



Excellence in Mental Health and Addictions Policy and Practice

# ADVANCING STANDARDS OF CARE FOR PEOPLE WITH SCHIZOPHRENIA

## PILOT PROGRAM OUTCOMES & CASE STUDIES

Measurable Benefits to Consumers, Behavioral Health Organizations, and Payers



NATIONAL COUNCIL  
FOR COMMUNITY BEHAVIORAL HEALTHCARE

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## ABOUT THE NATIONAL COUNCIL

The National Council for Community Behavioral Healthcare (National Council) is the unifying voice of America's behavioral health organizations. Together with our 1,950 member organizations, we serve our nation's most vulnerable citizens — more than 6 million adults and children with mental illnesses and addiction disorders. We are committed to providing comprehensive, high-quality care that affords every opportunity for recovery and inclusion in all aspects of community life.

The National Council advocates for policies that ensure that people who are ill can access comprehensive healthcare services. We also offer state-of-the-science education and practice improvement resources so that services are efficient and effective.

The National Council coordinates the Mental Health First Aid program across the USA and operates the SAMHSA-HRSA Center for Integrated Health Solutions to provide nationwide technical assistance in integrating primary and behavioral health.

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## CHALLENGES AND CHANGING PARADIGMS

It is a new era in healthcare. With soaring costs and ever-tighter budgets — both in government and the private sector — today's healthcare leaders are challenged to provide high-quality and efficient services. The result: a patient-centered healthcare paradigm, one that integrates primary and behavioral health, provides real accountability, and delivers measurable results.

While traditional mental health treatment programs generally concentrate on treating signs and symptoms, a recently completed six-month pilot program has achieved concrete and measurable improvements in daily living for people suffering from schizophrenia and schizoaffective disorder, among the most challenging of chronic mental illnesses to treat.

The project — Advancing Standards of Care for People with Schizophrenia — run by the National Council for Community Behavioral Healthcare, has positive implications for healthcare providers, payers, and patients. Specifically, hospitals and community behavioral health centers capture the quantifiable data they need to optimize treatment interventions, providers and clinicians can demonstrate effective clinical outcomes, and consumers are able to take a more active and engaged role in their treatment and day-to-day activities.

The National Council is a nationwide membership group — “the unifying voice” of America's community behavioral healthcare organizations, with 1,950 member organizations that together employ a

quarter-million persons serving some six million people. Ten community behavioral healthcare organizations across the United States, stretching from Spokane, Washington to Fern Park, Florida (see page 4 for listing of 10 pilot sites), were chosen to take part in the pilot program, which ultimately involved 292 people from January through June 2011. Program organizers noted that it was a tough group to treat: 88 percent of the participants were determined to have “serious symptoms” which affected their ability to function on a day-to-day basis. “The 10 sites did not pick their easiest clients,” says Willa Presmanes, the Lead Outcomes Consultant at MTM Services, who co-designed the program's functional measurement tool. “It was a very difficult population.” With an average age of 45.7 years, many of the consumers who participated in the project already had been in treatment for a number of years.

Even with these challenges, “our clinicians are excited about moving forward,” says Michelle Robison, the director of developmental disabilities and supported employment at Cobb and Douglas Counties Community Service Boards. “Some of these folks have been coming for ages and they actually saw progress.” Moving out of that rut, say several people who participated in the study, can breed a new self-confidence among consumers, which in turn can lead to more substantive clinical discussions. Joseph Judd of Spokane Mental Health says he noticed that conversations used



go no further than ‘How's the weather, and ‘Do you have a cigarette?’. “Now,” he says, “We're having a deeper conversation about the symptoms.”

### *The Changing Health Paradigm*

The enactment of the Patient Protection and Affordable Care Act in the spring of 2010 accelerated an already ongoing healthcare reform movement with two key themes: that treatment is a single, integrated function which includes both physical and mental health, and that payment systems must be realigned so that providers are reimbursed based more on the value of their care than the volume. Emphasizing value over volume is best done through cost-effective measures like preventive care, routine screenings, consistent application of effective treatments and reliable and valid outcome measures.

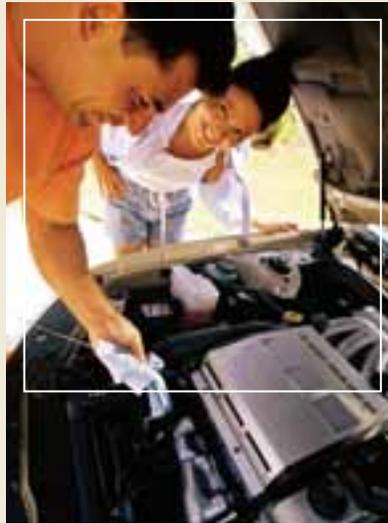


According to leaders at MTM Services, the National Council's pilot program was appropriately designed to address the demands of this new paradigm. For example, consumers play an active role in managing their treatment, which can sharply reduce the need for specialized, high-cost services. Additionally, the program design allowed the behavioral health centers to partner with a host of primary care and health home partners because the program provides the type of measurable outcomes — with a verified reliability and validity — that payers need and the new paradigm demands. In the past, says MTM Services founder and project consultant, David Lloyd, when clinicians were asked about their mission, they would generally respond: “‘To keep people out of the hospital.’ Now we say ‘We’re going to try and help you function better.’”

