Positive Partnerships:

How Consumers and Nonconsumers Can Work Together as Service Providers

Second Edition

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Preface

Partnership implies a degree of equality that can not be abridged.
- Pat Risser

The Intended Audience

This manual is about hiring mental health consumers as service providers in traditional mental health settings. It is written for both consumer providers and nonconsumer providers to raise awareness about issues that may arise when they work together to provide mental health services. This manual is intended for use in psychosocial rehabilitation programs, mental health centers, clubhouses, partial hospitalization programs, inpatient programs, residential facilities, drop-in centers and any other mental health setting in which expatriates/survivors and nonconsumers interact as peers and professionals. The manual is not directed toward consumer-run programs and self-help organizations since these settings generally minimize interaction between expatriates and nonconsumer providers (although some of the topics presented may be of interest and value to those involved in these types of programs).

We assume that many readers will be wondering where to start in preparing their organization to integrate consumer providers fully on their staffs. This manual begins with what we believe to be “step one,” which is preparing the organizational environment for consumer staff members. A lack of advance preparation can leave many staff members (nonconsumer and consumer) with the feeling that they are lost in the confusion and chaos that often accompany major organizational change. Even staff members who are dedicated to the consumer hiring initiative can become overburdened and resentful when left with the impression that their agencies did not adequately prepare for consumer hiring and that they are shouldering the burden of major change alone. Clearly, advance preparation is no longer possible for the many agencies which are well-underway in implementing peer provider initiatives; however, there are strategies that administrators, practitioners, and clients can utilize in order to achieve full inclusion of peer providers, regardless of how long they have been knowingly hiring consumers. This manual outlines several such strategies which can be utilized by agencies no matter where they are on the continuum of organizational development with respect to consumer hiring.

How the Manual was Prepared

This manual was written in two phases over a period of four years. The first phase resulted in a draft version of the manual that was disseminated widely for nearly two years. The second phase of the manual’s production involved responding to the feedback of the many people who read the draft version, including 16 recognized experts on this topic who were paid
to review the manual. Additional research also was conducted during the Spring of 1996 in order to rewrite the manual in its current form. The process of developing this manual is described in the following section.

We drew upon many sources of information about consumer providers and their experiences in order to write this manual. We received consultation from experts in the areas of consumer service delivery and advocacy, who gave generously of their time and expertise. Many of the individuals we spoke with also shared their writings with us, adding immeasurably to our understanding. We read the existing literature about consumer-run programs, as well as service settings in which consumer and nonconsumer providers worked together. We engaged in participant-observation by riding along with consumer staff members working on a mobile crisis assessment team for homeless persons with mental illness in Chicago. Additional information was gained from a series of focus groups with consumer providers and their nonconsumer colleagues and clients in a Chicago-based program called Thresholds.

Altogether, four focus groups were held to gather information for the draft manual. The first focus group was convened by inviting known consumer providers to attend a brunch to discuss confidentially what it was like for them to work at Thresholds. A total of nine consumer staff members attended and discussed a wide range of topics pertaining to their experiences as both psychiatric survivors and as members of the staff. For the second focus group, flyers were sent to all Thresholds' staff members inviting them to attend a luncheon for those who identified as mental health consumers. A tear-off portion of the flyer allowed staff members to R.S.V.P. anonymously to this invitation. Eight individuals participated in this focus group, responding to a series of structured questions. For the third focus group, invitations were sent throughout the agency inviting "Thresholds' staff members who have not experienced psychiatric disability themselves to discuss how they feel about working alongside people who have." All eight of the individuals who attended this group reported working closely with at least one client provider and also responded to a set of discussion questions. A fourth focus group included clients who met to discuss their feelings about having peers as case managers. Ten participants discussed their experiences related to stigma, their relationships with their caseworkers, and how they would feel if their case manager disclosed a history of psychiatric disability to them.

Our research on this topic, and the dissemination of the draft manual, brought us into contact with many of the leaders of the consumer empowerment movement and the individuals driving the consumer hiring initiative forward. These individuals contributed to this manual directly and also by helping us to create a nationwide network of people with expertise on building consumer partnerships within the mental health community. It is this network that we turned to in order to improve upon the draft manual.

In the Spring of 1996, Mardi Solomon conducted a series of 20 telephone interviews. To gain a broader perspective on the consumer hiring movement, she divided the country into nine regions and interviewed two people in each region. She first interviewed an inpatient/survivor in each region who had extensive experience working as a mental health service provider and/or
consumer advocate. She then asked each of these individuals to choose a nonconsumer in his or her region who was especially involved in promoting consumer hiring and to engage that person in the project. Two additional interviews were conducted through further networking resulting in a total of 20. The telephone interviews lasted one and one-half hours (the participants were paid for their time) and produced a wealth of anecdotal information as well as a great deal of practical advice. Along with the sources of information already mentioned, we drew upon our own experiences as service recipients, consumer professionals, and nonconsumer providers working alongside consumer colleagues to inform this manual.

Organization of the Manual

In the introductory chapter, we present an overview of the major issues addressed in this manual and outline our guiding principles in approaching organizational change efforts to promote consumer hiring. Chapters two through six fall under the broad heading of "preparing the workplace for the full integration of consumer providers." In Chapter 2, we suggest many of the benefits of hiring consumers to provide mental health services. Chapter 3 discusses the ways in which stigma and discrimination are manifest in our culture and within the field, and how these create a barrier to the integration of consumer providers. In Chapter 4, readers are encouraged to explore their values and attitudes towards people with psychiatric disabilities. Chapter 5 presents a model for beginning the process of integrating consumer providers, which starts with an agency assessment and proceeds through the development of an Organizational Action Plan for making changes in the agency culture. Chapter 6 suggests strategies for promoting consumer hiring and avoiding the common pitfalls of tokenism and co-optation.

The remaining five chapters can be grouped under the heading "working together." In Chapter 7, we discuss role confusion that results when service recipients become service providers, and then, present strategies for clarifying relationship boundaries. Chapter 8 demonstrates ways in which to establish clear expectations for staff members in terms of their job tasks and performance criteria. Chapter 9 provides a detailed discussion of questions to consider in disclosing a history of psychiatric disability to others at work. In Chapter 10 we discuss many of the issues that are raised when individuals experience psychiatric problems that affect their work, and present a tool to assist consumer providers and their colleagues in making advance preparations for coping with periods of illness. Chapter 11 deals with one's rights as an employee under the Americans with Disabilities Act and considerations related to reasonable accommodations. The final chapter, Chapter 12, concludes the manual by encouraging agencies to evaluate whether their organizational environment is one in which true integration of consumers and nonconsumers can and does occur.

Please Note...

Expect Discussion of Complex Issues. We recognized early in the creation of this manual that some of the material and ideas would be difficult to address. Rather than oversimplify the many complicated issues consumer hiring presents, we chose to discuss them in
all of their complexity. This makes for some challenging reading — challenging in terms of the intellectual demands made on the reader, and also in requiring readers to question their beliefs, values, and behaviors. Although avoiding the difficult issues would have made for a manual that is more "user friendly," we feel that this would not accomplish the ultimate goal of this manual, which is to encourage substantive changes in perceptions of people with mental illness and the way mental health services are delivered.

Throughout the process of talking with consumer and nonconsumer staff members to gather their input for this manual, we were reminded that the issues surrounding true empowerment and consumer hiring are complex and sensitive. First and foremost, this process requires all persons involved to remain open, honest, self-reflective, and willing to accept criticism. It has been our experience that individuals may "shut down" at any point along the way, finding it too hard to weather the challenges to long-held norms, values, attitudes, and behaviors, even if they admit that the "old ways" are not the most productive. Yet, by virtue of what they have learned in order to perform good clinical work, many of these individuals have the very skills that will help them to get through the difficulties of change. By virtue of negotiating and "surviving" social service systems, many consumers have a host of additional skills that aid this process as well. For instance, service providers and recipients often already have developed the ability to persist in the face of great challenge, to be creative and flexible, to use humor even in times of stress, and to allow change to unfold at a pace most comfortable for everyone involved. Therefore, strategies to facilitate the process of consumer hiring, based especially on these types of skills, will be presented throughout this manual.

Use of Language in this Manual. The language used to refer to persons with disabilities changes so frequently that it is an ongoing challenge to keep up with the latest terminology. Given this, our goals in choosing appropriate language for this manual are to use a variety of terms that consumers have chosen to describe themselves. These include the word "consumer" as well as "expatients," "clients," "expatient/survivors," and "service recipients." We use these terms to refer to individuals who have had experiences as clients in the mental health system.

We refer to expatients who work as mental health service providers as "consumer staff members," "consumer providers," or "consumer professionals." We have chosen to use these terms in a general way, to refer to expatients/survivors working at any level in the mental health field whether they are unpaid volunteers, paraprofessionals, or degree professionals. In other words, emphasis is on having a history of psychiatric disability and providing mental health services to other consumers, not on the individual's job status.

The term "nonconsumer staff member" refers to service providers who have not experienced disabling and persistent psychiatric symptoms. Again, these individuals may be working at any level and in any type of job in the mental health field. This term conveys the important point that nonconsumer professionals have not personally experienced psychiatric disability.
We also confronted the best way to use inclusive gender pronouns as we wrote each of the manual's chapters. Thus, throughout this document, we use the pronouns “she” and “he,” as well as “his” and “her,” alternately to reduce awkward phrasing and to minimize sexist biases in our language. We ask any readers who find our use of language jarring or offensive to try to look beyond our terms to the messages conveyed.

**This is Worth Doing.** We fully realize that not all consumers or nonconsumers will agree with our observations and suggestions. For example, some consumers may find that we allow too much time for changes to occur, while some nonconsumers may find that we are asking for too much, too soon. Such disagreement is expected and it is our contention that, however uncomfortable, conflict is often at the center of meaningful change. At the same time, it is important to keep in mind that change is a process which will occur at different paces within different organizations. The key is to stay with the challenge and to recognize that the end goal -- consumer hiring and empowerment -- is essential for everyone involved.

Ultimately, we believe that hiring consumers as service providers is one of the most important trends to occur in the field of mental health in decades. We fully support this movement as one of the best ways to help consumers become empowered and to help nonconsumers see people with psychiatric disabilities as their equals. Although this manual discusses difficult issues and potential barriers to the full-inclusion of consumer providers in traditional mental health settings, we maintain the belief that these barriers must be addressed and can be overcome.
Endnote

Preface

Chapter 1:

Introduction to the Issues that Arise When Consumers and Nonconsumers Work Together

*The National Association of State Mental Health Program Directors (NASMHPD) recognizes that former mental patients/mental health consumers have a unique contribution to make to the improvement of the quality of mental health services in many arenas of the service delivery system. The significance of their unique contributions stems from expertise they have gained as recipients of mental health services, in addition to whatever formal education and credentials they may have.*

*Their contribution should be valued and sought in areas of program development, policy formation, program evaluation, quality assurance, system design, education of mental health service providers, and the provision of direct services (as employees of the provider system). Therefore, expatients/consumers should be included in meaningful numbers in all of these activities.*

Overview: In this chapter we provide a brief overview of the major issues that we will discuss in this manual. We also outline the principles which guide us as we confront the challenges of creating an inclusive organizational environment.

The Impetus for this Manual

Consumer involvement in the provision of mental health services has gained increasing support over the past few years. The consumer hiring movement has been encouraged at the federal level with agencies such as the Center for Mental Health Services and the U.S. Department of Education emphasizing consumer involvement through their funding initiatives. Consumer service delivery also is endorsed by organizations such as the National Association of State Mental Health Program Directors, as is evidenced by such statements as the one that opens this chapter. However, in spite of this enthusiasm for inclusion and consumer empowerment, people in many mental health settings struggle with consumer involvement in programming and policy making. This often is true even if the program leaders, managers, staff, and consumers are committed to the philosophy of empowerment. Similarly, many agencies struggle with the shifts in philosophy necessary to initiate and sustain the hiring of consumers as members of the clinical staff. The material presented in this manual attempts to facilitate the process of consumer hiring.
by helping agencies to anticipate common challenges and to benefit from the experiences of others working toward similar goals.

Although mental health consumer hiring has been gaining increasing momentum in psychiatric rehabilitation settings, to date little attention has been given to strategies for preparing the existing workforce to accept the inclusion of consumer/survivor staff members. Typically, literature regarding preparation for consumer hiring has focused more on the potential training needs of peer providers themselves than on what might need to change within the organization as a whole. In so doing, many people have come to view the changes required as the responsibility of consumers. It also is the case that many organizations have begun hiring peer providers without thinking about what might need to change, or at least be examined, in the existing organizational environment for consumer hiring to be successful. Agencies need to consider how the consumer hiring movement fits into their overall missions, existing staff members’ perspectives and knowledge about consumer hiring, and the changes in organizational structures and practices that must happen to ensure success.

It is important to point out that we believe that agencies will not be successful in their efforts to fully include consumer providers if only consumers themselves are expected to change or grow. We believe that the consumer hiring initiative in traditional rehabilitation programs is best viewed as a partnership between consumers and nonconsumers, which inherently requires that nonconsumers re-examine their views of persons with psychiatric disabilities and re-think the ways in which mental health services are provided.

**Major Issues that Arise when Consumers and Nonconsumers Work Together**

The content of this manual is the result of distilling common themes from years of discussions. We have talked to people from all over the country in workshops, interviews, focus groups, conferences, technical assistance phone calls, and in our own workplaces. We have heard a lot of questions about consumer hiring such as: What to do when a colleague speaks in a condescending way about people with mental illness? What to do when a consumer professional is having mental health problems? How to distinguish supervision from therapy? Whether to disclose one’s history of psychiatric disability? What to do about friendships and romantic relationships between consumer providers and clients? We have generalized from the specific stories we have been told, identifying the larger issues and challenges that most agencies encounter as they promote consumer hiring. These issues are addressed in the following chapters:

* Confronting stigma and other attitudes and values that oppress people with psychiatric disabilities;

* Initiating changes in the organizational culture to promote the full inclusion of consumer providers;
* Recruiting the right person for a job;

* Avoiding tokenism;

* Dealing with "role confusion" and "boundary issues" in interpersonal relationships;

* Providing effective guidance, clarity, and supervision;

* Deciding whether and when to disclose a personal history of psychiatric problems; and

* Preparing for and managing periods of mental illness.

We have done our best to provide practical suggestions for confronting these challenges, but we certainly do not claim to have all of the answers. Instead, we hope to prepare agencies for the types of issues that are likely to arise, and suggest an orientation designed to foster the full inclusion and empowerment of consumers. This orientation is reflected in the guiding principles of this manual.

**Guiding Principles**

The first principle is that successfully integrating consumer providers on the staffs of traditional mental health agencies is best accomplished when consumers and nonconsumers approach this goal as partners. Everyone at the agency must be willing to re-examine their perceptions of people who have a history of psychiatric disability, and how they can work together to create an organizational environment in which all individuals feel comfortable. From this perspective, it is likely that both consumers and nonconsumers will identify changes they must make in their own attitudes and practices, as well as changes that must occur at the organizational level.

Another belief that underlies all that we discuss in this manual is that the changes an organization makes to promote consumer hiring will benefit consumers and nonconsumers alike. We are talking about changes that are good for all workers, and service recipients as well, not just consumer providers. The kinds of changes we are encouraging in mental health settings are those that will help organizations to facilitate open communication and maintain flexibility to meet the diverse needs of diverse individuals.

To a large extent, this manual can be characterized as an examination of the relationship dynamics between all of the people who participate in the workings of a mental health program (staff, administrators, clients, etc.). We are interested in how these dynamics must shift and change in order for expatients/survivors to work alongside nonconsumers as service providers. We focus primarily on two levels of experience: the internal and the interpersonal. On the
internal level we consider such factors as attitudes, values, and perceptions of self and others. On the interpersonal level we are most concerned with communication -- how can people create an organizational environment in which they can talk openly with one another, expressing their beliefs, expectations, needs, values, and ideas about best practices?

We see the stigma surrounding mental illness as a major barrier to the full inclusion of consumers in the workplace. Stigma must be addressed on both individual and interpersonal levels. Throughout the manual, and especially in the early chapters, we take time to explore stigma on both of these levels, discussing many commonly held prejudices, biases, and attitudes about people with psychiatric disabilities, and ways in which stigma is expressed in organizational practices. While we maintain a focus on organizational change, what we really are striving for is cultural change, such that persons with psychiatric disabilities are treated with the same respect and provided the same opportunities as non-disabled individuals.

We have observed that those programs which successfully integrate consumer providers share these philosophical underpinnings. As we discuss strategies for addressing common challenges and barriers to the full inclusion of consumer providers, we repeatedly refer to a set of guiding principles, which can be summarized as follows:

* Establish partnerships;
* Create a comfortable organizational environment for all participants;
* Encourage ongoing communication;
* Maintain flexibility;
* Explore attitudes and values at both individual and organizational levels;
* Attend to interpersonal relationships; and,
* Fight stigma.

As you read through the coming chapters, be alert to these themes and how your own orientation toward mental health services may reflect and encourage such principles. Perhaps you have additional points to add to this list. Please add them. Make this manual your workbook, and share your thoughts and experiences with us and others.
Endnote

Chapter 1

Chapter 2:

Why Hire Consumers as Service Providers?

I do have hope in my own process and I can see that I have been able to make significant changes in my life that have promoted my own journey on the recovery path toward my own wholeness again. I can see that I can be a model for that for my clients. Also, because I do have that sense of hope, that sense of hope pervades most of what I do. Just creating that kind of an atmosphere is really important because often people who have psychiatric disabilities have really lost hope, they are in despair. We can’t give hope to people, but what we can do is provide an atmosphere that is filled with hope, where all the activities are filled with hope, and where the people who work in it are also filled with hope.

- Dale Walsh  

Overview: This chapter presents some of the many unique skills and assets consumer providers bring to their work and how these may benefit the organization, the clients being served, and the consumer providers themselves.

Preliminary Exercise: Before reading further, take a few minutes to write down all of the assets consumer professionals may bring to their work and how everyone at your agency may benefit from them. Can you think of some specific situations in which a consumer provider’s strengths were particularly valuable?

Providing Support Differently

Fully supporting the consumer hiring initiative requires believing that peer support is a valid and valuable service, and also understanding that individuals who have received mental health services have much to offer in improving the ways in which these services are provided. This chapter describes many of the ways in which consumer providers can enhance the quality of every mental health agency’s services.

To begin, the nature of support delivered by consumer providers may differ from that of nonconsumer professionals in several ways. Support that is provided by people who have been through similar experiences tends to involve practical help based on knowledge gained through experience. Relationships between consumer providers and their clients may involve self-disclosure on the part of the helper, and incorporate elements of friendship and encouragement.
Peer providers can offer hope and reassurance, provide alternative interpretations of clients’ experiences, and convey that they understand what may seem inexplicable to most nonconsumers. In contrast, most traditional, clinical relationships are seen as an interaction between a “knowledgeable expert” and a “subordinate client” and focus on such elements as communication and listening skills, confrontation, goal-directed problem solving, and behavior change.2

Among the benefits of consumer hiring mentioned in the literature are potential reductions in recidivism for clients served, and the provision of beneficial levels of social support, acceptance, and problem-solving assistance.3 Consumers’ first-hand experiences with the mental health system may provide them with unique insights, practical skills for accessing services, and an enhanced ability to empathize with client experiences.4 Research studies have confirmed the effectiveness of consumers as case managers5 and as trainers of nonconsumer mental health professionals.6 Generally, hiring expatients to be part of the staff helps clients to aspire to roles which emphasize their strengths, while, at the same time, placing value on what consumers have learned through their interactions with such service systems as Social Security, vocational rehabilitation, housing, and mental health services.7

A national survey of supported housing programs identified 145 organizations that hired mental health consumers as paid members of their staffs.8 These organizations reported some distinguishing characteristics of consumer service providers. Because of their personal experiences with psychiatric disability, consumer professionals often relate to the people they serve with empathy and understanding of their emotional, physiological, and daily struggles. They typically are more tolerant of unusual behaviors and are less likely than nonconsumer providers to feel the need to maintain professional distance. Responding organizations noted that these factors make for very comfortable interactions between clients and consumer providers which result in better overall outcomes.9

The following material is divided into sections describing some of the benefits consumer professionals bring to an organization, their clients, their colleagues, and even themselves. When reading the remainder of this chapter, keep in mind the ways in which consumer providers may positively affect the entire system in which they work.10

**Ways in Which Organizations Benefit**

**Fighting Stigma.** The mere presence of acknowledged consumer providers in the workplace is a major force in the elimination of stigma and discrimination. These individuals may do a great deal to raise the consciousness of everyone at their agencies, and potentially have an impact throughout the entire mental health system and community in which they work.

**Dependability.** Consumer providers often are dependable and willing to do more than what is routinely expected.11 One consumer/survivor acknowledged this in herself and her peers remarking,
It's like we've missed so many years. We still chuckle that, on Christmas Eve, we look around and who do we see are the few people who are still working? It seems to be all of the consumer providers.

**Developing Creative Alternatives.** Peer providers often are amenable to exploring alternative service approaches having witnessed, firsthand, the deficiencies of the traditional mental health system. When existing services are found lacking, consumer providers can be uniquely creative in developing alternatives that are responsive to the expressed preferences and needs identified by their clients.

**Ways in Which Clients Benefit**

**Systems Knowledge.** People who have years of experience dealing with severe and persistent mental illness often have acquired extensive knowledge of the social services available to help them. Obtaining most social services requires navigating one's way through a complex bureaucracy to gain access. Public Aid and Supplemental Security Income are examples of entitlements that some people have been unable to obtain because they can not negotiate the tremendously complicated eligibility rules and regulations. As another example, consumer professionals often can provide better assistance in obtaining safe and affordable housing because they, too, have had to negotiate these systems. Experience accessing these needed resources gives consumer colleagues the skills to be powerful advocates for clients and for creating positive changes in the system as a whole.12

**Empathy.** There is an underlying understanding between consumer providers and their clients about the anger, frustration, and feelings of despair that may come from lengthy struggles with psychiatric disability and its accompanying challenges (e.g., discrimination, homelessness, loss of relationships). Nikkel, Smith, and Edwards13 explain the importance of the empathy consumers bring to their work:

> Because each staff member daily confronts his or her own experience of mental illness, a strong sense of identification develops between the worker and the program participant. This experience expands on the empathy that is customarily extended by a professional mental health worker to a client. An immediate sharing of experience and the bonding that inevitably occurs shape every aspect of the staff-participant relationship.

**Acceptance.** Consumer providers typically know how important it is to honor and respect the stated goals of consumers. Working with, respecting, and relating to consumers from an experiential knowledge base, rather than labeling and talking "psychobabble" to them, instills hope and the belief that they too can become vital, productive people.14

**Tolerance.** Peer providers often display greater tolerance for unusual behaviors and are less concerned with maintaining a professional distance than nonconsumers.15 This reduces the
risk of interactions seeming forced or artificial as they may when a nonconsumer does not see the significance or meaning of what a client is experiencing. In other words, validation of the other's experience is a critical component to building a supportive relationship, and because they have "been there," consumer providers may find it easier to develop this sort of bond with their clients.

**Flexibility.** Consumer providers may not be as concerned about "compliance" with treatment plans as are nonconsumer providers, and therefore, may exhibit the flexibility and patience that is frequently needed for clients to move toward their goals at their own pace.

**Coping Strategies.** Drawing from their own experiences, consumers/survivors generally have the ability to share coping strategies that they have utilized when addressing similar situations. Examples include how to cope with specific psychiatric symptoms or medication side effects, and vocational issues such as what to say about a spotty work history when applying for a job.

**Priorities.** Consumer providers may have a greater understanding of the priorities of their clients, responding first to help them meet their basic needs (e.g., food, shelter, safety), building trust, and then, addressing their mental health issues or other concerns.

**Positive Role-Modeling.** Staff who have experienced severe mental illness and have gone on to become gainfully employed can be an inspiration to others, particularly people who also are coping with psychiatric disability. Having a positive role model can promote healing and well-being, and can generate optimism towards recovery. Role models help to instill the notion that "if he can do it, so can I."

**Ways in Which Nonconsumer Professionals Benefit**

In addition to the ways in which consumer providers may enhance the quality of services an agency provides, those who are their colleagues may benefit directly as well.

**Educating Coworkers.** Consumer providers who are willing and encouraged to share their insights and experiential knowledge can assist in the development of greater sensitivity and skills among their coworkers. This transfer of information may occur in formal and informal ways such as in meetings, training sessions, and casual conversations over lunch.

**Providing Inside Information.** Working alongside colleagues who have "insider information" about the services available in the community is invaluable to providers when conducting treatment planning with clients. For example, while clients may be reluctant to talk to professionals about their negative experiences with a service agency because they fear retaliation or loss of needed services, they may be willing to talk to each other. An example will demonstrate just how important this information can be:
Matt, a caseworker at a clubhouse program, met with his client Susan who had just lost her housing. Susan was staying with a friend temporarily, but would need to move out within the next two days. Matt proposed that Susan take an available room he had located at a shelter-care facility. She refused although there were no other readily available alternatives. Susan appeared uncomfortable and would not explain why she would not take the available room, but was clearly against the idea. Matt described this situation to his coworkers in a team meeting and Tamara, a consumer provider, spoke up. She had stayed briefly in the same facility and experienced a lot of harassment from the men in the residence. It was difficult for a woman to walk through the door to the building or down a hallway without men making sexual comments. Tamara knew a woman who said she had been sexually assaulted in the building. The all-male residence staff appeared unwilling or unable to address the issue, and a few even contributed to the lewd comments.

**Demonstrating Possibility.** Consumers working in the role of mental health professional are potential examples to others that recovery is possible, and thus, may serve as a motivation and inspiration for working with persons who have severe mental illness. In this way, peer providers may help nonconsumers to gain a deeper understanding of psychiatric disabilities.\(^7\)

**Ways in Which Consumer Providers Benefit**

Additional positive outcomes related to consumer hiring are those experienced by the consumer service providers themselves.

**Valuing Experience.** Being in a helping role allows consumer providers to see their illness experiences as an asset rather than a liability, permitting them a greater understanding and capacity to provide assistance than they might otherwise have.

**Increasing Confidence.** As they develop and utilize their skills, consumers/survivors may gain or re-gain the self-confidence so frequently eroded by long battles with psychiatric disability and oppressive or inadequate treatment and services. To see oneself as a person with skills, knowledge, and valuable experiences to share greatly increases one's self-esteem. From this position of strength, these consumers can serve as role models for others, demonstrating that people with mental illnesses are contributing members of society, lead satisfying lives, and are able to support others in the same process.\(^8\) One peer-provider remarked about his work that it "gave me the strength to know I am more than my illness."

**Pursuing Vocational Goals.** Hiring consumers as service providers furthers vocational goals by helping persons with psychiatric disability to obtain community-based employment, gain financial independence, develop transferable skills, and establish an employment history on which to build.
Summary

The advantages of consumer hiring come mostly from the “insider knowledge” that consumer providers can bring to their work. Personal experience with psychiatric disability and the mental health system is an asset that can enhance the quality of services consumer staff members provide directly to clients. Thus, consumer hiring helps organizations to achieve their ultimate goal of providing quality care for the clients they serve, and obviously this benefits the clients too. Working alongside consumer colleagues benefits nonconsumer employees as well by raising their consciousness and expectations about recovery for persons with psychiatric disabilities. To the extent that peer providers share their knowledge and experiences, clients, coworkers, and others in the community may benefit from the insights consumer providers have gained through experience “on both sides of the fence.” Finally, for consumers, working as mental health professionals may help them to move further along in their own recovery process. It is clear that consumer hiring can be a win-win proposition.
Endnotes

Chapter 2


7. Ibid.


10. Much of the following information is adapted from Van Tosh, L. (1993, July). Working for a change: employment of consumers/survivors in the design and provision of services for persons who are homeless and mentally disabled. Rockville, MD: Center for Mental Health Services, SAMHSA.

12. Ibid.


16. Ibid.


Chapter 3:

Stigma and Other Barriers to Consumer Empowerment

*Why are there such clear examples of discriminatory treatment of consumers who are hired to work within the mental health system? Because the status differential between staff and consumers is deeply embedded within the mental health system as a whole. Until the underlying beliefs and attitudes about people with psychiatric disabilities are addressed within the system as a whole, the employment of consumers/survivors will not be free of such discrimination.*

- Deborah Reidy

Overview: In this chapter we take a critical look at ourselves, and the mental health field as a whole, considering the stigmatizing perspectives held about persons with psychiatric disabilities in our culture and our profession. The challenge to deal with issues around diversity in an authentic manner is raised.

How We See Each Other

Stigma still exists among mental health service providers, even within agencies attempting to provide community-based employment for their memberships. In fact, some have noted that the mental health field is one of the most stigmatizing and discriminating work environments for persons with psychiatric disabilities. It seems paradoxical that mental health professionals call for full integration of consumers into community life, including opportunities for competitive community employment, yet shrink from hiring consumers within their own agencies. Clearly, stigma takes many forms and creates serious barriers to consumer involvement and empowerment. Many of the ways in which stigma clouds our perceptions of others’ potential and leads to discrimination will be described in what follows.

Cultural Attitudes and Myths. There is a great deal of fear associated with mental illness, partly because we know so little about it. In general, in the United States, there is quite a bit of ambivalence and uncertainty about how to deal with people who are “different” because they deviate from majority cultural norms. Besides struggling with the stigma surrounding their disability, consumers also contend with the effects of a host of other “isms” with which many oppressed groups struggle, including classism, racism, and sexism. As is true of many oppressed groups, consumers typically do not have the political or economic clout to demand better
conditions or, at least, attention to the conditions that often accompany their disability. It is hard to combat stigma and cultural ignorance/ambivalence without the power it takes to be heard.

As do other minority groups which face such widespread societal discrimination, mental health consumers often internalize the prejudices against them. This means that they end up accepting and functioning within negative stereotypes about themselves and other consumers. As one consumer provider stated, "To break a stigma I first had to break it within my own self." Mental health professionals also are not immune to the societal beliefs and ambivalence that surround consumers. On some level, then, cultural stereotypes negatively affect both staff members' and consumers' beliefs about the abilities and rights of persons with serious mental illnesses: difficulty accepting that consumers can and do deliver effective therapeutic services largely grows out of the cultural ambivalence and prejudices about these persons in general.

**Stereotypes.** Mental health consumers and professionals often view one another in stereotypic ways which prevent them from seeing the advantages of working together and listening to one another. For example, in the field of vocational rehabilitation, there is a tendency evident in the literature and in service delivery models to believe that certain types of jobs are best for persons with psychiatric disabilities (e.g., repetitive tasks, low-stress/low-demand positions). The belief that consumers possess certain characteristics that negatively affect their work performance, such as a vulnerability to stress, concentration problems, and difficulty getting along with coworkers, is a related assumption. It is certainly the case that many people with psychiatric disability experience struggles, symptoms, or medication side-effects which affect their work, however, it is unproductive to limit the types of jobs to which consumers have access based on this generalization.

Similarly, it is absolutely essential to remain humble about one's ability to predict what is best for someone else, or what constitutes potential success or failure for them since it is not at all productive or empowering to limit people based on traditional or stereotypic thinking. All of us can think of people in our lives who have accomplished things that everyone else was convinced they never would. It is helpful to remember that our conceptions of what is possible for people change and expand all the time. For example, as recently as 15 years ago, it would have been unheard of to knowingly hiring consumers as service providers in mental health agencies, although undoubtedly there were unacknowledged expatients working in the system. Consumers expressing such career goals would have been told that they were being "unrealistic" or "grandiose." Today, many more agencies are willing to see this goal as not only realistic, but desirable. In other words, expressions of human potential vary widely with cultural norms and beliefs, sometimes changing quite significantly even from one decade to the next. Therefore, it is very important for staff and consumers together to question periodically all programmatic activities and philosophies, as well as their own attitudes and values. Such questioning should involve critically analyzing whether philosophies, practices, and policies are truly beneficial to consumers (as consumers define beneficial) or whether they are based on outmoded cultural attitudes and myths that may unnecessarily limit persons with psychiatric disabilities.
Consumers Hold Stereotypes Too. Interestingly, extensive experience as recipients of mental health services can lead consumers to view professionals in ways that create barriers to consumers’ own empowerment. The norm that decisions are made by the people at the top, and that communication is essentially a one-way interaction, prevents many consumers from seeing themselves as partners in a participatory process. Typically persons with mental illnesses are seen, and may come to see themselves and each other, as powerless, dependent, vulnerable, incapable, and apathetic. On the other hand, mental health professionals are perceived as relatively powerful and equipped to take care and take charge. Because of this, consumers may perceive (sometimes correctly) that they will be somehow “punished” if they challenge or question the authority and judgement of the staff. Professionals may find it difficult to relinquish or share the power to which they have become accustomed, and consumers may be reluctant or frightened to demand that they do so.

The stereotypes that consumers may hold about themselves and each other can make it difficult for them to believe that they, or their peers, might become good service providers. For example, one consumer provider told us about her hesitation to disclose her history of psychiatric disability to her clients:

That’s one I struggle with, not because I’m ashamed of anything. I struggle because I am afraid they might think that I might be less competent some how. It’s kind of like that woman/man thing where [women say] “Yes, I’d like to have your job Mister, but actually if the truth be known, I trust a man [to do it] more than I do a woman.”

Unfortunately, this concern that clients may not feel confident about the abilities of consumer providers is not unfounded. Without revealing her own history of psychiatric disability, one consumer clinician asked a group of clients at a psychosocial clubhouse program to comment on how they would feel if their casemanager disclosed having mental illness to them. This discussion raised some questions and concerns.

The consumers in this group stated that one of their primary concerns was wanting their case managers/therapists to “be strong for them,” and that they saw disclosure of psychiatric disability as a sign of “weakness.” One woman commented,

It is scary to think about your therapist having serious problems. I need her to be there every week.

These consumers viewed helping professionals as being on a different level than themselves. Such a viewpoint made the potential sharing of similar histories or problems by a therapist difficult for them. They expressed concern that a casemanager with mental illness might have difficulty helping them if he is dealing with the same problems. They worried that their casemanagers would need to turn to them for support. A few consumers worried about how they
would react if their consumer case managers were having mental health problems. For example, one participant commented,

For me, I would accept it, but I would be scared. What if she goes off her meds? How would she react? I wouldn't know, so I would be scared.

Upon further discussion by the group, these concerns were alleviated by the notion that a consumer provider would be more empathic having shared the experience of coping with psychiatric disability. This impression was summed up by one woman in the group who said,

People with mental illness have as good a chance of being a good caseworker as someone without mental illness. Perhaps the negatives such as they could take [their] problems out on you are balanced out by their understanding of what you are going through.

The fact is that consumers are socialized into the same stigmatizing attitudes as everyone else when it comes to their perceptions of people with mental illness, and it will take time for all of us to adjust our perceptions to see one another in more positive ways. Recognizing this, Macauley suggests,

Training and re-education also are needed for consumers who need to start looking at themselves as people with nothing to hide or apologize for, even as having a special "edge." They need to realize that conditions will not change overnight and that patience, effort, and open-mindedness will be required of them too.

"Just Because I'm Crazy Doesn't Mean I'm Stupid." When people make distinctions between themselves and others on the basis of disability, it can prevent them from seeing the strengths of others. An emphasis on illness within both the physical and mental health systems "can lead consumers and professionals alike to forget that the majority of consumers have extended periods of wellness when their ability to participate is completely intact."

