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# Redefining Consumer Roles

## *Changing Culture & Practice in Mental Health Care Settings*

Concerns regarding the use of seclusion and restraint (S/R) date back to the 1970s when ex-patients, then called liberationists, began to question the medical model of mental illness and protested against treatments they felt had been harmful. They demanded the right for people to speak for themselves and simultaneously began to talk about the establishment of their own self-help alternatives to medically based treatment. Their efforts continued as more ex-patients became involved through newsletters, grass-roots organizations, and conferences. With little or no funding, these ex-patients met informally in their homes, churches, or community centers to organize and provide mutual support. These informal gatherings later became formalized as drop-in centers after they began to receive funding and developed structures for self-governance (Chamberlin, 1990; Van Tosh & Del Vecchio, 2000).

By the 1980s, the federal government recognized these efforts and sponsored the first

Alternatives Conference in Baltimore, Maryland, which approximately 400 people attended. The attendees represented a wide range of perspectives and political ideologies, as reflected in the terms they used to describe themselves (e.g., inmates, survivors, clients, consumers, ex-patients). They selected the word “consumer” to describe themselves, but not without continued discussion and disagreement. Today, some people add the word “survivor” to this term, usually to indicate they survived the mental health system. Still others prefer not to use the term consumer at all.

The most important outcome of this conference was the validation of the value of peer support and self-help. In the 1980s, the National Institute of Mental Health’s Community Support Program provided nearly \$5 million to fund 13 consumer-operated demonstration programs (Van Tosh & Del Vecchio, 2000). In 1994, the same branch of the government

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funded a second technical manual to provide mental health clients with guidelines in accordance with the values of self-help (Harp & Zinman, 1994). Today, consumer/survivor providers (CSPs) are involved in all aspects of the public mental health system, perhaps most notably as mandated members of the federally funded state mental health planning councils.

There have been many accomplishments in building the legitimacy of consumer roles in their own care, and in the mental health system in general, during the past 30 years. Self-run consumer programs are being funded at increasing rates, and more recently, training programs for peer specialists are creating new job markets for consumers in a variety of treatment settings. Georgia was the first state to find a way for peer support services to be reimbursed by Medicaid (Riefer, 2003); other states are beginning to follow. Still, the inclusion of CSPs as “full partners” or as staff members in public mental health provider organizations remains limited, as is their involvement in private settings.

### **THE ISSUE OF SECLUSION AND RESTRAINT**

The use of S/R was discussed at a national, historic Dare to Vision Conference in 1994, which focused on the issues of women with histories of sexual abuse and trauma to examine whether current mental health treatment, including the use of S/R, was re-traumatizing. Many consumers and professionals had voiced calls for reform and demands to ban these dangerous and frightening interventions for years, but were largely ignored (Human Resource Association of the Northeast, 1995).

In an exposé published in *The Hartford Courant*, Weiss, Altamari, Blint, and Megan

<b>GLOSSARY</b>	
<b>Term</b>	<b>Definition</b>
<b>Clinical support</b>	Medically oriented services (e.g., medications, therapy) provided by professional providers.
<b>Consumer advocate</b>	Self-identified person whose services focus primarily on rights protection and education, complaint mechanisms, and measurement of satisfaction/dissatisfaction with services.
<b>Consumer/survivor provider (CSP)</b>	Person with a history of mental illness and psychiatric experience who works in the mental health system to provide specialized services.
<b>Peer specialist</b>	This is the most common term used for consumer/survivors who deliver recovery-based services to other consumers in a variety of mental health settings. Ideally, individuals are trained and certified in skills building and problem solving, conducting support groups, and other skills prior to taking these specialized positions.
<b>Peer support</b>	System of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement on what is considered helpful.
<b>Peer support services</b>	These services may include, but are not limited to, facilitating support groups, individual friendship/support, recovery information, helping with community integration, recreation, and assistance with activities of daily living.

*Note: These terms are common but vary greatly in different states and communities. For example, in some states, the word "consumer" is no longer used, and people are defined simply as "people."*

(1998) highlighted the issue of S/R and facilitated rapid changes in health policy that continue to this day. The investigators conducted a 50-state survey, which found that, from 1988 to 1998, 142 consumers had died during or after the use of S/R (Weiss et al., 1998). Laura Prescott (2000), a survivor of S/R, strongly believes these interventions are forms of coercion and that the words themselves convey dominance and control (2000). An advocate for the elimination of S/R, Prescott (2000) stated, "Violence only teaches violence and indifference, never kindness and compassion" (p. 99).

