Individual agency, community capacity building, and chronic illness care: Using participatory methods to implement the Stanford Chronic Disease Self Management Program in a Housing First program

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Background

Pathways Housing First Model

Pathways to Housing works to end chronic homelessness for individuals with experiences of psychiatric disability by providing housing first, and then combining that housing with supportive treatment services in the areas of mental and physical health, substance abuse, education, and employment. Housing is provided in apartments scattered throughout a community. This "scattered site" model fosters a sense of home and self-determination, and promotes reintegration into the community. The Pathways model has been remarkably successful in addressing chronic homelessness. The Pathways Program started in Philadelphia in 2008 serving 145 individuals. The program maintains a 92% retention rate even amongst those individuals not considered "housing ready" by other programs.

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Health, psychiatric disability, and chronic disease

- People with a diagnosis of a serious mental illness experience premature death and disease from treatable medical conditions and modifiable risk factors.
- Over 90% of Pathways clients have been diagnosed with a chronic physical disease such as diabetes or high blood pressure and over half are managing 2 or more chronic diseases.
- The majority of clients reported they wanted to address both health (67%) and mental health (68%) issues on initial needs assessment, but a much lower percentage report wanting to reduce substance use (23%) or take psychiatric medications (25%).

Integrated care

Pathways to Housing-PA has developed a novel integrated care program through a unique partnership with the Department of Family and Community Medicine at Thomas Jefferson University. A primary care physician has been embedded within the care team to provide direct clinical services and care coordination. Integrated care team members include staff from social work, nursing, psychiatry, primary care, community integration, substance abuse support, and peer support.

Capacity Building for Community Based Participatory Research

The critical Housing First principle of consumer choice is embraced in both individual health care and health services planning. CBPR projects directly involving PTH consumers in the exploration of health and healthcare issues have been ongoing since the program’s inception.

Chronic Disease Self Management

Research Questions:

Is a standardized chronic disease self management program (CDSMP) experienced as a valuable intervention by Pathways’ consumers?

What is the impact of collaborative inquiry into health program development on participant’s critical agency?

Methods:

- Baseline individual interviews were conducted with all participants
- All participants took part in the 6-week Stanford CDSMP facilitated by Center in the Park
- Participants completed weekly action plans and standardized pre and post program surveys
- Follow-up interviews were conducted with each participant with directed questions about "critical agency," or the freedom to act and question.
- All interviews were recorded and transcribed.
- Analysis incorporated a mixed methods approach.

Process Evaluation

- 25 participants took part in the pilot CDSMP session, with over half attending at least 5/6 sessions
- Average age of participants was 50
- Most common chronic illness diagnosis in the groups included: HTN, OA, DM and COPD
- Staff facilitation and reminders were important in assuring attendance
- With active and specific assistance from the facilitators the action plan process improved for clients
- Some clients with significant chronic medical and psychiatric issues were unable to participate in the group process

Critical Agency

Study team consisting of consumers, clinicians, and researchers actively participating in all phases of evaluation, analysis, dissemination, and future planning. "Agency" is viewed as critical to mental health recovery.

Qualitative Findings

- Participants would welcome further inclusion of pain management and mental health issues into the program
- Women participants would welcome further discussion of past trauma and its affects on current health
- Social isolation figures heavily in influencing self-management and dietary behaviors for many participants
- Regular group attendance and sharing was beneficial in counteracting social isolation and building relationships with other Pathways clients
- Participants feel responsible for their own health and acknowledge the ongoing challenges associated with action planning and self management
- Participants reported active involvement at Pathways but community integration is viewed as a much longer process
- Self management can be more challenging than community advocacy

Future Plans

- Consumer support program for newly housed and socially isolated individuals
- Training as lay leaders for CDSMP
- Development of participatory illness prevention and screening programs

Literature Cited

5. Henwood BF, Tsemberis S, Weinstein LC. Consumers, Community-based Participatory Research and Research Training as Lay Leaders for CDSMP

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