Transforming Mental Health Services:
Through the Use of Evidence-Based and Emerging Best Practices

Consumer Caucus Notes

About twenty consumer/survivor/ex-patients representing approximately ten counties participated in the Consumer Caucus. The topics that were presented in the conference's nine breakout sessions earlier that day were posted around the room. The topics from those breakout sessions were:

1. Medication & Recovery
2. Illness Management & Recovery
3. Peer Support & Peer Programs
4. Family Support & Education
5. Intensive Community Support
6. Supported Housing
7. Dual Diagnosis Treatment
8. Self-Directed Services
9. Supported Employment

Consumers were asked to write comments on the posters relevant to the above topics based on three questions:

1. What works in relation to this topic?
2. What doesn't work?
3. What else do you need to know about this topic?

Once consumers had an opportunity to write comments, a facilitated discussion took Place regarding the topic. Written comments were taken directly from the posters and appear in quotes. Additional comments based on the facilitated discussion are provided by three staff members from the OHSU Center on Self Determination, who assisted with the process (Anne Arthur, Dianne Duerscheidt, and Rollin Shelton). Please note that comments listed do not necessarily represent a consensus agreement among consumers. A diverse group of consumers brought a range of concerns, hopes, and perspectives to the process.

Consumers were also asked to provide recommendations to the Stakeholder Group in charge on implementing SB267. A list of recommendations for the Stakeholder Group follows discussion of individual topics, and a summary of key themes that emerged throughout the caucus can be found at the very end of this report.

1. Medication & Recovery

What works?

- "Trial & error as identified by the consumer." The consumer should have the opportunity to determine what works and what doesn't work in terms of self- Interpreted improvement balanced against possible side effects. This respects the consumer as experts on their own quality of life.
- "Herbs (skullcap, passion flowers, kava) and vitamins and good food." In other words, there are alternatives that may work for consumers, and ~consumers should have access to information about these alternatives. Sometimes very simple, inexpensive things such as changing a diet can impact health and mental health.
- "Psychosocial recreation if the consumer is interested in it and medication."
- "Dialoguing with people about how they will know if a medication is working or not working."
- "Consumers learning a 'total life' outlook such as coping skills, positive attitude, spirituality, diet, exercise, and having a strong support network." Reliance on medication management is not enough and may not be the most important factor in a person's recovery.

What doesn't work?

- "Carte blanche prescribing without engaging the consumer in ongoing feedback."
- "Psychiatrists cutting patients off drugs' cold turkey. ",
- "Consumers with the attitude that meds are THE answer for their diagnosis."

What else do you need to know?

- -Need more resources on alternatives.

2. Illness Management & Recovery

What works?

- "No pushing." Respect each individual consumer's process as they work toward recovery. Respect individual definitions of what "recovery" means. Let the consumer set recovery goals rather than assuming you know what he or she needs/wants.
- "Financial safety net."
- "Realization that results or recovery don't determine money available." [?]

- "Focus on strengths." Acknowledge and validate existing strengths while fostering additional skills.
- "Building alliances."
- "Identifying barriers to cultural change." Identify barriers to changing the culture and expectations of mental health systems to create a culture that is more responsive to the individual needs and goals of each consumer. This may sound too time-consuming, but it may prove to be less time-consuming because consumers would feel more supported and respected and would likely be more invested in goal outcomes if they set their own goals.

What doesn't work?

- "The medical dinosaurs."
- "Power imbalances." The power imbalances inherent in the process are often maximized rather than minimized.
- "Being told that is a symptom of my illness." Sometimes a consumer is angry, sad, or frustrated for a valid reason. Not every emotion or response is a symptom. When emotions become pathologies, the person is invalidated and may feel silenced, ignored, or devalued. Often consumers are angry because of the way they are treated, and the anger is valid.
- "Anti-stigma campaigns."

What else do you need to know?

- "Why there are no cultural mechanisms to create accommodations instead of assuming the person is always ill and needs to be fixed (support for individuality)."
- "Need more information about toolkits and funds for them to reach consumers."

3. Peer Support & Peer Operated Programs

What works?

- "The 'advocacy voice' as THE voice from the recovery community."
- "Imagination and flexibility."
- "SAFE -and consumers having a say in how SAFE is run." (Refers to the peer-directed organization in the Eugene/Springfield area; a peer-supporting-peers model that includes various services and activities.)
- "Recovering Consumer Action Group (Salem)."
- "Peer-to-peer of any kind."
- "Consumer drop-in center."
- "Consumers determine staff hiring and firing."
- "Committed community."
- "Recovery community needs to get buy-in and partnerships with larger
- community."

