The Environmental Change: Medical Model to Recovery-Oriented Services

As the public mental health system moves toward a recovery-based system, the value of persons with lived experience (those with experience in the public mental health sector as clients, caretakers, or family members of clients) has increased greatly. The Mental Health Services Act holds consumer and family member participation as one of its core values. As those in the public mental health system start implementing this value, who, exactly, these people with lived experience are, needs to be defined. In order to recruit, hire, and retain people with lived experience, a definition that is commonly accepted must be constructed. The ultimate goal is to provide services leading to the recovery of an individual. This paper examines the current status of definitions and suggests next steps in developing a common core definition for consumers and family members.

Without consensus in the definition and application of terms, California will continue to struggle to develop employment practices and policies that give each potential client and family member employee fair consideration. As well, counties and agencies stymied in defining eligibility terminology for consumer and family member employment goals, may also experience a distraction from consideration of other essential qualifications for employees, including those who may be consumers and family members and developing meaningful (for both employee and employer) employment opportunities.

The lack of consensus in self-definition among individual clients and family members is mirrored within the consumer and family movements at the state and national levels. California’s mental health stakeholders do not currently have a consistent understanding of the terms or how to apply them. As a result, county mental health departments and other public and private mental health entities use their own definitions to make decisions regarding employment. The recovery process dictates consumer and family member employment within all levels of the system and as the number of consumers and family member employees grows, the impact of definitions is increasing. Consistent definitions can help in knowing whom to recruit into the workforce as well as sharing best practices in recruiting this target population. Once consumers and family members are employed, they may require some support. Knowing who is being targeted for employment will allow employers and other stakeholders to provide support from peers and others in the workforce. Clearly defining who is being sought by employers also helps employers to consider programs which the employee may be eligible for which support successful employment, such as supported housing.
Identifying Current Terminology

Individuals from the California Network of Mental Health Clients, NAMI California, United Advocates for Children and Families and the California Institute for Mental Health were interviewed as representatives of statewide nonprofit organizations that provide services and supports to adult and child clients and their families. Leaders from these organizations make up the Working Well Together collaborative (WWT), which was formed by the California Department of Mental Health to establish a statewide Training and Technical Assistance Center that will provide resources for consumer and family member employment in the public mental health system. The primary goal of the WWT is to ensure that public mental health agencies are prepared to recruit, hire, train, support and retain multicultural clients and family members as employees. County agencies, community-based organizations, clients and family members involved with the WWT envision a client and family driven, recovery-oriented public mental health system built in part on a foundation of employing diverse clients and family members.

Interviews with representatives from the WWT collaborative elicited some consensus about preferred terms for identifying those who use mental health services and their family members. The terms “client” and “consumer” were preferred over such alternatives as “survivor” and “ex-patient.” At the state level, there is some variation in the terms used to describe individuals receiving services, but “client” is used by both the Department of Mental Health and the statewide consumer organization, the California Network of Mental Health Clients. California’s Mental Health Services Act, in its Code of Regulations, presents a legal definition of client: “‘Client’ means an individual of any age who is receiving or has received mental health services. As used in these regulations, the term ‘client’ includes those who refer to themselves as clients, consumers, survivors patients or ex-patients.” The terms “consumer” and “client” often compete for ascendancy in agencies and organizations, and both are considered to have active and passive as well as positive and negative connotations.

Equal to the intense interest in defining terms related to consumers is an interest in delineating the characteristics of individuals who are the primary caregivers of children and adults with serious mental health conditions. The representatives of WWT found that the term “family member” was generally preferred over such terms as “parent” and “caregiver.”

“Family member” is frequently used in connection with the term “consumer,” as in family member/consumer organizations. Oscar Wright, Chief Executive Officer, United Advocates for Children and Families, quotes the following definition of “family member”: “A family member is any individual who is now or was in the past the primary caregiver for a child or youth with a serious mental health condition who accessed services, particularly public services, for that condition. Families who have children and/or youth with a serious mental health condition can take a wide variety of forms. Families can include biological, adoptive, grand- or foster parents, siblings, other kinship caregivers, friends and others.”

Dede Ranahan, MHSA Policy Program Manager for NAMI-California, gave this description when asked about the nature of a “family member”: “Some say it should be immediate family members, parents, foster parents, siblings, grandparents—whoever is responsible for helping the child get mental health services and taking care of most of the other aspects of their life. It’s the child’s caregiver. It’s someone who on a day-to-day basis is involved with helping the individual meet the needs of their life, particularly those involving the public mental health system.”
In addition to family members, SAMHSA’s National Mental Health Information Center recognizes that many children have “key supporters who are not family members: they often use the term family and other supporters as well as family advocates.”

