Amplifying the Voices of Individuals Who Use Mental Health Services: A Commitment to Shared Decision Making

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The practice of shared decision making is central to the provision of recovery-oriented mental health care. Shared decision making promotes person-centered care, empowering individuals who use services and engaging them in treatment. In its seminal 2001 report, Crossings the Quality Chasm, the Institute of Medicine emphasized the importance of shared decision making in its ten rules for redesigning health care processes. The Affordable Care Act includes provisions for creating programs to facilitate shared decision making in a reformed health care system.

As part of a broad initiative to promote person-centered care, Community Care Behavioral Health Organization, a nonprofit behavioral health managed care company that is part of UPMC (University of Pittsburgh Medical Center), has implemented peer-run Decision Support Centers (DSCs) at 12 sites in its Pennsylvania provider network. The first of the 12 DSCs was launched in 2009, and Community Care has plans to open DSCs at several more sites across the state. DSCs provide individuals who have a diagnosis of severe mental illness with the tools they need to prepare to make the best treatment decisions with their psychiatrists and treatment teams.

Community Care DSCs use CommonGround, a unique software program designed by Patricia Deegan, Ph.D., that helps individuals who use services organize and express their treatment concerns clearly. Even individuals with low literacy and no computer skills can readily use the program’s interactive touch screens to help them prepare for a visit with their psychiatrist. Peer specialists are on hand to welcome individuals to the DSC and to provide assistance with the program. An innovative feature of CommonGround is its ability to generate a concise one-page report on the individual’s current status and questions and concerns about treatment, which is shared with the psychiatrist during the visit. In most cases, this is the first document that the psychiatrist and the treatment team have ever seen about the individual that is from the individual’s point of view—not compiled by other providers—and centered on the individual’s expressed concerns. By offering tools for self-management, recovery, and wellness, Community Care’s DSCs enable individuals to demonstrate that they are not “the problem” but essential participants in the process of solving the problems that they face.

Community Care began a collaboration with Pat Deegan & Associates (PDA) in 2007 to develop a replicable version of CommonGround and design a standard implementation process to facilitate adoption by DSCs at multiple sites. Community Care sponsored implementation of the second DSC in the United States to use CommonGround and was the first of PDA’s partners to take the program to scale, playing a crucial role in the migration of CommonGround into medical practice. To date, over 8,200 individuals have visited and benefited from DSCs. James M. Schuster, M.D., chief medical officer for Community Care, describes shared decision making as an “intensive and expressive form of informed consent” and credits DSCs and CommonGround with helping to spread a “culture of recovery” to Community Care’s provider organizations.

In recognition of its innovative efforts to amplify the voices of individuals who use services and to empower them to play an active role in their recovery by implementing DSCs throughout its provider network, Community Care has been selected to receive the APA’s 2013 Gold Achievement Award in the category of academically or institutionally sponsored programs. The winner of the 2013 Gold Achievement Award in the category of community-based programs is described in an accompanying article. The awards will be presented on October 10, 2013, at the opening session of the Institute on Psychiatric Services in Philadelphia.

Community Care’s commitment to shared decision making

Incorporated in 1996, Community Care Behavioral Health Organization supports Pennsylvania’s HealthChoices program by managing mental health and substance use disorder services for approximately 700,000 individuals covered by Medicaid in 39 of Pennsylvania’s 67 counties. Community Care’s approach to managed care is grounded in public-sector commitment, expert clinical competencies, and program and fiscal accountability. Community Care has been awarded full accreditation—the highest level—by the National Committee for Quality Assurance.

In 2007, Community Care embraced shared decision making as a practice that would make its commitment to recovery tangible throughout its provider network. Community
Care has helped 12 provider sites in its service area implement DSCs, including ten outpatient clinics, a peer center, and one site where the DSC is used by two assertive community treatment teams. In partnering with PDA to develop a standard implementation process for DSCs and CommonGround, Community Care staff described each stage of implementation, clarified costs, developed a train-the-trainer model, and specified the qualification of certified peer specialists. In addition, staff helped to address the question of how to ensure that individuals’ personal data would be secure and that procedures would be HIPAA compliant. To integrate shared decision making more fully into the organization’s standard approach to business, Community Care has prepared a training manual and integrated decision support into policies, procedures, and job descriptions. Community Care’s positive experience with implementing CommonGround provided proof of concept and helped to fully develop the unique software program as an emerging best practice.

