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# Consumer Supporter News

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## Break the Language Barrier

*by Jaime Delgado,*
*NCSTAC cultural competency consultant*

To eliminate the healthcare disparities that racial and ethnic groups face in the United States, it is critical that the healthcare system provide culturally competent services. Although experts in the field may disagree about what constitutes—and how to measure—this elusive concept, one element of cultural competency that can be easily defined and measured is language. It is unrealistic to expect that all service providers address the language needs of every ethnic minority in the country, but it is reasonable to expect providers to accommodate the language needs of the populations they serve.

### Historic Overview

Language and communication should be viewed within the contexts of ethnic origin, history, culture, geography and current use. The United States is home to large ethnic groups of non-native English speakers, including Latinos/Hispanics, Asian Americans, Pacific Islanders and American Indians. In addition, other populations of non-English speakers, such as Eastern Europeans, are growing rapidly in various regions of the country. And, although African Americans, the country's largest minority, speak native English, cross-cultural communication issues can arise.

*"Language and communication should be viewed within the contexts of ethnic origin history, culture, geography and current use."*

Furthermore, ethnic groups themselves are diverse. Subgroups within each ethnicity, such as different races, nationalities and tribes, have their own distinct languages and cultures. For example, although Chinese, Japanese, Korean, Filipino and Vietnamese people are all categorized as Asian American, they speak different languages. Native Hawaiians and people from the Federated States of Micronesia, the Republic of the Marshal Islands and Republic of Palau are categorized as Pacific Islanders but do not share the same language. Many of these groups have ethnic and regional distinctions that surface in language.

Languages of the various indigenous populations throughout North, Central and South America also vary significantly. Language scholars believe that before Columbus's arrival in the New World, approximately 300 languages were spoken in North America; since then, the number of indigenous languages has dropped considerably. Figures on current language use vary from 150 to 200 languages, including those spoken by Inuits and Aleuts. The languages of American Indians vary from tribe to tribe.

*Consumer supporter organizations are producing an increasing number of materials in languages other than English.*

Many U.S. groups are actually multi-ethnic. English, Spanish, French, Portuguese and other languages were spread throughout the Caribbean, Central America and South America following colonialism. Today, languages spoken in those areas are highly diverse. Many contain words from their countries of origin and from indigenous languages spoken when colonizers arrived. For example, the Spanish spoken in Mexico includes words from Aztec and other indigenous Mexican languages. Spanish spoken in Puerto Rico includes words that are African and Taino Indian. Spanish in other parts of the Caribbean, Central America and South America includes words from the Mayan, Incan, Quechua, Portuguese, French, Dutch and other languages.

### Making Provisions

For people with limited English proficiency to have meaningful access to health care, services and information must be provided in the

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# Chester County Consumer Satisfaction Team Learns to "Listen for a Change"

*by Rachelle Weiss, director, Chester County Consumer Satisfaction Team*

Although consumer satisfaction teams (CSTs) are now spread across the country, that was not the case six years ago when I started one in Chester County, Penn., following the closing of the Haverford State Hospital in the area.

CSTs first began appearing in the early 1990s with the closing of large state hospitals. As consumers moved from these large facilities into the community, they needed a mechanism to measure the effectiveness of community treatment. CSTs, which are groups of consumers and concerned family members, filled that gap by following consumers into the community and interviewing them to assess the quality of their new treatment. CSTs request consumers' feedback on all facets of community care from day-treatment programs to clubhouses to sheltered housing facilities.

Our group's initial staff training was led by Loretta Ferry and Marilyn Neumus, who founded the CST movement and created what is now considered the premier "Philadelphia Model" for consumer satisfaction teams. At this training, we defined our philosophy, which became part of our mission statement: "Consumer success is founded in consumer satisfaction." Those words guide us to this day. My team now consists of three full-time employees, including myself, and six part-time team members. State money diverted to our program after the closing of the Haverford State Hospital funds our efforts to visit day programs, children's programs, inpatient facilities, partial care programs, halfway houses and any other community care initiatives in our county. Through interviews, we evaluate consumers' satisfaction with their services and report our anonymous findings to the provider, who is then asked to respond to us. Our reports are also turned over to the county, which monitors the quality of community services.