**Developing Accepted Definitions Through Leadership**

Clear, comprehensive definitions acceptable to a wide range of counties, agencies and organizations require making distinctions between consumers and family members. This requires leadership in balancing the diverse perspectives in consumer and family member employment.

Developing acceptable definitions involves designating leadership of the process and balancing the interests of groups of stakeholders—interests that may be in competition when it comes to employment. The logical extension of a consumer’s and family member’s right to drive their own and their family member’s services is their right to lead the process of defining the terms that will affect their employment. Since the interests of various clients and family members differ, deliberate effort should be made to ensure that a representative range of stakeholders is involved in the decision-making process. Members of the decision-making group should represent a culturally diverse spectrum. The group should include clients with lived experience in all domains, as well as the family members of both children and adults.

Once questions of leadership, balance, and representation are addressed, decision makers can move forward to focus on the ramifications of definitions in relation to qualifications, career ladders, mobility, stigma, and other issues. Those engaged in the process of defining the terms “consumer/client” and “family member” may want to consider the ways in which definitions may create advantages for some potential employees and disadvantages for others. For example, traditionally unserved and underserved cultural communities may be overlooked as consumers if they have never participated in receiving mental health services - despite having mental health challenges. Because of historical injustice, different individuals may not have had access to receiving public mental health care, but still may possess important qualifications to consider for employment - perhaps *because* of their experience and first hand understanding of the impact of lack of access to culturally appropriate care.

**Challenges and Concerns: Finding and Using Common Ground**

A number of issues and concerns related to definitions of terms have arisen in relation to the employment of clients and family members in the mental health system. Among those are a concern about how lived experience should be evaluated and how cultural diversity will be a factor.

The term “lived experience” has been used to characterize potential client and family member employees whose experiences are likely to match up to individuals currently receiving services. When asked about the importance of lived experience to hiring practices, Gwen Lewis-reid, former Interim Executive Director of the California Network of Mental Health Clients, asserted that it is “absolutely essential.” She continued, “It is a bona fide occupational qualification in this instance. You can’t say you’ve been there and done that if you don’t have lived experience. People can learn other things, how to document or lead a group, but they can’t learn the experience of homelessness, for example, if they haven’t been there. Knowledge of issues of client culture is essential.”

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If you’re hiring for a peer-designated position, do not hire anyone without lived experience as defined by clients themselves. Lived experience is the essential piece of the puzzle to hiring clients. It adds extra cache to any position within the mental health department, center or agency. We have been proposing that any job announcement contain words like these—‘Persons with lived experience are encouraged to apply.’”

The term “lived experience” allows the employer to respect the individual right to medical privacy while still gaining the benefit of employees with this experience. It also allows the employee to freely volunteer information without feeling required to do so.

Differentiating between kinds of lived experiences in order to make hiring decisions may also be important. For example: having received Public vs. Private services, voluntary vs. involuntary care, or even by diagnosis. According to Donna Matthews, MSW, California Institute for Mental Health, “Defining terms is helpful to ensure that different people have a consistent understanding about what is meant by certain labels. It’s important, in defining terms, to realize as well that people can have different and equally valid definitions for the same label or term. In terms of the employment of consumers and family members within mental health, we always need to think about whether what we are doing (designating positions to be filled by certain individuals) will somehow improve the system, whether it will improve the services individuals receiving care get.”

Matthews is also interested in distinguishing between the importance of mental health-specific experiences and other experiences that might be relevant in peer support positions. She remarks, “When you’re matching consumers or family members with peer employees it would be helpful to think about the degree to which their experiences need to be similar. For example, should a client who is dealing with involuntary commitment be matched with a peer who has had that experience? Or should simply having a similar diagnosis be accepted? In the case of family members, is simply being a family member enough for peer support? The answer will be provided by clients receiving services and to the extent that employers can distinguish what characteristics are most important to those being served, matching employees with lived experience with clients and families will be optimized. Another important consideration is whether mental health-related experiences are the only relevant ones. It may be that cultural experiences, like sharing a language, being the same gender, having the same sexual orientation, or being the same ethnicity are equally important.”

In addition, the term “lived experience” can be contrasted with the phrase “individuals experiencing mental health issues.” Both phrases can be used to make distinctions among individual consumers seeking employment.

According to Matthews, “If, for instance, a county decides that ‘lived experience’ assumes having a diagnosis or having received public services, then the terminology ‘individuals experiencing mental health challenges’ may be used as a more inclusive term if a county wants to embrace those who have not been given a diagnosis and yet may possess certain qualities that make them a match in terms of their experience having mental health challenges.”
From the perspective of potential employers, defining “lived experience” in opposition to a phrase such as “experience with mental health challenges” may help in setting the parameters of peer-related job descriptions.