Once a person is identified as being a current or former recipient of services, coworkers and supervisors may watch her behavior more closely than other workers or may be more likely to judge it as inappropriate or illness-related. Consumers who work as service providers are labeled and objectified, just as all consumers are. "Their behavior and principles are filtered through their psychiatric disability."

Howie the Harp agreed, noting that,

Too often our actions are seen within the context of a disability and/or psychiatric history, rather than natural reactions to a set of circumstances for which other people may have similar reactions.
The tendency to over-interpret behavior, viewing normal feelings and actions as symptoms, is especially common among mental health professionals because so much of their time is spent assessing the pathology of others. When one goes looking for symptoms it is easy to find them. An example will illustrate this point:

One of the major goals at a community-based psychiatric rehabilitation program is to prevent unnecessary hospitalizations. Thus, staff members work with their clients to identify their "prodromal signs" (behaviors that signal the onset of symptoms, such as changes in sleeping habits). Both staff and consumers are trained to look for these signs in order to prevent a crisis from occurring. Staff members become so accustomed to watching closely for clients' prodromal signs that it is sometimes difficult for them to stop looking at others' behavior in terms of what is "normal" and "abnormal." When a consumer joined the staff of this agency, he became the target of such scrutiny. Knowing that he had a history of psychiatric disability, his colleagues were constantly assessing whether his behavior was "appropriate" or not. This consumer provider complained that he could never relax among his coworkers or feel confident in his abilities because it felt like the other staff members were always evaluating his prodromal symptoms, and thus, his competence. He pointed out that it was not fair of his coworkers to judge his behavior as "appropriate" or "inappropriate" since they only knew him in one way (as a "client"), and had not spent enough time with him in other situations to know all of his reactions and behaviors.

A nonconsumer who supervises consumer providers spoke to the same issue and suggested that an antidote to the stigmatizing perspectives described above is coming to see consumer colleagues (and clients, for that matter) as individuals apart from their illnesses:

The more I know the person, the less I concentrate on the illness... If the employer and coworkers know the person first and the illness second you are in a much better position for developing those natural supports than when they know the illness first. ...We talk about pathologizing thoughts and problems and behaviors. We too often look at every behavior and try to relate it to the illness rather than the fact that we all don't want to get up Monday morning and are drifting Friday afternoon. I find that the less I know the person, the more I concentrate on his or her illness and that's not fair to the person. I have more to go on the more I know the person.

Other consumers we spoke with expressed the feeling that their expertise or opinions were discounted by nonconsumer providers. Some of the comments we heard are:

When I have a disagreement, I think people might say, "What does she know, stupid lunatic." In my mind I feel like they dismiss me.
I feel people discount me because they do know I was a member [consumer]. It makes me timid and hesitant to disagree.

The fact that I’ve had mental illness doesn’t mean I’ve lost my skills. We need to break down the myths. Just because I’m sick doesn’t mean I’m stupid.

It is important to point out that, unlike coworkers in other types of jobs, mental health providers have dealt with many consumers who have experienced severe symptoms or serious difficulty functioning in everyday life. It may be quite difficult for some providers to hold two contradictory evaluations in mind at the same time: person who is severely disabled, and capable clinical worker. Furthermore, having seen many people in these difficult stages may lead nonconsumers to a misguided, although usually well-intentioned, tendency to want to “rescue” consumers from the potential pain and embarrassment that comes when taking on a challenging role.

Nevertheless, many consumers have educational and work experience in the mental health field and this knowledge is not invalidated by psychiatric disability. Like anyone, consumer professionals should hold their jobs based on skills and/or education, not primarily because of their consumer experience. If this is not expressed and believed, the job will be experienced by the consumers and those around them as paternalistic or tokenistic.16

The Role of Power and Powerful Roles

Perhaps the most serious and entrenched barrier to consumer involvement is “the issue of societally assigned roles and the power differentials that go with them.”17 For consumer-run agencies, hiring people with psychiatric disabilities is the norm. In agencies that have not made a concerted effort to hire consumers in the past, such a step represents a significant challenge to the status quo. Consumer hiring poses a significant threat to the established power structure, demanding that everyone shift their perceptions of themselves, their roles, and their interactions with one another. In fact, these required changes in the organizational culture pose the biggest challenge to the successful integration of consumers on the staff.18 (This issue is discussed in greater detail in Chapter 7: Changing Roles, Changing Perceptions.)

Agencies in which there is a more clear delineation of staff and client roles most likely will be slower to integrate consumers into their service delivery staffs. For example, on the continuum of integration, many clubhouse programs are highly integrated settings while in-patient hospital settings are not well-integrated. In general, the less well-integrated a setting, the more difficult it will be to establish the practice of consumer hiring.

Don’t Degrade My Degree. The attitudes of nonconsumer professionals are partly an outgrowth of years of training and higher education which has drawn a boundary between mental health professionals and their clients. As one person we interviewed stated,
Traditionally it has been considered both unethical and untherapeutic for professionals to interact with their patients the way they would with professional coworkers. Requiring these professionals to go against years of indoctrination by treating expatients as colleagues is problematic at the very least. Not only is it difficult for degreed professionals to question their training, but they have to face the possibility of equality with the mentally ill, people they have learned to look at as ill or in need of their assistance.  

A staff member of a program that was attempting to integrate consumers on the staff reported that the resistance they encountered from nonconsumer colleagues was primarily the feeling that “you’re degrading my degree.”

A situation described by one consumer advocate presents how this kind of attitude was displayed and then addressed by a mental health agency:

...somebody had been off work three or four days, and she was a supervisor [with a psychiatric disability]. There was a lot of resentment...and part of the resentment was that she was supervising people with more college degrees than she had. One of the reasons she was a supervisor was because of her direct experience. She had been off work, came back, and one of the people she supervised approached her and said, “Were you really sick or was this one of your mental things?” and pointed to his head. I encouraged her to file a formal complaint and then told the Executive Director that when he got the complaint he needed to do something because this was coming after many other complaints.

And so they did. They sat down with the person who had made the comment and he basically said that he would do it again. He didn’t see anything wrong with his comment and he displayed a whole lot of hostility towards this person and resented having a person with a psychiatric disability as his supervisor. So they wrote him up. There was a tremendous ripple effect throughout the agency because it was the first time that there was actually any kind of corrective action for this type of thing. So the consumer employees were feeling really empowered that someone had made a complaint and it had been taken seriously and there had been action. The nonconsumer employees were outraged and it created a lot of fear and it fostered some more resentment. So the agency really had to do a lot of work as far as training and really setting the expectation.

**Dealing with Diversity**

As a result of their fears and uncertainties, many people strongly emphasize the differences between themselves and those they label as “mentally ill” (often reflected in derogatory labels or limitations). This may be interpreted partly as a defense mechanism against thoughts that the differences between consumers and nonconsumers are one of “degree” rather
than of "kind." In other words, it often feels safer for nonconsumers to view people with psychiatric disabilities as entirely different from themselves. Nonconsumers often reassure themselves that consumers' experiences are well beyond anything that might happen to them, rather than face the fact that they, too, are vulnerable to mental illness, as well as the struggles that often accompany psychiatric disability, such as unemployment, poverty, homelessness, and loss of family.

However, this defense begins to break down when individuals who are seen as "different" start doing the same things as "normal" people, such as working in mental health agencies. As nonconsumers discover what they have in common with consumers, it becomes harder and harder to maintain a sense of distance and a conviction of difference. Nonconsumers in this situation are forced to confront the fact that it is only a matter of circumstance, perhaps a small twist of biochemical fate or a different set of life stressors, that leads one person to experience psychiatric problems and another to remain symptom-free. One consumer staff person, who was diagnosed with bipolar affective disorder in her mid-thirties, recognized how frightening it is for nonconsumers to realize that they are not immune to psychiatric disability when she commented:

*I think it's scary for other staff to see someone who got hit with mental illness later in life. It shakes some feelings of invulnerability.*

It is important to remember that there are many ways of understanding people's behavior. The stigma associated with mental illness is perpetuated by narrow definitions of what is "normal," as well as by the need to set others apart from oneself if their behaviors do not fall within this range. There are some who argue that mental illness does not really exist but is, instead, a social construct or label used by people from majority groups to maintain control over oppressed groups (such as women, homosexuals, or persons of color). Social labeling theorists believe that persons who deviate from cultural norms often are labeled as "mentally ill" so that those in power can maintain control over them. Others believe that mental illness is a "spiritual crisis" rather than a biochemical disorder. We mention these positions here not to debate their validity, but to emphasize that something as complex and dynamic as the human mind is not easily understood. Thus, remaining open to a variety of viewpoints will facilitate work between consumers and nonconsumers.

A more constructive way of viewing people allows for a greater range of acceptable behavior, whether or not one believes that mental illness truly exists. From such a perspective, we can view behavior on a continuum and imagine people moving back and forth along this spectrum over time. Everyone experiences depression, anxiety, and confusion to varying degrees at different points in their lives. There are times when some people are unable to function effectively because of such feelings, and in severe cases, may be completely debilitated. If we can first see such episodes as part of the continuum of human experience, we can draw from our own life experiences and relate to individuals who are in distress with understanding and compassion.
Many times in our interviews with consumer providers and nonconsumer providers, the comparison was made between hiring persons with psychiatric disabilities and individuals who experience discrimination for any other reason (e.g., homosexuals, people with physical disabilities, people of color). The focus must be on how people deal with diversity in general. As Ken Schlosser, a consumer provider and activist stated,

*If an agency is not good about diversity in general in terms of its staff, there’s no reason to think it’s going to be authentically good about [hiring] consumers. So what does it mean if a 99% white, 900-person agency is talking about its desperate need to have consumer providers on the staff? If you don’t train white program directors to deal with interviewing people of color or dealing with their anxiety about dealing with people of color, there’s no way they are going to be any better [in] interviewing consumers. What they’ll do is hire them because it’s correct, they’ll supervise them badly, and they’ll fire them.*

He goes on to stress the point about the agency’s authenticity and the importance of really questioning the motives behind a move to hire consumers:

*If you’re not really actively challenging people around the question of difference in general, there’s going to be all sorts of shortcomings in your campaign focused on [hiring] consumer providers. Then you are open to the charge — and it’s not just a charge but the reality for some agencies — that you’re really [hiring consumers] because it’s become politically amenable to do it. It gains you some status in certain circles within the agency provider group. The Department of Mental Health likes it. If you’re not generally good about these issues, then there is a real question, “Why are you so hopped up about this? For example, if you can’t deal with having a nonconsumer on staff who is Latino or African American, why are you so enthused about having somebody who’s a consumer?”*

These are critical questions and challenges for every organization to consider and reconsider periodically. On individual and organizational levels (and beyond that to community and national levels), an honest examination of the values and attitudes that are held regarding psychiatric disability, recovery, consumer hiring, and diversity in general must be made.

**“Think Globally, Act Locally”**

We need to look at stigma and discrimination from the broadest possible perspective to understand how pervasive they are and to begin to address them in ourselves, our mental health programs, and our communities. This approach to social reform is reflected in the slogan “think globally, act locally.” Historically, many of the original community mental health and rehabilitation programs emphasized the need for social reform (they were, after all, a reflection of the era), however, such efforts are rare or are fragmented in most mental health agencies today. Service delivery tends to focus more on the intrapsychic needs of clients, ways in which they can
adapt to their existing situations, and methods for basic survival in a resource-poor environment. While such goals are essential, mental health programs also must commit to organizing political and social advocacy efforts for bettering the lives of their clients. In the words of Estroff,

*Much of the suffering and distress that . . . affect our clients has very little to do with psychoses and a great deal to do with social, political, and economic circumstances. The public health perspective should remind us vividly of the futility of treating consequences without addressing the sources of distress and disease.*²²

Changing societal conditions begins with working to change cultural and political beliefs about persons with psychiatric disabilities. It is clear that, within the mental health system, this process probably will need to begin with honest and critical discussions between agency leaders, managers, staff, and clients regarding their own feelings about consumer empowerment and diversity, including the rights and abilities of people with mental illness. As Spaniol and his colleagues note,

...*Change is a developmental process that requires personal adjustment... Responding empathetically to individual reactions to change, especially those that are highly emotionally charged, can be especially helpful in aiding staff members to adopt new attitudes and behaviors.*²³

Mental health professionals and clients also can start with the following suggestions to work toward social change and improved societal perceptions:

- Educate agency consumers and staff about social change efforts and how such efforts could improve their lives, drawing on the feminist ideology that the “personal is political.”

- Institute self-assessments for all members of the staff to monitor continually their own prejudices and negative perceptions as a way to encourage self-development and growth (these would be completely confidential, but might be discussed with a supervisor or mentor if that felt comfortable).

- Become involved in public educational campaigns about psychiatric disability, challenging inaccurate and stigmatizing characterizations of consumers.

- Organize letter writings/phone calling campaigns to legislators.

- Organize political protests or support rallies around issues important to the lives of consumers.
Work to educate key sources of legitimation and funding for mental health agencies (as can be seen in the cases of the National Institute on Disability and Rehabilitation Research and the Center for Mental Health Services, such sources have been known to respond to innovative ideologies and services if only given the chance and the supporting logic).

Ultimately, neither staff members nor consumers will be empowered by a service delivery philosophy that encourages expatients to adapt to largely unequal and unjust circumstances. As Dr. Martin Luther King, Jr. points out, oppression and empowerment do not exist simultaneously; injustice to any one person is injustice to every person.24 If the mental health system does not directly address the ambivalent and hostile cultural views about persons with psychiatric disabilities, consumers certainly will continue to face backlash when they move into staff positions or any positions of power.

Summary

The mental health field is not immune to the stigmatizing attitudes toward persons with psychiatric disabilities that are prevalent in our culture. In fact, mental health organizations typically perpetuate this stigma by holding to common stereotypes, viewing consumers through the filter of their illness, and maintaining power dynamics that discriminate against consumers and others from diverse backgrounds. The challenge for individuals and organizations that wish to promote consumer hiring is to honestly evaluate the motives behind the push to hire consumer providers with the focus on how one deals with diversity in general.
Endnotes

Chapter 3


4. For an excellent discussion of the effects of stigma on consumers' lives, we recommend Deborah Reidy's (1993) document, “Stigma is social death: Mental health consumers/survivors talk about stigma in their lives.” This document is available Human Resource Association of the Northeast; 187 High St, Holyoke, MA 01040; Tel: (413) 536-2401.


17. Everett, B. & Steven, L.D. (1989). Working together...

18. Curtis, L.C. (1993). Consumers as colleagues...


20. L. Shepherd, personal communication, March 1, 1996.


Chapter 4:

Values, Attitudes, and Language

If [organizations are] going to hire consumers because they are getting pressure from a consumer organization, or because they feel like they need to give a little bit of power away, those are the wrong reasons to do it. You have to do it because you believe it and you know in your heart that these individuals can do the work, and that they come on board as equals. If you are not going to look at it that way, then consumers are better off starting their own organizations.

- Don Lavin

Overview: The purpose of this chapter is to encourage everyone involved in organizations that are promoting consumer hiring to explore their values and assumptions regarding persons with psychiatric disabilities. We present many of the attitudes and values that are critical to creating an organizational environment in which stigma and discrimination against consumers are reduced, if not eliminated. This includes attention to one’s language as a reflection of the attitudes and assumptions underlying what is said. The emphasis is on education as the tool to cultivate these core values, principles, and practices.

Exploring Your Values and Attitudes

An exploration of individuals’ assumptions about the capabilities of persons with psychiatric disabilities is needed to identify and address stigma and discrimination, and to create a hospitable organizational environment for consumer providers. Material throughout this manual should cause you to examine many of your existing attitudes and assumptions. We hope that you will continue reading with an open mind and willingness to question what you believe and how you behave. Everyone in the agency should be involved in self-questioning, either alone or in discussion groups, focusing especially on attitudes about consumer hiring. Not only must the staff engage in this process, but it is also important for clients to consider their feelings about receiving services from consumer providers. It is especially important that the top administrators in a mental health service agency be involved in this process since their support is crucial in creating an environment in which expatients/survivors will feel safe disclosing their histories, should they decide to do so.

Specific questions and exercises to guide you are included throughout the manual, particularly in the assessment described in the following chapter. The major questions which get
to the heart of making consumer hiring work and which are raised throughout this manual are:

1. What are the unique gifts consumer colleagues have to offer?
2. How can our agency be more supportive of consumer providers?
3. How should we address incidents of stigma in the workplace?
4. How can we deal with unexpressed, but real, currents of stigma?
5. What can we do to make the environment feel safe for disclosure as desired?
6. In what ways can we discourage hurtful labels and limits?
7. How can we be sensitive to a consumer professional’s particular needs regarding
   a.) supervision?
   b.) reasonable accommodations?
   c.) crisis prevention and management?

**Values, Principles, and Practices in Agencies That Support Consumer Colleagues**

What follows are some of the values and attitudes that we believe foster a good relationship between staff and consumers in general and are even more critical when consumers and nonconsumers work side-by-side as service providers. We begin with general attitudes regarding persons with psychiatric disabilities, and then, address attitudes toward consumer providers working in the mental health field.

**Attitudes Toward Persons with Psychiatric Disabilities**

- **Valuing the fundamental equality of all people.** This requires maintaining an understanding that the difference between mental health consumers and nonconsumers is simply one of degree, not of kind. Consumers are people who have merely gone through different sets of experiences than nonconsumers, but whose feelings, hopes, fears, and dreams are quite similar.

- **Respecting consumers/survivors for their struggles to overcome many obstacles** including psychiatric symptoms, poverty, discrimination, unemployment, stigma, etc. Holding such a respect for consumers means taking the time to find out from them some of the experiences that they have been through as a result of having mental illness. It also includes making an attempt to understand and appreciate the fact that consumers have survived an inordinate amount of stress because of having psychiatric disability, and thus, experiencing oppression. Consumers deserve recognition for the strength that they have shown in meeting their difficult obstacles head on. Schlosser tells how he maintains an awareness of where his clients have come from and what they have been through:

> What I’m beginning to do is to talk to people about what it feels like to lose your life. [Staff members] have become so hardened here it feels to me, working with seriously disturbed people who have really lost major parts of their lives and they’re not going to regain them. People get so hardened to that -- or they get so
sensitive to it and want to numb out — that there's a kind of way that that's denied, as if people are born to this role of being a consumer. So I talk more openly. Like I keep asking people, "Who is Bob's family?" [Staff members] don't know major chunks about consumers' lives — the times prior to becoming a consumer, or the dimensions separate from being a consumer. Partly, it is because the records are so bad, but also, I think providers don't want to know. Part of me is really resisting this idea to see people in such partial ways.  

**Attitudes Toward Hiring Consumer Providers**

Demonstrating acceptance of consumer employees as people and employees first, and as people with a disability second. As Raudenbush explains,

> It's a philosophical issue (not structural) of people having a clear willingness to look past the label of mental illness. There's a philosophical base that says the illness is not the person. We base our relationship with the person, not the illness. I don't know how you produce that except bringing it out in the open. A lot of people might say, "Sure that's how I feel," but if you don't bring it up perhaps they don't behave as if that's what they feel.

Raudenbush suggests some ways to bring this attitude into the open:

At orientation, at interviewing ... focus on skills and abilities, not on deficits. The introduction of individuals to coworkers has to do with the jobs they are going to perform and their abilities to do that, not on, "Here's all the things they can't do so make sure you watch out for them." Keeping the focus on abilities not disabilities [is the key].

...What we do in staff meetings is, not do a glaring focus on the individual with the illness, but rather, make sure we tap into [her/his] perspectives as a training element when talking about many different things (developing questionnaires or interview techniques, whatever). To highlight that perspective because then it gets [consumers] the respect of other staff members when they see they can learn something from somebody that has a history of receiving services from this same system. Some of it is in the orientation and some is in the way, on an ongoing basis, you use that knowledge and experience as something that is beneficial to the whole operation.

**Having a firm commitment to making consumer hiring work for the organization.** This commitment is bolstered by the belief that hiring persons with mental illness can be a "win-win" proposition for both the agency and the consumer:
You really have to value the competencies of people who have psychiatric
disabilities. You have to value what people with real life experiences with
psychiatric disabilities have to offer that's very special in terms of helping other
people. You have to believe in having integrated partnerships. The values are
just crucial.  

Creating a Positive Culture of Healing

In this section we discuss many of the attitudes and values that we have learned
contribute to what Dan Fisher has termed a “positive culture of healing.” That is,

...an environment in which, not just each individual can cope and recover, but an
environment in which communities of people can work together to facilitate the
healing of each of the members of that community.  

Such an environment emphasizes inclusion instead of exclusion, equality and valuing other
people instead of seeing people with mental illness as less human, and the belief that recovery is
possible. The values and attitudes listed in this section are included because they contribute to an
overall environment that is empowering of consumers and are not intended to imply a treatment
orientation toward one's consumer provider colleagues.

• Acknowledging the importance of participating in one's own recovery personally and
professionally.

• Acknowledging that consumers are (or should be helped to become) self-determining
agents of their own change. Consumers must have the freedom to define the terms of
their own lives, including whether or not they want to change at all. The role of the
service provider is not to make decisions or do everything for clients, but to assist
consumers in building on their own strengths and creating successes for themselves.
Service providers must avoid the need to create “successes” for personal ego
gratification. Gratification should come from facilitating and participating in this
process, not in the eventual outcome. This distinction was expanded on by one
administrator who described the importance of

...an agency culture that promotes a patient and collaborative approach to
working with consumers. When staff enjoy being “in charge” of others, holding a
big set of keys -- when they feel indispensable to consumers or eager to fix
everyone’s problems -- you’re sure to have trouble. Really good professionals are
able to convey the feeling of people patiently working things out together (rather
than pushing for a particular outcome). This means letting go of some of the
control, and trusting something in the consumer. That’s not easy for some people
Fostering an environment in which people can work together to facilitate all aspects of the healing process: physical, psychological, and spiritual.  

Maintaining the belief that work should be a healthy experience.  

Understanding that sensitivity to the needs of the consumer, whether acquired as a function of being a consumer or not, is the essential element in developing competent, humane mental health services.  

Being open to the perspectives of others is imperative for effective communication. This openness to others includes the following: a willingness to negotiate with other professionals and consumers in the development of client treatment approaches; listening to and learning from others, including consumers and consumer professionals, since they may be valuable on-site teachers about the needs and perspectives of clients; maintaining a sense of humbleness about your ideas; and always remaining open to suggestions from others.

The Power of Language

Since what people say is generally considered to be a direct reflection of how they feel, language can be a sensitive indicator of the values and attitudes held by individuals. Unfortunately, language is frequently used thoughtlessly or maliciously. This happens all too often among mental health service providers when they speak about the people they serve. A very common complaint among expatients is that their nonconsumer coworkers are always making disparaging remarks about people with psychiatric disability. As one consumer colleague said, “When they talk about the clients that way, they are talking about me.” (In our focus groups, we discovered the unfortunate fact that consumer providers also make such remarks as a way of appearing to “fit in” or to disguise their psychiatric histories.)

Witnessing their colleagues displaying blatant disrespect for people with psychiatric disabilities leads consumer staff members to do whatever they can to avoid becoming the target of ridicule. The result is that peer providers fear disclosure of their histories of psychiatric disability and go to great lengths to maintain their secrecy. For expatients who are already “out” to their coworkers, perhaps because they received services at the agency in which they are now working, they may never be able to feel truly integrated in the work environment.

Given the tremendous significance and impact of language in creating a comfortable work environment for consumers, mental health agencies should make a concerted effort to educate their staffs about how to speak respectfully about persons with disabilities. In educating staff members, it is important to emphasize that censuring speech is not the end goal of
improving one's use of language. Rather, a focus on language, and understanding the cultural beliefs behind it, should help professionals to think more critically about their attitudes and to develop ways to be more empowering. A program administrator explained the positive outcomes of this process:

...sometimes if you have someone on the staff who talks openly about being a consumer, colleagues who might have a tendency to speak or joke in a disrespectful way about consumers are made to edit their tone and language, particularly if the agency culture demands it. Having to go through that thought process of editing their speech is good because it helps them to change their thinking and behavior.11

The following guidelines provide some tips for thinking about how to analyze your own use of language. The most important point is to consider the attitudes conveyed by what is being said, rather than censureship per se.

**Tips for Improving Your Language Related to Disabilities**

- Emphasize abilities, not limitations.
- Do not label people as part of a disability group (i.e., do not say “the disabled,” but rather, “people with disabilities”).
- Do not speak in a patronizing way to or about persons with disabilities.
- Choice and independence are important: let the person do or speak for himself or herself as much as possible.
- Speak of the person first, then the disability.

<table>
<thead>
<tr>
<th>Say...</th>
<th>Instead of...</th>
</tr>
</thead>
<tbody>
<tr>
<td>person who has... or person diagnosed with...</td>
<td>afflicted, suffers from, victim</td>
</tr>
<tr>
<td>persons with mental illness</td>
<td>the mentally ill</td>
</tr>
<tr>
<td>emotional disorder, mental illness,</td>
<td>crazy, insane</td>
</tr>
<tr>
<td>psychiatric disability</td>
<td></td>
</tr>
<tr>
<td>person who has/diagnosed with schizophrenia</td>
<td>schizophrenic</td>
</tr>
</tbody>
</table>

**Employee First Language.** Kathleen Wilson suggests that, in addition to using “person first” language, we switch to using employee first language when talking about service providers who also are consumers. She explains,
The emphasis needs to be on employees not “consumer” employees, because right away that puts them in a different class than your other employees. When you hire people, they are employees. They aren’t “consumer” employees, they’re employees. If you start treating them in a different way -- by job assignment, by job pay, by job benefits, by job responsibility -- than you would treat any other person in that job...it’s not equitable and that’s creating problems right away.\textsuperscript{13}

This is an important point and we do not wish to diminish it in any way, but for the sake of clarity in this manual, we will continue to use the term “consumer staff member.” We share Wilson’s hope that:

...this term ceases to exist soon because it is an artificial term that we are using right now just to deal with our own need to label something until we can change our attitude.\textsuperscript{14}

**Humor.** Humor is an essential avenue of expression, in order to work successfully in social and mental health service systems. It is common in all human services professions for providers to talk and joke about the inherent tension and anxiety of their work. Especially in stressful work environments, such as mental health agencies, professionals frequently use humor as a way of releasing tension. As one nonconsumer provider put it,

*We have a staff meeting at the end of each day to vent so that we don’t take the problems home with us. It’s so necessary to have an outlet, especially with a team who understands and deals with the same things every day.*

Humor is clearly very important for stress management, as is a supportive group of coworkers. Problems may arise, however, if comments and jokes are made that are offensive to consumers. One consumer colleague, who has been offended by her coworkers’ behaviors many times commented,

*If you hire minorities or consumers you have to be more careful what you say about them. You can’t be your regular tacky self. You have to stop the stupid jokes.*

As with all types of interpersonal communication, humor is interpreted within the context of the relationship between the people involved. In other words, something may be very funny when said by a close and trusted friend, whereas the same statement may be insulting when it comes from a disliked colleague. Also, along these lines, the power dynamics of a relationship influence whether comments are interpreted with humor or offense. For example, when a man makes a joke about women, a white person jokes about someone of another race, or a nonconsumer teases consumers, there is great potential for those who are at the receiving end of the joke to be offended.
This is a sensitive area for both consumer and nonconsumer providers. Consumer staff members may be concerned about fitting in, and may be reluctant to express when their feelings are hurt by their colleagues' inappropriate comments. Also, as many women or people of color already have learned, expatriates/survivors may be told to 'stop being so uptight' or 'I'm only kidding' when they express discomfort with humor or jokes told about other consumers. This puts the burden of awareness on nonconsumer professionals who must become sensitive to the language they use. To this end, it helps if expatriates see that nonconsumers are able to laugh at themselves and their own struggles and limitations, as well as at others. Malicious humor may be a sign of underlying tensions between staff that should be addressed in individual supervision and team/staff meetings as soon as possible. The comments of one consumer professional may serve as a basic guideline for nonconsumers:

Joking can be a release. Sometimes you have to stand back and laugh and joke about what's going on around you, but humor should not convey a lack of respect.

A New Attitude

I used to think that [a belief in the recovery process] was a value that you either had or you didn't have. I've changed my mind on that.15

It may be that some of the values and attitudes discussed in this manual are new to you or are not generally held by others in your organization. This is not cause for alarm. Flexibility is the most important feature of any organizational environment that wants to promote consumer hiring. This is true for individuals as well as organizations. There must be a willingness to learn new ways of seeing and being for change to happen. Pat Kramer, a program director, gives a wonderful example:

...when we first started [our Community Treatment Team] we were very fortunate that we could immediately say that as part of the team we would have consumers and they would function fully as team members. We did that. We had a doctor who then left and I was in the process of hiring another doctor. Of course to me it was essential that the doctor would value the input of those particular team members. The doctor that we hired said, 'I can do that. I can work with that.' He was okay about it. It didn't take him long to realize that not only could he live with it, but he needed that. He has since gone out and given speeches and said, 'I used to say, here I'm sitting at this table and I'm listening to somebody who's a mental health consumer tell me how I should treat someone. Blasphemy! That used to be blasphemy. Now I welcome them. I go to them. I solicit their input because this makes a difference.'16

With an organization of individuals who are open to learning new ways of seeing each other and doing their work, education is the tool that will facilitate change. We heard over and
over again the need for education and, equally important, open communication, throughout the change process. Kathleen Wilson, an expatien/survivor who does training on issues around consumer hiring, stresses this point:

“There has to be education that, “you just talk about it.” If you don’t know what to do, you ask. If you don’t know what someone is feeling and you want to know, you ask. If you don’t know how you should treat somebody, you ask... If you don’t know something, don’t have a meeting behind closed doors to try to figure out what the person needs, ask the person.”

As your agency goes through the process of assessing what changes are needed to create an integrated organizational culture, staff training needs will arise. For example, the previous chapter raised the need for training around issues related to diversity. Lori Shepherd, a consumer advocate, described such a training agenda:

...we’ve set up training once a month for the next nine months on different disability groups. So there is training on psychiatric, physical, hidden, and developmental disabilities, as well as trainings on different cultural groups: African American, Asian, and Latino communities. They are required trainings.

There are many resources available to provide education on pertinent topics such as how to facilitate the change process, negotiate conflict, and utilize the Americans with Disabilities Act. In addition to written resources, which can be located easily by searching library on-line catalogues or accessing local college/university library references, there are likely to be many people in your area who have specialized knowledge on relevant topics. Make an effort to network with local mental health professionals, and also people outside the mental health field who are good at generalizing their expertise to a variety of fields. For example, there may be lawyers in the area who specialize in disability law, or people who typically present to business managers about organizational change, personnel development, or workplace morale. Not only may such networking pay off in terms of providing valuable training to mental health staffs, but it also might open up opportunities for educating people about psychiatric disability. Perhaps a training exchange could be arranged in which someone from your agency could train lawyers about what it is like to experience mental illness, and the lawyers subsequently could train your staff about legal rights of consumers.

Summary

We have presented many of the attitudes and values that should be firmly held in an agency that is fighting stigma and discrimination against consumers and creating an organizational environment in which the principles of recovery and empowerment are actualized. The intention is not to impose these values on people, but to encourage individuals and organizations to explore their values. This will involve cultivating an environment in which open communication can occur so that individuals feel free to express their beliefs. Discussing
the assumptions and principles underlying current practices creates the possibility for
reconsideration and doing things differently. Such flexibility is crucial for change to happen and
opens the door for learning new attitudes and ways of working.
Endnotes

Chapter 4


14. Ibid.


16. Ibid.

17. K. Wilson, personal communication, February 26, 1996.

18. L. Shepherd, personal communication, March 1, 1996.
19. For publications on organizational change, search the literature of the business and organizational psychology fields. Regarding conflict mediation, see "Managing Workplace Conflict: A Skills Training Workbook for Mental Health Consumers and Supervisors," available through The National Research and Training Center on Psychiatric Disability; 104 South Michigan Avenue, Suite 900, Chicago, IL 60603-5901; Tel#: (312) 422-8180. Chapter 11 of this manual provides resources to contact for more information on the ADA.
Chapter 5:

What Agencies Can Do To Create a Comfortable Work Environment

A planned change effort represents hard work and a substantial investment of time and talent. It requires mobilization of energy and resources that might otherwise be used for ongoing work with different purposes. Before initiating an episode of planned change, the practitioner should assess the situation carefully in order to avoid two pitfalls: unnecessary effort and hopeless effort.¹

Overview: This chapter addresses ways in which programs can refine organizational structures and practices in an effort to better accommodate peer providers. We introduce the concept of an "Organizational Inclusion Framework," which agencies can use both to develop and evaluate organizational changes over time with regards to consumer hiring. Developing such a Framework includes appointing a “Peer Provider Internal Change Team” to guide the effort. We describe an assessment process to determine needed changes and how to develop an Organizational Action Plan, including strategies to facilitate change.²

The work environment, also referred to as the “organizational culture,” is a rather abstract but very important concept which ultimately will determine the success of consumer hiring within an agency. For purposes of this discussion, we define the working environment as the context in which individuals at a given organization interact to accomplish their shared mission. Some of the factors that contribute to the organizational culture are:

- the organization’s structure, mission, and general philosophy;
- the roles, values, and attitudes held by individuals in the organization;
- the policies (spoken and unspoken) which govern the organization; and
- the physical environment of the agency.

The best place to begin in hiring consumers is to analyze the current working environment, and identify those aspects of the culture which present obstacles to the integration of consumers on the staff. We already have discussed the barriers that stigma and discrimination can create for consumer providers and have touched briefly on some ways of addressing them. In what follows, we present more systematic ways of identifying needed changes in the philosophy and practices that make up the organizational culture.

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Developing an Organizational Inclusion Framework

In conceptualizing the changes an agency will go through in creating a consumer-friendly agency, we suggest thinking in terms of an “Organizational Inclusion Framework.” This is basically a plan for encouraging active consumer involvement in all levels of an agency’s practices, particularly in the form of paid service-delivery positions. This type of consumer involvement requires acceptance of consumers/survivors in a variety of organizational realms in which they may not have been accepted in the past. Further, it suggests that all existing (and new) staff members come to endorse the idea that peer providers have unique perspectives and skills to bring to rehabilitation and treatment. The development of this Framework often requires restructuring of an agency’s culture, mission statement, values and goals, composition of personnel and leadership, as well as management practices. Ultimately, an Organizational Inclusion Framework can be utilized as a standard against which agencies evaluate their progress towards and outcomes of full inclusion.

Although there should be common elements in all Organizational Inclusion Frameworks (e.g., peer providers on staff, inclusion of consumers on the Board of Directors, surveys of clients/staff for their suggestions, etc.), it is important that each agency develop a Framework that meets its own unique management needs. As the individuals within your agency work through the process of implementing change, you will adapt models and recommendations in different ways and will generate new ideas that work best within your own agency.

Appointing a Peer Provider Internal Change Team

As described below in Figure 1, to facilitate the change process, we recommend that agencies appoint a “Peer Provider Internal Change Team.” This is a group of individuals who are particularly motivated to inspire and give direction to ongoing changes regarding consumer hiring. This Team will be responsible for developing and translating plans for change into a familiar and non-threatening message that can be persistently and clearly delivered to everyone.

The Change Team should include representatives from all of the diverse departments, branches, and job positions in the agency. The members must be able to make a time commitment to this work, have personal and professional competence in dealing with oppression and empowerment, and be respected by peers, subordinates, and superiors in the organization. It is best to rotate membership every two years to ensure that new ideas are continually represented in the work of the Team; this can also be accomplished with periodic formal or informal surveys of the agency’s staff members and clients to assess the relevance and effectiveness of the Team’s efforts. Ongoing evaluation of organizational change, conducted on an annual basis, is a key strategy for ensuring that momentum is maintained and proceeds in the desired direction.
Figure 1

I. Appoint Peer Provider Internal Change Team:

Selection of a group of individuals who will lead the agency through the process of identifying and implementing needed changes to create an equitable work environment.

