Building Bridges

*Mental Health Consumers
in Intergenerational Dialogue*

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Acknowledgements

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Originating Office

Contents

Somewhere along the line, as a young person, I got this impression that the adult [consumer] movement was a bunch of boring old people. I had my concerns and apprehensions about coming here, but you all are very cool. Hearing you share your stories, it's not that you just popped out as adults somewhere along the line. A lot of you started as consumers as young people, and I have so much in common with you. I can identify a lot with your stories. I'm interested in working with you guys now.

—Young adult participant

Overview

For nearly four decades, consumers of mental health services have advocated for improved quality and access to mental health services in the United States. This modern consumer movement is hardly the first reform effort to impact mental health care in America. Records show that as early as the mid-1800s, former psychiatric patients and others had worked to improve the deplorable, abusive conditions rampant among the mental institutions of the day.

Conditions have improved dramatically over the years, but advocates continue to fight for patients' rights, work to overcome prejudice and discrimination, and promote self-help, peer support, and recovery. As the Surgeon General's report on mental health indicated:

> The consumer movement has increased the involvement of individuals with mental disorders and their families in mutual support services, consumer-run services, and advocacy. They are powerful agents for changes in service programs and policy.

> The notion of recovery reflects renewed optimism about the outcomes of mental illness, including that achieved through an individual's own self-care efforts, and the opportunities open to persons with mental illness to participate to the full extent of their interests in the community of their choice. (U.S. Department of Health and Human Services [HHS], 1999)

The consumer movement's robust impact was highlighted just a few years later in the call by the President's New Freedom Commission on Mental Health (2003) for consumers to "stand at the *center* of systems of care and to *lead* the design, implementation, and evaluation of mental health services in the United States." The Commission established the primacy of the consumer in its second overarching goal: mental health care is consumer and family driven.

Until fairly recently, the consumer movement essentially focused on adults' mental health. Several major family-oriented advocacy organizations that organized in the 1970s and 1980s have since enjoyed substantial success in moving positive mental health policies forward for adults, children, and adolescents.

An important fact to note is that increasing numbers of youth have taken seats at policy-making tables since the mid-1980s.

Veteran consumer activists have expressed the need to share the history, knowledge, and skills of their movement with the younger generation. Likewise, many members of the younger generation want older consumers to be aware of *their* concerns and activities. While experiences in mental health care for both groups correspond in some respects, differences also have influenced the ways in which they have approached mental health in general, their primary issues, and their roles as advocates and leaders.

There is an identified need to bring these groups together to exchange views and to determine how to use the knowledge gleaned from their shared—and diverse—histories.

In September 2007, the Center for Mental Health Services (CMHS), Substance Abuse and Mental Health Services Administration (SAMHSA), U.S. Department of Health and Human Services (HHS), hosted a 2-day roundtable meeting in Rockville, Maryland. Mental health consumers and advocates across multiple generations attended. Together with CMHS staff, a representative planning committee identified participants, recommended facilitators, and developed an agenda for the dialogue.

The intergenerational dialogue aimed to:

- develop improved mutual understanding of the participants' shared history as mental health consumers;

- increase communication and partnerships among mental health consumers to forge a common agenda to promote mental health recovery;

- develop a set of recommendations to increase collaboration among consumers of all ages; and

- develop strategies to promote consumer leadership and recovery.

The dialogue brought together approximately 20 mental health consumers and supporters. Ranging in age from 20 to 75, participants included peer specialists, youth coordinators, national and local consumer leaders, consumer organization directors, trainers, mental health advocates, and others. With its emphasis on hearing the youth voice, which has strengthened markedly since 2000, this dialogue meeting was an historic event, a joining of minds across the lifespan and a bridge across the adult and youth mental health consumer movements.

History of Center for Mental Health Services Dialogues

In 1997, CMHS sponsored inaugural roundtables in a series of formal dialogues. These meetings offer mental health consumers and representatives of other groups the opportunity to improve communication and build partnerships to influence mental health services and promote recovery. Nearly a dozen dialogues to date have led to concrete outcomes, including advances in networking, training and technical assistance, and valuable recommendations for CMHS and the field. Formal dialogue reports help to disseminate these outcomes in printed documents and/or postings on SAMHSA's National Mental Health Information Center Web site (http://nmhicstore. samhsa.gov).

Examples of these reports include *Building Bridges: Mental Health on Campus: Student Mental Health Leaders and College Administrators, Counselors, and Faculty in Dialogue* (2007), and *Building Bridges: Consumers and Representatives of the Mental Health and Criminal Justice Systems in Dialogue* (2005). Additional monographs describe dialogues between consumers and psychiatrists, psychologists, social workers, and mental health/psychiatric nurses. Additional topics include the interface between consumers and primary health care representatives; consumers and representatives of faith- and community-based organizations; consumers and representatives of the mental health and criminal justice systems; and topics related to co-occurring disorders, consumers and service providers, policy makers, and researchers.

Mental Health Consumers: Similarities and Differences in the Evolving Movement

We're not two clearly defined groups, but I think the differences among our generations are important to address, because as the advocacy role falls onto my generation and younger, we're not necessarily going to follow through the way the older generation would want us to. It's important for us to learn what's important to the older generation, and at the same time incorporate our views and what we need.

—Young adult participant

Two major considerations may inform an examination of similarities and differences across the lifespan among mental health consumers, and also of the evolution of the consumer movement: (1) recognition of the impact of generational differences in the general population, and (2) the availability and impact of mental health treatments, services, and supports on the lives of consumers and on the development of the adult and youth consumer movements.

Generational Differences

Psychosocial research suggests that generations share both commonalties and striking differences related to experience and values, depending on year of birth and the nature of life's ensuing experiences. Table 1 presents a selection of broadly generalized comparisons among four current generations of Americans—Traditionalists, Baby Boomers, Generation X, and Generation Y or Millenials. Participants in the intergenerational dialogue ranged across the four generations described.

Table 1. Differences Across Generations

Categories	Generations			
	Traditional-ists	Baby Boomers	Generation X	Generation Y: Millenials
Birth date	Before 1946	1946–1965	1965–1981	1981–2000
Numbers in the popula-tion	35+ million	80+ million	45–80 million	60–80 million
Family constella-tion and environment	▪ Close family ▪ Mother at home ▪ One mar-riage	▪ Working mothers ▪ Dispersed family ▪ Divorced/ remarried	▪ Single mothers ▪ Working mothers ▪ Latchkey kids ▪ High divorce rate	▪ Single mothers/ single fathers ▪ Looser family unit ▪ Children increasingly protected and supervised by family
Formative experiences	▪ Great De-pression ▪ New Deal ▪ World Wars I and II ▪ Rationing	▪ Civil rights ▪ Sexual revolution ▪ Cold War ▪ Space travel	▪ Fall of Berlin Wall ▪ Watergate ▪ Women's liberation ▪ Desert Storm	▪ September 11 ▪ School shootings ▪ Oklahoma City bombing ▪ Technology ▪ Iraq War
Communica-tion	▪ Radio ▪ Mimeo-graph ▪ Rotary phones ▪ Slide rule	▪ TV ▪ Photograph ▪ Touch-tone phones ▪ Calculators	▪ Video games ▪ Computers ▪ Beepers ▪ Cell phones ▪ Laptop computers	▪ Internet ▪ DVD ▪ PDA ▪ iPod ▪ MySpace ▪ YouTube ▪ Instant messages ▪ Text messages

(continued)

