

# Schizophrenics Anonymous Evaluation Final Report: Member Engagement and Change

Deborah A. Salem, Thomas M. Reischl, & Katie Weaver Randall

Michigan State University

## Executive Summary

One hundred and fifty-six SA members were surveyed regarding their experiences in SA. Forty-nine SA members participated in ethnographic interviews which were structured to allow participants to tell the story of their SA involvement. Based on the survey results we learned that:

- ❑ SA serves a broad spectrum of individuals with schizophrenia, including those who live and work independently, those who live and work in supervised or sheltered settings, and those residing in mental health or forensic institutions. While SA members vary considerably in terms of their current level of functioning, almost all have histories of multiple hospitalizations.
- ❑ SA plays a unique role in the lives of its participants. They view the helping roles of SA and professionals quite differently. SA participants tend to view professionals as the *best* equipped to help them with medication and symptom management. Fellow SA participants, on the other hand, are viewed as *best* equipped to help when they are feeling lonely or want to talk to someone who understands what it is like to have schizophrenia.
- ❑ SA participants report that they experience a sense of identification with SA members and leaders. They do not tend to feel the same level of identification with their primary therapist. The majority of SA participants also feel that other SA members and leaders have valuable expertise to share.
- ❑ Participants are more likely to find SA helpful when they feel a sense of identification (i.e., referent power) with other SA members or believe that fellow members have valuable knowledge and expertise (i.e., expert power).
- ❑ The majority of members report that attending SA has helped them to manage their symptoms, increase their knowledge about schizophrenia, combat feelings of loneliness, and make friends and improve their social life.

The qualitative findings echo these results. SA participants report that their involvement in SA helps them in the following ways.

- ❑ SA helps members to learn about schizophrenia and how to cope with it. Learning about schizophrenia, through formal information disseminated at the meetings and through the sharing of experiences in the group, has given SA participants greater insight and understanding into their own illness and enhanced their ability to cope with it.

Participants value the sharing of information about schizophrenia; about resources, treatments, and medications; and about the experiences others have had coping with their illness. They feel that learning more about schizophrenia helps them to accept their illness and to adopt a proactive role in managing it. Some participants also report that the information they receive in SA helps them to educate their families about their illness.

- ❑ SA participants report that their involvement in SA helps them to change how they feel about themselves. They describe decreased feelings of shame; enhanced feelings of value, worth, and esteem; forgiveness and acceptance of themselves and others; development of more realistic expectations and new goals; and increased feelings of hopefulness.
- ❑ SA provides opportunities for participation in meaningful social roles, including the role of helping others, working on literature and other educational materials for SA, and public speaking to address the issue of stigma. These opportunities provide members with a sense of meaning and purpose that may not be available to them in other life domains.
- ❑ Involvement in SA helps to combat feelings of loneliness and social isolation. It helps members to realize that they are not alone with their illness, provides a sense of identification with others who really understand their experiences, provides a safe place to talk about their illness, and provides support, acceptance, friendship and fellowship. In addition, the shared experiences that emanate from having schizophrenia are an important aspect of SA. Participants value hearing each others stories and experiences. They value the sharing of experiential knowledge (i.e., knowledge gained from living with schizophrenia) and learn how to cope with their illness from the experiences of others.

Overall, these findings suggest that SA provides support, fellowship, and information to a range of people experiencing a schizophrenia-related illness. It helps participants to combat feelings of loneliness and isolation that often accompany a diagnosis of schizophrenia and provides a setting where members feel that their experiences are shared and understood by others. While most SA participants value the help they receive in professional settings, SA provides a unique type of help in dealing with schizophrenia that members do not receive from professionals or from other mental health organizations.