

Best Practice Guidelines for Consumer-Delivered Services

Developed by

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and Mental Health Association of

Southeastern Pennsylvania Best Practices Team

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Mental Health Association of Southeastern Pennsylvania (MHASP) Best Practices Team consisted of the following persons: Kathie Berkey, John Dodson, Tracy Duckery, Warner Rodgers, Joseph Rogers, Susan Rogers, Chris Simiriglia, Lavonia Waddington, and Jeanie Whitecraft. MHASP is 310-person organization in which consumers have significant administrative roles, ranging from supervisors and program directors to the president of the organization. Consumers also account for more than 50% of the board of directors.

Consumer-Delivered Services (CDS) have become increasingly integrated into formal mental health systems and are viewed as an important approach to expanding the continuum of services available to persons with mental illness, including those with serious mental illness. Many definitions of “consumer” exist. For our purposes we define a consumer as someone who has experienced, or is currently experiencing, symptoms associated with a diagnosable mental illness, and has received services to address these symptoms. CDS are those services where identified consumers interact with other identified consumers in services that are uniquely consumer-delivered (e.g., self-help groups) or as part of services that involve both consumer and non-consumer staff (e.g., case management). We believe that the sharing of personal experience is a critical element of CDS and is part of what make them beneficial. It is recognized that many professionals have personal experiences with mental illnesses but choose not to identify as mental health consumers and do not share their personal experiences as consumers. Services delivered by persons who do not identify as consumers or share their personal experiences as consumers are not CDS. A program or agency where consumers serve only as advisors or on a board is not a CDS.

Many different CDS types have developed over the years. The following typology is useful in appreciating the diversity of these services (see Solomon & Draine, 2001). *Consumer-operated services* are those that are planned, managed, and provided by consumers. *Consumer-partnership services* are those in which consumers deliver the services, but the control of the program is shared with non-consumers. *Consumers as employees* reflect services that employ consumers and non-consumers alike. The aforementioned program types can involve paid and unpaid/volunteer consumer roles.

There are an ever-expanding number of programs where consumers play a specific role in service delivery. Self-help groups, also referred to as mutual-help groups reflecting the notion that help is both given and received, are without a doubt the best-known examples of CDS. Alcoholics Anonymous began more than seventy years ago and is now in many countries around the world. Self-help groups for persons with mental illness emerged in the 1950s; examples include Schizophrenics Anonymous, the National Depressive and Manic-Depressive Association, GROW, and Recovery, Inc. More recent groups have emerged for persons with various anxiety disorders, eating disorders, and other mental health conditions. One study in the mid-1990s estimated that 18% of the U.S. population had participated in self-help groups at some point in their lives and almost 7% had done so in the past year (Kessler, Mickelson, & Zhao, 1997). Self-help has exploded on the Internet, including many listservs, chat rooms, bulletin boards, and other Internet communities devoted to peer support around mental health issues. National and local self-help clearinghouses have been established around the world to disseminate information about the existence and location of self-help group meetings and other types of CDS.

FountainHouse is another well-known example of a CDS. It was founded in the 1950s in New York City by persons with mental illnesses who desired to create a supportive community of peers. FountainHouse gave birth to a clubhouse movement where consumers play active roles in the management and operation of the program. However, with some exceptions, clubhouses have moved from consumer-operated to a consumer as employee model, as they now rarely have consumers in prominent management positions.

Drop-in centers differ from clubhouses in the services and programs that are offered and the degree to which they follow a since-codified clubhouse model. Not all clubhouses or drop-in

centers are consumer-delivered. Some only have paid consumer roles in, for example, the kitchen or for custodial work, and not for providing any unique support or experiential knowledge beyond the scope of these tasks. Consumers support their peers in these settings, but only in informal ways or through other CDS, such as a self-help group that meets at the facility.

A number of other types of CDS have been developed in local communities and mental health systems. For example, there are a growing number of case management services that are wholly consumer-operated or where consumers are one of several members of a larger case management team. Consumer staff have also been added to crisis and respite services, vocational services, one-to-one peer support programs, psychoeducational programs, advocacy, residential services, and supported education. References to articles describing the various CDS can be found in the bibliography.

