

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

May 2009

Review Panelists:

William Darrow, PhD

Stephen Hinshaw, PhD

Joia Mukherjee, MD/MPH

Jo Anne Sirey, PhD

Table of Contents

List of Figures	3
List of Tables.....	3
Executive Summary	4
Section 1: Background & Introduction	8
1.1 FIC Program Review	8
1.2 Methodology.....	8
Section 2: Program Background and Environmental Scan.....	10
2.1 Program Origin and Purpose	10
2.2 Program Structure	12
2.3 Program Niche.....	13
2.4 Alternate Mechanisms & Models.....	21
2.5 Section-Level Findings and Recommendations.....	22
Section 3: Program-Level Management and Partnerships.....	23
3.1 Program Management	23
3.2 IC Program Partnerships.....	23
3.3 The Network Meeting.....	27
3.4 Section-Level Findings and Recommendations.....	28
Section 4: Award-Level Management and Partnerships.....	29
4.1 Award-Level Management.....	29
4.2 Award-Level Partnerships & Collaborations	29
4.3 Stakeholder Involvement & Cultural Competence	30
4.4 Section-Level Findings and Recommendations.....	31
Section 5: Program Results	32
5.1 Descriptive Information for Awards	32
5.2 Publications and Other Research Outputs.....	38
5.3 Program Results: Enhanced Stigma Research Capacity	44
5.4 Section-Level Findings and Recommendations.....	45
Appendix A: Biographies of Expert Panel.....	46
Appendix C: FIC Mission Statement and Summary of Strategic Plan Goals and Strategic Priorities...	66
Appendix D: Glossary of Key Terms	67
Appendix E: CRISP Terms Associated with Awarded Stigma and Global Health Projects	68
Appendix F: Results of Search for Awards whose Abstracts use “Stigma”, 2001-2008	71
Appendix G: Results of Search for PAs and RFAs Using “Stigma”, 1992-2008	79
Appendix H: Coding of Stigma Awards by Discipline and Disease Focus.....	87
Appendix I: Coding of Seniority of Investigators.....	88
Appendix J: Bibliography of Publications Associated with Stigma Awards	89
Appendix K: Interview Guides	92

List of Figures

Figure 1: NIH-Funded Stigma-Related Activities by Fiscal Year.....	15
Figure 2: Distribution of New Stigma Related Awardees by IC, FY 2001-8 (181 New Awards)	15
Figure 3: NIH and CDC Research Opportunities (RFAs and PAs) on Stigma-related Topics by IC, 2000-2008	17
Figure 4: NIH Research Opportunities (RFAs and PAs) on Stigma-related Topics by Activity Code, 2000-2008.....	18
Figure 5: R01 Award Funding by IC, by Fiscal Year.....	24
Figure 6: Stigma Program-linked Publications by Activity Code and Year	38
Figure 7: Stigma Program-linked Publications by Awardee and Year	39

List of Tables

Table 1: Funding by IC, by Fiscal Year.....	25
Table 2: Stigma Program Funding by Awardee, by Fiscal Year	26
Table 3: International Stigma Program Research Projects (R01s and R21s).....	33
Table 4: Domestic Stigma Program Awards	33
Table 5: Fields of Stigma Program Awardees, by Activity Code.....	33
Table 6: Disease Foci of Projects, by Activity Code	35
Table 7: Location of Study Sites, by Activity Code	35
Table 8: Key Personnel Tallies, by Stigma Program PI.....	36
Table 9: Country and Region of Stigma Program Collaborators, by Project Scope and Activity Code .	37
Table 10: Affiliation of Stigma Program Grantees.....	37
Table 11: Publications Linked to Stigma Program, by Awardee.....	40
Table 12: Journals Publishing Stigma Program-related Publications, by Year	41
Table 13: Impact Indicators for Journals Publishing Stigma Program-related Publications	41
Table 14: Comparison of Journal Citations per Publication with Stigma Program Article Citations per Publication	42

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.

Section 1: Background & Introduction

1.1 FIC Program Review

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 Assessment⁴, Fogarty routinely conducts process reviews for each of its extramural award 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 the program reaches the ten year mark, the process review is followed by a more extensive evaluation effort to fully document program outcomes and lessons learned.

The Stigma and Global Health Research Program (“Stigma Program” or “the Program”) is currently undergoing a process review. 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.”⁵ A total of 18 R01 and R21 awards were made to investigators at US and international institutions in fiscal year 2003. While funding for the Program has concluded, several PIs have received no-cost extensions to their awards, and so research undertaken using programmatic funding has continued into 2009.



This report describes the results of the Stigma Program process review. After a brief description of review methodology, review findings and recommendations are then detailed in four sections: Program Background and Environmental Scan; Program-Level Management and Partnerships; Award-Level Management and Partnerships; and Results. Appendices include biographical information on the review panelists as well as additional documents to support the analyses presented in this report.

1.2 Methodology

The Stigma Program process review was conducted by a panel of four extramural investigators (the “Panel”) with a diverse set of backgrounds and no formal links to the Program or awarded investigators. Please see Appendix A for biographical information on the review panel members. Panel members participated in a preliminary teleconference on March 3rd, 2008 to approve a proposed evaluation design and data collection strategy. Program data were then collected and summarized by the Science and Technology Policy Institute (STPI), a contractor selected by FIC to support the evaluation. Panel members met on September 12th, 2008, again via teleconference, to review the summarized program data. A final teleconference was held on December 17th, 2008 to make preliminary recommendations, which were finalized after one-on-one conversations with STPI staff in February 2009.

The information collected for the Stigma Program Review is based on data obtained from various sources including:

- Interviews (Interview guides attached as Appendix K)
 - ◆ Program awardees: Sixteen of the 18 Principal Investigators (PIs), including seven of the nine grants awarded under the Developmental Research Grant (R21) and all of the nine awardees under the Research Project Grant (R01) mechanisms. The interview guides consisted of 23 open-ended questions

⁴ Available online at http://www.fic.nih.gov/about/plan/eval_framework.htm, accessed May 6, 2008.

⁵ RFA TW-03-001, “Stigma and Global Health Research Program”, Released June 20, 2002, “Purpose of this RFA” section.

covering four main topics: Application, Review & Management, Partnerships & Communication, and Research Results & Outputs.

- ◆ Program Officer (PO)s and Partners: Interviews with five POs, from the National Institute of Mental Health (NIMH); the National Institute of Drug Abuse (NIDA); National Institute of Neurological Disorders and Stroke (NINDS); the Office of AIDS Research (OAR); and FIC.
- ◆ Other experts in the field of global health, including a foundation PO and two strategists for leading global-health focused partnerships.
- Applications and progress reports (if available) from funded Stigma Program projects. These data sources included information regarding:
 - ◆ Publications;
 - ◆ Research projects;
 - ◆ Collaborators; and
 - ◆ Additional outputs
- Data collected from NIH databases, including:
 - ◆ Funding and co-funding information for Stigma Program awards
 - ◆ Information about additional NIH awards made to Stigma Program PIs
- Information collected on programs supporting research on stigma and health
 - ◆ Internet scan for similar programs
 - ◆ Discussions with foundation POs and other experts
- Information reflecting FIC's potential impact on the study of stigma.
 - ◆ Proceedings from the 2001 meeting, *Stigma and Global Health: Developing a Research Agenda*
 - ◆ Federal government-wide search for stigma-related research and investigator activities
- Reports and journal articles developed for and resulting from program planning and network meetings.
 - ◆ Papers delivered at the NIH/FIC-sponsored *Stigma and Global Health: Developing a Research Agenda* international conference and subsequently published in *The Lancet* as "The Lancet Series on Global Mental Health: Article Collection."⁶
 - ◆ Other summary materials from the *Stigma and Global Health: Developing a Research Agenda* website.⁷
 - ◆ Summary reports from the *Stigma and Global Health Network Meeting*, held April 24-26, 2006.⁸

⁶ For the full collection of articles, an additional paper by The Lancet Global Mental Health Series, and all accompanying comments, please see: *The Lancet.com*, "The Lancet Series on Global Mental Health: Article Collection," September 4, 2007, available at http://www.thelancet.com/online/focus/mental_health/collection, accessed October 10, 2008.

⁷ National Institutes of Health, *Stigma and Global Health Conference: Developing a Research Agenda*, September 5-7, 2001, Bethesda, MD. Available at <http://www.stigmaconference.nih.gov>, accessed October 10, 2008.

⁸ National Institutes of Health, Fogarty International Center, Office of Behavioral and Social Sciences Research, *Stigma and Global Health Network Meeting: Summary Report*, April 24-26, 2006.

Section 2: Program Background and Environmental Scan

The effects of stigma associated with disease or illness may be felt at many levels. They may limit the quality of care individuals receive, or lead individuals not to seek care. The effects of stigma may also be felt at a healthcare system level, and may have human rights and economic justice implications for a group or an entire community. Although stigma has the potential to have dramatic effects, understanding the etiology of stigma, and the effects on individuals and society when it occurs, is limited. FIC, as part of its portfolio of research and training programs, established the Stigma Program to stimulate research on the role of stigma in health and to develop interventions based upon the fruits of that research.

2.1 Program Origin and Purpose

2.1.1 Program Origin

Fogarty's focus on the topic of stigma began in late 2000 with a series of meetings with representatives from other Institutes and Centers (ICs) convened by a Fogarty staff member. These meetings featured presentations by outside experts on various topics related to stigma and its impact on public health. Attendees reported that the presentations helped them to see connections between their ICs' disease focus and the issue of stigma. As one PO stated, "We could think about how to contribute, how we could sell it to our Directors."



Several months later, in May 2001, the FIC Director first raised the idea of a "Stigma initiative" at an FIC Advisory Board Meeting.⁹ He suggested that the issue might be pursued in collaboration with NIMH, which already had an established portfolio of stigma-related research and an internal working group focused on stigma. Shortly after the Advisory Board Meeting, a trans-NIH working group was established jointly by POs at FIC and NIMH. This Working Group and its meetings were formed ad hoc, in that they involved no entities at higher levels within NIH. This working group advocated development of a stigma-focused research program, and it recommended convening an international conference for the purpose of determining the goals and focus of such an initiative.

In accordance with this recommendation, FIC convened an international conference, *Stigma and Global Health: Developing a Research Agenda*, in 2001. The purpose of the conference was to "examine the causes and consequences of stigma, both in the developing world and the United States... [and] identify the gaps in disease-associated stigma research."¹⁰ This conference was organized primarily by Fogarty, with one staff member devoted to assisting in the effort. The planning process for this conference was described by the Fogarty PO as being extensive; it focused on developing questions and topics for the attendees to discuss.

⁹ National Institutes of Health, Fogarty International Center, *Minutes of the Advisory Board*, May 22, 2001. Available at <http://www.fic.nih.gov/about/advisory/archives/minutes/052201.htm>, accessed October 15, 2008. Questions from the Advisory Board were focused on how the results of research on stigma would be translated into changing the attitudes of the public and how will successes would be measured and evaluated.

¹⁰ Please see for more information on conference partners, attendees, and proceedings. National Institutes of Health, *Stigma and Global Health: Developing a Research Agenda*, September 5-7, 2001, <http://www.stigmaconference.nih.gov/default.html>, updated August 2002.

In addition to FIC, the 2001 conference was supported by ten other NIH ICs¹¹ plus the NIH Office of the Director. Three other US government agencies (Substance Abuse and Mental Health Services Administration (SAMHSA); Centers for Disease Control and Prevention (CDC); National Science Foundation(NSF)) also provided support, as did the World Health Organization (WHO), Pan American Health Organization (PAHO), Global Forum for Health Research, March of Dimes, and Family Health International.

The conference brought together an international and interdisciplinary group of health science researchers and health care practitioners to discuss stigma's causes and consequences for public health in developed and developing countries. It included over 43 expert speakers and more than 100 attendees discussing the history and background of stigma research and covering disease areas (e.g., HIV/AIDS, epilepsy, schizophrenia, craniofacial disorders), public health issues (e.g., drug abuse, physical abuse), media impact, and other cross-cutting topics (e.g., population genetics, legal issues, and sexuality). In 2006, *The Lancet* published eight papers and essays drawn from conference background papers.¹²

The most significant outcome of the conference in terms of the planning process for the Stigma Program was the development of recommendations for a research agenda for the study of stigma and its relationship to a variety of global public health problems. These consensus recommendations were to:

- Further elucidate the etiology of stigma;
- Investigate the health consequences of stigma;
- Develop methodology for studying stigma with respect to health;
- Evaluate and develop new effective interventions to deal with stigma; and
- Lay the groundwork for guidelines on ethical conduct of studies on stigmatized individuals and groups who may face further negative effects, including physical violence or social isolation, because of their participation in such studies.

Development of the Stigma Program Request for Applications (RFA) was guided by these recommendations. Input on early drafts of the RFA was provided by the conference sponsors and other interested ICs. The final RFA was released in June 2002.¹³

2.1.2 Purpose and Objectives of the Program (RFA)¹⁴

The purpose of the Stigma Program (as stated in the RFA) was “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.” Specific objectives were to:

- Encourage research across a variety of scientific disciplines including the biomedical, social and behavioral sciences;
- Elucidate the etiology of stigma in relation to public health; and
- Develop and test interventions to mitigate the negative effects of stigma on health outcomes.

The RFA also encouraged research that:

¹¹ National Cancer Institute (NCI); National Human Genome Research Institute (NHGRI); National Institute on Alcohol Abuse and Alcoholism (NIAAA); National Institute on Child Health and Human Development (NICHD); National Institute of Allergy and Infectious Diseases (NIAID); National Institute on 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); National Institute of Nursing Research (NINR). Within the NIH Office of the Director, support was provided by the Office of AIDS Research and the Office of Behavioral and Social Science Research.

¹² Keusch, G, Wilentz, J, and Klienman, “A. Stigma and Global Health: Developing a Research Agenda,” *The Lancet*, 2006; **367**:525-527. Available at <http://www.thelancet.com/journals/lancet/article/PIIS014067360668183X/abstract> accessed October 10, 2008.

¹³ NIH, Request for Applications, “Stigma and Global Health Research Program,” June 20, 2002, NIH RFA # TW-03-001, <http://grants.nih.gov/grants/guide/rfa-files/RFA-TW-03-001.html>.

¹⁴ To view the complete Stigma and Global Health RFA, please see Appendix B: Stigma and Global Health Research Program Request For Applications (TW-03-001), June 2002.

- Examines stigma and public health in domestic, international and cross-cultural contexts, with an emphasis on studies that are relevant to global health issues;
- Involves an interdisciplinary approach, where possible, using behavioral, social and biomedical sciences; and
- Attracts investigators across a broad range of biomedical and non-biomedical fields.

