

Review of the Stigma and Global Health Program of the John E. Fogarty International Center: Final Report

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Executive Summary

The John E. Fogarty International Center (FIC or Fogarty) at the National Institutes of Health (NIH) supports international collaborative research and training programs that advance the NIH mission through international partnership. Guided by the FIC Framework for Program Assessment,¹ Fogarty routinely conducts process reviews for each of its extramural programs after the first five years. The purpose of these process reviews is to analyze program implementation, identify near-term outputs, and make recommendations for future improvements to the program. If a program reaches the ten year mark, the process review is followed by a more extensive evaluation effort to document program outcomes and lessons learned.



This report describes the results of a process review of FIC's Stigma and Global Health Research Program ("Stigma Program" or "the Program"). Established in 2002, the Program's purpose is to "stimulate investigator-initiated research on the role of stigma in health and on how to intervene to prevent or mitigate its negative effects on the health and welfare of individuals, groups and societies world-wide."² A total of nine R01 and nine R21 awards were made to principal investigators (PIs) at US and international institutions in fiscal year 2003. While NIH funding for these awards had largely concluded by the end of fiscal year 2007, PIs reported that 13 of the 18 awarded projects were still ongoing as of the end of fiscal year 2008, including five operating under no-cost extensions into 2009.

The Stigma Program review was conducted by a panel of four extramural investigators with a diverse set of backgrounds and no formal links to the Program or awarded investigators. During a series of three teleconferences held between March and December 2008, Panel members reviewed evidence compiled from sources including investigator progress reports, NIH databases, and interviews with stakeholders.

Forty-nine publications (including five in press) were identified as being affiliated with the Stigma Program – 28 from the nine R01s and 21 from the nine R21s. Dividing the total funding of \$17 million by the 49 publications to date yields a ratio of \$348K per published paper. An additional 19 publications were reported to be under review or in preparation. Few new interventions had been published or instruments validated to date.

Although these publication rates would ordinarily be considered low for a research program, the Panel identified several contextual factors that have likely slowed the rate of publications:

- Even though funding to investigators was largely complete by FY 2007, only five of the projects have been completed. Interviewed awardees who reported a small number or complete lack of stigma-related publications commonly stated that their data collection has been recently completed.
- There is no journal dedicated exclusively to stigma research, nor does stigma fit clearly within the boundaries of any single established discipline or field of research.
- Exploratory or developmental work such as that funded under the R21 mechanism can be particularly difficult to publish because it is often poorly understood by editors and reviewers.

¹ Available online at http://www.fic.nih.gov/about/plan/eval_framework.htm, accessed May 6, 2008.

² RFA TW-03-001, "Stigma and Global Health Research Program", Released June 20, 2002, "Purpose of this RFA" section.

- Many awardees indicated that they are working on developing communication skills because they are either new to the subject of stigma or are in an early-career phase.

Additional noteworthy findings of the review include:

- Awarded PIs represented a diverse set of fields, including psychology, sociology, medical statistics, epidemiology, community health systems, anthropology, occupational therapy, nursing science, and neurology.
- Ten of the Stigma PIs had never previously received an NIH award of any kind, and one additional PI had never received R01-level funding from NIH.
- Stigma-funded research occurred in North America, Europe, Asia, Africa, Latin American and the Caribbean, and Oceania/Australia.
- Four of the nine R21 awardees have received additional funding from NIH subsequent to their Stigma Program awards.

The expert panel made three recommendations regarding the Stigma Program.

Recommendation 1: The Stigma Program funding opportunity announcement (FOA) should be re-issued as a Request for Applications (RFA) soliciting proposals for R01 and R21 research grants focused on development of interventions. FIC should encourage partners, including NIAID, to participate. The review criteria and composition of review panels for the next round of Stigma proposals should reflect the change in objectives.

The Panel recommended that the next solicitation for the Stigma Program should narrow the goals and objectives of the Program to focus on developing interventions, researching the role of stigma at the community level, and exploring the role of stigmatizers as well as the stigmatized populations. In addition to an increased focus on outcome-targeted research, the Panel recommended encouraging “action research” where the investigator works directly with community members to develop an intervention, evaluate its outcomes, and report on reasons underlying the success or failure of the intervention.

The 2003 Stigma Program FOA was an RFA. Under an RFA, applications are solicited by a specific receipt date, as opposed to other types of solicitations under which applications are accepted and reviewed on an ongoing basis. However, under an RFA, dollars are set aside in advance to fund meritorious applications. Although the panel did recognize that another solicitation mechanism such as a Program Announcements might give applicants more time to coordinate their applications, the panel recommended that the Stigma Program issue another RFA because they believed that it is more important to ensure that funds are dedicated to the Program.

The Panel recommended that Fogarty continue to offer funding for the Stigma Program under both the R21 and R01 activity codes. The original RFA provided little guidance regarding how the content of R21 and R01 projects was expected to differ except to say that R21 awards were intended to provide preliminary data in support of future R01 applications. The Panel suggested structuring the Program such that the R21 mechanism would be used to support research on the design, targeting, and pilot testing of interventions to reduce the impact of stigma. The R01 could, in turn, support research on larger scale implementation of interventions. In addition, the continuation of the R21 structure allowing for three years of support rather than the normal NIH model of two years of support for this type of grant is encouraged because of the difficulties in initiating research in the field of stigma and global health.