Definitions of terms related to clients and family members should note the high degree of diversity among clients and family members. Few would dispute the benefits clients and families receive from being served by individuals who have a particular understanding of their cultural attributes. Areas of difference involve social and political categories (including age, gender, socioeconomic status, religion, race, ethnicity, sexual orientation and identity, mental health status and more.) As a result, the needs and preferences of consumers and family members are diverse and varied. The unique characteristics of individual clients and cultural groups should be considered in the employment of consumers and family members and those individuals and communities should be engaged as leaders in determining who will provide services to their peers.

Considerations of knowledge and verification of client or family member status needs to be addressed when selecting terminology. Medical privacy laws around employment preclude many agencies from asking questions about client or family member status during the hiring process. Addressing nondiscrimination in the hiring process, the Americans With Disabilities Act (ADA) states that, “An employer may not make any pre-employment inquiries regarding disability, but may ask questions about the ability to perform specific job functions and may, with certain limitations, ask an individual with a disability to describe or demonstrate how s/he would perform these functions.“ How can employers balance hiring a workforce that possesses the unique job qualifications of clients and family members while respecting employment law and individuals’ rights to medical privacy? Understanding these legal boundaries within employment hiring practices, it may be a worthwhile consideration to explore the use of terms such as “lived experience.” Beyond that issue, for employers who may utilize consumer and family member-specific language in recruitment and hiring, how do employers then verify a diagnosis and how do they proceed if verification is not possible?

The Next Steps

Clients and family members possess experiences that position them to provide services for other consumers and/or family members that is greatly enhanced because of that history. Achieving consensus across agencies and counties would be a monumental task to be completed in a short amount of time; however, there is an imperative need for a policy to apply to applicants who seek employment to have a clear sense of how they may qualify for targeted positions or be welcomed into non-targeted positions as consumers and family members. While it would be simple to apply a standard definition for all stakeholders to use, such a “blanket” application ignores the person-centered emphasis of the Mental Health Services Act. Stakeholders are instead encouraged to: engage in a process of deliberate consideration of terms they will use; ensure consumer, family member and community consensus on a local level; and then be consistent within local systems. All stakeholders need not start from the same place, however they must be deliberate in what they do. This will allow for tracking of progress towards a goal of improved services with public mental health. Working Well Together will track the challenges posed, as well as successes, as all stakeholders grapple with the terminology that fits best based on their own consumer and family member community. These best practices will be shared on a statewide basis.

Consideration for socioeconomic status, culture, gender and sexual orientation as well as the type of mental health services received (public, private, voluntary, involuntary, inpatient, outpatient) are critical to include in stakeholder decision making processes to assure the multiple identities of consumers and family members being served and to get a good balance of viewpoints.
Some questions to consider with stakeholders are:

- What constitutes mental illness--is it above and beyond medical necessity?
- Does a consumer have to have experience in public mental health?
- Does a family member have to be the primary caregiver of the consumer?
- What, if any, verification is needed to ensure status?
- If verification is needed, what would serve as appropriate verification?
- How might lived experiences translate into enhanced job-related qualifications that only consumer and family members may be likely to have?

In conclusion, this paper has attempted to collect currently used definitions of client/family member and lived experience for review. Following is a table of the data reflecting current definitions of prominent organizations. Regions are encouraged to review and identify those elements with which they may agree. Beyond the definitions, however, Working Well Together encourages - and supports the counties and agencies in anticipating - the next question: Once employed, how are consumers and family members valued and supported in bringing their unique perspectives and qualifications to bear in system improvement measures as well as service delivery?

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<thead>
<tr>
<th>Organization</th>
<th>Website</th>
<th>Consumer/Family Members</th>
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<tbody>
<tr>
<td>Substance Abuse and Mental Health Services Administration (SAMSHA)</td>
<td><a href="http://mentalhealth.samhsa.gov/consumersurvivor/listserv/020906.asp">http://mentalhealth.samhsa.gov/consumersurvivor/listserv/020906.asp</a></td>
<td>The term “consumer” should be understood to mean those people who are receiving or have received mental health services either voluntarily or involuntarily and in that context, “consumer” is intended to include those who refer to themselves as survivors, ex-patients, ex-inmates, clients, users or other similar terms.</td>
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<tr>
<td>National Mental Health Consumers’ Self-Help Clearinghouse (NMH-CSC)</td>
<td><a href="http://www.mhselfhelp.org/about/index.php">http://www.mhselfhelp.org/about/index.php</a></td>
<td>Consumers--those who receive or have received mental health services--continue to reject the label of “those who cannot help themselves.”</td>
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