Table 1. Differences Across Generations *(continued)*

Categories	Generations			
	Traditional-ists	Baby Boomers	Generation X	Generation Y: Millenials
Work style	▪ Work hard ▪ Team player ▪ Commit-ment to work ▪ Loyal	▪ Hard work and loy-alty equals career suc-cess ▪ Seek status ▪ Sacrifice family for advance-ment	▪ Work hard/ be well paid ▪ Do not defer rewards— cash and salary now ▪ Willing to change jobs ▪ Use technology ▪ Balance work and life	▪ Expect pay for what they do, not time given ▪ Boss is mentor/ coach ▪ Willing to job hop
Characteris-tics/ values	▪ Dedication and sacrifice ▪ Respect for rules ▪ Duty before pleasure ▪ Honor ▪ Financially conserva-tive ▪ Faithful to institutions	▪ Idealistic ▪ Optimistic ▪ Team oriented ▪ Personal gratification ▪ Personal growth ▪ Believe one can be and do anything ▪ Hard work and loy-alty equals career suc-cess ▪ Rights focused	▪ Prove it to me ▪ Self-centered ▪ Skeptical of the integrity of institu-tions ▪ Accept diversity ▪ Fun and informality ▪ Self-reliant ▪ Pragmatic ▪ Practical ▪ Fend for oneself ▪ Adaptable ▪ Loyalty to team	▪ "Go do it" ▪ "Can do" ▪ Diplomatic ▪ Collabora-tive ▪ Respect diversity ▪ Conformist ▪ Confident ▪ Achieve-ment oriented ▪ Instant gratification ▪ Respect their ideas ▪ Spirit of volunteer-ism ▪ Balance between material goods and spiritual happiness

(Sources: Duke University, n.d.; Wheeler, n.d.; Dittman, 2005; Gaylor, 2002; Thielfoldt & Scheef, 2004; Mayo Clinic, n.d.)

Consensus is elusive in the literature on the generations' inclusive time periods and on nicknames for the generations. Moreover, researchers describe generational characteristics differently. But they recognize universally that one's personal experiences within the family, work, and community impact one's outlook on life.

Experiences with Mental Health Services

As might be expected, personal experiences with the mental health services system influence the way consumers view and advocate for mental health care. The confluence of personal histories, in turn, has shaped development of both the adult and the youth consumer movements. Far too many adult consumers have shared the common experiences of institutionalization, forced treatment, incarceration, homelessness, poverty, poor mental health care, inadequate general health care, and social exclusion and discrimination.

By contrast, younger consumers perhaps are less likely to have experienced some of the adverse conditions endured by their elders—although certainly prejudice and discrimination, poverty, and probably inadequate medical care—continue as barriers in their lives. Since the 1980s mental health care systems for children and adolescents have changed dramatically in the United States. Shifts have occurred in:

- places where children and youth receive treatment, services, and supports: from hospitals and long-term residential care back to the community;

- nature of services: for example, the introduction of mentoring programs, new medications, anger management strategies, and family supports; and

- providers of the services and supports: for example, teachers, foster homes, child care staff, paraprofessionals, probation officers, peers, and even community volunteers.

Younger people may take advantage of services in many locales within the supportive context of comprehensive, coordinated, community-based, and culturally competent systems of care. In establishing systems of care for children and adolescents with serious mental health problems and their families, many communities have reaped the beneficial effects of the wraparound services they provide (CMHS, n.d.). Nevertheless, lacking those supports and services, many younger consumers have found themselves enmeshed in the juvenile justice, special education, foster care, and/or substance abuse treatment systems—or otherwise have fallen through society's cracks.

Consumer Movement(s): Evolution Highlights*

As early as the mid-1800s, former psychiatric patients worked to change laws and public policy regarding the "insane." In a brief history of the consumer/survivor movement, the National Mental Health Consumers' Self-Help Clearinghouse (Clearinghouse, 2000) explained:

> Beginning in 1868, Elizabeth Packard, founder of the Anti-Insane Asylum Society, published a series of books and pamphlets describing her experiences in the Illinois insane asylum to which her husband had had her committed. But in the nineteenth century, individuals fighting for patients' rights, such as Mrs. Packard, met great opposition. Due to ignorance and fear—many still believed that mental illness was the result of demonic possession—such early attempts at activism were largely ignored.

A founding father of the mental health consumer movement, Clifford W. Beers published *A Mind That Found Itself.* In this 1908 book, he described his personal challenges with mental illness and the harrowing treatment he received in three mental hospitals. His compelling narrative—together with his ability to enlist prominent individuals in the publication of his book and his subsequent reform efforts—changed the face of mental health in the United States (Friedman, 2002).

Throughout the 20th century, activists founded a number of organizations, some of which have since become familiar names in the mental health arena. In 1909, Beers formed the National Committee for Mental Hygiene, which aimed to "improve attitudes toward mental illness and the mentally ill; to improve services for the mentally ill; [and] to work for the prevention of mental illness and promote mental health." Its members claimed victory for a set of model commitment laws enacted in several States; conducted influential studies on mental health, mental illness, and treatment; and convened a worldwide congress for "constructive dialogue about fulfilling the mission of the Mental Health Movement." Eventually the group evolved into the National Mental Health Association, now known as Mental Health America (Mental Health America, n.d.).

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* A comprehensive history of the U.S. consumer/survivor movement has not yet been written.

In 1937, neuropsychiatrist Abraham Low founded Recovery, Inc., which offered a self-directed "self-help system of psychotherapy based on the management of fear, anger, and nervous symptoms." The organization's work continues into the present. As a supplement to professional treatment, participants seek to regain and maintain their mental health and productivity by regular participation in free meetings that help them learn to replace "self-defeating and illness-promoting thoughts and impulses" with "self-endorsing thoughts and wellness-promoting actions" (Abraham A. Low Institute, n.d.; Recovery, Inc., n.d.).

In the 1940s, in order to help ease for others the difficult transition from hospital to community, former psychiatric patients founded WANA (We Are Not Alone). In 1948, in New York City, the group established Fountain House, which offered psychosocial rehabilitation services to people leaving State mental institutions and fostered a community among people struggling with serious mental illnesses. Fountain House's innovative "clubhouse" model has inspired more than 1,400 similar programs worldwide (Fountain House, n.d.).

Scientific developments in the 1950s led to the introduction as well as

> widespread use of psychotropic . . . medications[, which permitted] many people—individuals who would once have been committed to asylums for life—to be released to live in the community. The goal of this "deinstitutionalization" movement was to allow people with mental illness to escape being warehoused in what were often terrible conditions, so that they could enjoy increased independence and opportunities. While the idea of releasing people from institutions was a worthy one, many people fell through the cracks because of the lack of community-based mental health services. In addition, many of the psychotropic drugs had terrible side effects. (Clearinghouse, 2000)

In the developing civil rights movement of the late 1950s and early 1960s, people organized to challenge inequality and social injustice. By 1970, the movements for women's, gay's, and disabled people's rights all had taken on parallel goals. Also in this context,

> former mental patients in several cities across the country began to organize groups with the

> common goals of fighting for patients' rights
> and against forced treatment, eradicating stigma
> surrounding mental illness, ending economic and
> social discrimination, and creating peer-run
> services as an alternative to the traditional mental
> health system.

> Unlike professional mental health services . . .
> based on the medical model, peer-run services
> were based on the principle that individuals who
> have shared similar experiences can help
> themselves and each other through self-help and
> mutual support. (Clearinghouse, 2000)

Many early organizers adopted a more militant view of mental
health systems. Their groups took on names such as Insane
Liberation Front and the Network Against Psychiatric Assault
(Chamberlin, 1978), and their members viewed the mental health
system as destructive and disempowering. But by 1980, another
approach was coming into vogue:

> Individuals who considered themselves consumers
> of mental health services had begun to organize
> self-help/advocacy groups and peer-run services.
> While sharing some of the goals of the earlier
> movement groups, consumer groups did not seek
> to abolish the traditional mental health system,
> which they believed was necessary. Instead, they
> wanted to reform it. Consumer groups encouraged
> their members to learn as much as possible about
> the mental health system so that they could gain
> access to the best services and treatments available.
> (Clearinghouse, 2000)

The psychiatric rehabilitation movement of the 1970s and
especially the 1980s promoted such community-based services
as group homes and apartments, employment supports, and
case management services. Upon passage of legislation in 1975
supporting the creation of community mental health centers, the
National Institute of Mental Health (NIMH) actively promoted
community-based services (National Institutes of Health, 1998).