While an emphasis was placed on research topics of importance to global health and understanding the role of stigma in international and cross-cultural settings, Program awards were not restricted to low- or middle-income countries. With regard to Fogarty, this was a departure from a general trend of funding research and training activities in low- and middle-income countries. In the RFA, FIC was the only IC that stated an explicit interest in applications that specifically involved low- or middle-income countries.

The Fogarty PO explained that the choice to not limit the awards to international projects was because, “we really wanted to get at the root of interventions; we needed to know what was going on in the [field] of stigma in the first world, too.”

2.2 Program Structure

2.2.1 Partnering ICs

The 2002 Stigma Program RFA was co-sponsored by 9 ICs, the NIH Office of the Director, and one non-NIH HHS agency:¹⁵

HRSA	Health Research Services Administration
FIC	Fogarty International Center
NCHMD	National Center on Minority Health and Health Disparities
NHGRI	National Human Genome Research Institute
NIAAA	National Institute on Alcohol Abuse and Alcoholism
NIAID	National Institute of Allergy and Infectious Diseases
NIDA	National Institute of Drug Abuse
NIDCR	National Institute of Dental and Craniofacial Research
NIMH	National Institute of Mental Health
NINDS	National Institute of Neurological Disorders and Stroke
OD	NIH Office of the Director ¹⁶

For more information on the funding levels of these partnering ICs, please see Section 3.2.

The Fogarty PO identified two sponsors of the conference who did not join the Program: NCI and NSF.

2.2.2 Funding Mechanisms

For fiscal year 2003, the Stigma Program funding allocated approximately \$2.5 million for up to 12 grants. Applicants were able to apply for funding under two different activity codes:¹⁷

¹⁵ The Canadian Institutes of Health Research (CIHR)/Institute of Neurosciences, Mental Health and Addiction (INMHA) with the International Development Research Centre (IDRC) also sponsored the RFA and did fund one Canadian grant. This entity and award are not included in this process review.

¹⁶ Within OD, the Office of AIDS Research, Office of Behavioral and Social Science Research, and Office of Research on Women’s Health all separately sponsored the RFA.

¹⁷ For descriptions of a subset of NIH funding mechanisms, including the R01 and R21, please see Appendix D: Glossary of Key Terms. The Stigma RFA used standard language to differentiate between projects to be funded under the two activity codes: “Note that the R21 mechanism is specifically intended to support innovative ideas where preliminary data as evidence of feasibility are sparse or do not exist. R21 grants are not intended for large-scale undertakings or to support or supplement ongoing research. Rather, R21-supported projects are intended to serve as a basis for planning and strengthening future research project grant applications (R01).”

- R21 developmental/exploratory grants with a project period of up to three years and a total direct cost of up to \$100,000 per year; and
- R01 research project grants with a project period of up to five years and total direct costs of up to \$200,000 per year or up to \$500,000 per year for comparative or intervention studies involving an international team of researchers at two or more international sites.

A unique aspect of the Stigma Program was that R21 awards could be funded for up to three years with a total direct cost of up to \$100,000 per year (\$300,000 combined), as opposed to the normal length of an award under this funding mechanism of 2 years for up to \$137,500 in total direct costs per year (\$275,000 combined). The addition of the extra year for the R21 studies was made in appreciation of the difficulties in collecting exploratory data in cross-cultural or international settings using interdisciplinary, mixed-methods approaches. All R21 awardees interviewed reported that they found the extra year to be very valuable due to the particular challenges of the grants. Awardees claimed that this additional year allowed them to conduct mixed-methods research; make up for time lost due to complications in international collaboration; and develop instruments and/or interventions. As one awardee stated, “to set something up de novo at all the sites and do something meaningful would have been impossible [if constrained to 2 years].”

2.3 Program Niche

Determining the Stigma Program’s fit with other activities at Fogarty and the NIH as a whole, and to what degree the Program addresses a need that isn’t met by other funders, helps to inform the assessment and program planning as well as future strategies for the Program. Information was collected to understand stigma-related activity taking place across NIH, and the level of that activity focused in whole or in part on developing countries or immigrant populations. In addition, information was collected regarding the research community and available support for stigma research and related topics.

2.3.1 Other NIH Activities Related to Stigma Research

Stigma-Related Grants at NIH

NIH’s CRISP (Computer Retrieval of Information on Scientific Projects) database was queried to identify NIH stigma-related awards for activities that began between fiscal year 2001 and fiscal year 2008, including those not funded through the Stigma Program.

The CRISP database supplies abstracts of awards funded by NIH. In addition to the abstract, the database indexes each study by terms denoting disease area, methods, location, study populations, etc, and ranks the applied terms on three levels (i.e., Primary, Secondary, Tertiary). Of the 8000+ terms used to index the CRISP database, the term “stigma” is not included. An analysis of the CRISP terms assigned to the Stigma Program projects found that among the primary CRISP terms, “psychosocial separation” was the most frequent term used (18 out of 18 grants).¹⁸ Other frequent primary terms were “mental health” (5), “social psychology” (4), “culture” (5), “health care quality” (4), and “AIDS” (4). (A full list of the primary, secondary, and tertiary CRISP terms assigned to the Stigma Program projects can be found in Appendix E). Because a query limited to the CRISP terms would not result in any “stigma”-tagged abstracts, the query was based on the inclusion of the term “stigma” in the abstract of any new (e.g., multi-year awards were only identified once) NIH-funded activity (i.e., not restricted to FIC) from 2001 to August 2008.¹⁹

¹⁸ The term “psychosocial separation”, however, is not specific to stigma-related awards; a CRISP search on that term yielded 13,985 hits.

¹⁹ Abstracts were coded to filter out projects using the word “stigma” that were not applicable (e.g., those studying the stigma of plants). CDC awards present in CRISP were also filtered out. An alternate search by FIC using “stigma” in the title of awards identified 44 of these 181 projects -- as well as two additional awards (one F31 and one K01) not included in this analysis.

Based on this query, while the Stigma Program RFA was only released once and has only one cohort of 18 NIH-supported investigators, awards across NIH for stigma-related activities appear to have increased from 2001 to the present (Figure 1a, below). Information from this query also indicates the following:

- A small increase in awards in FY 2003, coinciding with the first year of the Stigma Program awards;
- After 2003, four Stigma Program PIs won awards in support of new stigma-related projects or activities (i.e., CRISP entries that included the term “stigma” in the abstract) not funded through the Stigma Program; and
- An average of 23 new stigma-related awards per year were made over the eight-year period, ranging from 12 new awards made in 2001 to 35 new awards in 2007.

Of the 181 awards identified by the query, more than half (96, or 53%) are administered by NIMH (Figure 1b). Fifteen other ICs administer one or more awards using “stigma” in the abstract, including 23 (13%) by NICHD and 18 (10%) by FIC (Figure 1b). For a complete list of awards identified through this search, please see Appendix F.

Figure 1: NIH-Funded Stigma-Related Activities by Fiscal Year

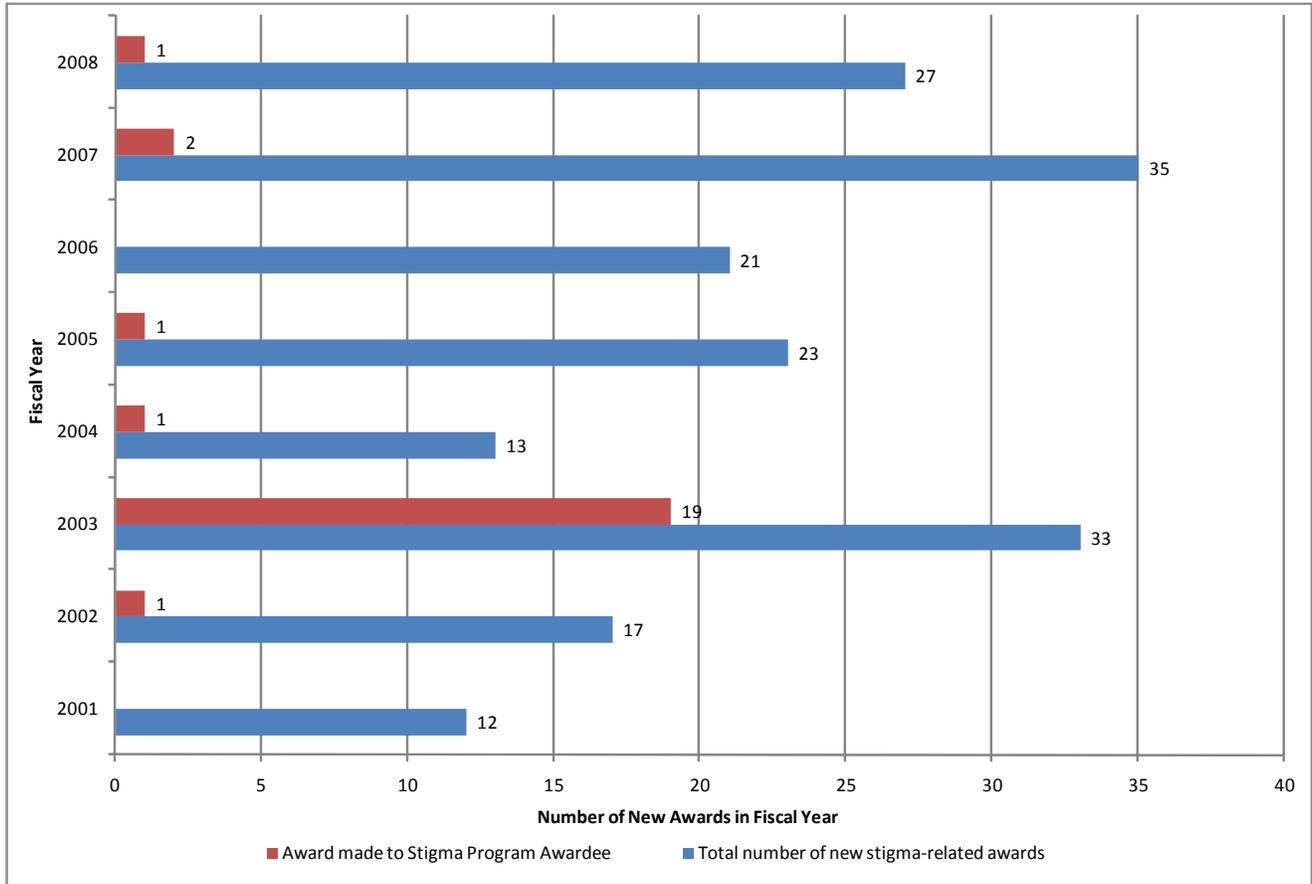
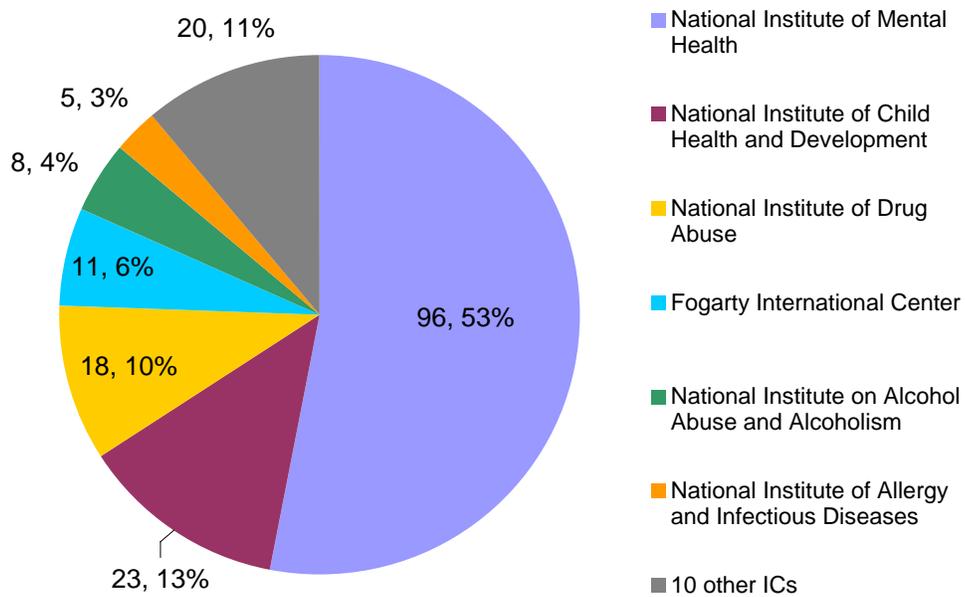


Figure 2: Distribution of New Stigma Related Awardees by IC, FY 2001-8 (181 New Awards)



International Stigma Activities Identified by the Query

The 181 awards returned by the query were further coded to identify whether the abstracts and CRISP Thesaurus terms indicated that the activity was to be conducted in or concerned with developing countries, or involved immigrant populations in the United States.

Sixty-three of the abstracts indicated that the activity would be international (35%), while 13 (7%) were to involve immigrant populations. Of the “international” awards:

- Sixteen (25%) were either Stigma Program awards or were made to Stigma Program awardees;
- Twenty-three awards (37%) were administered by NIMH; 11 by FIC; 10 by NICHD; and 19 by six other ICs (NCRR, NIAAA, NIAID, NIDA, NINR, and NINDS);
- Twenty-five (40%) aimed to research populations in Sub-Saharan Africa (10 in South Africa); eighteen (29%) applied to East Asian populations (10 in China); and thirteen to populations in Latin America and the Caribbean (5 in Puerto Rico). Four involved South Asia; two Europe and Central Asia; and one was a multi-region study; and
- While the conditions studied overlapped, 55 of the awards (87%) involved HIV/AIDS; seven awards (11%) involved mental health; four involved drug abuse; and three involved epilepsy (one each TB and Parkinson’s).