**CommonGround: a “disruptive” innovation**

All of Community Care’s peer-run DSCs use the CommonGround program to help individuals prepare for their psychiatrist visits. CommonGround was developed by individuals who use services with the knowledge that medication appointments with a psychiatrist are often very short—only 15 to 20 minutes—and the individual usually has many issues to discuss. Keeping one’s thoughts organized while answering the psychiatrist’s questions, asking one’s own questions, and speaking up about concerns can be a challenge. When it comes to making treatment decisions, the individual can feel more like a spectator than a full partner. CommonGround addresses this challenge by helping individuals prepare before the appointment, so that during the appointment they are ready to work with the psychiatrist and make the best decisions for treatment and recovery.

CommonGround has been recognized as a “Service Delivery Innovation” by the Agency for Healthcare Research and Quality. In 2013, CommonGround won the Scattergood Behavioral Health Foundation’s Innovation Award. In the application for this national award, Dr. Deegan observed: “As far as we know, we are the only group of patients in recovery who are actually engineering and implementing Web applications that reflect what we need and want in electronic health records. CommonGround is not just an innovation; it’s a disruptive innovation that is bringing recovery, empowerment, and the voice of the ‘patient’ to the center of the clinical care team.”

Key features of CommonGround are designed to activate and engage individuals in their treatment. Using the program’s touch screens, individuals develop personal goals, “Power Statements,” and “Personal Medicine” strategies. In their Power Statements, individuals inform the treatment team about what is most important in their life and how they expect prescribed medication to support their goals. Personal Medicine items consist of things individuals do for themselves to promote wellness, such as spending time with friends, bicycling, or reading a book. CommonGround also includes decision support tools, such as information on medications, and brief inspirational videos that offer models of recovery. The tools are designed to reengineer the discourse between the psychiatrist and the individual so that the conversation focuses on lifestyle modifications to improve overall health and wellness. [A three-minute video introduction to the program is available at www.patdeegan.com/commonground.]

**Welcome to the DSC**

Community Care created DSCs to change the way that the usual visit unfolds. A typical psychiatrist-client visit begins with a few minutes of conversation about the individual’s life, followed by a mental status exam, follow-up on any concerns, and, if needed, a medication change. In a typical visit, the individual is mostly passive—answering questions, receiving advice, and being handed a written prescription. With these repeated visits, individuals may begin to feel powerless. Shared decision making and CommonGround change this process.

The DSC is peer-run and redefines medication appointments to include 30 minutes of work in the DSC before the appointment. Instead of sitting in a waiting room before each visit, the individual enters the DSC—often a converted waiting room—where a peer support specialist greets him or her, offering a healthy snack and beverage. The individual receiving services touches a screen to open the CommonGround program. The program lists past and current medications and includes the individual’s Power Statement and Personal Medicine strategies. To create today’s report for the psychiatrist, the program prompts for additional information, including symptoms since the last visit, severity of recent symptoms, comparison of symptoms and severity at other recent visits, use of medications and any side effects, updates to the medical status and status exam (the software records any medical problem areas in red to ensure that they are readily seen and addressed by the psychiatrist during the visit), questions for the psychiatrist, and the goal for today’s visit. The result is a personalized document that is shared among the care team.

As an individual at one of the first of Community Care’s DSCs put it, “My biggest frustration was that doctors thought they knew what was best for me and I started believing [them].” Even though this individual tried several different medications, she said, “I just wasn’t getting any better, and my life was falling apart.” As she used the tools available in the DSC, she “learned that I have an important part to play in my own recovery, because this is about me, and what I think is important.”

CommonGround, with its focus on shared decision making, has also changed the way that psychiatrists and other team members approach treatment. One psychiatrist noted that she no longer feels that she has to “fix” things for each individual receiving services. Instead, she senses that they are a team and that treatment is shaped by the individual’s goals and supported by the individual’s strengths and resources. It’s a more equal—and human—relationship.