## A Learning Process

Although interviewing consumers is the cornerstone of Chester County CST's work, our team has discovered that consumer satisfaction is about much more than asking questions. It is about education and empowerment for the consumer, and it is a learning experience for the entire mental health system, including our CST team. I am proud to say that Chester County took the first step in consumer empowerment by hiring me—a consumer—as team director.

One lesson learned early on was that many of whom we term "consumers" do not identify themselves as such and were initially confused by the term. They see themselves as "clients" or "patients," but the term "consumer" was new to them. It took us two months to figure out our mistake and modify our language. This experience led to our motto, "Listening for a Change."

> *"Consumer success is founded in consumer satisfaction."*
> *– Chester County CST*

## Provider Responses

Our first major success with a provider empowered consumers as well as the CST. After our visits to group homes in Chester County, the homes installed air conditioning, which is so critical to those of us on psychotropic medication. With this victory, we realized that consumers could effect change in the Chester County mental health community system.

Provider agencies have had mixed responses to our efforts. Some welcome us warmly; others miss our scheduled visits. Between these two extremes are organizations that apparently believe that we "mentally ill" folk just need some good people to take care of us. Sadly, many people with mental illness have come to believe that themselves. Six years into our project, I can say with certainty that our CST is contributing to the dissolution of such attitudes.

> *"As consumers moved from large facilities into the community, they needed a mechanism to measure the effectiveness of community treatment."*
> *– Rachelle Weiss*

## Additional CST Projects

It is important that members of our CST remain actively involved not only in their interviewing work but also in other facets of the mental health community. Team members belong to committees on Human Rights and on the Recovery Model, and CST staff members participate in grievance hearings. We also cre-

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# Invisible Children's Program Helps Entire Families

*by Ellen Alderton, NCSTAC*

Through its Invisible Children's Project (ICP), the Mental Health Association in Orange County, N.Y., is supporting families in which a parent has a mental illness or co-occurring disorders to help maintain the family unit. The program serves 18 local families, providing such services as supported housing, 24-hour case management, respite, advocacy, parenting education/training and support groups. The project also provides vocational training, supported education, art therapy, in-home clinical consulting and funding for special needs to enrich participants' lives.

*"Our approach is systemic. With mental illness in the family, it is important to look at the entire family as a whole."*
*– Liz Mehnert*

"Our aim is to work with the families in assessing what their wants and needs are," explains Michael Bassett, the project's director. "We want to help the families achieve their own goals by drawing upon their strengths."

Because too many service providers tend to view parents with mental illnesses in isolation from their children, the children are often "invisible" and the needs of these families go unmet. ICP aims to increase these parents' ability to function in their communities and assist them in creating a nurturing environment for their children.

Two full-time staff people—a case manager and a program coordinator—work on the project. ICP also relies heavily on respite workers and consultants. Fifteen respite workers provide childcare services, and five consultants, all trained clinicians, offer different forms of treatment to parents. "Our approach is systemic," says ICP's Liz Mehnert. "With mental illness in the family, it is important to look at the entire family as a whole."

The program, which was developed in 1993, has seen such success that it now serves as a

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# A Year of Voter Empowerment Brings Big Results

*Visit www.ncstac.org for more information on how to conduct a voter empowerment campaign.*

*by Ellen Alderton, NCSTAC*

The National Mental Health Association's NCSTAC launched its National Mental Health Voter Empowerment Project last year to a huge response and encouraging results. Drawing upon the expertise of such renowned experts in the field as the late mental health advocate Kenneth Steele, NCSTAC offered four regional trainings across the country. More than 100 people representing 60 consumer supporter organizations in 29 states attended the trainings. The center also offered smaller workshops at Alternatives, the yearly conference for consumers, survivors and ex-patients of psychiatry, and at the annual conference of the International Association of Psycho-Social Rehabilitation Services.