2.3.2 NIH Support for Other Topics Related to Stigma

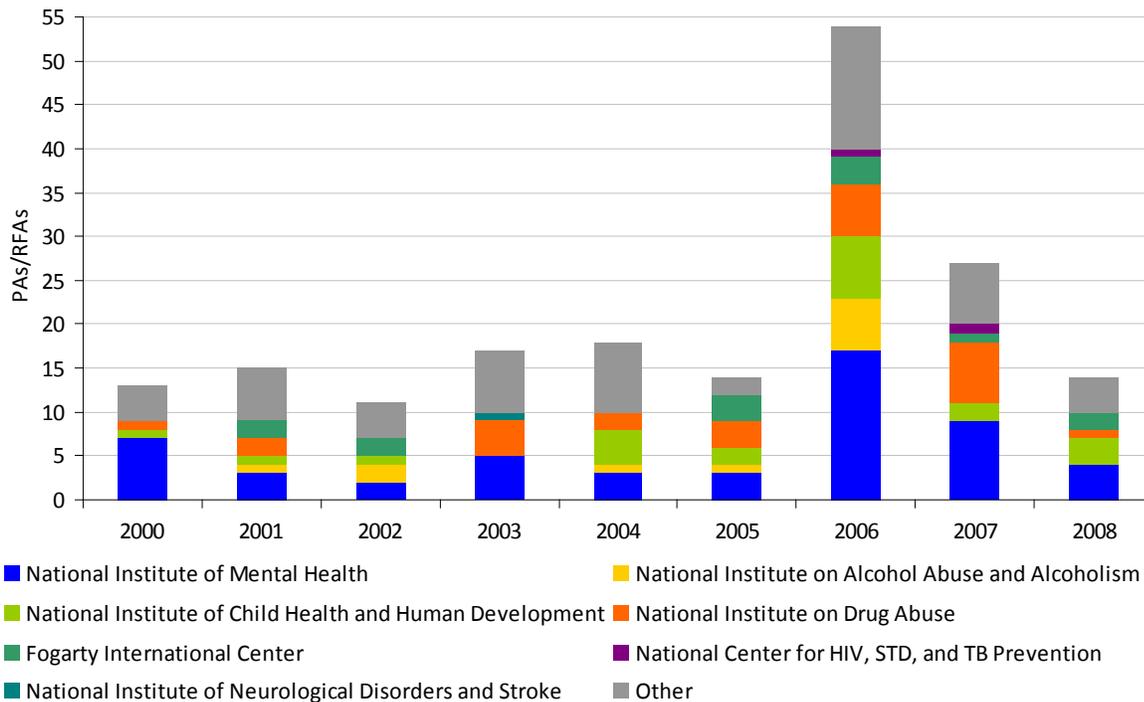
NIH Funding Opportunity Announcements

In addition to examining NIH funded projects, another way to consider the NIH portfolio of stigma-related activities is to assess NIH funding opportunities. Funding Opportunity Announcements, or FOAs, are released as either RFAs or PAs. FOAs were gathered from the website of the NIH Office of Extramural Research, which provides a search function for NIH-wide funding opportunities from 1992 to the present.²⁰ The Stigma Program RFA was one of the seven opportunities available in 2003. Three years later (2006), funding opportunities peaked at 54 with NIMH issuing the largest share. Figure 2 illustrates these funding opportunities by year, subdividing by issuing IC. Figure 3 shows the opportunities subdivided by NIH activity code. Most FOAs that cite “stigma” are for research awards – R01s, R21s, and R03s; the “multiple R-series” combination includes R01/R03; R01/R21; and R01/R03/R21 solicitations. As described in Appendix D, the R01 activity code is the most common funding mechanism and is used for “discrete, specified, [and] circumscribed” research projects. The R21 activity code is employed for research of an exploratory and developmental nature and requires no preliminary data. The R03 activity code (not used in the Stigma Program) supports smaller research projects lasting no more than two years.²¹

²⁰ NIH, Office of Extramural Research, Funding Opportunities and Announcements, <http://grants.nih.gov/grants/guide/index.html>. A similar search for “Stigma” only in the title of the RFAs and PAs identified three FOAs, the Stigma announcement and two from NIMH.

²¹ NIH, Office of Extramural Research, Types of Grant Programs, http://grants.nih.gov/grants/funding/funding_program.htm (accessed November 20, 2008). More information is also available in Appendix D: Glossary of Key Terms.

Figure 3: NIH and CDC Research Opportunities (RFAs and PAs) on Stigma-related Topics by IC, 2000-2008



Source: Search of OER RFA and PA databases using the keyword “stigma”

Description: Bar graph showing the number of NIH and CDC research opportunities (RFAs and PAs) on stigma-related topics, with one bar for each year 2000 through 2008: 2000 ~13 | 2001 ~15 | 2002 ~11 | 2003 ~16 | 2004 ~18 | 2005 ~14 | 2006 ~54 | 2007 ~27 | 2008 ~14.

Each bar showing different colors to show the breakdown by IC, including: National Institute of Mental Health (NIMH); National Institute of Child Health and Human Development (NICHD); Fogarty International Center (FIC); National Institute of Neurological Disorders and Stroke (NINDS); National Institute on Alcohol Abuse and Alcoholism (NIAAA); National Institute on Drug Abuse (NIDA); National Center for HIV, STD and TB Prevention (NCHSTP); Other.

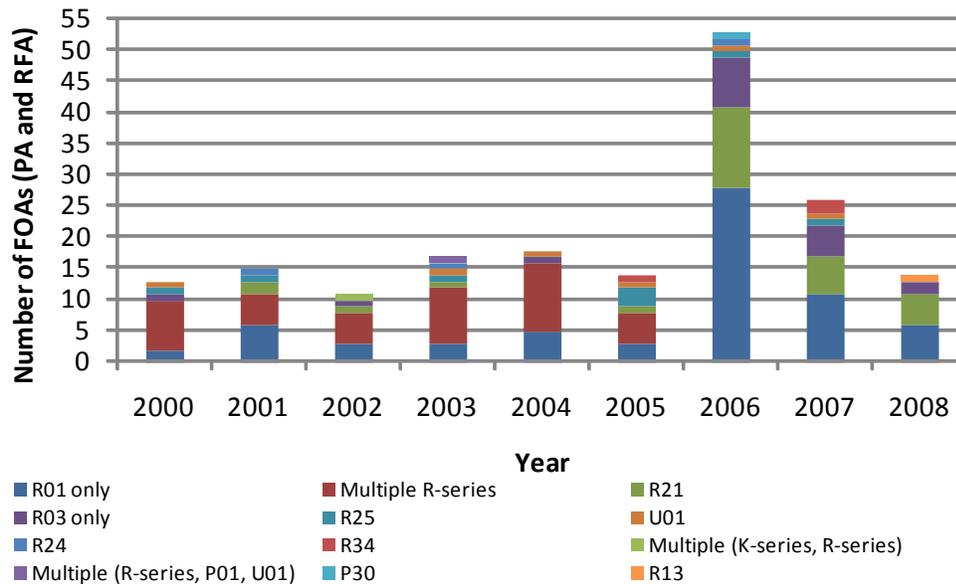
A search for NIH-wide funding opportunities using the keyword “stigma” likely understates the total magnitude of the effort devoted to stigma-related research. NIH also provides substantial funding to study health disparities, the most common topic that awardees cited as being closely related to their stigma research. Support for health disparities research at NIH take three forms:

- Career and loan repayment programs meant to attract and retain researchers in the area of health disparities research. For example, NCMHD offers loan-repayment support for health professionals conducting research on minority health and health disparities. Stigma is not included in descriptions of minority health research²² or health disparities research.²³

²² NCMHD defines **minority health research** as “basic, clinical, or behavioral research on minority health conditions, including research to prevent, diagnose, and treat such conditions.” **Minority health conditions** are described as “all diseases, disorders, and other conditions (including mental health and substance abuse) that are unique to, more serious, or more prevalent in racial and ethnic minorities, for which the medical risk factors or types of medical interventions may be different, or research involving such populations as subjects or data on such individuals is insufficient.” For more information please see NCMHD, “Extramural Loan Repayment Program for Health Disparities Research (LRP-HDR): Program Specific Information,” at <http://grants.nih.gov/grants/guide/notice-files/NOT-OD-08-086.html>.

²³ NCMHD defines **health disparities research** as “basic, clinical, or behavioral research on a health disparities population (including individual members and communities of such populations) including the causes of such health disparities and methods to prevent, diagnose and treat such disparities. For more information please see NCMHD, “Extramural Loan Repayment Program for Health Disparities Research (LRP-HDR): Program Specific Information,” at <http://grants.nih.gov/grants/guide/notice-files/NOT-OD-08-086.html>. The FIC search of “Stigma” by title identified six loan repayment awards with “Stigma” in the title not available via CRISP.

Figure 4: NIH Research Opportunities (RFAs and PAs) on Stigma-related Topics by Activity Code, 2000-2008



Description: Bar graph showing the number of NIH research opportunities (RFAs and PAs) on stigma-related topics by activity code, with one bar for each year 2000 through 2008: 2000 ~13 | 2001 ~15 | 2002 ~11 | 2003 ~16 | 2004 ~18 | 2005 ~14 | 2006 ~54 | 2007 ~27 | 2008 ~14.

Each bar shows different colors to indicate breakdown by activity code, including: R01 only, R03 only, R24, Multiple (R-series, P01, U01), Multiple R-series, R25, R34, P30, R21, U01, Multiple (K-series, R-series), R13.

Notes: The above information was gathered from the NIH Office of Extramural Research (OER). The OER database was searched for all active and inactive funding opportunities and notices (RFAs and PAs) from 1992 to the present containing the word (or word root) "stigma".

Explanation of codes: R01: Research Project; R21: Exploratory/Developmental Grants; K: Research Career Programs; R03: Small Research Grants; R34: Clinical Trial Planning Grant; R13: Conference; R25: Education Projects; P30: Center Core Grants; U01: Research Project Cooperative Agreements; "Multiple R-series" includes multiple of R01, R02, R21, and R25 activity codes.

- Projects related to service delivery to populations experiencing health disparities.²⁴ For example the NIH Office of Minority Health (OMH) administers several grant programs that do not support research projects (apart from demonstration grants), but instead fund service-oriented "science-based efforts to eliminate health disparities".²⁵
- R01 research grants. Several current opportunities exist for R01-level research grants related to health disparities. Unlike the Stigma Program, these research opportunities do not support the gathering of preliminary data and are predominantly focused on implementing interventions rather than supporting more basic research aimed at understanding the etiology of stigma.

NCMHD-supported programs did not appear in the CRISP search performed in Section 2.3.1; only one of the 181 awards identified by the query using the word "stigma" in the abstract were NCMHD administered. The number of awards that might be related to stigma made by NCMHD using this broader health disparities-based definition could not be quantified.

²⁴ Designation as a **health disparity population** is set by NCMHD and the Agency for Healthcare Research and Quality (AHRQ). NCMHD defines these populations as those "where there is significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality, or survival rates as compared to the health status of the general population." These populations are currently reported to be "Blacks/African Americans, Hispanics/Latinos, Native Americans, Alaska Natives, Asian Americans, Native Hawaiians, Pacific Islanders and the medically underserved, i.e., individuals from the Appalachian region." No mention was found regarding the immigration status or nationality of or within these populations. For more information please see NCMHD, "Extramural Loan Repayment Program for Health Disparities Research (LRP-HDR): Program Specific Information," at <http://grants.nih.gov/grants/guide/notice-files/NOT-OD-08-086.html>.

²⁵ <http://www.omhrc.gov/templates/browse.aspx?lvl=2&lvlID=1>

2.3.3 NIMH Activities Related to Stigma Research

Because NIMH has been an early and prominent supporter of stigma-related research at NIH, its stigma-related activities were assessed in greater detail. In 1999 NIMH established a Stigma Working Group (which preceded the trans-NIH group described in Section 2.1.1) comprised of outside experts who were asked to, “assist the Institute in developing a research agenda aimed at addressing the most pressing issues in changing mental illness stigma and discrimination.”²⁶ This working group suggested two areas of particular need: better understanding of stigma and discrimination reduction efforts and the role of media on knowledge, attitude, and behavior regarding mental illness. A 2004 NIMH program, “Reducing Mental Illness Stigma and Discrimination”, was created as a result of this working group. This program supported studies of effectiveness; pilot studies focused on developing measures for program outcomes; and studies of educational campaigns.²⁷ As described in Section 2.1.1, in 2001 FIC reported that it had established a separate trans-NIH working group focused on the topic of stigma in collaboration with NIMH, out of which the ideas to hold a conference on stigma and to develop a research program in stigma were formed.

In May 2006, NIMH’s Division of AIDS and Health and Behavior Research (DAHBR) sponsored a two-day meeting that convened scientists studying “prejudice, stereotyping, discrimination, stigma, and related areas.” The meeting was meant to aid NIMH in determining gaps in knowledge, new foci of support for translational research, and barriers to such research. This meeting was co-chaired by Bernice Pescosolido, a Stigma Program grantee.²⁸

Two Stigma Program PIs had received NIMH support prior to their receipt of a Stigma Program award for stigma-focused research. However, neither grant was made as part of a program explicitly targeting studies on the role of stigma in health:

- One awardee was granted an R03 awarded as part of NIMH’s Underrepresented Minority Dissertation Research Grants in Mental Health program supporting research “in any area relevant to mental health and/or mental disorders.”²⁹
- The other awardee received a P50 (Specialized Center) award for a research center focused on stigma and mental illness under the NIMH’s Translational Research Centers in Behavioral Science (TRCBS) Program. This program broadly supports “translation of work from basic behavioral science research, and relevant integrative neuroscience research, to pressing issues regarding all aspects of mental disorders.” Topical examples included in the announcement do include issues related to health disparities, but no mention of stigma is made.³⁰

2.3.4 Non-NIH Sources of Support for Stigma Research

As part of this review, external sources of support for research, meetings, and implementation in the area of stigma and health including from private, non-profit, and other federal sources were reviewed. Examples of prior external funding (before 2003) for stigma research reported by awardees include private support for dissertation research (McArthur Foundation); participation in a WHO-funded intervention related to a “stigmatizing” disease; intramural university funding for research related to health disparities; and stigma research as a sub-topic within a larger global health intervention project

²⁶ NIH, Reducing Mental Illness Stigma and Discrimination, Released June 18, 2004, PA Number PAR-04-112, <http://grants.nih.gov/grants/guide/pa-files/PAR-04-112.html>.

²⁷ NIH, Reducing Mental Illness Stigma and Discrimination, Released June 18, 2004, PA Number PAR-04-112, <http://grants.nih.gov/grants/guide/pa-files/PAR-04-112.html>.

²⁸ NIH, National Institute of Mental Health, *Scientific Meetings from 2006*, <http://www.nimh.nih.gov/research-funding/scientific-meetings/2006/index.shtml>.

²⁹ National Institutes of Health, Program Announcement: Underrepresented Minority Dissertation Research Grants in Mental Health PA number PAR-99-139 Release Date: August 6, 1999, Available at <http://grants.nih.gov/grants/guide/pa-files/PAR-99-139.html>, accessed Sept. 30, 2008.

³⁰ National Institutes of Health, Program Announcement: Translation Research Centers in Behavioral Science (TRCBS) PA number PAR-01-027 Release Date: December 5, 1999, Available at <http://grants.nih.gov/grants/guide/pa-files/PAR-01-027.html>, accessed Sept. 30, 2008.

(e.g., the PAHO, the Doris Duke Charitable Foundation, the Pfizer Foundation, and the Bristol-Myers-Squibb Foundation). At the federal level, SAMHSA announced in January 2008 that it would commit to providing funds under the State Mental Health Data Infrastructure Grants for Quality Improvement program to incorporate the Mental Health and Stigma Module, designed to provide a “prevalence estimation of serious psychological distress,” to the Behavioral Risk Factor Surveillance System (BRFSS).³¹ However, unlike the Stigma Program’s focus on elucidating the etiology of stigma in addition to developing and testing interventions, these other sources of funding predominantly target the implementation of previously-developed interventions as well as studies of health service delivery and infrastructure development.