Besides FIC, eight NIH Institutes and Centers³ plus the NIH Office of the Director (OD) and the Health Research Services Administration (HRSA) of HHS were listed as partners on the 2003 Stigma Program RFA. Five Institutes and Centers (FIC, NIAAA, NIDA, NIMH, and NINDS), OD, and HRSA contributed funds for awarded Stigma Program projects. The Panel encouraged FIC to work with NIAID to co-fund meritorious applications focused on infectious disease areas of interest in future rounds of competition.

Reviewers for future rounds of Stigma Program applications should have an appropriate set of skills and expertise. The Panel recommended that inclusion of reviewers familiar with qualitative methods should continue. Reviewers with backgrounds or experience in implementation research in international contexts should also be recruited.

Recommendation 2: FIC should convene another meeting of stigma and global health researchers to focus on identifying challenges and describing best practices regarding stigma and global health research and aim to publish the results.

FIC convened meetings in the stigma and global health field in 2001 and 2006. As there is much to be learned and developed in the area of stigma, a third meeting could consolidate what has been learned to date and re-evaluate areas of need. It would also provide invaluable opportunities for communication between researchers. The Panel recommended that FIC convene a meeting to discuss stigma along with key aspects of implementation science, to facilitate sharing ideas and resources, for networking, and to provide additional professional development for investigators studying diverse aspects of stigma and stigma-related interventions. The Panel suggested that FIC include other NIH Institutes such as NIMH, NCMHD, NIDA, and the National Institute of General Medical Sciences (NIGMS) as partners in the meeting. In addition, the Panel encouraged the inclusion of other federal agencies such as the Centers for Disease Control and Prevention (CDC) and Substance Abuse and Mental Health Services Administration (SAMHSA).

At the 2006 network meeting, researchers reported a set of common challenges at the third year of their studies in designing and implementing their research. A future network meeting might provide opportunities to describe the lessons learned in meeting those challenges. The Panel recommended that the experiences of grantees in project delays, development of productive international partnerships, and inclusion of stakeholders in research and implementation be included in the agenda or planning of an FIC-led meeting on stigma.

In 2006, *The Lancet* published eight papers and essays drawn from background papers of the 2001 international conference. The Panel recommended that a similar publication strategy, describing lessons learned and best practices, would be of value for the community of stigma and global health researchers and should be adopted for the proposed network meeting. Suggested venues for such a publication are as a special issue in a high-impact, international journal in order to increase awareness of stigma-related issues and stigma research-related developments across the world.

Recommendation 3: FIC's partnerships and outreach should work to incorporate stigma into global health research agendas.

³ FIC; National Center on Minority Health and Health Disparities (NCMHD); National Human Genome Research Institute (NHGRI); National Institute on Alcohol Abuse and Alcoholism (NIAAA); National Institute of Allergy and Infectious Diseases (NIAID); National Institute of Drug Abuse (NIDA); National Institute of Dental and Craniofacial Research (NIDCR); National Institute of Mental Health (NIMH); National Institute of Neurological Disorders and Stroke (NINDS).

Non-NIH funders of stigma research include the John D. and Catherine T. MacArthur Foundation and the Doris Duke Charitable Foundation. However, unlike the Stigma Program, these foundations predominantly fund implementation of previously-developed interventions as well as studies of health service delivery and infrastructure development. The Panel recommended that FIC work to ensure that stigma is included in the concerns of the global health community and that public-private partnerships (PPPs) with organizations where stigma is an area of focus be pursued. The meeting of stigma and global health researchers will yield a shared vision for needed stigma-related research, and the new RFA would fund a set of projects that would develop new interventions. The Panel suggested that FIC aim to serve as a conduit for connecting investigators who develop interventions through the Stigma Program with the funders who could help to implement the interventions that prove effective more broadly.

Summary Finding:

The Panel finds that the publication output of the Program has been reasonable, based on the goals and objectives of the Program's RFA.

The Panel concluded that the research outputs of the Program as described above, particularly as reflected in the publication record, have been reasonable. The Panel considered the publication of exploratory or developmental work (such as that funded under the R21 mechanism) to be particularly difficult to publish, so that the inclusion of a more focused set of goals and objectives may yield more publications in the next round of grants.

The Panel suggested that FIC encourage the Stigma Program grant recipients to publish monographs and other alternate forms of research dissemination. Given the disparate set of journals in which stigma-related research is published, there may well be a strategic advantage to grouping research findings in a monograph or journal special issue to consolidate the knowledge being accumulated. Moreover, at this point in the evolution of the stigma research field, some research results may not fit the missions of high-impact journals, and therefore they may best be disseminated through the grey literature. Nevertheless, peer reviewed journal articles are to be encouraged, to the greatest extent possible.