>OTHERS SAME AS FOR "DRAFT LEGISLATION THAT FUNDS TRANSFORMATION" |

## POLICY MAKERS: LOCAL ELECTED OFFICIALS

### Recommendations

Using the traditional social marketing model, the following "4P" strategies are recommended for *consideration*, based solely on barriers and motivators the target audience evidently perceives for the desired behaviors.

***Product***

- Credible and thorough informational pieces (e.g., white papers).

    - Recovery model.
    - Stigma principles.
    - Transformation effort in Washington State.
    - Empirical evidence that Transformation works.

***Price***

- More funding for Transformation priorities.

***Promotion***

- Key Messages:

    - The Recovery Model Works.
    - Transformation Efforts in Washington State.

- Key Messengers:

    - State leadership officials (i.e., the governor).

- Key Communication Channels:

  Conferences, presentations (e.g., legislative subcommittees) and other select speaking engagements with elected official audiences.

# POLICY MAKERS: LOCAL ELECTED OFFICIALS
## Summary of Barriers and Motivators

| DESIRED BEHAVIORS | APPROVE LOCAL BUDGETS THAT ALLOWS FOR TRANSFORMATION | REALLOCATE CURRENT FUNDING TO SUPPORT ELEMENTS OF TRANSFORMATION | SUPPORT EMPLOYMENT OPPORTUNTIES AT THE LOCAL LEVEL |
|---|---|---|---|
| **BARRIERS**<br><br>**What's in the way?** | Lack information about the Mental Health Transformation effort in Washington<br><br>Lack knowledge and understanding of mental health issues, particularly that people can recover<br><br>Budget priority for mental health is not high<br><br>Funding is seen as a state or federal responsibility<br><br>Mental health services are not always effective in communities as a result of lack of access/insurance coverage, transportation and knowledge on how to navigate the system | SAME AS FOR APPROVING BUDGETS | SAME AS FOR APPROVING BUDGETS |
| **MOTIVATORS**<br><br>**What would help?** | More funds from state or federal sources and/or help in budgeting to include Transformation priorities<br><br>Legislative support for making mental health a priority, dedicated to Transformation<br><br>Better information on officials and the public regarding Recovery Model and stigma principles<br><br>Empirical evidence that Transformation works; data and examples<br><br>Provide leadership in changing old habits, assure outreach and help at the grassroots level of the community | SAME AS FOR APPROVING BUDGETS | SAME AS FOR APPROVING BUDGETS |

# DETAILED FINDINGS - PROVIDERS

## Overview, Purpose and Method

Providers of mental health services have great potential for influencing how consumers and the general population approach, deal with and talk about mental health. Their input is critical to the development of a marketing strategy that will successfully address the Transformation goals. The purpose of gathering information from this segment was to assess provider behavior, knowledge and belief in relation to stigma reduction and promotion of the Recovery Model.

It was decided that the sample for the research should consist primarily of professionals who provide publicly funded mental health services, as almost all providers in the state utilize public funds. Furthermore, the sample should include a portion of administrators. DOH provided the names of individuals and clinics from which Gilmore could draw, and Gilmore augmented that list with names drawn from Internet sources. The questionnaire, a copy of which is shown in the appendix, was designed for telephone administration with both closed and open-ended questions. The Social Marketing Task Group, the DOH, and key members of the Transformation Grant staff all had input to and final approval of the questionnaire. The goal was to complete 50 interviews, but time and budget allowed a total of 62 to be completed—11 with administrators and 51 with practitioners. Interviews were administered by experienced Gilmore interviewers between August 4 and August 28.

## Practices for the Recovery Model

These providers were asked about several behaviors key to adopting the Recovery Model: 1) attending consumer discussions or workshops; 2) partnering with consumers; 3) using person-centered language; and 4) encouraging peers to use these practices. In addition, they were asked about current behaviors in relation to: 5) adopting the Recovery Model.

## *Dialogue or Workshop Practices*

Over half of the providers and administrators reached in this survey reported having attended a dialogue or workshop session where consumers interact to share personal stories around issues of recovery or stigma. Those who attended in the past year said they went an average of twice. (Table 1)

**Table 1**
**Experience with Mental Health Consumer Dialogues or Workshops**

| | Providers | Administrators |
|---|---|---|
| **(Base)** | **(51)** | **(11) *** |
| Q1 Have attended such a dialogue or workshop | 51% | 73% |
| Q1A If so, average frequency, past year | 1.8 times | 2.0 times |
| Q1B What are the barriers | | |
| Time, scheduling, too busy | 51% | 9% |
| Lack of awareness, availability of workshops | 43 | 36 |
| Other duties, tasks in my practice | 8 | 0 |
| Will it work with my type of consumers | 8 | 0 |
| Concern for ethics, confidentiality | 6 | 0 |
| Cost, transportation, other system concerns | 4 | 27 |
| All other | | 27 |
| | **(23)** | **(7)** |
| Q1C If not, what would encourage participation | | 0 |
| Advance scheduling; convenient location | 30% | 0 |
| Clear objectives; effectiveness for consumer | 13 | 14% |
| Lighter workload | 13 | 0 |
| Management support | 8 | 0 |
| Payment for time | 4 | 0 |
| Interaction with providers and consumers | 4 | 14 |
| Don't know/not sure | 13 | 71 |
| Q1F1. If not, have explained benefits of sessions to peers | 78% | 100% |
| | **(21)** | **(11)** |
| Q1F. Have encouraged consumers to attend (recommended to staff that they do so) | 80% | 82% |
| Q1F2. Aware that peers attend such sessions | | |
| Many do | 16% | 55% |
| A few do | 45 | 45 |
| Not aware than any do | 39 | 0 |

**Questions: 1:** Have you attended a dialogue or workshop session where consumers interact to share personal stories around issues of recovery or stigma? **1A.** IF YES, How often in the past year? **1B.** What do you think gets in the way of your getting more involved with these types of dialogues/workshops? **1C.** IF NOT, What would make it more likely that you would attend this type of dialogue or workshop? **1F**. Have you ever encouraged consumers or their families to attend a recovery-oriented workshop or training to assist in their recovery (**ADMIN:** Have you recommended to your staff that they attend a recovery-oriented workshop or training?) **Q1F1.** Have you ever pointed out the benefits of attending one of these sessions to your peers or co-workers (co-administrators)? **Q1F2**. Are you aware of any of your peers or co-workers (co-administrators) attending these dialogues or workshops?)

***Small sample size; interpret with caution**

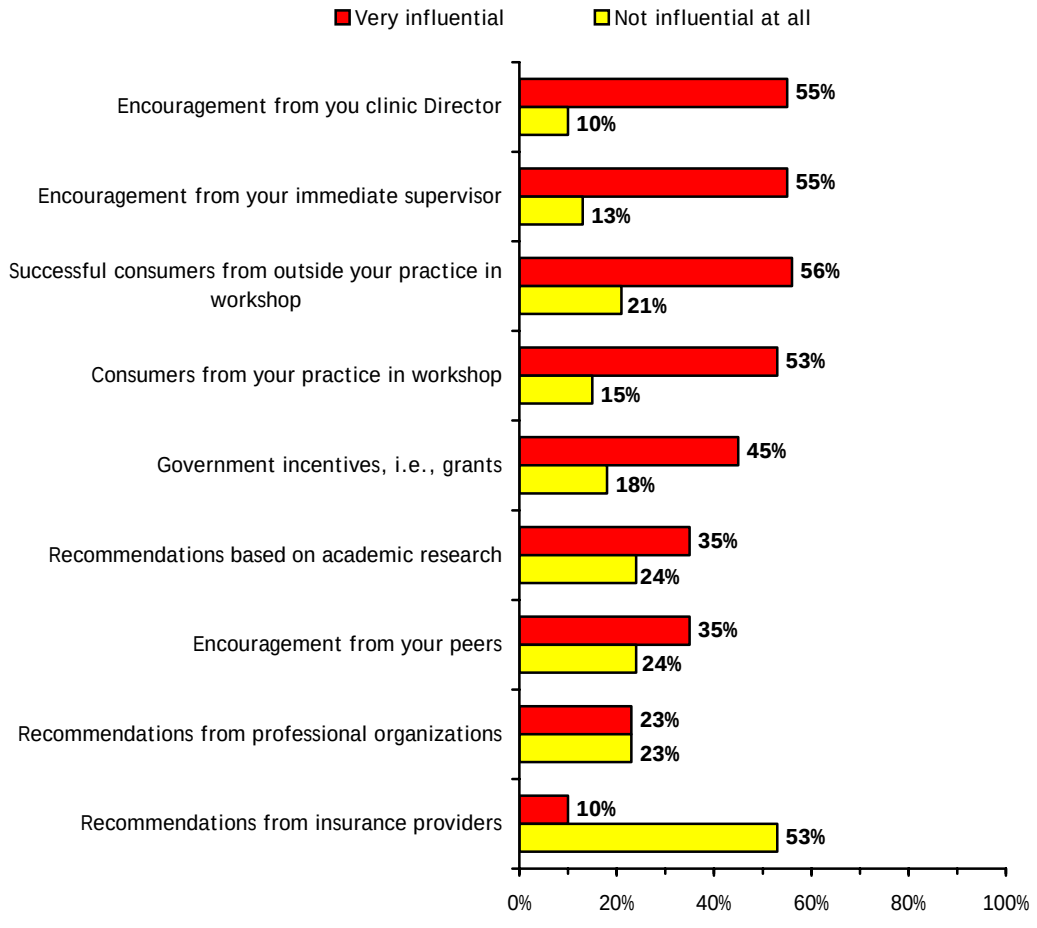
Barriers to attending or attending more often are time constraints, followed by a lack of awareness or availability of sessions. Providers who have never attended such sessions said that advance scheduling and convenient locations would help encourage them.

A high proportion of the administrators, however, could not think of anything in particular that would encourage them to attend workshops. Many of these respondents have discussed the benefits of such sessions with peers and have encouraged consumers to attend.

When asked about nine specific factors that might encourage their attendance at recovery-oriented dialogues or workshops, it was clear that the most promising factors were encouragement from management and meaningful participation by consumers, followed by grants or other incentives from the government (Figure 1). Recommendations from insurance companies held the least promise for encouraging these respondents.

**Figure 1**
**Factors that would Influence Attending Consumer Workshops**
Providers and Administrators

**Base=62**




**Questions 1DA-1DI:** Please tell me if any of the following would encourage or influence you to attend these dialogues or workshops...READ FACTOR...Yes/No IF YES: Would that be very influential or somewhat influential in encouraging you to attend?

Providers were more likely to be influenced by management's encouragement, while administrators were more likely to say that encouragement by their peers and academic research would influence them. Neither providers nor administrators would find any incentive from having insurance providers' recommendations.

The professional associations that would be influential to providers and administrators include National Association for Mental Illness (NAMI), American Psychiatric Association, Washington State Psychiatric Association and Association of Human Services.

## *Partnership*

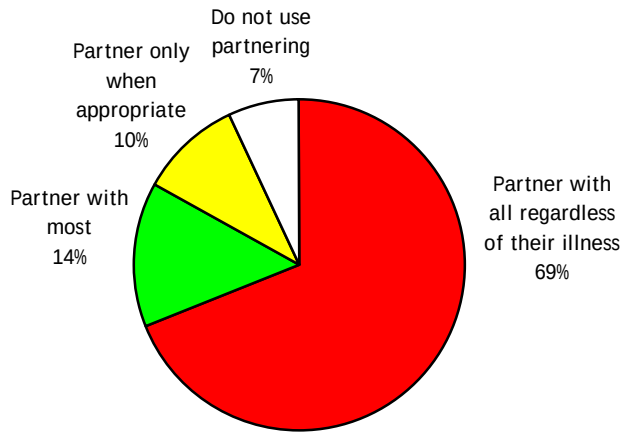
Most providers reported that they do currently partner with most or all of their consumers. Fewer than one in ten said they do not use partnering at all in their practices. (Figure 2)

Those who do not partner with all said that some consumers are not ready for that step. One respondent said that her agency does not allow that level of engagement.

Several said that if they knew more about the standards and had more training, they would partner with more consumers. Others simply said there was nothing that would encourage them to partner more because it isn't always appropriate.

**Figure 2**
**Approach to Partnership**
All Providers

**(Base = 51)**




**Question 2A:** Two of the components of recovery are "self-direction" and "empowerment." Both of these components imply a partnership between providers and consumers, emphasizing the consumer's role in their own recovery. Which of these statements best describes your approach with consumers you see in your practice…?

Over half of the administrators said that their guidelines are for staff to partner with all consumers, and another one-fourth said the guidelines are to partner with most. All of the administrators reported that they do use partnering, at least to some extent, in their clinic.

## *Stigma Reduction*

Almost all of these practitioners and administrators indicated that they do make a point of using person-centered language at least in some settings. (Table 2).

**Table 2**
**Use of Person-Centered Language**

| (Base) | Practitioners (51) | Administrators (11)* |
|---|---|---|
| Make a point of always using such language | 78% | 91% |
| Do this in some but not all settings | 22 | 9 |
| Don't do it very often | 0 | 0 |
| Haven't really thought about it/ don't know | 0 | 0 |

**Question 3:** One way to reduce the stigma surrounding people with mental illness is by using person-centered language. This means talking to and about consumers, not just during working hours, but in all situations, as people first, instead of referring to them by their diagnosis. An example of this would be to say, "John, who has schizophrenia," rather than "John, the Schizophrenic." Which of these statements best describes your approach to using this type of language?....
***Small sample size; interpret with caution**

Those who do not always use such language said they just forget or fall back on old habits. They also use other language with peers as a sort of shorthand. The most help in these situations would be reminders among peers—especially management—and making the use of such language a conscious goal.

Those who always make a point of using such language said they have seen their peers also using it most or some of the time. Not many, however, feel comfortable calling their peers on using language that is not person-centered. When that happens, practitioners are more likely to call their peers on it only sometimes (35%) or not at all (18%), rather than often (43%). Administrators, on the other hand, are highly likely to remind their colleagues to use person-centered language (80% said they do so often).

When asked to name the most important thing one can do to get rid of stigma, practicing the Recovery Model was the number one suggestion of both practitioners and administrators, closely followed by doing more to increase awareness and educate the public and consumers. (Table 3)

**Table 3**
**Most Important Action for Eradicating Stigma**

| (Base) | Practitioners (51) | Administrators (11) * |
|---|---|---|
| Adopt, use the Recovery Model practices | 33% | 45% |
| Increase awareness, sensitivity, speak out more | 22 | 27 |
| Educate the consumer and the public | 22 | 36 |
| Publicize success stories, positive experiences | 14 | 0 |
| Reframe issues, offer hope to the consumer | 10 | 0 |
| More/better access to care | 6 | 0 |

**Question 14:** What do you feel is the one most important or impactful thing you and others in your profession can do to help eradicate the stigma surrounding mental illness? MULTIPLE RESPONSES POSSIBLE
***Small sample size; interpret with caution**

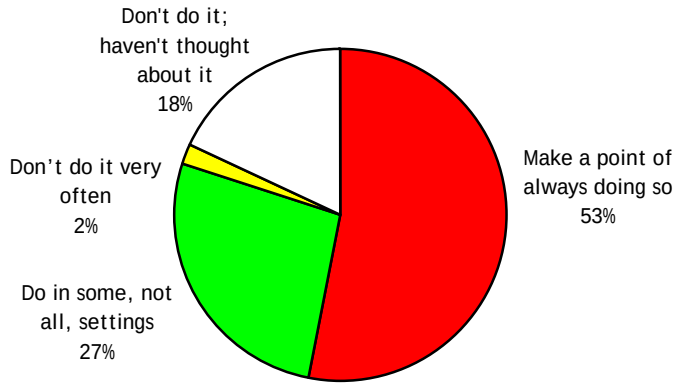
When asked to rate the urgency of eliminating stigma as an issue facing people with mental illness, all but one person interviewed felt that the issue is very (74%) or somewhat (24%) urgent.

## *Encouraging Use of Specific Practices*

When asked about encouraging peers and co-workers to use specific practices in their work with consumers, a slight majority of providers said that they always make a point to promote attending workshops, treating consumers as partners and using person-centered language. Another 27% said they do this sometimes, but 18% said they really have not thought about doing so. (Figure 3).

**Figure 3**
**Encouraging Use of Specific Practices**
All Providers

**(Base = 62)**




**Question 5:** We have been talking about specific recommendations – attending dialogues or workshops where you have the opportunity to interact with consumers, treating consumers as partners in their recovery, and using person-centered language. Have you ever encouraged your peers and co-workers to engage in these practices?

The primary reason given by providers who do not always encourage these practices is one of professional courtesy—they do not want to push their colleagues. Other barriers include a lack of awareness, lack of time for these practices, a lack of resources or access, and language or educational levels of the consumers.

Each of the eleven administrators said they do encourage these practices, at least sometimes. The main barrier for them is being involved with operational and other priorities.

Among the practitioners and administrators not already encouraging peers, there was agreement that raising awareness was something that would make it more likely that they would encourage others. That and other suggestions were:

- More education, usage and training; more overall awareness.
- Workshops and other resources more available and better "advertised".
- Make more time available; cut paperwork.
- Make this a priority, a specific goal; get management buy-in.

# Recovery Model and Mental Health Transformation in Washington

## *Awareness*

All of the practitioners and administrators had some awareness of the Recovery Model and most indicated they were very knowledgeable. (Table 4)

When asked about awareness of the mental health Transformation process in Washington, all of the administrators said they were aware. One-third of the practitioners said they were aware, another third said they were somewhat aware and one-third said they were not aware of the process happening in the state.

**Table 4**
**Aware of The Recovery Model**
Practitioners and Administrators

| | Total |
|---|---|
| **(Base)** | **(62)** |
| Very knowledgeable, practice/facility already using it | 71% |
| Very knowledgeable, not currently using | 10 |
| Somewhat knowledgeable | 16 |
| Heard of it, don't know much about it | 2 |
| Never heard of it | 0 |
| Don't know | 2 |

**Question 7A:** As you may know, the Recovery Model supports consumers in defining their life goals, exercising their independence and taking personal responsibility for their own self-care. Before this interview, how would you describe your knowledge or understanding of the Recovery Model…READ RESPONSE CATEGORIES.

## *Experience Related to Recovery Model*

Both the practitioners and administrators agreed that one thing they have done to help reduce stigma is to have worked with the consumer (and the family, if appropriate) to understand what a mental illness is and that one can progress and get better. (Table 5)

**Table 5**
**Experience in Stigma Reduction**
Practitioners and Administrators

| | Total |
|---|---|
| **(Base)** | **(62)** |
| Help consumer/family understand condition; medical model | 65% |
| Treat consumer as individual; as person not diagnosis | 42 |
| Social awareness; open discussion; involvement in recovery | 40 |
| Going into community; participate in events | 5 |
| Language normalization | 3 |
| Use of humor | 3 |
| Self-disclosure of personal/family mental illness | 3 |

**Question 9:** Reducing stigma and stigmatizing behaviors is an important part of the Transformation and is also a crucial step in moving toward the Recovery Model. Is there something you've done (with the consumers you see in your practice) (as an administrator) that you feel has helped reduce stigma? MULTIPLE RESPONSES POSSIBLE

Two additional shared actions were to treat the consumer as a person, not a diagnosis, and to move people into discussion groups and other self-help settings where they can meet others with similar conditions.

These three stigma-reduction actions were clearly the most prevalent ones taken by this sample of respondents.