Linda Rosenberg, president and CEO of the National Council for Community Behavioral Healthcare, notes that mental health treatment traditionally derives from a psychoanalytic orientation that prizes anecdotes and stream of consciousness expression, hardly a process that lends itself to the type of analytical measurements the new healthcare paradigm requires.

According to Rosenberg, through the Advancing Standards of Care pilot program, “we were able to provide hard data to examine progress or lack of progress,” and in doing so, “create partnerships between the practitioner and the consumer. It is an approach that can improve the chances for people with schizophrenia to live more independently and participate more fully

in their communities, and in doing so, reduce misperceptions and ameliorate the stigma now inevitably associated with the disease.



### *The Challenge of Schizophrenia*

Schizophrenia is far more widespread than most people realize, and affects an estimated 1.1 percent of the U.S. population over 18, or some 2.5 million people. About 100,000 new cases are diagnosed in the United States each year out of the 1.5 million found annually around the world. It is a tough disease to manage because its symptoms can be highly disruptive — an inability to tell the difference between real and unreal experiences, social isolation, delusions and hallucinations. Recovery rates with typical treatment approaches are 50 to 60 percent. Novel approaches to treatment and community supports, including the professionalization of peers, help people with schizophrenia to recover. Of those who are unable to recover, 10 percent die prematurely, mostly through suicide, 15 percent are hospitalized with

little or no improvement, and about 25 percent get better but require an extensive support network to function.

Other diseases, like muscular dystrophy, multiple sclerosis or insulin-dependent diabetes, occur at far lower rates — just 35,000 people suffer from muscular dystrophy, for example, and about 400,000 from multiple sclerosis and diabetes — but those diseases are far better known and in the public's eye, far less stigmatizing.

Ninety percent of people with schizophrenia have a co-morbid condition and suffer, in far greater numbers than the general population, from diseases such as diabetes, depression and addiction. As a result, their overall healthcare costs are inordinately high, and treatment is too often provided in emergency rooms rather than through screening, early intervention, and wellness self-management.

Although our understanding of schizophrenia as a disease has progressed over the decades, advances in the standards of care have lagged. Bringing more rigor and definition to those standards of care could lessen the disease's stigma by giving it the same outcome-based methodology as other ailments, leading one day to what behavioral health practitioners all want: a recognition of schizophrenia and other mental illnesses as chronic diseases spoken about without shame and in the same fashion as chronic physical ailments like heart disease, diabetes or epilepsy.



## ABOUT THE ADVANCING STANDARDS OF CARE PILOT PROGRAM

In August, 2010, the National Council sent out a competitive application looking for 10 behavioral health organizations to take part in a collaborative project with two principal objectives: one, to pilot a curriculum aimed at improving the ability of people with schizophrenia and schizoaffective disorder to increase their level of real-life functioning; and two, to implement a standardized, reliable tool they could use to measure how effective that treatment was.

The project consultants were Lloyd Presmanes and Dr. Bill Schmelter, all of MTM Services, a consulting affiliate of the National Council for Community Behavioral Healthcare. Financial support was provided by Sunovion Pharmaceuticals, which markets Latuda (lurasidone HCl), an anti-psychotic treatment for people with schizophrenia.

The project revolved around two evidence-based tools: a functional assessment scale used by the client and clinician called the Daily Living Activities (DLA-20) and a treatment intervention for consum-

ers called the Wellness Self-Management (WSM), a multiple-lesson group curriculum designed to help adults self-manage serious mental health issues. Individual site training took place in November and December 2010, followed by two conference calls with all 10 sites, and monthly individual web-based coaching sessions through the remainder of the project.

The 10 pilot sites started with a total of 568 consumers and conducted an initial baseline DLA-20 test in December 2010. Twenty percent of the participants scored an 'inability to function in all areas' on the pre-intervention functional assessment as estimated by the DLA-20. Fifty percent scored below 38 on the pre-test DLA-20 estimate of the APA DSM-IV diagnosis on Axis V, popularly referred to as the GAF or Global Assessment of Functioning scale, the numeric 1-100 scale used to clinically rate how well a client functions. GAF scores are calculated from the DLA-20 by adding up the scores received on all 20 of the DLA categories, then dividing that number in half. A score of 38 indicates major impairment in at least five critical areas of functioning in daily activities.