*"More than four-fifths of the organizations that participated in NCSTAC trainings conducted voter registration and education activities this past year."*

This past December, NCSTAC polled half of the organizations that attended its regional trainings to track the progress of the Voter Empowerment Project in the field during the past year. Congratulations to all of you who have been working so hard on this incredibly important initiative. Some of your accomplishments follow:

- More than four-fifths of the organizations that participated in the trainings conducted voter registration and education activities this past year.
- Approximately 4,800 consumers registered to vote.
- Approximately 3,650 of these newly registered consumers voted.
- Besides conducting voter registration, organizations also provided educational materials on the issues, distributed candidate surveys, circulated newsletters, organized candidates' forums, reminded consumers to vote, and provided transportation to and assistance at the polls.
- Most organizations that worked on this project also intend to continue their voter empowerment efforts in the future.

Other disability advocates also noted the mental health community's success. After completing a tour of 15 cities across the country to encourage disabilities rights coalitions to get out the vote, Jim Dickson of the National Organization on Disability reported that, by far, the most organized groups he came across were mental health organizations. Let's keep up the good work.

# TREM Intervention Supports Victims of Trauma

*by Maxine Harris, Ph.D., and Roger Fallot, Ph.D., Community Connections*

The mental health community is paying an increasing amount of attention to the prevalence and impact of violence and abuse in the lives of people with serious mental illness. Surveys have consistently shown high rates of physical and sexual abuse in this population and have connected traumatic experiences to the severity of psychiatric symptoms. A history of trauma is also linked to co-occurring problems such as substance abuse and to a risk for revictimization.

Among urban women with mental disorders and histories of homelessness, well over 90 percent may have experienced physical and sexual violence. Although men in similar circumstances report somewhat lower rates of violent victimization, histories of trauma are still strikingly common. Trauma, mental health problems and substance abuse create a viciously recurring cycle in which experience in one domain increases the likelihood of difficulty with the others.

There is a pressing need for integrated services that incorporate trauma theory and include interventions designed to address the impact of trauma. The lack of trauma services is especially evident where the need may be greatest: in the public mental health, substance abuse and criminal justice systems.

## A New Model

In response to this need, Community Connections of Washington, D.C., has been actively addressing trauma-related concerns for nearly 10 years. We are particularly proud of our Trauma Recovery Empowerment Model (TREM), an intervention program of 33 group sessions offered over a nine-month period to trauma victims. TREM is designed to address issues of sexual, physical and emotional abuse in the lives of women who are economically and socially marginalized and who have had no success with or access to traditional recovery treatment.

Over the past five years, Community Connections has facilitated dozens of TREM interventions at its Washington, D.C., office as well as dozens more as part of a women's prison project in Maryland. Our copyrighted model is being replicated at sites throughout the country, and we are now part of a multisite study recently launched by the federal Substance Abuse and Mental Health Services Administration.

Each of the model's 33 sessions, which are always led by a trained female clinician, begins with the group leader introducing the day's topic and the rationale for discussing it. Besides taking part in discussions, group members also participate in an experiential exercise such as an art or physical activity. A typical session includes six to eight women. Community Connections spent several years developing and modifying the program based on consumer feedback.

The TREM intervention is divided into four sections: Part I addresses trauma indirectly by focusing on the fact that women who have experienced trauma do not feel entitled to recover from the debilitating effects of abuse. Part II addresses the long-term impact of sexual, physical and emotional abuse. In Part III, group members learn how to communicate, establish healthy relationships and make good decisions. Part IV allows group members to assess their own progress and say good-bye. During Part IV, women are encouraged to plan for their continued healing either on their own or as part of a community of other survivors.

### TREM Intervention's Four Core Assumptions:

1. Some current symptoms may have originated as coping responses to trauma.
2. Women who experienced repeated trauma in childhood were deprived of the opportunity to develop skills necessary for adult coping.
3. Trauma severs core connections to one's family, one's community and ultimately to oneself.
4. Women who have been abused repeatedly feel powerless and unable to advocate for themselves.

## Supplementary Services

In an effort to provide fully integrated and trauma-informed services to all consumers as well as staff and consumers at Community Connections, we have developed a number of companion interventions to supplement the core model. These include:

- A self-help version of TREM titled "Healing the Trauma of Abuse." The self-help version is designed for women who cannot or who choose not to attend the group format, or for women who want to supplement their group work.
- A domestic violence group for women who are involved in or have recently left battering relationships.
- A substance abuse group that attempts to address trauma responses and substance using behaviors.