In her groundbreaking 1978 book *On Our Own*, consumer
activist Judi Chamberlin described living with a mental illness, and
she introduced readers to the emerging mental health consumer/
survivor self-help movement. During the next decade, NIMH
began to fund technical assistance efforts to expand the self-help

model across the Nation. Also with NIMH support, the first in a series of annual Alternatives Conferences took place in 1985. This national conference, organized by and for mental health consumers and survivors (and more recently funded by SAMHSA and other partner organizations), provides consumers from across the country with opportunities to network and exchange information (SAMHSA, n.d.; Van Tosh & del Vecchio, 2001; National Empowerment Center, n.d.a).

Independent support groups for parents of adults with serious mental illnesses formed and eventually merged (National Alliance on Mental Illness/NAMI Southwest, n.d.; Frese & Davis, 1997). The Federation of Families for Children's Mental Health organized in 1989 to promote a family- and youth-driven approach to enable children and youth with emotional, behavioral, and mental health challenges and their families to obtain the services and supports they need to enable children to grow up healthy and able to maximize their potential (Federation of Families for Children's Mental Health, n.d.).

Since the creation of SAMHSA in 1992, CMHS has championed consumers' strengthening voice in policy making and in the development, implementation, and evaluation of mental health services and supports, especially through its Office of the Associate Director for Consumer Affairs.

In 1999, two major events signaled a major new direction in the U.S. Government's approach to people with mental health challenges. The Supreme Court's *Olmstead v. L.C.* decision extended deinstitutionalization into "historically unprecedented mandates to integrate people with disabilities into communities of their choice" (Deegan, 2003). And *Mental Health: A Report of the Surgeon General* recognized the "emergence of powerful consumer and family movements" as a "defining trend in the mental health field" over the previous quarter century (HHS, 1999, pp. xii-xiii). In recent decades,

> self-help and peer support groups emerged to empower people to be proactively engaged in their own mental health, and to advocate for change within the mental health system as a whole. . . . [Consumers have come to be] accepted as valued service providers and participants in mental health policy and treatment planning. (Clearinghouse, n.d.)

Peer services include, among others, crisis prevention and respite care, drop-in centers that provide recreational and social

activities plus links to services, safe and affordable housing, peer companions, and peer support and counseling.

Since 1999, when the Surgeon General pointed to the "changing role of consumers and families, with attention to informal support services (i.e., *unpaid* services)" [emphasis added] (HHS, 1999, p. xiii), consumers' roles *have* changed dramatically. By 2001, Georgia had certified the Nation's first class of current and former mental health consumers who were newly trained as peer specialists. These "paid employees of our public and private providers . . . neatly transition ownership of the program into the hands of the consumers seeking services in peer support programs" (Georgia Certified Peer Specialist Project, 2008). Other States and the Department of Veterans Affairs have since incorporated peer specialists into their own mental health and primary care systems in a wide variety of support roles.

In setting out a blueprint for transformed mental health systems nationwide, the President's New Freedom Commission on Mental Health (2003) highlighted the critical role of consumers (and families) in its second goal: "Mental health care is consumer and family driven" (p. 27). The Commission offered a snapshot of a consumer- and family-driven system of care:

> Consumers choose their own programs and the providers that will help them most. Their needs and preferences drive the policy and financing decisions that affect them. Care is consumer-centered, with providers working in full partnership with the consumers they serve to develop individualized plans of care. Individualized plans of care help overcome the problems that result from fragmented or uncoordinated services and [mental health care] systems. (p. 28)

Since its founding in 2006, and guided by its vision of self-directed recovery, the National Coalition of Mental Health Consumer/Survivor Organizations (2008) has added a unified consumer/survivor voice to advocacy efforts to transform the nation's mental health services.

In recent years, with support from CMHS, consumers have directed or played other significant roles in the following initiatives, among many others:

- establishment of a Subcommittee on Consumer/Survivor Issues to serve as a fact-finding body for the CMHS National Advisory Council;

- Consumer-Operated Services Program to evaluate the "effectiveness of consumer-run services in improving the outcomes of adults with serious mental illnesses when used as an adjunct to traditional mental health services" (Missouri Institute of Mental Health, n.d.);

- technical assistance to improve the outcomes and operations of consumer-run and -operated services;

- Statewide Consumer Network Grants to "enhance State capacity and infrastructure to be consumer-centered and targeted toward recovery and resiliency, and consumer-driven by promoting the use of consumers as agents of transformation" (SAMHSA, 2006a), and Statewide Family Network Grants to "enhance State capacity and infrastructure to be more oriented to the needs of children and adolescents with serious emotional disturbances and their families" (SAMHSA, 2006b);

- project to chronicle the history of consumer/survivors in U.S. mental health systems. Articles on South Dakota's Hiawatha Asylum for Insane Indians (Yellow Bird, 2000) and the African American experience of oppression, survival, and recovery in mental health systems (Jackson, 2000) emerged from this initiative;

- support for the restoration of abandoned and neglected State hospital cemeteries, where markers identified deceased patients by number rather than by name; and

- multiple initiatives to eliminate prejudice and discrimination and to promote social inclusion.

Although many are still active in the consumer movement, activists of the late 20th century have matured, and a new, independent generation of leaders and advocates has come forward. Youth and young adults with mental health challenges, along with a cadre of allies and supporters, currently are creating their own history and a distinctive movement for change.

Built on the groundwork and leadership of CMHS, the Federation of Families, and other organizations and individuals since the 1980s, young people have increased their participation in and influence on local and State mental health systems. The youth viewpoint took center stage in 2000, during the pioneering Surgeon General's Conference on Child Mental Health, where

young people had joined with families and professionals to discuss children's mental health needs in the United States. However, because they felt "unwelcome and tokenized," at the conference, youth participants did not return on the second day until they had prepared a list of specific requests, asking to be treated with respect and dignity. At that moment the conference became more youth friendly (Matarese, McGinnis, & Mora, 2005). The Surgeon General's report of that conference acknowledged young people's importance as it expressed gratitude to "especially the youth whose input reminded us of the critical need to listen to their perspectives" (U.S. Public Health Service, 2000).

   Following that watershed event, the youth movement in mental health has gained momentum. With the emergence of a variety of independent youth advocacy organizations (several are listed in the appendix, along with other selected resources), young people are working to amplify their voices and to influence mental health policy more actively. To unite young people's perspectives and causes, a national organization was formed, Youth Motivating Others through Voices of Experience (Youth MOVE), now a subsidiary of the Federation of Families for Children's Mental Health. As a diverse collective, Youth MOVE's members "advocate for youth rights and voice in mental health and other systems that serve them, in the process of empowering youth to be equal partners in the process of change" (Youth Move, 2008). They act as consultants to youth, professionals, families, and other adults; develop training tools, guides, and other documents; and provide a voice in the development of mental health policies and services (Matarese et al., 2005).

> *The focus of our movement isn't just mental health services. Young people are in juvenile justice facilities, and conditions there are despicable. Imagine being a young person with a mental health issue in the juvenile justice system or a young person with a mental health issue in the child welfare system. We try to unite those voices.*
> —Young adult participant

   A history of the fledgling youth movement remains to be chronicled.

Issues and Concerns: Shared and Unique

Pearls of wisdom: It's the irritation of the sand that creates the pearl. Don't think that agitation, irritation, and all those things that make us uncomfortable are not necessary. Sometimes, they're very necessary to get things done.

—Adult participant

In an animated discussion of factors that have hindered or promoted wellness and recovery from their mental health challenges, dialogue participants identified a number of important themes. As might be expected, on some issues they expressed views unique to their generation(s); on others they differed regardless of generation; and on some issues participants shared views across the board. After having established strong group rapport, and in reviewing their conversations at the close of the dialogue, participants expressed surprise that their views so closely resembled each others' across generations.