Across the United States, consumer groups and advocates are pressing for new policies to make S/R use safer and, more important, encouraging its reduction and eventual elimination. Consumer/survivors have consistently identified the need for culture change in inpatient treatment settings. They cite pervasive practices characterized by control, paternalism, and a general lack of respect (National Executive Training Institute [NETI], 2003). Examples of using S/R as punishment for breaking simple rules or disobeying staff members are prevalent. The literature supports these beliefs,

showing that S/R is often used as a consequence for behavior deemed either "bad" or "non-compliant" and, even worse, before "unacceptable behavior" has reached the level of imminent danger (Huckshorn, 2004; NETI, 2003). In addition, staff in many inpatient treatment settings still do not discuss S/R incidents with either the patients involved or witnesses to the event.

A concerted effort to include consumers as partners or staff members in all levels of mental health treatment facilities may help resolve this situation. Many consumers, as well as a growing number of non-consumer professionals, believe treatment environments that encourage inclusion of consumers as full participants in their own care would discourage conflict and violence, thereby reducing the need for and use of S/R (NETI, 2003). Indeed, recognition of this idea is demonstrated in the 2004 *Joint Commission Standards for Behavioral Health Care*, released by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) (2004-2005). Influenced by consumer/survivor input, the JCAHO developed this new standard that expects S/R staff training models to incorporate the viewpoints of individuals who have experienced S/R and that, whenever possible, consumer/survivors contribute to the training curricula and participate in staff training and education activities (JCAHO, 2004-2005).

**CONSUMER/SURVIVOR ROLES IN INPATIENT SETTINGS Advocates**

The roles that have emerged for CSPs working in inpatient settings are not as numerous or varied as in other areas of the

mental health care system. Positions are created for “advocates,” but job qualifications do not always require, or even encourage, consumer/survivors to fill such positions. While many consumer advocates do not yet feel comfortable self-disclosing their consumer status, there are some who have found that self-disclosing has been a great advantage in working with people with psychiatric histories.

An excellent example of this is Pam Trammell, an outspoken advocate for many years, who has worked in a forensic hospital in Alabama as a disclosed consumer/survivor advocate. She is a frequent presenter at conferences and often comments about her experiences when she was first hired. She states:

They weren't looking for a consumer, but once I was hired, I was open [about my consumer/survivor status], mainly because I was already public in my advocacy activities. Some people did not feel that I should have gotten the job, and [they] challenged it, but in the end, my being open was an extra benefit to my clients and put us all on an equal playing field. (P. Trammell, personal communication, April 28, 2004)

Trammell admits that one takes risks when self-disclosing as a consumer but points out that if accommodations are ever needed, disclosure is required under the Americans with Disabilities Act of 1990.

As advocates, CSPs can assess clients' satisfaction with services through direct interviews or in dialogues with small groups using techniques similar to those used in focus groups. The questions are generally kept simple, although specific questions may be added to obtain particular information. Clients are asked what they feel good about, what they feel dissatisfied about, and how they would

like to promote change. This process differs greatly from the typical written surveys that use “checkmark” answers and seldom include any measures of dissatisfaction. Questions may be added to request specific types of information, such as that related to issues of S/R, feelings of coercion, and the availability of choices. The information gathered may be used to make changes in policies and treatment.

While there are many drop-in centers located throughout the United States, one center in South Florida is unique in that it is located on the grounds of a state hospital. Ilisa Smukler, an attorney of 15 years, as well as a self-defined consumer, was asked to comment about her dual role as resident advocate and director of the Forest Park Drop-In Center. The goal was to learn more about how she combines her roles and what she and her staff are able to provide for individuals in a long-term setting.

Smukler explained that she provides supervision, protects inpatients' rights, and promotes recovery in a supportive, educational, recreational, and therapeutic environment. Approximately 75 to 100 individuals are served daily in the center where self-selected recreational services (e.g., a pool table, ping pong, table games, television) are provided after regularly scheduled treatment hours and on weekends. In addition, Smukler stated:

In my role as advocate, I am able to act as a voice for the residents and as a conduit between the residents and administration. People served in the hospital know that I, and my team of peers, am available to them to answer their calls or to meet with them to listen and address their issues and concerns at any time. (personal communication, April 1, 2004)

She also believes the constant contact with residents is the key to building trusting and respectful relationships.