Schizophrenia is a thought-disorder illness, which often makes it hard to be around other people. That fact, combined with the functional disabilities of the pilot population, meant a high dropout rate was expected. By June 2011, when the project ended, there were 292 consumers still active in the group curriculum, an attrition



rate of 48 percent. Among the 10 pilot organizations, the attrition rate varied from a low of 36 percent to a high of 60 percent. More than half of the consumers who dropped out did so in the first 60 days, with only around 40 individuals leaving the program after they had participated four months or longer.

The DLA-20 reliably estimates a client's functioning levels in 20 different areas of daily living, such as productivity, coping skills, mental and physical healthcare practices, time management, nutrition, money management, problem solving and leisure time. Each of these areas is given a number ranking, ranging from one — extremely severe functional impairment needing pervasive supports — to seven — which means the client is functioning optimally and does not need any paid support services. As the DLA-20 is administered by the clinician in conjunction with the client, the shared experience using transparent data often encourages new treatment approaches. The difference in the consumers' views and those of the





clinician, for example, often provides a fertile area for discussion. The 20 categories provide concrete touchstones that help identify clear goals and targets for improving outcomes, a key requirement in today's healthcare landscape, which now demands much more than symptom stabilization or maintenance.

The Wellness Self-Management Program is a curriculum-based clinical practice developed collaboratively by the New York State Office of Mental Health, the Urban Institute for Behavioral Health in New York City, and the Center for Practice Innovations at Columbia Psychiatry, part of Columbia University Medical Center. The WSM is an "evidence-based" practice, that is, a practice that has been shown through replicable, scientific testing to improve consumers "outcomes." The program is based on Illness Management and Recovery, a nationally recognized, evidence-based practice for adults with serious mental illness that includes sections on recovery, mental health wellness, and relapse prevention. The WSM also includes a set of lessons stressing the connection between physical and mental health. The 57-chapter curriculum is designed to take about a year to complete for groups or individuals meeting roughly once a week, although it also could be effective for a shorter or longer period of time.

Chapter topics range from explaining how recovery can be aided by a social network and community resources to finding and using coping strategies that work; from understanding the role of goals in recovery



to making clear the connection between physical and mental health. Each lesson includes discussion points, personalized worksheets and action steps which describe specific "actions" a client can take to address the challenges of a lesson topic, such as how to handle a particularly stressful situation.

#### PILOT SITES

[AltaPointe Health Systems, Inc., Mobile, AL](#)

[AtlantiCare Behavioral Health, Egg Harbor Township, NJ](#)

[Cobb & Douglas Community Services Board, Smyrna, GA](#)

[Family Guidance Center for Behavioral Healthcare, Saint Joseph, MO](#)

[Gallahue Mental Health Services, Indianapolis, IN](#)

[Hill Country Community MHMR Center, Kerrville, TX](#)

[Mental Health Centers of Central Illinois, Springfield, IL](#)

[Recovery Resources, Cleveland, OH](#)

[Seminole Behavioral Healthcare, Fern Park, FL](#)

[Spokane Mental Health, Spokane, WA](#)



## PILOT PROGRAM OUTCOMES

The 10 centers in the pilot project ultimately created more than 50 WSM groups that met weekly or in some cases up to three times a week in a variety of settings including clinics, residential programs, ACT Teams, intensive treatment programs, rehabilitative day programs, peer-run groups, case-management services and day-treatment programs.

The average DLA-20 GAF estimate of all participants rose from an initial 37.76 to 41.07 by the fourth DLA-20 review, which took place six months later. Participants in six of the 10 centers showed modest but steady improvements from the baseline assessment to the final DLA assessment, and three centers experienced minor gains or flat scores. The one center that administered the pilot project in two “assertive community treatment” (PACT) teams saw the average DLA-20 GAF estimate drop from 42.05 to 40.45, a figure that is not statistically significant. Overall, there was a statistically significant gain in three of the DLA-20 sub-scales including communications (3.51 to 3.95), interaction with one’s social network (3.8 to 4.23), and coping skills (3.3 to 3.78).

The DLA-20 has an extremely high inter-rater reliability — with 90 percent of mental health therapists using the tool on the same client arriving at the same estimated GAF scores within a three-point margin of error. The DLA-20 defines and measures the concept of functioning “within normal limits,” which means that a DLA-derived GAF score can be used to confirm the



medical necessity for treatment. Under the DSM-IV standard mental health classification system, a “functional impairment which substantially interferes with or limits one or more daily life activities” is a criteria used to determine the medical necessity of treatment. “Rehabilitation” — defined in the Federal Register as a “restoration of functioning in daily life activities” — is the goal. Measurable criteria allow providers to offer payers results-oriented outcomes, and take part in incentive and bonus models of payment as well. And when integrated into a clinical assessment process already in use, clinicians can bill for the time spent with the client planning their steps to recovery. There is no charge for the actual use of the DLA-20, although training is a condition of use.