*"TREM is designed to address issues of sexual, physical and emotional abuse in the lives of women who are economically and socially marginalized."*

## TREM Intervention Supports Victims of Trauma

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- A parenting group that looks at the impact of trauma and violence on parenting styles and parenting choices.
- An HIV support and education group that looks at HIV infection from a trauma perspective.
- Two groups designed specifically for adolescent survivors of sexual or physical abuse, "G-TREM" and "G-TREM-2." These groups are for girls ages 12-14 and young women ages 15-18 and address trauma issues in ways that are suitable for adolescents of different ages.
- A group for male survivors of trauma, "M-TREM." The men's model addresses some of the same issues covered in the women's intervention, but instead of focusing on empowerment, the intervention helps male survivors to develop an emotional and interpersonal vocabulary for dealing with and understanding trauma issues.
- A 40-minute film titled "Women Speak Out" that features survivors of trauma discussing the impact of abuse on their lives.
- An eight-hour training video to teach clinicians how to lead TREM groups.

All trauma material is available through Community Connections by contacting Rebecca Wolfson, director of Trauma Education, at 202-608-4735 or rwolfson@communityconnectionsdc.org.

SAMHSA is offering **free grant-writing workshops** during March. Call the SAMHSA hotline at 301-984-1471, ext. 377, for more information, or visit www.samhsa.gov/grants/grants.html

## SAMHSA Guide Helps Consumers Faced With Employment Discrimination

Society's fear, prejudices and lack of information about mental illness too often lead to discrimination against people with psychiatric disorders in the workplace. The Americans with Disabilities Act (ADA) offers a legal tool to fight such prejudices by forbidding discrimination against people with both physical and mental disabilities in employment, transportation, public facilities and public communications.

To help people with psychiatric disabilities understand how the ADA employment discrimination charge process works, the federal Substance Abuse and Mental Health Services Administration's (SAMHSA) Center for Mental Health Services (CMHS) has released a new guide, *Filing an ADA Employment Discrimination Charge: Making It Work for You*.

"Since the ADA's inception, psychiatric disabilities have ranked second in terms of number of charges filed under its employment provisions," said acting SAMHSA Administrator Joseph Autry, M.D. "This new guide is a tool for understanding the extent the ADA can be of help and for assisting people to decide what is the best way to proceed with a complaint."

The guide provides information in a question-and-answer format about the ADA employment discrimination charge process and details what happens when individuals with psychiatric disabilities have filed administrative claims. It explains, through discussion and examples, when, where and how to file a charge. In addition, it outlines what typically happens during the investigation process and what factors influence whether people benefit from filing a charge.

"Discrimination by employers and co-workers are two of the many factors that contribute to the high unemployment rates of people with mental illness," said Bernard S. Arons, M.D., director of CMHS. "It is therefore important for people with psychiatric disabilities to know how the ADA employment discrimination process works and to assure that their rights are protected."

Copies of this new guide are available free of charge from the CMHS Knowledge Exchange Network at 800-789-2647, (TTY) 301-443-9006 or www.mentalhealth.org.

### Have you visited our Web site?

Visit us at http://www.ncstac.org and read *Consumer Supporter News* and other publications online, search the NCSTAC resource database and participate in discussion boards that cover such issues as voter empowerment, wellness and recovery, and advisory boards.

# Trend Alert: A New Shape to Volunteerism

*by The Herman Group*

Interest in making a difference in the lives of others is increasing, but interest in organized volunteerism is decreasing. What's happening? Do people want to volunteer or don't they? Traditionally, most contributions to those in need were done through active membership in volunteer organizations. People gave their time, energy, ideas and resources.

Today, people are more protective of their time — their nonrenewable resource. They are so busy with work, school, family and personal interests that it is often difficult for them to commit to a schedule of committee meetings, projects and other activities that interfere with their already full lives.

Rather than engaging in long-term endeavors that require meetings or commitments over extended periods, people are more inclined to participate in one-time events to help others. They will commit to a few hours, a day or so, but on a short-term basis. Activities such as clean-up days, helping to build a house for Habitat for Humanity, weekend projects to clear a walking trail in a park and car washes to raise funds will still attract volunteers.

People today will also send monetary contributions, donate clothing or furniture to the needy or provide food for the less fortunate. A number of established relief and support agencies increase their effectiveness by making it easier for people to be able to help with minimal trouble and time. One example of this is the use of the Internet to build support for worthy causes.