This section presents an overview of the general themes that emerged in the dialogue; participants' comments illustrate the range of perspectives on each theme. Topics include the power of language and labels; "wellness" and public health; recovery and resilience; education and work; recording and archiving the history of the consumer movement; treatment choice; treatment issues; cultural competence; voices and choices; trauma and trauma-informed care; peer support specialists and youth coordinators; co-optation of the peer support role; lesbian, gay, bisexual, and transgender issues; suicide and suicide prevention; and poverty. Organization of the themes does not necessarily reflect priorities attributed by individual participants.

Language and Labels

From the outset of the dialogue, the use of specific terms arose as points of intergenerational divergence. Participants recognized that terminology sometimes can lead to misunderstandings and sometimes to negative feelings, even when they may be used in a neutral or positive sense. *Mental Health: A Report of the Surgeon General* set the context for this tension nearly a decade before the dialogue took place:

> The lexicon is complicated by objections to the term "consumer." To some, being a consumer erroneously signifies that [mental health] service users have the power to choose services most suitable to their needs. Those who object contend that consumers have neither choices, leverage, nor power to select services. Instead, some consumers refer to themselves as "survivors" or "ex-patients" to denote that they have survived what they experienced as oppression by the mental health system (Chamberlin & Rogers, 1990). This distinction can best be understood in its historical context. (HHS, 1999)

Many younger dialogue participants expressed discomfort with the term "consumer" because of personal experience, political implications they attribute to the term, or for other reasons. By contrast, several more senior members at the table explained the usefulness and history of the term from their experience and perspective.

> *". . . consumer?" I thought. "That's language that's going to make me feel empowered?!" Then I realized that there was a history, and that this was a victory, trying to reframe the way people feel about mental illness.*
> —Young adult participant

> *. . . To us it was a very empowering word. We were "the customer." It meant quality. "Is what I'm selling you good? How can I improve it?"*
> —Adult participant

> *. . . We like the term "client." I can be a client. The client hires the therapist. That means you work for me, and I should be able to have some say in my treatment.*
> —Young adult participant

Discussion of "consumer" continued throughout the dialogue. Nevertheless, across the generations, participants expressed their belief that "no perfect language" exists. Several other terms about which participants expressed strong feelings are discussed in the sections below.

"Wellness" and Public Health

Dialogue participants observed that use of the term "mental wellness" avoids the prejudice and bias often associated with other terms related to mental health issues. Across the generations, they uniformly and emphatically discouraged use of the term "mental illness." They shared the general view that mental wellness is a public health issue that must be addressed as such by mental health systems, schools of public health and social work, and institutions of higher education in other disciplines that educate the next generation of service providers. A focus on mental wellness, they pointed out, encourages a holistic approach and better facilitates the integration of alternative treatment and support options into the portfolio of traditional mental health services and approaches.

> *. . . One thing I'd like to see is no use of the term "mentally ill." That's my "n-word." Don't call me mentally ill!*
> —Adult participant

> *. . . The label of mental illness is damaging. When I got that label, I was told I could never amount to anything, could never work, could never go to school, never have children. It took me a while to get through that. I want to be a person. I don't want to be the illness.*
> —Adult participant

> *. . . I like to use the term "mental health diagnosis," because not everyone believes that they have a mental illness. There's no perfect language, but we're trying to be inclusive.*
> —Adult participant

> *. . . Look at the growth of the international literature on mental wellness. It says that we all have mental health, we all have minds.*
> —Young adult participant

The National Association of State Mental Health Program Directors' report *Morbidity and Mortality in People with Serious Mental Illness*, which revealed that people with serious mental illnesses die an average of 25 years earlier than the general population, adopts the *American Heritage Dictionary* definition of wellness as the "condition of good physical and mental health, especially when maintained by proper diet, exercise, and habits." In describing the population designated by the Federal Government as adults with serious mental illness, the report asserts that "wellness is one of the ultimate goals of, and an integral part of, recovery, and that recovery principles and

approaches are necessary to achieve wellness" (Parks, Svendsen, Singer, & Foti, 2006, p. 30). Participants discussed the trauma of consumers' lives lost so early to ill health.

> *. . . The side effects of many of the medications that we take, in addition to smoking and the lack of access to general health care, have had a dramatic impact on our life expectancy.*
> —Adult participant

> *. . . I think about the loss of the contributions that we could have made to our communities—and how the trauma felt by the next generation continues in our society.*
> —Adult participant

Recovery and Resilience

The term "recovery" had gained currency in mental health circles by the mid-1990s. About a decade later, not long after issuance of the 2003 New Freedom Commission's report, SAMHSA convened more than 100 diverse stakeholders to develop a consensus statement on mental health recovery. Its participants determined that: "Mental health recovery is a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential" (SAMHSA, 2004). The consensus group agreed that the fundamental components of recovery include self-direction, individualized and person centered, empowerment, holistic, nonlinear, strengths based, peer support, respect, responsibility, and hope.

But some advocates assert that recovery does not address certain issues that apply especially to children and that "mental health services and supports . . . need to focus on using and developing the strengths of the young person and the family so as to build a full life." After all, young children with mental health challenges could not be expected to "recover" a life they had never experienced. They were children and they had to move ahead developmentally. These advocates looked to the concept of resilience to close the linguistic and practical gap. "Resilience brings attention to the strengths of the child as protective factors and as assets for the process of positive development. A focus on resilience also draws attention to the family as the most important asset a child can have" (Walker, 2005, p. 25). Dialogue participants weighed in on the issue.

. . . I don't like "recovery." You have to have recovered from something. I like to look at it as "resiliency." Things happen in life. Can you bounce back?
—Young adult participant

. . . Resiliency and recovery are the same thing.
—Adult participant

Productivity: Education and Work

Participants universally identified the critical need for access to, and accommodations for, education, employment, and meaningful activity. Some had been encouraged in their early years to pursue an education, but many participants recounted painful personal stories of having been taunted and/or their educational needs neglected as school-age children.

. . . Many people with mental illnesses don't have access to education, don't realize that they have access through disability services, and don't have to drop out of college and live in poverty.
—Young adult participant

. . . The sixth grade was the last grade that I completed, so they call me a drop-out. But I self-identify as: I pushed out of school. . . . I have no education, but I can learn stuff to survive in this world.
—Adult participant

. . . I had to go through a lot of hurtful things in the mental health system and the educational system.
—Young adult participant

Adult and young adult participants both asserted the importance of securing steady employment that accommodates their need for flexibility in difficult times and for maintaining their wellness. Training and supports that permit self-employment typically are unavailable to mental health consumers. (See also the section on poverty.)

. . . Employment—many people might not fit in the 9-to-5 mold.
—Young adult participant

. . . [Consumers] get into jobs where they basically have to fit in, where there's no reasonable accommodation to go to doctors' appointments and so forth.
—Adult participant

Recording and Archiving the History of the Consumer Movement

Dialogue participants observed that, like the civil rights movement, various aspects of the consumer movement have developed over time. They articulated unanimously the need to share and record the consumer movements' histories, experiences, and wisdom in order to educate future consumers and advocates, strengthen the movement, and promote understanding. They especially endorsed efforts to find a suitable institution to archive the documents and artifacts of the mental health consumer movement(s).

> *. . . An archives and our history are important, because there is common ground. The young people's stories were not unfamiliar today. They were my story, and then I got older.*
> —Adult participant

> *. . . There are two different movements, and I think it's important to bring their issues to the table.*
> —Young adult participant

> *. . . "Where is the university with an archive for our movement?" [a pioneer advocate asked]. "Where do my ten file cabinets of movement history go when I die?"*
> —Adult participant

> *. . . That's an intergenerational concern. When people are coming up, they'll get to see history [and learn about the] different people who were doing things in our movement.*
> —Adult participant

Treatment Choice: Traditional and Alternative

The consumer movement has promoted the choice of a therapeutic approach as an important value, as embodied in the recovery principle of self-direction. Traditional mental health services have included talking therapy and medications. In addition to, or instead of, these traditional strategies, many consumers have embraced one or more alternative approaches.

