

**Title:** Proposed Study of the Natural Course of Schizophrenia with Self-Help Supports

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**Description:** In response to the suggestions of advocates, mental health consumers, and researchers that people with mental illness suffer more from the disabling effects of psychotropic medications, institutionalization, and other treatments than from the disease itself, government scientists propose a study of the natural course of schizophrenia.

**Headings:** Study Design and Risk-Benefit Analysis; Experimental designs (randomization, clinical trials); Risks and benefits; Mental health disorders, participants with (including addictive disorders and developmental disabilities)

**Case Type:** Decision making

### **Proposed Study of the Natural Course of Schizophrenia with Self-Help Supports**

The New York Times has reported that a government sanctioned nontherapeutic experiment aimed at compiling data on the effects of the spontaneous evolution of schizophrenia has been proposed by the Public Health Service (PHS). Researchers hypothesize that those persons who receive no traditional treatment for mental illness will show better outcomes and satisfaction over their lifetimes than those who remain within the mental health system. Because of public outcry from families of people with mental illness and mental health providers, a review panel of researchers, bioethicists, mental health consumers and family members has been convened to debate the ethical issues involved in conducting such an investigation.

Many advocates, mental health consumers, and researchers have suggested that people with mental illness suffer more from the disabling effects of psychotropic medications, institutionalization, and other treatment modalities such as ECT than from the disease itself. In fact, recent studies of recovery have indicated that people can and do live meaningful lives within the community without traditional biomedical treatments. Since the Hippocratic Code instructs physicians to "Do no harm," scientists and mental health consumers argue that it is important to finally determine if current approaches to the treatment of people with schizophrenia are iatrogenic. Are evidence-based practices based on a legacy of biased science that values reduction in symptoms and social control over the desires of mental health consumers for an end to involuntary treatment and the nurturing of personhood, well-being and self-determination?

To answer this question, PHS has proposed a study to document the natural history of schizophrenia. Six hundred people diagnosed with a first psychotic break (400 experimental and 200 controls) are to be recruited into a long-term study. The control group members will receive standard treatments for schizophrenia; the experimental group members will receive no traditional mental health treatment. However, experimental group members will be allowed to participate in peer support and other self-help activities if they choose to do so. A crisis hostel managed by mental health consumers will be funded to provide support and care during psychotic episodes. As incentives, study participants will be offered free medical care, transportation, food, and a life insurance policy to be paid to their survivors. Certificates of appreciation will also be sent by the Surgeon General of the United States to encourage

participants to remain in the experiment. The study's principle investigators are government physicians and psychiatrists. Several mental health consumers will also be working as study consultants, coordinators and surveyors.

**As a member of the review panel, would you support the study? What ethical issues would you identify in making your argument?**