Theories Underlying Benefits of Consumer-Delivered Services

A number of theories have been used to explain the beneficial processes underlying CDS. These theories are described briefly below. Social comparison theory (Festinger, 1954) postulates that people seek out others with similar illnesses (i.e., peers) in order to help them maintain a sense of normalcy and understanding of the world. Interactions and comparisons with those who are perceived to be better off (i.e., upward comparisons) are thought to increase self-improvement (e.g., develop skills) and self-enhancement (e.g., increase sense of hope and decrease fears) efforts. Interactions with those who are perceived to be less fortunate (i.e., downward comparisons) are thought to be ego enhancing and maintain affect by providing examples of how bad things could be (e.g., “At least I am doing better than Susan” or “At least that did not happen to me”).

Social learning theory (Bandura, 1977) suggests that behavior change resulting from interactions with peers, as compared to non-peers, may be more likely because peers are perceived to be more credible role models and enhance self-efficacy. Persons who are successfully coping with the challenges of the illness provide examples and model appropriate coping and health-enhancing behaviors. The influence of peer support and education concerning treatment and coping issues provided by peer mentors is enhanced by their credibility as "people who have been there" and who understand the full ramifications of what it is like to have the illness. Enhanced self-efficacy occurs as a result of interactions with peers who have had positive outcomes associated with their treatment. Self-efficacy will in turn increase optimism and enforce positive treatment-related behaviors.

Social support is a mechanism that is not unique to CDS, as consumers and non-consumers alike provide such support. However, social support is a particularly important part of CDS, especially self-help groups, drop-in centers, and one-to-one peer support programs. CDS can increase the number of people that someone can turn to for support, the number of supportive behaviors directed toward a person, and perceptions of support. Five types of support are frequently discussed in the literature: 1) Emotional Support (someone to confide in, who provides esteem, reassurance, attachment and intimacy); 2) Instrumental Support (services, money, transportation); 3) Informational Support (advice/guidance, help with problem-solving and evaluation of behavior and alternative actions); 4) Companionship Support (belonging, socializing, feeling connected to others); and 5) Validation (feedback, social comparison).

Another mechanism underlying the benefits of CDS is that it is based on experiential knowledge of an illness rather than "book" or learned knowledge (Borkman, 1999). Both are viewed as unique, valid, and beneficial understandings of the illness. The experiential

knowledge shared in self-help groups, for example, offers alternative worldviews and ideologies to the “patient” role that sometimes results from participation in services based on learned knowledge that are delivered by non-consumers. Self-help groups are thought to offer an antidote to the passivity that may result from participation in services with a hierarchical structure, and diminish the isolation and despair that many experience. Overall, experiential knowledge promotes choice and self-determination that enhance empowerment.

Finally, CDS provide opportunities for consumers to benefit from helping others. This mechanism, referred to as the helper-therapy principle, acknowledges help-giving as extremely beneficial (Riessman, 1965). The power of the helper-therapy principle has been theorized to derive from four benefits (Skovholt, 1974): 1) Increased sense of interpersonal competence as a result of making an impact on another's life; 2) Development of a sense of equality in giving and taking between himself or herself and others; 3) Helper gains new personally-relevant knowledge while helping; and 4) Helper receives social approval from the person they help and others.

Evidence for Consumer-Delivered Services as a Best Practice

CDS have emerged as a best practice based on changing service philosophies that increasingly accept CDS as an important way to expand the continuum of care of beneficial services, as well as a growing, albeit limited body of research that has found consistently positive results for various CDS. The 1988 Surgeon General's Workshop on Self-Help and Public Health epitomizes the acceptance of CDS as important additions to the health care delivery system. This report outlined the benefits associated with self-help as well as strategies for increasing the proliferation of self-help groups as a public health initiative. In 1989, the National Association of State Mental Health Program Directors took the stance that inclusion of consumers in the provision of direct services should be sought to improve quality of care. State and local mental