With regard to available support for work in the field of health disparities, funding opportunities were identified from both federal and non-profit entities concerned with healthcare delivery and equity. However, as with other programs supporting this type of work, funding is primarily focused on development and deployment of interventions and the career development of researchers in the field. Examples of such programs include:

- The Agency for Research Quality (AHRQ) supports research on interventions for improving the quality of healthcare services for low-income populations.³²
- Promoting Psychological Research and Training on Health Disparities Issues at Ethnic Minority Serving Institutions Grants (ProDIGs), a small grants program administered by the American Psychological Association’s (APA) Public Interest Directorate’s Office of Ethnic Minority Affairs (OEMA) and in collaboration with the APA Minority Fellowship Program.³³

2.3.5 Stigma Program Awardees’ Perceptions of the Program’s Niche

During interviews, awardees were asked to describe any prior (before 2003) experiences in stigma-related research, sources of such support, and whether these efforts were focused explicitly on stigma or were stigma-related. A small number of awardees did characterize their prior research as explicitly stigma-focused, but none had received previous support from a program that focused exclusively on stigma. Instead, their funding was to support dissertation research or the translation of findings from behavioral science research into applied work with the mentally ill.

Many awardees who did not define their prior research topics as stigma-focused did report receiving prior NIH awards focused on what they considered to be related topics, such as health disparities (most common); HIV/AIDS risk behavior reduction; patient-oriented research; and adherence to antiretroviral and antibiotic treatment regimes for HIV/AIDS and Tuberculosis, respectively. Many of these awardees reported that the negative impacts of stigma frequently came up in their research, which lead them to include stigma a secondary focus or sub-topic in their research programs.

Awardees (both R01 and R21, as well as for both self-identified early- and later-career awardees) were unanimous in reporting that the Stigma Program is unique in its combination of an exclusive focus on the role of stigma globally and its impact on health and healthcare in a wide range of disease areas. Several awardees reported that NIH opportunities for research in stigma (in the form of RFAs and PAs) have increased since the initiation of the Stigma Program, which is consistent with the findings reported in Section 2.3.3 above.

³¹ DHHS, Substance Abuse & Mental Health Services Administration, Grant Announcement. “Application Information Center for Mental Health Services (CMHS),” http://www.samhsa.gov/Grants/2008/sm_08_013.aspx.

³² National Cancer Institute, Center to Reduce Cancer Health Disparities, “Research Funding Opportunities,” <http://crchd.cancer.gov/students/opportunities.html>.

³³ American Psychological Association, “Request for Proposals: Promoting Psychological Research and Training on Health Disparities Issues at Ethnic Minority Serving Institutions,” http://www.apa.org/pi/oema/2008%20prodigs_RFP.pdf.

2.4 Alternate Mechanisms & Models

2.4.1. Issuance of the FOA as an RFA versus a PA

Applications for the Stigma Program have been solicited via an RFA. Under an RFA, programs have a single receipt date for a well-defined subject area, as opposed to a PA, which allows for submission of proposals on a regular basis (e.g., three submission dates and review cycles per year), usually for three years. Several grantees indicated a desire to see the next funding opportunity under the Stigma Program be released as a PA rather than an RFA, a change that would allow for greater flexibility in proposal acceptance dates and more time to develop collaborative and/or international proposals. It should be noted, however, that such a change would also affect how funds are committed to the Program, possibly making it more difficult for meritorious proposals to receive funding when they are identified. This is because under the PA structure, program funding has not been designated in advance to support proposals recommended for support.

2.4.2 Leadership Role Played by FIC within NIH Regarding Stigma Research

Several POs recommended that FIC should promote research on stigma by leading another trans-NIH Working Group on the topic. The NIH Office of Behavioral and Social Science Research (OBSSR) was also suggested as an alternative convening entity, as they are “empowered to participate at more creative level on science that affects all of our institutions.” These POs indicated that such a working group could play a coordinating role for stigma research supported by different ICs, but would allow each IC to focus its stigma research agenda most effectively.

2.5 Section-Level Findings and Recommendations

- The Panel recommended that the Stigma and Program FOA continue to operate under the RFA mechanism. The Panel recognized the coordination and needed to produce a competitive application to the Stigma Program RFA. However, the need for more work in the field of stigma research and the desire for establishing dedicated funding for this work outweigh the benefits posed by a change to the PA mode of FOA.
- The Panel recommended that Fogarty continue to offer funding for the Stigma Program under both the R21 (developmental/exploratory grants) and R01 (research project grants). 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 in initiating research in the field of stigma and global health.
- The Panel recommended that the next solicitation for the Stigma Program narrow the goals and objectives of the program to more specific outcomes such as more focus on the development of interventions, researching the role of stigma at the community level, and elucidating 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 Panel suggested structuring the program such that the R21 mechanism supports research on the design of implementations, determining the most effective level (i.e., individual, community, organizational) for the intervention, or pilot test of interventions. The R01 could, in turn, support research on larger scale implementation of interventions.

Section 3: Program-Level Management and Partnerships

3.1 Program Management

3.1.1 Review Process

In response to the RFA, over 100 individuals submitted applications for funding. Due to the large number of applications and the wide range of topics and disciplines, a large review committee was assembled to discuss the grants over a two-day period. A few grantees interviewed expressed that they had initial concerns about a match between that their disciplinary or disease focus and the disciplines and expertise represented on the review committee. In addition, a few awardees were concerned that the international component of their studies and “the vagaries of [a foreign] system” would not be appreciated or accounted for by review committee members.

In contrast, several grantees also indicated that the comments they received from the Review Committee were helpful, “stigma-specific,” and ultimately beneficial to their study design. Examples of such impact were described abstractly in terms of helping the awardee to better “conceptualize” or “focus on” stigma. Other awardees reported more concrete impact on their study designs, most commonly scaling back sampling from one study group or adding an additional population to improve the validity of the study.

From the perspective of the partnering ICs’ POs interviewed who could recall the grant review process, interviewees stated that the review committee sessions went smoothly and any concerns they had regarding matches between application topics/foci and committee composition were allayed. Interviewees related that one downside of the review was that it was difficult to review multi-disciplinary grants. This was attributed to a preference against multi-disciplinary projects in NIH’s standard review processes, despite the fact that multi-disciplinary projects were what the RFA had solicited.

3.2 IC Program Partnerships

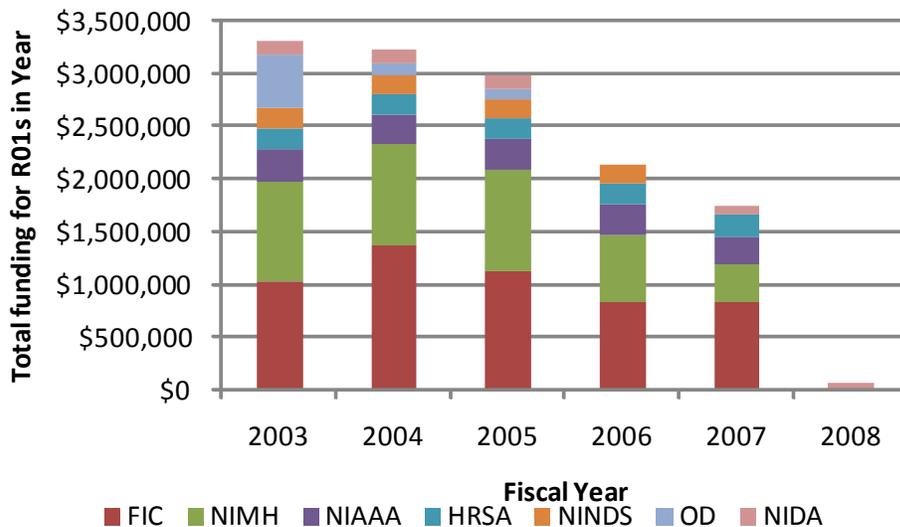
3.2.1 Funding by IC Program Partner

Five ICs (FIC, NIAAA, NIDA, NIMH, and NINDS), as well as OD and HRSA, contributed funds for awarded Stigma Program projects; the 18 awards were funded for \$17 million (Table 1 and Figure 4 below). FIC made the largest contribution to the total Program funding at \$5.9 million (\$5.3 million for R01 projects; \$0.7 R21s), or 35% of total funding.

Among the other Program partners NIMH and NIAAA followed FIC in support of R01 grants (\$3.8 million and \$1.4 million, respectively).

NIDA and NIMH provided the most support for R21s (\$1.0 million and \$0.9 million, respectively).

Figure 5: R01 Award Funding by IC, by Fiscal Year



Description: Bar graph showing the total funding for R01s in a year, by fiscal year 2003-2008. 2003 ~\$3,250,000 | 2004 ~\$3,200,000 | 2005 ~ \$3,000,000 | 2006 ~\$2,200,000 | 2007 ~\$1,750,000 | 2008 ~\$100,000.

Each bar uses different colors to show the breakdown by IC, including: Fogarty International Center (FIC); National Institute of Mental Health (NIMH); Institute on Alcohol Abuse and Alcoholism (NIAAA); Health Resources and Services Administration (HRSA); National Institute of Neurological Disorders and Stroke (NINDS); Office of Director (OD); National Institute on Drug Abuse (NIDA).

3.2.2 Program Funding by Award

2006 saw a drop off in funding by both NIMH and FIC due to the end of three R01 projects (Table 1 and Figure 4).

In the case of NIDA the drop-off was also due in part to a pause in an awardee’s research due to the death of the project’s co-PI and a change in institutional affiliation. This R01 project funding restarted the following year. Table 2 shows detail for funding levels by awardee and substantial variability in the funding of several of the R01 awards, such as PI B (where funding was delayed for a year after award year three) and PI F (whose funding declined sharply in award year three). There is greater variability in the funding of the R01 awards.

Funding levels for the R21 grants remained stable over the three-year time span of these projects.

Table 1: Funding by IC, by Fiscal Year

R01

Funding IC	FY 2003	FY 2004	FY 2005	FY 2006	FY 2007	FY 2008	Total
Health Resources and Services Administration	200,000	200,000	200,000	200,000	200,000		\$1,000,000
National Institute on Alcohol Abuse and Alcoholism	310,650	281,186	286,787	281,686	274,870		1,435,179
National Institute on Drug Abuse	129,355	127,537	128,376		87,942	85,527	558,737
National Institute of Mental Health	930,823	949,540	958,536	638,485	352,637		3,830,021
National Institute of Neurological Disorders and Stroke	191,781	179,635	177,175	176,615			725,206
Office of the Director	514,000	104,000	104,000				722,000
Fogarty International Center	1,048,432	1,389,818	1,139,713	848,629	844,872		5,271,464
R01 Total:	3,325,041	3,231,716	2,994,587	2,145,415	1,760,321	85,527	13,542,607

R21

Funding IC	FY 2003	FY 2004	FY 2005	FY 2006	FY 2007	FY 2008	Total
National Institute on Alcohol Abuse and Alcoholism	99,955	101,500	101,500				302,955
National Institute on Drug Abuse	342,500	342,500	342,500				1,027,500
National Institute of Mental Health	270,440	270,440	320,440				861,320
National Institute of Neurological Disorders and Stroke	110,471	102,719	97,357				310,547
Office of the Director	190,000	100,000	50,000				340,000
Fogarty International Center	170,587	255,126	241,592				667,305
R21 Total:	1,183,953	1,172,285	1,153,389				3,509,627

Totals	FY 2003	FY 2004	FY 2005	FY 2006	FY 2007	FY 2008	Total
R01 Total	3,325,041	3,231,716	2,994,587	2,145,415	1,760,321	85,527	13,542,607
R21 Total	1,183,953	1,172,285	1,153,389				3,509,627
Grand Total	4,508,994	4,404,001	4,147,976	2,145,415	1,760,321	85,527	17,052,234

Table 2: Stigma Program Funding by Awardee, by Fiscal Year

R01

PI	FY 2003	FY 2004	FY 2005	FY 2006	FY 2007	FY 2008	Total
PI A	440,650	411,186	416,787	408,631	398,134		2,075,388
PI B	129,355	127,537	128,376		87,942	85,527	558,737
PI C	255,448	232,290	241,286				729,024
PI D	260,375	247,250	247,250				754,875
PI E	191,781	179,635	177,175	176,615			725,206
PI F	299,607	300,000	90,000	257,885			947,492
PI G	259,000	301,250	165,448				725,698
PI H	710,904	610,000	814,000	595,665	578,391		3,308,960
PI I	777,921	822,568	714,265	706,619	695,854		3,717,227
R01 Total	3,325,041	3,231,716	2,994,587	2,145,415	1,760,321	85,527	13,542,607

R21

PI	FY 2003	FY 2004	FY 2005	FY 2006	FY 2007	FY 2008	Total
PI J	149,955	151,500	151,500				452,955
PI K	147,500	147,500	147,500				442,500
PI L	145,000	145,000	145,000				435,000
PI M	124,440	124,440	124,440				373,320
PI N	161,000	161,000	161,000				483,000
PI O	120,471	112,719	107,357				340,547
PI P	81,000	81,000	81,000				243,000
PI Q	134,125	137,750	122,750				394,625
PI R	120,462	111,376	112,842				344,680
R21 Total	1,183,953	1,172,285	1,153,389				3,509,627

Totals	FY 2003	FY 2004	FY 2005	FY 2006	FY 2007	FY 2008	Total
R01 Total	3,325,041	3,231,716	2,994,587	2,145,415	1,760,321	85,527	13,542,607
R21 Total	1,183,953	1,172,285	1,153,389				3,509,627
Grand Total	4,508,994	4,404,001	4,147,976	2,145,415	1,760,321	85,527	17,052,234

3.2.3 Program Officers' Perceptions of the Management of Stigma Program Awards

The FIC and NIMH POs interviewed reported that stigma-related research was a specific responsibility and partial focus of the research portfolio which they oversaw. For the other ICs, management of stigma-related grants was included in various portfolios rather than being managed under a single portfolio. A couple of POs also indicated that their ICs viewed stigma as an important topic and supported its research, but indicated that their IC was more interested in funding applied and translational research in their IC's area of focus. Applied and translational research was described as having a "bigger payoff" in terms of more direct and identifiable impacts on health.

3.3 The Network Meeting

FIC organized the Stigma and Global Health Network Meeting in 2006 (network meetings are held routinely for all FIC programs). The meeting was intended to bring together PIs and representatives from all of the Stigma Program awards. In addition to the PIs, five collaborators from outside the United States attended the meeting; other attendees included program partners, other NIH and DHHS staff, and representatives of foreign health institutions, and other key stakeholders.