- Strategies:
  - Identify individuals who are most enthusiastic about consumer hiring.
  - Ask for volunteers.
  - Select one or more individuals from each team, branch, department at the agency.
  - Use a pre-existing group that was formed to address related issues.

Conducting an All-Agency Assessment

The work of the Change Team should begin with an all-agency assessment. This type of assessment measures both attitudes and knowledge about consumer hiring, in order to identify barriers to and supports for inclusion of peer providers. The Change Team can utilize the information gathered to develop the individualized aspects of its agency’s Organizational Inclusion Framework. Typically, integration of consumer providers in community-based rehabilitation settings is the end result of a lengthy process with many complex stages. As shown in Figure 2, it is helpful to begin with a comprehensive agency assessment that addresses four major questions:

1) What are the agency’s ultimate goals regarding the inclusion of consumer providers?

2) How do the agency’s procedures and practices support or inhibit full inclusion of consumers?

3) How far along is the agency in attaining its goals?

4) What do existing staff members think about consumer hiring?

An assessment of this type requires involvement of everyone who has a role within the agency, including the clients, clinical and administrative personnel, and the Board of Directors. This is particularly important because an all-agency assessment typically reveals necessary changes at individual and organizational levels which will require commitment from all members of the organization.
II. Conduct an All-Agency Assessment:

A four-step assessment addressing questions about the agency's ultimate goals and progress toward the inclusion of consumers as service providers.

The four major questions are:

1) What are the agency's ultimate goals regarding the inclusion of consumer providers?
2) How do the agency's procedures and practices support or inhibit full inclusion of consumers?
3) How far along is the agency in attaining its goals?
4) What do existing staff members think about consumer hiring?

Assessment Methods. There are many ways to proceed with an assessment. Some useful methods include:

- paper-and-pencil questionnaires/surveys,
- in-person interviews with as many staff members and clients as possible,
- focus groups with different contingents within the agency, and
- a series of meetings where everyone comes together to discuss their ideas and feelings about the direction of the agency and consumer hiring (meetings may be facilitated by an outside moderator).

It is best to employ more than one of these methods of assessment since each will result in different types of information. Also, some individuals may find one method easier to respond to than another. Given the broad scope of the questions to be addressed, it is best to conduct the assessment in stages, addressing one or two of the major items at a time. Particular assessment methods may be best suited for particular questions or people, depending on the topic. For example, anonymous surveys are best for consumer staff who have not disclosed their history to everyone at the agency.

In the following sections, we discuss each of the four questions of an all-agency assessment. We consider the purpose and content of each question, and methods that best address the topics. For each step, we also present possible strategies for change. The information presented on each part of the assessment is summarized in a box within the sections.

Assessment Step One: Envisioning the Ultimate Goal

Depending upon the agency's history with consumer hiring, a clear definition of the goal it is trying to accomplish may be as specific as, "to have five consumer case managers on staff within two years," or as general as, "to work with staff members to help them understand and
value the need for peer providers during the next year.” In general, the vision of the end goal will evolve over time as members of the organization change and grow. Further, agencies may have two or three goals on which they are working that are related to hiring peer providers in general and to consumer empowerment overall.

Ideally, the Change Team should use its all-agency assessment to determine the ways in which staff members view the ultimate goal(s) of the organization. As further detailed below, the data they collect should be compared to the agency’s existing program mission, values, and culture to determine areas that need immediate attention. In this way, everyone in the agency is involved in the creation of a common vision or set of goals. Further, by envisioning the end goals together, a group of individuals, who have different roles in the organization, is able to share its perceptions about what is happening at the group level. They are thinking beyond their particular roles to how the whole organization functions, both ideally and in reality. By involving all personnel in the assessment process, the Change Team increases the likelihood that most staff members will become committed to growth and change.

Step 1: Questions. As shown in Figure 3, questions about the future direction of the agency include what staff members believe the current agency mission is and what they think it should be. The assessment also determines barriers staff members encounter in trying to fulfill the agency’s mission. In other words, as discussed below, staff members should be able to directly tie the program mission to their daily work. Additionally, it is useful to ask staff members what they themselves would like to see changed in the program mission and goals, in order to determine not only the priority they assign to consumer hiring, but other changes that they would recommend. Consideration of the complexity of staff needs in this manner may help reluctant individuals to feel more amenable to the changes suggested by the Team that are specific to the peer provider initiative. Ultimately, however, the desired outcome of this part of the assessment is to reach a consensus regarding the agency’s mission and goals with respect to consumer hiring.

Step 1: Strategies for Organizational Development. It is likely that the assessment will reveal needed changes in organizational mission, values, and culture in order to support inclusion of consumer providers. In all probability, many agencies will find that there are discrepancies between their ideal and actual program missions of empowering clients by helping them to become self-determining agents of their own change. Recognizing this discrepancy when it exists, and working to reconcile the real and the ideal, may be the greatest challenge posed by the consumer hiring initiative. Yet, as hard as it may be, to bring the agency’s mission, values, and culture in line with its goals is to establish the structural integrity of the Organization Inclusion Framework.

Agency Mission Statement. Based on the first question of the assessment, the Change Team is likely to find that the next step is to rewrite or refine the program’s mission statement. There are many variables that differentiate mental health agencies, for example, size, people served, and types of services provided. Even programs within the same agency may differ in
many ways. However, the thing that holds an agency together, the “cohesion factor,” so to speak, is the program mission. Through it, insiders and outsiders should be able to determine what an agency does and why it functions as it does. In a well-run agency, everyone involved in the organization is able to articulate the mission of the program. This does not necessarily mean that everyone agrees about the nature of psychiatric disability and its treatment, but that the objectives of the agency are clearly defined. This cohesion creates a reference point for all interactions. While practices will change over time, as knowledge of disability expands and new technologies evolve, the mission of the agency should remain a solid foundation permitting growth and change without chaos and upheaval.

The Change Team should work to create an organizational mission that describes not only clients to be served and program goals, but the agency’s values and beliefs about the rights of people with psychiatric disabilities. The Team should ensure that a fundamental belief in equality and self-determination for consumers -- which includes their right to hold paid and/or volunteer positions in service delivery programs -- is clearly conveyed in its mission statement. Once developed, the new mission should be reviewed by all staff members and clients and, to the degree possible, refined based on their feedback. If an agency has a large staff, serving numerous clients, it may be best to gather feedback about the new mission in staff and team meetings, individual staff supervision sessions, and/or client skills training or support groups. The agency mission then must be conveyed to everyone participating at every level of the program, including clients, staff, administrative personnel, and all individuals representing the agency to the community (e.g., development department staff, researchers/evaluators, members of the Board of Directors, etc.).

Incorporating a statement about consumer empowerment into all written materials about the program also will demonstrate that it is an important part of the organization’s mission. This includes personnel handbooks, client handbooks, training materials for new staff, agency brochures, and other important documents that are disseminated among the staff and public. The following example of such a statement can be expanded and modified to suit any program:

_The philosophy of our agency places central importance on the dignity and empowerment of its clients. Client input is sought and incorporated in all therapeutic and nontherapeutic interactions with staff, and clients have the final say in what services they will receive and from whom. Although the agency milieu is informal and status differences between clients and service providers are discouraged, clients and staff are expected to treat one another with respect and consideration at all times. All members of the staff are expected to honor this professional stance and behave accordingly._

_Implementation._ The Change Team could then recommend an orientation period for consumers and personnel new to the agency to help them learn about the new organizational culture. Additionally, it is important for the Team to discuss with agency administrators what supervisors will do to help people who are having difficulty accepting the refined mission,
Figure 3

Step 1: Envisioning the Ultimate Goal

Create a clear image of the goal(s) that the agency is striving to achieve, particularly for integrating consumer providers on the staff.

Sample Questions:

- How would you state the current agency mission?
- What do you think the agency mission should be?
- What are your goals for integrating consumer providers on the staff?

Possible Methods:

- Facilitate focus groups.
- Arrange individual interviews with people from all parts of the agency.
- Interview pre-existing groups at regularly scheduled meetings.
- Distribute a brief written questionnaire.

Analysis:

- Pick out key words, phrases, ideas, and goals that are common among participants' responses.
- Did the participants convey a consistent agency mission or did they see the agency's mission very differently?
- Identify discrepancies between the current mission and people's goals.
- Identify discrepancies between current agency mission and what people think it should be.

Strategies:

- Write a new Mission Statement.
  - Describe the clients to be served.
  - Describe the program goals.
  - Express the agency's values and beliefs about the rights of consumers.
  - Make the Mission Statement self-explanatory.
- Everyone at the agency should review the Mission Statement and offer feedback.
- Revise the Mission Statement based on feedback.
- Advertise it! Let everyone involved with the agency and the people in the community know what the new Mission Statement is.
- Revise agency documents (e.g., brochures, personnel policies, client handbooks) to include the new Mission Statement.

values, and culture. In general, it will probably take some people a good deal of time to adjust to new ways of thinking about consumers and their roles within the system, and these individuals may need some extra support from their supervisors and coworkers. The more the Change Team
involves everyone in the process of change, from the first goal-setting stage, the more people will feel a part of it, rather than that change is being imposed on them. It is important to give members of the staff the time and support they need while, at the same time, recognizing that the transition may be too uncomfortable for some, causing them to eventually leave the agency. Staff turnover during times of significant change within an agency is to be expected, but proceeding sensitively and encouraging staff involvement from the beginning should help to prevent too much upheaval within the organization.

Assessment Step Two: Connecting Program Mission and Culture to Practices and Procedures

Reevaluating and refining the work environment is a necessary first step to achieve inclusion of peer providers, but is not sufficient to create lasting change in and of itself. An agency must then move to reviewing and modifying its procedures and practices. The question that must be asked within each agency at this second stage of the assessment process is whether the organization’s procedures and practices support or inhibit progress toward the agency’s goals (see Figure 4). In considering this question, individuals at many organizations would have to admit that although consumer self-determination is identified as among their most important goals, they often do not truly integrate the self-identified needs of consumers into their daily activities. For example, while most agencies emphasize moving at the consumers’ own pace, clients who choose to work towards maintaining community living, creating social networks, and/or becoming employed tend to attract more agency resources -- such as staff approval and time -- than do clients who do not or cannot work towards these goals. Again, a major purpose of conducting an agency assessment is to make such discrepancies apparent so that they may be addressed.

Probably the best source of information about practical barriers to full inclusion of consumers on staff are peer providers themselves. If there are consumers currently on staff who have made their history publicly known, a meeting should be convened to safely discuss ways that the structure of the work environment enhances or detracts from their ability to participate fully in the functioning of the agency. If there are no identified consumers on staff, it may be possible to interview consumer professionals in neighboring mental health agencies. Former clients who have gone on to work in social services should be interviewed as they may provide particularly valuable feedback given their knowledge of the agency. Current clients, especially those who are trying to take leadership roles within the agency, also will have important information regarding ways in which the agency encourages or discourages their movement into positions of power.

Step 2: Questions. Conducting an assessment regarding agency procedures and practices with consumers and consumer professionals may involve no more than asking the questions, “Are there things that we do at this agency that make it difficult/easy for you to feel comfortable working here?” If these general questions do not provide enough information, there
are specific questions that could elicit more detail. For example, there are many questions around the issue of disclosure of one’s disability to supervisors, coworkers, and clients (e.g., who to tell, how much to tell, when to tell, etc.). In fact, this issue may serve as a “barometer of inclusion” since it is likely that disclosing one’s disability will be less difficult in a work environment that is accepting of consumer professionals than in one that is not. Another important topic for discussion in this area is formal and informal practices that are supportive of consumers and those that are stigmatizing or discriminatory. Examples of practices which may be explored are:

- the allocation of various resources such as space or funds for special activities;
- the language and attitudes used when discussing clients/consumers (even when they are not present); and
- the dynamics of established decision-making processes (e.g., who gets power, what happens when consumers challenge decisions of nonconsumers, etc.).

Procedures for recruiting job applicants, hiring new staff, and providing job training and continuing education should be reviewed in light of the consumer hiring initiative. Related to this is the agency’s response to the Americans with Disabilities Act, which is discussed in greater detail in Chapter 11. All agencies should have some established procedures for ensuring that job applicants with disabilities are not discriminated against and that reasonable accommodations are made for those employees with disabilities who request them. Conducting the second part of the assessment provides an opportunity to learn how well the agency has responded to the ADA and how receptive it is to requests for reasonable accommodations. Not only is this information an indication of how well the organizations’ procedures meet the needs of its consumer professionals, but it is also valuable in light of the potential legal ramifications of inadequate policies.

These are just some of the daily activities and procedures that may be addressed in this part of the assessment, and each agency will have different practices to review and analyze. This part of the assessment also can provide insight into whether established organizational practices help all staff members to experience their work as meaningful and to feel invested in their work. Such feedback can point the direction for revisions to existing practices and procedures that could not only foster inclusion of consumers/survivors at all levels of the organization, but improve the work environment for everyone.

Step 2: Strategies for Organizational Development. There are some general strategies that agencies may find helpful in responding to the need to alter activities to be more inclusive of consumers. We assume an initial goal of most agencies will be to get more consumers on staff. Depending upon the results of the assessment, recruitment and hiring practices for staff positions may need to be revised in order to accomplish this goal. The Change Team should first review the agency’s organizational chart in order to determine whether consumers are represented at all levels of the organization (if they do not know already) and to identify particular areas in which consumer involvement is lacking. The Team might then recommend the creation of a Personnel
Committee, at least half of which would be consumers/survivors. All job applicants would be interviewed by this Committee to ascertain the applicants' commitment to client self-determination, promoting consumers as colleagues, and their ability to help clients realize their full potential. This Committee also would be responsible for reviewing (and rewriting, if necessary) all job descriptions, so that they are reflective of the agency's commitment to equality and self-determination, as well as to accommodate the needs of people with disabilities. This Committee would be involved in ensuring reasonable accommodations for employees, upon request. Appointing consumers to the agency's Board of Directors also can ensure that consumer perspectives are represented when important decisions are made regarding the agency's policies, future goals, and methods for achieving them.

On a daily basis, strategies should be implemented to try to foster open communication between staff members so that an environment in which people trust one another is encouraged. Relationships between staff members and their supervisors are of primary importance, and thus, should be strengthened and nurtured, so that supervisees feel freer to discuss work-related problems. If time for regular (weekly or biweekly) supervision is not already provided at the agency, making this time will be critical for developing supportive relationships between supervisees and supervisors, which are especially crucial in times of major organizational change. Creating time and structure in which to foster other supportive relationships between staff members can increase the likelihood that open communication will occur. Establishing a mentorship arrangement in which new staff members (consumers and nonconsumers) are paired with senior staff persons (who are not their supervisors) to whom they can go for advice and support can help to encourage the development of supportive relationships. A consumer provider support group also might be started. Social gatherings and team meetings, as well all-staff and all-agency retreats, are other settings in which relationships may develop.

Encouraging open discussion of agency practices and policies that inhibit full inclusion of peer providers also means that staff may have difficulty dealing with heightened criticism and conflict. These are certainly good topics for inservice staff training, and local and national experts can be brought into the agency to share their advice for coping with conflict and change. Agencies also might consider creating a Mediation Committee, again including adequate representation of consumers, which would be called upon to negotiate disagreements or difficulties between peer providers, consumer and nonconsumer providers, and supervisors and supervisees.

Many of the suggestions we have made may be procedures and practices that already exist in the current organizational structure. For example, a well-run agency may have in place a support system for staff which includes regular clinical supervision, mentorship arrangements, and many opportunities for staff to interact and develop their relationships. Any features of the environment that enhance feelings of community, general morale, dedication to the agency and its mission, and a sense of participating in an important process will be significant advantages for
Step 2: Connecting the Program Mission to Practices

Determine whether the organization’s procedures, policies, and practices support or inhibit progress toward the agency’s goals.

Sample Questions:
- Are there things we do at this agency that make it difficult/easy for you to feel comfortable working here?
- (For identified consumers only) How did you feel about disclosing your psychiatric history to your colleagues at this agency?
- (Using anonymous survey only) Are you a consumer of psychiatric services? If yes, have you disclosed this to any of your colleagues?
- Are there any formal/informal practices or policies that are discriminatory?
- Does this agency actively recruit consumers into positions at all levels?
- Are opportunities for training and continuing education provided for all staff?
- Are supervisors responsive to staff members’ requests for reasonable accommodations?

Possible Methods:
- Create a forum for identified consumer professionals to discuss their work experiences.
- Interview consumer providers from other agencies.
- Interview current clients in leadership positions in your agency.
- Hold separate focus groups with identified consumer providers and other staff.
- Develop an anonymous questionnaire.
- Review the agency’s organizational chart in order to determine the representation of consumers at all levels and identify areas in which consumer involvement is lacking.

Analysis:
- Target specific formal/informal practices or policies which make respondents feel uncomfortable or are identified as discriminatory.
- Identify features of the organizational environment that promote integration.
- Determine how comfortable members of the staff feel about disclosing their psychiatric histories to their colleagues.
- Determine needed changes in recruitment, hiring, and training procedures.
- Ascertain whether the agency is in compliance with the Americans with Disabilities Act and is responsive to requests for reasonable accommodations.

Strategies:
- Revise policies in accordance with findings.
- Improve recruitment of consumers into staff positions at all levels of the organization.
- Create a Personnel Committee with at least 50% consumer representation.
- Review and rewrite job descriptions to reflect commitment to consumer hiring.
- Ensure that requests for reasonable accommodations are reviewed and granted fairly.
- Appoint consumers to the agency’s Board of Directors.
agencies that desire to promote consumer hiring. These assets should be identified through the assessment process and nurtured, while other areas that are not as conducive to promoting inclusiveness are changed.

**Assessment Step Three: Determining Readiness for Change**

A critical part of the agency assessment is to determine the organization’s readiness for change. As discussed above, clarifying the relationship between the agency’s mission and its existing procedures and practices can reveal many of the strengths and challenges that will be brought to the change process. Thus, this next stage of the assessment allows the Change Team to identify resources that are available to assist in accomplishing change. These resources might be current practices that promote consumer empowerment, a supportive administration, the physical layout of the agency, or any other features of the organization that may facilitate hiring consumers. At this point, it can be helpful to ask members of the agency directly — although anonymously — about their feelings regarding the agency, how it functions currently, and what they would like to see changed.

**Step 3: Questions.** As delineated in Figure 5, in conducting this step of the assessment, a survey might be developed to ask individuals what they admire most and least about the agency; what they see as the organization’s greatest strengths and weaknesses; and how optimistic or pessimistic they are about the chances for positive change to occur within the agency. This part of the assessment should ascertain whether there is general support for change at all levels of the agency (e.g., clients, staff, administration, etc.). Additionally, it is important to gather not only people’s opinions, but also some tangible evidence of support for this change from all levels of the organization. To this end, it may be helpful to review the agency’s “track record” in terms of introducing innovative ideas that have led to lasting changes within the agency’s mission, structure, policies, and procedures. Being able to remind staff members of similar major changes in the past and the success with which they were implemented may help them to envision and have faith in the current process and its eventual outcomes.

**Step 3: Strategies for Organizational Development.** Given the scarcity of time and money -- key resources in the change process -- in most settings, it is especially important to accurately identify during the assessment existing resources that can streamline the work involved. As an example, many of the strategies that we have outlined thus far require meetings to be held and committees to be formed. In all likelihood, individuals at the agency feel that they attend more than enough meetings already. Therefore, as much as possible, the Change Team should seek to utilize existing meetings for conducting assessments and utilize existing groups to form committees. Furthermore, while the work involved in preparing the organizational environment for peer providers will take time, there most likely are a number of other tasks each day on which individuals are spending time unnecessarily. The assessment can be a tool for determining what these tasks are and ways to phase them out.
Figure 5

Step 3: Determining Readiness for Change

Determine the agency’s readiness for making the changes that will be needed to accomplish the organization’s newly established goals.

? Sample Questions:

- What do you like most about this agency? What are the agency’s greatest strengths?
- What do you dislike most about this agency? What does the agency have difficulty doing well?
- Are you optimistic or pessimistic about the chances for positive change to occur within this agency?
- Is support for change demonstrated at all levels of the agency (e.g., consumers, staff, administration)?
- Is there evidence from previous experience that indicates that significant change within the organization is possible?
- What resources does the agency have to draw from to make consumer hiring work well (e.g., good consumer provider role models, staff training programs)?
- Are there resources (including staff time) that currently are being used inefficiently that could be re-allocated to assist in the change process?
- Are changes in the physical layout of the agency needed for integration of consumer providers to occur (i.e., are areas designated only for clients or staff)?

▲ Possible Methods:

- Conduct individual interviews with constituents from all parts of the agency.
- Facilitate focus groups.
- Hold a brain-storming session with the Peer Provider Internal Change Team to identify the agency’s resources that will facilitate the change process.
- Interview “old timers” at the agency (or those who have left over the past year) about the changes the agency has been through over the years and their recommendations for facilitating future changes.

■ Analysis:

- List the factors and features of the agency which indicate support for the goal of integrating consumers on the staff.
- List factors and features of the agency which are barriers to accomplishing the organization’s mission.
- List available resources (e.g., money, people, time).

◆ Strategies:

- Utilize existing structures (e.g., scheduled meetings, existing groups) as much as possible to reduce the demand for additional resources.
- Phase out activities that are not related to the agency’s mission.
- Train staff on the principles of “total quality management.”
Staff trainings regarding the principles of "total quality management" would be useful in this area, since one of its major tenets is reducing tasks that people cannot clearly identify as efficient and effective in fulfilling their agency's missions and goals. Similarly, the Change Team also should analyze whether daily operations and external regulations have become the end of programmatic activities rather than the means. They can recommend that any activities that staff members and clients cannot directly tie to fulfilling the program mission be dropped or refined accordingly.

Along these lines, financial resources may be needed in order to make some types of changes possible (e.g., money to hire consumers into newly created job positions, money to bring in experts for staff training, etc.). Whether such funds are allocated may very well be the primary test of the organization's commitment to change from the top administrative levels on down. In other words, in most cases, there must be a willingness to allocate resources (financial and otherwise) to this initiative for it to succeed. Again, however, the demand for financial resources may be minimized by evaluating whether there are current drains on agency funds that can be reduced or eliminated, given the agency's desire to succeed at consumer hiring and full inclusion.

**Assessment Step Four:**

**Improving Individuals' Perceptions and Understanding of Consumer Hiring**

As we discussed in the previous chapter, an agency is made up of individuals, each with her or his own set of values, beliefs, levels of knowledge, and ways of doing things. Thus, it is important to understand how each individual sees herself or himself as related to the whole and how each person feels about hiring consumers as service providers. The logical next question, then, is whether or not individuals are able and/or ready to take on a commitment to change.

**Step 4: Questions.** As outlined in Figure 6, in order to assess individuals' goals and perspectives regarding their roles within the agency, the Change Team can request that staff members share their ideas about what motivates them to be involved in service-delivery, how they feel about mental health consumers working as service providers, and ways in which they think their jobs might be enhanced and/or made more difficult by working with peer providers. It also is important to ascertain the level of knowledge among the staff about consumer hiring. To this end, the Change Team could assess what staff members know about the philosophy and history of the consumer hiring initiative, the various models of consumer service provision, and the advantages of utilizing peers in paid and/or volunteer staff positions. Evaluating levels of knowledge is done with the belief that most people find it hard to accept that which they do not understand or about which they are misinformed.

This part of the assessment is likely to reveal attitudinal and structural barriers that were discussed in the preceding chapter including: cultural attitudes and myths, power dynamics, and changing relationships between consumer and nonconsumer staff persons. Confronting these issues is bound to introduce a high level of uncertainty, and perhaps even distress, into the
change process. However, it is our view that unless these issues are directly addressed, full inclusion and empowerment of consumers is seriously compromised. As detailed below, there are a number of strategies at both the individual and group levels that can be utilized to begin to address these barriers to inclusion.

**Step 4: Strategies for Organizational Development**

**Consciousness Raising.** One of the first steps to overcoming issues of stigma, discrimination, and fear is consciousness-raising about these issues. Individual assessments, group meetings, and similar exercises are good ways to raise awareness about consumer empowerment and hiring. Time could be set aside during regularly scheduled meetings (e.g., staff meetings, team meetings, board meetings, community meetings, etc.) for such discussions, or special meetings could be called. A professional group facilitator may be brought in for one or more special sessions to assist those within the agency to work through their feelings about the changes they are making.

Because service recipients and providers are likely to have different concerns, they may choose to meet separately for some of these discussions. Similarly, nonconsumer and consumer staff persons also may wish to meet in separate groups to discuss these issues. Although some may worry about the ethics of separate meetings, this may be necessary at first so that nonconsumers and consumers feel safe in airing their concerns, personal biases, and fears. If separate meetings are held, however, they always must be facilitated by a person who, although sensitive to people’s hesitations, is a staunch supporter of the consumer hiring initiative. At some point, all parties also should meet together since it is important for everyone at the agency to be aware of how others are feeling and the impact that consumer hiring has on them.

An outside consultant also may be brought into an agency to confidentially interview all or key members of the staff regarding issues they worry about or have encountered when working with or supervising consumers, and how they might feel about being supervised by consumers. This consultant could then compile all the concerns and support for hiring consumers into a report to be discussed by the Change Team, staff, and clients, if appropriate.

**Inservice Training.** It can be helpful for agencies to arrange for training about the many factors that have an impact upon successful consumer hiring, including but not limited to: attitudes about mental illness, stigma, and power dynamics, as well as cultural beliefs and value systems. When addressing the issues that arise from consumer hiring, agencies also would benefit from staff trainings regarding conflict resolution, team building, job satisfaction and burnout, successful clinical supervision, managing change, and working with persons from a variety of cultures and/or oppressed communities.

In general, staff training will be needed at every stage of the process of consumer hiring. For example, inservice training for all members of the staff about the issues that arise when consumers transition from the role of client to coworker may help this process to go more
Step 4: Improving Perceptions and Understanding of Consumer Hiring

Determine whether or not the individuals in the organization are ready and/or able to change.

Sample Questions:

- What motivates you to be here each day?
- How do you feel about mental health consumers working as service providers? What are your concerns?
- Are there ways in which you think your activities at this agency might be enhanced by working with consumer providers?
- Are there ways in which you think your activities at this agency might be made more difficult by working with consumer colleagues?
- How much have you read/heard about the consumer hiring initiative and models of consumer service provision?
- Have you thought about, or experienced first-hand, the advantages of utilizing peer providers?

Possible Methods:

- Conduct individual interviews with constituents from all parts of the agency.
- Hold separate group discussions with clients, consumer providers, staff persons not identified as consumers, and administrators.
- Distribute anonymous questionnaires.
- Suggest exercises to encourage individuals to explore/express their attitudes and values related to consumer empowerment and hiring.

Analysis:

- Identify attitudinal barriers that may impede the process of integrating consumer providers on staff.
- Identify topics on which training is needed and the groups that could benefit from the training.

Strategies:

- Provide forums for ongoing discussion, consciousness-raising, and training.
- Identify experts to provide technical assistance as needs arise.
- Bring in a professional group facilitator to assist groups in working through their feelings about the changes they face.
- Provide staff training on conflict resolution, team building, job satisfaction and burnout, successful clinical supervision, managing change, and working with persons from a variety of cultures and/or oppressed communities.
- Create a resource library of materials related to consumer hiring and make time for people to read.
smoothly for everyone. Even when peer providers are well-integrated and things seem to be running smoothly, additional training may be needed to help coworkers make reasonable accommodations when necessary, to assist supervisors in working well with consumer colleagues, to help peer providers recognize situations in which they need to ask for support and to feel comfortable doing so, to explore areas in which stigma or inequality are problematic, and other similar issues. Time also should be set aside for reading literature specific to the agency, articles describing the treatment model(s) on which services are based, and research studies regarding the efficacy of various services. Opportunities for personal development and to learn new skills (within and outside of the agency) should be provided in order to help increase job satisfaction and reduce burnout.

Creating an Organizational Action Plan

As is always true of assessments of this type, it is crucial that the Change Team provide information as soon as possible about the assessment results and subsequent action steps to everyone in the agency. It is desirable to start by developing a concise and easily understood “Organizational Action Plan” that addresses each of the four areas of the agency assessment, since attention or change is likely to be needed in each of these areas (see Figure 7). Because resources to implement programmatic transformation often are scarce, agencies should use their assessments to determine where efforts are most needed. The Team should create one-year and three-year plans based on the results of the assessment, clearly outlining both the findings and recommendations for organizational changes. This document could then be read and discussed in a variety of team meetings and/or individual supervision sessions. A yearly re-assessment also will help to ensure that the change process is on track and will identify areas in which new issues have arisen.

| Figure 7 |

III. Develop an Organizational Action Plan

*Develop a concise, easily understood document that clearly outlines both the findings and recommendations for organizational changes.*

**Strategies:**

- Create 1-year and 3-year Organizational Action Plans.
  - Utilize information gained in all four areas of the assessment in developing plans.
  - Schedule time to discuss the plan and use every opportunity to generate support for its implementation.
- Create forums for addressing ongoing issues.
- Continually re-evaluate how the change process is proceeding and revise the plan as needed.
- Involve as many people as possible in the activities of the plan. Develop opportunities for individuals to become invested in the plan’s success.
Preparation and Integration

It is important to point out the need for individuals to strive to remain flexible and realistic about what an agency can accomplish and how long it will take. Certainly, it is very difficult to anticipate in advance every issue that hiring consumer professionals will create at an agency because many of the norms within a work environment are unspoken or informal practices that are generally taken for granted. Only when a change occurs within the existing system do these subtle patterns become apparent and are called into question. It may be that people are not consciously aware that they are doing something that is seen as problematic, or even, discriminatory. For example, we have heard about situations at some agencies in which separate bathrooms are provided for staff members and clients. When these agencies hired consumers from their own programs, the former clients naturally looked to other members of the staff as models of appropriate workplace behavior. Yet, when consumer colleagues used the staff bathrooms, they frequently encountered irritation and resentment from coworkers. Clearly, the consumer professionals were not yet seen as equals by their colleagues, and their transition to a staff position had not been clarified in advance. (Some might suggest that these agencies follow the model of clubhouses, allowing that no space be “off-limits” to consumers or limited to staff only.)

It is likely that few people are aware of the double standards which exist within their agencies until someone violates the established norm. When this occurs, individuals need to consider their unspoken rules regarding office etiquette and whether these are appropriate given their goal of hiring consumers and creating a workplace that is comfortable for them. This is why, as mentioned above, it is important for staff and consumers to reassess the program’s mission and goals to ensure that they remain comfortable, fair, and empowering to all involved. Nevertheless, no matter how much an agency prepares in advance for consumers to join the staff, some issues will arise which no one had anticipated. Part of the preparation process, therefore, should involve creating forums to address ongoing issues and fostering open communication so that new issues are discussed as they arise. These group forums should focus on general issues rather than discussion of situations involving particular individuals.

Change is Hard. There is no doubt that trying to change an organization and its staff is a very difficult process. Anyone who has undergone a major life change (e.g., getting married, moving to a new city, changing jobs, having a baby, etc.) can understand how difficult it can be to adapt to a new situation. “Change is a developmental process that requires personal adjustment.”10 People naturally resist change because it is challenging, and raises many complex issues. In making both personal and organizational changes, one must question basic values, beliefs, and habitual ways of doing things. Just asking the questions can be distressing because one must consider the possibility that the way things have been done may not be the best way. There may be a great deal of investment in the status quo and to ask oneself and others to give that up may meet with significant resistance. It is important for all involved in implementing organizational changes to understand that resistance to change is natural, to recognize the stress
and fear that change provokes for many people, and to respond in an empathic manner without compromising the ultimate goals of inclusion and equality. 11

Summary

In this chapter, we have focused on ways in which individuals can restructure their programs to fully integrate consumer providers. We have referred to this as a process of developing an Organizational Inclusion Framework. Much of this process involves serious questioning about the goals, mission, and daily practices of one’s organization, as well as the values and biases of individual staff members. Thus, strategies for assessing an agency’s ultimate goals and how far along it is in attaining these goals were presented in order to initiate this questioning process. We recognize that agencies are likely to confront many barriers to the full inclusion of consumers/survivors on both the individual staff and organizational levels, and thus, have presented various strategies for overcoming these difficulties.
Endnotes

Chapter 5


11. Ibid.
Chapter 6:
Strategies for Hiring Consumers and Avoiding Tokenism

I don't know if you can actively go out and hire consumers so much as you have to actively remove the barriers to hiring persons with a history.
- Kathleen Wilson\textsuperscript{1}

Overview: This chapter begins by outlining the many ways in which consumers may be employed within mental health settings. Competitive employment is emphasized as the approach which has the greatest possibility for consumers to achieve full equality in the workplace. This level of employment may be seen as the final step in a career ladder which offers a full array of employment options for individuals depending upon their level of training and preparedness to take on new responsibilities. Affirmative action policies are discussed in light of both their negative and positive consequences with the conclusion that such policies for consumer hiring should be part of a broad plan to encourage greater diversity within the workforce. Strategies for recruiting qualified consumers are presented, and involving them on hiring committees is encouraged. Tokenism is discussed as a common pitfall encountered by many agencies trying to increase consumer involvement and hiring. Typical mistakes that lead to tokenism are mentioned along with strategies for avoiding them. Co-optation also is presented as a danger for peer providers who may use the power of their professional status in ways that perpetuate the disempowerment of consumers. Establishing equality between consumers and nonconsumers in the workplace is seen as the most effective way of preventing tokenism and co-optation.

Job Configurations\textsuperscript{2}

There are many ways in which organizations might employ expatients/survivors. These positions can be viewed on a continuum ranging from those in which the individual is identified primarily as a consumer who works in a more informal capacity in mental health services to those in which the person is considered to be primarily an employee who may also have a history of psychiatric disability. This distinction is important because it effects agencies' practices regarding compliance with wage and hour laws, benefits, personnel policies, professional liability, billing for services, performance expectations, ADA guidelines, and so forth. The following chart presents some of the many ways in which agencies employ consumers.
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<th><strong>CONSUMER</strong></th>
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<th><strong>EMPLOYEE</strong></th>
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<tr>
<td><strong>Volunteer Work</strong></td>
<td><strong>On-the-Job Training</strong></td>
<td><strong>Created Positions</strong></td>
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<td>Advisory Councils</td>
<td>Peer Counselor</td>
<td>Peer Counselor</td>
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<td>Task Forces</td>
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<td>Drop-in/Self-help Services</td>
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**OPENLY IDENTIFIED** ↔ **PERSONAL CHOICE**

This chart, originally developed by Laurie Curtis (1993), of the Center for Community Change in Burlington, Vermont, lists five categories of consumer employment which begin at the left with those jobs in which the employee is identified as a consumer. Moving to the right across the chart, the individual is more often seen as an employee and may or may not have identified himself as a consumer. A brief description of each of these categories will reveal the expectations of each type of position.

**Volunteer work** is typically unpaid and involves performing any type of activity to support mental health services such as policy-making, governance, service delivery, and public education.

**On-the-job training** positions include a range of vocational rehabilitation placements (transitional and supported employment) and training internships. Individuals typically maintain many, if not all, of their financial entitlements during the training period. Completion of training internships often are prerequisites for holding created positions such as Peer Counselors and Case Management Aides.
**Created positions** are jobs created specifically for consumers. In these positions there is a blurring of the typical distinction between "clients" and "staff" and the individual is considered somewhere in between the two roles.