health systems have responded by providing funding to develop and implement CDS. Federal, state, and local funding have also been provided for technical assistance centers and clearinghouses to offer technical assistance to self-help groups and other CDS, as well as information about the location of groups to potential participants. The addition of consumer staff may also have the added benefit of bringing consumer voices and perspectives into programs and agencies. Consumer voices may alter stigma and negative perceptions of mental illness among non-consumer staff, and improve non-consumer staff attitudes and beliefs about hope and recovery for persons with mental illness. Overall, support for CDS represents a mental health system's commitment to recovery, rehabilitation, and consumer empowerment.

Research on CDS has been favorable (see reviews by Davdison et al., 1999; Humphreys, 1997; Van Tosh & del Vecchio, 2000). In general, research has shown that the addition of consumer staff in service delivery does not diminish treatment outcomes and that certain CDS are associated with positive outcomes. For example, studies have shown that consumer-delivered case management is as effective as non-consumer-delivered case management, and crisis teams involving consumers are as effective as those with non-consumers (Chinman et al., 2000; Solomon & Draine, 1995). Consumer-provided vocational services added to usual care is associated with, among other things, higher employment (Kauffman, 1995). However, it is unclear whether or not similar services provided by a non-consumer would be as effective or more effective.

Studies of drop-in centers have shown that they are associated with high satisfaction and increased quality of life, enhanced social support and problem solving (Mowbray & Tan, 1993). Research on mental health self-help groups indicates that they are associated with decreased symptoms, increased coping skills, and increased life satisfaction among long-term members

versus short-term members (e.g., Davison et al., 1999; Chamberlin et al., 1996; Humphreys, 1997; Raiff, 1984). One unpublished study found decreased rates of hospitalization for participants in one self-help group versus a matched comparison group (Kennedy, 1989). Research on peer support interventions has also been positive. One study found that case management services plus a peer specialist counselor were associated with enhanced quality of life, fewer major life problems, and greater gains in social support for those receiving such services than for those receiving case management services without a peer (Felton et al., 1995). A study of a one-to-one peer support program for persons with co-occurring mental health and substance abuse problems found that program participants had fewer crisis events and hospitalizations, improved social functioning, greater reduction in substance use, and improvements in quality of life compared to a non-matched comparison group (Klein, Cnaan, & Whitecraft, 1998).

The consistently favorable results for CDS lead to tempered optimism about their effectiveness as the research foundation has significant limitations, not unusual for a relatively unexplored research area. The current research base is limited by a relatively sparse number of studies, few replications of findings, and limited use of rigorous research designs. An exciting multi-site research initiative funded by SAMHSA's Center for Mental Health Services is currently underway in an attempt to use more rigorous research methods to understand the effectiveness of CDS. This initiative is called the Consumer-Operated Service Program; more information about this effort can be found at the Web address listed in the bibliography.

Guidelines

These guidelines are based on a review of the CDS literature and the perspectives of CDS leaders at the Mental Health Association of Southeastern Pennsylvania. The Mental Health

Association of Southeastern Pennsylvania currently administers a number of CDS, including, but not limited to: 1) Friends Connection – a peer support program for persons with co-occurring mental health and substance abuse disorders; 2) Mainstream – a vocational rehabilitation program; 3) ACCESS West Philly – a case management program for persons with a history of homelessness; 4) TCM SHARE – a case management program; 5) Community Companion – a volunteer peer support program; 6) Unity Clubhouse; 7) numerous drop-in centers; 8) Homeward Bound – a residential program; and 9) the National Mental Health Consumers’ Self-Help Clearinghouse, which provides technical assistance and other support to numerous CDS. Consumers have significant administrative roles in MHASP, ranging from program directors to the president of this almost 310-person organization. Consumers also account for more than 50% of the board of directors.

