

Advocacy movements in research and prevention: schizophrenia and autism

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Advocacy movements have emerged as a critical force in medical research and public health. The significance of advocacy forces is well known in the field of HIV research. Activists are also a familiar presence in other fields including breast cancer, diabetes and mental health. These movements represent communities of interest defined by disease group rather than location or social group. For many impacted by severe disease and disability, these virtual communities are very real and represent the members' social and emotional location, if not their physical location. Using examples from schizophrenia and autism, we discuss the ways in which these groups are altering the research environment.

Advocates have enormous potential to influence research and prevention and they increasingly demonstrate it. When considering a program of research or prevention, at least in the United States, it is often essential to partner with advocacy groups. We propose that these confederacies do not require compromise of purpose or rigor, and frequently make a positive contribution to research activities. Furthermore, we propose that a community based health research perspective provides an appropriate framework for understanding emerging issues.

A good example of advocates facilitating research is the landmark monozygotic twin study of schizophrenia¹. The research was conducted with the full support and assistance of family organizations. Virtually all participating twin pairs and triplet sets including an affected member(s) were recruited through the National Alliance for the Mentally Ill (NAMI) and Schizophrenia Society of Canada. In this and other endeavors requiring the participation of individuals with extremely rare characteristics (e.g., discordant monozygotic twins), family activists are often indispensable to applying a powerful research design.

The felt presence of advocacy interests may also run counter to scientific current. Science may be called upon to answer questions that the community needs to have answered, not necessarily questions that are the next logical step in the research program. A compelling example is found in the field of autism. An influential faction of parents believe that vaccines, more specifically the MMR vaccine, cause autism. In the scientific mainstream, however, opinion is virtually unanimous that the MMR does not cause autism. Our purpose here is not to support either position, but to point to the conflict.

The uptake of vaccines in some communities has been affected by this controversy. Vaccine policy has been placed center stage on the national health agenda in both the US and UK. The scientific and public health communities must craft a response to these parental concerns in a highly politicized climate.

In instances such as these, the perspective of community based research is useful. It implies that that the scientific and public health communities should be taking on family concerns, and answering the question the community needs to have answered. In the autism/vaccine example, this suggests that research directly examining the issue must be undertaken.

The alternatives to this approach are difficult. Rejecting family concerns based on indirect evidence will place the advocacy and research communities in conflict. To engage in a debate will accomplish little when the standards of winning or losing are not shared. In many circumstances the proof required to alter community concerns is not only a rebuttal of claims, but positive proof of an alternative explanation of the facts. Even more treacherous than rejecting family concerns is evading them. If the conflict is to be resolved without the participation of the scientific

community, political interests take on an expanded role. This serves no rational purpose or interest.

Researchers who do partner with advocacy groups struggle with substantial ethical and practical issues in real time.

Who are the legitimate representatives of the community's interest? Indeed who is the community served? Are families the legitimate representatives of the mentally ill, or are advocacy movements constituted by the mentally ill themselves the legitimate representatives? When conflicts arise between the disease-based community and the general public, whose interest takes priority? In an environment of

fixed or scarce resources, is redirecting resources away from the next logical step, or the most promising research towards questions the community needs answered in the community's interest?

In the mental health field, and increasingly in other fields of enquiry, these questions can no longer be overlooked. The precedent of community based research provides only partial guidance at best. The pace of both scientific advance and effective prevention are going to depend to an important degree on the way in which these questions are answered.

References

- 1 Torrey EF, Bowler AE, Taylor EH, Gottesman II. Schizophrenia and manic-depressive disorder. New York: Basic Books, 1994.

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