In the past year, various sites have invited visitors to register their support for the fight against breast cancer or hunger with a free click of the mouse. Best of all, providing this support costs these "volunteers" nothing, because advertisers underwrite these sites and make donations on behalf of each visitor. If charitable organizations seek volunteers creatively and with an understanding of the changing shape of volunteerism, they will greatly increase their own chances of attracting support.

*The Herman Group of management consultants, speakers and futurists provides information on future trends. Visit the group's Web site at www.herman.net or contact 3400 Willow Grove Court, Greensboro, NC 27410-8600. Phone: 336-282-9370, Fax: 336-282-2003. Toll-free:800-227-3566. E-mail: info@herman.net.*

### Volunteers Can Work From Home

Volunteers can do plenty of work off-site:

- Conduct research
- Provide professional consulting
- Design brochures, newsletters, logos, etc.
- Translate documents
- Maintain a database
- Electronically "visit" people in hospitals or homes
- Provide on-line mentoring or instruction
- Provide chat room or newsgroup support
- Staff a crisis line at home via call-forwarding

*– From NCSTAC's brochure, "Working With Volunteers," which is available free of charge at www.ncstac.org.*

# Chester County Consumer Satisfaction Team Learns to "Listen for a Change"

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ated a mental illness and stigma workshop that more than 5,000 people have attended, including adults from a wide variety of professions as well as children. This humorous and interactive program has seen amazing results. After workshops, participants often tell us that for the first time in their lives they are not ashamed of having a mental illness. We believe that must be the ultimate in consumer satisfaction.

Recently, the State of Pennsylvania and Chester Country asked our CST to manage a tremendously large and complicated mailing on consumer satisfaction and managed care. Although we did not create the survey, we did handle project logistics. Once again, we approached the task from a consumer satisfaction/education perspective: We knew from our six years of interviewing consumers that lack of work often leads to low self-esteem. With the full support of our county and some local providers, we created a no-fail work system in which consumers were paid a good wage and asked to commit to only 15-minute blocks of time to help with the mailing. On the first day, some consumers worked extensively while others only worked 15 minutes. By the project's end, consumers were asking for more work as their confidence and stamina increased— another example of consumer satisfaction and consumer success going hand-in-hand.

C-STAP, the Consumer Satisfaction Team Alliance of Pennsylvania, provides information on forming consumer satisfaction teams. Download free sample consumer surveys from its Web site at www.cstmont.com/cstap.htm. For more information, contact C-STAP, c/o Montco CST, 1001 Sterigere St., Bldg. 6, Norristown, PA 19401.

E-Mail: admin@cstmont.com. Phone: 610-270-3685. Fax: 610- 270-9155

## Break the Language Barrier

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language and within the cultural framework they understand. This can be done by:

- Hiring providers who are from the same population as their clients and fluent in their native language. Doctors, nurses and other healthcare professionals who are from the same ethnic background as the people they serve will be best able to communicate effectively with their clients.
- Translating existing written materials. It is not always possible to find professionals who speak their clients' languages fluently. In such cases, translated materials can be useful.
- Creating new non-English sources of information. Creating entirely new sources of information that are targeted to the cultural needs of a specific group is often preferable to translating existing materials.
- Providing trained interpreters and translators. It is important that these individuals not only speak the language of the population they serve but also have firsthand knowledge of the culture.

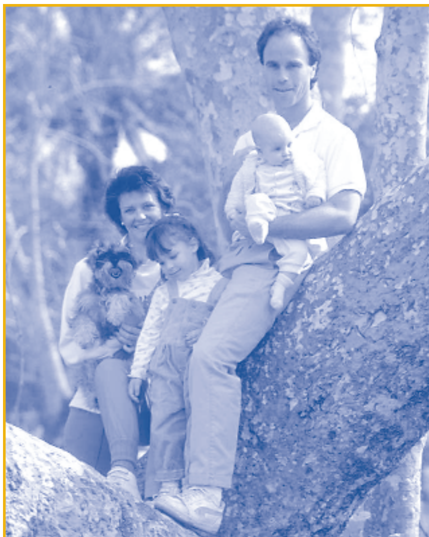
*"Providing services and programs in languages other than English is desirable and, in some cases, legally mandated."*

Remember, communication is about more than language: It is about culture—that vast body of knowledge, ideas, practices and beliefs that shapes human experience. Any individual's use of language is also influenced by such factors as exposure to the dominant white American culture, perceived prejudice or stigma, regional distinctions, politics, age and literacy levels (not only in English but also in one's native language). Consider all these factors when preparing to address the language needs of different populations.