“Until the DLA-20, nobody on our staff paid a lot of attention to GAF because it didn’t mean anything,” says Wayne Dregors, the senior director for community-

based medical services at Seminole Behavioral Healthcare. “Now, the GAF that’s tied to the DLA-20 is useful because it’s accurate.” In Florida, for example, state Medicaid programs require a GAF score below 50 to be reimbursed for day treatment services.

There was equal enthusiasm among pilot program sites for the WSM curricula. Ben Yamnitz, an ACT case manager at Mental Health Centers of Central Illinois, notes that use of the WSM gave consumers the vocabulary they needed to better explain what they were feeling. “Doc, I have these positive and negative symptoms,” says Yamnitz, quoting a client. “And the doctor was going, ‘Yeah!’” (See Appendix B for Client and Provider Profiles)

Practitioners from the various pilot programs also had criticisms and suggestions for improvement regarding the WSM and the DLA-20. The WSM curriculum, says Lee Stephan, the director of SMI Services at Gallahue Mental Health Services, begins with too much elementary information and “doesn’t move fast enough on the front end.” On the other hand, explains Ben Miladin, the manger for continuous quality improvement at Recovery Resources, “those people who are rolling their eyes, you make them the mentor.” Initial lessons also can be consolidated, suggested several clinicians, and later lessons could be previewed to keep more experienced consumers engaged. Still other practitioners noted that for visual learners, more hands-on examples would help



drive home important points. Although the DLA-20 was widely touted as effective, some pilot program professionals questioned whether smoking should be listed as a DLA-20 functional deficit. After all, they pointed out, about one in every five Americans as well as more than 80 percent of people with schizophrenia smoke cigarettes.

All 10 organizations in the six-month pilot program plan to continue using the DLA-20 and WSM curricula for individuals diagnosed with schizophrenia and schizoaffective disorders. And they plan to expand the use of both tools to treat other populations. Indeed, several practitioners said their consumers were ‘marketing’ the curricula to other consumers in their centers — a real life testimony to how helpful they felt the program was.

### ***Advancing the Discussion from “Me” to “We” to “Us”***

In the popular imagination, schizophrenia is still associated with violence, and generally not viewed as a treatable chronic illness. Overcoming that stigma is as much a challenge as improving treatment results. One key to mental health communications progress, explains Allison May Rosen of the Chandler Chicco Agency, is to move the conversation from “me” to “we” to “us.” The “me” stage implies that one’s story is unique and that one only feels comfortable managing the disease on his or her own. The “we” stage is the recognition that there are other people with similar stories and one can feel comfortable talking with them, while



the “us” stage opens the conversation up to the entire population, acknowledging that everyone is helped when stories are shared. “There’s a lot of myth that drives the stigma,” Rosen says.

To reach that “us” stage, stakeholders — and what they care about — must be identified, from consumers and their families to community partners, public and private payers, policy makers, and national health organizations. And don’t forget the media, an often overlooked, but crucial, stakeholder in how mental health is portrayed. “When it comes to news, and somebody is jumping off a bridge onto the Connector (Atlanta’s downtown freeway), you really do cringe, and you hope it’s not one of your folks, and you think: ‘How are they [the media] going to present them, because they don’t present them as people first,’” says Robison of Cobb and Douglas Counties Community Service Boards.

Key, says Rosen, is designing “compelling messages and stories that will be remem-

bered using language that will stick.” And using multiple means of telling that story, including national and local press releases, op-eds and extensive use of social media. And boiling down the many messages into one big theme — that schizophrenia is a chronic disease like many other physical illnesses — and telling it many times. “What is often repeated,” Rosen says, “is often remembered.”



## CASE STUDIES





## CASE STUDY: Spokane Mental Health and the DLA-20

Non-profit Spokane Mental Health was created by the merger of three mental health organizations in 1969, and served 9,800 people last year with a staff of 450 in 15 facilities in Spokane County, Washington. Most of its \$31.6 million budget in 2010 was provided by the Spokane County Regional Support Network. On July 1, 2011, Spokane merged with Family Services Spokane and became Frontier Behavioral Health.

Gathering enough people for the pilot study was not a problem for Spokane Mental Health, which already treats a large portion of the city's population of people diagnosed with schizophrenia and schizoaffective disorder. In fact, says Joseph Judd, Spokane's director of community support services, after the pilot study was advertised, community behavioral health center even heard from a few people with schizophrenia in their family who volunteered their relatives. Judd and his colleagues found the DLA-20 so useful that it is now being used with all 1,500 consumers in Spokane Mental Health's community support services, which operates mostly adult outpatient programs. And, says Judd, "We're piloting on our end for use in the whole center."

At Spokane, some 75 people started in the six-month program, with 42 finishing the pilot in groups of eight to 12 people meeting once a week. Clinicians discovered that they almost always rated a client worse off than the client believed. "We found that very interesting," Judd says.