These guidelines focus on program characteristics that are either unique to CDS or require specific mention. We do not offer guidelines on, for example, how to provide case management or vocational rehabilitation services. Guidelines for these and other program types are available elsewhere and the involvement of consumers does not alter the general philosophies and approaches underlying these programs. Instead, these guidelines target issues that cut across consumer-delivered program types. Specifically, we focus on two areas – practices as they relate to consumer participants and those pertaining to consumer-providers.

Consumer Participant Guidelines

Target Populations – Aside from specific target populations for specific programs, such as the special consumer characteristics targeted by case management, crisis, or vocational programs, CDS are appropriate for most mental health consumers, regardless of diagnosis or history. This includes persons with significant challenges as a result of their illness. Self-help

groups and drop-in centers have been argued to provide a niche for persons with serious mental illness who have had negative experiences with traditional services and avoid formal care. In this sense CDS are particularly important for targeting those who have become alienated from the more traditional mental health services and may be their only connection to the mental health system.

Drop-in centers can be ideal for persons with significant interpersonal difficulties because there is a wide degree of flexibility in how much they participate in activities and what types of interactions they have with others, yet they still can benefit from taking part in a community. Persons with significant interpersonal conduct problems, including a history of violence, may not be appropriate for drop-in centers, however. These programs allow for a great deal of independence and self-direction, and less supervision from drop-in center staff, which means that potentially explosive situations may not be defused in time. However, it must be recognized that consumer members who are not paid staff proactively and skillfully address the relatively rare interpersonal and intrapersonal problems that do arise prior to these situations getting out of control.

Choice is likely the single most important factor in assessing whether or not someone is appropriate for a CDS. CDS are not for everyone and cannot be prescribed. Research has not been successful in identifying who chooses to participate in CDS, but has been successful in documenting that CDS are not desired by everyone, even when consumers are encouraged to attend. Variation in desire for non-consumer-delivered services also occurs. For example, persons vary in the extent to which they desire medications. This lack of desire is associated with non-adherence. Adherence to psychotherapy and other psychosocial services delivered by non-consumers also varies, at least partly due to differences in desire for the intervention. The

bottom line is that CDS are sought out by some people in the same way that non-consumer services are sought out, and that lack of participation on the part of everyone encouraged to attend CDS should not be perceived as a weakness or indicator of lack of effectiveness. Consumer choice in seeking out CDS should be respected.

Contraindications for use – Based on the discussion of choice, consumers who choose not to participate in CDS should not be forced to participate. We believe that consumers should be encouraged to participate and provided with ample information about CDS options, but CDS participation cannot be prescribed. If a consumer chooses to attend only because it is prescribed, it will undermine how much they will benefit and their potential inclination to participate on their own in the future. Prescribed participation in CDS may also negatively impact CDS environments if persons who have limited interest in participating and who attend out of a sense of obligation or perceived coercion populate them. Otherwise, CDS are generally appropriate for all persons with a mental illness.

Implementation Steps – Paths to the successful development and implementation of CDS are as varied as CDS themselves. CDS have developed both from within and outside the mental health system. Self-help groups are the best example of CDS that have developed and prospered outside the mental health system. Self-help groups consist of persons who have come together in response to various distressing situations, such as the personal experience of an illness or the illness of a loved one. Self-help group leadership and direction come from within the group. Professionals play minimal roles, including referring persons to groups, helping to organize groups, providing space for groups to meet, and occasional assistance in dealing with specific issues. One exception to this general rule is Alcoholics Anonymous and other substance abuse

12-step groups that have become increasingly incorporated into behavioral health care service systems.

Other CDS, especially those where consumers are employees in services that are also delivered by non-consumers, are frequently developed and implemented within the mental health system and receive substantial financial support. The success of these CDS is furthered by non-consumer professional involvement, collaboration, and support that appreciate the unique contributions that consumers can make in these programs. Such support should also be sensitive to the unique operations and benefits of these programs and avoid situations and demands that might lead to changes in critical aspects of CDS programs. CDS that depend too heavily on professional involvement and financing are at risk of losing their unique qualities and benefits. For example, self-help groups that become overly dependent on professional assistance may encounter diminished commitment from group members to take leadership roles as well as the initiative needed to help the group survive. Such groups may be more likely to disband. Communication between and among consumers and non-consumers is critical to prevent changes that diminish the unique qualities of CDS. These unique qualities are what make them an important addition to the continuum of services.