### **Providers**

CSPs can contribute significantly in making changes to the “culture” of an institutional setting, and may participate on treatment teams that make decisions about patients' progress and ongoing treatment plans. CSPs are often more sympathetic to patients, can help make discharge plans more compatible with patients' wishes, and can listen to patients' concerns, which they are able to channel to appropriate sources for resolution.

CSPs can also serve on performance improvement committees to explore new service approaches and establish new policies and procedures. Their firsthand knowledge of systemic deficiencies can enable them to develop fresh remedies and be uniquely creative in developing alternatives that are responsive to patients' expressed preferences and needs (Solomon, Jonikas, Cook, & Kerouac, 1998).

### **Peer Mentors**

CSPs may also serve as peer mentors to patients who have been in institutions for long periods of time and who are ready for transitional planning and discharge back into the community. One successful example of this is the PEER Bridger project in New York state. The PEER Bridger project provides support to patients in institutions beginning 3 to 5 months prior to discharge, and continuing 6 months to 1 year afterward in the individuals' homes or residential settings. The staff may conduct peer support groups, teach living skills, direct people to community services and natural support systems, and offer friendship—possibly the

most important contribution to successful transition.

Mike Friedman, now an advocate living in Washington, DC, was asked to comment about the New York PEER Bridger project, for which he had previously served as director. Friedman had also worked collaboratively on several other projects with the author. Friedman was asked to explain what was unique about the Peer Bridger project; how services are delivered differently; and in what special ways the project contributes to individuals' recovery. He said:

PEER Bridgers have the ability to tear down walls of fear that exist in clients and are able to communicate more fully with the individual. Relationship building and trust are key factors to motivate people for release. (M. Friedman, personal communication, April 7, 2004)

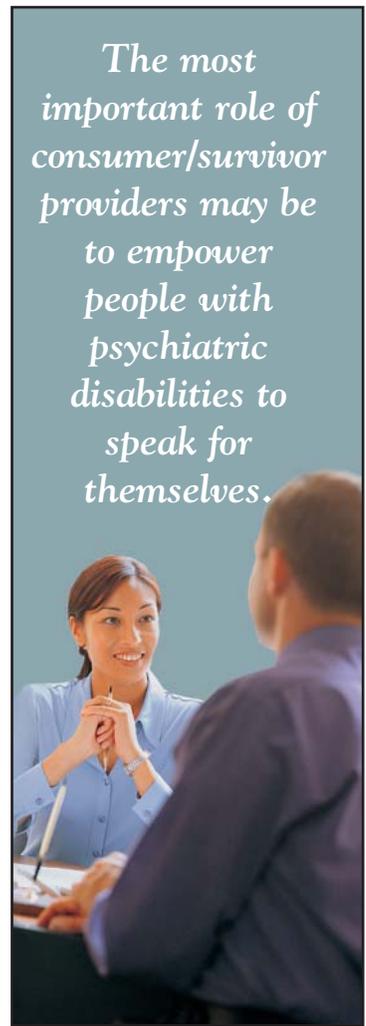
He uses the phrase, "shared experiences equal shared solutions" and explained that a PEER Bridger is always a motivator but does not try to be an expert (M. Friedman, personal communication, April 7, 2004). Friedman also noted that peers are given the luxury to spend time with people, something clinical care staff may not be able to do, which may also contribute to the reason staff do not always communicate as well with consumers. Another aspect of being a PEER Bridger is the development of relationships with clinical staff. This allows them to serve more effectively as liaisons between consumers and staff (M. Friedman, personal communication, April 7, 2004).

### **Volunteers**

Many CSPs are integrated into the community in volunteer capacities. These may include commonly known services and supports such as Schizophrenics Anonymous and Double Trouble

in Recovery. Peer-provided wellness education models include the *Wellness Recovery Action Plan* (Copeland, 2002) and PEER-to-Peer training (National Alliance for the Mentally Ill, 2003).

In addition, external advocates from protection and advocacy agencies are often people



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with disabilities, who provide advocacy and reporting mechanisms to people in institutional and hospital settings. Very often, all of these programs work together to develop, build, and enhance the capacity for peer services (NETI, 2003).

### **Summary**

Ultimately, the most important role of CSPs may be to empower

people with psychiatric disabilities to speak for themselves. Traditionally, people with psychiatric histories have been deemed incapable of maintaining control over their own lives. Empowerment infuses individuals with a sense of self-worth and belief in their capacity to "do for themselves" (Ridgway, 1988, p. 247).