When asked how they felt consumers can play a role in their own recovery, most respondents said that consumers must take an active role in defining for themselves what recovery looks like and then being an active partner in the recovery process. (Table 6)

**Table 6**
**How Consumers Can Promote Their Own Recovery**
Providers and Administrators

| | Total |
|---|---|
| **(Base)** | **(62)** |
| Take active role, take responsibility, educate themselves | 65% |
| Believe in themselves, advocate for themselves | 40 |
| Understand that recovery is possible; face fears | 16 |
| Develop support system; peer/family/provider | 10 |
| Celebrate success | 5 |
| Lay off drugs, alcohol; get a job | 3 |

**Question 8:** What do you think is the one most important thing that people with mental illness can do for themselves to promote their own recovery? MULTIPLE RESPONSES POSSIBLE

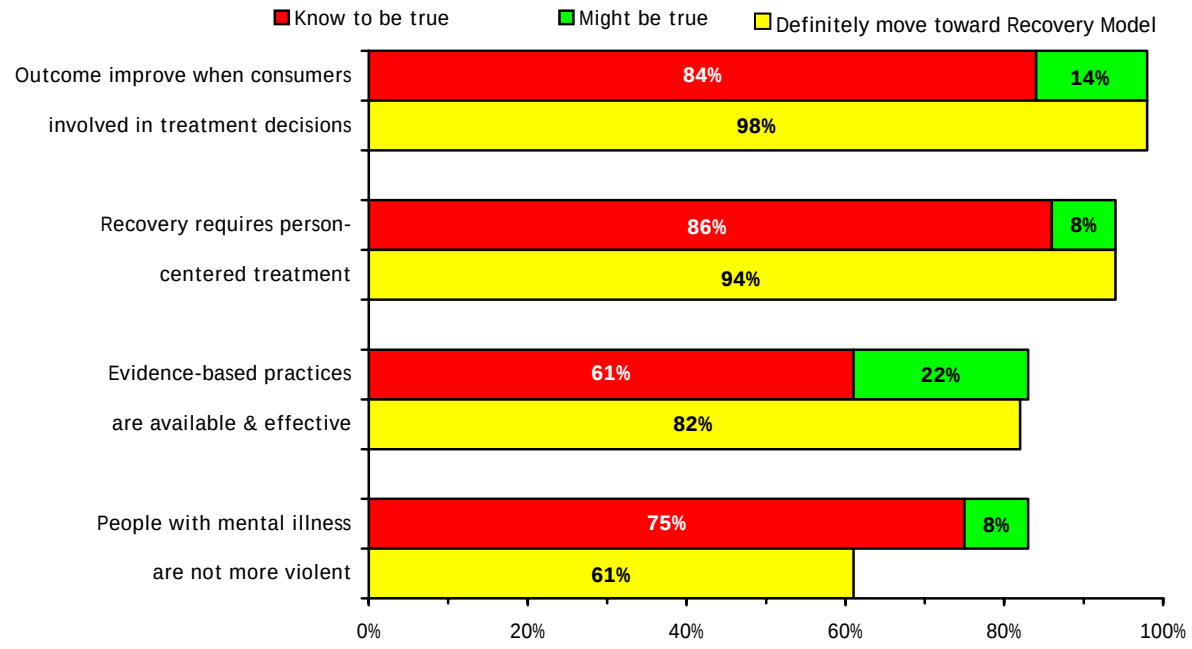
Second, respondents felt that consumers need to have belief that they can recover and be encouraged to speak up about their wants and needs.

## *Knowledge and Influence*

Almost all providers said that they know certain statements about the Recovery Model are true or might be true. These statements and responses are shown in Figure 4. Not all providers, however, feel that knowing the truth of those statements would necessarily cause them to adopt the Recovery Model. There is a strong relationship on two statements between what providers know and how that knowledge influences their adoption of the Recovery Model: "outcomes improve when customers are involved in treatment decisions" and "recovery requires person-centered treatment." Somewhat fewer respondents said they know this is true and it would influence them: "evidence-based practices are available and effective." And while a high proportion of providers said they see truth in the statement that "people with mental illness are not more violent than anyone else," far fewer feel that knowing that to be true would actually move them toward the Model. In other words, that last statement would be less effective than the others in persuading providers to adopt the Recovery Model.

**Figure 4**
**Factors that would Influence Moving Toward Recovery Model**
Practitioners

**(Bases = 51)**




**Question 9A-9D, 10A-10D:** I am going to read several information statements. For each, please tell me if you agree with that statement and believe it to be true…READ FACTORS…I am going to read these statements again. Please tell me for each if you definitely knew this statement to be true, whether it would influence or did influence your decision to move toward the Recovery Model in your practice. READ FACTORS..

Every one of the administrators felt the four statements were true, except for "evidence-based practices are available and effective," where only 73% of the eleven respondents said they know it to be true or think it might be. Nine to ten of the eleven respondents said that each statement would or did move them toward the Recovery Model.

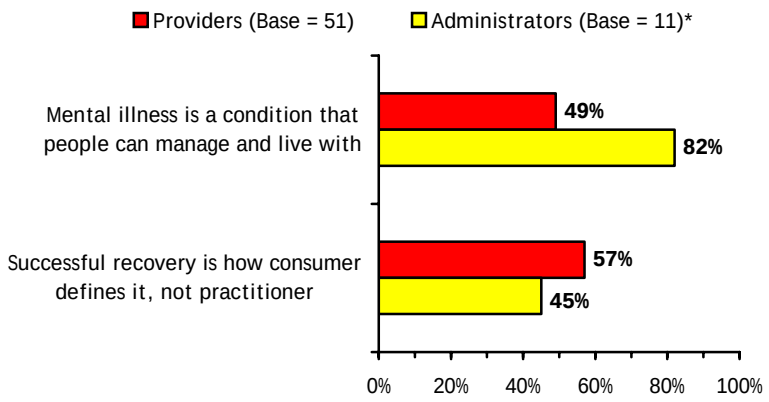
Across all respondents—practitioners and administrators—having more evidence of effectiveness was most frequently mentioned when asked what would be most compelling to adopt the Recovery Model. Other mentions included having more funding and state support, and having better access, particularly in remote parts of the state.

# Beliefs

## *General Beliefs*

Even though there were only a few administrators in this survey, it is interesting that their responses were so different than those of the practitioners. The administrators were far more willing to agree completely that mental illness can be managed and somewhat less willing to agree completely that successful recovery is how the consumer defines it. (Figure 5). Taken together, however, nearly everyone agrees with both statements: a majority agree completely with each statement and another 40% agree generally with some exceptions.

**Figure 5**
**General Mental Illness Beliefs**
Agree completely with statement



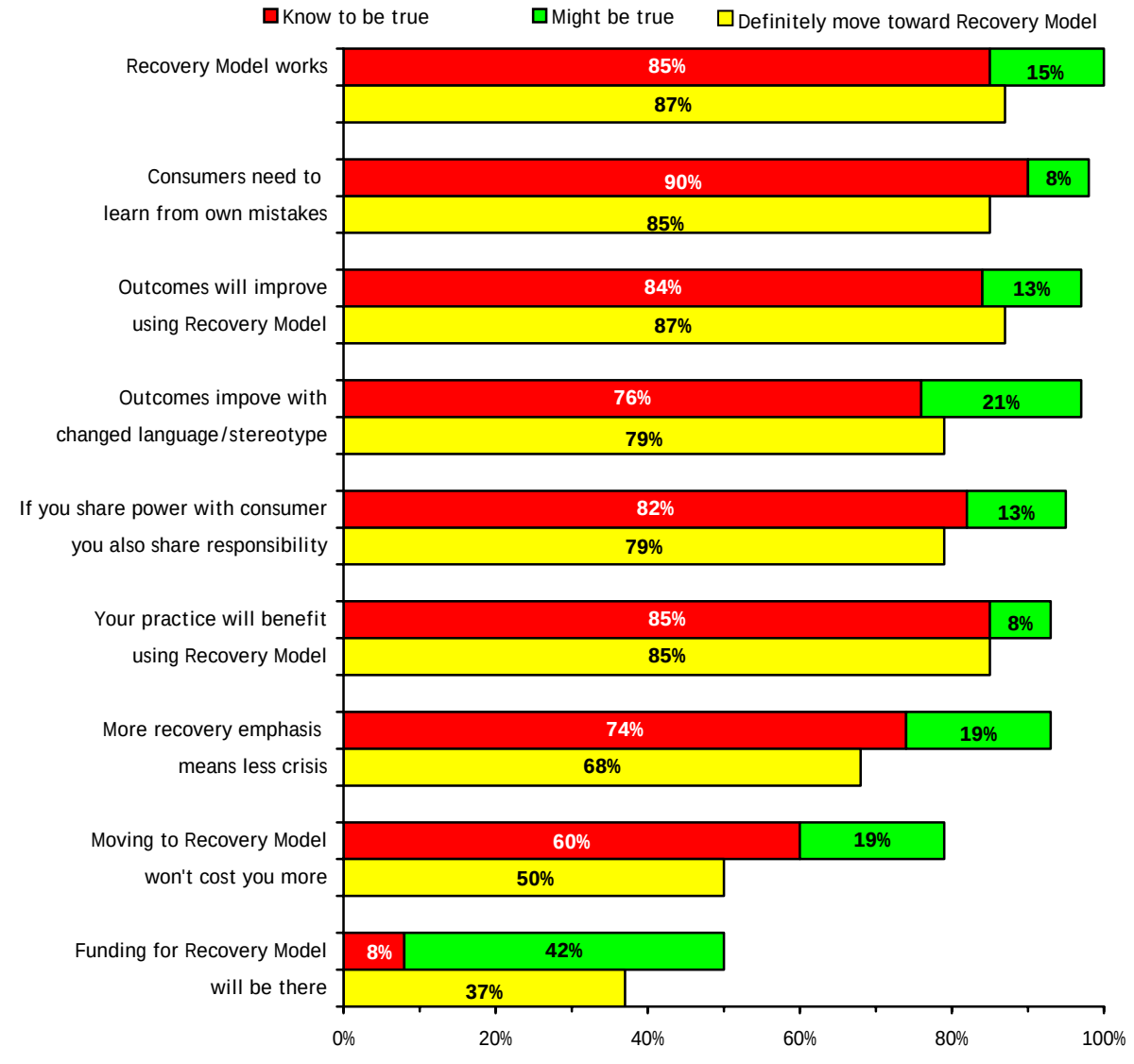

**Question 6A-6B:** To what extent do you believe that, like diabetes and asthma, mental illness is a condition that many people can learn to manage and live with, would you say you agree completely, agree generally with some exceptions, agree only somewhat with many exceptions, or do you not at all agree with the statement? To what extent do you agree that successful recovery is how the consumer defines it for himself or herself rather than how the practitioner defines it...READ RESPONSE OPTIONS.
***Small sample, interpret with caution.**

## *Recovery Model Beliefs*

Respondents were asked to respond to nine statements about the Recovery Model, first to what extent they believed the statement and then, if believing the statement would (or did) influence their decision to adopt the Recovery Model. These responses are shown in Figure 6.

**Figure 6**
**Recovery Model Beliefs and Impact on Moving Toward Recovery Model**
Providers and Administrators

**(Bases = 62)**




**Question 11A-11I, 11J-11R:** For each statement, please tell me if you BELIEVE the statement or not...Believe; Believe, but qualified; Do not believe. READ EACH STATEMENT I am going to read those same statements again. Please tell me for each one whether believing it would or did impact your decision to adopt the Recovery Model in your practice...Definitely make more likely to adopt; Might; Would have little or no impact. Do not believe this statement (volunteered).

The top six statements in terms of both belief and being a strong influence on adopting the Recovery Model are shown below. Nearly everyone believed each statement and eight out of ten respondents said each would definitely be an influence:

- The Recovery Model works. Consumers can help themselves and each other.
- Consumers need to have the dignity of risk and the right to fail in order to learn from their own mistakes.
- You will achieve better outcomes by adopting the Recovery Model.
- By modifying your language and abandoning stereotypes, real improvement in consumer outcomes will happen.
- When you share the power with the consumer you also share the responsibility.
- Your practice will benefit by adopting the Recovery Model.

One statement was believed by nearly everyone, but only two-thirds of the respondents said it would move them toward the Recovery Model, indicating some ambivalence in how the facts might impact their choices around the Recovery Model. Two people said believing the statement would have no impact, another three said they did not believe the statement and five would not commit a response to the question (total 16% saying something less than they definitely or might adopt the Model). This statement was as follows:

- More emphasis on recovery will result in less need for crisis intervention.

The two statements about cost/funding had the least support on both belief and influence. Even though eight in ten respondents believed that moving to the Recovery Model would not cost them any more, only half said that belief would definitely move them to adopt the Model. Another 21% said it "might" influence them, and 21% said they just didn't believe the statement or could not commit to an answer. Providers were somewhat more likely than the administrators to say that belief in this statement would move them toward adopting the Model: 55% of the providers said it would "definitely" make them more likely versus 27% of the administrators. The statement was:

- Moving to the Recovery Model won't cost any more than the way you have always practiced.

The second statement about funding suggests that neither practitioners nor administrators have much faith that an effective program will be funded for the state. Only 10% of the practitioners and none of the administrators said they believe the statement, and another 37% and 27%, respectively, said they do not believe the statement. If the statement could be believed, a slight majority of administrators (55%) stated it would encourage their adoption of the Recovery Model, but only 33% of the providers felt that way. The statement was:

- The funding will be there to help get the Recovery Model up and effective in Washington State.

Most respondents could not add anything further that, if believable, would make them more likely to adopt the Recovery Model. A few mentioned that they already use the Model or have seen co-workers go through the process and have come to believe through that personal experience. Several others mentioned that they would need some evidence and reassurance about the state's intentions and the funding in order to adopt the Model: "If the state would learn how to do that and not just be forced to write it into a treatment plan. They need to truly learn the benefit of this approach"; "I just have some cynicism about the way it is being funded." Finally, one person said that management would need to indicate that the Model was to be adopted, and another asked that all new information on the Model would be publicized as soon as it became available.

## *Confidence in Mental Health Transformation for Washington*

There is guarded confidence that the Transformation initiative can be successful in Washington. As seen in Table 7, about one in five of the respondents reported being very confident and another three in five were only somewhat confident.

The providers were somewhat more optimistic than the administrators, with proportionately more providers saying they were very confident.

The primary reason given by some for their confidence is that they feel the state is progressive with strong leadership that can carry this off. Other positive reasons include the fact that some therapists are already having success with the Recovery Model, that research shows the Model works, and that the movement will be strengthened because it has the media and legislature behind it.

**Table 7**
**Confidence in Implementation of Mental Health Transformation**
Providers and Administrators

| | Total |
|---|---|
| **(Base)** | **(62)** |
| Very confident | 18% |
| Somewhat confident | 60 |
| Not very confident | 16 |
| Not at all confident | 3 |
| Don't know | 3 |

**Question 13A:** The Mental Health Transformation initiative seeks to transform the mental health system and change the perception of people with mental illness and those who seek or use mental health services. How confident are you that this can be done in Washington State? READ RESPONSE OPTIONS

Those who are less than very confident gave four main reasons for their apprehension (in this order of frequency):

- This process involved large societal changes that will take a long time; can the state sustain the effort?
- Funding will not be sufficient or won't be handled efficiently. Too much bureaucracy/vested interests.
- There is evidence of mental health system problems that already exist in the state; if they aren't solved, how can a new process be introduced?
- Today's political climate, nationally and locally, suggests that mental health is not a priority and will not get the financial, staffing or philosophical support needed.

Other comments from less confident respondents included the feeling that Recovery Model goals are not clear, there is too much emphasis on measurement, administrative support is lacking, and the Model is too much a one-size-fits-all approach. Several people also mentioned that the pharmaceutical and insurance industries present complications to success and that access to mental health is still the real problem and without access, no Model can work.

## Characteristics of Respondents, Practices and Clinics

This group of respondents was well balanced in terms of state geography and urban/rural settings. (See Table 8)

About half reported having some type of counseling license. Providers had an average of 11.6 years practicing in the state, while administrators had been in management positions 19.4 years.

Over three-quarters of the practices/clinics serve almost all public mental health consumers (85% to 100% public). An effort was made to have some representation from practices that have only private consumers (8%).

Those in private practice reported having a range of 20 to 75 different consumers in 2005, while those in public practice reported having from 15 to 600. The median number of different consumers served in 2005 was 90 by the providers and 1,900 by the administrators' clinics.

Three-quarters of the practices/clinics reported serving children and youth, and among these, about 44% of their consumer base is under age 18.

**Table 8**
**Characteristics of Respondents, Practices and Clinics**
Providers and Administrators

| (Base) | Total (62) |
|---|---|
| Providers | 82% |
| Administrators | 18 |
| | |
| Eastern Washington | 44% |
| Western Washington | 56 |
| | |
| Urban/Suburban area | 50% |
| Small town/Rural area | 50 |
| | |
| Male respondent | 52% |
| Female respondent | 48 |
| | |
| Professional License | |
| Counselor | 47% |
| MSW/Social work | 16 |
| MD/Psychiatry | 8 |
| Administrator – MBA/Public Administration | 6 |
| Administrator – Licensed clinical social worker | 5 |
| Registered Nurse | 5 |
| Administrator – MSW/Social work | 3 |
| Administrator – Psychology | 3 |
| Administrator – Counselor | 3 |
| Licensed clinical social worker | 2 |
| Psychology | 2 |
| | |
| Years Working in Washington | |
| Mean Years Practicing (based on 51 providers) | 11.6 years |
| Mean Years in Administration (based on11 administrators) | 19.4 years |
| | |
| Type of Practice | |
| Working with consumers under age 18 | 74% |
| Mean % of practice devoted to under age 18 (based on 45 responding) | 43.7% |
| Number of consumers seen in 2005 | |
| Median seen in practice (based on 43 providers responding) | 90 people |
| Median seen in clinic (based on 9 administrators responding) | 1,900 people |
| Mean % of consumers with co-occurring conditions involving more than one mental illness diagnosis (based on 51 responding) | 28.4% |
| Mean % of consumers with co-occurring conditions involving substance abuse and mental illness (based on 58 responding) | 47.6% |
| Public or private practice (based on 60 responding) | |
| 100% private practice | 8% |
| 5% to 80% public | 15 |
| 85% to 100% public | 77 |

**Question 15-20:** What is your professional license? How many years have you been practicing in Washington? What percent of your practice is devoted to working with consumers under the age of 18? How many different consumers did you see in your practice in 2005? What percentage of those had co-occurring conditions that involved more than one mental illness? What percentage of consumers you saw had a co-occurring condition with substance abuse and mental illness? What percentage of your practice is spent working in the public sector rather than in the private sector? Are you practicing in an urban or suburban area of the state, or in a rural or small town setting?

# DETAILED FINDINGS – CONSUMERS

## Overview: Purpose and Methodology

A series of one-on-one and small telephone focus group interviews were conducted with consumers from three segments: adult consumers, parent consumers and youth consumers. Older adults were not considered separately from the adult population of consumers, in general. Various contacts established through the Department of Health, DSHS and organizations such as NAMI provided names of individuals who would be interested in participating in these interviews as consumers of mental health services in Washington. In addition, a few consumers were also willing to provide names of others who they thought might have interest. This is sometimes called, snowball sampling, a common technique when contacting hard to reach segments.