Involvement or Dosing Recommendations – There are no general involvement or participation recommendations for CDS. Specific programs and program types (e.g., case management, vocational rehabilitation) may have recommendations for the level of involvement that is associated with maximum gain. The lack of a general involvement guideline is consistent with the principles of choice and self-determination that are important features of CDS. For example, drop-in center participation varies greatly among individuals. Less frequent users may still benefit because knowledge about the existence of a drop-in center may be empowering and

beneficial even if the person does not frequently utilize the center. One study of participation in self-help groups, however, did show that persons who were more committed and attended the group more often appeared to benefit more than those who did not.

Monitoring of side effects, progress, and problems – Specific programs have their own unique methods, including formal and informal methods, for monitoring side effects, progress, and individual problems. Those programs where consumers serve as employees should have formal procedures for monitoring side effects, progress, and problems that are consistent with the program type. For example, case management teams involving consumer-providers should have a process for conducting reviews of participant status and progress, as well as goal planning. CDS, including self-help groups and drop-in centers, are not focused on the individual member and do not have individual treatment plans to monitor program participants in any formal way. Informal monitoring oftentimes occurs, however. It is not uncommon for self-help group members to speak with another member either as a group or individually if it is felt that the person is having a particularly difficult time. Drop-in center staff or individual participants may similarly speak with a drop-in center participant if they feel that person is not doing well. Informal support may include the provision of emotional support, information, or encouragement to speak with mental health professionals about problems.

Gender and cultural issues – The power of interactions between those with similar or shared experiences is one of the key principles underlying CDS. Gender and cultural factors, as well as diagnostic, personality, interests, and mental health experiences, are important factors that may influence the extent to which CDS are beneficial to a particular individual. Poor matches or “fits” will occur and can diminish the connection made between consumers. CDS that have only one or two consumers involved in service delivery are obviously limited in the extent to which

they can make changes to improve a particular match. Differences that may interfere with the development of a positive relationship should be considered and discussed as appropriate.

Gender and cultural issues are particularly important for any program. CDS emphasize acceptance and cultural sensitivity as core values. Guidelines have also developed over time for how to address gender and cultural issues in self-help groups and one-to-one peer support. Self-help groups often include both sexes, but there are also many same-sex groups for those who desire such groups. Group members often have enough similar experiences to promote connections and a sense of community. They also encourage connection through respect for diversity and have enough common ground within group diversity that friendships among specific members can develop. However, the self-help group movement has been criticized for not promoting enough cultural diversity among group members, especially among non-Whites and low-income persons. There is an increase in self-help groups involving a greater percentage of non-Whites, but more effort is still needed to expand in this direction. An individual's fit with a particular group culture may not always be a good one. Potential self-help group members should be encouraged to attend different groups, assuming there is more than one local group pertinent to their issues, until they find one that they feel comfortable with.

One-to-one peer support programs oftentimes will match on gender and attempt to match on culture as much as possible to increase similarity in personal experiences. Same-sex matching among heterosexual participants will also inhibit the occurrence of sexual relationships, an issue discussed in more detail later in the section on dual relationships. There is no perfect or generalizable formula for producing successful matches in peer support programs. For example, matching persons from similar cultures may be less important in some cases than matching on similar illness characteristics or addictions. Successful programs monitor the extent to which

interpersonal relationships seem beneficial and will make changes if the match is perceived to be inadequate.

Consumer-Provider Guidelines

The following issues generally pertain only to CDS that involve paid consumer-providers. Consumer-provider guidelines are similar to guidelines for non-consumer staff of any program. Hiring, training, and supervisory issues do generally not affect self-help groups and other programs involving consumer volunteers. However, all CDS (and non-CDS for that matter) are affected by dual relationships, including sexual relationships, confidentiality issues, and role conflicts.