Staff have noted several changes and benefits introduced by shared decision making and DSCs. Individuals
receiving services are more engaged in their treatment, more prepared to interact with their team, and more educated about their choices. CommonGround presents some information in chart form, which helps individuals see that they are making progress. For example, an individual who disliked medications changed his mind after the system captured his progress over time. Treatment team members unite around the individual’s goals, Power Statements, and Personal Medicine. Any treatments are explored together, in light of this information. Should a crisis occur, shared knowledge of the individual’s strengths, resources, preferences, and goals informs the team’s response.

**Overcoming obstacles and barriers**

In implementing DSCs and shared decision making, the Community Care team, PDA, and providers had to address several barriers. Initially, although many psychiatrists saw the program as potentially valuable, some viewed it as an impractical addition to already limited time with individuals receiving services, and some disliked the need to work with computers. In addition, scheduling and supporting individuals to arrive at the DSC 30 minutes before seeing the prescriber required a significant change in practice. Also, nearly one-third of CommonGround reports at the initial DSC sites did not meet fidelity standards for shared decisions. Direct service staff sometimes underutilized CommonGround and failed to incorporate it into treatment planning. Some individuals’ Power Statements were not included in the treatment plan.

To help providers implement shared decision making effectively and with fidelity, Community Care designated several “recovery specialists” within the organization. These staff members received special training and were made available to support providers who were willing to undertake the substantial organizational changes required to implement the practice. Community Care also funded staff training and technical support from PDA. Concerns about these innovations among some psychiatrists were addressed in part by having one of Community Care’s medical directors—a psychiatrist—provide a convincing demonstration of effective ways to utilize input from individuals who use services. The chief medical officer, also a psychiatrist, provided strong support for DSC implementation and use of CommonGround, addressing concerns and answering questions. Community Care sponsored multiple annual institutes across Pennsylvania focused on clinical strategies that support recovery, including shared decision making.

**Funding**

DSCs are funded by fee-for-service billing to Community Care. The single exception is the DSC located in a peer-run drop-in center, which is supported by county base funding. Costs vary for the 12 centers, depending on the size of the DSC and the need for incremental staffing. Funding spans a wide range, from approximately $30,000 to $125,000 per year per site. Start-up funding was provided by reinvestment funds (available Medicaid funds from prior-year capitation) made available by several Pennsylvania counties and Pennsylvania’s HealthChoices program. These funds were used for initial facility and training costs. Ongoing support has been provided in all of the treatment settings by Medicaid billing for the level of care involved (outpatient or assertive community treatment).

**Effectiveness and focus on quality improvement**

Community Care carefully monitors outcomes associated with CommonGround to determine its impact and identify areas where improvements may be needed. Satisfaction surveys are completed by individuals who use CommonGround at six, 18, and 36 months after a DSC is launched. Over 650 individuals have completed the satisfaction survey at nine of the DSCs. Seventy percent of respondents reported improved discussion with their psychiatrists since they began using CommonGround, and 66% reported improved quality of their office visits. Seventy-five percent reported that CommonGround reports were used in making shared treatment decisions, and 71% rated their understanding of their medications as excellent or very good. Seventy-two percent reported the highest levels of satisfaction (excellent or very good) with the CommonGround program, and only 4% reported problems (not having enough time) completing CommonGround reports.

An analysis of the one-page CommonGround reports generated by 5,584 individuals found that the proportion of individuals with concerns about medication side effects decreased significantly from first to most recent completed reports, on average 12 months apart, from 29% to 19%. The proportion of individuals who believed that their medication was helping them increased from 56% to 64%. In addition, the reports indicated that psychiatric symptoms and general health functioning improved significantly from the first to the most recent completed reports.

**A model for others**

With the implementation of DSCs, Community Care has put into everyday practice two essential innovations in the delivery of community mental health services: peer support and shared decision making. As evidence grows regarding the benefits of recovery-oriented approaches to psychiatric care, other providers and payers will seek ways to structure the introduction of shared decision making into practice. Community Care’s carefully designed and tested implementation process can be used by others to guide innovation and to ensure that individuals and their recovery goals are at the center of care.

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