All of the consumers interviewed were participating in recovery and had some degree of involvement in public sharing. It should be noted here that consumers not engaged in recovery were not interviewed for this study. In addition, all were in recovery for at least one major mental illness, and a few mentioned several co-existing conditions. Most of the participating youth also had a co-occurring substance abuse issue they were dealing with. (People were not asked to disclose or share their diagnosis, but this information was usually shared spontaneously.) In all, 32 people were interviewed, 15 adult consumers, 10 parent consumers and 7 youth consumers. Interviews ranged in length from 45 minutes (individual interviews) to over ninety minutes (telephone focus groups with three to four participants).

The specific purpose of these interviews was to investigate to what degree consumers are participating in the desired behaviors, what motivated them to start doing these things and what continues to motivate them, and for any desired behaviors in which they are not engaged, what are some of the things that prevent them from participating in these behaviors. Inquiry also focused on what would need to happen, what they would need to know or believe in order for them to engage in these behaviors if they were not already doing so. The designated behaviors promoting recovery and reducing stigmas for consumers, as determined by the Transformation Taskforce are:

- Advocate, tell their story, share publicly, participate (to influence and educate community, other consumers, leaders and policy makers).
- Take responsibility in recovery, including seeking treatment and partnering with their provider in treatment decisions, exercising independence and being responsible for own self-care.

At first glance, this appears to be a fairly straight-forward undertaking. This research, however, is not in a vacuum; all of the complexities that influence human behavior, perceptions and beliefs are involved. Most consumers interviewed were very willing to "tell their story," to share their unique experiences, especially in the context of the small group setting of the telephone focus group. While much can be learned from these stories, and they reinforce what the recent literature also reports, this report will focus primarily on experiences and perceptions related to recovery and stigma, thus adhering to the above stated purposes of investigating the barriers and motivators to participation in recovery and in advocating and sharing publicly.

# Recovery

## *Unaided*

All of the participants indicated that they are participating in recovery. Descriptions of this process, what they are currently doing, and how they perceive recovery, however, varied from person to person. One adult consumer described being in recovery as "being a little better today than I was yesterday." Another described it as making sure she seeks treatment as soon as she feels she needs it. Everyone interviewed considers it a process of continually striving to manage their illness. Two consumers interviewed feel they have gone beyond recovery and have progressed into resiliency.

## *Specific Components of Recovery – Perceptions and Reported Behavior*

### Defining Life Goals and Exercising Independence

Again, just as every person's journey of recovery is unique to that person, so too are the goals and the process for setting those goals different for each consumer. Some of the commonly held goals include continuing to manage their illness, continuing to follow treatment guidelines, improving or developing social skills, refraining from substance abuse, improving skills leading to employment, having a place to live (not wanting to return to homelessness), finding or keeping a job and finishing school. One parent explained that they *are very dependent on whatever system he* (the youth) *is in at the time, public education, regular mental health system, transition to adulthood…there are a lot of factors that come into play.*

### Taking an Active Role in Managing their Illness

Those consumers we interviewed all felt they were taking an active role in managing their illness. They perceived this as involving such things as following their treatment guidelines, including taking their prescribed medication and doing the things that helped them feel better such as eating right, getting enough sleep and exercising. A few also mentioned community involvement and activities through church as ways they were actively managing their illness. Involvement in a clubhouse was mentioned by one consumer as a way to manage her illness, as a support system and as a way to build her self-esteem. *Before then, I was sleeping all day.* [Adult]

### Fully Participating in all Decisions that will Affect their Lives, Including Treatment Options / Being a Partner with Their Provider

While most consumers interviewed feel they are in a partnership with their provider, there were a few consumers interviewed who said they do not feel that they are currently sharing in treatment decisions to the degree that they would wish. This is especially true of parent consumers of youth aged 13 and up where a few parents felt shut out from this process. In addition, one adult consumer contradicted herself by later saying that she deferred to the doctor in all of these [treatment] decisions. A few others described being frustrated because they perceived their providers as being too ready to prescribe medication without involving them in that decision.

### Having an Advance Directive

Adult consumers were also asked if they had a plan in writing designating the person who would make decisions for them should they temporarily become unable to make these decisions. Most adult consumers asked either said they did not have one or said they had a plan but it wasn't in writing or that they didn't need one because they did not plan on sliding back and being in that position. One was not aware of this advance directive. Interestingly, these are the some of the same adult consumers who feel they are well into recovery or resiliency. This may indicate that the Advance Directive may be better received before the consumer is well into recovery and before he or she feels one is unnecessary.

## *Barriers – What Gets in the Way of Participating in Recovery*

We asked consumers what was in the way of participating in recovery goals before they became actively involved as well as what might be getting in the way of recovery now. Among the most common barriers cited by consumers are:

- Lack of knowledge about choices and options. This barrier was common to all three groups, youth, adult and parent. Once they became educated about their illness, simply not knowing the treatment options available appears to be a major obstacle to obtaining help and in participating in recovery.

- Lack of coordination and communication among agencies was brought up numerous times, both in terms of awareness of options as well as in service delivery. *There is no communication from one agency to the other.* [Parent]

  - Related to this, the absence of a centralized "clearing house" of information about available resources and options were also noted several times. *There is no central clearing house of information. There is no place that knows what anybody else does.* [Parent]
  - A few consumers perceive the help lines and resources to be available on a limited basis (9 to 5, 5 days per week). *They say there is a 24-hour help line here, but all the options end up being that you have to wait until Monday morning during office hours.* [Adult]

- A lack of seamless access to appropriate care and services that addresses the whole person is a barrier mentioned by a few parents who have experience navigating across several systems and agencies including Juvenile Justice, Education and Mental Health:

  - This becomes particularly onerous with youth turning 18 when delivery of services shifts to other systems. Parents perceive that it is *beyond our control…the state laws define what system…and thee is very little transition between multiple systems.* Also indicative of this perceived barrier from another parent, *They have a huge gap in services which need to be covered…As soon as they hit 18, there is no service for those people until they turn 21.* [Parent]
  - Also perceived as lacking or insufficient are educational "programs" that teach needed social and life-skills, making it difficult to meet goals for independence, education and employment. *They need social skills appropriate for having a job, getting along with people, going to college.* [Parent]

- There was a feeling among both parents and youth that there are not enough appropriate services for younger consumers. In addition there was frustration over specific programs that have been eliminated recently. One example mentioned was a bridge program that provided respite beds for kids that closed about a year ago. *They have to open another facility where they can have short-term resting beds.* [Parent].
- One youth consumer related that she could not get the counseling that she wanted, and was instead treated only with medication by her DSHS psychiatrists and CSO office. Not until she became pregnant did the state offer her more choices in treatment.
- There are a few services with only limited availability geographically. The appropriate service is too far away to access.

- Lack of hope (a pervasive feeling that they could not get better from their illness or that it might get progressively worse):

  - Two adult consumers cited their earlier providers as conveying the hopelessness of their illness and related that they were told they would never get any better.
  - This lack of hope is also related to lack of knowledge about their illness and lack of knowledge about what recovery is.

- Lack of education and knowledge about mental illness or about specific mental illnesses:

  - Not understanding or knowing about their illness and its manifestations and not knowing about recovery prevented some consumers from initially seeking treatment.
  - A lack of knowledge in the community about mental illness presents a barrier for some consumers. In addition to the effects of stigma resulting from ignorance, this general lack of knowledge among educators, parents, family, law enforcement, the judicial system including juvenile justice, and the medical profession, itself, also results in failure to identify the illness early on or even in misdiagnosis. One parent related that their family physician discouraged the family from seeking treatment, believing the child was simply a "high spirited" boy.

- Effects of the illness itself, including low energy or inability to navigate the system to find appropriate treatment. As one parent consumer described it, "*when you are in the acute stage, you are not capable of making these decisions…"*

  - Many are too ill to advocate for self or seek appropriate treatment.
  - The long waiting lists and the difficulty in getting a first appointment can be a huge barrier.

- Internal factors were mentioned by several as being barriers to seeking treatment. Often, the basis of these internal factors is a result of the external factors experienced such as stigma, discrimination and stereotypes.

  - Feelings of shame, isolation and lack of self-worth were mentioned by several consumers as barriers to seeking treatment as exemplified by this comment: *The panic attacks; it does make you feel shameful because you get embarrassed.* [Youth]

- One consumer summed up the feelings of several consumers by stating that just entering a building that has a name like *Mental Health Services of…is stigmatizing and labeling.* She felt it would be much better if that building served multiple purposes so that you would not be automatically labeled as you entered. Another consumer remembered her feelings when beginning recovery, stating, *I was very involved from day one…I was very afraid to do that because of the stigma.* [Adult]
- Two consumers, both of whom are actively managing depression, mentioned a perceived attitude toward consumers that it (the illness) is their own fault. *You see the world differently, people look at you differently if they know; with depression there seems to be an attitude that it is your own fault.* [Adult]
- Parent consumers also face stigma as this parent describes, *I have felt stigma being a parent of a child with mental illness.* [Parent] Another parent related that there was a perception by others that *I could not control my child.*
- A few described family members as trying to hide or deny the illness for fear of discrimination and stigma. One parent consumer who shared his experiences publicly with other consumers and providers would not share these things with his employer or co-workers, for instance, for fear of repercussions affecting his employment.

- A few perceived providers as not being open to sharing in treatment decisions with the consumer:

  - Several feel that some providers are rigid in their treatment approach and rely too heavily on medication. Combined with the weight gaining attributes of several of the medications often prescribed, this barrier is exacerbated. (In addition, these large weight gains resulting in obesity add one more dimension of shame, stigma and isolation to people already consumed with these feelings. Consider someone with a mental illness also facing the stigmas of being poor, unemployed, and obese).
  - Some parents do not feel in partnership with the provider once the child turns 13 because *providers cannot discuss therapy sessions because our child is over 13* This parent does believe her child is in partnership with his provider but says she has no way to know for sure.
- Consumers in partnership with their providers related that they had to search for the right provider. *A lot of doctors act like they are better than you and know everything, but they don't.* [Youth] *The most important thing in getting treatment is to be reminded that we know what we need and that we are the experts.* [Parent] This was a frustrating process for a few, especially those with limited economic resources. *People with mental illness need to know that there is a doctor or therapist that is right for them out there.* [Adult]

- Finding affordable treatment is also considered a formidable barrier to seeking and continuing treatment:

  - A few perceived that if you have insurance, you have access to better levels of care and service. There was also a perception that public facilities provide fewer choices in providers, services and treatment options than do private providers.
  - A few consumers with insurance cited a lack of insurance parity as a barrier to seeking and continuing treatment. They described their health insurance as discriminating against mental health related services. When insurance benefits have been exhausted for the year, several related that they could not access affordable treatment; there is a huge hole because they have to pay out of pocket. *There has to be better funding for those of us who are privately insured.* [Parent]
  - A couple of consumers also described a gap in accessing affordable treatment if you are poor but do not qualify for Medicaid or SSI. Said one, *If people don't have a Medicaid coupon they basically get lost between the cracks.* [Adult]

## *Motivation to Seek and Continue Treatment*

For many consumers, a life event or crisis, often a suicide attempt or one resulting in hospitalization first initiated the initial impetus or motivation to seek treatment. In several cases there was someone in that setting who offered encouragement and support to continue with the treatment and to participate in Recovery. More rarely for the adult consumer did that support come from a family member because as several related, they had burned so many bridges with family members that they had given up the right to expect support from that source. A couple consumers (not in the same focus group) said that the decision was easy, that it was either get treatment and participate in recovery or die. Among the other events that occurred which motivated people to begin the process of recovery were the positive corollaries to the above barriers.

The most often unaided mentions include:

- Education about mental illness and about their own illness(s). Knowing more about their illness gave them a sense of empowerment and helped them make better choices regarding their treatment and recovery.
- Believing that there is hope, that their condition is manageable and that they can get better. Explained one youth, consumer, *if you can work for it, it can get better. People need to know that.* [Youth] This need to believe **there is hope** was stated in all of the interviews and seems to be one of the most **overriding themes** emerging from these interviews as this representative comment indicates: A youthful consumer in a different focus group made a similar observation, *Hope is very important (in beginning the recovery process).* [Youth]

- Knowing that they are not alone, that there are others who are having similar experiences and who can offer encouragement is also very important and reinforces the belief that there is hope. A number of participants alluded to the power of hearing these messages from others consumers. The following three comments are representative of this powerful motivation:

  - *"A huge barrier for me in moving forward was in believing that I was alone."* [Adult]
  - *"To know I wasn't alone and that there are other parents that are going through the same thing gave me hope."* [Parent]
  - *"People who tell their stories help you to see yourself in them and realize, 'Wow, I can get better, too.'"* [Youth]

- Support and help in navigating through the system(s) and finding the appropriate treatment and services can make the difference between people receiving appropriate treatment and services or not. The following comment sums up this commonly held sentiment well:

  - *"You have to be at least healthy enough to fight through the maze and jump through the hoops you have to get through (to get help), and a lot of people get left by the wayside."* [Adult]

- Support and encouragement to continue recovery from those who see them as people first and not their illness. This includes family, friends and providers among others.
- Knowing that there are choices in treatment and services and what some of those choices are.
- Across all three groups (adult, youth and parent), the need to have access to affordable services and treatment in order to participate in recovery was stated. The following request is indicative of this need:

  - *"Make programs available to people whether they have money or not."* [Youth]

- Encouragement from providers to take an active role in treatment decisions or by not erecting barriers to partnering, empower the consumer to help in the decisions regarding treatment.
- Believing that they are worthwhile human beings with the right to get better was mentioned by several consumers as something they needed to believe before fully participating in recovery:

  - "*There is help out there and my child is entitled to it."* [Parent]
  - *"They can feel better and they are worth feeling better."* [Adult]

- Support from the community for continued recovery was acknowledged as crucial. This support could be from family, friends, employment, school, youth organizations, their church and other organizations. Community resources, especially those operated by consumers (consumer driven), such as clubhouses, offer valuable resources, support and motivation to continue Recovery. Mentioned earlier, as well, are consumer driven dialogues, workshops and peer support that offer the much needed hope that recovery is possible. Other support groups or resources frequently mentioned were NAMI, Safe-WA, CLIP and WRAP programs. The following comments are among those made about community and peer support:

  - *"We are involved in a wrap-around team that comes from different parts of the community. If there was a team that could always stay around regardless of where he is located, that would help with recovery – transitioning him into facilities, rehab, and transitioning back to the community…all that time maintaining the same relationship and setting goals and being familiar with what has been happening in the past."* [Parent]

## *Aided Responses*

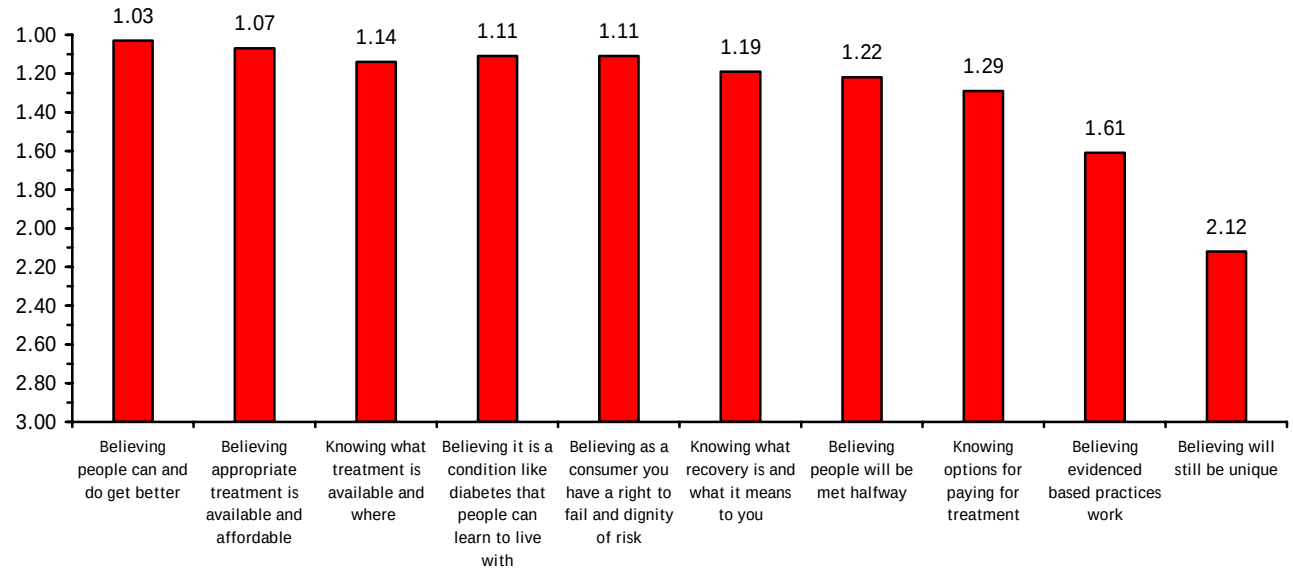
We also wished to investigate consumer response and reaction to **ten** pre-identified possible motivators. Consumers were read statements regarding beliefs and knowledge focusing on recovery and were asked to indicate for each, whether that would convince them to participate in recovery if they were not already doing so. The following graph represents the average rating for each category with 1.00 being *Definitely* would motivate/convince you, 2.00 being *Might* motivate you and 3.00 *Would Not* motivate you. As can be seen, all of the statements were found to be motivating, but *believing evidence based practices work* and *believing you will still be unique if you get treatment* were seen as definitely motivating by the fewest people.

There was a dichotomy of feelings around *evidence-based practices*; some felt knowing that these exist is extremely convincing while others viewed *evidence-based practices* with a degree of suspicion, especially those who feel strongly about individualized treatment. A few did not like the sound of the phrase, describing it as too de-individualizing and implying a narrow scope of options. There was a degree confusion around *if you seek and get treatment you will still be unique,* because several reflected that one reason to get treatment is to "fit in better and be more like other people." The few respondents who did not feel motivated by *If you change your behaviors you will be met half-way and it will be worth your while* felt that it was a little demeaning, that it "talked down" to them. Those who said *knowing the options for paying for treatment* **might** be motivating for them to engage in recovery said that while this was very important to know, it wouldn't "stand alone;" they would also need to believe that the appropriate treatment was available and that people can and do recover from mental illness. It was knowing or believing a combination of things that they found to be **definitely** motivating**.**

Participants were also asked what they felt was the most important thing to know or believe that would convince them to take an active role in recovery. Overwhelmingly, the responses heard most often were that **you are not alone** and that **there is hope**; **you can get better.** Because *knowing you are not alone* was offered unaided (was not included in the statements being evaluated in Figure 7), this appears to be an especially strong statement/motivation.

**Figure 7**
**Motivation for Recovery**
Does not include Don't Know and No answer

**(Base = 32**




**Questions For each statement**, would this definitely (1), might (2) or not (3) convince you to take an active role in your recovery.

# Public Sharing/Becoming an Advocate

## *Unaided responses*

Respondents were next asked about their public sharing experiences because it is through speaking out in the community and spreading the message that recovery is possible that many of the myths and stigma surrounding mental illness are dispelled. Among the consumers interviewed there was a range of public speaking experience. There were those who are very active in organized workshops and presentations, organizations such as NAMI, SafeWA and the Washington State Transformation process itself. One consumer has spoken at several high school and middle school assemblies, another has been interviewed on television, one writes inspirational stories for a newspaper/newsletter and several have shared their experiences at events where providers are present as well.

Other consumers are involved on a smaller scale, perhaps not sharing with large audiences but still sharing on a personal one-to-one basis. Several reported being very involved in volunteer roles, boards, committees and other advocacy activities.