- "Without transportation (rural area) drop-in center keeps us from being isolated."
- "Variety of peer-directed services or peer support." Variety was emphasized in
- terms of individual preferences and what works for particular regions based on population, transportation options, degree of support and respect of providers or county, etc.
- "Community involvement along with peer operation." -"Compassionate tolerance."
- "Taking money out of acute care and giving it to Consumer/Survivor/Ex-patient
- prevention." Focus on prevention and support rather than waiting for things to get to the crisis stage.

What doesn't work?

- "Treatment providers being seen as the only 'experts,'" Consumers are the experts on their own lives and situations. They know what they need, and what would help them move toward recovery.
- "Not enough [peer support programs]."
- "Lack of (or too little) structure."
- "Over-controlling providers."
- "Not having alternative treatments." -"Medical model."
- "Elevating peer support to be all/end all." One consumer expressed concern that
- drop-in centers tended to segregate and "ghettoize" mental health consumers.
- "No place to go for peer counselors (no jobs)." Concerns were expressed that some drop-in centers train peer counselors, but that there are no paid positions or structured volunteer positions to put those skills and knowledge to use.

What else do you need to know?

- "I'm hopeful, but need more info."
- "Where to find money [for these programs]!"
- "Funding streams and more examples of structures." Consumers need more
- information on various models of peer support and peer-run services that can be tailored to meet the needs of particular groups.
- "How to get more ALL-CONSUMER councils, committees, boards."
- "Where can we find a directory of peer-led, peer-driven, peer-directed services?"
- "What else is available when folks from group homes have to leave their "homes" all day long?"
- "Developing peer-services based on what each county/constituents need!"

4. Family Education & Support

What works?

- "Early intervention in cases of abusive/controlling parents."
- "Understanding trauma within families."
- "Consumer/Survivor gets to define "family" [for themselves]."
- "Change 'family' to 'personal support system.'"
- "Consumer/survivor should be primary voice for family education."
- Family education and support can be a good thing *if* the consumer gets to: define who "family" is; decide whether they want biological family members involved; .and consumers get to take the lead on education (rather than education being provided by clinicians or family members about what consumers need- consumers need to be seen as the experts and potential trainers in terms of education.)

What doesn't work?

- "Giving control to families."
- "Losing fact that most families do care."
- "Using it as a means to create a 'compliant kid."
- "Having to give up parental rights of children."

What else do you need to know?

- "How to create loving parents."
- "How or what do we want to educate the next generation -more education about mental illness in schools to develop better educated families."

5. Intensive Community Support

What works?

- "Specialized MH courts with trained judges and good values." There was discussion and disagreement about the usefulness of mental health courts, and more information dissemination about them would be helpful. People were confused by the role of .these courts and the degree to which they could be beneficial of harmful depending on their philosophy, purpose, procedures, training for staff, etc.
- "Being offered a menu of services, greater flexibility in choosing what works for the individual." .
- "More education for the judicial system."
- "More responsible legal system."
- "Education for all!"
- "Supports that work-support the individual."
- "Have real relationships with people."
- "Community acceptance."

- "True and lasting community for the individual; sense of belonging and personal
- worth! empowerment. "
- "Community outreach [to encourage better understanding of mental health issues and to create more respectful attitudes towards consumers] ."
- "Taking care of helpers (workplace democracy)." Create more support for people who work in the field so they have the resources and support they need.
- "Stigma busting. NAMI."
- "Building community and authentic friendships."
- Questions were raised during discussion about the definition of "community." (Community of peers? Peers and providers? The community at large?)
- Intensive community support might be desirable fit is created and defined based on what consumers define as relevant and helpful (rather than being based on existing ACT models that are perceived as coercive).
- Desire for more community education to foster greater support, respect, and community inclusion.

What doesn't work?

- "Without the ability to have autonomy, recovery cannot happen."
- "Lack of knowledge by community about mental health issues."
- "No [support] system in place after you get out of legal system and re-enter community."
- "ACT" (Assertive Community Treatment)
- "Mental health courts-judges may not know mental health issues."
- "Paid friendship."
- "Institutional support."
- "Low wages."
- "No benefits."

What else do you need to know?

- "Why the money can't follow client and client empowerment."
- "Why is the money poured into [psychiatric] drugs instead of real supports?"

6. Supported Housing

What works?

- "Section 8 vouchers which allow some contribution by consumers."
- "Non-infantilizing assistance."

- "Housing without punitive consequences."
- "Housing facilitation/management as non-intrusive. Training for house
- managers." .
- "Preference for Section '8 vouchers-no waiting list for disabled or disabled homeless."
- "Funds to guarantee apartment condition in case of damage."
- "No discrimination."

What doesn't work?

- "Landlords who believe that 'leopards don't change their spots' and the laws, statutes, regulations that do not attempt to educate them."
- "Collusion between landlords, law enforcement officers, and realtors (re: eviction)."
- "Coercion and programs required to keep apartment."

What else do you need to know?