**Set-aside positions** are existing jobs that the agency has determined may be enhanced by employing individuals who have relevant personal experience in addition to other specified qualifications. Common examples of set-aside positions are homeless outreach workers, crisis support staff, and programs utilizing self-help models such as consumer-operated drop-in centers.

**Competitive positions** may be any position in the agency. Individuals applying for these jobs may or may not be consumers.

**Affirmative Action Policies.** Within the category of competitive employment, agencies may have **affirmative action** policies, giving preference to persons with disabilities in the hiring process. This strategy has its pros and cons, just like affirmative action for ethnic/racial minorities and for women. A negative side to these policies is that by giving preferential treatment to consumer colleagues, they are singled out and treated differently from other employees from the very beginning of the hiring process. The positive effects of affirmative action policies are that they may help to combat discrimination and stigma which persist in keeping consumers “in the closet.” Bob Goodson, expatiant and team leader in the program, Mind Empowered in Oregon, describes the way that stigma and fear of discrimination can hinder the recruitment of qualified consumer providers:

> **It is very difficult to recruit. [At our agency,] we view ourselves as mental health professionals. All of us but one are Qualified Mental Health Professionals, which is the designation [in our state] for Medicaid billing... It made it difficult for us to recruit because of what that standard is.**

One might assume that the explanation for the difficulty of finding consumers to meet this standard is that there are not many consumers out there who have this level of training, but that is not necessarily the case. Rather, “there aren’t that many Qualified Mental Health Professionals who are willing to state that they are, or have been, mental health consumers.”

Affirmative action policies, and other ways of demonstrating the value placed on personal experience, are important to explore in developing methods of recruiting consumer providers. Making consumer hiring part of a broad based plan to ensure a workforce which reflects the diversity of the clients and the community is one approach to affirmative action for consumer hiring, which can help alleviate the negative consequences of preferential treatment.

**Creating a Career Ladder.** This manual focuses mainly on issues around competitive employment and we believe that the ideal toward which agencies should strive is hiring
consumers into competitive positions in which they receive “equal pay for equal work.” A program director described the process his agency went through in progressing toward this ideal:

A few years ago we designated some positions as consumer positions... I think that helped open the door and get the message across to a lot of folks. I think it’s important to do it in that way only as long as is necessary. I think you should fairly quickly move to the notion that consumers can work in many positions beyond the positions that are “consumer positions.” We don’t designate positions any more.

This is not to say that agencies should abolish their training programs, or that all consumers working in the mental health field should hold full-time jobs. Gaining the education and training necessary to be qualified and prepared to take on competitive positions is essential for a successful work experience. Volunteer work, paid and unpaid internships, and on-the-job training programs are good ways to get this training and to ease into the role of service provider. However, agencies must be aware of the possibility of creating dead ends for individuals with an acknowledged history by limiting their access to the full range of employment options in the field. Like anyone else, consumers are concerned with opportunities for advancement. They want to know about education and skill levels needed in order to move up in the system in which they are employed.

Developing some type of career ladder is one solution to the potential problem of restricting consumers’ access to the full array of job types:

You’ve got to give people a chance to work up to something... There needs to be a ladder. It’s a lot of the same kind of things anybody else would want.

For example, make sure that an on-the-job training program does not become an end in itself, but is rather a means for moving toward the eventual goal of working on equal par with other members of the staff, earning the same salary and benefits, and having access to the same opportunities for advancement.

Pacing the Climb up the Career Ladder. While some consumers are prepared to assume the responsibilities of a full-time service provider job without any transition period, others may find it helpful to ease into full-time positions more slowly. Lovejoy and Reinhold suggest that consumers without experience or requisite skills begin the transition to a service provider position by participating in self-help groups to gain training and practice skills. They also suggest that, for consumers interested in developing social service careers, working as a paid or unpaid apprentice is a good way to meet people, acquire and practice skills, and to figure out what tasks and roles are most appropriate for them.

A volunteer position is another way to begin easing into a service provider role. Volunteering will help the individual to determine her level of commitment to the job and
readiness to work, allowing for experimentation and exploration without the fear of losing benefits. The volunteer period provides time for learning the skills needed for the job and learning how the work environment runs. For consumers who have not worked in a while, a volunteer job can help them become reacquainted with the demands of work, such as showing up on time, fitting work into one’s schedule, and having a structured responsibility during the day.

Scheduling work hours to increase gradually over time will make the transition into a job easier for most people. The following “career ladder” can be used as a guide.

**Phase I:** Start with a very small number of work hours per week (8-12 hours/week) in a volunteer or apprenticeship position. This is a reality-testing period in which both the employer and consumer can determine if this is a good job match. Especially if the consumer is receiving job training during this period, she should be given periodic feedback on her job performance (at least monthly during this phase of employment). It is a good idea to evaluate consumers using the same format and criteria used to evaluate other members of the staff holding that or similar positions. Some consumers may benefit from more frequent feedback, and this should be their choice.

**Phase II:** The next step involves the move to substantial, part-time employment (10-20 hours/week paid). During this time there is a status change and the consumer officially becomes part of the staff. The switch from volunteer to paid status provides a sense of validation for the individual, since the agency is demonstrating that it values the consumer’s work and is willing to pay for it. The consumer staff member also must make a more significant commitment when paid status is initiated. As with all staff, periodic evaluation of the consumer professional’s work performance should continue, with the frequency of evaluation determined by the worker’s performance and preference.

**Phase III:** This step involves a move to full-time employment (20-40 hours increasing gradually over time). Individuals’ increased presence at the work setting results in their incorporation into the work environment as contributing members of the workplace with equal voices. At this point, fringe benefits such as health insurance and time off are available to the employee, demonstrating further investment of the agency in maintaining this person’s employment. The advances made during this period should give consumer providers a sense of accomplishment at having met personal career goals. Periodic work evaluations should continue, but may be less frequent (quarterly or annually).

With the gradual increase in the hours worked per week should come slow increases in the number of tasks included in the job. Add responsibilities one task at a time, making sure the consumer provider is comfortable with the job before adding something new. Proficiency will build confidence.

**Losing Disability Income Benefits.** The pace at which a consumer makes the transition to full-time paid employment may be determined by the rules around financial and health care
benefits such as Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI), as well as medical assistance (e.g., Medicare, Medicaid). Fear of losing these benefits can be a major disincentive to work for persons with disabilities. One part of this issue is the fear of failure and reluctance to give up benefits “just in case.” This may hold people back in terms of both their potential financial earnings and vocational advancement, and also may create a psychological barrier to success. This is on top of the reality that a stable income is important for one’s general well-being, whether that money comes from a paid job or from government subsidies. The bottom line is that the money needs to be there, and people are seldom willing to gamble away their benefits for an uncertain job prospect that doesn’t pay a living wage. The sad fact is that the disability payments most people receive from Social Security keep them in poverty. Although it is a frightening gamble, a paid job will likely be a step up financially. At the same time, it is important that employers also provide health insurance that includes mental health coverage and does not exclude pre-existing conditions, or alternatively, pay employees a salary high enough to compensate for loss of benefits and health insurance.9

We asked consumer providers what factors affected their success at their jobs, and Andrea Everett responded,

A wage that makes up for my loss in benefits. That’s the bottom line -- that I can afford to work.10

Of course, a lot will depend on how many hours a person can work. Everett explained her desire to work full-time and give up government benefits:

I felt that I missed out on a lot of the aspects of the job that I enjoyed because of only working 15 hours a week. It just was important. I wanted to be self-sufficient and leave Social Security behind just for my own self-respect and sense of being able to know that I could support myself, that I can rely on myself. Gene [my supervisor] was phenomenal. He even sat down and helped me calculate how much I needed to earn to make up for all of the things [benefits] I would give up.

Working much less than full-time will make it hard to make ends meet financially without benefits, though some individuals may want to work fewer hours. There are “work incentives” developed by government benefit programs to encourage people who have been receiving benefits to work, and may allow people to transition gradually to full-time employment. However, these work incentives vary according to the benefits one receives, and if not understood, often result in barriers or disincentives to work. Therefore, it is important for consumers to understand how working for pay will affect one’s benefits and plan in advance for adjustments in income.11 There are many written resources that are available to explain work incentives and other factors related to how work affects benefits. Some suggestions are:


**Recruitment Strategies**

**Attracting Applicants.** Job postings of available positions, especially those that encourage consumers to apply, provide an opportunity to demonstrate the agency’s desire to hire consumers. The job posting/description should present the requirements of the job in such a way that people understand your agency’s orientation and the type of individual you want to hire. Kathleen Wilson explains the rationale behind openly encouraging consumers to apply for positions with statements in job listings:

...*We definitely put in all our job descriptions: “Direct consumers and family members encouraged to apply.” In some ways we don’t want to label anybody, but unfortunately, historically, people have assumed that their experience is not going to be valued. So we do include that in our job advertisements.*"\(^{12}\)

At every point in the hiring process, there are opportunities to convey an openness or desire to hire consumers. Lori Shepherd describes the combination of strategies used at her agency:

...*Each of the job descriptions has as a minimum qualification of “a well-developed sensitivity towards people with disabilities.” And people with disabilities get extra points. One of the questions [on the job application] is, “What is your experience with people in the disability community?” One of the desirable qualifications is that you have to have experience in, or contacts with, people in the disability community. Plus, people in their letters of hire have to talk about their motivation for wanting the job including personal motivation. A lot of people who are familiar with our agency will disclose [their history of psychiatric disability] either in the interview or in their written application. Plus, when we do the outreach for hiring, we always mail our job descriptions to disability groups. There is a phrase at the bottom that says, “People with disabilities are encouraged to apply.”*"\(^{13}\)
Included in this description of recruitment strategies is an affirmative action statement in which “people with disabilities get extra points.” This type of policy can be effective in increasing the number of consumers on staff. A note of caution, however, is to avoid the tendency to hire people simply because they are or have been consumers, without regard for their ability to do the job. This issue is discussed in greater detail below. Again, agencies choosing to implement affirmative action policies for people with acknowledged psychiatric histories should do this as part of a larger effort to increase the diversity of the workplace. Also, maintaining the goal of providing high quality services as the foremost focus when recruiting new staff will help guide recruitment and hiring efforts in the right direction.

**Getting the Word Out.** Some agencies may include in their Organizational Action Plans (as described in Chapter 5) a goal for the percentage of staff that are persons with a known history of psychiatric disability. Sheila Boltz, a program coordinator in California, explained that her organization did this:

*I don’t think we’ve got a quota but we’ve established a goal (it’s more than a goal because we take it so seriously). There’s a standard that we will have 50% of our staff be consumers. That’s up-front as a stated goal that guides hiring.*

The exact number of consumers to involve in any particular capacity is not absolute. It varies according to the task and the context. Regarding participation on boards, Valentine and Capponi report that the literature generally recommends a range from 25% to 50% or more consumer representation. This goal may be decided by each agency individually, or may be a decision made at the upper-levels of the state or regional mental health system.

In order to achieve such goals, it may be necessary to make special efforts to attract job applicants who are qualified consumer providers. Some outreach strategies that have proven successful are:

- **Advertise in publications consumers read.** Include ads in the newsletters of consumer organizations. Kathleen Wilson makes the analogy to advertising a job for someone who does not speak English. Advertising in the appropriate foreign language newspaper would be a more effective recruitment strategy than using the English papers.

  *If we want to proactively recruit persons with a history of psychiatric disability for jobs, and we are interested in the benefits that a person with a history could offer in certain job positions in particular, then we need to make sure that that is disseminated in their language, so to speak.*

- **Send announcements to the National Mental Health Consumers Self-Help Clearinghouse, the National Empowerment Center, and other national consumer organizations.**
- Post announcements in local drop-in centers, clubhouses, and all other local mental health agencies.

- Post job listings at libraries, churches, or other community centers where consumers are known to go.\(^8\)

- Allow sufficient time for people to respond to job listings (at least 30 days), and include a deadline for responding.\(^9\)

- Use the Internet and computer bulletin boards to announce jobs.

- Get information out through word of mouth. A number of program directors described how they made themselves known as representatives of agencies that promote consumer hiring and now advertising available positions takes minimal effort. These directors know key individuals in the consumer community to tell about job openings who will spread the word.

- Hiring from within the agency is another frequently used strategy. This includes hiring current or former clients, and hiring volunteers. There are many benefits to hiring a "known entity." Hiring from within also creates many interpersonal issues which will be discussed in Chapter 7: Changing Roles, Changing Perceptions.

**Establishing Hiring Committees.** A major point that we heard emphasized time and again in the interviews we conducted is the need to involve consumers at all levels within an agency. Hiring Committees are a good example of where consumer input is very important and, in many agencies, sorely lacking:

*The committee structure is, by its very nature, an attempt to bring different ideas and principles together in order to broaden all perspectives and to make decisions based on a broader understanding of issues. Consumer participation is therefore invaluable: it cannot be duplicated and must not be ignored.*\(^20\)

Lori Shepherd, a consumer advocate, related her experience setting up a Hiring Committee to include persons with disabilities. She outlined the following strategies for avoiding tokenism and getting the right Committee makeup:\(^21\)

- There has to be **more than one consumer on the Committee**.

- Make sure that **everyone on the Hiring Committee has relevant experience** and is otherwise qualified to serve in this capacity. Provide training if needed.

- **Pay people for their time.**
I insisted that people be paid. ... We [consumers] are always expected to donate and volunteer our expertise, and we always are expected to sit alongside people who are getting paid to do the exact same thing.

- **Involve people on the Committee from outside the agency.** Shepherd explained the importance of gaining this outside perspective.

> Involving consumers from outside the agency really stirred things up in the beginning. [People] said, "Well why can’t we use the people already on our staff?" I kept saying, "We have a different interest because we are looking at people as potential coworkers. We need people [from outside the agency] who will look at the applicant... as a person who will be providing services." They would have a different relationship with the person. I might like someone as a coworker, but that doesn’t mean the person is going to be providing good services. I also see this a lot in agencies that have hired consumers. They tend to not go outside [the agency] and get consumer input. They just use who they have in-house, and then, it becomes a very closed process. We’re saying we need to continually open up the process and we continually need to bring in consumers from the community to help guide our work.

**Tokenism**

Tokenism is a common pitfall to avoid in consumer hiring and in consumer involvement on boards and committees. Tokenism refers to a situation in which one “token” individual is chosen (for a job, committee, etc.) simply because they are a consumer in order to give the appearance of inclusion. There are three common mistakes that we heard about related to tokenism and they are described in what follows.

**Don’t Hire Just One Consumer.** Hiring just one consumer is a start, but this action alone will not create desired changes in the workplace regarding the acceptance and integration of peer providers. Being the lone consumer is a very vulnerable position as Sheila Boltz, a nonconsumer and Program Coordinator in Florida, explained:

> I have a fairly large staff (25-30 staff), and when you’ve got one consumer you’ve hired out of 25, it is much harder to integrate that person onto the staff. It is much easier for him to be viewed as a client, not be accepted as a colleague, and have his competencies minimized. It’s also easier for people to relegate him into roles where he is doing less than a full job of someone else.\(^{22}\)

Once Boltz hired more consumers on staff things changed for the better:

> One thing that has made it more successful has been the numbers. It’s hard to have somebody be a token when she represents the majority of your workforce...
Just having those numbers means that people feel like it's an environment in which [consumer hiring] is accepted and valued.23

Gayle Bluebird, Director of the Office of Consumer Affairs in District 10, Florida, remarked how wonderful it is to work in a mental health system in which consumer hiring is accepted, expected, and respected:

It's not just me. I'm not having to hang out there as the one sore thumb sticking out and saying, "This is what needs to happen." We all have made a commitment to this, and we're all very together on it. There are times where I don't even have "to look or act like the consumer" because we all are talking the very same language.24

Don't Hire Just Any Consumer. Programs sometimes respond to the call for consumer hiring from funders or advocacy groups by recruiting every consumer they can find regardless of whether or not the individual is qualified for the job. Program administrators soon realize their error in using this approach:

At first what initially happened is people flooded to this and it was like a committee couldn't happen unless they had a consumer. It's like all of a sudden an unwritten law. I think it did a disservice to people because a lot of consumers were more than anxious to do this, but no one ever trained them. No one ever supported them on how you interact on a committee, how you research information. People in the daily workforce are coming with education in terms of having sat on committees (you sort of grow up in them), and perhaps, some professional education... Most consumers were coming without that. It was very unfair.25

Being a consumer alone does not make one qualified to do a job:

If there's any one thing we've learned over the course of time it's that, if you're going to hire consumer providers, make sure they're qualified, and don't hire them just because they are consumers. If you are going to hire a manager to run an employment program, hire somebody who has management experience and has the background, skills, and talents to do that kind of work.26

Consumer providers tend to agree with this general position as Andrea Everett, from Minnesota Mainstream, clearly states:

I think I'm a provider that happens to be a consumer. So I don't look at being a consumer as a qualification in and of itself. I try to impart that to the people I work with because anyone could get a mental illness. It's not a qualification for anything. I think people can learn to use it to enhance what they are able to do. That is how I try to treat it. It is a disability.27
Don’t Turn to the Same Consumer for Everything. The combined effect of making the previous two mistakes is to turn to the same individual every time there is any call for consumer representation without regard to whether or not he is the best person for the job. Often agencies heap attention and opportunities on the same one or two articulate, highly motivated consumers. Not only does this put the token consumers at risk for burnout, but it also means that only a narrow sample of consumer perspectives will be represented in the system. It is necessary to distinguish between “representation and representativeness.” Consumer representation on a committee does not automatically ensure the representativeness of various consumer constituencies. Similarly, one individual’s participation and support on a committee should not be misinterpreted as broad consumer support for the committee’s activities or decisions.

Another drawback to selecting the same few individuals every time there is a call for consumer representation is that if these individuals are no longer able or willing to take on so much work and responsibility, there will be no one ready to step into their places. One Program Director expressed her concern about this possibility:

> We are very fortunate that we have a number of consumers who easily can lead the way. They are very well-informed. They are very well-read. They are very well-spoken. ...They have modeled for other people... My concern is that, as time goes on and either these folks get hired in other areas, or are no longer interested, or move out of the area, we aren’t seeding new people to be ready to move into their slots.

It is important to make training opportunities, jobs, and special assignments available to less-experienced consumers so that there can be broader based consumer representation in the mental health system. Also, consumers in leadership positions should consider how they might serve as mentors to actively cultivate future leaders.

**Strategies for Avoiding Tokenism**

- **Don’t involve just any consumer.** Make sure the individuals have experience that is related to the task at hand (the same is true for nonconsumers).

- **Seek representativeness, not just representation.** Do not assume that one consumer (or more with similar views) can adequately represent the various consumer constituencies; broad consumer representation should be sought.

- **Avoid choosing for committees only persons who will support the views of current members.**

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Seek out less experienced consumers to participate on boards and committees rather than relying solely on high-profile, articulate consumers, who are frequently overwhelmed with numerous requests and may face burnout.³²

Respect the workers and their work, regardless of whether or not they have a disability.

*I think you need to set an example from the top down -- from the agency President or Vice President on down -- where people know that we didn't hire these folks as a side show. These are not token employees to whom we are going to give a little piece of the action to appease them... They have skills and talents to do the work. That's why they were hired... When we communicate that message to our consumer professionals, they realize why they are on board. They are not hired because they are consumers. They are hired because there is a job to do and they are skilled and talented at doing it.*³³

Co-optation

Consumer advocates³⁴ have expressed concern over the tendency for some consumers to become co-opted by the system; that is, taking on the traits that they have observed and experienced in the traditional mental health system. This may include using the power associated with being a mental health professional in an oppressive way. In their attempt to fit in with their colleagues, consumers may "trade their clienthood for professionalism."³⁵ Co-optation is especially likely when consumer hiring is done in a tokenistic fashion, without a commitment to consumers' input and appreciation for the unique perspectives consumers can bring to their work.³⁶

Yaskin³⁷ presents several "early warning signs" that individuals are becoming co-opted by the larger system. Yaskin was writing specifically for expatients/survivors, however these warning signs also should be considered by nonconsumers, especially in their work with clients, since they are indicators that one's behavior is out of synch with an empowerment philosophy. The warning signs include:

- Individuals who staff the organization start to act as if they are "better" than the people who use it.
- A single person (or perhaps a few individuals) makes decisions on her own or establishes rules or guidelines without consensus from other staff members and program participants.
- People in leadership positions withhold information that is relevant to the organization as a whole.
- People are penalized because their ideas and/or behavior do not conform.
Decisions about the day-to-day operations of the organization are dictated by the concerns of program funders as opposed to what is best for staff and clients.

Promoting equality is the major strategy for avoiding co-optation. Consumer providers should have equal rights and carry equal status with their coworkers. This equality must be supported by appropriate training and supervision. Consumer staff members must receive equal pay for equal work. To compensate consumers less than nonconsumers doing the same job is blatant discrimination.38

Can You Change The System If You Are In It? A concern that is closely related to co-optation is that becoming a service provider will limit the extent to which consumer professionals can challenge the system since they are now paid to carry out its mission. To criticize would be essentially to “bite the hand that feeds you.” This concern was well-expressed by Pat Kramer, a program director and nonconsumer who works closely with the advocacy groups in Florida and who supervises many consumer providers:

....The other thing that I was very concerned about is that as soon as people really think that they can start working -- and I'm talking primarily about folks that have been advocates and they are ready to move on -- and they are hired into the system, that shuts the doors for them in a lot of ways because they can not continue to advocate at the level that they were advocating before. It's hard to be a provider and be able to stand up there and say, "Hey, this is what's wrong with the system." One of my big concerns in the very beginning was, am I doing a disservice to the advocacy movement because the majority of people who came to work were folks who had been really involved in that movement. I'm still seeing that. I don't feel that it's possible to truly do some of that advocacy work and be [a provider] in the system.

...I think for awhile folks thought that hiring consumers was a movement on the part of providers to co-opt. I think there is some danger of that. ...I know on our part it wasn't any kind of a mass movement, "Well let's get them quiet by hiring them," but I do think it's an end result.39

Kramer feels that advocacy efforts are crucial to maintaining the integrity of the mental health system, and that it is consumers' (expatriates/survivors and their family members) responsibility to keep the advocacy movement going.

To avoid co-optation, Dan Fisher40 recommends that consumers/survivors do the following things:

- Become familiar with the literature and the people most involved in the consumer empowerment movement and carry out consciousness raising efforts locally.
Read such publications as *Reaching Across* and *Nuts and Bolts* which include important sections on the dangers and prevention of co-optation in consumer-run organizations.

Establish your goals and philosophy clearly, in writing, at the outset of your work in order to maintain your values despite pressure to change.

Consumer providers can avoid co-optation through critical self-reflection and seeking feedback from a wide variety of individuals with experience and expertise. However, it is wise to keep in mind that an agency that truly values consumer perspectives will not ask its staff to make this kind of trade-off. Risser points out that co-optation can not occur if there exists a partnership; a relationship in which both parties listen, share, contribute, negotiate, and are mutually invested.

**Summary**

This chapter described ways in which consumers might be hired ranging from volunteer positions to competitive employment. Affirmative action policies were mentioned throughout the chapter as a way of combating discrimination and stigma. It was stressed that, should agencies choose to give preferential treatment to consumers in the hiring process, this should be part of a broad plan to increase diversity within the workforce. We suggested strategies for recruiting qualified consumers, including paying attention to the language used in job postings and creatively advertising available positions in places where consumers will be likely to see them. Involving consumers on hiring committees was presented as a necessary step for all agencies concerned with increasing consumer participation. Tokenism was discussed as a common pitfall when half-hearted efforts are made to include consumers on staff, boards, and committees. For consumers who become mental health professionals, co-optation is a potential danger as one becomes part of the system and the possibilities for being an advocate are limited in some ways. The major way to avoid such tokenism and co-optation is for agencies to sincerely value the contribution consumers can make to the organization and demonstrate and promote that belief in all efforts to include them.
Chapter 6

1. K. Wilson, personal communication, February 26, 1996.


4. Ibid.


17. Ibid.


19. Ibid.


22. S. Boltz, personal communication, March 12, 1996.

23. Ibid.


31. Ibid.

32. Ibid.


42. Yaskin, J.C. (1992). Nuts and Bolts...

Chapter 7:
Changing Roles, Changing Perceptions

In a four year follow up study, role confusion and the damage it did to both parties in the relationship was identified as the number one obstacle to consumers being successfully integrated and accepted into the provider workforce.
- Risser

Overview: This chapter focuses on how a consumer’s transition to a service provider position affects relationship dynamics with supervisors, coworkers, clients, and feelings about oneself. We emphasize the need for both clarity and flexibility and suggest strategies for achieving this goal. There are particular issues which call for policies to be established and we present questions to consider in approaching this task. We discuss the process of identity change that consumers may confront as they become service providers, and suggest that by gaining training and establishing a solid support network this transition may be made easier.

Redefining Relationships: Clarity and Flexibility

Clarity is an essential condition for creating an organizational environment that can successfully integrate peer providers, both in terms of individual’s expectations of one another and interpersonal communication. The need for such clarity is undoubtedly essential for any working environment to run smoothly and for individuals to feel comfortable in their jobs. However, when consumers and nonconsumers work together there is even greater potential for confusion, misunderstandings, and general lack of clarity than usual. This has to do largely with a lack of role clarity given such ambiguous job classifications as “created positions” and “set-aside positions” that leave individuals dangling somewhere between consumer and employee identities. This lack of role clarity also is experienced by nonconsumers as well when they find themselves colleagues with people they thought of as clients.

To restate a major point of Chapter 3: Stigma and Other Barriers to Consumer Hiring, integrating consumers as mental health service providers requires that everyone in the field shift their perceptions of themselves, their roles, and their interactions with one another. It is likely that a great deal of people’s discomfort around consumer hiring can be alleviated by creating some guidelines for interaction, and through efforts to clarify what individuals can expect of one another. In this chapter we will address various relationship dynamics, exploring points where
boundaries are blurry, and suggest guidelines for clarifying interactions between people. We will focus on the following three relationship issues that are particularly common:

1. The dynamics of the supervisory relationship, particularly the tendency for supervisors (and also coworkers) of consumers to take on the role of therapist.

2. Difficulty determining what limits should be set regarding interpersonal interactions between staff and clients.

3. The challenges for consumers in coming to see themselves in a new way as they make the transition from the identity of "mental patient" to mental health professional.

Note that all three of these issues share a common theme: lack of role clarity. Therefore, the major goal in resolving these issues needs to be clearly defining the role of each individual in the agency, and establishing policies that will guide the way in which these roles are carried out. The trick is to achieve this level of clarity while maintaining flexibility in the ways we see one another. In other words, organizations hiring consumers must accomplish the seemingly contradictory tasks of setting rules for interaction based on people's roles, while simultaneously developing an organizational culture that promotes change and growth and does not set limits on people's potential to take on new roles. Now there's a challenge! Finding the balance between clarity and flexibility in our views of ourselves and each other will be the work of each individual in every agency, and will be not be the same experience for everyone.

The Supervisory Relationship

In the following chapter, Chapter 8: Establishing Expectations, we will point out a number of areas in which the supervisor or program manager has a great deal of responsibility for creating the clarity that helps all employees to know what is expected of them. For instance, a critical factor in making the performance appraisal process go smoothly is establishing a positive supervisory relationship from the start. Cultivating a supervisory relationship in which both parties feel free to discuss their concerns with one another makes it possible for supervisors to give frequent feedback to their supervisees, and for employees to clarify any areas in which expectations are unclear. Both supervisors and supervisees need to do whatever they can to facilitate effective and ongoing communication.

While there are many possible ways for communication between supervisors and supervisees to go awry, we heard about one common tendency that is worth special attention. Among supervisors in the mental health field there is an inclination to bring their clinical training into the supervisory relationship. This is even more likely to happen when the employee is an expatiant/survivor. Supervisors and supervisees should be aware of this potential and not mistake a therapeutic style of interaction for good supervision. To confuse or blend the roles of
therapist and supervisor creates a blurred relationship boundary that is not helpful for either the employee or the supervisor. A consumer provider simply summed up the main point:

*You can not be a supervisor and a mental health provider to the same person.*

*That needs to be communicated loud and clear to people doing that kind of work.*

Supervisors should ask themselves the question:

- Do you tend to slip into a therapist role with the individuals you supervise?

If so, some helpful strategies are to:

- Think about the environment in which you are meeting. If it is where you do casework/therapy with clients, you may want to have supervision in another room such as a different office or a conference room.

- Keep the focus of supervision on the job. What needs to be accomplished? What is the best way to get the work done? Is any support needed to perform work tasks?

- If a staff person is asking for support that feels like it is beyond the boundaries of your relationship, point this out and work with the individual to identify other people he might turn to for support (e.g., friends, family, therapist, support group).

When receiving supervision, individuals need to think about their expectations of their supervisors and consider whether these are appropriate given the nature of the relationship. Supervisees should ask themselves such questions as:

- Am I asking for support from my supervisor that I should be getting from someone else?

- Do I have a broad base of resources to use when I need assistance around non-work issues? If not, what can I do to expand my resources?

Also relevant are questions around how much consumer providers should disclose to their supervisors about their psychiatric disabilities. Disclosure issues are discussed in detail in Chapter 9: Considering Disclosure.

Much of this discussion of the supervisory relationship is true for non-supervisor coworkers as well. Again, it is important that a supportive relationship between colleagues not develop into a therapist-client dynamic, and that consumer providers not overly rely on their coworkers for support.
The relationship between staff and their clients also can be one in which there is a blurring of boundaries and many questions about what individuals should expect of one another. When consumers become service providers the issues are made even more complex.

Relationships with Peers/ Clients

When a person with a known history of psychiatric disability holds a staff position in a more traditional mental health setting, service recipients may experience confusion about how to treat these peer providers. Reactions run the gamut from resentment, distrust, and envy to praise, admiration, and support. At the same time, consumer providers' reactions to their own changes in identity, and the responses of others to this change, require that they examine carefully their relationships with program clients. This situation can create confusion among all parties for a brief period until everyone can sort out their feelings and establish ground rules for interaction. As Risser points out,

_The rapport that consumer providers are able to establish with other consumers is often an additional source of role confusion. At what point is a consumer a peer to other consumers and at what point are they individuals?_

One consumer provider we interviewed explained his thoughts about these questions related to his shifts in identity:

_What does “peer” mean? “Peer” means that I’m at their level. I’m someone that knows what they’re going through. I’m a friend (or I might not be a friend depending on the situation) and I have no particular boundaries to maintain at all, other than being a friend. Now I [become] a mental health worker. Am I really a peer anymore? I don’t know, but as far as the agency is concerned, I’m probably not. So, therefore, because I’m providing support, I’m placed in a separate or different situation with different boundary issues going on now. First of all, with peers, I might have sex with [them]. But in the mental health world, can I have sex with peers if I’m providing support? No. That’s an example._

A consumer and supervisor explained why he sees the need to set limits on the types of interactions staff may have with clients:

_One thing that tended to occur is people viewed clients as friends. There was a quality of being buddies. One of the things I have focussed on is the idea that we are there as clinicians to serve the client within a clinical context. Perceiving a client as a friend has implications of asking something of the client. For me it is implicit in the idea of being a friend that means the client needs to be there for you too. That’s not the work that we’re doing._
For interactions in which people can rely on peers more as friends and sources of support without as many complex boundary issues, self-help groups and drop-in centers should be explored. Again, the disclosure issue is relevant as consumer providers should consider thoughtfully how much to reveal about their personal experiences with their clients (see Chapter 9). Establishing policies to guide the interactions between clients and staff can help to alleviate some of the role confusion that is inherent in these relationships.

**Fraternization Policies.** Although it is by no means mandatory to establish organizational policies regarding social contacts between staff and clients (sometimes referred to as “fraternization policies”), it is highly advised by those who have had to negotiate these relationship issues without such policies in place. For instance, while a taken-for-granted taboo against therapist/client sexual activity exists among most mental health professionals, this is not a forgone conclusion when staff are former clients. Consumer professionals may be in friendships or sexual relationships that predate the job and where neither person desires to terminate the relationship. This may contribute to the reluctance among some consumers to shift to provider positions because they worry that they must then give up many peer supports. The following example illustrates such a case:

Maria had worked for three months as a caseworker on an assertive community treatment team in the same agency in which she had been a client for the past two years. During her time in the program, Maria had befriended Susannah. Susannah had periodic bouts of severe depression in which she would become suicidal. At these times, Susannah was scared to be alone and found comfort in being with Maria. They would stay together at one of their apartments until Susannah was feeling better and was able to be alone without feeling that she would hurt herself. When Maria became a caseworker at the agency, she continued to socialize with Susannah. Then Susannah became depressed again and asked Maria if she could stay overnight at her apartment as they had done in the past. Maria felt that this was okay since she knew Susannah was in need of support, but when Susannah's caseworker found out about this arrangement, she disagreed. She objected to clients and staff spending the night in the same apartment. Both Susannah and Maria were upset by this intrusion on their friendship, and a heated debate erupted in the agency about what kinds of limits were acceptable to impose on staff/client relationships.

Some basic questions raised by this example are:

- Should Maria continue to socialize with Susannah?
- Is it within the power of an agency to dictate the people with whom members of the staff can and can't have relationships?
- Does it make a difference if the relationship predated one party becoming a staff person, as in the case of Maria and Susannah?
- When Susannah is in crisis, is it okay for her to ask her friend Maria for support?
Is it okay for Susannah to ask Maria for support in her role as a caseworker at the agency?

What should Maria have done when Susannah came to her in crisis?

Is it permissible for a client to spend the night in a staff person’s apartment?

Is it permissible for staff members to stay at clients’ apartments?

There are no easy answers in this case, and any agency confronted with such a situation will have to do a lot of work to sort out the various points of view and come to some conclusion. Agencies may choose to consider these situations on a case-by-case basis, and, in an organization with traditional, strongly defined boundaries between staff and clients, this may work just fine since such issues will seldom arise. However, in agencies with less clearly defined divisions between staff and clients (in most clubhouse programs, for example), some general (or specific) guidelines will be needed to help staff and clients consistently negotiate their relationships in ways that are healthy, safe, and respectful.

Given the relative recency of the consumer hiring initiative, there is no single fraternization policy to which all organizations adhere. Most are still working to come up with policies that are reasonable and comfortable for everyone. A few examples of policies are:

A relationship that existed before anyone became part of the staff is allowed, but that staff person can not provide any services to, or be in any kind of supervisory position over, the other party.  

Consumer providers agree to limit or cease social relationships with current clients.

All members of the staff agree to refrain from any inappropriate personal relationship with clients, including romantic or sexual relationships, financial ventures, cohabitation, or any other relationship which potentially compromises the care or well-being of consumers.

A staff person can not engage with a client in any way in which she can potentially exploit the client. (This policy covers both money and sexual relationships in one statement.)

The people involved at each agency will have to decide among themselves what type of guidance to provide to clarify relationship boundaries and reduce role confusion enough to function effectively. In most relationship boundary dilemmas, there are few definitive “yes” or “no” answers; they are typically answered “it depends.” There are many variables which can influence these decisions such as: the consumer’s history with relationships, cultural norms, legal liability, clinical dynamics, potential discrimination or stigmatization, staff comfort and values, and the history of the relationship in question. As Curtis and Hodge note,
Given the ambiguity and the complexity of ethical and boundary decisions, supervisors and managers have a responsibility to assist staff to make thoughtful decisions and to develop a work environment where such questions can be safely and comfortably raised by staff.\textsuperscript{11}

The following section provides some general guidelines for this decision-making process.