Knowing they can help others with Recovery seems to be a major motivation in becoming active in public sharing and advocacy. Making public sharing an important part of their own recovery plays a role, but the desire to help others takes primacy amongst many of the participants. Reasons or motivators given unaided for publicly sharing their experiences include:

- To let others know they are not alone:
    - *"It is surprising how common the experiences are. Hearing other people makes it easier."* [Parent]
- To encourage others to seek and get treatment, to let them know there is hope:
    - *"I just want to prevent other families from going through the pain that I have."* [Parent]
    - *"It is good to let others know that although they may lose friends, they still keep a lot, and that the illness is something you can live with…It is empowering when people want to listen to you."* [Youth]
    - *"They may need a name of someone to talk to, they may need someone to help them explore what their insurance benefits are."* [Adult]
- To educate the public about mental illness in hopes of eliminating some of the misconceptions and negative labels – to reduce the stigma of mental illness:

- "*I don't think parents are listened to often enough; we are the ones in the trenches…and I don't think we are heard…I get angry…when people say they don't feel that way or that they haven't been affected by it or it's not in their family. They would be surprised how many people…it might be their next door neighbor, but it pretty much affects almost all of us in some way or another."* [Parent]

- The need to tell their story:

  - Knowing they have something to say and that others want to hear builds self-esteem.
  - As a way to reach out and lose the loneliness of isolation brought on by keeping the mental illness shrouded in secrecy. Public sharing helps with their own recovery.

When asked what got in the way of sharing publicly or what some of their *initial barriers* were to sharing, not surprisingly, several participants said that they were insecure or shy about speaking in front of others. One participant volunteered, *Just insecurity and shyness, I think.* (barrier) [Youth]

In a few situations, receiving encouragement from Consumer advocates whose opinion they respected, provided the impetus or motivation to begin speaking publicly. *I would take* [another youth consumer] *with me to a place where I am going to speak publicly and maybe they would feel empowered to do the same thing, and I would just explain to them how I feel afterward, and maybe they should try it*…. [Youth]

A few felt that they didn't have as much to offer, that others had more experience with mental illness. This sentiment was especially representative of parents whose children were only recently diagnosed. There was also a common fear among consumers that their stories would not be listened to or heard; it was very important to know that people will listen. *Knowing that somebody wanted to hear my story and that they really cared to listen to me would be very encouraging to share more publicly.* [Adult]

Stigma presents another barrier to speaking publicly. The fear of discrimination or stigma that might be encountered by disclosing that they or a family member has a mental illness can be a daunting obstacle for some to overcome as one consumer admitted, *I used to be afraid of judgment…from other parents, from other people in the community, even other people in our family.* [Parent] Another explained, *I typically don't tell co-workers, unless they were going through a similar stage.* [Parent] This (the fear of stigma from disclosing) is a catch 22 because one of the ways to reduce the stigma and eliminate the myths surrounding mental illness is through educating of the public about mental illness through sharing personal experiences with mental illness publicly.

Another barrier to speaking or sharing in public is simply not knowing what opportunities for sharing exist. How do consumers find out about these workshops and dialogues and

speaking opportunities? Explained one consumer about this, *Just not knowing what opportunities there were out there, I guess (barriers to sharing publicly).* [Adult]

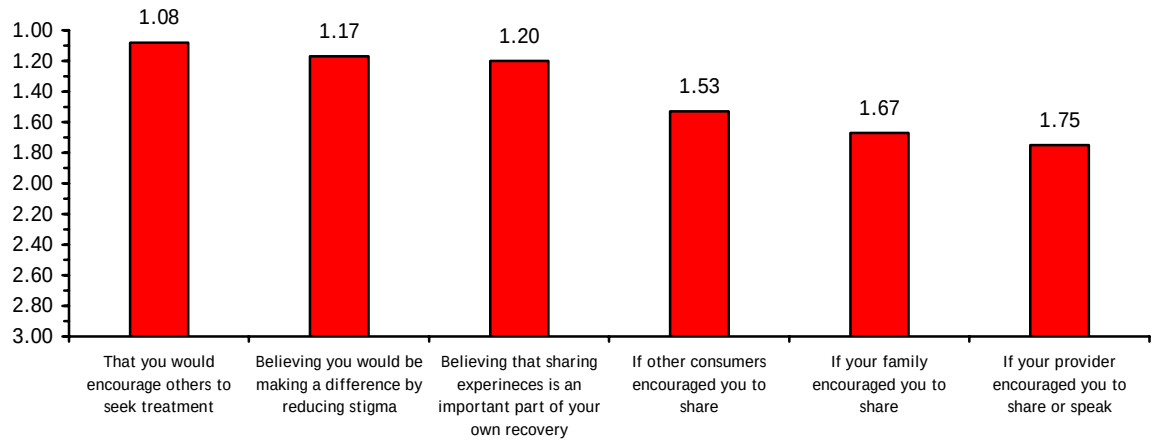
Progressing from more casual or private sharing to advocating or telling one's story to policy makers or legislators can be a daunting experience. One parent consumer stated that before he would consider doing this he would get training in this type of speaking, that he would need more skills. *I need more help in learning how to present to somebody who doesn't understand.* [Parent]

### *Aided*

Consumers were also instructed to rate a series of six statements regarding Public Sharing. For each, would knowing or believing that statement be Very likely to convince them to share publicly if they were not already doing so (1), be Somewhat likely to convince them (2) or Would not convince them (3). The ratings were then averaged and results were found to be consistent with the findings from the earlier unaided responses. Believing they are encouraging others to seek treatment by showing that people can and do get better and that they are helping to reduce the stigma of mental illness are the most powerful motivations to become speakers or advocates who publicly share their personal experiences with mental illness. One consumer expanded upon this by explaining, *My motivation is in helping others avoid the difficulties I have had in finding help and appropriate treatment.* [Parent] Encouragement from others plays a lesser role in motivating them to speak and varies by the perceived level of credibility of the person offering the encouragement. One consumer who would be motivated to share is she knew providers would be present stated; *providers need to hear from the consumers and families.* [Parent]

**Figure 8**
**Motivation to Share Publicly**
All Respondents

**(Base =28)**




**Questions Aided Motivation for Public Sharing:** For each, would this definitely, (1) might, (2) or not, (3) convince you to share publicly…

Participants were also asked which of the above would be the most compelling or motivating to share publicly, and most said either knowing they would be convincing others to get the treatment they need or that they would be reducing stigma as being the biggest motivators, thereby mirroring the above ratings (Figure 8).

## *Closing Comments*

Consumers were asked to describe the one thing they would like policy makers in this state to know or do in order to promote better outcomes for people with mental illness. Several suggested changes to funding practices including promoting insurance parity, providing a safety net of services for those consumers falling between the cracks financially, providing and funding services for those who are marginally employed or whose private insurance benefits have been exhausted. Another common desire was to see greater coordination between the systems, to *better connect the dots* with more than one parent concerned about the discontinuity of services as children transition to adulthood. Several consumers (youth and parents) see a real need for more services and programs designed specifically for youth. One adult consumer advised, "*It needs to be consumer driven, peer driven, there needs to be more consumer voice. Have the money follow the consumer; this will help eliminate hospital visits.*"

# DETAILED FINDINGS - POLICY MAKERS

## Methodology and Overview

The third and final phase of this research focuses on those serving in policy making capacities, including local elected officials, Legislative Taskforce members and members of the Transformation Workgroup. One-on one qualitative interviews using pre-scripted questionnaires were conducted with people from the Legislative Taskforce, local elected officials and members of the Transformation Workgroup.

## Transformation Workgroup

From this group information was gathered about funding legislation and support for key Transformation initiatives including elimination of stigma, advancing recovery and increasing the understanding of the populace of this state that people with mental illness can and do recover. The first two desired behaviors for this group are to eliminate stigma language and to adopt processes that promote recovery; the third behavior is to champion legislation for funding to accomplish the first two goals. Some members of the Transformation Workgroup represent special populations such as older adults, Native Americans, youth, NAMI and mental health providers; thus, information was also gathered about the Transformation initiatives pursuant to these special interest groups.

### *Perceptions of Budget Priorities*

Members of the Transformation Workgroup are mixed in their assessment of the level of budget priority legislators place on mental health. Of 25 participants interviewed, the majority feel legislators place a medium (12) or high (7) priority on funding mental health services. Those six members believing it is a low priority attribute this to a lack of understanding on the part of legislators regarding the scope of the problem as well as to a lack of understanding about the mental health system, itself, and how services are accessed. A few members believe it is not a high priority because of all the other urgent issues also needing to be addressed. The Mental Health Division is not seen as advocating for itself, which probably contributes to this lack of understanding.

The members of the Transformation Work Group perceiving it as a low priority feel this lack of understanding leads to misconceptions, reactive rather than proactive behavior (legislation) and inadequate or non-existent funding for services deemed necessary.

- *"Adults in the mental health system still drive the funding stream; kids get only a small portion, and it makes it difficult to get funding for children and families. There is not a clear understanding."*
- *"They think there are other issues more urgent."*
- *"They don't understand how much money can be saved by investing in mental health."*

Those feeling it is a medium or high priority most often cite the recent funding increases legislated in the last two sessions. The following comments are representative of the statements volunteered:

- *"Legislators feel mental health services are a very high priority; however, I also feel that since the last two legislative sessions brought in significant new state dollars towards mental health, my guess is that…they will not want to step up with those kind of numbers ($82 million in 05 and $50 million in 06) again, although I think their understanding and appreciation of the need is very high."*
- *"Medium - They have paid it a little more attention lately from the perspective of funding changes in 2005."*
- *"High in the last couple of years. They have funded a considerable amount of money in the last couple of years."*

## *Impact of Stigma*

Members of the Transformation Workgroup were also asked to describe the major impact of stigma on the people whom they represent. All were emphatic that it is a huge issue for people with mental illness, in general, with added components for specific sub-segments of that population that often result in poor outcomes for people with mental illness. The degree of access to healthcare is also seen as being impacted by stigma.

- *"The stigma they* (adult consumers) *face personally, the way they are treated by the community, co-workers and families."*
- People are afraid of mental illness and *"view all of them as being the same as the extreme, dangerous, non-treatable section."*
- *"People (*Community at large*) do not accept mental illness as a real problem."*
- The label of being mentally ill is stigmatizing.
- *"There is still a lingering lack of understanding that mental illnesses are health conditions, and are worthy of the same level of healthcare treatment, and are not about personal or family failure."*
- *"The biggest issue is a lack of access to medical services and employment. The general cultural perception of people who have been identified as mental health consumers, particularly long term mental health consumers, have a problem accessing health care services."*

Several members also see youth, the elderly, those on Medicaid and other minority groups often facing the specific stereotypes ascribed to those groups as well as the stereotypes ascribed to mental illness, thus leading to additional barriers to recovery. The following are representative of these barriers as described by the workgroup:

- The older generation has trouble normalizing mental illness to be like physical illness due to stereotypes of the generation in which they were raised, i.e., *"It's a weakness, it's a character flaw; you will go into the state hospital and never come out."*
- *"I guess it would be labeling by other kids and being devalued by peers."*
- *"The stigma is that some people perceive that some diseases aren't treatable."*
- *"Our opinions (youth) are often not included or not as valued."*
- There is difficulty in finding employment for people not on Medicaid. *"If you are an applicant and asked if you have a disability most will work with you unless the disability is a mental illness."*
- *"Some schools find it easier to expel kids under the zero tolerance rule than to work with them."*
- Many people with mental illness end up impoverished, thus they have the added stigma of being poor *"and they get stuck in a cycle they can't get out of."*

### *Number One Issue Affecting Recovery*

These Workgroup members were also asked what they believe to be the number one issue affecting recovery for the people whose interests they represent. Members cited several major areas of concern: awareness and understanding about mental illness by the consumer, the family, the education system and the community, stigma, ability to access services, and community support fostering an environment that encourages people's resiliency and ability to recover from mental illness and attain *self-sufficiency*. Central to this is the need for adequate, secure housing and employment, which is currently viewed as inadequate.

Another area of concern is the concept of *Recovery* itself. Some members believe that the concept is not well understood; and a couple believe that for some segments of the population, senior citizens in particular, certain goals of recovery may not be realistic or appealing, such as those advocating partnering with their provider, a concept with which, they believe, many seniors are not comfortable. For children and families, the system is perceived as being adult driven and that the adult model is not one that always works well for children and families. Youth in transition are seen as being underserved once they reach 18.

An additional challenge, perceived by a couple of members is in disseminating information about Recovery to consumers and providers and is perceived as being evolutionary.

- *"For consumers, it is sending accurate information to people about what is possible, a whole variety of information….but I'm not sure how cohesive that body of information is; it comes from all different settings and we pass it along, and I am not sure if there is a common centralized place or mechanism for consumers and providers to find that."*
- *"Recovery does not always follow everyone's expectations…There is that general cultural expectation that recovery means that if you have a broken leg it gets better, and if you have a mental illness you should get better and go back to work and be like everyone else."*
- Neurological damage should be included in an understanding about mental illness.
- Assessment for older adults, "*Primary care providers are all not well trained in recognizing or asking the right questions…lots of depression* (in older adults)*."*
- (From the perspective of youth) it would be learning how to *fit in* and being perceived as OK by peers; "*when you have a mental illness you are labeled as weird."*
- Promote a secure environment in which to live, including housing, food and nurturing ("*having someone who cares about you"*).
- *"Implement community based 24/7 recovery oriented activity programs."*
- *"Make sure that people are not deprived of service, and that they are getting their prescriptions, and counseling and they have a place to live so they do not commit crimes and go to jail.... Keep the mentally ill in recovery so they don't go back into the* (criminal justice) *system."*
- *"Services should be more accessible on a community basis, not just one area of a county, but all small town areas."*
- *"They* (youth) *age out of the system. Transition is very weak."*
- *"They should have access to recovery oriented services."*
- *"Services are approved and funded for adults…and it is not a good match for families and children."*
- Transformation should include *"education for children, employment for adults and/or meaningful activities for older adults with a focus on self-direction or consumer driven services."*

## *Legislative Action*

Transformation Work Group members were then asked what legislative action they *believe* might contribute to reducing stigma and advancing Recovery. This question elicited a variety of responses, with many members mentioning the need for funding changes or support promoting the specific type of legislation they would like to see. Several mentioned funding activities that would promote "normalizing" behaviors that would have the effect of reducing stigma, such as being employed. A couple of members noted that stigma reduction is *less a legislative issue than it is a public health issue*, but funding could be legislated supporting education, awareness and social marketing approaches. Specific suggestions for legislative action include:

- Increase community support such as for clubhouses and mentoring groups like Big Brothers/Sisters. "*Clubhouses need to be peppered across the state."*
- *"Earmark dollars specifically for older adult."*
- *"Difficult to legislate attitudes…You could fund more employment or summer work programs for kids who are in the mental health system…behaviors and skills to help them be more normal and help move them into a regular workforce. More normalization would reduce stigma."*
- More funding for service, resources, counselors and programs that help people with mental illness. *"Provide resources and a secure place for people to go other than jail for those people with mental illness who should be in an environment where they can get help for their illness rather than being incarcerated."*
- *"You cannot legislate morality, values and philosophies."*
- *"We need programs supporting employment."*
- *"They need to allocate money for helping people get back to work, for education and transportation."*
- Fund or promote affordable housing.
- *"Allocate funds to promote the message that people with mental illness are out there in the community functioning…more social marketing around wellness."*
- *"Real parity; a lot of states have parity laws, but REAL parity in insurance benefits and not separating mental health from physical health in the health care system. The health care community needs to accept mental health."*
- Fund public service announcements, more education.
- Fund youth advocacy groups… "*I heard that from the kids themselves."*
- *"Ensure enough funding to divert them* (people with mental illness) *from jail to treatment instead and include training on how to better fit into society."*
- *"Consider mental illness not as a behavioral issue but as a health issue. Include mental health treatment in health treatment."*
- "*They need to pass legislation making it easier for people to access mental health services."*
- Include in the plan a mandate requiring agencies to make the "*necessary changes… and addressing the integration of funding required fostering a consumer-driven environment conducive to recovery."*
- *"Further define the standards of care for children."*
- *"Make access to care less crisis driven."*

In addition, a few members looked at legislative action more globally, wanting to see action that would promote systemic change. They would like to see a holistic system with more emphasis on identifying the greatest barriers to Recovery and then on choosing those two or three things on which to focus legislative action. The Medicare Waiver was mentioned specifically as an example of a challenge that could be addressed because it *drives so much of the money*, influences how people operate and excludes some services from being reimbursed.

- *"I would like to see the legislature direct the various state agencies to look at what it is about the current state laws and regulations that may inhibit successful Recovery oriented services…like the language in our Medicaid contract…some could be changed on a state level and some would require negotiations with the Feds….If someone actually looked at the system and found 'these three things are the biggest barriers,' then change those few things, it would be a very strong statement to consumers and providers that the legislature is putting their efforts most toward helping Recovery efforts."*
- *"Change from current system to a fee per service system."*
- *"Articulating the public policy, and how that translates into public policy decisions."*
- *"Overhaul design of system to address delivery issues creating a more holistic system and creating parity between physical and mental health insurance benefits."*
- *"System change, that provides quality service to those who are in need with an accountability in the system to show and document the efforts that individuals are receiving services….the RSN's, we don't have a common data system…13 different RSN's which lack consistency and have no accountability and no parameters."*

Asked if their agencies would support the legislative action they described, all said yes. A few members, however, tempered their "yes" by saying they and their agency/organization would support it in concept, but would only offer more support if the legislation was supported at the highest levels of the State government (governor). One member also said it would depend on how the legislation was written and would want to know which programs were being cut in order to allow for the funding legislation. Another member indicated her agency would support legislation, but only if done in a non-partisan way.