The DLA-20 was administered four times, and between the first and the last assessment, 19 of the 20 categories showed measurable improvement, with "coping skills," "household stability," and "communications" jumping more than half a point on the 7-point scale. Work and productivity climbed the most, from 2.32 to 2.95. "Productivity means getting more things done in the day, and is really important, because it speaks to the quality of one's life," Judd says. "For a lot of people, it was 'Cokes and smokes,' that was the bulk of their day," he adds, referring to soft drinks and cigarettes.

Nick LeDoux, a clinician at Spokane Mental Health, says the DLA allowed for a more "pointed" conversation with consumers. "Our clients are stuck in a rut. 'I can't get better,' they say." But, Judd adds, when all you know is that your clients 'don't feel good,' it's tough for the clinician to know what to work on. Because of its precision, says Judd, the DLA-20 gives clinicians "a tool to ask questions."



**When all you know is that your clients 'don't feel good,' it's tough for the clinician to know what to work on. Because of its precision, the DLA-20 gives clinicians 'a tool to ask questions.' "**  
**says Judd**



*Images are from stock and do not represent actual subjects/individuals featured in the report.*



## CASE STUDY: Mental Health Centers of Central Illinois and External Relations

With seven locations in six mostly rural, central Illinois counties, Mental Health Centers' staff of 230 treats 9,000 people annually. Springfield, with 120,000 people, is the largest city in the area. An affiliate of Memorial Health System, Mental Health Centers has an annual budget of \$13 million for its seven locations.

Mental Health Centers had an extensive marketing and communications program built around the Advancing Standards of Care pilot program, says Cindy Kiriakos, the center's director of marketing, training and development. "Our approach was to develop a plan for communications for the whole year with a wide variety of communication tools — to explain that with a diagnosis of schizophrenia combined with evidence-based treatments — recovery is possible," she says. When the pilot began, a press release was sent to more than 60 media outlets and posted on the Center and Memorial Health System's website as well as its Facebook page.

Articles on the program were also submitted to regional newsletters, printed in two hospital affiliate newsletters and a newsletter for 70 Memorial Health primary care physicians because, says Kiriakos, "It is rare that any (mental health) illness exists without some other illness." Mental Health Centers president Jan Gambach localized a National Council-drafted op-ed about the program and it was published in the local Springfield newspaper.

Most importantly, Mental Health Centers was able to personalize the study and the disease, finding a 24-year-old man who had struggled with schizophrenia since he was 16 years old, who found the program extremely helpful, and was willing to speak out about it. "He had really committed himself to the 'advancing standards for care' project, did 37 of the Wellness groups consecutively without missing one, and is now setting goals for himself like getting his GED and hopefully going on to college," Kiriakos says. "And he wants to inspire others." Part of Mental Health Centers' "strategic imperative," says Kiriakos, is to "help the communities we serve understand more about mental health issues and decrease the stigma surrounding them — to put a face on the illness so it's not about mental illness, it's about people who are diagnosed with mental illnesses."



To help the communities we serve understand more about mental health issues and decrease the stigma surrounding them,” says Kiriakos

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## CASE STUDY: Family Guidance Center for Behavioral Healthcare and the WSM

For more than 40 years, the Family Guidance Center has served nine contiguous counties in rural northwest Missouri, an area whose biggest city, St. Joseph, has just 75,000 people. With a 2010 budget of \$11.4 million, Family Guidance' 30 case workers served 1,435 adults with serious mental illness.

The Wellness Self-Management curriculum is a group program, but one of the biggest problems Family Guidance Center encountered was the basic issue of transportation. Consumers might wait up to two hours each way using the county's rural bus system, explains Kristina Hannon, Family Guidance' vice president of behavioral health. The solution: "We paid staff overtime to go pick up people in the vans we have to have for our addiction services." Family Guidance had a 60 percent attrition rate — from 100 participants to 40, and the highest of the ten organizations in the pilot program — a fact Hannon attributes both to transportation difficulties and staff turnover, which during the six months of the pilot project had jumped to nearly 40 percent, about twice its normal rate.

Despite these difficulties, and in just six months, the WSM helped Family Guidance achieve one of its key goals: to lower the percentage of people with schizophrenia who were admitted into acute care mental hospitals from roughly one-third of admissions to about one-fifth of admissions. Hannon says the WSM's group model gave consumers a sense of community. "People with schizophrenia are very socially isolated, and they liked coming into a group setting. People were talking about the fact that they got to know someone who was not their caseworker, they talked about the homework assignments, they seemed kind of energized about that." The WSM's 57 chapters also provide the kind of flexibility that make them useful to clinicians with a Bachelor's degree as well as someone with more advanced training, she says.

Melissa Gasper, a Family Guidance Center community support specialist, recalls one WSM lesson that focused on identifying signs of stress. "And so the action step was thinking of three different situations that might cause stress, and writing those down — getting in front of a group, riding a bus, does my head hurt, does my stomach hurt, and eventually, what can I do to alleviate it." Gasper says it's important for someone to know that "I'm feeling stress because I'm in this situation" instead of "All of a sudden I'm feeling stress and why?"