**Guidelines for Making Decisions about Relationships.** Curtis and Hodge\textsuperscript{12} suggest several general strategies for addressing relationship issues and coming up with policies that work:

- The first point is to work together on these tough issues.

  Delicate ethical or boundary decisions are not best made independently. When such decisions result in negative consequences, it is the individual staff person who typically takes the heat. When decisions are made in a group context, it is more likely that a variety of alternatives are considered and that the broad implications of each option are explored. If a team decision results in negative consequences, it becomes the team’s responsibility to review its decision making process, rather than to put responsibility on any particular individual.\textsuperscript{13}

- Provide as much clarity as possible regarding staff roles, intended service outcomes, sanctioned interventions, methodologies, rights, etc.

- Strive for consistency in agency values and develop a set of ethical expectations which embrace standards of conduct applicable to both staff and clients.

- Communicate these expectations explicitly and often through thought, word, and deeds.

- Establish a safe forum for the staff to regularly raise and discuss boundary and ethical issues in a productive, nonpunitive way. Front-line staff and managers must realize that these are not “special” issues to discuss occasionally or only when there is a problem. They are part of day-to-day decision-making and must be talked about frequently. Participating in forums of this type also provides the staff with the opportunity to learn and internalize the parameters for appropriate behavior so they can make good decisions independently.

**Changing Roles Within the Same Agency**

The question regarding whether or not consumers should work in the same agencies in which they currently receive or have recently received services is as yet unresolved within the consumer hiring movement.\textsuperscript{14} Consumers of rehabilitation services represent a convenient pool
of prospective employees for an agency. For example, they are likely to be unemployed or underemployed, have insider knowledge of the field and workings of the agency, and may have an established rapport with other clients. However, there is no doubt that "hiring from within" increases the amount of role confusion experienced by everyone who knows the individual as both a client and staff member. The most likely result of this role confusion is that it will take longer for staff and clients to accept the consumer provider in his new role than it would otherwise.

Some organizations have implemented the types of on-the-job training programs we discussed in Chapter 6: Strategies for Hiring Consumers, which make the transition from client to member of the staff a gradual one. Training programs can give consumers an understood structure within which to make the transition to service provider. Training programs also may involve current staff members helping the consumer develop skills needed to become a provider, thus increasing their investment in making the consumer's role change to a staff position successful. Some individuals and agencies have found that on-the-job training programs that target only consumers can set them aside as different from other providers, thereby making their transition to full-time provider more, not less, confusing. Thus, this type of training program needs to be handled with care and sensitivity, so as to avoid creating role confusion when consumers are in "limbo" as they transition to becoming a full-time staff member.

Other organizations have established a moratorium, requiring that consumers be gone from the program a specified period of time (generally 1-2 years) before they can apply for a staff position. This rule makes it less likely that consumers will be providing services to their friends or partners, since these people probably will have moved on as well. Also, it allows time for members of the staff who knew people as clients to shift their perspectives, and for staff turnover to occur so that there will be new staff on board who have no preconceptions about previous clients. The moratorium also gives consumers time to accumulate training and work experience, and adjust their self-image before returning to the agency as staff members.

We have presented a few of the pros and cons to hiring from within, and have no intention of resolving this debate here. In deciding on a policy, a lot will depend on the individuals and agencies involved. Some of the variables that will make a difference are:

- **The size of the agency** - Is it big enough so that consumers can work as staff in a different building, program, branch, etc. from the one in which they received services?

- **The type of job** - Is it a position in which the freshness of someone's experience as a service recipient may be a good thing (e.g., a consumer advocacy role)?

- **The agency's training resources** - Does the organization provide enough training and support to equip consumers and nonconsumers to become good service providers?
Current attitudes - Are current members of the staff willing to accept their clients as colleagues? Are current clients willing to accept their peers as service providers?

While it may be possible to proceed on a case by case basis -- hiring from within when everyone feels there is a good match between a particular individual and a specific position -- agencies should give thought to establishing a policy on internal hiring. The goal of such a policy should be to add clarity to the process and reduce some degree of role confusion.

Some Questions to Consider When Establishing Policies

When occasions arise in which decisions about relationships must be made, or a policy written, reflection on the following questions may help. These questions can help front-line staff and supervisors to better understand broad boundary issues (e.g., after-hours involvement, friendships) as well as more subtle issues such as selective enforcement of rules and preferential treatment. As you read, reflect upon the situation between Maria and Susannah described earlier in this chapter, in order to understand how such questions can be helpful.

1.) Is there an overriding or governing code of ethics which delineates a clear course of action about a given boundary or relationship issue? If so, why does this course “fit” or “not fit” the presenting situation?

2.) What is the clinical or treatment justification for the course of action? What are the intended effects? Can the staff person clearly state the rationale and desired outcome in support of his/her judgement? What are the benefits of this action for the client?

3.) Are there other, less problematic ways of achieving the same outcome? Have they been considered? Why are they being ruled out?

4.) What are the benefits to the staff person? Is he/she getting some gain from doing things this way?

5.) What are the possible problems that could occur for the client, the community, or the staff person? How could the behavior be misconstrued by the client or by others?

6.) How comfortable would you be with this action if it were published in the newspaper? How will you feel about yourself after the action is taken? How will your action affect others’ perceptions of you?
We suggest that organizations not wait to think about relationship issues until they arise, but rather, take a proactive approach and develop basic policies before a situation presents itself and emotions are running high. Consider including the development of fraternization policies and policies regarding internal hiring as part of your Organizational Action Plan (as discussed in Chapter 5). In working on these tasks, the above questions can be asked in playing out various hypothetical scenarios in order to arrive at the desired course of action.

A New View of Oneself

The impact of the transition from consumer to service provider affects no relationship more than the one an individual has with himself. Consumer professionals may feel that they are in a “no man’s land” since consumers who are service recipients see them more as staff than as peers, and their coworkers may view them more as clients than as professionals. One consumer provider described the feeling of having “one foot on each iceberg.” Another individual said,

_It’s like being in the middle and sometimes in a very unpleasant way. You are made to feel, on the one hand, that you’re not really a true-blue professional or practitioner, that you’re sort of damaged goods or questionable goods. That does happen. And, on the other hand, you feel you’re not a real consumer. You’re obviously much better off financially/materially in your life situation. ...Even the term [“consumer practitioner”] is so awkward it sort of feels like you’re saying nothing. I do really think it’s a distinct position... In my situation I don’t feel like it is valid any longer to consider myself simply as a consumer. I’m not running from that identity, it just does not fit. I’m a consumer practitioner._

This shift in identity may be accompanied by much excitement and feelings of achievement, and in all likelihood, a great deal of anxiety. The fears of both success and failure are frequent among many persons. All turning points and changes have the potential to elicit these fears, but perhaps none so much as vocational growth. It is important to acknowledge these fears when they exist, to predict and plan for their emergence, and to seek out support and guidance to cope with them.

Most people can readily identify with the fear of failure. An important component of this fear for persons with psychiatric disabilities has been most eloquently stated by Lamb, who suggests that people who have mental illness often mask their fear of failure by allowing others to see them as lazy and unmotivated rather than fearful or inadequate. They can not tolerate further social disapproval and rejection, so they just do not try.

It is easy to understand the fear of failure, however, fearing success may sound quite incongruous. For persons with psychiatric disabilities, success requires giving up the concept of self as a “mental patient” and accepting a new identity. This type of success involves loss, and loss issues are extremely difficult to handle. Even if one is displeased with one’s current identity, there is a certain security in the known. Some other psychological factors which may
cause people to fear success are low self-esteem and symptoms such as apathy and lack of motivation which impede risk-taking behavior, as well as the fear of not being able to maintain success once attained. In addition, there are possible external consequences associated with success such as encountering stigma and discrimination from other professionals, losing financial entitlements and medical coverage, and perhaps some negative reactions from peers (discussed above).

Both fear of success and fear of failure can impede consumer staff members trying to adjust to their new role. Some consumers, fearing success, may over-identify with their consumer status and cling to it, resisting moving into an unknown staff role. Other consumers, fearing failure, avoid the transition to their new role, passively refusing to redefine themselves or insisting that others be responsible for this redefinition. As with any change in identity for any person, these reactions are expected. For example, most people experiencing a promotion go through a period of questioning their abilities to handle expanded responsibilities. Promotions typically lead to role renegotiation with former peers and new colleagues. It is important to remember that much of the role change that accompanies assuming a service provider position is a predictable part of a career move, rather than a byproduct of being a mental health consumer.

Navigating one’s way through these complex and changing identities is a critical part of making a successful transition to a new role. Some suggestions for dealing with the transition issues we have discussed follow:

❖ **Be patient.** It will take time (3 months or more) for others to accept you in your new role.

❖ **Keep your role straight.** When you are unclear about what your role is, chances are that others are unclear as well. If you feel confused about what you are supposed to do or how you should behave toward others, discuss this with your supervisor.

❖ **Use your staff status wisely.** Assure the clients in your program that your role is to help them and not to wield power over them. When you make a request for someone to do something, do so in a reasonable manner. Do not be bossy or aggressive, or behave in a condescending way.

❖ **Listen to the feedback you get from clients regarding your job performance,** but realize that all staff tend to receive complaints (and often too few compliments) from their clients. Don’t let this get you down.

❖ **Let your friends, family, self-help group, and everyone else you rely on, know** that this is a new role for you and that this is the time you need their understanding and support.
Talk to others who are going through, or have gone through, a similar transition. Ask what they have done to make this role change easier.

**Getting the Training You Need.** Much of the stress and disorientation consumers experience in taking on the service provider role comes from lack of training or perceived lack of training for the job. While there are certainly assets consumers bring to their jobs from their personal experiences, they also need practical skills that one learns through education and work experience. Some suggested topics for training are:

- Overview of historical and theoretical foundations of psychiatric rehabilitation;
- Negotiating access to collateral services (e.g., housing, vocational services, self-help groups);
- Clinical training and supervision;
- How to complete required paperwork (e.g., Medicaid billing, intake forms, case notes, job placement forms, etc.);
- Learning diagnostic classifications;
- Understanding basic psychopharmacology;
- Team building techniques.

Many of these skills can be learned on-the-job with adequate supervision and establishing mentorship arrangements and training experiences. The pace of the transition one makes from service recipient to service provider should allow for acquiring any needed training (see Chapter 6: *Pacing the Climb up the Career Ladder*).

It is important to note that peer providers may have to be selective and savvy consumers of education and training services. The literature on human resource development suggests that most preservice training provides poor preparation for positions in the public mental health sector.\(^2\) Traditional notions of client-provider boundaries, failure to build on a foundation of client choice, and a focus on symptoms and deficits are features of an antiquated approach still taught in many colleges. Consequently, some nonconsumers hold attitudes that may depersonalize and distance clients, and this may extend to the way that they treat their consumer colleagues. A second outcome of this training is that it can poorly prepare and unnecessarily demoralize potential staff. Because of this, consumer (and nonconsumer) providers should spend time investigating potential training to be sure that it is relevant, current, and uses an empowerment philosophy. Lovejoy and Reinhold\(^2\) provide a list of resources for this type of training:

- Continuing education courses, not necessarily tied to pursuing a degree and chosen on the recommendation of someone in the field;
- Becoming a staff person at a self-help organization;
- Books and magazines recommended by someone in the field as relevant to public mental health services;
- Computer-based learning programs;
Division of Employment and Training or Department of Rehabilitation Services courses;

- Professional training schools that grant certificates in psychiatric rehabilitation, counseling, etc.;
- Volunteer roles in schools, YMCA, after-school groups;
- Mentoring groups and relationships provided by agencies;
- Job-shadowing arrangements whereby individuals who want to learn more about a particular position can observe someone doing this work by "shadowing" them for a day or more;
- Specific skill-building workshops sponsored by agencies or community groups;
- Individual tutoring and/or experiential learning contracts with professionals, peers, and other consumer colleagues in various fields.

**Establishing a Support System.** For anyone facing major shifts in identify, roles, and relationships, such as the transition from service recipient to service provider, it is helpful to have a support system of people who care about what you are experiencing. A support system may include anyone who has the time and desire to talk and offer helpful feedback when needed, but as the consumer hiring and self-help movements demonstrate, people often find it especially helpful to talk to someone who has shared a similar experience. The idea of **Consumer Provider Groups or Peer Support Groups** for members of the staff with histories of psychiatric disability has been suggested as one version of this support mechanism. 25 As Shepherd describes,

*We have a Disability Support Group within the agency that's open to people with all types of disabilities who work for the agency. What's helpful is that we all experience the same sort of difficulties around stigma in the organization and some of the discrimination no matter what people's disability labels are. It's very supportive.* 25

A nonconsumer program coordinator, who supervises many peer providers, talked about support groups as a part of a political movement that can give participants a sense of belonging to something even bigger than the group itself:

*One of the things that has helped us is that there is a network of clients locally that is pretty active politically. They are involved in policy things... They've got a support group for employees working in the system. Having people connected with that, and involved in the movement, has really strengthened the valuing of the integration of [consumer employees] here. It's a way to see it also as political, and I think it is. Most movements like the women's movement and Black power are as much political as anything else. To the extent to which people see themselves as part of a movement, there is some identity there. There is a sense that they belong, of their own value, of their own sense of self-changes. It's been
really nice to see that network getting strong again, and seeing a number of my staff getting involved in that.27

A consumer provider told us what a peer support group has meant for her and the way she has used it:

The very reason for the group was to talk about what does it feel like to be on both sides. ...I have to attribute my peer support group to my making it on to the other side. ...Because I was able to come into the group for instance and say, “My God, I was giving somebody a haldol-decanoid shot today who was talking like I remember talking,” or say, “Today I was giving a shot to someone who said something that I just thought two minutes ago and this is what it feels like.” I feel like saying, “Gee if you want to switch places... Maybe you should be giving me the shot.” Just those kind of things that you go through, saying, “but for the grace of God I’m just a step away from sitting in that chair instead of here.” It really was helpful to have a place to go and talk about those things.

An example of a peer support group is one that was started by Joe Kerouac at Thresholds in Chicago. The members of this “Prosumer Support Group” meet outside of work and maintain strict confidentiality. Many participants have expressed a strong desire to keep their attendance at meetings secret because they have not disclosed their histories to their colleagues. The Prosumer Support Group initially was intended to be purely supportive in nature, but over time has taken on an advocacy role for some participants. As the group’s facilitator, Joe now meets regularly with the agency Executive Director to advocate for the rights and concerns of consumer providers.

Often consumer providers who are having a crisis at work will call Joe for support. In some of these cases, Joe has been asked to act as a mediator between consumer providers and their supervisors or coworkers. In this role, he has had to maintain a difficult balance between serving as an objective party mediating a conflict, while simultaneously representing the concerns of consumer professionals and providing support for individuals who have requested it. This is obviously a precarious and uncomfortable position, and several suggestions have been made for ways to provide alternative sources of support for consumer providers and their nonconsumer colleagues in times of crisis or conflict.

One suggestion for alleviating some of the burden placed on the Prosumer Group facilitator is for group members to rely more on one another. Given the wealth of clinical skills and experience in a group of service providers such as this, participants have a potential supportive resource at their fingertips. Consumer staff members who are willing to participate can put their names on a list for their consumer colleagues to call should a crisis arise. Joan Nobiling, a consumer advocate and provider, has referred to this type of support as a “5-minute mutual aid phone call.”28 This takes the burden off of the group facilitator to be
available to all group members, and allows consumer professionals to call the individual with whom they feel most comfortable.

Another suggestion is for agencies to provide mediation training for the staff. A manual entitled *Managing Workplace Conflict: A Skills Training Workbook for Mental Health Consumers and Supervisors* is available as one excellent resource for this type of information (see references for ordering information). Agencies also might retain the services of a professional mediation center. Within most agencies, it is difficult to find an individual who is perceived as neutral, is trusted by everyone involved, can remain unbiased, and has the skills to negotiate a fair resolution (unless the staff has had training in conflict resolution). Mediation centers can provide professionally trained mediators with the skills and objectivity needed for successful conflict resolution. The disadvantage to using a professional mediation service is that it generally costs money that agencies with tight budgets may not have. In addition, mediation centers may not exist in small towns or rural areas. However, for agencies that are not confined by these limitations, outside intervention of this type may be a viable solution when grievances arise.

Another source of support an agency may offer for providers (consumers and nonconsumers) who are new to their jobs are mentors. One agency that developed an all-consumer job support team matched each consumer placement specialist with a mentor from another agency who was performing similar work. A mentor can offer some training, help with networking in the field, lots of good advice, and most importantly, support for the employee through the nerve-wracking period of adjusting to a new job. With good matching of employees and mentors, long-lasting, supportive relationships may evolve.

Consumer providers also may turn to traditional mental health care providers as key members of their support teams. When we asked one consumer about her sources of support she said,

*Probably the most significant is a therapist and a psychiatrist that are supportive of what I'm doing, because I'm still hospitalized fairly frequently... So that's very important. They work with me and support me in working. I see my therapist weekly and my psychiatrist monthly and they are very sensitive. They don't try to tell me to just not work, which is the recommendation a lot of people receive from their mental health professionals. And if I'm really anxious about something, like a presentation [I had to give] in Washington, they figure out ways to support me. They don't try to hold me back. Whether it's a long distance phone call or another option, they will do that rather than say, "You're not ready for this."*

Perhaps the most precious and relied upon members of a support network are family and friends with whom one has long-term (perhaps life-long) relationships. Within these
relationships one may gain invaluable perspectives on which to reflect during times of difficulty and triumph.

Summary

This chapter has emphasized the need for clarity and flexibility in the face of change. Consumer hiring creates a need for all involved with an organization to see themselves and each other in new ways. A common result of shifting perspectives is role confusion, in which people are not entirely sure how they are supposed to interact with one another and what is expected of them. In the first part of this chapter, we described how certain relationships may be affected by consumers becoming service providers, and why this situation calls for clarity and flexibility. We focused on the supervisory relationship and relationships between staff and clients, highlighting common boundary issues, including supervisors taking on therapist roles with staff and socializing between staff and clients. Additionally, we explored the unresolved issue of whether or not consumers should work as service providers within the same agency in which they have received services. We encouraged establishing guidelines (preferably in the form of written policies) to reduce role confusion, and posed questions to aid in the development of such policies. Finally, we considered ways in which individuals going through an identity change, like the one from consumer to service provider, may confront psychological and external challenges to their self-definition, and suggested strategies to ease the potential turbulence that change may provoke.
Endnotes

Chapter 7


5. W. Montague, personal communication, March 2, 1996.


11. Ibid.

12. This section is adapted from Curtis, L.C., & Hodge, M. (1994). Old standards, new dilemmas...p.29


15. This section is adapted from Curtis, L.C. & Hodge, M. (1994). Old standards, new dilemmas... p. 28.

17. K. Schlosser, personal communication, April 26, 1996.


25. L. Shepherd, personal communication, March 1, 1996.


27. Nobiling, J. Written review of the draft version of this manual, August 27, 1994.

28. This manual is available through The National Research and Training Center on Psychiatric Disability; 104 South Michigan Ave., Suite 900; Chicago, IL 60603-5901; Tel#: (312) 422-8180.


Chapter 8:

Establishing Expectations

...We are learning how to do a very new thing in a place that has not been traditionally safe for consumers. We must give ourselves credit as pioneers and revolutionaries.

- Mary Ann Beall

Overview: In this chapter, we will address the need to establish expectations so that people are clear about their job duties and the standards to which they will be held. We present three different strategies for achieving such clarity. First we discuss a supervisory style that places emphasis on outcomes rather than the specific methods employees use to accomplish their work tasks. Next we present instructions for developing detailed, task-based job descriptions which clearly state expectations for tasks to be performed while maintaining as much flexibility as possible. Third we discuss performance appraisal as an opportunity to generate open communication about expectations for work performance, and present some guidelines for conducting effective performance appraisals.

Most everyone who has ever started a new job has probably experienced feelings of anxiety over not knowing what her or his new boss expects. Supervisors can do a great deal to alleviate this type of anxiety by making their expectations, not only when someone starts a new job, but on an ongoing basis. Coworkers can help each other in this respect by discussing their work with one another and coming to a shared understanding of what each person is expected to do and the most effective ways of accomplishing these tasks. Such communication and cooperation will go a long way toward making a work environment run smoothly.

Management Style

A great deal of responsibility falls on program managers to create clarity for their staffs by making their expectations explicit. A few directors of successful programs shared some of their philosophies in this regard. An oft repeated message was: Manage for results and don't sweat the small stuff.

I try to give the staff a lot of room... I am less concerned about sweating the details as I am managing for bottom line results. The [members of my] staff know this. If we say we are going to place 60 people [in jobs], then I am concerned
about placing 60 people in a good profession, good wages, making a livelihood, etc. If you accomplish those aims and objectives, then I'm going to stand back and give you enough room to decide how you are going to do this... I try to keep them focused on why they are here and the fact that they need to support one another and work as a team if the program is going to succeed.  

A consumer professional working in an organization in which the management conveys such a philosophy describes the flexibility this approach allows her:

They've often said here (in a joking way), they don't care if I'm standing on my head if I can do my job. They don't care if I'm talking to the wall as long as the work gets done.  

Another supervisor talked about how he balances expectations about work getting done with the flexibility needed by some employees who are dealing with mental illness:

I try to draw a balance between being sensitive to the issues individuals might be facing with regard to their illness, while, at the same time, trying to maintain (for their self esteem and my needs as a supervisor) a consistent level of expectation. It's, on the one hand, sensitivity, and, on the other hand, clear expectations of the job. That doesn't mean we say to someone, "You're fired because you're having a bad day," but people know the expectation is there which conveys the importance of their work, and the importance of their involvement in what we do. If there are days they're sick for whatever reason, that's fine because everybody gets sick, but we don't take a stand that the work isn't important. [Our approach is], "If you can't be at work today, that's fine. We're hoping you're going to be back tomorrow or the next day and be able to get back into it," which I think acts as an incentive to the person because they see the value in what they're doing. By changing the expectation, we lessen the importance of their effort, both in our eyes and their eyes.  

The general expectation is clear: the work must get done, but the specifics of what the work entails and how well it gets done are additional matters that we will address below.

**Job Analysis**

The Americans with Disabilities Act (ADA) uses the term “essential functions” to describe the basic tasks of a job which one must be able to complete (with or without reasonable accommodations). With the signing of the ADA into law in 1990, employers have added incentive to identify what these essential functions are for each position in the workplace and to write them down in job descriptions. This process provides legal protection for the employer, and guidance for the employee in terms of knowing whether a position is a good fit given their abilities and limitations. This is one of the many reasons to create a detailed, task-based job
description for every position within an agency. While developing such descriptions is a time-consuming process, there are many more reasons it is worth the trouble:

- It serves as a basis for clarifying job expectations with workers.
- It facilitates worker performance reviews, since there is specific information about job tasks and competencies necessary for assessing outcomes.
- The analysis is job related and not worker specific so that it provides continuity during staff turnover.
- It serves as an information base for assessing staffing needs.
- It serves as a tool for monitoring the relationship between the work performed by the staff and the goals and objectives of the agency.
- It serves as a tool for ensuring consistency and equitability of work performed and salary levels across a range of workers.
- It is useful for identifying training needs of workers, defining a body of required knowledge, and providing trainers, trainees, and employers with a benchmark by which essential skills and their development can be measured.

The remainder of this section presents some tips and instructions for developing detailed, task-based job descriptions. Before doing that, however, please consider an important point raised by Rebecca Macauley in a written plan she developed for her agency, Community Enterprises, in Western Massachusetts, to become more inclusive and accommodating of employees with psychiatric histories. She states that,

*To begin the process, the “essential functions of the job” must be clearly delineated for each position, keeping in mind that ways of performing these functions need not necessarily be what had traditionally been done. Each function needs to be looked at in a new light, asking the question, “why does it need to be done this way? What are the limits of flexibility?”*

This is where the management style described above becomes important to consider. A job description should not dictate to employees the methods they must use to accomplish specific tasks, but should make clear what the tasks are in terms of activities that must be completed, as well as the expected performance standard. The balancing of clear expectations and flexibility is the major issue, once again, and will require careful consideration of each task statement in the job description to make sure this balance is attained.
Developing Task-Based Job Descriptions. There are some general questions one can ask in beginning a job task analysis that will help to pinpoint the important requirements for performing a particular job adequately.¹⁰

- What are the physical demands of the job? What levels of coordination, strength, and manual dexterity are required?

- What are the cognitive demands of the job? What type of attention span, task complexity, and concentration will be needed?

- What levels of social interaction are necessary to do the job? Will the staff person interact directly with clients, need to coordinate tasks with coworkers, or use social skills such as persuasion or confrontation?

- What is the degree of technical knowledge required by the job? Will the staff person need special training, certain educational levels, and prior work experience?

- How much stress is associated with the job? Are there frequent deadlines, fast or slow periods, and recurrent crises?

- What level of supervision will be provided for the worker? Will a supervisor be present at the worksite or will the worker be expected to perform autonomously?

Keeping these questions in mind, incorporate the answers into descriptions of each task involved in the job.

When starting the process of writing job task statements from scratch with no existing job description, your might follow these steps:¹¹

1. list all of the various job activities or specific responsibilities of the position;
2. divide the job into 4-6 major components or broad areas of responsibility;
3. attach a percentage weighting to each of the responsibility areas, adding up to a total of 100%;
4. distribute all the major work activities under the areas of responsibility, adding additional activities as they are identified; and
5. convert activity statements (e.g., “drive clients to clinic”) to task statements (e.g., “transport clients to clinic in order to assist them to secure health care for their children”).

Activities should be stated as tasks to be accomplished and always should be linked with expected outcomes. Thus, instead of writing, “The individual is responsible for completing paperwork,” state that, “The individual is responsible for completing forms for insurance
reimbursement for every client on her caseload, and submitting forms to her supervisor before the specified deadline.” Additionally, the job description for a position should be written without reference to the individual who will be performing the job. In other words, the stated tasks and expectations presented in the job description should be the same for any person hired into that particular position.

Performance standards should be considered in the job task analysis as well. Job analysis is an important method of establishing expectations so that everyone knows what they are supposed to be doing. Regular feedback through performance appraisal also affords an additional way of providing information about what is expected of each individual at the agency.

Performance Appraisal

Performance appraisal is one of the most difficult and challenging tasks of a supervisor. It is also one of the most critical tasks for establishing expectations of the job and levels of achievement. Performance appraisal serves three major purposes: documenting the relative value of the employee’s contribution to the agency (including ways in which his/her work is unsatisfactory); identifying areas where training is needed or desired by the employee; and motivating the employee to accomplish specific career goals.

The performance appraisal process is typically anxiety-provoking for both the supervisor and the employee for various reasons. For employees, there is clearly a lot at stake and they may fear a negative evaluation. For supervisors, anxiety may be caused by having to give negative feedback which is not an easy thing for most people to do. The anxiety experienced by both parties can be reduced by creating a situation in which the only surprises during the meeting are positive ones (e.g., news of a raise). In order to achieve this goal, supervisors should make an effort to discuss their employees’ job performance with them regularly. As problems arise, they should be dealt with immediately rather than waiting for a regularly scheduled performance appraisal. Involving employees in the assessment process by including them in the design of the appraisal form or using a self-evaluation system also will reduce the possibility of unpleasant surprises during annual reviews.

For the individual completing a performance appraisal, it is important that you:

1. have enough time to do the appraisal;
2. be willing to recognize personal limitations and seek advice in conducting the performance appraisal;
3. communicate performance feedback to the employee;
4. be flexible, honest, and objective; and
5. have a sincere interest in the performance appraisal process.

In designing a performance appraisal system that works well for your organization, there are five key questions to address:
I. What is being evaluated?
II. When to do the evaluation?
III. Who should evaluate the employee?
IV. How is information collected for appraisal?
V. How is evaluation feedback given to the employee?

Each of these questions is discussed in the following sections.

I. What is Evaluated? What criteria will you use to evaluate the employee? Make sure that you are evaluating the individual’s work behavior and not his personality or attitude (unless, of course, his work attitude is negatively affecting his work performance and/or office morale). The criteria for performance appraisal should come from a thorough analysis of the tasks required to perform the job. It also is necessary that standards of performance be established prior to the evaluation and that these be measurable, relevant to the job (i.e., reliable and valid), unbiased (i.e., based on work behavior), and practical (i.e., easily assessed). Some examples of factors on which an employee may be evaluated are: quantity of work, quality of work, how well the employee gets along with coworkers and clients, and job knowledge.

II. When to Evaluate? Most agencies require performance evaluation once a year, although as mentioned above, providing ongoing feedback during regularly scheduled supervision sessions is certainly desirable. Some organizations may choose a certain day or week during the year for performance appraisal. With this arrangement, supervisors are required to complete all of their employees’ evaluations at once which, for some supervisors, may be a major task. Some agencies may decide to evaluate employees on the anniversary of their dates of hire. With an annual appraisal, supervisors must be aware of the potential to evaluate employees based on their most recent behavior, rather than on what has occurred throughout the year. To prevent this type of biased evaluation, supervisors should thoroughly document employees’ performance (both positive and negative) throughout the year. They also should consider whether recent events, such as a consumer employee having a hospitalization, may unduly influence the appraisal process. In such a case, it may be advisable to reschedule the performance appraisal in order to make it as fair and constructive as possible. One supervisor described such a situation and how she handled it:

_A consumer provider’s performance evaluation was due at the time when she was in this very bad depression. I waited for 2-3 months after that to give her performance review because I didn’t think it was fair to evaluate her specifically on this period. I wanted to be sure that [the evaluation] was indicative of her performance for the whole year.... I think I would do that for anybody who was having a hard time. It was important for me to let her know that I knew that this was something she was going through that I thought would pass, and I wanted the evaluation to be representative of the bigger picture._
Her performance was greatly affected by the situation. We talked about that too. It wasn’t like we said, “Let’s erase these months.” We talked about her performance going down and what things have improved since that time. It wasn’t like the whole thing was erased. We discussed the problems I had seen during that time as well and put that into the evaluation too.\textsuperscript{13}

III. Who Evaluates the Employee? It is critical that the person conducting the performance appraisal know the employee’s abilities and job performance. Therefore, if the employee’s official supervisor is not the individual who works most closely with the employee, the employee’s most immediate supervisor should be included in the appraisal process. For example, a Job Coach may work outside of the agency at a grocery store, which is the site of agency job placements, during the majority of her work day, and the store manager actually may know more about her on-the-job performance than her supervisor who sees the employee for supervision back at the agency only once a week. In this situation, the store supervisor should be included in the performance appraisal by completing evaluation forms and/or being included in the appraisal session. Coworkers and clients also may be included in the performance appraisal to provide additional perspectives, as long as this is something that is done with all evaluations, not just with those of the consumers.

IV. How is Information Collected? Choosing a method for conducting a performance appraisal is a matter of balancing utility with time and resources. Evaluation techniques range from open-ended written descriptions of the individual’s work to structured rating scales, with a lot of variation in between. Collecting a number of methods from local businesses and social service agencies should provide good ideas about how to proceed. A review of the literature focusing on human resource management also will produce a wealth of information on performance appraisal methods. The method selected should be applied consistently across the agency with all employees held to standards based on analysis of their job tasks and explicitly stated in their job descriptions.

V. How is Evaluation Feedback Given to the Employee? The major purpose of a performance appraisal is to provide feedback to employees about their job performance and, as such, should be done thoughtfully and with care. The performance appraisal session should include the creation of a plan of action that employees can use to improve job performance and/or mark progress toward career development goals. Supervisors should pay special attention to the way in which they present feedback on employees’ performance and attend to the following points:

1. Initiate the interview on a friendly, sincere, cordial note to put the employee at ease;
2. Restate the purpose of the meeting to make sure everyone involved understands the process;
3. Avoid interruptions during the session (i.e., don’t take phone calls or visitors);
4. Discuss the evaluation in terms of the employee's work and specific behaviors rather than personal characteristics;
5. Encourage the employee to speak; Listen and reflect on what is said; Encourage the employee to openly discuss factors that might be obstacles to better job performance;
6. Discuss and reinforce positive performance indicators first, if possible;
7. Do not ignore areas needing improvement; Negative feedback should be directed toward specific work behavior, with the goal of alleviating problems in the future, not solely criticizing the past;
8. Avoid comparing employees; Each worker should be compared to the performance expectations obtained from the job description; and
9. Help the employee to set objectives for achieving organizational and personal goals; Develop an action plan around these objectives.

The optimal outcome of the performance appraisal process is that employees may receive feedback that will enhance self-perceptions of achievement, accomplishment, and pride in their work. These intrinsic rewards are associated with greater job satisfaction, productivity and loyalty to the organization.14

Summary

In this chapter, we discussed several ways in which to help people understand their job responsibilities and the performance standards to which they will be held. We presented an effective management style that places emphasis on setting clear expectations while allowing for flexibility to accommodate periods of disability and individual work styles. Next, we presented methods for developing job descriptions and performance appraisals. Explicitly stating expectations for staff in detailed, task-based job descriptions, providing frequent feedback, and conducting formal performance appraisals can help to create clarity through establishing a flexible structure in which members of the staff can work and develop their skills.
Endnotes

Chapter 8

1. Beall, M.A. Written review of the draft version of this manual, August 30, 1994.


6. Ibid.


11. The following items are from Pecora, P.J. & Austin, M.J. (1987), p.29.

12. The following information on performance appraisal is from Bordieri, J.E.; Crimando, W.; Riggar, T.F., & Schmidt, M.J. (August, 1992). Performance appraisal: A primer for rehabilitation managers. Journal of Rehabilitation Administration, 77-82. This article provides a comprehensive overview of the many considerations involved in conducting effective performance appraisals and is recommended reading for supervisors and employees.

13. N. Richardson, personal communication, April 11, 1996.

Chapter 9:

Considering Disclosure

An honorable human relationship—is a process, delicate, violent, often terrifying to both persons involved, a process of refining the truths they can tell each other.

It is important to do this because it breaks down human self-delusion and isolation.

It is important to do this because in so doing we do justice to our own complexity.

It is important to do this because we can count on so few people to go that hard way with us.

- Adrienne Rich

Overview: For consumer providers, there are many issues to consider in deciding whether or not to disclose a history of psychiatric disability. Central questions are when to say what and to whom. The answers depend on one’s motives for making the disclosure. This chapter presents the issues that arise in disclosing one’s psychiatric history to an employer or supervisor, coworkers, and clients. Also included are examples of both helpful and unhelpful ways of responding when someone discloses her psychiatric history to you.

It takes a great deal of trust within a relationship to confide important information about oneself to another. For this reason, trust is the foundation upon which disclosure decisions often rest. At the same time, disclosing one’s experience with psychiatric symptoms to people at work can be a significant part of building an even more trusting and meaningful relationship with them over time.

Considerations in the Decision to Disclose

Individuals with “hidden” or non-apparent disabilities, such as psychiatric disability, are faced with a dilemma in the workplace: To disclose or not to disclose their disability. As Mancuso points out,

*The worker with a non-apparent disability must make a choice without knowing, in advance, how the employer will respond to disclosure, how far the information*
will spread in the workplace, or in what ways it might impact on his or her personal or professional quality of life over time.\textsuperscript{2}

Even in the most progressive treatment setting, consumer staff persons must carefully consider the benefits and potential negative consequences of disclosure. As one consumer professional put it,

*There has to be a climate of safety for consumers to feel comfortable disclosing their psychiatric histories. Individuals need to feel part of a community.*

As we have stated already in *Chapter 5* (Assessment Step 2), consumer providers' willingness to disclose their personal histories of mental illness can be seen as a "barometer of inclusion" indicating the degree to which the organizational culture is accepting and comfortable.