SAMHSA advises that an "alternative approach to mental health care . . . emphasizes the interrelationship [among] mind, body, and spirit" (SAMHSA, April 2004). In parallel with traditional approaches, some alternative approaches have enjoyed a long history while others remain controversial. The National Center for Complementary and Alternative Medicine at the National

Institutes of Health helps to evaluate alternative methods of treatment and to foster integration of effective practices into mainstream health care practice. Examples of alternative treatment approaches include self-help and peer support, diet and nutrition, exercise, prayer and meditation, animal-assisted therapies, expressive therapies (such as art, dance/movement, and music therapies), culture-based healing arts, relaxation and stress-reduction techniques, and such technology-based applications as telemedicine, telephone counseling, electronic communications, and radio psychiatry.

Dialogue participants expressed a range of similar views supporting treatment choice, including one young person who had anticipated a sharp divide "between radicals and mainstream"—that disagreements would crop up between those who supported the use of traditional treatments, including medications, and those who supported the use solely of alternatives. One young adult explained that receiving a diagnosis and effective medications set the foundation for her recovery. Although many participants strongly advocated for the use of alternative and nontraditional treatments—and for affordable access to them—one young adult expressed excitement "that I've learned today that we're all on the same team." Participants agreed that choice was paramount, including the choice to take, or not take, medications.

> . . . We don't have a manual on how to live. What works for me is naming it, claiming it, and taming it. I take the meds and find they help me to balance.
> —Adult participant

> . . . I think it's so sad that we have millions of people who die by suicide or who are toxic because our system does not give access to choices in treatment.
> —Young adult participant

> . . . Medicines change the brain, but so do the ancient Asian ways, such as meditation and qigong.
> —Adult participant

Treatment Issues

Participants discussed several issues at the center of ongoing controversy. Some expressed impassioned concern about the practice of prescribing psychiatric drugs for very young children. Some participants emphasized the need to promote public awareness of alternatives to psychiatric drugs and of the

possibility to make informed—pro-drug or anti-drug—choices as they direct their own or their children's treatment. (See the *Report of the Surgeon General's Conference on Children's Mental Health* [U.S. Public Health Service, 2000] for background on these issues.)

> *. . . I was a canary in the coal mine. What happened with me [as a youth in a psychiatric hospital where drugs were forcibly administered] now affects millions. When I started this work [decades] ago, this was about the back wards. Now it's about your next door neighbor and the school down the street.*
> —Adult participant

> *. . . When you're forcibly given a chemical that shrinks the brain, it's an emergency. There's an emergency of human rights violations against youth in the mental health system.*
> —Adult participant

> *. . . We're pro-choice to choose psychiatric drugs or not.*
> —Young adult participant

> *In the AIDS world, we bless the pharmaceuticals. Give us more drugs, keep us alive. In the mental health world, it's the complete opposite. How do we balance that attitude?*
> —Adult participant

Through the years, recipients of electroconvulsive therapy (ECT) often have complained of persistent amnesia and deficits in cognitive abilities as a result of the procedure, and advocates (including several dialogue participants) have protested its use. The foremost ECT researcher during the past quarter-decade has reversed his position on the safety of the procedure in publishing findings that these adverse effects in fact persist for an extended period (Sackheim, 2007).

The use of seclusion and restraint, in institutional and community-based settings, on persons with mental health and/or addictive disorders has resulted in deaths and serious physical injury and psychological trauma—at the rate of about 150 mortalities annually (SAMHSA, 2003).

Some participants described their personal and advocacy experiences with involuntary treatment, including ECT and seclusion and restraint.

> *. . . I'm a trauma survivor. I took all kinds of medications and ECT. Now I'm going back to my roots of believing in mind-body-spirit. Spirit is the lead in healing ourselves.*
> —Adult participant

. . . People who are diagnosed in youth are told that they don't have insight into their condition. That's how they validate forced treatment.
—Young adult participant

. . . Anytime you say "restraints" in our field, you should say "physical and chemical restraints." [Folks may be] on the bandwagon to oppose physical restraint, but the amount of forced chemicals goes up.
—Adult participant

. . . It's important that we promote safe, humane treatment choices.
—Young adult participant

Cultural Competence

Dialogue participants universally expressed the need for cultural competence. Practitioners must be trained to understand and address the unique needs of individuals from divergent ethnic and cultural backgrounds. Participants particularly observed that mental health service providers must understand the different lenses through which nonmajority consumers view the mental health system.

Mental illness means different things in different cultures, and culture applies to more than race. In fact, observed one participant, special cultural competence is warranted to support and respond to individuals whom the psychiatric system has traumatized and to those who do not speak English. In addition, participants noted the need to avoid "tokenism" in bringing members of ethnic and racial minority groups to decision-making tables.

. . . We have a right to culturally competent services—a wide array of services, including spiritual components.
—Young adult participant

. . . A culturally competent workforce is an issue. How are we engaging and recruiting individuals into the workforce to help our communities?
—Adult participant

. . . We had [Asian American/Pacific Islander] people in mental health systems from across the United States [at a conference]. We had Mandarin and Cantonese and Korean and Filipino—we had 19 different ethnicities with their translators. Some of our cultures' languages did not even have a word for "mental illness."
—Adult participant

Voices and Choices

Participants across generations echoed the theme "voices and choices" throughout the dialogue, underscoring their recognition that advocacy must continue to promote alternatives to the status quo. Several participants, both younger and older adults, cited what has now become a mantra for the consumer movement: "Nothing about us without us."

> *. . . We need to all be equal members at the table, even if we are under 18.*
> —Young adult participant

> *. . . We have to have a voice at all levels of decision making—not only heard but understood.*
> —Adult participant

> *. . . Some might advocate for adults' voices for choices, but with youth, it's "oh, they're children, and they need someone to take care of them."*
> —Young adult participant

> *. . . The underlying issue is that you don't have the same rights as the rest of society once you have that diagnosis.*
> —Young adult participant

Trauma and Trauma-Informed Care

A number of participants disclosed that though traumatic events had led to their own involvement in the mental health system, treatment typically had not addressed—or even acknowledged—their trauma issues. Their comments called attention to the need for providers who understand the role that trauma may play in triggering and sustaining mental health problems. They also highlighted the need to use treatment techniques that address the roots of the problem and avoid retraumatization.

> *. . . I'm an immigrant. No one really considered the impact of trauma. They figured, "She's white, and she speaks English, and she'll be fine." I wasn't.*
> —Young adult participant

> *. . . None of my trauma was ever dealt with, just meds and talk therapy that didn't deal with the trauma. And I was made to feel like it was my fault.*
> —Young adult participant

. . . I was marched into the psychiatrist's office, who was chain smoking and showing me inkblots and asking about my day at school. But it was unrecognized trauma.
—Young adult participant

. . . When we think of trauma, we never think about men suffering trauma.
—Adult participant

Peer Support Specialists and Youth Coordinators

The value of peer support transcended generations among the dialogue participants. Most told stories of the vital role that peers have played in their recovery from mental health challenges.

. . . Through the peer support group, I was able to feel like I wasn't alone anymore.
—Young adult participant

. . . Hearing others' recovery stories is what saved my life— and also telling my stories.
—Adult participant

. . . Peers need to feel empowered that they can give back something on the lived experience, and I think that's what youth wants to do. It's something we need to work on together.
—Adult participant

Recognizing the power of peer support in creating the hope and reality of recovery, consumer activists have launched advocacy efforts to incorporate mental health consumers into mainstream care systems. Over the past two decades, increasing numbers of States have hired and/or certified peer support specialists. The goal is to leverage their personal experience with mental health systems to facilitate consumers' recovery. In addition, within the last decade, the Federal Child Mental Health Initiative has supported development of a cadre of youth peer support facilitators, called youth coordinators. Under a variety of models, persons with both job descriptions draw on their lived experience to promote wellness and recovery among others who contend with mental health struggles.