During this meeting, research progress was shared and participants discussed successes and challenges in stigma research and intervention development. The meeting also fostered networking opportunities among the grantees and the identification of commonalities in topics or methods. The meeting included presentations by representatives from all but one project and was organized by disease/health area. In addition, "breakout" groups were organized on a geographical basis (the Americas, Africa, and Asia) to suggest possibilities for future research in those regions.³⁴

Throughout the Network Meeting, researchers reported similar challenges at the 3rd year of their studies:

- Adapting instruments and measures for diverse settings;
- Navigating human subjects and other clearances;
- Recruiting and retaining study participants;
- Communicating key concepts to participants, working with institutional hierarchy;
- Maintaining communication with distant collaborators, revising research in response to cuts in funding or variable exchange rates, and
- Confronting the stigma-by-association of studying a stigmatized people.

While all of these concerns influence the outputs of the projects and programs as a whole, the Network Meeting was likely too early to capture later concerns expressed by awardees regarding difficulties in publishing their research due to their mixed methods approach, lack of a disciplinary "home" for their research", and length needed to adequately communicate their data. These issues are discussed in more detail in Section 5.2.2.

Most grantees described the Network Meeting as well-organized and a good forum for sharing ideas and discussing common problems. Reflections on networking opportunities were mixed; more established researchers in the area of stigma were in general happy with the networking that took place at the meeting, while a few of those newer to conducting research on stigma felt that they would have benefited from a chance to meet and discuss research experiences with some of the more experienced researchers among them. Others sought out these kinds of interactions with other Stigma Program grantees and did continue

³⁴ This section draws upon National Institutes of Health, Fogarty International Center, Office of Behavioral and Social Sciences Research, Summary Report; Stigma and Global Health Network Meeting: Summary Report, April 24-26, 2006, page 1.

communicating with them after the meeting. Similarly, POs who attended the Network Meeting expressed a unanimously positive impression of the meeting.

Two Network Meetings were planned for in the original RFA and applicants were requested to budget for travel to both. The second network meeting never took place, and many of the grantees hope to have the chance to attend another meeting before the end of their funding.

3.4 Section-Level Findings and Recommendations

- The Panel recommended a more tailored selection of reviewers for the application review panel. The next review panel should focus on developing a better match with the suggested revision of program goals. The inclusion of qualitative researchers was encouraged to continue. In addition, the inclusion of reviewers with backgrounds or experience in implementation work in international contexts is encouraged.
- The Panel strongly encouraged Fogarty to establish a partnering relationship with NIAID in the Stigma Program.
- Noting the value exhibited by the Stigma and Global Health Network Meeting in 2006, the Panel recommended that Fogarty convene a meeting to discuss stigma along with key aspects of implementation science. The Panel suggested that Fogarty include other NIH institutes such as NIMH, NCMHD, NIDA, and NIGMS as partners in the meeting. In addition, the Panel encourages the inclusion of other federal entities such as the CDC and SAMHSA.
- The Panel recommended publishing the presentations made at the proposed second network meeting. Suggested venues for such a publication are as a special issue in a relevant journal.
- The Panel recommended that Fogarty 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.

Section 4: Award-Level Management and Partnerships

4.1 Award-Level Management

4.1.1 Project Delays

Administrative/Bureaucratic Delays

Some awardees reported bureaucratic and administrative challenges that resulted in project delays. International projects faced administrative and bureaucratic delays most commonly on the side of the foreign site. A few of these delays were the result of clearances and processing required by the U.S. Department of State and its foreign equivalent and/or the foreign site's national-level biomedical research governing bodies (e.g., the Indian Council for Medical Research, the IRB of the Thai Ministry of Public Health). These types of delays were described by awardees as anticipated, unavoidable, and unpredictable in length (18 months in one case). In the case of the delay due to a required State Department clearance, the FIC Project Officer was described as "very accessible" and helpful in "smooth[ing] out the process" and working with a contact at the State Department to help further expedite the process.

In other cases, it was the establishment of financial agreements and required administrative procedures between institutions that resulted in project delays. For one award, a language barrier required a large amount of administrative work and assistance from the awardee, despite there being a well-developed research infrastructure at the foreign site. Delays resulting from a lack of research infrastructure at the foreign site did present an opportunity for institutional capacity building, particularly in terms of building the institution's grants administration capabilities. The issue of institutional capacity building is discussed at greater length in Section 5.5.)

Financial Issues

Decreases in funding also led to project delays. Some decreases were a result of the declining value of the dollar, requiring an entire re-budgeting of one project, including the addition of supplementary funds from the awardee's home institution. Another project (R01) lost almost a third of its funding in its third year due to a funding gap caused by an administrative misunderstanding ("glitch") with a funding IC. In that case, the decrease in funds also led to a scaling back of the study from four to three subpopulations. Another awardee reported a three month delay and scaling back of the grant 75% due to a change in funding ICs at the beginning of the project period.

4.2 Award-Level Partnerships & Collaborations

The potential for collaborations between awardees as a means to disseminate knowledge and lessons learned was one theme that emerged from the Network Meeting. These types of collaborations were recognized by awardees as an opportunity to learn from each other and avoid or solve common research challenges and "[overcome] barriers in instrumentation, design, pilot testing, and Institutional Review Board (IRB) process."³⁵

Several grantees did indicate that they were planning future collaborations with other Stigma Program awardees or their project partners whom they had met for the first time at the Network Meeting. A few reported meeting other awardees while participating in other funded studies, particularly activities funded by the Doris Duke Foundation. While many awardees indicated that they knew of other awardees prior to the Network Meeting, all saw the meeting as a valuable venue to enhance these connections, particularly as the

³⁵ Ibid, page 7.

field of stigma research grows. As one awardee stated, “There is a growing body of stigma research, frequent[ly] separated by disease frontiers. We wouldn't know one another otherwise.”

4.3 Stakeholder Involvement & Cultural Competence

4.3.1 Importance of Stakeholder & Community Engagement with Research



Issues related to the involvement of stakeholders such as healthcare providers and community members in research were also discussed at the Network Meeting. There was consensus among the grantees that stakeholder involvement in research and intervention development was important for ensuring support for the research and sustainability of any interventions, and ensuring cultural competency. However, grantees were reported to differ on “the responsibility of researchers to incorporate and translate research for application and broader communities or to involve non-researchers.” An NIH PO (not recorded who) did stress to the attendees the importance of involving the community in the research and testing of potential interventions and indicated NIH’s increased emphasis on research going beyond being reported in academic journals to impacting the community and policy.³⁶

4.3.2 Modes of Communication with the Community and Stakeholders

Several awardees discussed the impact that an early meeting between collaborators and stakeholders had a successful start or “kick-off” to their project. These grantees remarked on the importance of a face-to-face meeting with project collaborators early in the life of

the project to discuss and disseminate research with each other and community members as well as discuss the operational details of the project (e.g., rotation of authorship, ownership of data). These early meetings were unanimously viewed as a crucial element to project success and sustainability because they encouraged the different team members to begin speaking a “common language” and enhanced trust in each other and the study methodology through discourse on study plans and instruments.

Some grantees also discussed the success of convening a “dissemination meeting”, where presentations of either data collected prior to the start of an R01 award or of findings/results at the completion of the Stigma Program project (for both R21s and R01s), in engaging the community and stakeholders. These meetings were frequently held at the site of the collection activities (e.g., clinics or hospitals), and were deemed successful in collecting ideas for next steps and improving the cultural validity of the research, and increasing a sense of “ownership” for the local site.

³⁶ Ibid, page 5.

4.3.3 Awardee Experiences

Some awardees reported successes in disseminating the results of their Stigma Program projects – successes that they attributed to communication skills and knowledge gained earlier in their career. In one case, the awardee’s previous career had been in public relations, and she was able to transfer those skills to the communication of her findings to a wide variety of audiences (e.g., communities, policy makers, government agencies). In another case, the awardee had been a recipient of a grant from the McArthur Foundation and received training from a media consultant as part of that grant’s resource package. The media consultant came to the awardee’s research center and helped the staff establish models for data dissemination to a variety of audiences. These models are still being used to disseminate research results from various research projects including those from the Stigma Program project. Neither awardee recalled discussing these prior experiences with their PO or with other awardees during the Network Meeting.

On a similar note, a few researchers who were new to the subject of stigma or are in an early-career phase indicated frustration with not knowing how to communicate their data. The Network Meeting was described as a useful “forcing function” to organize and communicate data, but these researchers were otherwise challenged in identifying different audiences for their findings. Challenges related more specifically to the issue of “communicating stigma” were also raised by these grantees and are detailed in Section 5.2.4.

4.4 Section-Level Findings and Recommendations

- 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.

Section 5: Program Results

Section 5 describes the results to date of the research conducted under the Stigma Program RFA. Although the funding for all 18 awards had been provided to PIs by the end of fiscal year 2008, investigators interviewed related that only five of the 18 projects were completed by the end of 2008 (and one scheduled for completion in 2009); others had received no-cost extensions to continue research or research had concluded, but data analysis and preparation of manuscripts for publication was continuing. The identification of near-term outputs, therefore, is preliminary, but still of use in a process review in assessing progress and identifying potential problems or issues. A review of publications is included in this section. In addition, near-term outputs with relevance to Program goals and objectives are included, such as:

- The variety of scientific disciplines represented within and across the funded projects
- Efforts to elucidate the etiology of stigma and its role in health and disease
- The development and testing of interventions to mitigate the detrimental role of stigma on health outcomes
- The examination of stigma and health in domestic, international, and cross-cultural contexts
- The involvement of researchers from a range of biomedical and non-biomedical fields

5.1 Descriptive Information for AwardUs

5.1.1 Award Types

NIH awarded a total of 18 grants as part of the Stigma Program.³⁷ Half (nine) of these awards were funded using the R01 Research Project Grant mechanism; only one of these nine awards supported a domestic (study populations and collaborators US-only) study and the remaining eight awards supported international projects. The remaining nine awards were funded using the R21 Exploratory/Developmental Research Grant activity code. Five of these R21s supported domestic projects and the remaining four awards supported international projects (projects with one or more collaborating institutions outside the U.S.). A list of the 12 international Stigma Program awards by awardee, funding mechanism and project title can be found in Table 3, below. Table 4 presents the same information for the six domestic or US-focused studies. More information on the awardees' fields of research, the disease topics covered by the Program, and the geographic locations of the grants can be found in the following sections.

³⁷ For a complete list of the Stigma and Global Health Program awards by PI, funding mechanism, discipline, location, and disease focus, please see Appendix H: STPI Coding of Stigma Awards by Discipline and Disease Focus.

Table 3: International Stigma Program Research Projects (R01s and R21s)

PI	R01/R21	Project Title
Birbeck, Gretchen	R21	"Epilepsy-associated Stigma in Zambia"
Coreil, Jeannine	R01	"Stigma and Tuberculosis in Haitian Populations"
Corrigan, Patrick	R01	"Stigma and Behavioral Health in Urban Employers from China and US"
Eckstrand, Maria	R01	"AIDS Stigma and Gender: Health Consequences in Urban India"
Holzemer, William	R01	"Perceived AIDS Stigma: A Multinational African Study"
Li, Li	R01	"HIV Related Stigma among Service Providers in China"
Li, Xiaoming	R21	"Social Stigma/Mental Health Symptoms in Urban Workers"
Pescosolido, Bernice	R01	"Stigma and Mental Illness in Cross-National Perspective"
Saewyc, Elizabeth	R01	"Enacted Stigma, Gender and Risk Behaviors of School Youth"
Solomon, Suniti	R21	"Stigma in Health Care Settings in South India"
Tickle-Degnen, Linda	R01	"Culture, Gender, and Health Care Stigma in Parkinsonism"
Van Rie, Annelies	R21	"Social Stigma of the New TB"

Table 4: Domestic Stigma Program Awards

PI	R01/R21	Project Title
Alvidrez, Jennifer	R21	"Stigma Psychoeducation for Black Mental Health Clients"
Dohan, Daniel	R21	"Poverty, Substance Use, and Stigma in Four Organizations"
Ellis, Beverly	R21	"Stigma and PTSD in Refugee Adolescents"
Kohlenberg, Barbara	R21	"Reducing Felt Stigma in Substance Use Disorders (SUC)"
Miranda, Martha	R01	"Clinical Implications of Depression- Based Stigma"
Varas-Diaz, Nelson	R21	"AIDS stigma and health professionals in Puerto Rico"

Table 5: Fields of Stigma Program Awardees, by Activity Code

Field	N	Activity Code	
		R21	R01
Psychology	9	5	4
<i>Clinical</i>	6	3	3
<i>Social</i>	2	1	1
<i>Educational</i>	1	1	
Sociology	3	2	1
Medical Statistics	1	1	
Epidemiology	1	1	
Community Health Systems	1		1
Anthropology	1		1
Occupational Therapy	1		1
Nursing Science	1		1
Neurology	1	1	
Totals: 9 fields	17	8	9

Note: Field of research could not be characterized for one R21 awardee. One award was coded as both "Social Psychology" and "Occupational Therapy" and another as "Epidemiology" and "Medical Statistics"

5.1.2 Award Characteristics

The first research objective of the Stigma Program was "to encourage research across a variety of scientific disciplines including the biomedical, social and behavioral Sciences."³⁸ To better understand the

³⁸ NIH, Request For Applications, "Stigma and Global Health Research Program," June 20, 2002, NIH RFA # TW-03-001, <http://grants.nih.gov/grants/guide/rfa-files/RFA-TW-03-001.html>.

breadth of the Stigma and Global Health awards, the breadth of academic disciplines of the Program awardees, project research methods, disease foci, and geographic locations are detailed below.

Academic Disciplines of Stigma Program Awardees

For the purposes of this review, PI disciplines were determined by subject of highest degree and in one case departmental affiliation (for an awardee whose PhD had been awarded 20+ years prior). The disciplines represented by the Stigma Program awardees covered nine fields of research, representing the biomedical, social, and behavioral sciences (Table 5). Overall, the awardees represent nine fields of research, largely from the fields of Psychology (N=7), inclusive of Clinical, Social, and Educational Psychology. Sociologists were the next most represented field (N=3). For information on the fields of research organized by award, see Appendix H. More information on the fields of awardees' collaborators and key personnel can be found in Section 5.1.3 below.

Research Methods

During the awardee presentations that took place at the Network Meeting, almost all of the grantees reported using a mixed-methods approach in their research. The methods used fell into three main categories (from most to least common):³⁹

- A three-phase model consisting of an initial qualitative phase, followed by a quantitative phase, and concluding with an intervention development phase. In this approach, each phase builds upon the previous one.
- A parallel approach where several data collection efforts (e.g., focus groups, surveys, ethnographic studies) occurred concurrently without directly informing each other.
- A comparative ethnography approach based on a longitudinal design involving a variety of different methods including participant observations, quantitative interviews testing instruments, etc. Qualitative and quantitative portions of the project were used synergistically to inform and contextualize during the development or implementation of interventions.