### A Legal Mandate

Providing services and programs in languages other than English is desirable and, in some cases, legally mandated. For example, organizations and individuals who receive funding from the Department of Health and Human Services (DHHS) have a legal obligation under Title VI of the Civil Rights Act of 1964 to ensure that persons with limited English proficiency can meaningfully access their programs and services. The DHHS Office of Civil Rights (OCR) considers access to native language health services and information a pressing civil rights issue. Policy materials published by the OCR outlining the responsibilities of health and social services providers can be accessed at OCR's Web site at http://www.hhs.gov/ocr.

## Invisible Children's Program Helps Entire Families



*The Invisible Children's Project is providing services to families in which a parent has a mental illness or co-occurring disorders.*

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model program for a national initiative. The National Mental Health Association (NMHA) is replicating ICP in five sites across the country. "NMHA is thrilled to be working on this innovative model with Orange County," said NMHA President and CEO Michael Faenza. "The MHA sparked a movement to serve families, and our aim is to expand our efforts in this area."

Each of the five sites will set their own goals, and the MHA of Orange County will provide technical assistance based on its model in Orange County, said Mehnert, who is currently charged with taking the program to a national level. NMHA will also provide technical assistance.

With funding from the federal Center for Mental Health Services (CMHS), the University of Massachusetts is also studying ICP closely. Specifically, university researchers are exploring the cost effectiveness of the program compared to foster care and investigating to what extent the program succeeds in keeping children in their own families and out of foster care.

Funding for the many components of the Invisible Children's Program comes from a variety of sources, including the Department of Housing and Urban Development, CMHS, United Way, and state and local grants from the New York Office of Mental Health.

For information on bringing the Invisible Children's Program to your area, contact Maril Olson, NMHA's director of Community Education for Children's Mental Health, at 703-837-3377 or 800-969-NMHA, ext. 3377.

# SAMHSA Offers Guidance on Organizing Provider-Consumer Group Meetings

Recent changes in the nation's public mental health care system are emphasizing rehabilitation and recovery, and calling for more involvement by consumers of treatment services and their family members. At the same time, the adoption of managed care, new technologies and the continued discrimination surrounding mental illness all present challenges to mental health care providers. These changes make the creation of partnerships and alliances between consumer and provider groups at the system and policy level more important than ever.

To promote the dialogue needed for these alliances to succeed, the federal Substance Abuse and Mental Health Services Administration's (SAMHSA) Center for Mental Health Services (CMHS) has released a new guidebook, *Participatory Dialogues: A Guide to Organizing Interactive Discussions on Mental Health Issues among Consumers, Providers, and Family Members*.

Offering a blueprint for action, this participatory dialogue manual, developed by mental health consumers, provides easy-to-follow action steps on how states, local communities, providers, managed care organizations, advocates, family members and consumers can organize meetings to develop working partnerships that will help improve mental health service delivery. The action steps cover issues such as location selection and meal planning. The manual presents two models of dialogue: the conference model and the roundtable model. Helpful tips and examples are provided in the form of vignettes.

"Through dialogue people can come together for a mutual exchange of ideas, observations and experiences," said SAMHSA acting Administrator Joseph H. Autry, III, M.D. "Dialogues, as outlined in the new guide, go beyond the usual one-to-one interactions between practitioners and recipients of mental health services. They provide a safe environment in which providers and consumers can work together to improve mental health services."

Free copies of this new guidebook are available from the CMHS Knowledge Exchange Network at 800-789-2647 or (TTY) 301-443-9006.

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**The National Consumer Supporter Technical Assistance Center** was established in 1998 by a grant from the Center for Mental Health Services. Our purpose is to strengthen those organizations supporting mental health consumers, survivors and ex-patients by providing technical assistance.

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