Hiring – Recruitment of paid consumer-providers is frequently done through advertisements placed in mental health agencies and other venues where consumers may congregate, as well as in newspapers. Advertisements generally include statements such as “Current and former mental health consumers encouraged to apply.” Substantial recruitment also occurs through word of mouth and conversations among consumers.

CDS involving paid positions generally require at least a high school education to ensure that the employee has some degree of ability to complete paperwork and meet minimal job demands. Volunteer CDS programs generally do not have education requirements. Skills and education may become a bigger issue in the future for CDS that are able to obtain Medicaid and other forms of reimbursement (e.g., managed care). Reimbursement often requires being added to a provider panel that has requirements, such as the need for staff with degrees, certification, experience, and training that are thought to be associated with the provision of a higher quality of care. Such requirements will severely limit the pool of potential consumers who are eligible to be hired. The demand for more formalized education and skills may be important as a strategy

for eliminating persons from the hiring process who may not have sufficient work skills (e.g., ability to do paperwork, maintain attendance, follow directions). This may be an issue for consumers and non-consumers, but it is not consistent with theories underlying CDS that emphasize experiential knowledge of mental illness and the benefits of sharing this knowledge and experiences with others. The bottom line is that more stringent personnel requirements may alter the nature of CDS and diminish their unique benefits.

Training – Programs involving paid consumer-provider staff should have specific training procedures outlining the mission, philosophy, goals, and procedures associated with the delivery of the program. Exceptions to this are CDS involving non-paid persons, including self-help groups and similar voluntary CDS programs, especially those emphasizing companionship. However, even these latter types of programs could benefit from informal training on leadership, organizational, and listening skills. Specific topics for paid consumer-providers should include a discussion of how they can use their personal experiences to build empathy with program participants, and provide emotional support, informational support, and validation. Additionally, training should involve a discussion of issues that might arise in their interactions with non-consumer staff and consumers, especially topics such as dual relationships, role conflicts, and confidentiality, discussed in the next section.

Supervision – As with any human service program, good supervision and monitoring is essential. Such supervision ensures that the program is being delivered with some degree of fidelity and is useful for addressing any issues that may arise, especially personal and interpersonal issues that may affect an employee's performance or the performance of the program as a whole. Frequent team meetings and individual supervision are beneficial in this

regard. Personnel manuals should also thoroughly describe rules and procedures to assist all employees and supervisors in their interactions.

CDS should be particularly sensitive to providing accommodations that are consistent with the Americans with Disabilities Act. While accommodations might not always be necessary, supervisors should provide an environment for discussion of personal and professional issues that might interfere with work and do everything possible to address any issues that arise. Supervisors should also be proactive in discussing dual relationships, role conflicts, and confidentiality. The following discussion of these topics borrows heavily from the excellent article by Carlson, Rapp, and McDiarmid cited in the bibliography.

Dual relationships refers to the existence of more than one relationship, either professional, social, personal, business, or financial, between an individual and another individual or organization. Dual relationships are a concern for both consumer and non-consumer providers. Multiple relationships are a fact of life. Specific concerns related to consumer-providers are the existence of past or current relationships between the consumer-provider and the employing organization or non-consumer staff, and consumer-provider relationships with other consumers participating in the CDS. There are no hard and fast rules for how to deal with dual relationships. The following alternatives might be used to address this issue.

In large urban areas consumer-providers could be hired from outside a particular agency or could require that care be sought from another agency. The former strategy is problematic because it prevents persons from within a particular agency from working in that agency's CDS. The latter solution may be particularly challenging because it disrupts already established care relationships. These solutions are nearly impossible for persons residing and receiving treatment in rural areas. The most promising and acceptable strategy may be that supervision and persons

with whom the consumer-provider does not have a dual relationship should conduct personnel matters.

Dual relationships with consumer participants are also a concern. Consumer-providers should not be required to sever ties with consumer participants who have become an important part of their social network. However, a number of strategies can be used to diminish potential conflicts that might occur. First, those programs that match consumer-providers with a specific consumer participant should avoid matches when a dual relationship involving close, personal contacts has been established. Second, matches should be avoided with persons who reside in the same housing situation or program. Third, supervision should include monitoring of dual relationship issues that might arise over time and steps should be taken to actively address these issues.