³⁹ This section draws upon National Institutes of Health, Fogarty International Center, Office of Behavioral and Social Sciences Research, Summary Report; Stigma and Global Health Network Meeting: Summary Report, April 24-26, 2006, pages 3-4. As described on page 4, qualitative methods used included key informant interviews, focus groups, comparative ethnography, participant observation, memos and papers, and regular meetings. Quantitative methods included analyses of written questionnaires/surveys; formal and informal assessments; randomized tests of instruments; and oral quantitative interviews.

Table 6: Disease Foci of Projects, by Activity Code

Field	N	Activity Code R21	Activity Code R01
Mental Health	7	3	4
HIV/AIDS	6	2	4
Substance Abuse	3	2	1
Tuberculosis	2	1	1
Epilepsy	1	1	
Parkinson’s Disease	1		1
Totals:	20	9	11

Note: One Stigma Program award coded as three topics (Mental health, HIV/AIDS, Substance Abuse). All others coded as single topic

Disease Foci of Projects

Stigma Program awardees addressed a total of 20 different diseases (or disorders) in the 18 funded projects.⁴⁰ The 20 study topics represented six general disease foci (Table 6, below). The most common disease foci for the Stigma Program awardees was Mental Health (n=7), followed by HIV/AIDS (n=6) and substance abuse (n=3). There were eight instances of studies focused on infectious diseases (HIV/AIDS and Tuberculosis). The domestic studies are predominantly focused on substance abuse and mental health topics, apart from the

Puerto Rican study on HIV/AIDS. No funding from the Stigma Program was used to support research on AIDS-related stigma in the United States.

Project Locations

Stigma Program awards took place in 10 world regions covering North America, Europe, Asia, Africa, Latin American and the Caribbean, and Oceania/Australia (Table 7). The US was the most common site for Stigma Program research (including both domestic grants as well as international grants with US study populations). Asia followed, being chosen as a site for eight Stigma Program studies. Two studies took place in whole or in part in Africa, Latin America and the Caribbean and in Oceania/Australia. Canadian and European sites were included in a single, multi-region study each. The trends in distribution of studies across locations, with the US being the most frequent site followed by Asia and Africa, largely held true for both the R21 and R01 grants.

Table 7: Location of Study Sites, by Activity Code

Field	N	Activity Code R21	Activity Code R01
US	10	5	5
Asia	8	3	5
East Asia	5	1	4
South Asia	1	1	
Southeast Asia	2	1	1
Africa	2	1	1
East Africa	2	1	1
Southern Africa	1		1
Latin America/Caribbean	2		2
Oceania/Australia	2		2
Canada	1		1
Europe	1		1
Total (5 R01 studies were in multiple regions)	26	9	17

5.1.3 Key Personnel

The 18 Stigma Program projects involved 126 key personnel (including collaborators) from 17 countries and eight world regions over the course of the Program (Table 8). Key Personnel are listed in the awardee’s application and progress reports and include collaborating researchers as well as other research staff members (e.g., technicians and research assistants). Key personnel on grants ranged from two to 16 individuals, with an average of approximately eight for each study. Almost half of these individuals were listed as “Site PI,” “Co-PI,” or “Co-Investigator” in the grantee applications and progress reports. For domestic grants, the average number of key personnel was approximately seven (two to

12) and involved two organizations (one to eight). As noted above, only one of the domestic grants was an R01, with a team size of nine at three different institutions.

⁴⁰ For more detail on the disease focus of stigma grants by discipline, disease focus, and activity code, please see Appendix H.

Table 8: Key Personnel Tallies, by Stigma Program PI

PI	N	Activity Code	Scope (Intl/Domestic)	US Personnel	Foreign Personnel
PI C	9	R01	D	9	
PI J	4	R21	D	4	
PI K	12	R21	D	12	
PI L	5	R21	D	5	
PI M	2	R21	D	2	
PI N	6	R21	D	6	
Total, Domestic Awards:	38	1 R01 / 5 R21	6	38	

PI	N	Activity Code	Scope (Intl/Domestic)	US Personnel	Foreign Personnel
PI A	16*	R01	I	8	6
PI B	13	R01	I	4	9
PI D	8	R01	I	2	6
PI E	2	R01	I	1	1
PI F	6	R01	I	4	2
PI G	4	R01	I	2	2
PI H	9	R01	I	8	1
PI I	12*	R01	I	3	8
PI O	6	R21	I	1	5
PI P	2	R21	I	1	1
PI Q	8*	R21	I	4	3
PI R	2	R21	I	5	2
Total, Int'l Awards:	88*	8 R01 / 4 R21	12	38	46

Totals	N	Activity Code	Scope (Intl/Domestic)	US Personnel	Foreign Personnel
Total, Domestic Awards	38	1 R01 / 5 R21	6	38	
Total, Int'l Awards	88*	8 R01 / 4 R21	12	38	46
Grand Total	38	1 R01 / 5 R21	6	38	

Locations not given for all indicated personnel; location information not available for two PI A collaborators, one PI I collaborator, and one PI Q collaborator.

Note: For non-public information (e.g., publications, funding of awards) PIs were coded from A to R. When fully public information (e.g., names of projects) is presented, PI names are used. Please see Appendix H for more detail on disease focus, PI discipline, and region of study by award and activity code.

International Collaborations

Apart from the US, which had the largest number of awardee-identified key personnel (76: 38 participating in “international” projects, 38 participating in “domestic” projects) China was home to the largest number of foreign Stigma Program key personnel (11), followed by New Zealand and Zambia at five key personnel each (Table 9). International key personnel also averaged seven individuals (range of two to 16), and more than five institutions per award.

- International R21s had smaller teams on average – five individuals and two institutions.
- International R01s’ teams were roughly twice as large as the R21s, involving nine individuals and five institutions on average.
- Regionally, East Asia (China, Hong Kong, Taiwan) housed the largest number of Stigma Program personnel (15; 13 R01s, two R21s). East Africa (Zambia, Malawi, Tanzania) followed with seven (two R01s, five R21s).

Table 9: Country and Region of Stigma Program Collaborators, by Project Scope and Activity Code

Number of Collaborations	Country	Int'l Scope	Domestic Scope	Activity Code		Region
				R01	R21	
76	USA	38	38	41	35	Northern America
11	China	11		9	2	Eastern Asia
5	New Zealand	5		5		Australia & New Zealand
5	Zambia	5			5	Eastern Africa
4	Canada	4		4		Northern America
4	South Africa	4		4		Southern Africa
4	UNKNOWN	4		3	1	UNKNOWN
4	Hong Kong	3		3		Eastern Asia
3	India	3		2	1	Southern Asia
3	Thailand	3			3	South-Eastern Asia
3	Australia	1		1		Australia & New Zealand
1	Haiti	1		1		Caribbean
1	Lesotho	1		1		Southern Africa
1	Malawi	1		1		Eastern Africa
1	Swaziland	1		1		Southern Africa
1	Switzerland	1		1		Western Europe
1	Taiwan	1		1		Eastern Asia
1	Tanzania	1		1		Eastern Africa

Note: Regional classifications based on the sub-regions of the United Nations Statistics Division geoscheme. "China" does not include Hong Kong.

Table 10: Affiliation of Stigma Program Grantees

Institution Type	Count
Education organizations other than higher education	0
Higher Education	16
Independent hospital	0
Other health, human resources, environmental organizations	1
Research organization, institute, laboratory, foundation	1
Total	18

5.1.4 PI Backgrounds

A majority of the Stigma Program PIs (78%) had been awarded a PhD degree and were affiliated with a university or university medical school (Table 10). Most (72%) of the Stigma Program PIs were women.

Career Stage of grantees

Career stages were determined based on self-reported descriptions of the PIs' career and analysis of years since highest degree or post-doctoral experience.⁴¹

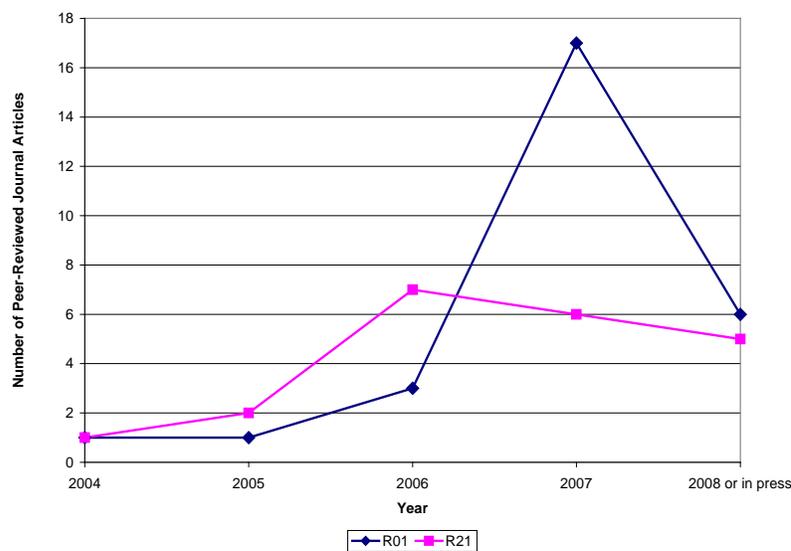
- Elapsed years from completion of highest degree or last post-doctoral experience ranged from 35 to two;
 - Eight PIs were determined to be relatively senior researchers, ranging from 35 to 19 years since highest degree;
 - Four PIs were identified as mid-career, ranging from 11-16 years since completion of PhD or Post-doc/Fellowship; and
 - Six PIs were identified as junior researchers, ranging from two to nine years since completion.
- Senior researchers were more commonly associated with R01 and International grants (seven of nine R01s were held by senior PIs; seven of 12 international grants were held by senior PIs).
- CRISP searches on the names of Stigma Program investigators identified 10 PIs (Alvidrez, Birbeck, Coreil, Dohan, Ellis, Kohlenberg, Li Li, Solomon, Tickle-Degnen, Van Rie) for whom their Stigma Program award was their first NIH grant; one awardee (Varas-Diaz) had won an R03 previous to his Stigma Program award. The other seven investigators had received NIH R01-level funding previous to their first Stigma Program awards.

5.2 Publications and Other Research Outputs

5.2.1 Publications Attributable to the Stigma Program

Progress reports, interviews with the Stigma Program awardees, and searches of NIH databases (QVR, MEDLINE) were used to identify publications attributable to the Stigma Program. Forty-four publications were identified as resulting from Stigma Program funding, and an additional five were reported to be in press.⁴²

Figure 6: Stigma Program-linked Publications by Activity Code and Year



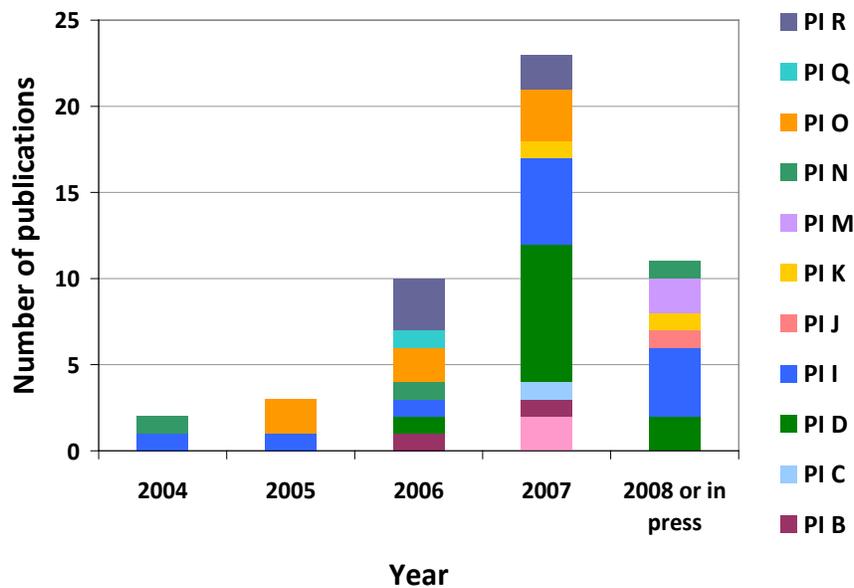
- Twelve of the 18 (67%) Stigma Program awardees had published one or more articles (or had an article in press) by October 2008 (See Figures 5 and 6, Table 11)

⁴¹ For more information on the career lengths of the Stigma PIs, please see Appendix I.

⁴² The full list of 49 publications is found in Appendix J

- Five of the nine R01 awardees had published,
- for a total of 28 articles;
- Seven of the nine R21 awardees had published, for a total of 21 articles
- Three of the Stigma Program awardees
- (PI D, PI I, PI O) had published 30 of the 49 total articles (61%);
- Across the Stigma Program as a whole, an average of 2.7 publications per award has been produced thus far;
- The Program’s nine R01 awards currently average 3.1 publications per R01 award;⁴³
- The nine Stigma R21 awards currently average 2.3 publications per R21 award.

Figure 7: Stigma Program-linked Publications by Awardee and Year



Description: Bar graph showing the total number of stigma program-linked publications by awardee and year, for the calendar years 2004-2008: 2004 ~2 | 2005 ~3 | 2006 ~10 | 2007 ~23 | 2008 or in press ~11.

Each bar shows different colors for each awardee, and the awardee is indicated by a unique letter, using A through R.

Note: For non-public information (e.g., publications, funding of awards) PIs were coded from A to R. When fully public information (e.g., names of projects) is presented, PI names are used.

Several contextual factors were cited as partial explanations for the publication rates to date. As stated in Section 5, only five of the projects have been completed – even though funding to investigators was largely complete by FY 2007 (Table 2). Awardees interviewed who reported a small number or complete lack of stigma-related publications commonly stated that their data collection has been recently completed.

As shown in Figure 5 and Table 11, publications were the greatest in 2007. There was a sharp spike in article production for R01 awardees, with 17 of 28 publications (61%) in 2007. The peak of publication rates was broader for R21 awardees, with seven publications (33%) in 2006, six publications (29% in 2007), and five publications in 2008 or in press (24%). When reported, the common timeframe for publication of the first article from their Stigma Program grant was two to three years after the initiation

⁴³ A 2005 study of MEDLINE articles linked to NIH R01 grants made in 1996 found that on average, 7.6 MEDLINE-indexed publications were produced per R01 award. No similar analysis or benchmark is available for R21 grants. See Druss BG, and Marcus SC, Tracking Publication Outcomes of National Institutes of Health Grants,” *American Journal of Medicine*, June 2005, 118(6), pp 658-63.

of their grant. The earliest reported year for the first Stigma Program-funded publication was 2004 by a senior researcher (33 yr career), who also reports the highest number of publications (12). There was no correlation, however, between the career stage of researcher (as measured by number of years since last postdoc/terminal degree) and the number of publications identified (Pearson correlation coefficient $r = -0.01$). Of the three most-published researchers, one was senior; one was mid-career; and one was junior.