Recently, the concept of recovery has received increased attention. Research studies and collections of consumers' first-person narratives have shown that people can return to complete and empowered lives in full recovery. Ralph, Lambert, and Kidder (2002) have conducted much research on this issue. They asserted that:

There is a great deal of interest in recovery throughout the mental health community. Consumers of mental health services who discover that there is such a concept are given hope that they can reach some level of normal life. (Ralph et al., 2002, p. 2)

The President's New Freedom Commission on Mental Health (2003) devotes sections of its final report to explaining the goal of a transformed mental health system based on recovery. According to the report:

In a transformed system, consumers and family members will have access to timely and accurate information that promotes learning, self-monitoring, and accountability. (The President's New Freedom Commission on Mental Health, 2003, *The Goal of a Transformed System: Recovery*, ¶1)

Daniel Fisher, MD, PhD, the only self-disclosed consumer member of the Commission, is working on specific steps and goals to help create this newly transformed system, based on a recovery culture through consumer leadership (Fisher & Chamberlin, 2004).

## **CONSUMER/SURVIVOR CONTRIBUTIONS IN REDUCING S/R USE**

The presence of CSPs contributes both directly and indirectly to creating cultural change in institutional settings. Their ability to relate to patients often results in unique, trusting relationships that may reduce future crises. In addition, CSPs may be able to prevent crises through their more frequent interactions with patients exhibiting “problematic behaviors.” Their own experiences can produce greater tolerance and openness in such situations, and their ability to provide a different interpretation can provide a more sympathetic perspective of a situation and make it possible for patients’ voices to be heard.

Even their definitions of “crises” may differ. Whereas clinicians may talk about decompensation, people with psychiatric histories may see crises as opportunities for growth (Mead, 2003). Mead (2003) believes crisis can be a healing force, and that something meaningful can be learned from each crisis, an experience, she states, that “will enable us to do it differently and understand ourselves in new ways” (p. 2).

When inpatients become upset, CSPs may be more able to successfully divert their attention to activities they have previously identified as helpful on a personal safety or de-escalation form (e.g., taking a walk for stress relief, listening to music, or doing artwork). CSPs may also refer inpatients to a “comfort room,” which is a converted seclusion room used for the prevention of crises. Use of the comfort room is voluntary, and such rooms are creatively designed to provide sanctuary from stress and allow people to experience feelings within acceptable boundaries. The author is an expert in this

area and has been a consultant for the development of comfort rooms in several hospitals throughout the United States (Bluebird, 2004; NETI, 2003).

In the aftermath of S/R use, it is important that CSPs participate in debriefing sessions as patient advocates. Prior to debriefing, they can talk to the patient who was secluded or restrained, to gain an understanding of the patient’s perspective of the experience. This may make a significant difference in the analysis of what actually occurred.

One example of this took place at a public state institution. An inpatient admitted to the hospital left a group meeting without permission and was confronted by staff, resulting in an aggressive incident in the hallway, which caused injuries to two staff members and the patient himself (NETI, 2003). Prior to the debriefing that followed the patient’s seclusion, the CSP learned that the patient did not relate well to men in authority positions and was unable to sit still for long periods of time due to a symptom of his illness. The staff would not have known these facts if not for the CSP. The staff also learned that the patient would have willingly returned to the group if he had been allowed to restore his calm by taking a walk or watching television for a short period of time (NETI, 2003).

Greater CSP involvement in treatment decisions and alternatives to S/R helps staff learn better ways of providing care during crises, including methods emphasizing individuality, dignity, and the attainment of optimum health. According to Taxis (2002), “Consumer providers should be present at all meetings that relate to changes of policy, especially in regards to seclusion and restraint.”

Finally, there are current examples of the significant contributions many CSPs are making in S/R reduction training initiatives or by serving on national policy-making committees. One such individual, Joyce Jorgenson, who previously was a director of an Office of Consumer Affairs in Minnesota, currently is project director with the National Association of Consumer/Survivor Mental Health Administrators (NAC/SMHA). She is developing a consumer-driven training manual for direct care staff in hospital settings under a federal contract from the Center for Mental Health Services within the Substance Abuse and Mental Health Services Administration. This curriculum, titled *Roadmap to a Restraint-Free Environment for Persons of All Ages* (NAC/SMHA, 2003), supports a public health, trauma-informed care model, and offers many supportive and valuable tools, such as peer-delivered services and self-help techniques, with a focus on recovery techniques. The curriculum has been pilot tested in two states and is in the final revision process with the expectation that it will soon be available for distribution (J. Jorgenson, personal communication, April 9, 2004).