When contemplating disclosure, it is important to question your motives and try to anticipate the reactions and repercussions of revealing this information. Ask yourself:

- What do you hope to gain by telling a particular person about your history?
- Are you seeking support or advice?
- Are you challenging a coworker's assumptions?
- Are you building an honest, open, intimate friendship?
- Do you have no one else to talk to?
- Are you struggling with role-confusion?
- Are you trying to express empathy with your clients?
- Are you trying to explain your recent poor work performance?

**When to Say What to Whom**

At each different stage of the employment process, consumer providers are faced with decisions about when to disclose what and to whom. The question about when to disclose refers to the individual's job status (e.g., interviewing for a new job, recently hired, employed at the same organization for many years), and the occurrence of events such as a need for accommodations, or an opportunity to use one's history to educate or assist someone. **What to say will depend on to whom** one is speaking (e.g., supervisor, coworker, client) and the reason for the disclosure. The following general questions deserve some thought before deciding what to say about one's psychiatric history:

- How much information does the person you tell need about the nature of your disability?

- How much detail should you give about your history, symptoms, and treatment? (Too much detail is generally unappreciated whether you are discussing a mental or physical illness. On the other hand, giving only a fragment of information to
someone, such as "I’ve been hospitalized 13 times," may leave them with many unanswered questions and concerns.)

The remainder of this section presents many issues around when to disclose and what to say to one’s employer or supervisor, coworkers, and clients.

**Disclosing to One’s Employer/Supervisor.** Individuals who are trying to decide whether to disclose a history of psychiatric disability in a job interview should know that job applicants are under no obligation to disclose a disability before being hired unless they want to ask for an accommodation to perform any tests or other tasks during the hiring process (e.g., filling out an application form, taking a typing test). However, it is possible that an employer may ask certain questions that are difficult to answer honestly without revealing information that may alert the employer to some history of illness. For example, many people with mental illness have “gaps” in their resumes during periods of illness and unemployment. It is perfectly legal for an employer to ask about these employment gaps during a job interview. Individuals should prepare themselves in advance to answer such questions so they are not surprised by them.

**Once hired,** there are other questions regarding why and when to disclose one’s history of psychiatric disability to an employer. It is imperative that persons with disabilities such as mental illness know about their rights under the Americans with Disabilities Act (ADA) so that they can make knowledgeable decisions about what may be gained or potentially jeopardized by disclosing one’s disability (see Chapter 11: Dealing With Discrimination). For example, if a consumer provider does not need accommodations to do the job, then there is no obligation to disclose a history of psychiatric disability to anyone. However, if a consumer staff person develops a need for an accommodation because of symptoms related to her disability, then she will probably have to disclose the reason for the accommodation being requested to her supervisor.

While the ADA is intended to reduce uncertainty about disclosing one’s disability by imposing penalties on employers who discriminate, it does not eliminate the risk of negative consequences. New employees should consider carefully what accommodations they may need to do the job and ask themselves the following question:

- Are these accommodations only necessary occasionally (e.g., a leave of absence in case of illness), or are they modifications of the job or work environment that you would need all of the time (e.g., a quiet work space, frequent breaks)?

The more critical the accommodations are to one’s ability to do the job, the more important it is to discuss them with the employer and to do so shortly after beginning employment.

One employer we spoke with shared the ways in which disclosure can serve both the employee and the employer:
You want to eliminate surprises, especially with an employer. If your illness is going to surface on the job, you want your employer to know as much as possible about what they are seeing so they don’t misread what they are seeing for something else, such as lack of desire. I understand the whole issue of stigma. I know there is a lot of shame people we work with are trying to put behind them, but one thing they have to think through carefully is that if an employer is aware that [you] are gone for long periods and doesn’t understand what’s going on, and if you haven’t talked with [him or her] about how the job is going to be handled, how the work is going to get done, you are creating more red flags. ...But we respect the right of the individual not to disclose if that’s [his or her] choice. But if you don’t disclose, you can’t expect an employer to be making accommodations for you.

Proving Oneself First. For individuals with hidden disabilities who do not need to ask for accommodations to perform their jobs, there is more flexibility in making the disclosure decision. Many people choose to wait until they have worked at an agency quite a while before disclosing a history of psychiatric disability. This allows them time to form interpersonal relationships and establish their reputations as competent workers before making themselves vulnerable to potentially negative or stigmatizing reactions from their colleagues. A number of the individuals we interviewed take this approach. As one individual explains,

I never disclose at first. The reason I never do at first is... that if people don’t know I’m mentally ill and they get me on the job, they’ll treat me just like anybody else, and they’ll expect things just like they would from anybody else. They won’t expect any more or any less. ... If you add on to that, “she happens to be mentally ill,” I personally believe, and have proof, that in the past that has affected the way I have been treated...So I’ve always made it a practice to start my job and get myself established the way I feel good about.

...What I like to do is disclose down the road after I’ve proven myself on the job. It’s an effective way of dispelling a lot of people’s prejudices. I’ve done that before and I probably will with this particular job... I’ll probably just say, “Do you know you’ve hired a crazy person, and I’m as crazy as you’ll ever hire probably?” That kind of just blows them out of the water, and their perceptions of mental illness are changed immensely.

Disclosing to Coworkers. There certainly are advantages to be gained by disclosing one’s disability. Challenging people’s assumptions about persons with mental illness is one positive outcome. Another is being able to speak openly about one’s history and to use personal experience to enlighten colleagues in their work with clients. One consumer provider we spoke to works at both a community mental health center where she is an acknowledged service recipient, and on the inpatient unit of a hospital where she has not disclosed her own history. She described how disclosure makes a difference in her work experience:
I think the differences of being in a setting where I was openly hired are really
tremendous. Though some of the fears are the same (such as what will people
think), the acceptance and the openness to talk about accommodations, or what
would be helpful, is just much easier. ...In settings where I can't identify, the
whole conversation is different. The difference is, in my conversations at work at
the community mental health center, I can freely state, "This is what was helpful
for me when I had that kind of experience," which can be helpful information in
staff meetings. I don't have to be scared to elude to that kind of thing. Verses if
I'm working at a more traditional setting where I'm not identified, I have to watch
how I word it, and not personalize. I can't speak from the "I" as easily because
nobody does that. We want to talk about everyone else's uncle who has
schizophrenia. We want to talk about everybody else's aunt who gets paranoid,
but I can't say, "You know when I was paranoid this is what was helpful for me."
It's a whole different language that you [use].

Additionally, taking the risk to disclose one's own history may encourage other consumer
providers who have been "in the closet" to come out and thereby create a potential for mutual
support. One consumer provider told of this fortunate outcome:

I outed myself real quick in my position as a director of a division of services. I
[already] had outed myself to some senior managers in the interview process, but
[then I] basically outed myself in the whole [agency], as I went from staff meeting
to staff meeting to introduce myself. One of the good things that has come from
that is that one of the staff people who has also been a consumer, who actually
was active in the 70's in the consumer movement, outed herself to me. That's
probably going to turn out to be an important source of support. Outing myself
this quickly, given the umbrella of support that the agency does provide (to a
certain extent anyway), is probably a good thing. 7

Service recipients also should be aware of the risks of disclosing to one's coworkers.
Many consumer providers have experienced their colleagues treating them differently following
disclosure. One consumer professional offered four bits of advice to others who are considering
disclosing to their colleagues:

- Be prepared to be an outsider;
- Have tough skin;
- Build support systems around you; and
- Challenge tokenism. 8

**Disclosing to Clients.** Just as disclosure allows consumer professionals to dispel some
myths and confront stigma with their colleagues, it also may facilitate this work with clients.
Seeing a peer in a position of status and responsibility sends a very powerful message to clients
about what is possible for them. For such role-modeling to happen requires that expatients be
willing to reveal their histories of psychiatric disability and share at least some of their own experiences with others. A peer provider described how she did this with one of her clients:

One time I shared a personal thing that I had had shock treatments with one of my clients and he was like in awe. He said he "had never known a real person that had shock treatments." He ended up getting this great job as an Assistant Scientist, but before that he thought he was ruined for life because of his shock treatments...  

The main question service recipients must ask themselves in considering whether or not to disclose to their clients is "how will my disclosure help them?" A consumer clinician puzzled over this question for himself:

I think the issues are it being a very mixed blessing for me to disclose. How do people hear that without feeling like "look where he is and look where I am?" How can I offer that to people in a way that they can really use it? For people who sometimes see me in my role as an authority -- the person who can be saying, "No, we're not going to let you be med independent at this moment" -- what's it like to hear that information [about me]?  

The reason to disclose must be based on the clients' needs and not done for one's own benefit. This is a difficult thing to determine and it may take some time to learn when disclosure is appropriate, as one service provider explained:

I would share [my personal history] occasionally, and I would share it when it was effective for the support of the other person, but not necessarily to everyone, and not indiscriminately. It would have to be based on the other person’s need. If they were going through a crisis situation and I felt it might be effective for them to hear that I've been through the same, or similar experience, then I would tell them. But if I thought it wouldn’t be relevant to the situation, I would not say a word. ...So it was based on the relationship. It was based on the other person’s need, and it wasn’t based on my need to share. That’s real important. It’s real hard to learn that too... At first you make mistakes. You sit back from that more and watch how it might affect certain individuals and you get a feeling for that after awhile... I found [disclosure] to be a very useful tool, but it was just another tool. I felt that I could use that occasionally, but it was almost non-essential in some ways. What’s more essential is your empathy to the situation. If you have an idea what that experience might feel like for another individual, then you probably are going to be more effective in providing good support for that person.
Consumer providers should examine their motives for disclosing, weigh the benefits and risks, and then, decide on the extent of the disclosure, based on what will be most helpful for the client to know.  

**Responding to a Colleague’s Disclosure**

Whether disclosing a history of psychiatric disability will be a positive or negative experience depends on the response of others to this information. While one’s response will vary depending upon who is making the disclosure (e.g., coworker, boss, therapist), in general, responding with interest, concern, warmth, and caring will go a long way toward building a close and trusting relationship. This section offers more specific advice regarding helpful responses and those to avoid when someone discloses her history of psychiatric disability to you.

**Accommodating.** In the situation in which an expatriate/survivor discloses his psychiatric disability to a supervisor, it can be tricky because the power dynamics of the relationship already are skewed. It may be that the reason for an employee’s disclosure is because advice, support, or accommodations are needed. In this case, it is necessary for the supervisor to clarify the reason for the disclosure and make sure that she takes whatever actions are required if accommodations are requested. The supervisor also must be very aware of the power dynamics between them and never use this information in an exploitative or inappropriate manner.

**Normalizing.** In some situations, it can be very helpful to respond to a colleague’s disclosure by “normalizing” their experience with statements such as “I know what you mean. Everyone seems to be having a rough time lately,” or “Most people I know have gone through that, at one time or another.” This approach can alleviate the anxiety people may experience when they think that they are the only one who is having particular difficulty with a situation. On the other hand, this response can also appear to minimize the significance of another’s experience. When someone confides to you his history of psychiatric disability, to say that everyone goes through difficult times, or to joke that everyone in the workplace is “a little crazy,” is to dismiss the unique experiences that the individual is sharing with you. Therefore, one should listen carefully to what is being said, and the underlying messages, and attempt to determine whether or not normalization will be helpful. An example of how this strategy was used effectively was given by an agency administrator:

*One person was struggling through a particularly bad time. I could see that this person had a lot of shame and a feeling that [she was] the only one in the history of the organization who had ever had such problems. I made a point of mentioning to the person that this was far from true: as an administrator, I was aware of several similar situations, although I could not give details. The person’s response was one of genuine surprise.*

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Sharing. Often, when one person in a relationship reveals personal information, the other individual feels free to share something private as well. Responding in this manner, with one's own disclosure, is a good way of showing empathy for someone's situation. This must be done sensitively, however. Make sure not to belittle the individual's experience with tales of your own hardships and triumphs. In other words, do not say something like, "You think you had it bad, that's nothing compared to what I went through." Before sharing your own experiences, it is important to acknowledge the individual's experience. When doing so, avoid passing judgement on the person's experience by making such comments as, "That's the worst experience I can imagine." Keep in mind that you do not know what they have been through, or how they feel about it. Non-judgmental responses that help the individual feel good about sharing with you will open the way for future interactions. Thank them for trusting you and confiding in you.

Communicating. A relatively common and unsettling experience related by consumers we spoke with is that once they disclosed to their supervisors and colleagues, no one talked about it again. This response was interpreted by one consumer provider in the following way:

There's a kind of empathetic failure at some point. I took it as a kind of aggression. I'm very interested and very involved in stuff around anti-racism and racism, and I'm more and more aware of ways racism works a lot around real micro-aggressions and not these big overt, splashy things. I really felt that the silence and avoidance in response to my disclosure was a micro-aggression of sorts, like, "We're not going to accept that."\(^{14}\)

He went on to describe how he would handle the same situation if someone he supervised were to disclose her psychiatric history to him:

I think what I would say to me if I were in that situation, I'd ask lots of questions. It wouldn't be the only line of questioning for me, but I would say, "I know you had mentioned that you've had this history, and that you had been active [in the consumer empowerment movement], and that you had been hospitalized, and I would be real interested in how you use that in your work. I don't know much about it but I am open to learn about it. It's something I know secondhand and I would be real interested in what you can tell me and teach me about that. I'm not saying you have to bring it up in supervision, but I certainly believe it is appropriate for and relevant to discussions of your work."\(^{15}\)

The conclusion here is that the most effective response to a colleague's disclosure is to respond. Don't ignore what the person has just told you or treat it as a closed topic once the disclosure has been made. Disclosure provides an opportunity to get to know one another better and build a deeper relationship upon the trust that made the disclosure possible in the first place. Having made the point that it is better to respond than not, we will go further to say that some types of responses clearly are better than others. A few common responses to avoid follow.
Assuming the Role of Counselor. The most natural response mental health professionals have when someone tells them about his or her experiences with psychiatric disability is to step into a caregiver role. With one’s coworkers or supervisees, however, this tendency can appear demeaning. Professionals should make it a practice to avoid the assumption that an individual is disclosing his history because he needs support or advice. It is not necessary or desirable for nonconsumers to take a counselor role in these conversations. This sets up an inequality in the relationship by putting the colleague in a helping role and the consumer provider in a help-seeking role. It is more important for colleagues to express how glad they are that the individual is making it easier to know him better and that they enjoy talking to him.

Expressing Prior Knowledge of a Person’s History. An inappropriate type of response to a colleague’s disclosure of a psychiatric history is to suggest that this was something people had suspected or assumed. This response gives the individual many reasons to distrust her colleagues and to feel uncomfortable about sharing personal information. Even if people do know (or suspect) that a colleague is coping with mental illness, it is critical that they let her tell them in her own words about her experiences and respond solely on the basis of what she directly says.

Reacting with Disbelief. A negative response to disclosure that reveals a stigmatizing attitude toward people with mental illness is to show disbelief by conveying the message, “I can’t believe that someone who does such a good job and seems so ‘normal’ could actually have a history of psychiatric disability!” A consumer provider describes how this response comes across:

...The way I used to deal with stigma and the whole thing is I would go into a job and work for 3-4 years. I would always gain respect. I have a way of always moving to the top. I would get to the highest position, and then, in conversation at some point would tell somebody that I had been hospitalized. It was a good way because they couldn’t get rid of me then because they knew me as they knew me, and so, what were they going to say, “All of a sudden we think you’re no good?” That was the positive end, so I felt secure and that I wouldn’t lose my job. The negative side was nobody ever believed me. Or they would say, “Oh it couldn’t have been that bad,” or “That couldn’t be really true,” because it just didn’t fit. They just couldn’t believe that I could be what I was saying I had done and been. That felt frustrating to me because I had lived it! Dealing with their disbelief became very frustrating.

Throughout the course of our many interviews, we were told that the best way to respond to disclosure is with common sense, conveying to the individual interest and respect.
Confidentiality

Confidentiality is clearly an area in which trust is critical and may be easily violated. In addition to direct disclosure, individuals may learn information about each other’s psychiatric histories from many other sources. It is important to treat this personal information with the same care as one would to something shared in confidence. Especially when a consumer becomes a staff person in the same agency or mental health system in which he received services, numerous confidentiality issues must be addressed. New complexities arise with each type of relationship one considers. For example, what happens when...

- your former caseworker becomes your coworker?
- your former client becomes your coworker?
- your former caseworker and your supervisor are friends?
- your former caseworker is your supervisor’s supervisor?
- you become your best friend’s job coach?
- your boyfriend is on your supervisor’s caseload?
- you belong to the same support group as one of your clients?

Space limitations prohibit exploring the nuances of each of these situations, but some general comments about confidentiality issues which agencies frequently encounter follow.

When an expat chooses to disclose her consumer history to only a few people in the workplace, there is significant burden on these individuals to maintain the consumer colleague’s confidentiality. This may create some problems for those bound by confidentiality. A typical situation occurs around requests for reasonable accommodations. For example, it may be difficult for a consumer provider’s supervisor to explain certain job accommodations to other members of staff if these coworkers are not aware of the individual’s psychiatric disability. These individuals may feel the accommodations are unfair. While it is not necessary to justify making reasonable accommodations for workers with disabilities to their coworkers, it can fuel resentment when members of the staff feel that some of their colleagues are getting special treatment.

There may be times when staff persons who know about a colleague’s history of treatment for mental health problems may feel it is important to share this information with someone; however, breaking confidentiality is never acceptable. If you feel it is very important that someone know something that you were told in confidence, ask the individual who trusted you before sharing her information.

The same advice holds when discussing one’s clients. Consumer providers may have received mental health services at the same time as some of their clients. For example, a consumer provider and client may have been hospitalized at the same time, or may have participated in a therapeutic group together. Because of these prior relationships, consumer professionals may be privy to confidential information about particular clients that the clients do
not want other staff to know. Information gained through such interactions is confidential and should not be revealed to other members of the staff, even if it is potentially important to the clinical process.

Members of the staff will have access to clients’ case files and these files might include those of friends or coworkers. While this information is discussed among service providers, it violates confidentiality to discuss client records with other service recipients or anyone outside of the agency. Such breaches of confidentiality may result unintentionally from providers having received no formal training about confidentiality issues. It is, therefore, critical that agencies provide all staff persons with clear, written protocols and specific training for dealing with confidential information about people.16

There certainly are occasions when it is important that everyone be able to speak openly about a situation in order to deal with it effectively. A typical example is when a consumer provider is hospitalized for psychiatric reasons and his coworkers avoid speaking to him about it because they do not want to violate his privacy. It is possible to become so concerned about protecting an individual’s confidentiality that one neglects to offer support to a coworker in need. In most cases, the best approach is to ask the consumer professional what he or she would like coworkers and clients to be told. Follow these wishes whenever possible. (This topic is discussed in greater detail in Chapter 10: Managing Mental Illness.)

Coming Out

Throughout this manual we suggest ways to foster an organizational environment in which trust allows for open communication. Creating a place where it is comfortable for expatriates/survivors to take the risk of disclosing their histories can have positive effects on the agency and beyond. Jackie Parrish, formerly with the Center for Mental Health Services of SAMHSA, sees disclosure as a way for consumer providers to combat the myths and stigma surrounding mental illness and wants to encourage people to take the risk and come out of the closet. She states,

*I am aware how delicate and personal a decision disclosure is. Yet, I would encourage people to disclose as soon as they can and not keep their histories a secret. To me, doing this only reinforces societal myths and undermines the individual’s self-esteem and self-image. Like gay people, it is not going to be easy for the first brave ones, but somehow, somewhere it must start and continue until mental illness is no more shameful than diabetes.17*

Summary

In this chapter we have presented a discussion of issues around disclosure, examining the benefits and risks of disclosing one’s psychiatric history to supervisors, coworkers, and clients. This information was intended to help expatriates/survivors make their own decisions about when
to say what and to whom, and also to reveal ways in which nonconsumers' behavior and responses might facilitate and hinder such disclosures. In order for the mental health field and service recipients to benefit fully from the knowledge and insights of those members of staff who have personal experiences to share, conditions must be safe for consumer providers to disclose this information. It is in the best interest of everyone to create an organizational environment in which individuals trust one another enough to open up and disclose.
Endnotes

Chapter 9


15. Ibid.


17. J. Parrish, written review of the draft version of this manual, September 1, 1994.
Chapter 10:

Managing Mental Illness

Our organization has employed a number of qualified staff who have experienced psychiatric problems themselves, and who have been successful in their positions. One person who was very successful in a demanding supervisory role turned to me in the middle of supervision one day and said, "I'm going to have to go out and pick up some medication; the trees are starting to talk to me again." I was shocked because, even though she had been open about her psychiatric history, it had been in a matter-of-fact way that did not prepare me for the possibility of such dramatic symptoms in the present. I learned a lot from that because I saw that she had learned to manage her situation effectively and was able to consistently do a good job.

-Karin Kahn

Overview: In this chapter, we first discuss some of the "myths" that make it difficult for service providers to deal with situations in which a colleague is having mental health problems, then we confront the "reality" of coping with a colleague in crisis. Throughout this chapter, we rely a great deal on the words of the consumer providers we interviewed to tell us how they would like to be treated during periods of illness, and interviews with supervisors of consumer professionals who have a wealth of experience and helpful advice to share as well. We address the tricky question of determining when a colleague's behavior is a problem, and the need to communicate directly with the individual to be most effective in addressing the problematic behavior. We make suggestions for how to ease a colleague's transition back to work following a leave due to illness, and also discuss ways of creating flexibility in staffing and program structures to best accommodate absences. We discuss planning to prevent crises, which involves preparing for periods of staff illness as well as for the stressors of work in the mental health field and the potential for burnout that accompanies such stress.

In the second part of this chapter, we present a method for crisis planning called the Employment Support Plan (ESP). This is a tool for getting to know as much as possible about how a consumer provider defines a mental health crisis for herself, and what types of assistance she would find most helpful should a crisis occur. The ESP is a way to alleviate much of the anxiety that consumer providers experience about the possibility of getting sick again by making a plan in advance, just in case. It also helps supervisors and colleagues of these employees to know as much as possible about the consumer staffs' experiences of psychiatric problems and how they would like people to respond.
Part I: Myths and Reality

Dealing with employee absences due to illness is a part of any manager’s job and must be considered in planning the structure of any work setting. When hiring persons with psychiatric disabilities, absences may be more frequent than usual, and therefore, it makes good sense to prepare in advance for how they will be handled. This includes making practical preparations, such as considering ways of staffing to ensure that clients will receive services and that other necessary work gets done. It also includes preparing to handle everyone’s emotional response to mental illness.

We have found that it really does make a difference to coworkers whether an employee is absent from work due to mental health problems or for some other reason. When a coworker is out for such reasons as physical health problems, a death in the family, or to take care of an ill relative, this typically is dealt with very sensitively by colleagues and supervisors. When an employee is having psychiatric problems, however, colleagues may suddenly feel at a loss for how to best respond. It makes a difference to consumers as well when their work is affected by psychiatric problems, as opposed to physical problems or other reasons, with the former being much harder to deal with for most people. In the following sections, we will discuss some of the reasons why it may be hard for service providers to respond effectively to their own mental health problems or those of a colleague, and then, suggest ways of making interactions during periods of illness more constructive and comfortable.

Addressing the Myths

It may seem surprising that problems would arise when a peer becomes ill in a work setting full of providers specifically trained to help people with mental illness. There are, however, a number of "myths" perpetuated by consumers and nonconsumers alike which make it very difficult to cope effectively with a consumer colleague’s relapse.

Myth 1: If I’m One of Us, I Can’t Be One of Them

Ironically, the very fact of being a professional in the mental health field poses a number of barriers to effectively dealing with psychiatric disability when it is oneself or a colleague who is affected. For example, it may be hard for people to ask for help when they are in a helping profession. They have taken on the role of support-provider -- the one who has it all together -- and therefore, can not have hard times of their own. A group of mental health professionals in Chicago met to support one another after a colleague committed suicide and they made a list of the "unspoken rules" they experienced working in the field. The list included the following items:
• Members of the staff must always be strong.
• Staff members are not vulnerable to mental health problems.
• Taking a “mental health day” is unacceptable.
• Thou shalt not let colleagues know you are depressed.

It is very threatening for people who hold a polar perspective of mental illness, believing that consumers and nonconsumers are two distinct types of people, to see a colleague’s behavior as indicative of a psychiatric problem. This challenges the whole premise of the “us and them” perspective, which conveys, “It can’t happen to one of us because we are mental health professionals.” For individuals who maintain this myth, it is easier to ignore a peer’s psychiatric problems than to adjust their understanding of psychiatric disability or change the way in which they see their colleagues and clients.

For consumer professionals a similar conceptual block may make it difficult to acknowledge one’s own symptoms. With training, education, and a change in roles from consumer to service provider, some expatients may differentiate themselves from their clients. That can happen to such a degree that consumer professionals may come to see psychiatric symptoms or difficulties as something in their past and not as a possibility in the present or future.

In an atmosphere in which psychiatric disability is seen as a weakness, admitting to a need for mental health treatment, or just some support, indicates an unacceptable level of vulnerability, and the consequences can be very destructive for some people. Some staff members may be so concerned with maintaining a strong facade that they ignore or deny that they are “crumbling” on the inside and eventually fall apart.

**Myth II: If I Understand It, I Can Control It**

Intellectualization is a very effective psychological defense. As one staff person put it, “The more you know about something the more you can deny it and distance yourself from it through intellectualization.” The assumption underlying this defense is that the more you know about psychiatric disability, the better able you are to control it or prevent it. While in some cases this may be true (e.g., attending extra sessions of a support group or increasing medication when one begins to recognize signs of mania), it is not always the case, and knowledge alone may not be sufficient for preventing the onset of mental health problems. Unfortunately, people who consider themselves to be experts in the mental health field may see their knowledge alone as an inoculation against illness.

The potential for problems arises when knowledge is used to distance oneself from one’s experiences. It is very painful to admit to oneself, much less anyone else, that you are not functioning well. Especially for mental health professionals who are experiencing psychiatric symptoms for the first time, there may be a great deal of resistance to recognizing mental illness for what it is and seeking help. The tendency to rationalize or intellectualize symptoms is a
natural one, especially when the consequences of acknowledging one’s psychiatric problems are expected to be very negative.

**Myth III: If I Ignore It Maybe It Will Go Away**

How many times have you seen people pass by an individual on the street who is behaving bizarrely and act as if he or she was not there? People often are embarrassed or frightened to acknowledge unusual behavior and choose to ignore it instead. This tendency carries over to the workplace. Between close friends or family members we may feel comfortable drawing attention to disturbing behavior, or something that seems out of character. We may ask, “What’s wrong?” or “Is something the matter?” and really listen to the answer. With coworkers, this can be difficult to do. We fear being offensive or intrusive. We also may fear the feelings of responsibility and the burden of providing assistance that comes with the knowledge that a coworker is in crisis. Just like on the street, it is easier to pretend that everything is all right and hope the individual will “just get back to normal” or will get help on her own.

Between the human tendency to ignore others when they are doing something that makes us embarrassed or uncomfortable, and the expectations we have that staff always be strong and able to cope with everything, a situation evolves in which denial becomes an acceptable response to the mental health problems of staff. Ironically, however, out of a desire to avoid potentially upsetting situations, people may wind up creating greater discomfort. An example demonstrates how this can happen:

*Over the course of a few months, Darren, a case manager at a Day Program, began to experience severe anxiety and paranoia. He was hearing voices that made him distrustful of everyone and distracted him from his work. He became withdrawn, lost quite a bit of weight because he feared poison in his food, and was unable to sleep. Darren’s coworkers noticed that he was not looking well, and wondered aloud to one another what was wrong with him, but no one asked Darren directly. He sensed that people were talking behind his back, and this increased Darren’s feelings of paranoia. When he admitted himself to a hospital for treatment, the rumors flew. Darren’s coworkers were concerned and wanted to help him, but no one knew what was going on so they did not know whether it was all right to contact him at the hospital. As a result, Darren’s coworkers did not call, write, or visit him the entire time he was away from work. When he returned to the office, Darren felt very uncomfortable with his coworkers, increasing their feelings of awkwardness with him.*

What this account of dealing with staff illness indicates is that secrecy generates rumors which are frightening and alienating for everyone. When staff members are inadequately or inaccurately informed about what is going on with one of their colleagues, there is confusion about how to appropriately respond to help the individual. A natural tendency in this situation is
to try to act as though nothing has happened and avoid talking to the individual about his recent behavior, or avoid talking altogether. One professional described this situation in which people avoid talking about the most obvious issue as feeling like “there’s an elephant in the living room.” Another service provider told about how guilty he felt as a result of not doing or saying anything to help a peer who was decompensating: “Why didn’t I handle this better? I’m a clinician. I should know what to do.”

Both consumers and nonconsumers must recognize each of these myths for what they are -- ways in which people distance themselves from the fear they feel about confronting psychiatric disability. Denying, intellectualizing, and rationalizing our feelings away can be temporarily effective coping mechanisms, but the long-term consequences of these techniques are that people who may be in need of mental health care may not get it. For the sake of all members of the staff, it is important to deal with the reality that health care providers are not invulnerable to illness and may need care themselves at times.

**What Is a Problem and What Do I Do About It?**

A very tricky question with which mental health professionals frequently struggle is discerning when behavior is “symptomatic.” There is a danger of being too critical, and over-interpreting behavior that is typical for the individual as an indicator of illness. To avoid this pitfall, one needs to take into account the context in which the behavior is occurring. What may be a strange reaction in one situation may be perfectly appropriate in another. A simplistic example illustrates this point: Observing a consumer professional who appears to be withdrawn, has dark circles under her eyes, and is moving slowly and talking to no one, you worry that she is in the midst of a serious depression. After talking to her, however, you learn that she has not slept in three days because she has exams and papers due for her college classes. As one expatient cautioned,

*Don’t be so quick to judge that our behavior is our illness. It could be merely that we are having a bad day like many of you do.*

The crux of the issue can be reframed in the following way: The issue is not so much whether the individual is experiencing symptoms, as whether he is behaving in ways that are problematic for himself, his coworkers, clients, etc., within the context of the workplace. Having clear expectations for performance provides some basis for a definition: Problematic behavior is that which interferes with people getting their jobs done. Figuring out what is a problem involves a questioning process, an example of which was given by a consumer advocate:

*What do you mean by “problematic behavior?” If someone is talking to themselves...is that a problem? Is that a problem because it makes you uncomfortable, or is it a problem because they can’t get their work done? It’s
defining “problematic.” If it makes the person next to them nervous, then do something to make the person next to them less nervous. Move the person next to them.4

But what if an individual’s behavior is not just making coworkers uncomfortable, but is keeping them from getting their work done? That is a problem, too, and certainly needs to be addressed, especially when agencies are not able to rearrange staff offices or desks to provide reasonable accommodations. Sometimes, it may simply be that coworkers have to be tolerant and patient as a colleague works through a difficult period. In most cases, however, a direct approach to resolving these situations is preferable.

Some advice for how to handle this type of interaction was offered by a couple of consumer advocates:

[Start by], talking with the person and giving the person some feedback about what he/she is doing and how that is having an impact on everyone. Get some ideas from the person as to, “Are there things that need to be modified or changed, or are there other types of assistance that you need? Is there something going on with you where you need some extra support, maybe need time off, or maybe need a change in job tasks?” See what the person’s ideas are.5

I would approach the person and say, “Do you recognize that you’re talking [out loud to yourself] and you have these gestures? Do you recognize that it makes the other people uncomfortable? Now you are entitled to do that. As long as you get your work done, that’s fine. But, I have to come up with some kind of compromise so it’s not so disruptive to the other people. What do you suggest?” Right away you are showing respect for the person. The person may say, “I didn’t realize it bothered anybody.” This is the thing I love. Seldom do people tell the person. If someone was smoking we would say, “Excuse me, could you put that cigarette out?” But how many people are going to go up to someone and say, “Excuse me, could you not talk to yourself because I can’t concentrate?”6

A supervisor described a situation in which he took this recommended course of action:

A staff person I supervise had a problem with his hygiene and it was really, really bad. Nobody would say anything. It got to the point where my supervisor said, “You have to talk to this person,” and I didn’t want to do it. I really didn’t want to do it. I was saying to my supervisor, “I have more to lose than you do. This is going to jeopardize the relationship.” I ended up role-playing with some peers and trying to figure out how I was going to present this. I brought the person into my office and told him. Initially, he pretended like he didn’t know what I was talking about and left, then came back and said, “I know what you’re talking about. My doctor said this might be a problem for me.” We talked about it and tried to figure out how to handle it if it happened in the future, which it has. It
was a terrible experience. Ultimately it was a good learning experience for me as a supervisor to be able to address something that was so personal yet affects the workplace.

These conversations, while admittedly uncomfortable, can create the opportunity for planning with individuals how they would like such situations to be handled if they happen again. In the example we just presented, the supervisor took this opportunity and described the outcome:

My director had given me a [newsletter for managers] describing a similar situation. The supervisor would leave a picture of a flower on the employee’s desk. That would let the person know, “This is a problem again, please address it.” We just decided he would try to change it, and if it was a problem again I would just tell him, be direct, not use any sort of symbols but just talk about it. Also use that time to ask him, “Is there anything going on? How are you feeling?” because I think it’s directly related to his health. It’s a good indication things aren’t going quite right.

While it often falls on program directors or supervisors (who may or may not be consumers themselves) to address problematic behaviors, consumer providers can do some things to prevent their behavior from becoming a problem, or address it if it does. One suggestion is for consumer providers to make an agreement with peers to honestly discuss their symptoms and tell one another if they are manifesting in behaviors that are creating problems. This often is easier to hear from another expatient/survivor than from a nonconsumer. A consumer provider described such an arrangement she set up with a consumer colleague:

We have one day that is our heaviest clinic day. Between the two psychiatrists, 50-60 people come and go in about a five-hour period. Every 15 minutes they see a different person. It’s a crazy-making day and we are constantly looking at how to do that day differently and how we can communicate, because I can get really carried [away] with it to the point where I sometimes find myself wanting to run down the hall. The day always winds up feeling like it carries us. I said to [my coworker]. “Let’s make a certain glance as we go down the hallway that says to me, ‘Take a walk. See you in three minutes.’” That has been very, very helpful. Sometimes he will literally come in and say, “Hey, quick walk” very kindly, and I will accept it from him because I know that he knows what I know. I also...do some things that way with him too. I know symptoms of his that I can, in turn, say a word or give a quick piece of feedback that can help him come back around. We really, as a team, have developed quite a nice way of communicating.
The following list presents a summary of the strategies for identifying/addressing problematic behaviors that we presented in this section:

- **Don’t over-interpret behaviors as symptomatic.**
  - Consider the context.
  - Determine if the behavior is a problem and, if so, for whom.

- **Be direct.** Don’t ignore problematic behavior, talk about it.
  - Get advice from a supervisor who has had such conversations with staff members before.
  - Role play with a colleague to prepare for the discussion.

- **Ask the individual** whose behavior is a problem what she thinks should be done to address it.

- **Make plans** with the individual for how this situation should be dealt with if it happens again.

- **Agree on a signal** with the individual that you will use if he is behaving in a way that indicates a problem. This feedback often is heard best from another expatient.