The total number of citations (times cited) and the citations per publication for were collected as available for each of the 49 Stigma Program-linked articles (Table 11). In total, Stigma Program-linked publications currently average 4.64 citations per publication (CPP);

- R21 publications currently average 5.56 CPP
- R01 publications currently average 4.13 CPP

Table 11: Publications Linked to Stigma Program, by Awardee

Awardee	2004	2005	2006	2007	2008 or in press	Awardee Total	Indexed Subtotal*	Total Citations	CPP**
PI A				2		2	1	4	4
PI B			1	1		2	1	6	6
PI C				1		1	-	-	
PI D			1	8	2	11	6	24	4
PI I	1	1	1	5	4	12	8	32	4
R01 Subtotal:	1	1	3	17	6	28	16	66	4.13

Awardee	2004	2005	2006	2007	2008 or in press	Awardee Total	Indexed Subtotal*	Total Citations	CPP**
PI J					1	1	-	-	
PI K				1	1	2	-	-	
PI M					2	2	-	-	
PI N	1		1		1	3	1	4	4
PI O		2	2	3		7	6	42	7
PI Q			1			1	1	3	3
PI R			3	2		5	1	1	1
R21 Subtotal:	1	2	7	6	5	21	9	50	5.56

Totals	2004	2005	2006	2007	2008 or in press	Awardee Total	Indexed Subtotal*	Total Citations	CPP**
R01 Subtotal:	1	1	3	17	6	28	16	66	4.13
R21 Subtotal:	1	2	7	6	5	21	9	50	5.56
Year Total:	2	3	10	23	11	49	25	116	4.64

Note: Citation counts were collected from Scopus.com on November 21, 2008.

*Citation information not available for 24 articles due to: a.) manuscripts are still in press, b.) manuscripts have only recently been published and have not yet been indexed, or c.) the publishing journal itself is not indexed.

**Citations Per Publication; number of total citations per subtotal of indexed publications.

Note: For non-public information (e.g., publications, funding of awards) PIs were coded from A to R. When fully public information (e.g., names of projects) is presented, PI names are used.

The 49 peer-reviewed journal articles were published in 33 distinct journals (Table 12). Eight journals published multiple articles (for a total of 24 publications). Among the other twenty-five journals publishing one paper each were the *American Journal of Public Health* and *Lancet Neurology*.

Table 12: Journals Publishing Stigma Program-related Publications, by Year

Number of Papers	Journal	'04	'05	'06	'07	'08 or in press
5	<i>Epilepsy Behav</i>		1	2	2	
4	<i>World Health Popul</i>			3	1	
4	<i>AIDS Care</i>				3	1
3	<i>AIDS Behav</i>			1	1	1
2	<i>AIDS Educ Prev</i>				2	
2	<i>J Assoc Nurses AIDS Care</i>		1			1
2	<i>J Health Care Poor Underserved</i>					2
2	<i>Afr J AIDS Res</i>				1	1
25	<i>25 Other Journals</i>	2	1	4	13	5
49		2	3	10	23	11

To understand the impact of the published articles, impact factors (IFs)⁴⁴ and yearly citations per publication (CPP)⁴⁵ were collected or calculated for the eight journals publishing multiple Stigma Program-linked articles (Table 13). For the eight journals publishing more than one Stigma Program-linked article, IFs range from 0.657 to 2.093. While publication in a prestigious and highly cited journal does represent a valuable and potentially high-impact contribution to the field, IFs are most useful when used to compare journals within the same discipline or field and are therefore add limited value to an assessment of quality or impact in a nascent area such as the study of stigma and global health. Until a more defined set of “stigma journals” is established, it is more appropriate to compare the CPP of an individual Stigma Program-linked article to the average CPP of the publishing journal for that year.

Table 13: Impact Indicators for Journals Publishing Stigma Program-related Publications

Journal (Number of Stigma Program Papers)	Impact Factor(2006)	Average CPP '04*	Average CPP '05*	Average CPP '06*	Average CPP '07*	Average CPP '08*
<i>Epilepsy Behav</i> (5)	2.026		4.41 (0.07%)	6.44 (0.09%)	8.76 (0.14%)	12.53 (0.35%)
<i>World Health Popul</i> (4)	N/A				N/A	0 (0.91%)
<i>AIDS Care</i> (4)	2.093		11.84 (0.09%)	15.17 (0.04%)	14.61 (0.24%)	13.86 (0.51%)
<i>AIDS Behav</i> (3)	1.979		6.98 (0%)	10 (0.03%)	8.84 (0.1%)	8.14 (0.39%)
<i>AIDS Educ Prev</i> (2)	1.424		15.08 (0.09%)	21.23 (0.08%)	25.24 (0.15%)	39.24 (0.50%)
<i>J Assoc Nurses AIDS Care</i> (2)	0.657		7.28 (0.32%)	6.74 (0.47%)	8.82 (0.50%)	5.37 (0.84%)

⁴⁴ 2006 impact factors (IFs) are a measured by the Institute for Scientific Information (now part of Thomson/Reuters) and are calculated for each ISI-indexed journal on a yearly basis. For a given year, the IF is the total number of times that journal's articles are cited during the two previous years, divided by the total number of citable items in that journal over the same previous two years (See Thomson Reuters, *Sciencewatch.com*, “Sci-Bytes – Journals Ranked by Impact http://sciencewatch.com/dr/sci/08/nov9-08_1/). Journals such as *Science* and *Nature* have impact factors above 25.

⁴⁵ Citations per Publication (CPP) can be calculated for a given author over a defined period of time or for a specific journal, usually on a yearly basis. CPPs are used to calculate other bibliometric indicators such as the Hirsch index (*h*-index).

Journal (Number of Stigma Program Papers)	Impact Factor(2006)	Average CPP '04*	Average CPP '05*	Average CPP '06*	Average CPP '07*	Average CPP '08*
<i>J Health Care Poor Underserved (2)</i>	0.846		6.93 (0.24%)	4.47 (0.26%)	5.33 (0.33%)	5.75 (0.73%)
<i>Afr J AIDS Res (2)</i>	N/A		1.10 (0.33%)	1.12 (0.5%)	1.61 (0.65%)	1.83 (0.71%)
Stigma Program-linked publications by year	2	3	10	23	11	

*(% articles not cited)

Citation information was available for 10 Stigma Program-linked articles published in *Epilepsy and Behavior*, *AIDS Care*, *AIDS and Behavior*, *AIDS Education and Prevention*, *Journal of the Association of Nurses in AIDS Care*, and *African Journal of AIDS Research*. Two of the 10 Stigma Program-linked articles were more than 25% above the average citation rates for the years and journals of publication, indicating greater potential impact on the field; six were more than 20% below; and two were within 20% of the average. Details for the 10 articles can be found in Table 14.

Table 14: Comparison of Journal Citations per Publication with Stigma Program Article Citations per Publication

Journal	Year	Journal CPP	Stigma Program article(s) CPP	Comparison	N
<i>Epilepsy and Behavior</i>	2005	2005	6.44	13	Above
<i>Epilepsy and Behavior</i>	2006	2006	8.76	9	Similar
<i>Epilepsy and Behavior</i>	2007	2007	12.53	2	Below
<i>AIDS Care</i>	2007	2007	13.86	1	Below
<i>AIDS Care</i>	2007	2007	13.86	2	Below
<i>AIDS and Behavior</i>	2006	2006	8.84	7	Below
<i>AIDS Education and Prevention</i>	2007	2007	39.24	1	Below
<i>Journal of the Association of Nurses in AIDS Care</i>	2005	2005	6.74	9	Above
<i>African Journal of AIDS Research</i>	2007	2007	1.83	2	Similar

Comparing funding with number of peer-reviewed articles produced suggests differences in the ratio between funding and publications to date between the R01 and R21 awards. Dividing the total funding of \$17 million by the 49 publications to date yields a ratio of \$348K per published paper. Interviewees identified another 19 publications in preparation or in review. Were all these publications included the ratio would be \$251K per paper.

- R21 funding of \$3.5 million / 21 publications to date is \$167K per published paper. R21 PIs interviewed mentioned that nine articles were in progress (one in review, two in revise and resubmit, and six in preparation). If all result in publications, the total would be 30 publications, or an average of \$117K per publication.
- R01 funding of \$13.5 million / 28 publications to date is \$483K per published paper. Since R01 funding continued in 2006 and beyond for five of the nine R01s, there may be substantial number of additional publications from the R01s in future years. R01 PIs interviewed mentioned 10 additional articles in progress (seven in review, and three in preparation). If all result in publications, the total would be 38 publications, or an average of \$356K per publication. It should be noted that as many of the R01s have just completed data collection, there may be additional publications beyond the 38 mentioned.

5.2.3 Other Outputs

Interventions

Only two PIs reported that interventions had been developed based on their Stigma Program-funded research.

- One of these was an R21 who successfully won a R01 that has supported the development of the intervention; and
- Three R01 researchers identified intervention development as the clear next step for their research.

Scales, Measures, and other Instruments

Eleven instruments were reported to have been developed with another two under development, ranging from one to five for the projects.

- The PI reporting five developed scales is a relatively senior researcher (20 yr career) who undertook an international R01 study.; and
- Only one PI reported that the measures had been culturally validated.

Very few PIs indicated that they had published their instruments. Five PIs, however, reported that the instruments had been requested by other researchers for use.

Conference presentations

Lists of conference presentations were identified for eight of the 18 Stigma Program awardees

- Two awardees (PI D, PI I) specifically identified 35 presentations related to their Stigma Program awards; and
- Six awardees (PI B, PI E, PI G, PI K, PI L, PI R) identified an additional 54 Stigma Program-related presentations in the same year as or subsequent to their Stigma Program award, but did not differentiate whether those presentations were related specifically to their Stigma Program awards.

Other dissemination activities

- Six books or book chapters were identified by five awardees (PI A, PI B, PI G, PI K, PI L); and
- Two awardees (PI E, PI K) identified seven invited talks they gave

FIC Success Story: Dr. Gretchen Birbeck

Dr. Gretchen Birbeck, Michigan State University, in collaboration with colleagues Dr. Alan Haworth, Dr. Masharip Atadzhanov and Dr. Elwyn Chomba, University of Zambia School of Medicine and Mr. Eddie Mbewe, Chainama Hills Hospital are spearheading research to improve the lives of children and adults with epilepsy.

The team has been conducting research into epilepsy-associated stigma, under the program, since receiving an R21 planning grant--awarded by NINDS and co-funded by Fogarty in 2003.

"The Zambian colleagues are proud to work with Dr. Birbeck who is leading our team's work on epilepsy and stigma--an often neglected and ill understood area in which these lives can be improved," said Dr. Elwyn Chomba.

"Epilepsy remains the most common chronic cerebral disease among adult and pediatric neurological patients in Zambia. The study highlights not only the social and economic impact of epilepsy in Zambia, it sheds light on the major problems encountered by both patients with epilepsy and health professionals. The role of Dr. Birbeck in this study is not possible to overestimate," Dr. Alan Haworth stated.

In the January 2007 issue of *The Lancet Neurology*, Birbeck and her collaborators described some of the social and economic effects associated with epilepsy in Africa. The team investigated the social and economic consequences of epilepsy from the perspective of diverse groups--its aim to elucidate the social, psychological and economic context necessary to facilitate development of interventions that will improve the lives of people living with epilepsy in the region.

Their study shows people living with epilepsy in Zambia are likely to be poorer and of lower social status than people living with other non-stigmatizing chronic disorders. Having the disease meant that people were less likely to marry or have had formal education. Their housing was poorer and they had less access to water, electricity and other basic resources than their peers--suboptimum housing exposed these individuals to burns and drowning during a seizure.

People with epilepsy reported higher rates of physical abuse from members of their households. Women with epilepsy were significantly more likely to have been raped. Rape rates were 20% for women with epilepsy vs. 3% of the control group (p=0.004). The prevalence of HIV in Zambia would suggest that women with epilepsy are at an increased risk of contracting this and other sexually transmitted infections

(Reprinted from

http://www.fic.nih.gov/programs/research_grants/stigma/report.htm

5.2.4 Perceptions of Awardees Regarding Publication Outputs

Awardees commonly reported experiencing difficulties with involving collaborators and participants with different disciplinary backgrounds. The quantitative and qualitative orientations of these different disciplines at times led to significant differences in the conceptualization and definition of stigma.

- One awardee described the impact of this multi-disciplinarity on the structure of the research: “the social scientists think of it [stigma] a social construct, very abstract. In the medical field, they want to quantify what percent of people experience stigma. That’s why you need to look at stigma on an individual level, on a structural level, on a cultural level;”
- Another described the impact of the multidisciplinary approach on collaborations: “I thought I would have some real translational issues with [country] and other ethnicities. But the greatest cross-cultural difference was not here but between the statisticians. Not until we got them together in one place did it start to work. They spent two days together just talking. And then suddenly we had a huge amount of trust built between the statisticians;”
- One grantee detailed the impact of this phenomenon on publications: “sociologists’ understanding [of stigma] is very different than clinicians [understanding]. For us, it is a social process. For physicians, it seems like laying blame. You have to explain to them that that’s not it. There were some challenges with reviews of the articles – [some clinicians] thought we were [laying] blame.”

5.3 Program Results: Enhanced Stigma Research Capacity

5.3.1 Continued Research of R21 Awardees

One goal of the R21 mechanism is to allow awardees to gather sufficient data to apply successfully for an R01 award. Four of the nine R21 awardees had received follow-on funding from NIH subsequent to their Stigma Program awards. For seven of the nine R21 awardees, their Stigma Program R21 was the first research award that they had received; four of the awardees had been trainees previous to the receipt of their R21.

As of October 2008, three of the Stigma Program R21 awardees (Birbeck, Van Rie, Xiaoming Li) had won one or more R01 awards subsequent to receiving Stigma Program funding identified during interviews as being linked to their Stigma Program award; two of those awardees, along with Varas-Diaz, won other R01 funding not linked to their Stigma Program R21.⁴⁶ Two other awardees (Birbeck, Solomon) have won other NIH funding. Four of the nine R21 awardees (Birbeck, Van Rie, Solomon, and Xiaoming Li), therefore, have won funding linked to their Stigma Program R21 awards, while one awardee (Varas-Diaz) has won additional funding not linked to a Stigma Program award. The other four awardees (Alvidrez, Dohan, Ellis, and Kohlenberg) have not received additional NIH funding subsequent to their Stigma Program awards.