Peer support specialists work around the Nation, in both the public and private sectors, in a variety of roles and settings, including inpatient, outpatient, and hospital emergency rooms.

Some adult dialogue participants helped to develop and implement early peer support specialist models.

The development of a peer support model among young people has evolved along an independent path from the adult consumer movement. Since 2002 the Child Mental Health Initiative has required State grant recipients to hire local youth coordinators. At every level within communities' systems of care, these youth coordinators foster "youth development and involvement within their own group as well as throughout the community." Based on the understanding that the "power of youth participation helps to rebuild the community, fosters resiliency, and combats [negative attitudes] around mental illness, youth coordinators serve as coaches for youth with mental health issues." They help establish youth-run groups to create social change, to "raise awareness [in the community] of the importance of valuing youth voice and incorporating the youth voice into policy development and service delivery" (Matarese et al., 2005, viii, pp. 5, 15, 25).

Co-Optation of the Peer Support Role

The issue of co-optation of both peer support specialists and youth coordinators elicited strong reactions among all generations taking part in the dialogue. Some experts describe co-optation as a situation in which "consumers begin to identify less with the consumers they represent and more with [the organization that engages them to] serve" (National Mental Health Consumers' Self-Help Clearinghouse, 2006).

Some young adult participants described the tug of coming to terms with their own presence at the government-funded dialogue. Some participants described problems with the way systems use the services of peer specialists. Some questioned whether earning a livelihood in a peer support role is consonant with consumers' interests—or whether the employment arrangement inherently represents co-optation. Some pondered whether co-optation hampers their ability to advocate for change, and other participants, mostly veteran activists, asserted the usefulness of their official peer support role and resources to advance both their clients' recovery and the consumer movement.

> *. . . Peer support is a natural function of the human condition. That is how we have been helping each other for generations, without anyone getting paid for it.*
>
> —Young adult participant

. . . When peers get these jobs, they're trying to be role models, to talk about their lived experience, to share that with the peers they're working with. Sometimes that's missing, because the provider agency has its own agenda. The agency wants to make peers into mini-case managers, doing casework and not the kinds of peer support that they're supposed to be doing.
—Adult participant

. . . I don't consider ourselves co-opted because we're not pushing their agenda in the traditional sense of pushing the government agenda with government money. They knowingly give us money to do this work that has to be done, and I think that's the attitude that we must have on this. We cannot be scared to act.
—Young adult participant

. . . I hesitate for us to think that there's any one way of our doing things, that anything else means co-optation. Many of us need to work in many ways.
—Adult participant

The conversation appeared to raise consciousness about the potential for other types of co-optation.

. . . The youth movement . . . is where it's at, and we need to get on their team. We don't need to bring them into the room. People ask how we can get children and youth more involved, but that's co-opting them. I think they should come in and talk to us about how we can get more involved. We should be the people they are using to further their agenda.
—Adult participant

Lesbian, Gay, Bisexual, and Transgender Issues

Until 1973, homosexuality was considered a mental illness. Only after a successful advocacy campaign by gay and lesbian psychiatrists and leaders did the medical designation change.

Dialogue participants described several concerns about the lesbian, gay, bisexual, and transgender (LGBT) population in their discussions of both cultural competence and suicide (see also those sections). Some participants highlighted the effects of prejudice and discrimination. Others pointed to the difficulty of LGBT persons, especially those who also cope with mental health challenges, in accepting and adjusting to the awareness of their sexual and gender identities. Other participants highlighted the outreach model the LGBT movement has adopted.

. . . Homosexuality is not a mental illness. When it was taken out of the [Diagnostic and Statistical Manual of Mental Disorders], we called that our "day of instant cure."
—Adult participant

. . . I've come up with an acronym that works in my life, with all the "isms" that I'm working with and trying to dispel the myths. I consider myself a "MESSS." My MESSS has three S's: I have Medical, Emotional, Social, Spiritual, and Sexual needs. But I'm HIV-positive, so my last S is silent!
—Adult participant

. . . The LGBT movement folks have it down. I think we have a lot to learn about their organizing tactics, because they're the ones who are doing the most inspiring, powerful work on college campuses. They're basically finding kids who show up at college, always the ones who feel like outcasts and don't fit in, saying, "Hey, look! You should be proud of who you are."
—Young adult participant

Suicide and Suicide Prevention

Dialogue participants included survivors of suicide attempts, survivors of the suicide deaths of people to whom they were close, and active advocates for suicide prevention efforts. Some participants represented more than one category, and suicide prevention emerged as a universal concern. Studies have shown that suicide and injury account for more than 30 percent of early deaths that affect persons in the U.S. public mental health system (Parks et al., 2006, p. 11).

. . . I learned from others that thoughts and feelings are just thoughts and feelings, and you don't have to commit suicide.
—Young adult participant

. . . We're [LGBT] an invisible culture with suicide rates up to six times higher, as kids explore their sexual and gender identities. It amazes me that LGBT is not considered in developing data on suicide rates.
—Adult participant

. . . Suicide prevention should include access to peer support.
—Adult participant

. . . My medications and my therapy have helped save my life, keep me from being suicidal. Now I'm living as a functioning member of society. I'm a wife and have a job that I love.
—Young adult participant

Poverty

Recent studies show that poverty, unemployment, inability to afford housing, and lack of health insurance represent risk factors for developing a mental illness, including depression (Hudson, 2005; Mauksch et al., 2001). In addition, mental illnesses link indirectly with the stressful, adverse economic conditions experienced among lower income groups (Hudson, 2005). Participants expressed their opinions about the intersection of poverty and mental health challenges.

> *. . . Our government and our society don't want to take responsibility for the cause of mental health problems. It's easier to blame individuals: "You're the one who's sick. Let's try to fix you." Instead, we should look at it the other way around: "This person is responding to a horrible environmental situation."*
> —Young adult participant

> *. . . I'm a person in recovery from a lot of things that happened in my life, alcoholism, depression, and poverty— mostly poverty in my family.*
> —Adult participant

> *. . . Part of being human is having access to wellness, including medical insurance and the other benefits that come with employment. The other is economic empowerment—otherwise we live in poverty.*
> —Adult participant

Recommendations

If we took different paths at times, experienced frustration, maybe different ways of communicating, maybe some struggles, a bit of tension once in a while during this dialogue, is that a part of our intergenerational coming together? Clearly, we probably do some things differently. Some of that may be personal, but maybe that's what we need to consider as we move forward, working together in partnership.
—Adult participant

Dialogue participants developed a short, focused set of recommended actions to promote increased collaboration among consumers of all ages. They envisioned activities to be undertaken by consumers, by the multiple movements that advocate on mental health issues, and by SAMHSA.

For Consumers

1. Advocate through the media to reduce (and eliminate) prejudice and discrimination—specifically in such quality-of-life arenas as employment and housing—at the national, State, and local levels.

2. Serve as public health advisors and health educators to foster understanding of the importance of overall wellness, which includes both mental and physical health.

3. Use the arts as an engagement and empowerment strategy to raise awareness and advocate for consumer services and supports.

For the Youth and Adult Consumer Movements

1. Work together, while maintaining the values of each movement. Learn from each others' experiences, and collaborate on common issues and goals.

2. Create a history of the adult and young adult movements that chronicles multiple aspects of the saga, including attention to injustices, civil disobedience, and the unique experiences of people of color.