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**When the Helpers Need Help**

If a staff person is behaving in ways that are extremely disruptive to the agency, and upsetting to colleagues and consumers, a supervisor might need to ask the individual to take a leave of absence. This may be only until the end of the day, or for an undetermined length of time. Asking a staff person to take time off must be handled very delicately since multiple messages are being conveyed. One message is that the individual’s behavior is not appropriate for the workplace. At the same time, an individual who is unable to function at work is in need of a lot of support, and to send her away without offering assistance is irresponsible. First, reassure the staff person that you are not firing her, then discuss with the individual options for getting help. Possible questions to initiate this discussion include:

- Is there someone you can talk to about how you are feeling?
- If not, may I suggest some resources you might find helpful?
As one supervisor who has been in this situation described,

It's again this sensitivity and balance between trying, [on the one hand], to offer supports for connect her with existing supports that she has in her own system and, [on the other hand], protect her without taking charge of her life or the particular situation she might be experiencing at that time. ¹

Depending on the person's condition at the time -- his level of insight into his behavior and ability to respond to others in a constructive way -- an alternative to a leave of absence is a temporary suspension with pay. This option was presented by consumer advocate, Howie the Harp ², who gave the following advice:

This concerns asking a disruptive employee to take a leave of absence. It may be offered as support or as an accommodation for that employee. As such it may be refused. It is my opinion that, if this occurs, and the problem continues, that it be presented as a temporary suspension with pay. It may sound harsher to take what is essentially a disciplinary action rather than [offer] support or accommodation (although this can still be done in a supportive manner). However, when such support is not accepted, it may set up feelings of patronization and resentment. To present it as a disciplinary action is more honest. After all, the employee has been doing something very wrong by being disruptive. And, if the employee disagrees that s/he has been doing anything wrong s/he would have rights under the agency's personnel policies for redress of that grievance.

The consumer providers with whom we spoke were very clear about treating them in the same way as anyone whose behavior is not acceptable in the workplace (although by law, of course, accommodations must be made upon request). The point that they wanted most to convey is that colleagues should not assume the role of counselor or therapist while at work. Our interviewees were adamant about not giving consumer employees extra leniency. Remarks by a few expatients/survivors reflect this opinion:

...I've never seen [giving consumers extra leniency] ...to really make it helpful for the person down the road. It only has given the message, "Well, I guess I've got a little extra license because I'm crazy."

If a person's skill level has deteriorated to the point where [he] can't do the job effectively, then that person should be either laid off for a period of time, given a leave of absence until [he] can deal with [his] own personal life, or somehow dealt with effectively that way. ...Giving support... to a coworker beyond what is normal for the workplace, I think is a definite no-no. It breaches many boundaries. What it does for me is I'll take advantage of that boundary. I might have a tendency to use it as a person who has a lot of needs at that point. I might misuse that less strict boundary and that's not good for either myself or the
workplace. If I were a supervisor, I would try my very best to avoid that situation. Instead just allow some accommodations around a leave of absence... or maybe if that person requests some accommodation in terms of the kinds of work or what have you, as long as it’s very reasonable for the situation, then great. If it gets beyond reason, or if it gets to the point where your expectations as a supervisor of another person lower, then you should really stop and think about what you’re doing because at that point you’re becoming patronizing toward that person.9

These comments confirm the lessons of Chapter 8: Establishing Expectations. With expectations for workplace behavior clearly established, the ground rules are in place for treating all members of staff with the same fairness, tolerance, support, and sense of equality.

What Concerned Colleagues Can Do. People definitely notice when a colleague is absent for a day or more of work. There will, no doubt, be questions. If consumers will be gone for more than a day or two, their supervisors should discuss with them how they would like their absence to be explained to colleagues and clients. Encourage open communication rather than maintaining secrecy, but respect consumer providers’ choices about what to say to others.

When a colleague is hospitalized for psychiatric reasons, many questions arise and this is a time when rumors can fly out of control. This is especially true if consumer providers have not disclosed their history of psychiatric disability to coworkers. We asked consumer professionals to give advice about how to respond to a colleague’s hospitalization:

The very first thing you do is you have someone ask them if they want their coworkers to know or not. Never, never assume that somebody doesn’t want people to know, or does want people to know. ...People are not going to be real intrusive. If people know someone was hospitalized for psychiatric reasons, I think they should be reminded to treat that the same way they would any other illness. If people don’t know, and the person doesn’t want them to know, you don’t do anything. Then they will treat [the person] the way they would treat anybody, and that probably means when [the person] comes back they will say, “What was the matter?” Then the person can decide what to tell or not to tell.10

While we certainly agree with the values represented in this position, the fact is that this approach may not be possible if someone was clearly demonstrating psychiatric symptoms or difficulties prior to her absence, which mental health professionals are going to recognize. Other advocates suggested the following approach:

We acknowledge that the person is hospitalized for psychiatric reasons in the same way that we acknowledge people who have serious illnesses or physical problems. For instance, in our agency we send people flowers and get well cards. I think one of the biggest dangers I’ve seen is that many times when somebody gets hospitalized for psychiatric reasons, it’s so uncomfortable that people just
sort of ignore it. I advise doing whatever is traditional for when people have any other type of problem, and that includes visiting the person and keeping in contact with the person if that's what [he/she] wants. Some people don't want any contact with work, other people would welcome a phone call or a visit. So finding out what the person would like in the way of support from [his/her] coworkers is the best thing to do.\textsuperscript{11}

Once again, direct communication with the consumer provider is the recommended course of action. Pat Kramer, a nonconsumer program director who has worked with a lot of peer providers, agrees about the importance of ongoing communication, and shares her perspective on how to facilitate that dialogue during an employee's hospitalization:

\textit{To me it really occurs before the person even goes into the hospital. A lot of it is setting up that previous relationship. That’s so important. Then, while they are in the hospital, if it’s ok, if they’ll let you see them, call them. It really depends on what that person is comfortable with. The more that they’re comfortable with, the better it is, at least that is what I have found personally. When any of the folks who work for us have gone into the hospital, with their permission, I have gone and seen them. Just having that contact. It’s almost like the first day of school, it’s so awkward, but if you've gone to summer school, if you’ve been there, it’s not so difficult again. I think it’s the same thing. “You’ve had this break. Whatever occurred happened, but if I’m there with you through it, then when I see you back in the workplace, it’s nothing different. I’ve seen you already.”\textsuperscript{12}

The fact is that staff illness is something any agency may deal with frequently. Establishing a standard way of responding to a colleague's illness, be it physical or psychiatric, can reduce the discomfort of coworkers and relieve the anxiety of individuals returning from an absence. For example, a “get well” card and/or flowers may be sent to any member of the staff who is absent from work for a week or more regardless of the type of illness they may have.

\textbf{Involuntary Commitment}. Hospitalization is a controversial and difficult topic for both consumers and nonconsumers. Some people believe that hospitalization is always to be prevented. Others may see inpatient treatment as one service in a continuum of care and feel it should be available to people in periods of acute illness. Involuntary commitment is seen by some as an extreme violation of human rights and, by others, as a way of helping people who are in extreme distress and may harm themselves or someone else. Our purpose in presenting these opposing viewpoints here is not to resolve them, but merely to point out that there are major issues around hospitalization, particularly involuntary stays, that should not be ignored. Agencies hiring expatients/survivors may be challenged to reconsider their typical protocol for hospitalization, just as consumer staff may find themselves in the uncomfortable position of being committed to a hospital by colleagues, or taking a client or coworker to the hospital.
To take someone to a psychiatric hospital, particularly if it is against her will, is a terribly hard thing to do. While this is true for most, if not all, service providers, it may be especially difficult for consumer providers who have been through this experience themselves. When the consumer providers we spoke with mentioned hospitalizing clients and involuntary commitment, it was clearly a very uncomfortable task and considered to be a last resort:

Most of us in this district, the consumers, don't believe in "Baker Acting" people. Our [state law regarding] involuntary treatment, for having somebody hospitalized, is The Baker Act. That's the name of the law for having somebody picked up. If it is at the Peer Center, which is a drop-in center, we try to be pretty tolerant for quite a long time. We try to intervene in other ways. We've had times when we've called the police to break up a situation. Ultimately, if it does require the intervention that somebody has to be involuntarily hospitalized, then that would be the very last resort.13

One consumer provider described the experience of escorting a client to the hospital who wanted to be admitted. Even though the client had asked to go, taking her to the hospital created a great deal of ambivalence for the caseworker because of his own history and feelings about hospitalization:

A story comes to mind where I was supporting an individual right back to the state hospital. It was a failure on our part and it was a personal failure, I felt, because I was bringing this person back to the same ward where I used to be incarcerated. It was very difficult for me to support that person. I totally understood where she was coming from, [but] it was such a strong feeling in me too. I felt at the time that I wasn't as effective a support worker at that point because it was touching me even closer than I wanted it to. Even though she felt it was very helpful for her, at the time I felt it was very unhelpful to me to be bringing this person back to the state hospital. That was an experience that really taught me this can be very close to home at times...it goes beyond the call of normal duty in some respects.14

As this example illustrates, it may be hard to maintain any emotional distance from an individual's situation when it evokes a lot of mixed feelings or bad memories for oneself. When consumers work as service providers in traditional mental health settings, chances are that they may be faced with such a situation and it is important to prepare oneself emotionally for this eventuality.

It is important to discover whether peer providers have strong feelings about hospitalization and involuntary commitment, preferably before a crisis situation arises. This is a topic about which consumers with previous experience as patients in psychiatric hospitals have much to teach nonconsumers. Drawing from their experiences, expatients may be able to suggest effective alternatives to hospitalization, and can advocate for the creation of new options for care
in the community (e.g., respite care, safehouses, etc.) to prevent some hospital stays. They may be leaders as well in efforts to monitor the psychiatric hospitals in their communities to ensure that they are providing quality care and safeguarding human rights.

**Returning to Work.** It is important to consider ways to ease a staff person's return to work following an illness, whether or not she has been hospitalized.\(^\text{15}\) Conveying that you expect her to come back to work and that her contributions are valuable is a start. However, this approach may not be enough to ensure an easy transition. There is often a great deal of awkwardness following a colleague's absence or hospitalization for psychiatric reasons (on the part of coworkers and the consumer herself), especially if some "dramatic events" preceded it.

A number of the people we talked with (both consumers and nonconsumers) referred to consumers' feelings of shame or embarrassment regarding periods of illness and hospitalization, and thought that those feelings present an obstacle in one's comfortably returning to work. Bob Goodson describes the hesitance he and his colleagues experience:

> Part of what does happen is there is a tentativeness after a person becomes symptomatic. Even for myself, when I've been off work for awhile, and then, I come back, there's a kind of shyness about whether I am okay to return, not for me, but for the team. I've seen that happen with the other staff too, the feeling of, "Are you guys going to let me back in, even though this happened to me?"...The tendency has always been that we treat the folks gently and welcome them home.\(^\text{16}\)

A supervisor of a consumer provider talked about how he tries to prevent situations that will lead to feelings of shame later:

> I'm going to think about your position here in the work environment and try to maintain from your perspective, as best I can, your sense of dignity, because my expectation is that you're going to be coming back and working and doing everything. I want to not set up a situation where you're going to feel uncomfortable, either just the first hour that you return, or forever, because of what went on.\(^\text{17}\)

Consumer providers identified being treated in any way differently from usual as the most disturbing thing about coming back to work following an absence for mental health reasons. A desire to avoid this may lead some consumers to keep the truth about an absence to themselves thereby shutting doors to open communication. An example will illustrate this point:

> Somebody told me a story about how he called in sick because he was having psychiatric problems, but he didn't say he was having psychiatric problems, he said he had the flu. So a couple of his coworkers called that day to see how he was feeling and one person even offered to bring him chicken soup that night. He was out about 1-1 ½ weeks, and when he came back, people just said, "Glad
you’re feeling better” and went on with what they were doing and it was forgotten. He said he always had a sense that had he been honest about his having psychiatric problems, one, his coworker probably wouldn’t have brought him chicken soup, but also, when he came back, people would be looking at him with this hesitation, [asking themselves], “Is he really all back together and can he really handle stressful assignments or complete his tasks?” He said there was none of that because people thought he was out for physical reasons.3

A matter of fact approach is much preferred to any kind of coddling or pretending like nothing has happened:

Try to help them feel that this has been no bigger a deal than it has been. “You got help, you’re out, we’re glad you’re here, now let’s talk about your job and how we can make that more workable for you.” Just real matter of fact. Let’s not gloss it up and say, “No, it never happened.” Let’s not avoid it. Let’s just sit down and talk about it.19

We also heard that it is helpful when supervisors and colleagues directly help consumer providers get back up to speed and convey that they were missed as valuable members of the team or office:

Help the person get right back in. Depending how long she’s been gone, there’s going to be a sense of being out of the flow. You want to facilitate the person’s, immediate integration into the situation. Even if I go on vacation for a week, there’s a couple of days where I feel like I’m not up to speed on things. There’s a level of discomfort I have. If I had gone out on a psychiatric hospitalization that I’m already uncomfortable about, then I’m going to feel even worse. Anything we can do to help people get back up to speed. Let them know what kind of changes have gone on while they were gone, if any. If nothing’s changed, just for somebody to say, “We’re where we were when you left, doing it the same way,” to give them that security, rather than, if nothing has changed, just ignoring it because the [individuals’] thinking will be that things are all different because that is their sense. So, give them security that the environment is still reliable, that they know what’s going on, and second, highlighting that their value as an employee is there. You missed them both as a person and as an employee, a productive person.20

It also is important for supervisors and coworkers to assist in the transition back to assuming specific job tasks and responsibilities. For example, some people may want to start slowly in returning to their responsibilities, reassuming some of their less stressful tasks. Others may want to work half-days or have a three-day weekend during the first week they return. Others may need an hour during the day, in addition to their lunch breaks, to talk with a therapist/support person or to take a walk around the neighborhood to relieve stress. A number
of consumers offered the following suggestions about easing the way back into job tasks and responsibilities:

[Create] a very welcoming environment, a supportive environment. Reach out, [do] not over-coddle. [Set up] a gradual easing back into the job within a certain amount of time, with an expected [full return]. The other thing would be to ask them, "Do you have other supports and are you using them?" It is important that if you are in the field you don't have just [the workplace] as your only support, because it is your [place of] employment and they are not going to be able to do it all. You're not receiving services from them.

I've seen situations in which people are hospitalized and when they come back they are treated as being too fragile and patronized. One of my consumer staff who is a supervisor has done a nice job of sitting down and actually looking at how they feel about coming back. Do they feel they need extra support? Do they need to come back part-time initially, or are they ready to come back and dive in? Let them take the lead in determining that and not treat them [as though they are fragile.] Treat them as a partner in figuring out what is going to work.

Importantly, many consumers acknowledged that the success of these types of transition approaches will depend partly upon how much colleagues and clients know about why someone was absent from work. The less that colleagues know about someone's mental health problems, the harder it can be to negotiate the transition back into the workplace.

<table>
<thead>
<tr>
<th>To summarize the suggestions presented in this section for helping consumer providers return to work:</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Be aware that people may feel some shame or embarrassment about their illness or events that preceded their leave of absence. Try to help them feel comfortable again.</td>
</tr>
<tr>
<td>☐ Let the individuals who have been absent take the lead. Ask them what they want to do and what kind of support they need.</td>
</tr>
<tr>
<td>☐ Treat the individuals like you would anyone who has been absent from work. Let them know you missed having them around and are glad they are back.</td>
</tr>
<tr>
<td>☐ Do not treat them as if they are fragile or need to be coddled. Talk to them like you would normally.</td>
</tr>
<tr>
<td>☐ Make sure the individuals have sources of support outside the workplace.</td>
</tr>
<tr>
<td>☐ Update them on any changes, or lack of changes, that occurred since they have been gone. Re-orient them to the work.</td>
</tr>
<tr>
<td>☐ Give consumer professionals time to ease back into their responsibilities, if they request such accommodations.</td>
</tr>
</tbody>
</table>
**Ways to Prepare in Advance to Accommodate Periods of Illness.** Illness and absenteeism are inevitable in any workplace, whether or not acknowledged consumers are hired. Therefore, it makes sense to have a plan in place so that service recipients’ needs are met and work that must get done is done. With consumer providers on staff, creating the most flexibility possible is desirable, and so it is even more important to consider how to handle coverage when people are absent, and also how to accommodate flexible schedules. The best strategy to use will depend on how your agency structures its services (e.g., individual caseloads, teams of caseworkers, drop-in center, etc.). Some structures accommodate absenteeism and flexible scheduling better than others. With a “team approach” for example, service providers work together to serve a group of clients. Goodson finds this structure especially good for the all-consumer team he supervises:

The “total team” is ideal for consumers. For instance, if a case manager had responsibility for 20 clients, with the way the absenteeism works, the process of people cycling in or whatever, there’s no way they could manage to provide good services for 20 clients. With the team, we are all responsible, so we move to where the need is. The clients don’t have the expectation of a given case manager being there so you don’t have to address abandonment or any of those things.22

The ideal team, from Goodson’s and others’ perspective, is a blended team of consumers and nonconsumers. That is our perspective, too, as it represents the possibility for true partnerships. On a blended team, equality is achievable since all team members hold parallel positions and serve the same clients together. The team model provides the opportunity for frequent communication between staff since they generally meet twice a day (at the beginning and end of the shift) to update one another on what is happening with the clients. This gets people used to talking to each other and sharing their experiences, and that can make it easier to talk about personal mental health concerns as well.

There are ways to achieve some of the same benefits of the total team approach using other structures. For example, a drop-in center can be run by a blended staff of consumers and nonconsumers with a roster of substitute staff available to cover in case of absences. In situations where providers are responsible for individual caseloads, some arrangement should be made for passing information on to other members of staff in case of absence. One individual we spoke with supervises a consumer provider who is hospitalized quite frequently for one to three days at a time. The supervisor arranged with the staff person that she would always keep her written schedule up to date and in an identified place. When she is absent, he can look in the calendar, see what appointments she is missing, and arrange to cover for her.

Job sharing is another alternative structure that may suit people who desire a flexible schedule. A job sharing arrangement may be as loosely or tightly scheduled as is feasible for the people involved. The most flexible schedule is to split one full-time equivalent position between two people and let them decide how to divide the time. Goodson describes how he set up such an arrangement with two members of his staff:
I set up that these two staff members needed to have a total of 70 hours over a two-week period. They could do anything they wanted between them. One could work one week and one the next week. Whatever they wanted. Whoever showed up that day, that’s all they had to do was show up.23

It is certainly possible with this arrangement that both individuals might be unable to come to work on the same day and, in fact, that did happen in the case Goodson described. However, having someone absent in a shared position would, in all likelihood, happen much less frequently than if only one person held the job. Also, if a particular pair of employees who were sharing a position were both sick a lot (frequently on the same day), then these individuals might be re-matched with other employees who are sick less often and want to work less than full-time.

While the possibilities for creative work arrangements are endless, the degree of flexibility within one’s agency may limit the ability to use them most effectively. Part of the initial assessment process agencies go through in developing their Organizational Inclusion Framework (see Chapter 5 for details) should be to identify areas in the agency structure in which there is flexibility, and think about ways to make creative use of it. For example, we heard that a few agencies saw room for flexibility in their use of sick leave, and thus, devised a plan to help individuals who had used up all of their paid sick days to still be able to take time off when in crisis:

We have a policy where people with excess amounts of sick leave can donate to a pool which can be used by other individuals experiencing extended illness. That applies to any illness not just mental illness. You have to have a certain amount of accrued sick leave, and then, you can donate up to three days per fiscal year to the pool. Time is drawn from the pool based on need and request, although there are limits as to how much any single individual can be granted (it’s something like no more than a third of what the existing pool contains).24

With all policies and arrangements for covering absenteeism, such as those presented above, it is essential that they be offered to all employees, not only the consumer providers. For example, any employee should be able to request extra sick days from a surplus pool, or take a “paperwork day” if they are not up to seeing clients. This is another example of how personnel policies that meet the needs of consumer staff can be beneficial to all employees.

Stress and Burnout. Mental health service providers can be relatively sure that they will encounter stress on the job. Previous research has documented the high levels of stress and burnout experienced by workers in the social service and mental health professions.25 Chronically low funding of mental health services has created a system that is frequently unable to meet demands for services. Unrealistic caseloads, unclear expectations, and inadequate resources can create stress for all members of the staff. Such conditions may result in exacerbation of longer-term health conditions (psychiatric or otherwise) among consumer and

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nonconsumer professionals alike. Recognizing the possibility for high levels of stress to affect workers in unhealthy ways calls for advance preparation to prevent the possibility of burnout.

Since stress and burnout are problems for most mental health professionals, agencies must address the need for training and resources to help their staff manage stress effectively. It is critical for mental health staff to develop insights about their unique triggers and reactions to stress, as well as reliable strategies for coping with them. While many mental health organizations help clients develop stress management skills, staff members also can benefit from such training. The agency’s Employment Assistance Program (EAP) may provide relaxation or yoga classes, and other types of stress management techniques, that should be made available to the whole staff. At all agencies, and particularly those without an EAP, inservice training on avoiding burnout and strategies for managing stress should be held. Another idea is to have a regularly scheduled relaxation session led by a skilled instructor which could be open to all staff and clients. Also, acknowledging the stressful nature of jobs in the mental health field, and allowing employees to use paid time off to alleviate stress, will help to prevent more major mental health problems.

Early in an employee’s job tenure, it may be helpful for supervisors to address with the staff the possibility that stress may occur, and encourage them to talk about it if the work or other areas in the employee’s life become overwhelming. A supervisor might say something like:

This type of work can be very stressful, and burnout is common. We want to help our staff to manage their stress and prevent people from burning out in their jobs. In thinking about the sources of support you have and what coping strategies you might use, you should know that we have the following resources available for all staff... I also hope that you will let me know if you are feeling really stressed out so that we can try to do something about that.

The ensuing discussion provides the supervisor with opportunities to inform the new members of the staff about agency better-health programs such as EAPs, health club plans, or Consumer Provider Support Groups (discussed in Chapter 7).

Sometimes people are hired or promoted to positions of responsibility for which they are not prepared in terms of their education, training, or the stability of their own mental health. It is important that individuals find their jobs challenging, but a job which is too demanding relative to one’s abilities is a set-up for stress and possible failure. Sometimes, increased job responsibilities will lead to increased stress. Try to determine whether the stress is caused by unfamiliarity with the new task and will be relieved when competency is attained, or whether the job includes too many tasks causing one to feel overwhelmed. If a consumer provider is feeling overwhelmed by his job responsibilities and asks for some accommodations, one suggestion is to drop the last task that was assigned, and maintain the job at the level it was before, for an agreed upon period of time. Another is to delegate job tasks to another worker for a given time period. These and other possible resolutions should be discussed fully between the employee and
supervisor and every effort should be made to reach a joint solution. Additional strategies to help service providers avoid burnout follow.

**Strategies for Avoiding Burnout**

- Don't permit workers to take on too many jobs. It is better sometimes to leave a job undone than to overload someone who often steps in.

- Circulate jobs so no one feels burdened by one particular and “indispensable” job.

- Regularly evaluate the system by which tasks are divided among people.

- Hold meetings focused on feelings and group-dynamics issues.

- Provide social time for parties, luncheons, outings, etc., when people can just be people with each other.

- Send key people to meetings and conferences to get rejuvenated and gain new insights.

- Provide training opportunities for more people to learn new skills.

- Maintain a conscious commitment to the higher purposes of the organization. The work involves more than job placements and filling out forms. Find ways to remind one another periodically of the agency mission (e.g., post the mission statement throughout the building, print it in the agency newsletter, discuss it in meetings, etc.).

In general, easing the transition back to work and dealing with stress and burnout are important issues when striving to include consumers at all levels of an organization. We heard repeatedly that success is achieved by maintaining respect and dignity for all involved, and to use simple common sense. These approaches, however, also represent good organizational policy in helping to make the job environment better for all workers.

**Part II: Employment Support Plans**

We have discussed some ways to plan in advance for employee absenteeism by thinking about your program's staffing/service structure, and areas of flexibility that will allow for adjustments and accommodations. Developing a plan with a consumer provider before illness occurs (that is not to say that relapse is inevitable, just possible) is another way of planning in advance for periods of illness. This is important to do because it addresses one of consumers'
biggest fears about working: what will happen if they get sick again. Instead of having the attitude that everything will be fine and there is no reason to worry about it, the process of developing a crisis plan before there is a crisis takes the consumer’s feelings seriously, as well as allows the expatien/survivor and supervisor to explore the questions, “What kind of crisis might occur, and what are we going to do if it does?”

Many agencies have developed some form of crisis planning or “advance directives” in which consumer providers discuss what constitutes a crisis for them and how they would prefer such a situation to be dealt with by colleagues. The following presents one technique for crisis planning that was developed by Kathleen Wilson while she was employed at Matrix Research Institute, which she calls the Employment Support Plan (ESP). We use Wilson’s words to describe the ESP:

My whole [approach] is based on the idea of talking beforehand, before people are in crisis, and getting to know what they think a crisis is and how they would like to have things handled, and then, putting that plan into place.

The idea is that the plan itself is a tangible tool for the intangible concept of getting to know the individual really well and respecting the individual. It’s more process than product. ...It’s a tangible way to establish honest and candid communication between a couple of people, with an option for trial and error, and to build some mutual respect for each person’s feelings. Like my supervisor admitted to me, “Sometimes I just don’t know what to do and I feel bad, so then I’ll just do nothing because I don’t know what to do.” So, of course, I interpret that as uncaring, “You don’t care about me. You didn’t do anything.” And he said, “Because I didn’t know what to do and it made me feel bad to see you hurt so much and know I couldn’t do anything about it.” That gave me a chance to hear that he was human and he acknowledged his feelings, and it gave me a chance to see, too, that he recognized that, “When you are able to tell me what you want me to do, you will.”

[The ESP] could be a really good tool for people to feel more confident about taking the risk [of becoming employed]. I find that consumers don’t want to let their job coaches down, they don’t want to let their families down, they don’t want to let other people down, they don’t want to let themselves down, and so they would rather not risk going back to work, [because they worry about] going back to work and having something happen and then they lose the job. With [the ESP], they’ll recognize the signs before they are going into crisis. For example, where a clinician would say, “I can tell [she is getting sick] because of her clothing or her hygiene,” or something like that, a person knows [she is getting sick] even a week or two before that. She can tell that she is having trouble waking up in the morning, that she is starting to avoid completing tasks... And so, this way, instead of the anxiety escalating because she knows she is getting sick and doesn’t know
what's going to happen when she does (not if that happens, when that happens), she can right away activate [the ESP and say], “You know this plan we have, well I can tell I'm heading into a depressive period so just be aware of that.” And then, she can go and do as much as she can for as long as she can, and not have the added anxiety of having to worry about if somebody will recognize how badly she feels, or what happens if she gets sick at the job.

[The goal of the ESP is to address disability-related issues] in a way which is both manageable and strengthens the individual's ability to initiate self-support, natural support, and professional support. The [ESP is] based on three basic principles:

1) Anticipating what are known to be potential concerns for the individual, talking openly about them, and building a set of coping/management strategies specific to the demands of employment which will help to decrease the length and severity of symptom recurrence;

2) Giving the individual the opportunity and responsibility to be an active participant in this planning process from the very beginning will increase both his understanding and investment in the plan; and,

3) Developing a set of natural and generic supports on an ongoing basis, with opportunities to test their strengths, as well as their limitations, will maximize individuals' potential to both access and maintain long-term meaningful employment.

We have adapted the ESP form developed by Wilson for the purposes of this manual, and it is presented in the following pages. We recommend that consumer providers, their supervisors, and/or other people who the employee turns to for support (i.e., the Support Team), use this general format as an outline of the topics to cover in developing a plan. We have included suggested questions in each section to generate discussion. The final ESP should be a written document that can be used as a reference by the consumer and any members of the Support Team, should a crisis situation arise.

Keep in mind that it will take time to develop a good ESP. As Wilson noted, it involves a supervisor and staff member getting to know one another, and that always takes time. Also, while the ESP is a written document, it is not written in stone. It is a work in progress -- a process not a product -- and, therefore, should change with time and experience. It is helpful to discuss with consumer providers who develop ESPs that they will not be judged based on their answers to some very personal questions. Answers to these questions should not introduce doubt into others' minds about consumer providers' abilities, but are to be understood in the context of crisis.
Of course, not all consumer colleagues will want to develop ESPs, which is their prerogative. In our experience, some individuals decide to create ESPs only after a crisis or hospitalization has occurred. This is okay, since the plan cannot work unless the consumer is invested in it. Supervisors may want to occasionally revisit development of ESPs with consumer colleagues in a tactful and sensitive manner, so that they know this option is always open to them.
Employment Support Plan (ESP)³⁰

Step 1: Exploration

Strategies:

- Identify potential ways in which the individual’s psychiatric problems might affect his/her work.
- Discuss strategies the individual may have used already, or may develop, for addressing problems when they arise.
- Keep in mind ways in which reasonable accommodations might be made to reduce the frequency or impact of the individual’s physical/psychiatric problems on her/his work.

Suggested Questions:

- Do you experience any physical limitations because of your psychiatric disability or medications that might interfere with your ability to work? If yes,
  a) What do you experience?
  b) When does this tend to happen?
  c) What are some things that can be done to help you deal with these physical problems?
  d) What tends to make the problems worse?
  e) How do you typically handle these problems when you are not working?

- Do you experience any psychological problems that might interfere with your work? If yes,
  a) What do you experience?
  b) When does this tend to happen?
  c) What are some things that can be done to help you deal with these psychological problems?
  d) What tends to make the problems worse?

Step 2: Historical Review

Strategies:

- Describe past “crisis” situations.
Listen for mention of prodromal signs, precipitating events, coping strategies, and positive and negative interventions.

**Suggested Questions:**

- Have you ever experienced a “crisis” caused by your psychiatric problems that affected your work?
  a) What happened?
  b) What led up to the crisis?
  c) What did you do to try to cope with the crisis?
  d) How did the people around you respond? (Ask about coworkers, supervisors, family, friends, etc.)
  e) How would you have preferred they respond?
  f) What were some helpful things people did in this situation?
  g) What things were not helpful?

**Step 3: Definition**

**Strategies:**

- Establish a mutual definition of what constitutes a “crisis” or “critical event(s)” for the individual that would require significant action by the individual and/or outside intervention/support.

- Explore “crisis” incidents that might occur outside of the work setting, with attention to those environments that have a direct impact on work performance (e.g., onset of symptoms at home affecting attendance, etc.).

- Distinguish between situations in which the individual would desire assistance from others and situations which he would prefer to deal with on his own.

**Suggested Questions:**

- How do you define a “crisis” situation for yourself?
- In your opinion, at what point does a problem related to your psychiatric disability become a “crisis?”
- How might this differ from what others (e.g., family, friends, coworkers) perceive as a crisis?
- Are there particular situations or conditions that tend to be “triggers” for you?
- In what kinds of situations would you need to take significant action to cope with a crisis (e.g., take a leave of absence from work, hospitalize yourself, etc.)?
- In what kinds of circumstances would you need/want others to intervene?
Step 4: Involvement

Strategies:

- Identify specific people who might make up the individual’s Support Team.

- Discuss the types of support and intervention that these individuals currently provide and might provide as part of the ESP.

- Raise the issue of disclosure regarding the involvement of people who may not be aware of the individual’s psychiatric history. Discuss the potential impact of disclosure to each person in terms of her potential value as a Support Team member.

Suggested Questions:

- Who do you turn to now when you are having difficulties?
- What do others do to help you manage your psychiatric problems and cope with “crisis” situations?
- What would you like other people to do to support you in keeping your job?
- Who would you like to involve in implementing these supports?
  - Do these people know about your psychiatric history?
    - If not, are you comfortable disclosing to them? If so, do you want to talk to them yourself or with the help of someone else?

Step 5: Intervention

Strategies:

- Develop a tentative list of situations and preferred interventions (see the next page for examples).

a) Emphasize that these are basic guidelines and that changes can be made at any time.

b) List specific behaviors in order from the least to most disturbing that you have identified as leading to an acute episode.

c) Note the primary person, or people, who are responsible for initiating an intervention and the particular things they should do. Emphasize self-management whenever possible.
Example

<table>
<thead>
<tr>
<th>Identifiable Signs</th>
<th>Network Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Leaving T.V. on all night</td>
<td>I make note in calendar. Friend calls me weekly to see how often it has happened.</td>
</tr>
<tr>
<td>2) Oversleeping</td>
<td>Selected coworker/supervisor notes late days. Mentions it after 3 incidents in a row.</td>
</tr>
<tr>
<td>3) Calling in sick frequently</td>
<td>Supervisor notes sick days. Draws attention to this after 2 incidents in a row.</td>
</tr>
<tr>
<td>4) Talking loudly and rapidly</td>
<td>Selected coworker/supervisor identifies behavior as previously requested by me. I call friend, write in journal, make appointment with psychiatrist/therapist.</td>
</tr>
<tr>
<td>5) Intense, unpredictable reactions (e.g., anger, tears)</td>
<td>Selected coworker/supervisor identifies behavior as previously requested by me. Suggests walks, breaks from work, etc.</td>
</tr>
<tr>
<td>6) Insistence on supervision to “fix things”</td>
<td>Supervisor suggests calling therapist. Has permission to call therapist if I am unable.</td>
</tr>
<tr>
<td>7) Unaware of people talking to me</td>
<td>Supervisor has my permission to call my therapist if I am unable.</td>
</tr>
<tr>
<td>8) Obvious manic behavior</td>
<td>Supervisor has my permission to call my therapist if I am unable.</td>
</tr>
<tr>
<td>9) Threats of suicide or harm to self</td>
<td>Supervisor has my permission to call my therapist if I am unable. If hospitalization is the agreed upon action, supervisor requested to contact parents for transport.</td>
</tr>
</tbody>
</table>

Specify actions to be avoided if at all possible. Identify specific alternatives to any action listed.

Example

<table>
<thead>
<tr>
<th>Avoid</th>
<th>Alternative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do not call the police or an ambulance.</td>
<td>Specific coworker or parent will transport if needed.</td>
</tr>
<tr>
<td>Do not crowd around.</td>
<td>Have a “safe room” chosen in advance where I can be directed to go and can be left alone for awhile.</td>
</tr>
<tr>
<td>Do not touch or physically restrain.</td>
<td>Identify one individual to physically handle, only if absolutely necessary for safety.</td>
</tr>
</tbody>
</table>
Step 6: Communication

Strategies:

- Encourage and facilitate communication among all individuals who may be involved in the ESP.

- Hold meetings in which the interventions outlined on the tentative ESP are discussed.

- Team members agree to, or negotiate, the responsibilities to which they are assigned.

- Draft a final copy of the ESP and have each member of the Support Team initial it.

- Distribute a copy of the final ESP to each person on the Support Team.

Suggested Questions:

- Would you like to hold a meeting of all individuals involved in creating and implementing the ESP or discuss the plan with each one individually?
- Have you informed each individual on your Support Team about your disability?

Step 7: Implementation

Strategies:

- Hold a regularly scheduled meeting monthly to review the ESP with the individual and make any needed changes. Include members of the Support Team in monthly meetings as necessary and/or possible.

- Make changes to the plan as needed. Members of the Support Team must be included in any discussions of changes to the plan.

- Document all changes to the plan in writing. A copy of any revisions to the ESP should be sent to each member of the Support Team, and all should re-initial it.
Step 8: Evaluation

**Strategies:**

- Following any “crisis” or “critical incident” in which the ESP was used, it is important that those members of the Support Team involved in the incident meet to reinforce the activation and effective use of the plan and/or to identify problems and make needed revisions.

**Suggested Questions:**

- How did each person feel about what happened?
- What parts of the plan worked well?
- What did not go well?
- Are there things we should do differently if this happens again? If so, what changes should be made to the ESP?