## *Actions to Reduce Stigma/Promote Recovery*

When asked what specific actions would be most effective in reducing stigma for the people they represent, most re-emphasized or expanded upon earlier suggestions and concerns. Several members suggested education and training as being vital. This would include education and training of professionals such as primary care providers to recognize mental illness and then to be able to address it in a non-stigmatizing, matter-of-fact manner. Others mentioned a need for more evidence-based programs and reduced labeling of people with mental illness

- One would like to see less labeling after receiving or seeking services and another felt that just going to a building that is labeled or designated as *Community Mental Health* is stigmatizing.
- "*By abandoning the thinking that separates physical and mental health.*"
- *"One avenue is working with health care professionals…to the extent that physicians are able and comfortable to notice mental health issues….attitudes of those professionals about mental illness and going, 'oh, here's probably what's going on with your child, and we know a great resource that can help them, and this is a very common thing'….the manner un which information is conveyed has a big influence on if someone feels more or less ashamed and more or less able to take the next steps towards getting the help they need."*
- Several workgroup members called for more funding to support Consumer/Family run groups and organizations, including for the teen and child level there are "*few family driven support organizations and that needs to be addressed."*
- "*Need to consider older adults separately by tailoring messages for them that focus on their special needs and understanding."*
- *"It would be helpful to intervene earlier talking to them* (kids) *about mental health issues that can occur; start awareness earlier as part of healthy education."*
- *"Families with young children tend to listen to their primary care doctor or pediatrician; that's a pretty powerful voice."*
- *"Promote consumer and family member involvement, and give them a stronger voice…not treating them as tokens….more consumer representatives everywhere including governing boards."*
- Providing emergency services within the community instead of sending them off to institutions; prevention services; "*creating services that won't force a person to become extremely disabled/dysfunctional before their eligibility for care kicks in; interventions that are sort of 'status-enhancing' like going to 'spa-like' facilities."*
- "*Provide training about cultural competency to employees that includes competency in working with people in recovery.*"
- Training of officers (both street and corrections)…. "*Changing how they address people with mental illness and how they talk about them so they don't embarrass them or make them uncomfortable. People need to understand that their contact can affect others and can create stigma."*
- "*Increase diversion from incarceration in jails and prisons, perhaps by setting up teams that would work within the home-setting as well as by providing more early intervention and support of the family at the fist signs of mental illness."*
- Several Workgroup members reiterated the need to "*change thinking from mental illness to mental health, thus focusing on health rather than the symptoms of the illness, giving consumers hope as well as the responsibility to work toward a healthier state."*
- *"Make services more accessible* (to Native American Tribes)."
- *"Peer orientation to help people make that jump. Respect the individuality of wherever that person might be on the bridge.* (in ability/readiness to seek treatment/help) *This is particularly true for the homeless population."*
- *"Education – of anybody who is outside the mental health delivery system…we may need crusaders."*

- *"Evidence based programs and any kind of therapy that helps normalize….Move the child and family out of crisis into a different part of the world….School-based programs would really be a great way to drive mental health services around early assessment and early intervention."*
- *"Teaching people not to label…starting in school such as* (ADHD)*."*
- *"More education and trainings to break stigmas and to help people respond appropriately to people with mental illness."*

### *Promoting Increased Awareness that People with Mental Illness Can and Do Recover*

Members responded to the question, *What specific actions do you think Washington State could take to increase understanding that people with mental illness can and do recover* with thoughtful and often concrete suggestions. Again, many of the suggestions centered on education and community outreach to showcase successful recovery and resiliency and to spread the message that people do recover. Some of the specific suggestions are described below:

- Hire a full-time staff for geriatrics that would serve as *"a point person for research, education, training and program development for older adults with mental illness."*
- An education campaign to let people know that people with mental illness do get better.
- Fund a newsletter featuring inspirational stories of recovery (letting people know others are going through the same thing).
- Develop a state funded marketing campaign on resiliency.
- *"Help* (the public) *view mental illness as a mainstream issue, helping people to feel comfortable talking about these issues."*
- Talking at schools and other organizations because *"showing examples from true life is very important in giving people hope and inspiration."*
- *"Create awareness that there is an issue, meaning that there are people who have mental illness that aren't bad or aren't disgusting…with more awareness you can start accepting and changing your behavior. When you are educated you develop a values system around it."*
- *"Through conferences…buying tracks in other organizations…bring in the theme"*
- *"Stories of real people vibrate. There should be a centralized advocacy community. Consumers need their own media access and organizations."*
- *"Develop mandatory community forums for service providers, police, judges and mental health professionals, as well as for the community. These forums would also showcase successful recovery and inspirational stories and examples."*
- *"DSHS should issue a proclamation of some kind, a statewide plan on how they are going to implement changes and that they believe in it."*
- *"Find successful stories and share those with the public…As policy makers, we have to figure out ways for people to be successful; we need to give support in work and school environments and look for ways for people with mental illness to have positive experiences that work for them."*
- *"Focus more on the people who are successful and recovering and less on the people in hospitals."*
- Funding for peer support positions.

- *"Training and policy discussions promoting the belief that recovery works. As more people get on board believing this, transformation goals are more likely to occur. Change policy and contract wording to reflect this. The people in charge need to expect and push that this will happen; those in schools need to train and push these principles as well."*
- *"As policy-makers, we have to figure out ways for people to be successful; we need to give support in work/school environments and look for ways for people with mental illness to have positive experiences that work for them."*
- *"A universal language needs to be established* (non-stigma producing)…*"*
- *"It is very lonely to have a mentally ill child, and it helps to know that you are not alone and to learn from other parents. There are networks and organizations that do that, and just supporting those and making that apart of the intake packet anytime a new family comes into services."*
- *"Have more consumers on the Transformation workgroup."*
- *"Greater implementation for peer support and peer counseling."*
- *"Educate parents, schools, providers to foster the same level of support for mental health as for any other illness."*
- *"The most helpful thing is the employment of people with mental illness in a variety of ways…particularly in mental health agencies, and peers saying, 'I know what you are going through…but hang in there.'"*

## *Other Comments about Mental Health and Related services*

Many Workgroup members reiterated comments made previously and several members of the Workgroup stated that they felt confidence in those working on Transformation or felt they were doing a good job. There were others, as well, who observed that it (delivery of mental health services) needs to be transformed. One said she hoped that it (Transformation) happens for real and not just at a *paperwork/policy level.*

- *"Older adults need a louder voice in the process of transformation; very few advocates from this population are involved in the process."*
- *"There is not enough funding utilized for prevention."*
- *"Widen eligibility rules or expand them to give more access or easier access for a group of people who rely on public health."*
- Older adults are not comfortable with the term, consumer, and would be more so with a term like client or even patient. In addition, "*consumer implies choices and that is not true in public mental health."*
- Jails should not be "*holding tanks for the mentally ill…There are people with mental illness that are in jail longer than those who actually commit crimes because of all the paperwork that needs to be filed…the process is lacking resources, and we need funding for those who are mentally ill seek treatment and (not in jail)."*
- *"Crisis intervention training for all police in the State."*
- *"Keep those with mental health issues out of the criminal justice system and provide them with treatment instead."*

- *"The attention that is being paid to mental health right now can only lead to something positive. The transformation grant process has been excellent…there will be improvements whatever the outcome. There are a lot of people and professionals trying to seek pathways to individualized recovery; I see that as a real positive value…This is a caring state."*
- *"Would rather it be preventive and proactive…the front end; to me that means children and families….Build live."*
- *"More evidence-based programs for kids….More work and support for kids and families to let them know they aren't losing their voice and their choice."*
- *"Even though people want to do the right things, they do not understand how to implement them. We need to depend on people who are professionals and look outside of the state at states that have been successful. This is different than a statewide plan to quit smoking; you have to treat it very differently."*
- Include mental health in mainstream health issues.
- *"When it comes to services for mental health, do not keep overlooking rural Native American tribes."*
- *"Make mental health services more available, including for those who are low income but do not qualify for Medicaid or SSI. Insurance benefits have limitations and are not at the same levels as for physical illness. Running out of benefits and having to pay out-of-pocket can impoverish those who otherwise could have continued working and continued being self-sufficient."*
- *"I really hope we can move from visionary statements of community input and all the committees and define some tangible and measurable pieces that we are going to tackle and accomplish. That's what will give it holding power. Struggle with the priorities, pick the ones that are going to make the biggest difference and make a collective commitment to do them."*

# Legislative Taskforce

Five desired behaviors were identified for this segment of policy makers: 1) Draft legislation that funds Transformation; 2) Reallocate current funding so that the elements of Transformation can be supported; 3) Ensure adequate funding for Transformation; 4) Re-interpret current regulations; and 5) Support development of employment opportunities.

## *Current Behavior*

These respondents feel that a change in public awareness and attitude is just starting, and they suggest or support several ideas to help this momentum:

- *"People are becoming more aware, have come some distance already to reduce stigma. We are not as secretive as we used to be…coming out of that stigmatized environment. Make it more public."*
- *"It helps that some legislators have had their own personal experiences with family members with mental illness…Now people can realize that someone with a mental illness can touch their lives. The awareness is higher."*
- *"Pass a resolution, National Mental Health Week or something like that to draw public attention to it. Passing bills does not raise public awareness; they need to do something the media would pick up on."*
- *"Mental Health Parity bill helped. Making people realize it is a medical condition…and insurance companies pay for it does do some normalizing."*
- *"We should fund the advocacy groups that provide support and understanding."*
- *"Fund financial literacy classes for people to get a grasp on their finances to help avoid depression and mental health issues."*
- *"We need a comprehensive children's mental health bill."*

No one feels that the current funding system or state agencies are working particularly well for people who need and use mental health services. Respondents rated the state efforts as "fair" or "poor". They would like to see a high level coordination across all services.

- *"We have a silo of money for the mentally ill, silo of money for substance abuse. One person can have many problems. The programs need to be more person-oriented and we need to be able to draw from all the funding."*
- *"I would support some seamless kind of record keeping, particularly between crisis centers. People don't stay in one place."*
- *"For mental health, we need a bottom-up approach, not top-down."*
- *"There needs to be a high level coordinating entity that could pull together all services, including children's and adults." "There needs to be an ongoing coordinating group across agencies."*

- *"We have to stop re-inventing the wheel. Look at what's being done by provider groups out there…what is already successful and apply that to a system."*
- *"Most do an abysmal job* (serving youth)*, and I would like to enact policies that assure that our mental health delivery system is serving youth."*
- *"Priority used to be low, but after the mental health parity bill, it's gone up to 'moderate'."*

While one respondent feels that job and job-training opportunities are good for people who use mental health services in the state, others rate these opportunities as "fair" or "poor." Several qualified their lower ratings:

- *"In this district there are many opportunities but they tend to be lower paid."*
- *"There are employment services in the state, but I don't know how well they are accessed."*

When asked what funding priority level they feel mental health services are for legislators as a whole, nine of these ten respondents said "medium" or "low" while one said "high."

- *"Funding has been high recently, almost $130 million has been set aside in the last two sessions. That's definitely better than it used to be."*
- *"Most legislators do not understand the true cost of failing to provide adequate services. These costs are seen in our education system, our criminal justice system and in our health care system."*
- *"Education is the highest priority, transportation is also high. People don't like to acknowledge that mental health is a problem…don't see counseling as a major service."*
- *"When thinking about the budget there are things that are higher; we are competing against other needs, especially education."*
- *"Should be a high priority because it is preventative health care."*

The Clubhouse Model, now being used in some communities, is seen as a very good example of a successful way to help people with mental illness get back into the community.

### *Current Beliefs*

There are key beliefs that, if held, would encourage support of legislation to ensure adequate funding for mental health Transformation, reallocation of existing funds and re-interpretation of any existing regulations that would support Transformation. Most of these respondents either personally hold these beliefs or indicate it would be important for them to believe in order to support Transformation legislation.

- Most believe that stigmatization exists and that they, individually, can learn to use different language when referring to people with mental illness.

- They agree that anyone can experience mental illness.
- They believe these key tenets of recovery:

- People can learn to live with and manage mental illness.
- Sharing personal stories can be a start to recovery.
- More emphasis on recovery means that less crisis intervention will be necessary.
- It's important to support people with mental health and encourage them taking an active role in recovery.
- People with mental illness can recover and can lead active and productive lives.

These respondents believe that stigma can lead to discrimination and make it difficult or impossible to get an education, a home or a job.

These respondents are unsure about one element of the Recovery Model. They are not sure that successful recovery is how the consumer of mental health services defines it, rather than how the health professional defines it. Several of these respondents want more evidence that this is true, while others definitely do not believe it.

- *"I believe in a consumer driven program, but not always. At some point people need to have others take control until they are able to take control on their own."*
- *"There is a limit to this. Consumers need to have a voice but there needs to be a balance."*
- *"A counselor plays an important role. It's absolutely important to empower people but the counselor must serve as a guide."*

These respondents are mixed on the belief that people with mental illness pose no greater violence risk to the community than people without mental illness.

- *"If we could make that case, it would be very enlightening."*
- *"Making an assumption that all people are the same doesn't make sense. People with mental illness are not like everyone else—they need treatment."*
- *"Not sure. I'd have to see statistics of this being true."*

### *Barriers*

As with other policy makers, these state level respondents agree that the funds and resources for mental health Transformation are limited and uneven. Uneven resources exist geographically and by category.

- *"There are limited resources and demands across the entire budget area."*
- *"Money and resources are portioned in categories but we need to be able to draw from across all the categories."*
- *"We don't have the resources available in the more rural part of the state."*
- *"It's easier in the western part of the state because there is greater population base and more hospitals and institutions available there."*
- *"I'd rather put the money directly into housing, not passing laws about it."*

As noted above, the legislature is perceived as putting mental health service funding at a medium to low priority, particularly for people in the middle who have no or insufficient health care coverage but are not in crises.

- *"The really poor are OK and the rich are OK, but the in-between people do not have good coverage."*
- *"The amount of resources dedicated to non-Medicaid people who are not seriously mentally ill are few and far between. They are doing a reasonable job of taking care of the seriously ill and becoming Medicaid eligible is difficult."*
- *Many legislators believe mental health is a black hole, that they cannot put enough money into it…people are discouraged about it."*

Health care coverage for mental illness is inadequate, and people don't always understand what they have.

- *"There is no easy access to mental health services*
- *"Our access to care standards is too strict. It's difficult to get access to health care coverage."*
- *"Not all health insurance even covers mental health, and the good ones only cover 50%. It's being phased in now because of the Mental Health Parity bill, but most people with private insurance don't have it."*

There is little effort at prevention or early intervention, while too much attention and resource goes to handling crises.

- *"Prevention is overlooked in this system, which focuses more on those who are already in crisis."*
- *"The way the eligibility rules are written, you have to have a very severe problem in order to get services in most areas. So basically there is no prevention or early intervention health network."*
- *"The state emphasis has been on the most severely ill, but many now realize that early intervention is better."*

Misconceptions exist about the nature of mental illness; and, like the general public, legislators don't have sufficient information about the issues.

- *"Mental illness is seen as a 'flaw,' not as a 'disease'."*
- *"Legislators don't hear enough from advocates and providers to get a good representative overview."*

People with mental illness, or their caretakers, do not know where to turn for services.

- *"It is a situation that has a lot of stigma to it. People and families struggle so long they don't want to admit it, and when they do, they are unsure where or how to look."*

Legislation cannot address public attitude or solve the problem of stigmatization.

- *"I don't believe that mandating will accomplish the goal of eliminating stigma."*

Several respondents feel there are not enough mental health service providers to meet the needs of consumers in the state.

### *Motivators*

Replicate the Clubhouse Model around the state. Several respondents report that it is working well in some communities.

- *"It helps people function normally and give back to the community."*
- *"Look at the Clubhouse Model. The role modeling that goes on there is invaluable.*
- *"The Clubhouse Model has been underutilized because it can be a daily treatment for people that congregate there. The Clubhouse concept can also help with housing and employment problems."*

Prepare a strategy on changing the system to a more recovery-based model.

- *"If we change to a more recovery-based model, the community will start understanding that with proper treatment people can be productive in our society."*
- *"I want to see our system based on outcomes. We spend too many hours on audits to assure we are compliant with government policies. Audits take away from clinician's time to spend with consumers."*

Promote legislative action requiring accountability on a range of outcomes of mental health services, such as employment, job training, housing and self-sufficiency. This type of legislation will have a better chance of support if legislators believe or can be convinced of these tenets of the Recovery Model:

- People can learn to live with and manage mental illness; they can lead active lives and contribute to the community.
- Stigma exists and everyone can play a part in helping to reduce it. Stigma leads to discrimination in education, employment and housing.
- People with mental illness should take an active role in their recovery. Sharing personal stories can be an important step.
- If there is more emphasis on recovery there will be less need for crisis intervention.

In addition, there will be more legislative support if it can be shown that the state will save money in the long run.

- *"Show that you would reduce the amount of people in state hospitals and that you can safely and cost-effectively treat people in the community."*

- *"It would be helpful if legislators that have experienced a mental illness in their family would speak out. Make it personal, have consumers come in and testify."*
- *"It would take a very clear-cut cost-benefit description for me to make funds available.*
- *"We need a less tight budget. There is some interest in services such as more employment opportunities and expansion of community resources, but there is not enough money so we fund crisis. We need to see evidence of what reduces services down the line."*
- *"Not everything can be high priority. It would take some evidence-based practices, really being able to demonstrate that the investment is effective."*

Better mental health coverage by private insurers.

- *"Currently private insurance gives mental health coverage to businesses who have more than 50 employees. We need to expand coverage for every individual." We need parity in the small group (health care coverage) market and in the individual group market."*

More legislative emphasis on prevention and early intervention, paying particular attention to youth and perhaps also to those in prison.

- *"I would like to see the eligibility change so that children and youth have access to mental health services early on…at early signs of trouble. Now, they have to really be in deep water to get help and that has tremendous long-term consequences."*
- *"Early enough screening to address mental health issues early in the ball game…prevention is the key. Also make sure the issue of incarceration is addressed…there are a lot of inmates there because of mental health problems that could have been prevented."*
- *"More investment in earlier intervention types of services…working with families with young children."*
- *"We need to look at earlier interventions. By the time we get people into the mental health system they have failed in school, failed in a job, they have been in trouble with the law, and they have been involved with substance abuse."*

More providers and better training.

- *"We need training and technical assistance to get providers up to speed on evidence-based practices. We need a system that encourages them to use those promising practices and discourages them from using ineffective practices."*
- *"Providers need to be trained and there needs to be continuous consultation. I'd rather put money into training and consultation than into having them attend meetings."*

Create an awareness or education campaign, but keep it targeted so that it does not take funds from services.

- *"The legislature is a reactive body so the more they are aware, they will be pressed more to fund mental health needs."*
- *"Any educational effort cannot be a statewide campaign. People are more desperate for services, and education is not as high a priority."*
- *"Success stories at the community level are what will get people to understand that there is hope of getting better from mental illness. We have wasted a lot of money on public service announcements. Doesn't work; we need to help people tell their stories."*

Show that communities can be kept safe.

- *"The mantra is 'safety first,' and we want to make sure the communities are safe, and we want to support the legislation to protect the community. I think people tend to muddy the water between mental health issues and addiction issues."*

Provide more community-based services.

- *"Institutions are a last resort. These solutions don't work if you do not have funding. We need to look at our lowest cost and most effective options first so that we can reach more people."*
- *"A focus all on the state level will not be able to show improvements as fast as if we focus on the community level. "*

# Local Elected Officials

There were three desired behaviors identified for this segment of policy makers: 1) Approve local budgets that would allow for Transformation; 2) Reallocate current funding so that the elements of Transformation can be supported; and 3) Support employment opportunities at the local level.

## *Current Behavior*

It was difficult to obtain much information about budgeting and funding for Transformation because only three of the 13 officials interviewed had even heard of the Mental Health Transformation process, and those three were not well informed about it. One said it was a federal grant with money to deliver mental health services in the state, while another felt it would help break down barriers between local and state agencies. The third person was unable to name any details about Transformation.

Only one person felt that mental health services were adequate in his area, while a few said it depended upon the service. Most (nine) said services are not adequate, primarily because they lack funding. Funding is either insufficient or not going where it is most needed.

- *"We're not prepared or funded." "Sufficient funding is the biggest problem."*
- *"Money is being taken from state hospitals in the areas where we have high risk people."*
- *"Constant budget cuts are a huge issue. Makes it hard for the counties to fund cities."*
- *"We have trouble finding 72-hour beds for people with mental health issues."*
- *"VA is overworked and veterans are not getting enough help."*
- *"We need more specialized project managers."*
- *"There is not enough out-reach, not enough follow-up, not enough services for crime victims." "No access for functional family therapy."*
- *"The working poor fall through the cracks because they can't afford the service."*

While most of these respondents said they think it's easy for people to get information about mental health services in their areas ("*once they know where to look*"), there is agreement that it is not particularly easy for people to access those services or to find affordable services.

- *"If people aren't able to find what they need, the only way to really help is when we find them in jail."*
- *"Many don't have health coverage, making them dependant on government-run programs which are limited in their ability to help." "Without insurance, it is very difficult for people to get service."*
- *"It's particularly tough on children. Often their parents are already overwhelmed."*
- *"Access is limited because people don't have transportation to take advantage of programs."*
- *"It's hard to find long-term mental health treatment."*

The one person who felt that there are adequate affordable mental health services in her community said that she sees the hospitals serving low income when they have need of these types of services.

When asked about job training opportunities in their area for people with mental illness, some of these officials felt that opportunities are available in their communities.