People with schizophrenia are very socially isolated, and they liked coming into a group setting. People were talking about the fact that they got to know someone who was not their caseworker. ”



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## PROFILES OF CONSUMERS AND PRACTITIONERS





## AltaPointe Health Systems: Christopher

“I learned valuable life skills, how to stay healthy, anger management, and how to prevent a relapse.” These are the powerful words of Christopher, a participant in the Advancing Standards of Care for People with Schizophrenia pilot program. The program really seemed to make an impact on Christopher, who previously had trouble managing his anger. “I learned that when I get frustrated, I can take a walk, ride a bicycle, draw, or listen to music,” he said, all things that can prevent his anger from getting out of control.

Christopher said the program encouraged him to think about and solve problems in new ways. “When I feel like I’m frustrated or like I can’t do something, I try to tell myself, ‘Maybe if I try this a different way, if I don’t give up, I’ll get the hang of it,’” he explains.

Before participating in the program’s Wellness Self-Management sessions, Christopher had difficulty setting attainable goals, which added to his frustration. But in the group sessions, participants were encouraged to break down big goals into more manageable steps and then state the individual actions steps they would take. At the end of lessons, each group member would say, “This is the action step I’m going to take before our next meeting.”

“Instead of saying, ‘I want to get my GED,’ the group would break it down,” Christopher’s team leader, Davey explains. “Smaller steps gave Christopher more encouragement.” To approach earning a GED, the group came up with a list of steps to make it possible. “Together, we said, ‘First, I have to call the office to sign up for a practice test. Then, I have to get a ride to the testing center. After that, I have to take the practice test,’” Davey explained.

Christopher says he’s glad to have participated in the program. “I know a lot more about my illness, and I can talk about it with my group. I am calmer, and I work harder to show others respect and treat them the way I want to be treated.”

*He wants to get his GED*

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## AltaPointe Health Systems: Nate

Nate, 57, says his parents and siblings don't understand his mental illness. And the stigma Nate says he faces because of his mental illness meant he had very few places where he felt safe to open up about his illness. A consumer at AltaPointe, Nate was invited to participate in the Advancing Standards of Care for People with Schizophrenia pilot program.

After participating in the program, Nate said the Wellness Self-Management group finally gave him and others a safe place to open up about the stigma they face because of their mental illness. The group provided a time to explore challenges of explaining that even though a person may have a serious mental illness, it doesn't mean that person is violent.

"The program helps me with my problems," Nate explained. He said that group members encouraged him to talk to his doctor about symptoms he was experiencing – something he hadn't thought to do before.

Nate also worked on setting goals for himself, such as getting healthier. He took weekly action steps to reach his goal. Now, Nate says, "I learned to take better care of myself. I walk more, eat more fruits and salads, and smoke fewer cigarettes."

Nate also has started to focus on the future and is looking for a part-time job. He spends more time with his roommates and girlfriend, staying away from drugs and alcohol. Nate says he's ready for what's next: "I know that I can do things and prove myself."

### *He felt comfortable opening up to group members*



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## Family Guidance Center for Behavioral Healthcare: Carol

### *19-year mental health field veteran, very proud of her group's progress*

"It surprised me that it took this long to do something that made so much sense," said Carol Cunningham, a 19-year veteran of the mental health field, as she reflected on the Advancing Standards of Care for People with Schizophrenia pilot program in which her center participated.

Carol said the program changed her view about what's possible in the treatment for people with schizophrenia, and it has changed how her agency treats people with mental illness. Spurred by the positive experience of Family Guidance professionals in the pilot program, Carol said her agency has started using the DLA-20 (a measure of a person's ability to perform 20 daily living activities) across the agency. At Family Guidance, the consumer and the professionals fill out the DLA-20 together.

Explaining why the agency took that across-agency step, Carol pointed to her experience working with one participant in the pilot program. She said he was initially reluctant to review his DLA-20 form with her, but when she asked him a few of the questions, he started opening up. The result: he ended up doing an in-depth review of himself, becoming more open to conversation and feedback, and working on issues that he had resisted acknowledging before.

Carol said that the pilot program underscores an anti-stigma, anti-stereotype way of thinking. To that end, it encourages mental health professionals to know the people they are working with and their special characteristics. "Based on this experience," Carol said, "My hope is that the mental health field breaks out of the box and stops categorizing individuals, and starts treating them as individuals."

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## Hill Country: **Aurora**

During her 18 years receiving care for schizoaffective disorder, Aurora Martinez said she had never been able to confront her diagnosis. “I always said, ‘No, I don’t have this; it can’t be true.’”