3. Organize to create a permanent archive for documentation and artifacts of mental health consumer movements.

4. Work together to foster access to alternative, as well as traditional, services and supports.

5. Ensure the availability of educational and employment supports for youth and adults.

6. Develop leadership within the movement(s) to facilitate promotion of mental health recovery.

7. Offer cross-movement mentoring services to promote greater knowledge and understanding of the issues, as well as skills for advocacy.

For the Substance Abuse and Mental Health Services Administration

8. Reframe the issue of "mental illness" as "mental wellness," part of overall wellness and a public health approach.

9. Continue to promote the understanding that mental health affects everyone and is essential to overall health.

10. Learn from consumers at SAMHSA-sponsored events about their activities that foster—or would lend themselves to—intergenerational collaboration.

11. Promote intergenerational dialogues at the local level. Supports would include, for example, funding, training, and technical assistance for facilitators.

12. Provide financial support for youth to attend conferences, such as the Alternatives Conference, to learn about the consumer movement and mental health services delivery issues, and to share their perspectives and experiences. In addition, offer opportunities for virtual training and distance learning.

13. Provide support to compile and publicize the history of the mental health consumer movements, covering, among other topics, human injustices, civil disobedience, and cross-generational issues.

14. Assist with the identification and engagement of an appropriate institution to serve as steward of the documents and other artifacts of mental health consumer movements, in order to preserve the history and to promote scholarship and public awareness.

Conclusions

At the close of the intergenerational consumer dialogue, participants were invited to identify which generations had made the following statements.

"We need to work in partnership."

"Some of us believe we don't have a voice."

"We want to live, learn, and work."

"We are not always listened to."

"We must consider our strengths."

"We need to become empowered."

"Let's recognize the value of our lived experience."

"We need to know more about your movement."

"We need to express all our voices."

"We need alternatives to make our choices."

In fact, these statements were made by individuals across the generations, highlighting the reality that participants' viewpoints converged more than they differed.

Dialogue participants spent a long day sharing personal stories and discussing the array of issues that consumers face in recovering from their mental health challenges. As they learned about each other and broadened their views of the multi-pronged consumer movement, they also developed heightened levels of trust within and across the generations.

On the final day of the dialogue, the participants distilled their ideas and observations down to selected areas of shared concern. As prescribed in the overarching goals of the dialogue, they then compiled a list of recommendations for actions to increase collaboration among consumers of all ages to promote mental health recovery.

But this group did not stop there. As the dialogue came to a close, participants concretely demonstrated their commitment to further the cause of mental wellness and to promote consumer leadership and recovery. Virtually every consumer, leader, and supporter articulated a specific plan, some in concert with others at the table, to collaborate on cross-generational advocacy efforts. Some commitments that were made are the following:

- Find out whether their States have a youth movement and to "network to find the commonality";

- Develop training for people to facilitate their own mindfulness groups that translate to youth or any age and teach techniques of breath awareness, body awareness, and being grounded in the present;

- Use the dialogue experience with "my peers and people in the mental health field. Our strength is not in this room, but out there, walking on the streets, with the general public";

- Try locally to connect both movements and form a local action plan;

- Listen to and promote "youth voices for choices through surveys, forums, and dialogues";

- Address the "emergency of overuse of psychiatric drugging, while affirming those who choose to use a medical approach";

- Write a paper about "youth in the mental health system, then and now; he's going to do the now, I'm going to do the then";

- Build a Web site for "people of color, including youth as part of our voices"; and

- Initiate local dialogues, "including a dialogue with the foster care alumni movement. We share a common experience and have some common goals."

> *The biggest thing we need to change is attitudes.*
> —Young adult participant

Appendix

Selected Resources*

Center for Mental Health Services
Substance Abuse and Mental Health Services Administration
U.S. Department of Health and Human Services

The Center for Mental Health Services (CMHS) leads the national system that delivers mental health services in order to provide the treatment and support services needed by adults with mental disorders and children with serious emotional problems. CMHS supports the meaningful participation of mental health consumer/survivors in all aspects of the mental health system, including the planning, design, implementation, policy formulation, and evaluation of mental health services. To accomplish this goal, CMHS sponsors a variety of consumer affairs activities, such as scholarships to attend national conferences, meetings to address the needs of consumer/survivors, regional consumer meetings, programs to promote social inclusion and acceptance of persons with mental illnesses and other issues related to mental illness, the development and dissemination of educational materials, and much more.

Web sites: www.samhsa.gov and www.mentalhealth.samhsa.gov
Address: 1 Choke Cherry Road, Rockville, MD 20857
Telephone: 1-877-SAMHSA-7 (toll free) or 1-877-726-4727 (toll free)
E-news Alert: www.mentalhealth.samhsa.gov/consumersurvivor
Funding opportunities: www.grants.gov

Active Minds, Inc.

Active Minds is a national organization that develops and supports student-run mental health awareness, education, and advocacy organizations on college campuses. Each peer group works to increase students' awareness of mental health issues,

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* This report provides contact addresses and Web sites for information created and maintained by other public and private organizations. This information is provided for the reader's convenience. SAMHSA does not control or guarantee the accuracy, relevance, timeliness, or completeness of this outside information. Furthermore, the inclusion of information or addresses or Web sites for particular items does not reflect their importance and is not intended to endorse any views expressed or products or services offered.

provides information and resources regarding mental health and mental illness, encourages students to seek help as soon as it is needed, and serves as a liaison between students and the mental health community. By planning campus-wide events that promote awareness and education, Active Minds aims to change the negative attitudes that surround mental illness and create a comfortable environment for open discussion of mental health issues.

Web site: www.activeminds.org
Address: 1875 Connecticut Avenue, NW, Suite 418, Washington, DC 20009
Telephone: (202) 719-1177
E-mail: info@activeminds.org

Federation of Families for Children's Mental Health

This national family-run organization is dedicated exclusively to helping children with mental health needs and their families achieve a better quality of life. The Federation of Families for Children's Mental Health provides leadership to develop and sustain a nationwide network of family-run organizations, focuses the passion and cultural diversity of its membership to be a potent force for changing how systems respond to children with mental health needs and their families, and helps policy makers, agencies, and providers become more effective in delivering services and supports that foster healthy emotional development for all children.

Web site: www.ffcmh.org
Address: 9605 Medical Center Drive, Suite 280, Rockville, MD 20850
Telephone: (240) 403-1901
E-mail: ffcmh@ffcmh.org

Icarus Project

The Icarus Project envisions a new culture and language that resonates with our actual experiences of extreme states of consciousness rather than trying to fit our lives into a conventional framework. We are a network of people living with the dangerous gifts that are commonly labeled as bipolar or related "mental illness." The Icarus Project is a collaborative, participatory adventure fueled by inspiration and mutual aid. We bring the Icarus vision to reality through a national staff collective and a grassroots network of autonomous local support groups across the United States and beyond. The Icarus staff serves and nourishes local groups by facilitating a Web site

community, distributing publications, educating the public, offering tools, sharing skills, creating art, engaging in advocacy, enhancing community capacities, offering technical assistance, providing inspiration and solidarity, and taking care of national housekeeping tasks. The grassroots network of local groups gathers people locally for listening, education, support, mutual aid, art, activism, access to alternatives, and any creative ventures they can dream up.

Web site: www.theicarusproject.net
Address: The Icarus Project, c/o Fountain House,
425 West 47th Street, New York, NY 10036
Telephone: 1-877-787-5883 (toll free)
E-mail: info@theicarusproject.net

Jed Foundation

The Jed Foundation is a nonprofit, public charitable organization committed to reducing the suicide rate among college and university students nationwide. Its programs target the full range of audiences that can influence college mental health, including students, educational institutions, politicians, mental health professionals, and parents. The Jed Foundation's work fosters greater public awareness of the extent of college-age suicides; collaborates with colleges and universities to strengthen mental health services on campus; creates linkages between the academic research community that works on suicide prevention and the higher-education professionals who work directly with students; and produces innovative, Internet-based intervention systems for college students.