- *"If people stay on their meds and so forth, they don't seem to be having too much difficulty with jobs."*
- *"We have several organizations that focus on finding jobs. Their success is mixed."*
- *"We have diversified industries in our area that helps make it possible to serve this population."*
- *"The quality of programs I have been exposed to are great."*

Others admitted that opportunities in their areas were not good.

- *"There is on-the-job training for the average population, but not for the mentally ill."*
- *"Opportunities in my area are just non-existent."*

### *Current Beliefs*

Many of these local officials hold beliefs that would allow them to support approval of Transformation budgets and reallocation of funds to support initiatives to eliminate stigma and establish the Recovery Model in their areas:

- Almost all believe stigmatization exists and that they, individually, can learn to use different language when referring to people with mental illness.
- They agree that anyone can experience a mental illness and that it affects almost every family in America.
- Almost all believe these key tenets of recovery:

    - People can learn to live with and manage mental illness.
    - Sharing personal stories can be a start to recovery.
    - More emphasis on recovery means that less crisis intervention will be necessary.
    - People with mental illness can lead active and productive lives.

All but one official all agree that stigma can lead to discrimination and make it difficult or impossible to get an education, a home or a job.

There are doubts, however, that people with mental illness can recover completely. Four of the 13 respondents said they believe that is true, while one did not believe it at all, and eight said they really did not know or thought it was borderline:

- *"Not sure; it's really a day-by-day thing."*
- *"Maybe sometimes, but not everyone."*

These respondents tend to believe that people with mental illness pose more risk to the community than do people without mental illness. Seven of the 13 hold this belief, and four were unsure.

- *"There is a very different risk (with people who have mental illness)."*

### *Barriers*

Information about the Transformation process and goals has not yet reached the local levels. These officials, even those in large counties and cities, were not aware of this effort or what it might mean for them.

Along with information about the Transformation process itself, more education on mental health, in general, would benefit local officials as they make decisions about funding and job resources. For example, it would be helpful for these respondents to have examples of people with mental illness who have recovered completely and statistics that demonstrate community risk is no greater from people with mental illness.

Nine of the 13 officials felt that mental health services is currently "not adequate" in their communities, and nine said that mental health funding is not a high priority item at the local level. Only two officials said such funding was a high priority, another three said "medium" and six of the 13 said it was low priority (two declined to say).

- *"Low priority. Council members don't really hold a discussion about mental services in (our area). What it is, is what it has always been."*

Some officials feel that funding is a state or federal responsibility, not a local responsibility.

- *"(Funding) is a state issue, not county. We need more funding from outside sources."*
- *"Federal cuts have created issues so there aren't a whole lot of funds to reallocate."*
- *"Help from the city is almost nonexistent."*

The path to effective mental health services needs to be more clear and easier to navigate. Some officials feel that consumers need some level of sophistication and knowledge of how to navigate government bureaucracy in order to access and understand the services that are available.

Consumers can get into programs, but then it's hard to stay in the programs because of ongoing costs and/or lack of insurance coverage.

Some communities lack adequate public transportation options for consumers to access mental health services.

### *Motivators*

Some officials want to see more funds coming in from state or federal sources. It may not be intuitive to see what monies are already available and how reallocation can occur to make those funds more effective. Perhaps some help could be provided to do this.

- *"It's hard to choose between fire or police departments and mental heath."*
- *"We can't reallocate funds for Transformation without having more funds. We can hardly provide what we do now."*

More and better information would help educate local officials as well as the general public as to what funding is really needed, where it can do the most good and why mental health services can be seen as an investment in the community. More leadership may be a part of this effort.

- *"We need to make people more aware of what is going on in terms of employment opportunities."*
- *"We need an initial plan and information. Find out where the money comes from. Do an analysis of trends of various mental health services, including employment."*
- *"We need a full-time leader."*

Several of these officials asked for evidence that the Transformation works and that recovery programs are effective.

- *"We want outcome-based evidence, proof that there is efficiency and savings tied to the treatment."*

While many of these local officials did not know anything specific that the state could do to improve communication and coordination among state agencies, those who had an opinion were nearly unanimous in wanting to see the state demonstrate such improvement.

- *"Each agency needs to show better leadership to promote understanding between agencies about what each agency actually does."*
- *"Streamline the process between drug and alcohol abuse, mental health and developmental disabilities. Join the three."*
- *"Rather than reinvent the wheel, they need to learn to share resources. Stop burning funds on administrative costs. All city, county and state groups need to communicate."*

These officials would like to see the legislature make mental health funding a higher priority and create a revenue source that is dedicated to the principles of Transformation.

- *"Get the politics out of the usage of mental health funds. Make funding of services a priority." "Priority funding." "Dedicated funding."*
- *"Try blended funding, making it easier for counties to allocate funds."*
- *"The state should recognize that when people are dismissed from the state hospital that many end up in the local jails where there is no help. These people need medications, but the funding isn't there for cities or counties to provide them."*
- *"Make sure there is funding for education about mental health."*

Other actions that would help local officials be more interested in and supportive of Transformation goals include changing old habits, providing more outreach and specific steps with Medicaid.

- *"Create a positive spin on the hopefulness of people living with mental illness. Show that people with mental illness can contribute to the workforce."*
- *"Talk about mental health as a treatable disease rather than a disability."*
- *"We need more outreach to community groups, particularly youth." "More emphasis on youth mental health in schools."*
- *"Provide Medicaid enrollment for inmates who are living in prison. Many need mental heath services but have no money or information on how they might be helped."*

Overall, most of these local officials have at least some confidence that this Transformation process can help transform and mental health system and change how services are organized and delivered in our state. Several want to be sure that we look to other states for proven success and that we set up effective data systems and performance goals. Two officials said they were not confident because they see too much risk for local government and not enough funding or commitment to partnership between the state and local levels. One official summed up his final comments as follows:

- *"I think the State has made a strong attempt. Progress is being made, but we have a long road ahead. We need to keep local government in charge more than the private sector because ultimately local government has the answers to their communities' needs."*

# APPENDIX

**Appendix A:** Mental Health Transformation Survey, Providers

**Appendix B:** Consumer Audience Discussion Guide, Telefocus Groups

**Appendix C:** Questions for Transformation Workgroup

**Appendix D:** Questions for Legislative Task Force Members

**Appendix E:** Questions for Elected Officials

**5:** **TYPE**

N = .....
East.....1
West.....2

**6:** **INTRO**

ASK TO SPEAK TO <cont>: Hello, I'm ___ from Gilmore Research Group, calling in regard to the Mental Health Transformation research project. We are interviewing mental health professionals from around the State involved in the delivery of mental health services. I hope you have seen the letter from the Washington State Department of Health regarding this research. IF NOT, OFFER TO FAX AND RESCHEDULE INTERVIEW. Is this a good time for you to complete the interview with me? It will take 15 to 20 minutes. IF NO, ARRANGE CALL-BACK.

N = ..... Continue 91
=> /LASTQ .....11 100%

**7:** **QA**

Thank you for agreeing to take part in the research. As stated in the letter, the State of Washington is engaged in a Transformation process for the delivery of mental health services. One focus of Transformation is reducing issues of stigma and increasing support for the Recovery Model in service delivery. To better understand how to promote the goals of the Transformation, we are interviewing professionals like you regarding their perceptions, current practices and beliefs.

N = ..... Continue 11
100%

**8:** **Q1**

These first questions are about activities that may be considered to be "recommendations" for helping consumers in their recovery process. I am going to describe these activities and ask about your experiences with each. One recommendation for reducing stigma involves opportunities for providers and consumers to interact in dialogues or workshops. These public sessions may involve consumers sharing personal stories or be discussions around issues of recovery or stigma. Have you ever attended a dialogue or workshop such as this? IF NEEDED: This means beyond just what you do when you see consumers as part of your practice.

N = .....
Yes.....1
No.....2
Don't know .....3
Refused.....4

**9:** **Q1A**

About how often in the past year?

=> +1

si NOT Q1=1

N = .....
Three or more times a year.....1
Once or twice a year.....2
Less than once a year.....3
Don't know .....4
Refused.....5

---

**10:** **WORDA**

=> *

si IF((Q1=1),1,2)

N = .....
workshops more frequently? .....1
workshops?.....2

---

**11:** **Q1B**

What do you think gets in the way or might get in the way of your getting more involved with these types of dialogues or <worda>

N = .....
RECORD COMMENTS .....97
Don't know/Not sure.....98
Refused.....99

---

**12:** **Q1C**

Assuming these dialogues or workshops were available, what might make it more likely that you would attend this type of dialogue or workshop where consumers advocate and tell their stories? PROBE: What could someone say or do or give you that would make a difference?

=> +1

si NOT Q1A=1,2

N = .....
RECORD COMMENTS .....97
Don't know/Not sure.....98
Refused.....99

---

**13:** **WORD**

=> *
si IF ((NOT Q1A=1,2),1,2)

N = .....
Please tell me if any of the following WOULD ENCOURAGE or
Influence you to attend these dialogues or workshops. .....1
Please tell me if any of the following influenced your
decision to attend these dialogues or workshops.....2

---

**14:** **WORDD**

=> *
si IF ((NOT Q1A=1,2),1,2)

N = .....
Would that be very influential or somewhat
Influential in encouraging you to attend? .....1
Was that very influential or somewhat influential? .....2

---

**15:** **Q1D**

<word>
N = .....
Continue .....1

---

**16:** **Q1DA**

(<word>...)
Consumers you see as part of your own practice? IF YES, ASK: <wordd>
N = .....
Very influential.....1
Somwhat influential.....2
No/Would have no influence.....3
Don't know .....4
Refused.....5

---

**17:** **Q1DB**

(<word>...)
Consumers successful in their recovery other than those you see as part of your own practice? IF YES, ASK: <wordd>
N = .....
Very influential.....1
Somwhat influential.....2
No/Would have no influence.....3
Don't know .....4
Refused.....5

---

**18:** **Q1DC**

(<word>...)

Your peers or co-workers encouraging you to attend. IF YES, ASK: <wordd>

N = .....
Very influential.....1
Somwhat influential.....2
No/Would have no influence.....3
Don't know .....4
Refused.....5

---

**19:** **Q1DD**

(<word>...)

Recommendations from professional organizations that you attend. IF YES, ASK: <wordd>

N = .....
Very influential.....1
Somwhat influential.....2
No/Would have no influence.....3
Don't know .....4
Refused.....5

---

**20:** **Q1DE**

(<word>...)

Guidelines or recommendations based on academic research. IF YES, ASK: <wordd>

N = .....
Very influential.....1
Somwhat influential.....2
No/Would have no influence.....3
Don't know .....4
Refused.....5

---

**21:** **Q1DF**

(<word>...)

Encouragement from your immediate supervisor to attend. IF YES, ASK: <wordd>

N = .....
Very influential.....1
Somwhat influential.....2
No/Would have no influence.....3
Don't know .....4
Refused.....5

---

**22:** **Q1DG**

(<word>...)

Encouragement to attend from the Director of your clinic or facility. IF YES, ASK: <wordd>

N = .....
Very influential.....1
Somwhat influential.....2
No/Would have no influence.....3
Don't know .....4
Refused.....5

---

**23:** **Q1DH**

(<word>...)

Recommendations from insurance providers. IF YES, ASK: <wordd>

N = .....
Very influential.....1
Somwhat influential.....2
No/Would have no influence.....3
Don't know .....4
Refused.....5

---

**24:** **Q1DI**

(<word>...)

Government sources offering incentives such as grants. IF YES, ASK: <wordd>

N = .....
Very influential.....1
Somwhat influential.....2
No/Would have no influence.....3
Don't know .....4
Refused.....5

---

**25:** **Q1E**

You mentioned that having encouragement from professional organizations to which you belong would make it more likely that you attend one of these workshops. Which organizations come to mind as having the most influence?

=> +1
si NOT Q1DD=1 OR NOT Q1A=1,2

N = .....
RECORD COMMENTS .....97
Don't know/Not sure.....98
Refused.....99

---

**26:** **Q1F**

Have you ever encouraged consumers or their families to attend a recovery-oriented workshop or training to assist them in their recovery?

N = .....
Yes.....1
No.....2
Never had the opportunity - IF VOLUNTEERED.....3
Wasn't aware of any of these discussion groups
(in our community) IF VOLUNTEERED.....4
Don't know.....5
Refused.....6

---

**27:** **Q1F1**

Have you ever pointed out the benefits of attending one of these sessions to your peers or co-workers?

=> +1
si NOT Q1A=1,2

N = .....
Yes.....1
No.....2
Haven't thought about it.....3
Don't know.....4
Refused.....5

---

**28:** **Q1F2**

Are you aware of any of your peers or co-workers attending these dialogues or workshops?

N = .....
Yes, many of my peer attend.....1
Yes, a few of my peers attend.....2
Not aware of any that do.....3
Don't know.....4
Refused.....5

---

**29:** **Q2A**

Two of the components of recovery are "self-direction" and "empowerment." Both of these components imply a partnership between providers and consumers, emphasizing the consumer's role in their own recovery. Which of these statements best describes your approach with consumers you see in your practice... IF NEEDED: Partnering would involve the consumer taking an active role in their recovery

N = .....
Partner with all, regardless of their illness.....1
Partner with most.....2
Partner with some when you feel it is appropriate.....3
Or do not use partnering process with consumers in your practice .....4
Don't know - DO NOT READ .....5
Refused - DO NOT READ.....6

---

**30:** **Q2B**

What are some of the reasons you think that you do not make all consumers you see in your practice your partners in their recovery process?

=> Q3
si Q2A=1

N = .....
RECORD COMMENTS .....97
Don't know/Not sure.....98
Refused.....99

---

**31:** **Q2C**

What do you think would encourage you to treat all of the consumers you see as partners in their recovery? PROBE: What could someone say or do or give you that would make a difference?

=> Q3
si Q2A=1

N = .....
RECORD COMMENTS .....97
Don't know/Not sure.....98
Refused.....99

---

**32:** **Q3**

One way to reduce the stigma surrounding people with mental illness is by using person-centered language. This means talking to and about consumers, not just during working hours, but in all situations, as people first, instead of referring to them by their diagnosis. An example of this would be to say, "John, who has schizophrenia," rather than "John, the Schizophrenic." Which of these statements best describes your approach to using this type of language... IF NEEDED: This

includes talking with consumers, with their families, with other professionals, and with your own friends and family.

N = .....
You make a point of always doing this .....1
You do this in some, but not all settings.....2
You don't do it very often.....3
Or you haven't really thought about it .....4
Don't know - DO NOT READ .....5
Refused - DO NOT READ.....6

---

**33:** **Q3A**

What do you think prevents you from always using this type of language approach, that is, refrain from referring to consumers by their diagnosis?

| |
|---|
| => +1<br>si Q3=1 |

N = .....
RECORD COMMENTS .....97
Don't know/Not sure.....98
Refused.....99

---

**34:** **Q3A1**

Do you see your peers and co-workers also using this person-centered language?

| |
|---|
| => +2<br>si NOT Q3=1 |

N = .....
Most of the time .....1
Some of the time.....2
Not too often.....3
Haven't noticed/Don’t' know .....4
Refused.....5

---

**35:** **Q3A2**

When you have observed language being used by your colleagues that is not person-centered, have you pointed it out to them?

N = .....
Yes, I often do that .....1
Yes, but not too often .....2
No.....3
Don't know .....4
Refused.....5

---

**36:** **Q3B**

What do you think would make it more likely that you would always use person-centered language when talking with or about the consumers you see in your practice or other persons with mental illness? PROBE: What could someone say or do or give you that would make a difference?

| |
|---|
| => +1 |
| si Q3=1 |

N = .....
RECORD COMMENTS .....97
Don't know/Not sure.....98
Refused.....99

---

**37:** **Q4**

One more way to reduce stigma by using person-centered language is to refer to their diagnosis as something a consumer has, not something he or she is. For instance, it is considered less stigmatizing to say, "the person has a mental illness," rather than, "the person is mentally ill." How consistently do you use, "has a mental illness" instead of "is mentally ill"...

N = .....
You make a point of always doing this .....1
You do this in some, but not all settings.....2
You don't do it very often.....3
Or you haven't really thought about it .....4
Don't know - DO NOT READ .....5
Refused - DO NOT READ.....6

---

**38:** **Q5**

We have been talking about specific recommendations - attending dialogues or workshops where you have the opportunity to interact with consumers, treating consumers as partners in their recovery, and using person-centered language. Have you ever encouraged your peers and co-workers to engage in these practices? IF YES, ASK: Do you...READ 1-3

N = .....
Make a point of always doing this.....1
Do this in some, but not all settings.....2
Or don't do it very often.....3
No/Haven't really thought about it - DO NOT READ.....4
Don't know - DO NOT READ .....5
Refused - DO NOT READ.....6

---

**39:** **Q5A**

What do you think gets in the way of encouraging your peers to engage in these recommendations?

=> Q6A
si Q5=1

N = .....
RECORD COMMENTS .....97
Don't know/Not sure.....98
Refused.....99

---

**40:** **Q5B**

What do you think would help you or make it more likely that you encourage your peers to engage in these behaviors?

=> Q6A
si Q5=1

N = .....
RECORD COMMENTS .....97
Don't know/Not sure.....98
Refused.....99

---

**41:** **Q6A**

To what extent do you believe that, like diabetes and asthma, mental illness is a condition that many people can learn to manage and live with, would you say that you...

N = .....
Agree completely .....01
Agree generally, with some exceptions.....02
Agree only somewhat, with many exceptions .....03
Or do you not at all agree with the statement .....04
Other (SPECIFY:) - DO NOT READ .....97
Don't know - DO NOT READ .....98
Refused - DO NOT READ.....99

---

**42:** **Q6B**

To what extent do you agree that successful recovery is how the consumer defines it for himself or herself rather than how the practioner defines it? Would you say that you...

N = .....
Agree completely .....01
Agree generally, with some exceptions .....02
Agree only somewhat, with many exceptions .....03
Or do you not at all agree with the statement .....04
Other (SPECIFY:) - DO NOT READ .....97
Don't know - DO NOT READ .....98
Refused - DO NOT READ .....99

---

**43:** **Q7A**

The next question is about "The Recovery Model." As you may know, The Recovery Model supports the consumer in defining their life goals, exercising their independence, and taking personal responsibility for their own self-care. Before this interview, how would you describe your knowledge or understanding of the Recovery Model… IF NEEDED: Or family members if the consumer is under 18. IF NEEDED: It is considered a process rather than an end result and emphasizes the full participation of the consumer in all decisions that will affect their lives, including treatment options and the allocation of resources.

N = .....
Very knowledgeable/Practice, facility already utilizing .....1
Very knowledgeable, but not currently engaged in .....2
Somewhat knowledgeable .....3
Have heard of it, but don't know much about it .....4
Or have not heard about it at all .....5
Don't know .....6
Refused .....7

---

**44:** **Q7B**

Before receiving our letter prior to this interview how aware were you of the mental health Transformation process occurring in this state?

N = .....
Very aware .....1
Somewhat aware .....2
Not very aware .....3
Or not at all aware .....4
Don't know - DO NOT READ .....5
Refused - DO NOT READ .....6

---

**45:** **Q8**

What do you think is the one most important thing that people with mental illness can do for themselves to promote their own recovery?

N = .....
RECORD COMMENTS .....97
Don't know/Not sure.....98
Refused.....99

---

**46:** **Q9**

Reducing stigma and stigmatizing behaviors is an important part of the Transformation and is also a crucial step in moving toward the Recovery Model. Is there something you've done with the consumers you see in your practice that you feel has helped reduce stigma?"