- "Why is there no disabled home ownership? Section 8 Program does not support single, individual home purchase."
- "Where can one go to advocate for more housing?"

Dual Diagnosis Treatment

What works?

- "Peer to peer support groups."
- "A proper diagnosis."
- "Accepting that 'consumers' can, will, and should use alcohol and drugs as much as 'normal people. "

What doesn't work?

- "Mental health and addiction agencies/groups not working together!"
- "Separate funding streams."
- "Moralizing, punitive, and 'abstinence' values and behaviors. Not only can we live, work, and seek inclusion, we can party and have a good time without anthologizing judgments."

What else do you need to know?

- "How to create communication between programs."

8. Self-Directed and Brokered Services

What works?

- "Community support."
- "Creating maps for your process." .
- "Person-centered planning."

What doesn't work?

- "Assuming what a customer might want or need."
- "Too intrusive when case managers are involved."
- "Peer review."

What else do we need to know?

- "Where's the money?"
- "How to set one up in other cities/counties?"
- "Ways to get person-centered planning to more people!"
- "More on PASS plan!"
- "How do we replicate EI Brokerage in other areas of the state? Funding?"

Supported Employment

What works?

- "IPS (Individual Placement and Support)"
- "All social work assumes roles in community (work, schooling). Need culture shift."
- "Normalized social role."
- "Being employed." Recognition that having a job can make a huge difference in a person's life.

What doesn't work?

- "One faction of a program that handles" employment. Empoyment as outreach to few deemed worthy of employment."
- "Social Security, PASS, and Ticket to Work are a failure which can be statistically proven."
- "Unsafe workplaces."
- "Toothless EEOC and BOLl."
- "Being a stand alone program." Suggested that supported employment be better integrated with other services.
- What else do you need to know?
- "Why supported employment continues to be determined by administrators and not CSX (consumer/survivor/ex-patients)."

- "How to shift funding to allow folks to get employment -an 'employment center."
- "Ways to create cottage industries or entrepreneurial ventures."

Key Themes from the Consumer Caucus

- We are individuals. We have different needs and goals. We define recovery differently from one another. The system needs to be flexible and respectful of our individual needs and circumstances.
- We want to be respected as people, as adults, and as experts on what we need in order to recover.
- We want to define what recovery means to us as individuals. We want our individual definitions to be respected by people in the mental health system that work with us.
- We want people in the mental health system to work *with* us, not *on* us.
- If we've experienced trauma that we feel is relevant to our mental health issues, we may want to be able to talk about that trauma in order to heal. Don't silence our voices because our experiences are difficult to hear or because you don't think it's relevant.
- We want as many options, alternatives, and resources as possible. We want to be educated on what is available and we want to know how to access what we need.
- Finally, we not only want to be empowered, but we want power within the system. We want to be seen as experts with valuable input, and not as tokens. We want the power to develop policies to veto decisions that we find inappropriate or coercive; to sit on boards with fellow consumer peers and advocates; and to comprise more than a majority of the seats on those boards. We want to have a say in the hiring, firing, and training of mental health staff.

Recommendations to the Stakeholder Group

- Dignity arid respect must be foremost!
- All "coercive" methods need to be re-examined.
- More consumers on *all* councils and boards (including state review boards). ("More" refers to no less than 55% consumer representation.)
- More medical doctors. **(Do we want to keep this comment? This was one person's comment, but I don't know if there was any kind of consensus around it...)**
- More proactive outreach to consumers. Instead of consumer/survivors going to Salem, Salem needs to reach out to drop-in centers or wherever consumer/survivors are.
- Employment issues and SSA benefits need to be addressed. If a consumer feels well and is able to work for a period of time, they need to be able to quickly and easily re-apply for benefits if they have a period in which they are unable to work. Consumers shouldn't be penalized for working or have difficulty getting benefits during times when they are unable to work.
- Make laws more understandable. [?]
- One stop shopping for peer-operated services. For instance, supported employment services should be located in a place where other peer-directed services are offered. Similarly, all evidence based practice services should be located in one place.
- Create an all-consumer council that would have the authority to approve or veto each EBP suggested for implementation by OMHAS.
- Spread resources equally across the state.
- More education about options and resources available to consumers.
- Initial concern about move to EBP, but rhetoric so far by OMHAS has been positive.
- Define the terms used! ("Family," "recovery," "person-centered planning," etc.).
- Statistics can be manipulated to support anything. Consumers are aware of anecdotal evidence and know what works for them based on their own experiences-this needs to be acknowledged and validated.
- Because of Olmstead Decision, EBP can't have final grade. The final grades will be the level that EBP has brought the consumer/survivor to full participation and inclusion in the community. [?]
- Communication should be clear. Do not use jargon or acronyms that have not been clearly defined.
- EBPs need to be understood by regular doctors as well as mental health providers.