The existence of sexual or dating relationships is a particularly important issue to address. Again, these issues are not unique to consumer-providers, as all mental health disciplines struggle with the establishment of professional rules of conduct for effectively dealing with these potentially harmful relationships in service delivery situations. Active sexual or dating relationships are prohibited in more formal CDS, and past relationships prevent the consumer-provider from offering direct services to a person with whom he or she had such a relationship. CDS that are less formal and involve voluntary participation, such as self-help groups, sometimes overtly discourage sexual relationships or dating among members, while others allow discreet romantic relationships. Most recognize that romantic relationships may overly complicate the peer support that is provided and increase the chances that negative or harmful interactions will occur. Sexual relationships are a natural part of healthy interpersonal relationships, but are not part of the mission of one-to-one peer support programs or self-help.

Role Conflicts and Confusion refers to issues that arise for the consumer-provider as a result of assuming an identity that combines their experiences as a consumer with the role of a provider of services. Conflicts with non-consumer staff may arise if consumer-providers are treated as if they are of lesser importance or have less to offer in terms of providing a beneficial service. Non-consumer staff may also treat consumer-providers as if they are “junior staff” or less than equal in terms of skills and ability. Non-consumer staff may even assume the role of “therapist” with consumer staff. These relationships are obviously harmful to all persons involved and can undermine the success of CDS. Consumer-providers are also challenged by the need to balance their consumer and provider identities. That is, they may not be accepted within the provider community as full-fledged providers and no longer accepted as consumers among peers.

One solution to role conflicts and confusion includes the clear specification of roles and responsibilities of consumer and non-consumer positions. This will assist the consumer-provider in clearly understanding their roles and duties and highlight to other staff that the consumer-provider role is an integral and valued part of the service being provided. Consumer-providers may also experience difficulties in regard to advocating for a consumer participant’s needs that are in conflict with the agency or program or with other non-consumer staff. These situations should be closely monitored by a respectful and open-minded supervisor to ensure that the consumer-provider feels comfortable expressing their perspective -- a potential goal of the agency in hiring the consumer-provider in the first place -- and that non-consumer staff are not threatened or respond in a hostile way. Conflict resolution strategies should be considered in extreme cases and both parties should be encouraged to respect the team decision-making process and conclusions. Other solutions include: 1) Creating an atmosphere within the agency

and programs that respects the contributions made by consumer-providers and encouraging dialogue with those who have concerns about consumer-providers; 2) Providing supervision where these issues are respectfully addressed; and 3) Respecting the right of consumer-providers to disclose as much or as little information about their personal experience with other staff and not publicly requesting that they share personal experiences with others or to provide the “consumer perspective” on issues.

Confidentiality concerns include the disclosure of personal information about the consumer-providers to their colleagues and the consumer-providers breaching a consumer participant’s confidentiality. As discussed earlier, consumer-providers should not be forced to disclose personal information to others, and such information, if shared with a supervisor or colleague, should not be freely disclosed to their colleagues or others in the agency or program without permission. Gossip among colleagues is common, but consumer-providers are particularly vulnerable because the voluntary sharing of their experiences is done within the context of their position and attempts to help others. Gossip can be damaging to anyone; but such gossip may undermine the consumer-provider’s willingness to disclose to others in the future, which might limit the benefits associated with their involvement in the service delivery system. Supervisors should also be sensitive about releasing information about the exacerbation of an illness or hospitalization of a consumer-provider. Such discretion is important in any employee-employer relationship.

Concerns about breaching the confidentiality of a program participant are a concern for any mental health provider. Major confidentiality violations are not an infrequent occurrence. A chart with a consumer’s name is occasionally left out in view for many to see. Information is divulged to others without a signed release of information, or information is divulged that falls

outside the scope of information where permission has been given. The most frequent violation may be the use of last names in public waiting rooms and personal conversations that take place in clear earshot of others.