N = .....
RECORD COMMENTS .....97
Don't know/Not sure.....98
Refused.....99

---

**47:** **Q9X**

I am going to read several information statements. For each, please tell me if you agree with that statement and believe it to be true. The first statement is....

N = .....
Continue .....1

---

**48:** **Q9A**

(For each, please tell me if you agree with that statement and believe it to be true....)

There is research data available showing that improved outcomes are possible when clients are actively involved in their treatment decision process. IF AGREE, PROBE: Do you know it to be true or think it might be true?

N = .....
Know this to be true .....1
Think it might be true.....2
Would like it to be true but are not sure (IF VOLUNTEERED).....3
Do not believe it is true .....4
Don't know .....5
Refused.....6

---

**49:** **Q9B**

(For each, please tell me if you agree with that statement and believe it to be true....)

The next statement is: Evidence-based practices promoting the Recovery Model are available and effective. IF AGREE, PROBE: Do you know it to be true or think it might be true?

N = .....
Know this to be true .....1
Think it might be true .....2
Would like it to be true but are not sure (IF VOLUNTEERED) .....3
Do not believe it is true .....4
Don't know .....5
Refused .....6

---

**50:** **Q9C**

(For each, please tell me if you agree with that statement and believe it to be true....)

The next statement is: Recovery requires that treatment be holistic, individualized and person-centered. This means that the whole person is taken into consideration, including his OR HER unique strengths and CIRCUMSTANCES, and not just his OR HER diagnosis. IF AGREE, PROBE: Do you know it to be true or think it might be true?

N = .....
Know this to be true .....1
Think it might be true .....2
Would like it to be true but are not sure (IF VOLUNTEERED) .....3
Do not believe it is true .....4
Don't know .....5
Refused .....6

---

**51:** **Q9D**

(For each, please tell me if you agree with that statement and believe it to be true....)

The next statement is: Most people with a mental illness are not more violent than anyone else. IF AGREE, PROBE: Do you know it to be true or think it might be true?

N = .....
Know this to be true .....1
Think it might be true .....2
Would like it to be true but are not sure (IF VOLUNTEERED) .....3
Do not believe it is true .....4
Don't know .....5
Refused .....6

---

**52:** **Q9F**

Is there anything else, that if you knew it, it would make you more likely to adopt the Recovery Model?

N = .....
RECORD COMMENTS .....97
No/Nothing/Can't think of anything .....00
Don't know/Not sure.....98
Refused.....99

---

**53:** **Q10**

I am going to read these statements again. Please tell me for each, if you definitely knew this statement to be true, whether it would influence or did influence your decision to move toward the Recovery Model in your practice...

N = .....
Continue .....1

---

**54:** **Q10A**

(Please tell me for each, if you definitely knew this statement to be true, whether it would influence or did influence your decision to move toward the Recovery Model in your practice...)

There is research data available showing that improved outcomes are possible when clients are actively involved in their treatment decision process. IF YES, PROBE: Is that definitely or might?

N = .....
Definitely make you more likely to move toward the Recovery Model..1
Might make you more likely .....2
Would have little or no impact, one way or other .....3
Would make you less likely to move toward the Recovery Model (IF VOLUNTEERED) .....4
Don't know - DO NOT READ .....5
Refused - DO NOT READ.....6

---

**55:** **Q10B**

(Please tell me for each, if you definitely knew this statement to be true, whether it would influence or did influence your decision to move toward the Recovery Model in your practice...)

The next statement: Evidence-based practices promoting the Recovery Model are available and effective. IF YES, PROBE: Is that definitely or might?

N = .....
Definitely make you more likely to move toward the Recovery Model..1
Might make you more likely .....2
Would have little or no impact, one way or other .....3
Would make you less likely to move toward the
Recovery Model (IF VOLUNTEERED).....4
Don't know - DO NOT READ .....5
Refused - DO NOT READ.....6

---

**56:** **Q10C**

(Please tell me for each, if you definitely knew this statement to be true, whether it would influence or did influence your decision to move toward the Recovery Model in your practice...)

Recovery requires that treatment be holistic, individualized and person-centered. This means that the whole person is taken into consideration, including his OR HER unique strengths and CIRCUMSTANCES, and not just his OR HER diagnosis. IF YES, PROBE: Is that definitely or might?

N = .....
Definitely make you more likely to move toward the Recovery Model..1
Might make you more likely .....2
Would have little or no impact, one way or other .....3
Would make you less likely to move toward the
Recovery Model (IF VOLUNTEERED).....4
Don't know - DO NOT READ .....5
Refused - DO NOT READ.....6

---

**57:** **Q10D**

(Please tell me for each, if you definitely knew this statement to be true, whether it would influence or did influence your decision to move toward the Recovery Model in your practice...)

The last statement is: Most people with a mental illness are not more violent than anyone else. IF YES, PROBE: Is that definitely or might?

N = .....
Definitely make you more likely to move toward the Recovery Model..1
Might make you more likely .....2
Would have little or no impact, one way or other .....3
Would make you less likely to move toward the
Recovery Model (IF VOLUNTEERED).....4
Don't know - DO NOT READ .....5
Refused - DO NOT READ.....6

---

**58:** **Q10E**

Is there anything else, if you knew it, you would find it convincing or compelling adopt the Recovery Model?

N = .....
RECORD COMMENTS .....97
No/Nothing/Can't think of anything .....00
Don't know/Not sure.....98
Refused.....99

---

**59:** **Q11A**

For each please tell me if you BELIEVE the statement or not. The first statement is: The Recovery Model works. Consumers can help themselves and each other. Do you or do you not believe this?

N = .....
Believe.....1
Believe, but qualified (would like to believe, etc.).....2
Do not believe .....3
Don't know .....4
Refused.....5

---

**60:** **Q11B**

Next: Your practice will benefit by adopting the Recovery Model. Do you or do you not believe this?

N = .....
Believe.....1
Believe, but qualified (would like to believe, etc.).....2
Do not believe .....3
Don't know .....4
Refused.....5

---

**61:** **Q11C**

Next: When you share the power with the consumer you also share the responsibility. Do you or do you not believe this? IF NEEDED: It's not all on your shoulders.

N = .....
Believe.....1
Believe, but qualified (would like to believe, etc.).....2
Do not believe .....3
Don't know .....4
Refused.....5

---

**62:** **Q11D**

Next: You will achieve better outcomes by adopting the Recovery Model. Do you or do you not believe this?

N = .....
Believe.....1
Believe, but qualified (would like to believe, etc.).....2
Do not believe .....3
Don't know .....4
Refused.....5

---

**63:** **Q11E**

Next: Moving to the Recovery Model won't cost anymore than the way you have always practiced. Do you or do you not believe this?

N = .....
Believe.....1
Believe, but qualified (would like to believe, etc.).....2
Do not believe .....3
Don't know .....4
Refused.....5

---

**64:** **Q11F**

Next: The funding will be there to help get the Recovery Model up and effective in Washington State. Do you or do you not believe this?

N = .....
Believe.....1
Believe, but qualified (would like to believe, etc.).....2
Do not believe .....3
Don't know .....4
Refused.....5

---

**65:** **Q11G**

Next: By modifying your language and abandoning stereotypes, real improvement in consumer outcomes will happen.

N = .....
Believe.....1
Believe, but qualified (would like to believe, etc.).....2
Do not believe .....3
Don't know .....4
Refused.....5

---

**66:** **Q11H**

Next: More emphasis on recovery will result in less need for crisis intervention.
N = .....
Believe.....1
Believe, but qualified (would like to believe, etc.).....2
Do not believe .....3
Don't know .....4
Refused.....5

---

**67:** **Q11I**

The last statement is: Consumers need to have the dignity of risk and the right to fail in order to learn from their own mistakes. Do you or do you not believe this?
N = .....
Believe.....1
Believe, but qualified (would like to believe, etc.).....2
Do not believe .....3
Don't know .....4
Refused.....5

---

**68:** **Q11X**

I am going to read those same statements again. Please tell me for each one, whether believing it would or did impact your decision to adopt the Recovery Model in your practice....
N = .....
Continue .....1

---

**69:** **Q11J**

(Please tell me for each one, whether believing it would or did impact your decision to adopt the Recovery Model in your practice....)

The Recovery Model works. Consumers can help themselves and each other. IF YES, PROBE: Would that definitely or might make you more likely to adopt Recovery Model principles in your practice?

N = .....
Definitely make more likely to adopt Recovery Model.....1
Might .....2
Would have little or no impact .....3
Do not believe this statement (IF VOLUNTEERED) .....4
Don't know .....5
Refused.....6

---

**70:** **Q11K**

(Please tell me for each one, whether believing it would or did impact your decision to adopt the Recovery Model in your practice....)

Your practice will benefit by adopting the Recovery Model. IF YES, PROBE: Would that definitely or might make you more likely to adopt Recovery Model principles in your practice?

N = .....
Definitely make more likely to adopt Recovery Model.....1
Might.....2
Would have little or no impact .....3
Do not believe this statement (IF VOLUNTEERED) .....4
Don't know .....5
Refused.....6

---

**71:** **Q11L**

(Please tell me for each one, whether believing it would or did impact your decision to adopt the Recovery Model in your practice....)

When you share the power with the consumer you also share the responsibility. IF YES, PROBE: Would that definitely or might make you more likely to adopt Recovery Model principles in your practice?

N = .....
Definitely make more likely to adopt Recovery Model.....1
Might.....2
Would have little or no impact .....3
Do not believe this statement (IF VOLUNTEERED) .....4
Don't know .....5
Refused.....6

---

**72:** **Q11M**

(Please tell me for each one, whether believing it would or did impact your decision to adopt the Recovery Model in your practice....)

You will achieve better outcomes by adopting the Recovery Model. IF YES, PROBE: Would that definitely or might make you more likely to adopt Recovery Model principles in your practice?

N = .....
Definitely make more likely to adopt Recovery Model.....1
Might.....2
Would have little or no impact .....3
Do not believe this statement (IF VOLUNTEERED) .....4
Don't know .....5
Refused.....6

---

**73:** **Q11N**

(Please tell me for each one, whether believing it would or did impact your decision to adopt the Recovery Model in your practice....)

Moving to the Recovery Model won't cost anymore than the way you have always practiced. IF YES, PROBE: Would that definitely or might make you more likely to adopt Recovery Model principles in your practice?

N = .....
Definitely make more likely to adopt Recovery Model.....1
Might.....2
Would have little or no impact .....3
Do not believe this statement (IF VOLUNTEERED) .....4
Don't know .....5
Refused.....6

---

**74:** **Q11O**

(Please tell me for each one, whether believing it would or did impact your decision to adopt the Recovery Model in your practice....)

The funding will be there to help get the Recovery Model up and effective in Washington State. IF YES, PROBE: Would that definitely or might make you more likely to adopt Recovery Model principles in your practice?

N = .....
Definitely make more likely to adopt Recovery Model.....1
Might.....2
Would have little or no impact .....3
Do not believe this statement (IF VOLUNTEERED) .....4
Don't know .....5
Refused.....6

---

**75:** **Q11P**

(Please tell me for each one, whether believing it would or did impact your decision to adopt the Recovery Model in your practice....)

By modifying your language and abandoning stereotypes, real improvement in consumer outcomes will happen. IF YES, PROBE: Would that definitely or might make you more likely to adopt Recovery Model principles in your practice?

N = .....
Definitely make more likely to adopt Recovery Model.....1
Might.....2
Would have little or no impact .....3
Do not believe this statement (IF VOLUNTEERED) .....4
Don't know .....5
Refused.....6

---

**76:** **Q11Q**

(Please tell me for each one, whether believing it would or did impact your decision to adopt the Recovery Model in your practice....)

More emphasis on recovery will result in less need for crisis intervention. IF YES, PROBE: Would that definitely or might make you more likely to adopt Recovery Model principles in your practice?

N = .....
Definitely make more likely to adopt Recovery Model.....1
Might.....2
Would have little or no impact .....3
Do not believe this statement (IF VOLUNTEERED) .....4
Don't know .....5
Refused.....6

---

**77:** **Q11R**

(Please tell me for each one, whether believing it would or did impact your decision to adopt the Recovery Model in your practice....)

Consumers need to have the dignity of risk and the right to fail in order to learn from their own mistakes. IF YES, PROBE: Would that definitely or might make you more likely to adopt Recovery Model principles in your practice?

N = .....
Definitely make more likely to adopt Recovery Model.....1
Might.....2
Would have little or no impact .....3
Do not believe this statement (IF VOLUNTEERED) .....4
Don't know .....5
Refused.....6

---

**78:** **Q11S**

Is there anything else, that if you believed it, it would make you more likely to adopt the Recovery Model principles in your practice?

N = .....
RECORD COMMENTS .....97
No/Nothing/Can't think of anything .....00
Don't know/Not sure.....98
Refused.....99

---

**79:** **Q12**

How would you rate the urgency of eliminating stigma as an issue facing people with mental illness?

N = .....
Very Urgent.....1
Somewhat urgent.....2
Not very urgent.....3
Or not at all urgent.....4
Don't know - DO NOT READ .....5
Refused - DO NOT READ.....6

---

**80:** **Q13A**

The Mental Health Transformation initiative seeks to transform the mental health system, and change the perception of people with mental illness and those who seek or use mental health services. How confident are you that this can be done in Washington State?

N = .....
Very confident.....1
Somewhat confident.....2
Not very confident.....3
Or not at all confident.....4
Don't know - DO NOT READ .....5
Refused - DO NOT READ.....6

---

**81:** **Q13B**

Why do you say that?

| |
|---|
| => +1<br>si Q13A=6 |

N = .....
RECORD COMMENTS .....97
Don't know/Not sure.....98
Refused.....99

---

**82:** **Q14**

What do you feel is the one most important or impactful thing you and others in your profession can do to help eradicate the stigma surrounding mental illness?

N = .....
RECORD COMMENTS .....97
Don't know/Not sure.....98
Refused.....99

---

**83:** **Q15**

I have a few final questions that will be used for helping to classify our information. What is your professional license?

N = .....
Counselor .....01
MD/Psychiatry.....02
MSW/Social work .....03
Psychology .....04
Licensed clinical social worker .....05
Other (SPECIFY:) .....97
Don't know/Refused .....99

---

**84:** **Q16**

How many years have you been practicing in Washington?

N = .....
Less than 1 year.....00
Don't know/Refused .....99
.....2
.....4
.....8
.....10
.....12
.....15
.....18
.....22
.....23

---

**85:** **Q17**

About what percent of your practice is devoted to working with consumers under the age of 18? This would include the time you also spend with their families IF NEEDED: Just your estimate is fine. RECORD NUMBER, USE OTHER ONLY IF NUMBER NOT GIVEN.

N = .....
None .....000
RECORD COMMENTS .....997
Don't know/Not sure.....998
Refused.....999
.....5
.....20
.....30
.....33
.....50
.....95
.....100

---

**86:** **Q18**

How many different consumers did you see in your practice in 2005? Just your best estimate is fine. RECORD NUMBER, USE OTHER ONLY IF NUMBER NOT GIVEN.

N = .....
RECORD COMMENTS .....999997
Don't know .....999998
Refused.....999999
.....15
.....50
.....80
.....100
.....150
.....500

---

**87:** **Q19**

About what percentage of those had co-occurring conditions that involved more than one mental illness diagnosis (such as schizophrenia and bi-polar disorder)? IF NEEDED: Just your estimate is fine. RECORD NUMBER, USE OTHER ONLY IF NUMBER NOT GIVEN.

N = .....
None .....000
RECORD COMMENTS .....997
Don't know/Not sure.....998
Refused.....999
.....15
.....20
.....25
.....40
.....60
.....70
.....80
.....100

---

**88:** **Q19A**

About what percentage of the consumers you saw had a co-occuring condition (meaning substance abuse and mental illness)? RECORD NUMBER, USE OTHER ONLY IF NUMBER NOT GIVEN.

N = .....
None .....000
RECORD COMMENTS .....997
Don't know/Not sure.....998
Refused.....999
.....10
.....15
.....20
.....25
.....30
.....50
.....60
.....70
.....75

---

**89:** **Q19B**

About what percentage of your practice is spent working in the public sector rather than in the private sector? RECORD NUMBER, USE OTHER ONLY IF NUMBER NOT GIVEN.

N = .....
None .....000
RECORD COMMENTS .....997
Don't know/Not sure.....998
Refused.....999
.....80
.....90
.....95
.....100

---

**90:** **Q20**

And finally, are you practicing in an urban or suburban area of the state, or in a rural or small town setting?

N = .....
Urban/Suburban area .....1
Rural or small town setting.....2
Don't know/Refused .....3

---

**91:** **GENDR**

RECORD GENDER
N = .....
Male.....1
Female .....2

**Appendix B**

CONSUMER AUDIENCE DISCUSSION GUIDE

TELE-FOCUS GROUPS

Parents

I. INTRODUCTION / GROUP WARM – UP **5 minutes**

Welcome

Thank you for agreeing to take part in the research. Purpose of groups: State of Washington involved in an effort to foster and increase support for programs that encourage consumers to take on a larger role in their recovery and to publicly share their experiences and insights. Your input will help develop the messages and strategies to accomplish this goal.

A. Moderator introduction / Research explanation / Basic ground rules (First name only, Speak Up, No right or wrong answers, taping for my use only, will not identify (anonymous)

B. Group introduction and Repeat of Purpose

1. Again, remind First name only

2. Warm up topics:

Actual interview will be fairly structured, but first, I would like you to introduce yourselves, first names only, and in a minute or two, tell us briefly about your situation – your story. Even though this is brief, much of your story will also emerge during the interview process. Please don't be offended if it appears I am cutting you off.

**Appendix B**

We have very specific topics and questions we need to discuss because the purpose of the group is to help the State of Washington develop messages and strategies to promote recovery and reduce the stigma of mental illness.

1. On the paper you have in front of you, please write down what you think of when you hear the word, "stigma." Then, what does it mean to you personally.

Share ideas /discuss. Allow a minute or two each for their story. Take a minute or two, a little something about yourself and what motivated you to agree to join this discussion and help us with the research.

Allow 5 or 6 minutes for above discussion. Then remind that we have to get to the purpose of the group that was first mentioned.

RECOVERY 25 minutes

A. READ: Taking an active role in managing your mental illness is described in research we've done as being in recovery or the Recovery Model. Have you heard this term used? PLEASE ANSWER QUESTIONS THROUGHOUT THE GROUP AS A PARENT CONSUMER. FOR INSTANCE, WHEN I SAY YOUR ILLNESS, I AM REFERRING TO THE ILLNESS YOUR CHILD HAS AND THAT YOU ARE WORKING WITH/MANAGING/ WITH YOUR CHILD AS WELL AS DEALING WITH AS A PARENT..

**Appendix B**

One definition of Recovery is:

> " The Recovery Model supports the consumer in defining their life goals, exercising their independence, and taking personal responsibility for their own self-care. It is considered a process rather than an end result and emphasizes the full participation of the consumer in all decisions that will affect their lives, including treatment options and the allocation of resources. It utilizes the support of the community to create and maintain opportunities for consumers and promotes the elimination of stigmatizing behaviors and discrimination against people who have a mental illness."

In other words, Recovery involves:

**a.** The consumer defining his or her life goals and exercising Independence

b. Taking full responsibility for their own self care/ Taking an active role in managing their illness, including seeking treatment and following treatment guidelines

c. Fully participating in all of the decisions that will affect their lives, including treatment options

. Being a partner with their provider in treatment decisions

d. Having completed an advance directive, a Written crisis plan.

