



The Mental Health Block Grant Ten Percent Set Aside Study

BRIEF REPORT | Participant Perspectives on Change

OVERVIEW

Coordinated Specialty Care (CSC) programs often assess change in participants using standardized measures and scales. Understanding client perceptions of change over time, from their *own* perspective, can help clinicians understand what outcomes matter most to them, as well as identify possible areas that need more attention. Site visits to CSC programs included interviews with current or recent past participants to find out what changes they saw in themselves since beginning the FEP program.

Core Symptoms. Across all responses, reduction in core symptoms was the change participants most commonly identified, reported by 38 percent of participants (see Exhibit 1). These symptoms included delusions, paranoia, and auditory hallucinations as well as negative symptoms and cognitive deficits that were explicitly tied to psychosis. In some cases, participants noted significant reductions in frequency or distress, and in others the total amelioration or disappearance of particularly distressing symptoms.

Individual Interview Participants (N=121)

Sex: 41% female, 59% male

Age: 14-35 years (M=22.7)

Race: 41% White, 31% Black or African American, 21% Hispanic

Forty nine percent of the individual interview participants had been in the CSC program for 6-18 months, while another 31% had been in the program 19-30 months.

“ *The most important change is probably, not hearing the voices or seeing anything anymore, because I used to just see that all the time. Shadow people, used to hear people talk, that when they really wasn't there, and everything else.* ”

Social Functioning. Thirty percent of participants reported improved relationships and the ability to be social as a change they experienced. Participants described improved relationships with friends and family, strengthened relational skills (such as compassion and empathy for others), and increased socialization. In some cases, participants situated these changes as secondary to reductions in core psychopathology, but for others improved social functioning was referenced independent of changes in symptoms.

“ *Since I've been here I've built more relationships. I learned how to be more social. I learned how to be more interactive. Connecting with people has been a problem for me before and now I'm a lot better at that.* ”

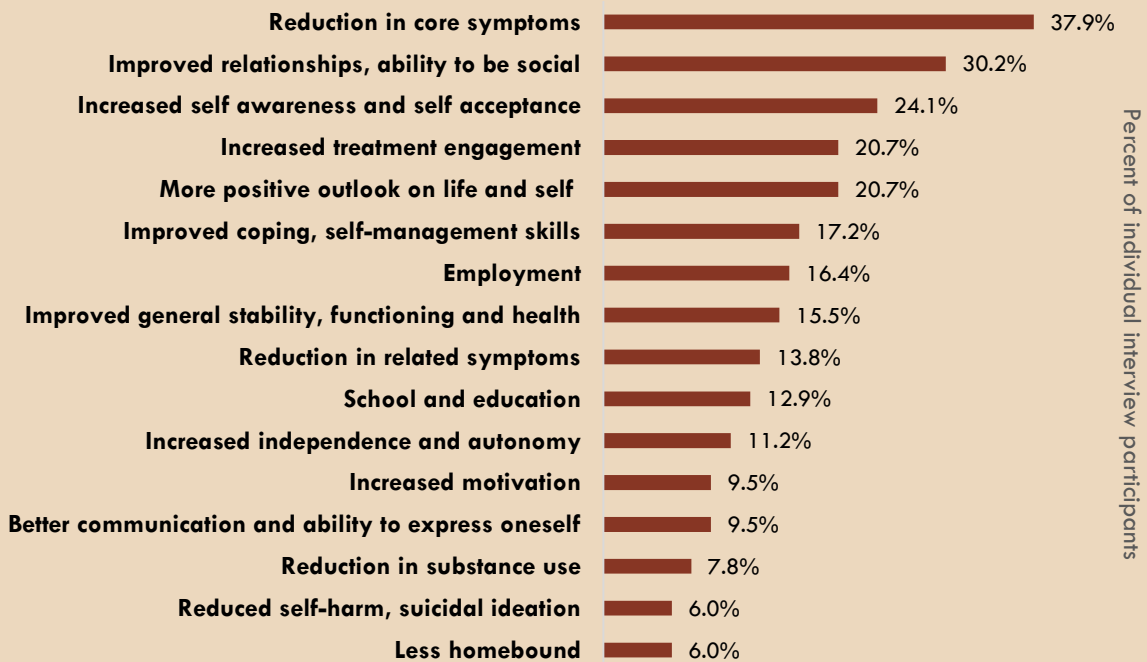
MHBG 10% Set-Aside Study Methods

The MHBG 10% Study is a collaboration among the Substance Abuse and Mental Health Services Administration (SAMHSA), the National Institute of Mental Health (NIMH), and the Office of the Assistant Secretary for Planning and Evaluation (ASPE). The study includes 36 CSC programs that were selected from among the 250 CSC programs across the U.S. that use MHBG 10% set-aside funding. Data presented in this brief report were collected during two site visits conducted between January-June 2018 and January-May 2019. We interviewed 57 participants during the first round of site visits and 83 participants during the second round, with 19 participants participating at both time points. All interviews were recorded and transcribed to facilitate analysis.

Self Awareness and Acceptance. Nearly a quarter (24 percent) of participants described greater self-awareness and/or self-acceptance. In some cases, this manifested as acceptance and a deeper understanding of their diagnosis and mechanisms underlying specific symptoms or emotional challenges, while in other cases it meant coming to accept themselves for who they are. Participants talked about being someone not defined by their diagnosis, and as someone able to help others and contribute to their community.

“ I would say that the most important change has been a greater understanding of myself, both my strengths and my weaknesses. You know, kind of like my view. That can be taken in many ways because I didn't really have an understanding of the limitations, nor did I have an understanding of things that I excel at, that I can be really good in and work towards. The program has helped me work through so many of life's obstacles. But what I've really taken away from all of that work has been an understanding of how I can best operate within these constraints. ”

Exhibit 1. Percent of Participants Reporting Each Type of Change



Note: N=116 participants. Five participants responded that they did not know or there were too many changes to identify. Categories above were developed inductively, and interrater reliability on 25% of the responses resulted in Cohen's Kappa of .85.