One might argue that consumers may be more sensitive to confidentiality issues than providers are because of consumers' personal experiences. Nonetheless, concerns about consumers breaking confidentiality have been identified as a major barrier to consumers being hired in certain organizations. A reasonable argument could be made that while consumer-providers may be sensitive to the issues, they have not likely received the same amount of training on what is confidential and how to maintain confidentiality. Also, consumer-providers may not have thought about whether or not they can discuss information about a program participant that they obtained outside of the service settings. Such disclosure may increase their role conflicts with other consumers, who may begin to distrust the consumer-provider as someone who might share information about them that they did not want to share with the program or agency.

Consumer-providers should be able to maintain social relationships, but also boundaries between work and peers. As with almost all situations, clear policies and procedures regarding confidentiality should be written, and confidentiality issues for everyone in the agency should be openly and frequently discussed among team members and supervisors. Consumer-providers should adhere to confidentiality principles that all agency staff abide by. Similarly, consumer-providers can socialize with peers, but should obviously refrain from disclosing information about program participants and should convey this to others. Consumer-providers should refrain from sharing personal information about others with program or agency staff that was obtained through social rather than work interactions even if such information is important clinically.

Moreover, they should inform program participants that even though they are peers, they are obligated to report relevant personal information to other providers.

Creating a Positive CDS Environment – The inclusion of CDS into the continuum of care challenges beliefs about who can provide services and what services are beneficial and important to persons in recovery. Research indicates that non-consumer staff generally believe that self-help groups, and likely other CDS, can be helpful (reference). However, there is a substantial minority who do not feel this way and who may create a hostile, non-collaborative environment. In addition, even among the vast majority who do believe that CDS are helpful, many still perceive non-consumer-delivered services to be more helpful, which leads to CDS being viewed as less important or ancillary to the promotion of mental health.

Non-consumers should receive training on the unique benefits associated with CDS and should be provided with opportunities to observe and participate in CDS programs as much as possible. This could include attendance at self-help groups or drop-in centers, as well as joining consumer-providers for a day as they provide services. Agency administration and staff need to be respectful to all employees regardless of level of training, discipline, or consumer status, and should be encouraged to discuss issues that might disrupt full support for CDS. Such concerns may include perceptions that consumer-providers may somehow harm program participants or divulge confidential information, as well as fears that consumer staff might someday replace non-consumer staff.

A positive environment for consumer-providers must also be created to combat the challenges and barriers discussed earlier. Supervisors should create opportunities for issues and concerns to be openly discussed as part of the supervision process as well as in teams. The agency should promote acceptance and provide education about consumer staff and their unique

contributions without breaching or requiring loss of privacy. Additional agency support for consumer-providers might include special support, assistance, and mentoring from an agency staff person not affiliated with the specific CDS. This may be particularly helpful to a consumer-provider who has justifiable concerns about expressing problems, especially with their program supervisor. Finally, an agency might consider providing opportunities for consumer-providers to get together and provide support to one another as peers.

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Relevant Internet Resources

Mental Health Association of Southeastern Pennsylvania – www.mhasp.org

MHASP offers a wide-range of consumer-delivered services, including, but not limited to: 1) Friends Connection – a peer support program for persons with co-occurring mental health and substance abuse disorders; 2) Mainstream – a vocational rehabilitation program; 3) ACCESS West Philly – a case management program for persons with a history of homelessness; 4) TCM SHARE – a case management program; 5) Community Companion – a volunteer peer support

program; 6) Unity Clubhouse; 7) numerous drop-in centers; 8) Homeward Bound – a residential program; and 9) the National Mental Health Consumers’ Self-Help Clearinghouse, which provides technical assistance and other support to numerous CDS.

National Mental Health Consumers’ Self-Help Clearinghouse -- www.mhselfhelp.org

Consumer-Operated Services Program – www.cstprogram.org

The National Empowerment Center – www.power2u.org

Consumer Organization & Networking Technical Assistance Center – www.contac.org