**Appendix B**

In your opinion, are you actively engaged/participating in recovery? Share discuss in general terms. Then:

A. Have you or are you in the process of defining your life goals and exercising independence?

What are you doing?

What motivated you to do this / these things?

What prevents or prevented you before from doing this?

B, Are you taking an active role in managing your illness or illnesses by seeking treatment and following treatment guidelines?

What motivated you to do this

Before you were doing this, what prevented you? What were some of the barriers?

What are some of the things that you do on a daily basis to take an active role in managing your mental illness

a. Share responses and discuss

b. Were you always doing these things or has it been recently?

d. When you weren't doing these things, what was preventing you?

e. Who/what prompted you to start?

f. Who/what helps you maintain?

g. Would there be something that could happen that would support you or motivate you in doing these things if you weren't already doing them?

h. Would there be something that could happen on a larger scale in your neighborhood, community, city, state that would support you in doing these things?

If you think about people you know who are not taking an active role in managing their mental illness, or if you think about yourself prior to taking an active role in managing your mental illness – what large scale program, activity, event, attitude change, etc. could motivate someone to start taking an active role?

2. Do you feel that you and your mental health provider (psychiatrist, psychologist, therapist, counselor, etc.) are in a "partnership" when it comes to treatment/support of your mental illness? How so?

- Describe
- What made it possible or motivated you to assume an active/partner role with your provider?
- If not, what do you think is getting in the way of that?
- What would need to change or happen for you to become a partner
- Do you think this is something that you could change or is that the role of your provider or both? Discuss.

**Appendix B**

**AIDED**

We have been discussing obstacles or things that might encourage or prevent you from taking an active role in your own recovery and what it would take to convince you to de these things if you are not already doing them.

1.. READ: For each of the following conditions, please write down if it (1)**definitely** would convince you, (2)**might** convince you or (3)**would not** convince you to take an active role in own recovery. Or, if you are already doing so, whether it was definitely, somewhat or not a motivator for your doing so. First:

a) Would knowing what treatment is available and where it is available motivate you to take an active role in treatment? (Please write down definitely, might or would not) Score _____

b) Would knowing the options for paying for treatment motivate you to assume an active role by seeking and continuing treatment? Please write down… DISCUSS Score_____

c) Would believing that appropriate treatment is both available and affordable motivate you to seek treatment?… DISCUSS Score _____

d) Would knowing what recovery is and what it means to you encourage you to seek and continue the appropriate treatment or to take an active role in treatment? DISCUSS Score _____

e) Would believing that people do and can get better motivate you to take an active role in treatment?… PAUSE SHARE DISCUSS Score _____

**Appendix B**

f) Would <u>believing</u> that if you get help and change your behaviors, you will be met halfway and it will be worthwhile encourage you to take an active role recovery?… DISCUSS Score _____

g) There are some people who fear that if they seek and get treatment and work towards recovery, they will no longer be unique. Is it important to believe that you will still be unique if you seek and get treatment? How would believing this motivate you to take an active role?… DISCUSS Score _____

h) Would believing that mental illness is a condition, like diabetes or asthma, that many people can learn to live with be important in motivating you DISCUSS Score _____

i) There are practices and treatment options that evidence shows really work. Does believing evidenced based practices work motivate you to play an active role in recovery/to participate in recovery? SHARE DISCUSS Score _____

j) Would Believing that you as, a consumer, need to have the dignity of risk and the right to fail in order to learn from your own mistakes encourage you to assume an active role in all aspects of recovery? Score _____

**Appendix B**

2. Of the motivators we just discussed, which do you think is the most convincing or motivating in the decision to begin the journey of recovery? Read them if necessary

2B. What are the most important things that you think people with mental illness or their families need to know and believe to take an active role in managing their mental illness?

3. What do you think would be the one most convincing thing you could say or do that would encourage or convince someone to participate in recovery, that would convince them to seek treatment and begin the recovery process? Can you think of anything else that would be important to know or believe?

PUBLIC SHARING

The Recovery Model also endorses opportunities for providers and consumers to interact in dialogues or workshops. These sessions may involve consumers sharing personal stories and/or discussions around issues of recovery or stigma. These individuals not only take an active role in their own wellness and recovery plan but also serve as advocates for improved services for others with mental illness. By speaking out in the community, these consumer advocates not only spread the message that recovery is possible, but they serve as ambassadors disproving many of the myths and stigma surrounding mental illness. Have you ever attended a dialogue or workshop such as this or have you ever spoken out in public?

**Appendix B**

Thinking of these dialogues, workshops, trainings, peer support organizations, panels, speaker's bureau, etc. where insights are shared with others or less formal venues for being public about mental illness such as disclosing to a friend, neighbor, co-worker, etc.

- Are you doing or have you done any of these things? Which ones? If not mentioned, are any of these events where providers are also present?
- What do you see as the major benefits for speaking publicly? If not mentioned: For other consumers or persons with a mental illness?
- In what format? For what audience? (Who did you wish to educate or engage in discussion)
- What motivated you to share your experiences and insights publicly?
- Before you were public, what prevented you from doing so?
- For the things you haven't done, what do you think were your major obstacles/barriers or reasons why you haven't?
- What do you think would make it more likely that you would?
- What would you need to know?
- To hear?
- To believe?
- What would it take to convince you if you are not already doing so?

**Appendix B**

**AIDED**

- Would believing that through these contacts and sharing of your insights and experiences you will make a difference - that you would be helping to reduce stigma convince you? Would it motivate you a lot or a little?
- Would believing that sharing publicly would encourage others to seek treatment and work toward recovery? Would it motivate you a lot or a little?
- Would encouragement from other consumers to become involved encourage you to participate or share publicly? Would it motivate you a lot or a little?
- Would encouragement from your provider… (If your doctor or provider suggested you speak? Would this motivate you to become a speaker advocate? Would it motivate you a lot or a little?
- Would encouragement from your family…? Would it motivate you a lot or a little?
- Would believing that sharing your insights and experiences are an important part of your own recovery motivate you? Would it motivate you a lot or a little?

What do you think would be the one most convincing thing you could say or do that would encourage or convince another consumer to engage in dialogues or start sharing publicly their insights and experiences with mental illness?

**Appendix B**

V WRAP UP **5 minutes**

What one thing would you like the policy makers for mental health in this state to know or do in order to promote better outcomes for people with mental illness?

**Appendix C**

## QUESTIONS FOR TRANSFORMATION WORKGROUP

Name _____

Agency or Title _____

Date of Interview _____

Interviewer _____

### OBJECTIVES:

- Determine how best to support key Transformation initiatives
- Gather information about funding legislation

### INTRODUCTION

Thank you for helping us with this research. As you know, the State of Washington is engaged in a Transformation process for the delivery of mental health services. Two major focuses for this Transformation include the reduction of stigma associated with mental illness and promotion of recovery principles .

### QUESTIONS

1. How do you think legislators feel about funding mental health services, do you think that in general they feel such services are High, Medium or Low budget priorities? _____

1. A IF LOW ASK: Why do you think that is?

**Appendix C**

2. As a member of the Transformation Workgroup, you represent a specific sector or group of people. When you think of stigma, what do you think is the number one issue affecting the people whose interests you represent?

3. When you think of recovery from mental illness, what do you think is the number one issue affecting the people whose interests you represent?

4. What legislative action do you believe might contribute to reducing stigma and advancing recovery?

4.A Would your agency (organization, etc) support legislation of this kind?

4.B Would YOU support this legislation.

4.C F NO: Why not? What will it take for your agency (YOU) to do so?

**(INTERVIEWER: Some people are representing a special interest, e.g. native American, mental health providers, NAMI, youth, older adults. For them, please frame the next two questions in terms of the people they represent as indicated by the parentheses. This will not be needed for the more general agency-reps, e.g. DOH, Governor's Policy Advisor.)**

**Appendix C**

5. Consumers of mental health services say that the stigma surrounding mental illness – feelings of shame, isolation and hopelessness – create barriers to seeking help. (Thinking about the people you represent,) what specific actions do you think would be most effective in reducing the stigma surrounding mental illness?

6. Consumers of mental health services also say that it is very motivating to hear that people with mental health problems can and do get better, and that they are not alone. (Thinking about the people you represent,) what specific actions do you think Washington State could take to increase understanding that people with mental illnesses can and do recover?

7. Finally, do you have any other comments about mental health and related services in Washington?

**Appendix D**

## QUESTIONS FOR LEGISLATIVE TASK FORCE MEMBERS

**Name** _____

**District and Title** _____

**Date** _____

**Interviewer** _____

**OBJECTIVES**:

- Determine level of awareness and beliefs around mental health issues.
- Gather information about budget decisions and allocations.
- Learn about potential for legislation and funding.

## INTRODUCTION

Gilmore Research Group has been retained by the Washington Department of Health to gather opinion from across the state and from a variety of sources regarding mental health services. As part of the legislative task force for the Transformation of mental health services, we would also like to include your opinions.

**Appendix D**

**QUESTIONS**

1. Before being asked to be a member of this Taskforce had you heard of a movement in Washington State to transform mental health services to more recovery oriented services?)

2. Thinking about the population of Washington State, in general, what is your perception of people being able to get the information they need about mental health services? Would you say it is very easy for people to get information, somewhat easy, somewhat difficult or very difficult?

IF SOMEWHAT/VERY DIFFICULT ASK: In your opinion, why is information/access difficult?

3. Again, thinking about the people in Washington, in general, how do you feel about the ability of people to access these mental health services? Would you say it is very easy for people to get access, somewhat easy, somewhat difficult or very difficult?

IF SOMEWHAT/VERY DIFFICULT ASK: In your opinion, why is information/access difficult?

4. And how do you feel about their access to affordable mental health services? Would you say it is very easy for people to get access to affordable mental health care, somewhat easy, somewhat difficult or very difficult?

**Appendix D**

IF SOMEWHAT/VERY DIFFICULT ASK: In your opinion, why is information/access difficult?

5. How would you rate the availability of employment opportunities or job-training opportunities for people who use mental health services in Washington, would you say those opportunities are Excellent, Good, Fair or Poor?

6. How do you think legislators feel about funding mental health services, do you think that in general they feel such services are High, Medium or Low budget priorities?

IF LOW/MEDIUM ASK: Why do you think is not a high priority; what keeps it from being a higher priority? SUGGEST SO THAT MORE PEOPLE WILL BE ANSWERING THIS.

7. What legislative action do you believe might contribute to reducing stigma and advancing recovery? (The Recovery Model supports the consumer in defining their life goals, exercising their independence and taking personal responsibility for their own self-care.)

8. Here are several statements that reflect the body of knowledge behind mental health Transformation. For each one, please tell me if knowing or believing it would make you more likely to support the above proposed programs or legislation? (Definitely would make me more likely, Might make me more likely, Would have no impact, Already believe, Not sure.

**Appendix D**

- First: Like diabetes and asthma, mental illness is a chronic condition that many people can manage and live with. -__

- Next: Many people needing mental health services are pigeon-holed with labels and made to feel disgrace because of their condition. It can also be said they are "stigmatized" because of their condition. ____

- I can help reduce the stigma and discrimination experienced by people with mental illness if I adopt language that puts the person first before their disease,. An example of this would be to say, "the person has a mental illness," rather than "the person is mentally ill"____

- Successful recovery is how the consumer defines it for himself or herself rather than how the counselor or physician defines it.____

- In learning to live with and manage their illness, it is important to support and encourage people with mental illness to take an active role in decisions regarding their treatment._____

- In terms of violent behavior, the population of people with mental illness poses the same risk to the community as the population without mental illness. ____

- Consumers of mental health services who share their personal stories and experiences recovering from mental illness can become role models who can motivate others to seek treatment and begin their own path to recovery. _____

- If there is more emphasis put on successful recovery from mental illness, there will be less need for crisis intervention. (The Recovery Model supports the consumer in defining their life goals, exercising their independence and taking personal responsibility for their own self-care.) Mental illness affects almost every family in America. _____

    - Anyone, regardless of age, race, gender, ethnicity or economic background, can experience a mental illness._____

**Appendix D**

- Studies show that many people with mental illness recover completely. _____

- People with mental illnesses lead active, productive lives and contribute to their communities_____

- Many people who do not understand mental illnesses think that there is something shameful about them. This "stigma" can lead to discrimination and stop people from getting an education, a home, a job._____

9. What types of new or revised legislation would you like to see for the State regarding mental health services and funding? OPEN-

10. What do you think it would take for the Legislature to allocate funds to support recovery oriented services, such as creating more employment opportunities for mental health consumers, expanding community resources for consumers or promoting behavior and language changes designed to reduce the barriers created by the shame or stigma many people with mental illness encounter. OPEN-END

11. How would you rate the coordination and communication among the agencies and systems within your community who are working with people using or needing mental health services? Would you say Excellent, Good, Fair or Poor?

12. How do you feel about the coordination and communication among the State agencies and systems who work with people using or needing mental health services? Would you say Excellent, Good, Fair or Poor?

**Appendix D**

If not excellent, what actions would you support the State in taking to improve this coordination between agencies and systems? How can they better help mental health consumers "connect the dots" among services?

13. How likely are YOU to support each of the following by ensuring adequate funding? High chance of supporting, Medium, Low chance of supporting

LIST:

- Improved employment opportunities for mental health consumers____

**If Medium or Low ASK**: What prevents you from being more supportive? What would it take for you to be more supportive of allocating the adequate funds?

- Expand warm lines or community resource lines to reach every community in Washington_____

**If Medium or Low ASK**: What prevents you from being more supportive? What would it take for you to be more supportive of allocating the adequate funds?

- Increased education about mental illness geared to decreasing misconceptions, stereotypes, demeaning language and isolation_____

**If Medium or Low ASK**: What prevents you from being more supportive? What would it take for you to be more supportive of allocating the adequate funds?

- More opportunities for mental health consumer involvement in all aspects of mental health service planning, delivery, legislation and community outreach._____

**If Medium or Low ASK**: What prevents you from being more supportive? What would it take for you to be more supportive of allocating the adequate funds?

**Appendix D**

- Legislation prohibiting discrimination of those with mental illness, including discrimination in housing._____

**If Medium or Low ASK**: What prevents you from being more supportive? What would it take for you to be more supportive of allocating the adequate funds?

- Compensation for mental health providers to attend dialogues and meetings with consumers_____

**If Medium or Low ASK**: What prevents you from being more supportive? What would it take for you to be more supportive of allocating the adequate funds?

- Promoting the message that there is hope, people can and do get better from mental illness._____

**If Medium or Low ASK**: What prevents you from being more supportive? What would it take for you to be more supportive of allocating the adequate funds?

- More mental health services geared specifically toward youth with mental illness (i.e. peer support programs, youth advocacy opportunities, etc_____

**If Medium or Low ASK**: What prevents you from being more supportive? What would it take for you to be more supportive of allocating the adequate funds?

**If Medium or Low ASK**: What prevents you from being more supportive? What would it take for you to be more supportive of allocating the adequate funds?

14. The Mental Health Transformation initiative seeks to transform the mental health system and change how services are organized and delivered. How confident are you that this can be done in Washington State?

15. Finally, do you have any other comments about mental health and related services in Washington?

**Appendix E**

## QUESTIONS FOR ELECTED OFFICIALS SEGMENT

**Name** _____

**District and Title** _____

**Date** _____

**Interviewer** _____

**OBJECTIVES**:

- Determine level of awareness and beliefs around mental health issues.
- Gather information about budget decisions and allocations.
- Learn about potential for legislation and funding.

## INTRODUCTION

Thank you for participating in this research. Gilmore Research Group has been retained by the Washington Department of Health to gather opinion from across the state and from a variety of sources regarding mental health services. As an elected official, we would also like to include your opinions.

**Appendix E**

**QUESTIONS**

1. Before being asked to take part in this research, had you heard about the mental health Transformation process occurring in this state? **Yes/No**

1a. IF YES: What have you heard?

2. Do you feel that mental health services in your (county)(city) are or are not adequate for your population? **Adequate, Not Adequate, Depends on Service/Need**

2a. IF NOT ADEQUATE/DEPENDS: What do you feel is missing?

3a. Thinking about the population of your (county)(city) what is your perception of people being able to get the information they need about mental health services? Would you say it is **very easy** for people to get information, **somewhat easy, somewhat difficult or very difficult?**

3b. Again, thinking of your (county)(city), how do you feel about the ability of people to access these mental health services? Would you say it is **very easy** for people to get access, **somewhat easy**, **somewhat difficult or very difficult**?

**Appendix E**

3c. And how do you feel about access to affordable mental health services? Would you say it is **very easy** for people to find affordable mental health care, **somewhat easy**, somewhat difficult or **very difficult?**

3d. How would you rate the availability of employment or job-training opportunities for people who use mental health services in your (county)(city), would you say those opportunities **are Excellent, Good, Fair or Poor**?

4. Here are several statements. Please indicate if you **believe or do not believe each, or if you are not sure.**

4a. First: Like diabetes and asthma, mental illness is a chronic condition that many people can manage and live with. _____

4b. Next: Many people needing mental health services are pigeon-holed with labels and made to feel disgraced because of their condition. It can also be said they are "stigmatized" because of their condition._____

4c. Next: I can help reduce the stigma and discrimination experienced by people with mental illness if I adopt language that puts the person first before their disease,. An example of this would be to say, "the person has a mental illness," rather than "the person is mentally ill"_____

4d. In terms of violent behavior, the population of those with mental illness poses the same risk to the community as the population without mental illness. _____

**Appendix E**

4e. Consumers of mental health services who share their personal stories and experiences recovering from mental illness can become role models who can motivate others to seek treatment and begin their own path to recovery_____

4f. If there is more emphasis put on successful recovery from mental illness, there will be less need for crisis intervention. (The Recovery Model supports the consumer in defining their life goals, exercising their independence and taking personal responsibility for their own self-care.)_____

4g. Mental illness affects almost every family in America. _____

4h. Anyone, regardless of age, race, gender, ethnicity or economic background, can experience a mental illness._____

4i. Studies show that many people with mental illness recover completely._____

4j. People with mental illnesses lead active, productive lives and contribute to their communities _____

4k. Many people who do not understand mental illnesses think that there is something shameful about them. This "stigma" can lead to discrimination and stop people from getting an education, a home, a job._____

5a. How are mental health services funded in your (city)(county) OPEN-END

5b. What priority do you feel that such services are given during budget allocations, would you say High, Medium or Low?

**Appendix E**

6. What do you think it would take for your (city)(county) to reallocate funds to support and provide the resources necessary for Mental Health Transformation? These resources may include such things as creating more employment opportunities for mental health consumers, compensating mental health providers for attending workshops with consumers, developing more mental health services for young consumers, and funding community workshops and consumer support organizations. OPEN_END.

7a. How would you rate the coordination and communication among the agencies and systems in your community who are working with people using or needing mental health services? Would you say **Excellent, Good, Fair or Poor**?

7b. How do you feel about the coordination and communication among the STATE agencies and systems who work with people using or needing mental health services? Would you say **Excellent, Good, Fair or Poor**?

7c. (If not excellent/good in 7b): What would you like to see the STATE do to improve coordination of services and communication between the systems and agencies? OPEN-END

8. What legislative action do you believe might contribute to reducing stigma and advancing recovery? (The Recovery Model supports the consumer in defining their life goals, exercising their independence and taking personal responsibility for their own self-care.)

**Appendix E**

9. The Mental Health Transformation initiative seeks to transform the mental health system and change how services are organized and delivered. How confident are you that this can be done in Washington State

10. Finally, do you have any other comments about mental health and related services in your area?