The NETI’s (2003) curriculum on S/R reduction is another national, federally funded initiative involving a faculty of experts from across the United States. Faculty members who have expertise and experience as consumers, providers, and administrators of offices of consumer affairs travel around the country providing training sessions to interested institutions. These faculty members include Joyce Jorgenson (see above), the author, and Tom Lane, a national leader and consultant in the area of consumer/survivor leadership.

## K E Y P O I N T S

1. People who have direct experiences are the ones who best know the possibility of recovery from mental illness.
2. The most important role of consumer/survivor providers (CSPs) may be to empower people with psychiatric disabilities to speak for themselves.
3. CSPs' firsthand knowledge of systemic deficiencies can enable them to develop fresh remedies and alternatives that are responsive to patients' preferences and needs.
4. Whereas clinicians may talk about decompensation, people with psychiatric histories may see crises as opportunities for growth.

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### **GUIDELINES FOR HIRING CONSUMERS/SURVIVORS AS PROVIDERS**

According to Solomon et al. (1998), there are several guidelines for hiring CSPs to provide mental health care.

#### **Qualifications**

CSPs should have the necessary qualifications to do the job for which they are hired. Having a psychiatric history is only one of many requirements. Other qualifications may include level of education, knowledge of advocacy issues, past work history, or previous experience related to the job.

#### **Self-Disclosure**

This occurs when a person openly and intentionally discloses a past or continuing history of receiving mental health services, or having been diagnosed with a psychiatric disability. This element is the crucial key that unlocks fear and enables the exchange of experiential knowledge.

#### **Tokenism**

Tokenism refers to a situation in which an individual is hired for a job simply because he or she has a psychiatric history, thus giv-

ing an appearance of inclusion. To avoid tokenism, administrators should avoid hiring only one CSP, hiring just any CSP, and turning to the same CSP for representation in everything.

#### **Supervision**

CSPs in leadership positions should report directly to senior management to facilitate communication and problem solving. Without support from top management, these positions will not be taken seriously and will always be in jeopardy.

#### **Salary and Benefits**

Salaries and benefits should be commensurate with other positions of equal status. Some positions may be created as part time for people who are on disability but should allow for incentives should the individuals wish to transition to full-time work.

#### **Training, Support, and Mentoring**

For CSP hiring to be successful, preparation and training is extremely important for both CSPs and clinicians, to create positive partnerships and smooth working relationships. Training programs have been developed in several states (Collins, Kobzar, &

McDiarmid, 2002; Riefer, 2003; Ryder & St. George, 2003) to enable consumer/survivors to be employed as mental health care service providers, frequently called "peer specialists." Programs for peer specialists offer training in skills building, goal setting, and problem solving, while emphasizing recovery and focusing on promoting each individual's strengths. Training participants can learn the difference between peer support and clinical support and how to conduct peer support groups. They are given information about ethics, boundaries, confidentiality, and client rights. Some states have created mechanisms for reimbursement for recovery services provided by peer specialists (Riefer, 2003).

An excellent example of the work done to guide professional agencies in creating work environments that incorporate consumer/survivors is *Positive Partnerships: How Consumers and Non-Consumers Can Work Together as Service Providers* (Solomon et al., 1998). An entire chapter of this manual is devoted to things agencies can do to create comfortable work environments (Solomon et al., 1998). The work environment, also called the "organizational culture," is evaluated by the administration to identify needed changes, including those related to the mission statement, roles, values, and governing policies of the agency. Agencies should conduct an all-agency assessment of staff attitudes, followed by a review of needed modifications of procedures and practices. Strategies for organizational development may include consciousness-raising, inservice training, and the creation of an organizational plan (Solomon et al., 1998). Depending on the environment and general staff acceptance of working side by

side with CSPs, the CSPs may need flexible access to senior management to facilitate communication and problem solving.

## SUMMARY

The creation of positions for CSPs is a phenomenon with a promising future for the delivery of mental health services. People who have direct experiences are the ones who best know the possibility of recovery from mental illness. They are the only ones who can serve as role models for others, providing them with hope and inspiration. With courage and determination, CSPs will make good partners with non-consumer providers, each needing to listen and learn from the other to work together effectively and to keep the wishes of those they serve as their highest priority.

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## FOR MORE INFORMATION

To obtain more consumer/survivor mental health information, access <http://www.mentalhealth.samhsa.gov/consumersurvivor/>.

This Web site, which is part of the Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, provides updates regarding the involvement of the federal government in consumer/survivor activities and issues.