Now, Aurora, who recently turned 49, has a new perspective on life and acceptance of her illness, thanks to her participation in the Advancing Standards of Care for People with Schizophrenia pilot program. Working through the lessons in the Wellness Self-Management program empowered Aurora to confront her fears. She says the program has motivated her to talk to her doctor about her medication, and she has even shared what she learned in the lessons with others in her group home.

While she was participating in the pilot program, Aurora says she had a relapse. “I was hallucinating and I was scared, but I faced my illness,” she said. With clinic director Robert, and study facilitator Kristi, Aurora and other participants became more comfortable in public. Together, the group discussed the stigma they often face in public and were able to talk openly about their illnesses in a safe place.

After participating in the program, Aurora said she is looking forward in her life, and that the wellness self-management study has helped her take things day-by-day. “I feel brighter, and I feel better. I get to do the things I want to do.”

***Program gave her new perspective on her illness, going out in public***

*Images are from stock and do not represent actual subjects/individuals featured in the report.*



## Hill Country: Kristi

### *Wellness self-management group*

Kristi has worked in mental health for three years and currently serves as an Adult Case Manager. After a year of participating in the Advancing Standards of Care for People with Schizophrenia pilot program, she said she witnessed amazing changes in her patients. “It’s a great program,” she said.

While leading her group through the Wellness Self-Management portion of the pilot program, Kristi watched members of her group advance. She was impressed by the changes. “I can honestly say that this program affected my group differently than my rehab group.”

One of the reasons for these changes in both actions and dialogue was that as the facilitator, Kristi took the Wellness Self-Management program to heart. “I could see that [the program] really worked,” she said. “The information we discussed helped me individually, and as we filled out action steps for the participants, I filled them out too.”

“In this study, I did see hope,” Kristi reflected. During one lesson, she recalled that the group had a great discussion about stigma and mental illness. But instead of talking only about the negative aspects of the illness, they talked about acceptance. Another lesson led a program participant to talk to her doctor, who made a medication change that helped her to feel less scared. “To have people saying things like, ‘forget everything except what you’re going through now’ was amazing for this group,” Kristi said. “People really got to know each other and help each other.”

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## Mental Health Centers of Central Illinois: Demetrius

Demetrius not only learned about setting goals in the Advancing Standards of Care for People with Schizophrenia pilot program, but also about commitment. He attended 35 consecutive sessions of the pilot's Wellness Self-Management program and found productive ways to talk about how he was doing and what he was feeling.

"In the group, we work on taking things one day at a time," Demetrius said. Ben, Demetrius' case worker, said he was impressed with the way Demetrius began taking ownership of his mental illness. Every week, Demetrius approached Ben to talk about his symptoms and he started reading a book on treatment and medication for schizophrenia. Even though Demetrius said there is still a lot for him to learn, "Now I understand more about my illness."

Since beginning the program, Demetrius increased his volunteer time in the community to four days a week, working more than three hours each visit. Through volunteering, Demetrius said he hopes to establish references and contacts to use when he looks for employment. "I want to get a job, maybe in a church," he said, "and go back to school."

"I don't want to fail; I want to succeed," Demetrius said. "I have to take steps to get there, but it's going to be okay."

*...talks about his illness and volunteers in the community on a farm and other places*



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## Seminole Behavioral Healthcare: Carolyn

"My life with mental illness has become more manageable and less stressful," said Carolyn, reflecting on her participation in the Advancing Standards of Care for People with Schizophrenia pilot program. She said her active involvement in the Wellness Self Management portion of the program taught her stress management and health and wellness tips. "I am conscientious of my food choices, and I haven't smoked in six months," she said.

Carolyn, 42, has an 11-year-old son and noted that the program achieved wonders for their relationship. It not only helped her to learn more about herself, she said, but it also taught her ways she could be there for him. "I've been able to talk to my son about my mental illness because I know more about it," she reflected.

Although Carolyn recently lost a family member, she said she used the coping skills learned in the pilot program to manage herself through the grieving process. She has a Facebook page featuring behavioral health postings and is working to become a Peer Specialist to help others.

Carolyn said she feels the future is very bright. She has almost completed her GED, after which she plans to attend college to study business. She also continues to learn about her mental illness. "I now know I can do things I didn't think I could do. I can live a fulfilling life with a mental illness."