Step 9: Transitions

**Strategies:**

- Any “crisis” resulting in the individual being away from the workplace for some time requires special attention to the period of absence and the transition back to work. Develop a plan for facilitating these transitions.

- Document the transition plan and distribute it to identified members of the Support Team.

**Suggested Questions:**

- Who would you like to be informed of the reason for your absence?
- What type of contact would you like with people from the workplace while you are gone?
- What can we do as your Support Team to make your first days back at work go more smoothly?
- Are there some changes we might make to your schedule or tasks for some period of time following your return to work?
  a) What type of changes?
  b) For what period of time?
- How would you like people to treat you upon your return?
  a) Are there certain things people might say/do to make your return easier?
  b) Are there certain things people should avoid saying/doing because they make you uncomfortable?
Summary

Experiencing psychiatric problems is often quite distressing for both the individual in crisis and his/her colleagues. We discussed a number of the myths held by service providers that stand in the way of giving and receiving constructive help when such problems become apparent. The first task is to understand when a problem needs attention, which is when it interferes with the ability to perform one's job. In such situations, we suggest approaching the individual whose behavior is problematic and talking to her directly about how she wants to deal with the situation (this exchange certainly could be initiated by the consumer provider as well). The same strategy was recommended in helping an individual and his colleagues to minimize the awkwardness that may occur when he returns to work following an absence due to psychiatric disability.

Given this emphasis on direct communication between consumer providers and their supervisors and colleagues, the most important way to manage mental illness in the workplace is to work on developing a healthy relationship before illness occurs. Clearly, this will not be possible all the time, but it is well worth the effort to establish a trusting relationship in which consumers feel free to discuss their experiences with psychiatric problems, and how they would like them to be dealt with in the future, if necessary. Other types of advance planning for the sake of crisis prevention can be used as well, and these include: establishing a total team approach to service delivery, developing creative sick leave policies, and managing stress to prevent burnout. An additional method for crisis planning, called the Employment Support Plan, was presented in the second part of this chapter.

The consumer professionals we spoke with made it clear that they do not want to be held to different standards than their colleagues. Strategies for managing mental illness in the workplace are comparable to ways of addressing any staff crisis. In general, the more flexibility that is possible in the structure of the workplace, the better able an agency will be to accommodate its diverse staff and their diverse needs.
Endnotes

Chapter 10


5. L. Shepherd, personal communication, March 1, 1996.


10. Ibid.

11. L. Shepherd, personal communication, March 1, 1996.


15. Although this section focuses on service providers returning to work after an absence, the information and recommendations presented also are relevant for clients returning to a rehabilitation program after a period of illness.


18. L. Shepherd, personal communication, March 1, 1996.


23. Ibid.


27. Besio, S.W. & Mahler, J. (1993). Benefits and challenges of using consumer staff in supported housing services. Hospital and Community Psychiatry, 44
Chapter 11:

Dealing with Discrimination: The Americans with Disabilities Act

The most important value is acceptance of the person as a person first — as a capable individual first — and as a person who has a disability second. This valuing of personhood and valuing of individuality — who somebody is — is absolutely essential for any kind of accommodation to make sense...We can get all kinds of things like flexible working hours and shortened work days and other accommodations, but if the attitude isn't there of value and acceptance and realizing people with psychiatric disabilities are people first, then we're really not going to get anywhere.

-Dale Walsh

Overview: In this chapter we discuss how knowledge about the Americans with Disabilities Act (ADA) can be used to address discrimination against persons with psychiatric disabilities. We present basic information about the ADA to inform readers of some of the key elements of the law as it relates to employment of persons with disabilities. Additionally, we discuss issues around making reasonable accommodations for employees with disabilities, including how consumer professionals and employers might introduce a conversation about accommodations, and possible responses. Following this chapter is a list of resources for more information about the ADA.

Throughout history, people with mental illness have faced discrimination which has made it very difficult to live comfortably in our society. Discrimination in the area of employment has made it hard for consumers to get any kind of job, much less a job as a provider of mental health services. The consumer empowerment movement and the conscious effort being made in many mental health agencies to hire consumers as service providers are indications that things are beginning to change. Another hopeful sign is the passage of the Americans with Disabilities Act (ADA) which was signed into law on July 26, 1990, and is arguably the most far-reaching disability rights legislation ever adopted. As the doors to employment open for people with mental illness, it becomes increasingly important to be able to identify discrimination when it occurs, and to know one's legal rights and responsibilities.
The Americans with Disabilities Act

This chapter will focus on the ADA, but it is important to remember that other employment protections are mandated by law, such as the Civil Rights Act of 1964 and the Equal Pay Amendment of 1963. The technical assistance literature explaining the ADA contains a great deal of relevant information for employed people with psychiatric disabilities. This literature should be read by anyone with a disability who is seeking or holding employment, as well as for all managers, supervisors, and coworkers. The list of resources following this section includes some pertinent publications and additional sources of information regarding the ADA and how it applies to people with psychiatric disabilities. A document published by the Equal Employment Opportunity Commission, EEOC Enforcement Guidance: The Americans with Disabilities Act and Psychiatric Disabilities, contains excellent, current information on the ADA, based on case law and other relevant materials (see the resource list at the end of this chapter for the EEOC’s phone number and address).

Why You Need to Know About the ADA. Since the ADA has the potential to affect the lives of millions of people, it is critical that consumers and everyone working as a mental health service provider learn as much as they can about this law. An unfortunate research finding is that, in general, service providers are not well-informed about the ADA. This is problematic, since people with disabilities who participate in rehabilitation programs often will turn first to frontline staff (e.g., job coaches, case managers, etc.) when discrimination occurs. As the first resource for clients, members of the staff need to know enough about the ADA to recognize situations in which discrimination on the basis of disability may be an issue. They also should know where to go for more information about the ADA, and what steps to take if they believe discrimination has occurred. Acting as advocates for people with psychiatric disabilities, mental health professionals may be called upon to protect the rights of consumers and to educate others (e.g., employers, landlords, school officials, etc.) about these rights. It also is essential for consumers, and especially those who are or have been consumers, to be well-educated about the ADA so that they can protect themselves and help one another.

Whether or not an agency makes a conscious effort to hire people with mental illness, it is important to acknowledge that there certainly are individuals already employed within the organization who have some disability that is covered by the ADA, such as cancer, HIV infection, or chronic back problems. Hiring and firing practices should be re-evaluated by all employers and supervisors to ensure that they are not in violation of the ADA. Not only will this be helpful for consumer providers, but for all employees who may need accommodations.

The ADA is a potentially powerful weapon to combat discrimination against people with psychiatric disabilities; however, for the ADA to be effective, we all must learn what this law says about the rights of persons with disabilities and be able to recognize discrimination when it happens. As Helf notes, the ADA presents the opportunity for mental health organizations to serve as a model for the community in recognizing the contributions that can be made by people with psychiatric disabilities.
**The Protections of the ADA.** The ADA is divided into five titles regulating access to employment, public services and public transportation, public accommodations, telecommunications, and miscellaneous provisions for persons with disabilities. Title I of the ADA includes important regulations which seem likely to increase access to work and job retention for people with psychiatric disabilities. The employment provisions in the ADA are designed to improve vocational opportunities for persons with disabilities by providing protection to qualified individuals from discrimination in hiring, compensation, promotion, and termination decisions. The method through which this is to be accomplished is by creating equal opportunity, not affirmative action. This means that employers are not required by the ADA to hire a certain number of people with disabilities. Rather, the ADA is intended to reduce discrimination by prohibiting many common hiring and firing practices which systematically exclude individuals with disabilities.

Examples of some specific protections the ADA provides are:

- Employers may **not** ask job applicants about the existence, nature, or severity of a disability.
- Employers, either verbally or through an application form, may **not** inquire as to whether a job applicant has ever received mental health treatment.
- Employers can **not** require a medical examination **prior** to making an offer of employment.
- Employers must make reasonable accommodations for applicants and employees with disabilities unless doing so would impose an undue hardship on the business.

**Who Is Covered by the ADA.** The employment provisions of the ADA prohibit discrimination against "qualified individuals with disabilities." This includes applicants for employment and current employees. An individual is considered to have a disability if she has a physical or mental impairment that substantially limits one or more major life activities, has a history of such a disability, or is regarded as having such an impairment. A "substantial impairment" is one that significantly limits or restricts a major life activity such as hearing, seeing, speaking, walking, breathing, performing manual tasks, caring for oneself, learning, or working. Individuals with minor, short-term conditions such as a sprain, broken limb, or the flu, generally would not be covered. The definition also does not include physical characteristics, such as left-handedness and environmental, cultural, or economic disadvantages, such as being lower-income, lacking in education, or having a prison record. Also not included are personality traits, such as poor judgment or a quick temper, unless they are shown to be symptoms of covered mental impairments.
For people who have disabilities which are not generally visible, such as psychiatric disability, there may be a need to document past or present disability to an employer when requesting reasonable accommodations. With a mental disability, obtaining a diagnosis, such as those listed in the American Psychiatric Association's *Diagnostic and Statistical Manual* from a physician, psychologist, social worker, or other service provider, is generally an acceptable form of documentation. Other good sources of documentation are health-related public-benefits documents, such as Social Security or Medicaid forms. A diagnosis is not in itself enough, however, since some conditions may have relatively little impact on some individuals. What matters is that the disability, or combination of disabilities, make it very difficult to perform one or more "major life activities." One is protected by the ADA if, without treatment, he would have a condition that substantially limits his ability to perform either:

- **An entire category of jobs** (for example, with dyslexia, one may have great difficulty performing any job that requires extensive reading and writing skills), or

- **A broad range of jobs in a number of categories** (for example, with schizophrenia, one may have great difficulty performing any job that requires working in a large, crowded, noisy room).

The ADA uses the term "qualified individual with a disability" to refer to a person who meets legitimate skill, experience, education, or other requirements for a particular job that he holds or seeks. The individual also must be able to perform the "essential functions" of the position with or without reasonable accommodation. Essential functions are the fundamental duties of a particular job. They are generally the tasks described in a job description. As we discussed in Chapter 6 (in the section on Job Analysis), one of the important steps employers should take in responding to the ADA is to review all job descriptions and, if necessary, rewrite them to accurately reflect the essential functions of each position. This action protects both the employer and employee by reducing the possibility for misunderstandings about what the employee’s job entails.

**Beware of Ongoing Discrimination.** Unfortunately, many employers are not aware of (or choose to ignore) the ADA regulations and continue to violate this law in various ways, such as requiring medical exams prior to making a job offer, and including questions which are now illegal on application forms and job interviews. These hiring practices are a direct reflection of continuing discrimination against persons with disabilities. Health care organizations are generally more enlightened about the ADA and accommodating workers with disabilities than other employers, but discrimination and lack of information remain ongoing problems even in these settings.

As explained above, the ADA does not require that employers must hire people with disabilities. An employer is under no obligation to hire a job applicant with a disability and, while the ADA reduces many barriers to employment, the employer still has ultimate control.
over the hiring process. If an employer chooses not to hire a person with a disability, it would be difficult to prove that discrimination was the motive since, in any hiring decision, many variables come into play.

There are several reasons why employers may try to avoid hiring individuals with disabilities. The cost of health care is an obvious disincentive for employers to hire someone who may need hospital treatment for a psychiatric or medical illness. Another frequently voiced concern among employers is that this law will make it impossible to fire someone with a disability. The ADA does make it illegal to terminate an employee simply on the basis of a known or suspected disability, and also requires employers to make reasonable accommodations to help workers with disabilities perform their jobs. However, there are valid reasons for terminating any employee from a job, and these reasons apply to individuals with disabilities as well. For example, an employee must be able to perform the essential functions of the job with or without accommodations. If unable to do so, this may be acceptable grounds for termination. In addition, an employee who makes a serious error or endangers the safety of oneself or others may be fired, as long as this is "uniform procedure" and is documented in the agency’s personnel handbook. The reader should not interpret these examples as legal advice. The ADA is not written in a specific way and leaves a lot of room for interpretation in individual situations; therefore, the grounds upon which one may be fired from a job must be explored on a case-by-case basis, with legal advice, if necessary.

The stigma associated with mental illness, and other conditions such as AIDS or chemical addiction, also causes employers to discriminate in their hiring practices:

...The ADA is premised on the idea that people with disabilities can and must be treated equally, but at the same time is far ahead of contemporary thinking about people with mental disorders.\textsuperscript{15}

Misconceptions and stereotypes about individuals with disabilities promote employers’ fears of violence, frequent or extended absences from work, poor job performance, and expensive accommodations, and thus, lead to discrimination:

The ADA is a vehicle to question stereotypes and assumptions and to preclude easy inferences and predictions about capacity and behavior from the mere existence of a psychiatric diagnosis.\textsuperscript{16}

**Reasonable Accommodations**

One of the major ways the ADA assists persons with disabilities in obtaining and maintaining competitive employment is by requiring employers to provide reasonable accommodations upon request. A reasonable accommodation is any agreed upon change in a particular workplace environment, or in the way things are usually done, that makes it possible for a person with a disability to do the job. Since everyone is different, whether a
particular accommodation is appropriate and "reasonable" must always be decided on a case-by-case basis. It cannot be assumed that people with the same type of disability will need the same accommodation, which is why employers must always first consult with consumers themselves. Mancuso divides typical accommodations for workers with psychiatric disabilities into four categories:

1. **Changes in interpersonal communication** - an example is training a supervisor to provide positive feedback along with criticism to bolster low self-confidence;

2. **Modifications to the physical environment** - for example, room dividers to reduce distractions and help concentration;

3. **Job modification** - for example job sharing arrangements; and

4. **Schedule modification** - such as time off for psychotherapy appointments.

Accommodations should be discussed and agreed upon by the employee and the supervisor so that both parties understand what accommodations are, which accommodations are needed, and which accommodations are approved. This process can be structured through the development of an Accommodations Plan at the beginning of employment, assuming the consumer has disclosed her mental health needs at that time.

Suggestions for several ways that employers can accommodate their employees with psychiatric disabilities follow.

- Provide extra training and repeat training as needed. Especially for those consumers who do not have previous relevant work experience, or who lack formal education, extra help with things like paperwork and learning office protocol may be needed.

- Flexibility in the assignment and re-assignment of duties is useful.

- Develop schedules with flexible hours. Job sharing arrangements which create part-time positions, or involve the exchange of job duties which take advantage of employees' strengths and minimize stress, are desirable.

- Provide advocacy and assistance with benefits and entitlements such as social security and health insurance.

- Whenever possible, provide liberal and extended leave as needed -- with or without pay, if necessary.
Guarantee job security if extended leave is necessary.

Consider the physical work environment and make sure each person has adequate space, privacy, and a place to go to “sound off” if necessary.

Match the employee with a supportive, understanding supervisor (perhaps another consumer, if possible). Find other employees who want to help (without trying to rescue) the consumer and encourage them to work as a team.

Encourage consumers to establish and maintain ties to the self-help community, peer counseling, and recovery services. Permit phone calls to support services during work hours, and promote on-the-job peer counseling/support arrangements.

Promote and appreciate the different perspectives that people with disabilities add to the work place.

Address coworkers’ negative attitudes assertively and constructively to minimize stigma and maximize integration of workers with disabilities. This may involve sensitivity training for coworkers, structured open discussions, and education about stigma, discrimination, and labeling. As one person noted:

*I think one of the best revelations I’ve come to is that patience, tolerance, and understanding are reasonable accommodations. In certain cases, allowing an employee to continue working, even though [his] behavior might be socially unacceptable to some, has proven to be a positive experience for me, the individual, and the agency.*

**Asking for an Accommodation**

**Disclosure.** The first step employees with mental illness must take to request reasonable accommodations is to disclose their disability to their employers. The ADA does not require employers to accommodate conditions they do not know about, and it is up to the employee to reveal this information. This is a frightening decision for anyone who has encountered discrimination because of their psychiatric disability in the past. Whether or not to disclose one’s psychiatric disability to an employer is probably the most delicate and complex issue involved in implementing the ADA effectively. This difficult decision is one individuals must make for themselves after carefully gathering as much information and advice as possible. The discussion presented in Chapter 9 on disclosure can guide individuals through part of this decision-making process, but there are some particular issues to consider when an accommodation is needed.

Regarding when to discuss the need for a reasonable accommodation with an employer, it is best to do so from a position of strength rather than when in crisis or as a last resort. A strong
position is one in which the expatiant/survivor is knowledgeable about her legal rights and what she needs to perform a job effectively. It also is to the consumer professional’s benefit if she has a good work history and has proven herself an asset to the organization, although these are not required to receive an accommodation, of course. It is important that consumers discuss needed accommodations with their supervisors before they are threatened with losing a job. Waiting too long may put the consumer staff person at a disadvantage, since her work performance and relationship with the employer may have badly deteriorated.²⁴

The next question is who to tell. The only people who would legally need to know about any disability are the people who would grant permission for a reasonable accommodation. The consumer provider also might inform anyone who would be immediately affected by the accommodation. For example, if someone began taking a new psychotropic medication which had the temporary side effect of making it very difficult to wake up in the morning, he might need to request a change in schedule allowing him to work later hours for a few weeks. He should explain the problem to his immediate supervisor and request the accommodation. Together, the supervisor and consumer could then decide which colleagues would need to know about this schedule change, if any.

The next major question is what to say. It is not necessary for an expatiant to reveal to an employer every detail of his psychiatric history before requesting an accommodation. Furthermore, the requests do not have to be made in writing and the employee is allowed to ask for accommodations in “plain English,” which means he does not need to use the term “reasonable accommodation” or other terminology of the ADA per se. Enough information must be disclosed, however, for the employer to understand the nature of the disability and how it affects the employee’s work performance. Employers may ask for reasonable documentation in the form of a letter from a mental health or health professional, indicating the employee’s functional limitations due to disability, and this should be provided if requested.

Part of approaching the situation from a position of strength requires the consumer professional to have some insight into the aspects of a particular job that are problematic and what is needed from the employer to make things better. Consumers should think through the following questions before requesting an accommodation so that they can approach an employer with a plan in mind:

♦ What must change for you to be able to perform the essential functions of your job?

♦ Is there a way for these changes to be made without significant inconvenience or expense?

Creating Reasonable Accommodations. Making reasonable accommodations for persons with disabilities is an ongoing, cooperative process requiring open communication between employers and employees. It is important to approach the formulation of reasonable
accommodations as a continuing dialogue rather than a one-time solution. The following suggestions will help the process of creating reasonable accommodations go smoothly:\(^{25}\)

- Identify the need for accommodation before performance problems arise.
- Clarify what an employee needs in order to perform the essential functions of a job.
- Look for solutions that incorporate ideas from the employee, the supervisor, and other resources both within and outside of the agency.
- Use consistent and fair processes for developing accommodations.
- Be flexible and willing to try alternatives.
- Use conflict resolution mechanisms (and perhaps professional mediators) to handle difficulties that may arise regarding accommodations.
- Keep written records about accommodations that have been implemented.
- Maintain ongoing communication, including periodic review and assessment of an accommodation.

Generally, consumers themselves are in the best position to suggest needed accommodations. Discussion with employers should focus on the expatien’t’s particular abilities and limitations as they pertain to the essential functions of the job, and should evaluate how an accommodation might overcome barriers to performance. If several effective accommodations are possible, then the employer should consider the individual’s preference and select the accommodation that is most appropriate for both parties.\(^{26}\)

The employer has the right to deny the desired accommodation if it would place an "undue hardship" on the organization. **Undue hardship is defined as an “action requiring significant difficulty or expense.”**\(^{27}\) If a request for an accommodation is considered unreasonable, then the employer should propose an alternative accommodation. In this case, the employee is not required to accept the alternative suggestion. Similarly, people need not accept accommodations that they have not requested and believe are unnecessary. If the proposed alternative is not acceptable to the employee, she should ask:

- Can we compromise? Is there another solution to this situation which will allow me to perform my job and that my employer will feel is reasonable?

**Legal Action.** Should a consumer feel that he is being discriminated against on the basis of his disability, both the employee and employer should do some reading about the ADA and
talk to some knowledgeable people to get their opinions about whether or not discrimination has occurred in the legal sense, before the employee takes any official action. Some agencies have a legal consultant or a committee that can help resolve employee grievances. There are regional technical assistance centers, serving every area of the country, with ADA experts on staff who can address your questions (see the list under “Resources” at the end of this chapter). In addition, there are private and federal organizations specializing in the ADA and the legal rights of people with disabilities. A few of these organizations also are listed at the end of this chapter.

If a consumer provider and an employer are unable to arrive at a compromise that will allow the individual to perform her job, the next question the consumer should consider is how far she is willing to go to pursue her legal rights:

♦ Are you willing to lose your job?

♦ Are you willing to do the work needed to file an official complaint against your employer? This involves filling out a lot of paperwork; documenting in detail all of the interactions between you and your employer; talking to investigators and lawyers; and possibly going to court.

♦ Are you willing to take your employer to court?

♦ What do you hope to gain by fighting for your legal rights? If you are seeking a large financial settlement, this may not be the way to go. If you feel that your rights have been violated and you want to try to correct the discrimination, the ADA provides recourse for you to do so.

If a consumer provider decides to pursue a complaint against an employer, the first step is to contact the local Equal Employment Opportunity Commission (EEOC) office. The employee should do this soon after the discrimination has occurred, since there are time limits for filing a complaint (generally 180 days). To contact the EEOC, look in the telephone directory under U.S. Government. All complaints must be filed first with the EEOC, which will conduct an investigation into the charges. The officials at the EEOC will then give instructions about how to proceed with the case.

**Being Accommodating Can Cause Problems.** When applying reasonable accommodations in the workplace, one should be alert to potential problems which may arise. The most common problem is resentment among other staff people who see the accommodations as unfair privileges. Flexibility in leave policies, scheduling, and work environment are common accommodations which are often desired by both consumer and nonconsumer members of staff. In fact, most accommodations are, in actuality, sound personnel practices and should be adopted as standard procedure whenever possible.
Some consumer professionals, realizing the potential for colleagues to feel resentment, decide that they would rather not ask for any accommodations than single themselves out by getting some “special treatment:”

I have a conflict with the ADA as to whether I ask for accommodations at work. I think it’s wonderful at many levels that the ADA exists and that people can ask for accommodations. The negative side for me, and where I fight it a little more is that it feels like, once again, just because we have emotional problems, that we need something that you don’t need. It once again separates us and makes us different than [you]. Part of my recovery has been normalizing the process and needing to believe that I could probably use a four-day work week and my guess is you could too. Because, I think, often it sets us up to be resented. ...I just use the same sick days everyone else has. I really don’t ask for many accommodations. I just try to use the benefits I get.

There are times, however, when a particular individual will need a little extra support or flexibility because of a disability, and in the process of accommodating this request employers may also need to help non-disabled coworkers understand why this is important and necessary. Involving others in the process of designing reasonable accommodations for employees with disabilities can lessen the chances of coworker resentment. Agencies might consider establishing a committee made up of consumer and nonconsumer staff persons to discuss implementation of the ADA, though such conversations should be kept on a general level rather than focusing on specific accommodations for a particular employee.

**Making it Okay to Ask for an Accommodation.** Part of creating an organizational environment that is comfortable for both consumers and nonconsumers is helping people to feel okay about asking for what they need to do their jobs most effectively:

My sense is, not only at our agency, but at some of the agencies that I’ve worked with, that people with disabilities really have to fight some of the stigma issues, as well as feeling okay about asking for an accommodation. I know many people who could benefit from accommodations who don’t ask for them because they are afraid about how they will be viewed. 30

One supervisor described how his agency helps to encourage people to discuss accommodations if they need them:

Whenever we hire [people], if they have disclosed a disability, we ask if there’s anything we can do to make the environment easier for them to do their jobs. We make that overture, we don’t wait for them to ask. We ask when [people are] starting their job, and again a couple of times after that, because you don’t always know. Sometimes people are scared to request something because their position is so fragile they don’t want to make any waves, so we do the asking.
What we try not to do (this is another recommendation) is to out-guess the people with the disability, but rather we create an opportunity for them to get what they want. We don’t want to guess what they need in fear we will guess wrong and out of embarrassment they won’t say it’s wrong. We say, “We want it to be right. You tell us how to make it right.”

It really is up to agency administrators to set the tone regarding how seriously the ADA will be taken by providing training, making sure all staff and clients understand what the law entails, and demonstrating flexibility and a desire to accommodate employees with disabilities:

Because we are hiring more and more people with disabilities, we are having to provide more and more accommodations, and a wider range of accommodations. There is some resentment in the agency. When we did a training a couple of months ago in one of the offices, ...some of the support staff were saying, “Can we refuse to provide an accommodation? Are our jobs in jeopardy if we say, ‘No, we don’t want to do the accommodation?’” The managing attorney and the supervisors in the agency were very strong and said, “This is the policy of the agency -- that we will provide accommodations -- and that may mean that you do things differently.” They really said, “Here is the expectation.”

A critical element in implementing reasonable accommodations is the creation and expansion of an organizational culture that is receptive to change and supportive of people with disabilities. Creating an environment in which the spirit of the ADA is agency policy requires education about this law, technical assistance, and ongoing communication among everyone in the organization. This will help to develop and promote an environment that is open to an employee’s disclosure of a mental illness, is flexible in discussing accommodations, and is sensitive to the relationships among all workers.

Summary

The ADA is a potentially powerful tool in preventing and combating discrimination against employees with psychiatric disabilities. It is essential that all workers with disabilities, employers, and supervisors understand the basic elements of this law so that they may recognize discrimination when it occurs, and have some ideas about how to deal with it. We have briefly presented some general information about the ADA and encourage readers to take advantage of the resources listed at the end of this chapter to gather more information. The ADA allows employees with acknowledged disabilities to request reasonable accommodations enabling them to perform their jobs better, and we have suggested ways in which this topic might be broached between employees and their supervisors. Disclosure is a major issue in this regard and we have discussed some of the decisions that consumers must make should they choose to utilize benefits of the ADA such as reasonable accommodations. Not all employees with psychiatric disabilities need reasonable accommodations, and many consumers choose not to request accommodations regardless of their need. This is largely out of fear of stigma and resentment from coworkers.
who may view accommodations as "special treatment." It is the role of agency administrators to take a strong stance in supporting consumer providers' rights under the ADA, and promoting an organizational environment which is humane and accommodating of all employees.
Resources for More Information About the ADA

Job Accommodations Network
tel/TDD: (800) 526-7234 or (800) ADA-WORK
Computer Bulletin Board: (800) DIAL-JAN
Internet Address: http://janweb.icdi.wvu.edu

Policy Resource Center
1730 Rhode Island, N.W., Suite 308
Washington, DC 20036
tel: (202) 775-8826
FAX: (202) 659-7613
Policy Information Exchange on Internet: www.pie.org

The National Association for Rights Protection and Advocacy (NARPA)
587 Marshall Avenue
St. Paul, MN 55102
tel: (612) 224-7761

The U.S. Department of Justice operates an “ADA Information Line” offering information on any aspect of the ADA. Call:
tel: (202) 514-0301
TDD: (202) 514-0383

To locate the Protection & Advocacy office in your state call:
National Association of Protection & Advocacy Systems
tel: (202) 408-9514

The U.S. Equal Employment Opportunity Commission has prepared free pamphlets offering basic information to employers and workers about the ADA entitled, “The ADA: Your Employment Rights as an Individual with a Disability,” “The ADA: Your Responsibilities as an Employer,” and, “The Americans with Disabilities Act: Questions and Answers.” They also have published an informative document called, EEOC Enforcement Guidance: The Americans with Disabilities Act and Psychiatric Disabilities (1996). To order these materials or ask ADA-related questions, call:
tel: (800) 669-EEOC
TTY: (800) 800-3302

The Judge David L. Bazelon Center for Mental Health Law has published a booklet entitled “Mental Health Consumers in the Workplace.” They cost $6.95 each (the price goes down as the quantity goes up), and can be ordered by calling:
tel: (202) 467-5730
The ADA Regional Technical Assistance Centers provide training on the ADA and will respond to your questions. Identify the Center in your region.

**Region 1: CT, ME, MA, NH, RI, VT**

University of Southern Maine  
Muskie Institute of Public Affairs  
96 Falmouth Street  
Portland, ME 04103

Tel: (207) 780-4430  
Fax: (207) 780-4417  
TTY: (207) 780-5646

**Region 2: NJ, NY, PR**

United Cerebral Palsy Association of New Jersey  
354 South Broad Street  
Trenton, NJ 08608

Tel: (609) 392-4004  
Fax: (609) 392-3505  
TTY: (609) 392-7044

**Region 3: DE, DC, MD, PA, VA, WV**

Mid-Atlantic ADA Information Center  
2111 Wilson Boulevard, Suite 400  
Arlington, VA 22201

Tel/TTY: (703) 525-3268  
Fax: (703) 525-6835

**Region 4: AL, FL, GA, KY, MS, NC, SC, TN**

ADA Regional Resource Center  
1776 Peachtree Street, Suite 208  
Atlanta, GA 30309

Tel/TTY: (404) 888-0022 or within region call (800) 949-4232  
Fax: (404) 888-9091
Region 5: IL, IN, MI, MN, OH, WI

University of Illinois at Chicago
Institute on Disability and Human Development
1640 West Roosevelt Road
Chicago, IL 60608

Tel/TTY: (312) 413-1647
Fax: (312) 413-1326

Region 6: AR, LA, NM, OK, TX

Independent Living Research Utilization
The Institute for Rehabilitation and Research (TIRR)
2323 South Shepherd Boulevard, Suite 1000
Houston, TX 77019

Tel: (713) 520-0232
Fax: (713) 520-5785
TTY: (713) 520-5136
Internet Address: www.bcm.tmc.edu/ilru/

Region 7: IA, KS, NB, MO

University of Missouri at Columbia
Human Resource Services (MU)
Heinkel Building, Room 103
201 South Seventh
Columbia, MO 65211

Tel: (573) 882-4859
Fax: (573) 882-9975
TTY: (573) 882-1794

Region 8: CO, MT, ND, SD, UT, WY

Rocky Mountain ADA Technical Assistance Center
3630 Sinton Road, Suite 103
Colorado Springs, CO 80907-5072

Tel/TTY: (719) 444-0252
Fax: (719) 444-0269
Internet Address: www.usa.net\ada_infonet

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Region 9: AZ, CA, HI, NV

Berkeley Planning Associates
440 Grand Avenue, Suite 500
Oakland, CA 94610

Tel: (510) 465-7884 or within region call (800) 949-4232
Fax: (510) 465-7885
TDD: (510) 465-4493
Internet Address: www.pacdbtac.org

Region 10: AK, ID, OR, WA

Northwest Disabilities Business and Technical Assistance Center
P.O. Box 9046
Olympia, WA 98507-9046

Tel/TDD: (360) 438-4116 or within region call (800) 949-4232
Fax: (360) 438-4014
Endnotes

Chapter 11


3. Other employment protections are offered by the Civil Rights Act of 1964 and the Equal Pay Act of 1963 (as amended). Title VII of the Civil Rights Act prohibits race and sex discrimination in hiring, promotion, discharge, pay, fringe benefits, and other aspects of employment. Employees of most private firms, local governments, and public or private educational institutions are protected by this legislation. Also covered are employment agencies, labor unions, and apprenticeship programs. The Equal Pay Act prohibits sex discrimination in payment of wages to men and women performing substantially equal work in the same establishment. This means that workers who perform similar tasks in the same organization should receive similar pay, and that “men’s” jobs can not be paid higher than “women’s” jobs when the nature of the work performed is essentially the same. Be aware that many workers not covered by Title VII (because their employing organization is too small) are covered by the Equal Pay Act.


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11. Mental Health Law Project (1992). Mental health consumers in the workplace...

12. Ibid.


17. Mental Health Law Project. (1992). Mental health consumers in the workplace...


24. Ibid.

26. Ibid.


30. L. Shepherd, personal communication, March 1, 1996.


32. L. Shepherd, personal communication, March 1, 1996.

Conclusion: Realizing the Possibilities

...An empowered society will not occur until we understand that the responsible leaders are all of us, that the "disabled and disadvantaged" are all of us, and that the productive self-realization and quality of life of the person with mental illness or the single mother in the ghetto are just as important to our pocketbooks and our happiness as the productivity of the president of Coca-Cola and the quarterback of the Redskins...

-Justin Dart

As we explained in the preface of this manual, this version of Positive Partnerships was written with the primary intention of providing helpful, practical advice about how to make consumer hiring work in traditional mental health settings. We realize that the extent to which we accomplished our goal in the preceding pages is a hit-or-miss proposition, given the wide variability in agencies. The suggestions we have made of actions to take to prepare the workplace, confront stigma, deal with crises, establish expectations, etc. will be more or less successful in different settings. Just a few of the variables that will make a difference in how to proceed with organizational change efforts are: current relationships between people, prevailing trends in treatment philosophy, visibility of client/practitioners, the commitment of colleagues, and the degree of flexibility in the current agency structure. For these reasons we emphasize that agencies will need to adapt the material in this manual to suit their particular settings. We strongly recommend looking again at Chapter 5 and, if you haven’t done so already, begin by conducting an assessment of your agency’s needs and readiness for change.

Along the way, as you implement advice from this manual and from others, you may encounter unforeseen obstacles not discussed in written resources. Real life problems call for real live problem-solvers, and therefore, on the following pages we have listed several places you can call to get technical assistance from an actual human being. We have included ourselves on this list (under UIC National Research & Training Center). We certainly want to hear from you! We are available to provide technical assistance and we want your feedback on this manual. What do you think of what we have written? How have you used it? What is especially helpful? What material needs to be added? What worked and what didn’t? We value your opinions and experience. Please share them with us.

Finally, we appreciate your interest in this topic and applaud your efforts to create more hospitable environments in which consumers and nonconsumers alike can feel comfortable expressing themselves, relating life experiences, and working together to provide the highest quality mental health services. We believe in your power to make change happen and wish you the best of luck as you realize the possibilities.

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## Resources

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<thead>
<tr>
<th>Organization</th>
<th>Tel.</th>
<th>Fax.</th>
<th>TTY.</th>
<th>E-mail</th>
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<tbody>
<tr>
<td>UIC National Research &amp; Training Center on Psychiatric Disability</td>
<td>(312) 422-8180</td>
<td>(312) 422-8180</td>
<td>(312) 422-0706</td>
<td><a href="mailto:jonikas@psych.uic.edu">jonikas@psych.uic.edu</a> or <a href="mailto:bamberger@psych.uic.edu">bamberger@psych.uic.edu</a></td>
</tr>
<tr>
<td>Center for Community Change</td>
<td>(802) 658-0000</td>
<td>(802) 658-7435</td>
<td></td>
<td><a href="mailto:ccc@courage.trinityvt.edu">ccc@courage.trinityvt.edu</a></td>
</tr>
<tr>
<td>Human Resource Association of the Northeast</td>
<td>(413) 536-2405</td>
<td>(413) 536-4166</td>
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<tr>
<td>MATRIX Research Institute</td>
<td>(215) 438-8200</td>
<td>(215) 438-8337</td>
<td></td>
<td><a href="mailto:workmri@aol.com">workmri@aol.com</a></td>
</tr>
<tr>
<td>National Empowerment Center</td>
<td>(800) POWER-2-U</td>
<td>(508) 681-6426</td>
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<tr>
<td>National Mental Health Consumers’ Self-Help Clearinghouse</td>
<td>(800) 553-4KEY(4539) or (215) 751-1810</td>
<td>(215) 636-6310</td>
<td>(215)751-9655</td>
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Endnote

Conclusion