Web site: www.jedfoundation.org
Address: 583 Broadway, Suite 8B, New York, NY 10012
Telephone: (212) 647-7544
E-mail: emailus@jedfoundation.org

Mental Health America

Mental Health America (formerly known as the National Mental Health Association) is a national nonprofit organization dedicated to helping all people live mentally healthier lives. With its more than 320 affiliates nationwide, Mental Health America represents a growing movement of Americans who promote mental wellness for the health and well-being of the Nation. Mental Health America educates the public about ways to preserve and strengthen its mental health; fights for access to effective care and

an end to discrimination against people with mental and addictive disorders; fosters innovation in research, practice, services, and policy; and provides support to the more than 60 million individuals and families living with mental health and substance use problems.

Web site: www.mentalhealthamerica.net
Address: 2000 North Beauregard Street, 6th Floor, Alexandria, VA 22311
Telephone: 1-800-969-6642 (toll free); (703) 684-7722
E-mail: infoctr@nmha.org

National Alliance on Mental Illness (NAMI)

NAMI is a national grassroots organization for people with mental illness and their families. Founded in 1979, NAMI has affiliates in every State and in more than 1,100 local communities across the country. NAMI is dedicated to the improvement of the quality of life for persons of all ages who are affected by mental illnesses. NAMI's activities include public education and information, peer education and support, raising awareness and fighting prejudice, and State and Federal advocacy. (See also STAR Center below.)

Web site: www.nami.org
Address: 2107 Wilson Boulevard, Suite 300, Arlington, VA 22201-3042
Telephone: (703) 524-7600; toll free information helpline, 1-800-950-NAMI (6264)

National Coalition of Mental Health Consumer/ Survivor Organizations

The National Coalition of Mental Health Consumer/Survivor Organizations works to ensure that consumer/survivors have a major voice in the development and implementation of health care, mental health, and social policies at the State and national levels, empowering people to recover and lead a full life in the community.

Web site: www.ncmhcso.org
Address: 1300 L Street, Suite 1000, Washington, DC 20005
Telephone: 1-877-246-9058 (toll free)
E-mail: info@ncmhcso.org

National Consumer Supporter Technical Assistance Center (NCSTAC)

NCSTAC works to strengthen consumer organizations by providing technical assistance in the form of research, informational materials, and financial aid.

Web site: www.ncstac.org
Address: 2000 North Beauregard Street, 6th Floor, Alexandria, VA 22311
Telephone: 1-800-969-6642 (toll free)
E-mail: ConsumerTA@mentalhealthamerica.net

National Empowerment Center

The National Empowerment Center, a SAMHSA-funded national technical assistance center, carries a message of recovery, empowerment, hope, and healing to people who have been labeled with mental illness. Run by consumer/survivor/ex-patients, each staff member lives a personal journey of recovery and empowerment. The National Empowerment Center provides information and referrals; networking services; conference planning services; lectures, workshops, and consultation; publishing and media services; education and advocacy on policy issues; representation on national boards; research; development of educational resources; and development of self-help resources.

Web site: www.power2u.org
Address: 599 Canal Street, Lawrence, MA 01840
Telephone: 1-800-power2u (1-800-769-3728) (toll free information and referral); (978) 685-1494

National Mental Health Consumers' Self-Help Clearinghouse

The nation's first national consumer technical assistance center played a major role in the development of the mental health consumer movement. The Clearinghouse works to foster consumer empowerment through its Web site, up-to-date news and information announcements, a directory of consumer-driven services, electronic and printed publications, training packages, and individual and onsite consultation. The Clearinghouse helps consumers organize coalitions, establish self-help groups and other consumer-driven services, advocate for mental health reform, and fight the prejudice and discrimination associated with mental illnesses. The organization also strives to help the movement grow by supporting consumer involvement in

planning and evaluating mental health services, and encouraging traditional providers and other societal groups to accept people with psychiatric disabilities as equals and full partners in treatment and in society. The Clearinghouse maintains an extensive library of information on topics important to consumer groups interested in self-help and advocacy, including peer counseling, deinstitutionalization, fund raising, involuntary treatment, patient rights, using the media, and many others. The Clearinghouse provides targeted technical assistance to individual consumers, self-help and advocacy organizations, and consumer coalitions.

Web site: www.mhselfhelp.org
Address: 1211 Chestnut Street, Suite 1207, Philadelphia, PA 19107
Telephone: 1-800-553-4539 (toll free); (215) 751-1810
E-mail: info@mhselfhelp.org
Consumer-Driven Services Directory: www.cdsdirectory.org

Peers Helping Peers

The Depression and Bipolar Support Alliance (DBSA) Technical Assistance Center fosters strengthened consumer organizations and leadership in States (primarily Wisconsin and Arkansas), skills development for consumers, consumer participation in policy development, and recognition of recovery among mental health providers. The technical assistance center assists consumers with online/media-supported training, peer leadership coaching programs, peer specialist training, consumer organization assistance, and focus group development, knowledge exchange, and skill-building activities.

Web site: www.dbsalliance.org/site/PageServer?pagename=home
Address: 730 North Franklin Street, Suite 501, Chicago, IL 60610
Telephone: 1-800-826-3632 (toll free); (312) 642-0049

Recovery, Inc.

In existence for more than a half century, the nonprofit, nonsectarian, and member-operated Recovery, Inc. offers free training in a self-help method to regain and maintain mental health. The comprehensive system incorporates concepts embedded in the more recently developed techniques of cognitive therapy and behavior modification. Participants attend local or phone meetings held weekly throughout the United States and abroad.

Web site: www.recovery-inc.com
Address: 802 North Dearborn Street, Chicago, IL 60610
Telephone: 1-866-221-0302 (toll free); (312) 337-5661
E-mail: inquiries@recovery-inc.org

STAR Center

The STAR Center provides Support, Technical Assistance, and Resources to assist consumer-operated and consumer-helper programs meet the needs of underserved populations. The STAR Center offers a broad array of technical assistance to consumer-operated and peer-run programs, leadership trainings, national teleconferences, consumer scholarships for attendance at the annual Alternatives Conference, national identification of culturally competent consumer-operated programs as part of its Consumer-Operated Service Identifier (COSI) project, and an online Cultural Resource Directory.

Web site: www.consumerstar.org
Address: 2107 Wilson Boulevard, Suite 300,
Arlington, VA 22201-3042
Telephone: 1-866-537-STAR (7827) (toll free)
E-mail: star@nami.org

Technical Assistance Partnership for Child and Family Mental Health

The Technical Assistance Partnership for Child and Family Mental Health (TA Partnership) provides technical assistance to systems of care communities funded by SAMHSA's Comprehensive Community Mental Health Services for Children and Their Families Program. The TA Partnership is a collaboration between the American Institutes for Research, which is committed to improvement in the lives of families and communities through the translation of research into best practice and policy, and the Federation of Families for Children's Mental Health, an

organization dedicated to effective family leadership and advocacy to improve the quality of life of children with mental health needs and their families.

Web site: www.tapartnership.org
Address: 1000 Thomas Jefferson Street, NW, Suite 400, Washington, DC 20007
Telephone: (202) 403-6827
E-mail: tapartnership@air.org

Youth MOVE

Youth MOVE, an organization to empower youth to be equal partners in the process of change, is made up of a diverse group of youth coordinators and young people from systems of care communities and Partnerships in Youth Transition sites. The organization unites the voices and causes of youth; offers consultation to youth, professionals, families, and other adults; and advocates for youth rights and voice in mental health and the other systems that service them. Youth MOVE assists in developing the Youth Leadership Program at meetings, creating youth movement principles and policies, and developing training tools, guides, and other documents.

Web site: www.youthmovenational.org
Address: Youth M.O.V.E. National c/o National Federation of Families for Children's Mental Health , 9605 Medical Center Drive, Suite 280, Rockville, MD 20850
Telephone: (240) 403-1901
E-mail: c.yonder@youthmove.us

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