*...has a better relationship  
with her son and has almost  
completed her GED*



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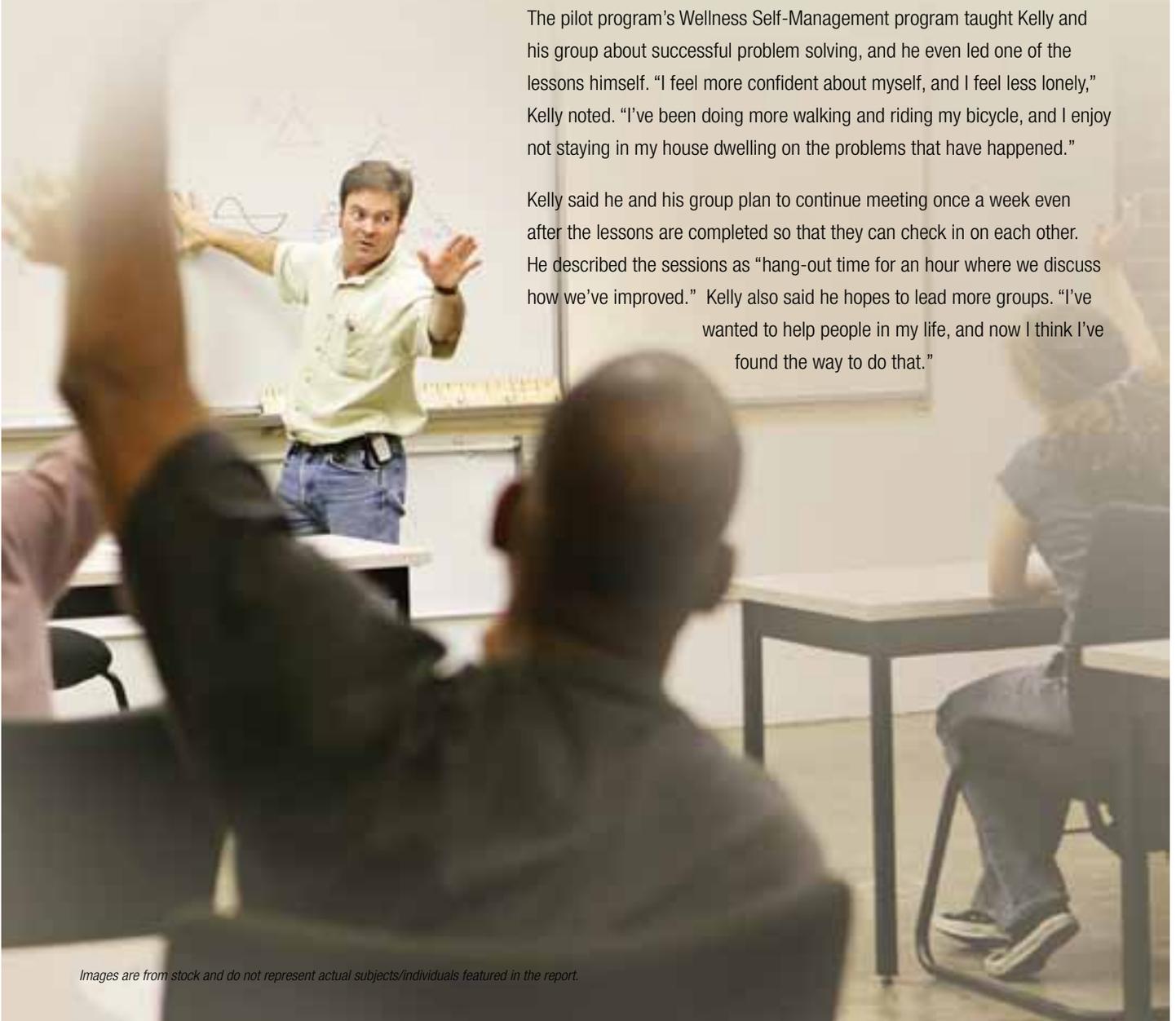
*Worked on successful problem solving in the group*

## Spokane Mental Health: Kelly

Kelly said he thought he already understood his diagnosis of paranoid schizophrenia but, at age 25, he found a group that helped him to learn more. By participating in the Advancing Standards of Care for People with Schizophrenia pilot program, Kelly realized that he's not alone in working to manage a mental illness. "I had problems with people harassing me, and I thought they were doing it because I was different," Kelly said. "But in this group I realized that there are other people like me."

The pilot program's Wellness Self-Management program taught Kelly and his group about successful problem solving, and he even led one of the lessons himself. "I feel more confident about myself, and I feel less lonely," Kelly noted. "I've been doing more walking and riding my bicycle, and I enjoy not staying in my house dwelling on the problems that have happened."

Kelly said he and his group plan to continue meeting once a week even after the lessons are completed so that they can check in on each other. He described the sessions as "hang-out time for an hour where we discuss how we've improved." Kelly also said he hopes to lead more groups. "I've wanted to help people in my life, and now I think I've found the way to do that."



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Information on resources and training for the Wellness Self Management Curriculum is available on the Center for Practice Innovations website at <http://practiceinnovations.org/WellnessSelfManagementWSM/tabid/118/Default.aspx>

Information on the DLA-20 is available at [www.thenationalcouncil.org/cs/functional\\_assessment\\_tool](http://www.thenationalcouncil.org/cs/functional_assessment_tool)

A peer-reviewed study of the DLA-20 can be found at <http://rsw.sagepub.com/content/11/3/373.abstract>

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