A majority of grantees reported personally having other funds from both NIH and non-NIH sources prior to applying for the R21/R01. The NIH sources were reported to be fellowship and career development awards, while the non-NIH sources were internal department funds, other federal agency funds, or foundation funds.

⁴⁶ While PI-specific information cannot be presented because of confidentiality issues, these awardees were successful in 7 of their 18 R01 applications (39%). While no comparable studies are available of R21 winners applying for R01s, the overall success rate for NIH R01s has been between 20-25% between 2003 and 2007. <http://report.nih.gov/NIHDataBook/Charts/SlideGen.aspx?chartId=29&catId=5>.

5.3.2 The Impact of the Stigma Program on the Stigma Research Community.

The Stigma Program also served to strengthen research on the role of stigma in health by providing support and an enhanced sense of community to researchers who study stigma or stigmatized topics/conditions. As was mentioned earlier in Section 4.3, awardees found the Network Meeting valuable in terms of meeting other stigma researchers and learning of common problems related to research on the topic.

The Stigma Program has also benefited the stigma research community by providing validation to its awardees as well as the topic as a whole. Partnering IC POs explained that it can be difficult to attract researchers to stigma-related research topics (e.g., such as substance abuse) because the act of conducting such research is itself stigmatizing. The Fogarty PO also stated that one of the lessons learned at the Network Meeting was that the existence of an explicitly stigma-focused research program was validating for the awardees, stating that it, "...was so important to them to be able to openly work on [stigma] as an acknowledged field of research."

5.3.3 Institutional Capacity Building

Instances of institutional capacity building were also reported by a few awardees. In these cases, the ability of the foreign-country site to administer and report on the award to the level required by NIH was the primary challenge. While addressing this issue caused project delays (See Section 4.1.1), these efforts also resulted in institutional learning and capacity building. In one instance, having a record of successful award administration led in part to those sites winning other NIH awards and foundation grants.

5.4 Section-Level Findings and Recommendations

- The Panel considered the number of publications and interventions developed under the Stigma Program to be reasonable, based on the goals and objectives of the Program's RFA.
- 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 Fogarty encourage the Stigma Program grant recipients to publish monographs and other alternate forms of research dissemination. Still, peer reviewed journal articles are to be encouraged, to the greatest extent possible.

Appendix A: Biographies of Expert Panel

William Darrow, Florida International University: Dr. Darrow is a Professor of Public Health at Florida International University (FIU) in Miami, Florida. He teaches graduate-level courses in the Robert R. Stempel College of Public Health and Social Work on theories of health behavior, community organization for health promotion, program planning and evaluation, and survey research methods in public health. He continues to conduct research and to publish on the social and behavioral aspects of AIDS and other sexually transmitted diseases. Dr. Darrow serves as Project Leader for the REACH project in Broward County. Before accepting a position at FIU in August 1994, Bill served as Chief, Behavioral and Prevention Research Branch, Division of STD/HIV Prevention, National Center for Prevention Services, Centers for Disease Control and Prevention (CDC). He has published over 100 scientific papers in professional journals, books, and research monographs. In addition, he has presented more than 100 scientific papers at national and international meetings, and has consulted with many professional and service organizations, including the Global Program on AIDS, the World Health Organization, and the European Union.

Stephen Hinshaw, University of California, Berkeley: Dr. Hinshaw is Professor and Chair of the Department of Psychology at UC Berkeley. The author of over 200 empirical articles, plus 6 books, he is editor of the journal *Psychological Bulletin*. His main interests lie in the fields of clinical child and adolescent psychology and developmental psychopathology. Increasingly, his research interests are focusing on adolescent and young adult outcomes, as the children in his various projects continue to participate in prospective, longitudinal studies. In addition, his research program has a new area of focus, on the stigmatization of mental illness.

Joia Mukherjee, Brigham and Women's Hospital: Dr. Mukherjee trained in Infectious Disease, Internal Medicine, and Pediatrics at the Massachusetts General Hospital and has an MPH from the Harvard School of Public Health. She is an Assistant Professor in the Division of Global Health Equity at the Brigham and Women's Hospital and Harvard Medical School where she teaches medical students, residents and fellows in the fields of infectious disease, global health and health disparities. Since 2000, Dr. Mukherjee has served as the Medical Director of Partners in Health, an international medical charity with clinical programs in Haiti, Rwanda, Lesotho, Malawi, Peru, Mexico, Russia, and inner-city Boston. In this capacity she is involved in programmatic and clinical work to provide health care and reduce health disparities by developing public sector, community based programs with local colleagues in those countries. Additionally, Dr. Mukherjee consults for the World Health Organization on the treatment of HIV and MDR-TB in developing countries and is a member of the Executive Board of Health Action AIDS, a campaign conducted with Physicians for Human Rights to engage the US health professional community in the international advocacy and education effort to stop the global AIDS pandemic.

Jo Anne Sirey, Cornell University: Dr. Sirey received her Ph.D. in Clinical Psychology from City University of New York and completed a post-doctoral Fellowship at Weill Cornell Medical College. Dr. Sirey is an Associate Professor of Clinical Psychology in Psychiatry, Weill Medical College of Cornell University, Associate Attending Psychologist and Clinical Director of the Geriatric Outpatient clinic of the New York Presbyterian Hospital.

Dr. Sirey has an expertise in developing partnerships and conducting mental health interventions in community based settings that serve older adults. In her research on the treatment of depression in community based clinics she documented the negative impact of stigma on mental health treatment participation and adherence to antidepressant medication. Her research focus is on the development, implementation and impact of interventions that address psychological barriers and stigma. Dr. Sirey is the Principal Investigator of an intervention to increase use of mental health services among depressed community dwelling elders (R01) and an intervention to improve adherence among elders in primary care settings (K23). She is Director of Community Network Core the Cornell ACISR (P30) and is Associate Director of Advanced Research Institute in Geriatric Mental Health (R25).

In addition to her research, Dr. Sirey is on the Board of Directors of the Mental Health Foundation and is a reviewer for The National Registry of Evidence-based Programs and Practices (NREPP) for SAMHSA and serves as a guest reviewer on NIMH CSR review panels as an expert on stigma.

Appendix B: Stigma and Global Health Program RFA (RFA-TW-03-001)

STIGMA and Global Health Research Program

RELEASE DATE: June 20, 2002

RFA: TW-03-001

PARTICIPATING INSTITUTES AND CENTERS (ICs):

Fogarty International Center (FIC)

(<http://www.nih.gov/fic/>)

Health Research Services Administration (HRSA)

(<http://www.hrsa.gov>)

National Center on Minority Health and Health Disparities (NCHMD)

(<http://ncmhd.nih.gov/>)

National Human Genome Research Institute (NHGRI)

(<http://www.nhgri.nih.gov/>)

National Institute of Allergy and Infectious Diseases (NIAID)

(<http://www.niaid.nih.gov/default.htm>)

National Institute of Dental and Craniofacial Research (NIDCR)

(<http://www.nidcr.nih.gov/>)

National Institute of Mental Health (NIMH)

(<http://www.nimh.nih.gov/>)

National Institute of Neurological Disorders and Stroke (NINDS)

(<http://www.ninds.nih.gov/>)

National Institute on Alcohol Abuse and Alcoholism (NIAAA)

(<http://www.niaaa.nih.gov/>)

National Institute on Drug Abuse (NIDA)

(<http://www.nida.nih.gov/>)

Office of AIDS Research (OAR)/ NIH Office of the Director

(<http://www.nih.gov/od/oar/>)

Office of Behavioral and Social Science Research (OBSSR)/ NIH Office of the Director

(<http://obssr.od.nih.gov/>)

Office of Research on Women's Health (ORWH)/ NIH Office of the Director

(<http://www4.od.nih.gov/orwh/>)

Canadian Institutes of Health Research (CIHR)/Institute of Neurosciences

Mental Health and Addiction (INMHA) with the International Development

Research Centre (IDRC)

(<http://www.cihr.ca/>, <http://www.idrc.ca/>)

LETTER OF INTENT RECEIPT DATE: October 14, 2002
APPLICATION RECEIPT DATE: November 14, 2002
THIS RFA CONTAINS THE FOLLOWING INFORMATION

- Purpose of this RFA
- Research Objectives
- Mechanisms of Support
- Funds Available
- Eligible Institutions
- Individuals Eligible to Become Principal Investigators
- Special Requirements
- Where to Send Inquiries
- Letter of Intent
- Submitting an Application
- Peer Review Process
- Review Criteria
- Receipt and Review Schedule
- Award Criteria
- Required Federal Citations

PURPOSE OF THIS RFA

The purpose of this initiative 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. Collaborative interdisciplinary applications are particularly encouraged. The following Institutes and Centers from the U.S. Department of Health and Human Services (DHHS): the Health Research Services Administration (HRSA), the NIH including: the Fogarty International Center (FIC), National Center on Minority Health and Health Disparities (NCHMD), National Institute of Neurological Disorders and Stroke (NINDS), National Human Genome Research Institute (NHGRI), National Institute of Alcohol Abuse and Alcoholism (NIAAA), National Institute of Allergy and Infectious Diseases (NIAID), National Institute of Dental and Craniofacial Research (NIDCR), National Institute of Drug Abuse (NIDA), National Institute of Mental Health (NIMH), Office of AIDS Research, Office of Behavioral and Social Science Research (OBSSR), Office of Research on Women's Health (ORWH), and the Canadian Institutes of Health Research (CIHR), seek domestic and international applications which address stigma-related issues, across a variety of global public health problems, among individuals and in society. Relevant issues include:

1. How stigma and its consequences, such as discrimination affect health (e.g. through physical and psychological abuse, denial of economic opportunities, poor provision and seeking of health care),
2. How stigma associated with specific health conditions interacts with stigma associated with individual or group characteristics (such as gender, race, religion, sexual orientation and nationality),
3. How to prevent and mitigate the negative effects of stigma and discrimination on health and health care,

4. Development of quantitative and qualitative methods and techniques to investigate, measure and analyze the extent, degree and effects of stigma and the effectiveness of current and new interventions,
5. Examination of the cultural, social, political and economic dimensions of stigma and its manifestations,
6. Methods and safeguards to ensure safety of vulnerable research subjects.

Such research, which may range from basic to clinical and operational, requires expertise across a broad range of bio-medical, social and behavioral science fields. The participants in this RFA therefore encourage interdisciplinary, domestic and international collaboration to build the scientific foundation of stigma research related to health. Meritorious applications must also be relevant to the mission and interests of one or more of the participating Institutes or Centers.

This RFA is based on recommendations developed in conjunction with the NIH sponsored International Conference on Stigma and Global Health: Developing a Research Agenda, September 5-7, 2001, Bethesda, MD. Applicants are encouraged to refer to the stigma conference website (www.stigmaconference.nih.gov) for extensive information related to the topic of this RFA including the agenda with links to speaker abstracts, commissioned background papers and a video-cast of the conference.

RESEARCH OBJECTIVES

The objectives of this initiative are to encourage research across a variety of scientific disciplines including the biomedical, social and behavioral sciences, to elucidate the etiology of stigma in relation to public health as well as to develop and test interventions to mitigate the negative effects of stigma on health outcomes. Studies may examine stigma and public health in domestic, international and cross-cultural contexts, with an emphasis on studies that are relevant to global health issues. Applicants are encouraged to undertake interdisciplinary studies, where possible, using behavioral, social and biomedical science approaches.

The initiative is also designed to attract investigators across a broad range of biomedical and non-biomedical fields, including but not limited to anthropology, epidemiology, infectious and non-infectious diseases, geography, sociology, psychology, psychiatry, neuroscience, law, genetics, ethics, economics, political science, biostatistics, evaluation and others.

Background

According to a seminal work by sociologist Erving Goffman (1963 "Stigma: Notes on the Management of Spoiled Identity") a stigma is an attribute that — according to prevailing societal attitudes - is deeply discrediting and reduces a person to one who is in some way tainted and can therefore be denigrated. Individuals may internalize the stigmas applied to them by others. Researchers, therefore, differentiate between the "felt" stigma a person perceives and "enacted" stigma, which refers to actions upon the individual expressed through various forms of discrimination.

Stigma, when applied to health conditions, is a globally pervasive problem threatening psychological and physical health at the individual and group level. Stigma helps to perpetuate health inequalities. The poor treatment of an individual because of the stigma of the condition itself, or of another aspect of that individual's being or position in society (such as gender, race, sexual orientation or socio-economic status), leads to poor outcomes and perpetuates other adverse health, social and economic consequences for the individual, their families and communities. Felt stigma prevents individuals from coming forward for timely diagnosis and treatment and impairs their ability for self-care, to access care or to participate in research studies designed to find solutions. Enacted stigma perpetuates public health problems and prevents societies from appropriately addressing health care issues at the community and national levels with the appropriate delivery, funding and support of research, health care services and legal and educational interventions.

Many diseases and conditions, which persist or worsen if left untreated, affect a person's ability to fulfill necessary, culturally expected and economically productive roles in society. The burden of their continued care may then fall upon families and communities lacking adequate resources or support. For this reason, stigma and discrimination may greatly magnify the social and economic, as well as personal consequences of such diseases and conditions, often well beyond their prevalence in the population. In the case of infectious disease (for example, sexually transmitted diseases), stigma and discrimination related to the mode of transmission and preexisting attitudes towards some affected individuals can lead to fear of disclosure, inadequate and inappropriate treatment of all affected, and the further spread of a disease which might otherwise be contained. The effects on individuals, families, communities and nations can be devastating, as illustrated by the HIV/AIDS epidemic, particularly in Sub-Saharan Africa.

The disability and loss of productivity due to treatable mental illnesses and neurological disorders (such as depression, schizophrenia, epilepsy, movement disorders, substance abuse disorders, mental retardation and cerebral palsy), when inadequately treated due to stigma and discrimination, contribute greatly to the burden of illness on societies around the world (for more information please see the "World Health report 2001: Mental Health-New Understanding, New Hope" and the Institute of Medicine report on "Neurological, Psychiatric and Developmental Disorders: meeting the Challenge of the Developing World", 2001, available at <http://books.nap.edu/books/0309071925/html/>).

The same is true of other physical and developmental health conditions (including those which are disfiguring such as craniofacial disorders, and those that are physically disabling, such as spinal cord injury leading to paralysis) which if treated, mitigated or accommodated need not serve as barriers to full and productive lives. Yet stigma and discrimination often prevent the necessary societal action to treat, research and accommodate such conditions. Other public health problems, such as domestic violence and abuse, when ignored because of the associated stigma, perpetuate the same problems in individuals and across generations, along with other, often stigmatized health problems such as mental illnesses, drug and alcohol addiction and abuse.

To have an impact, research on stigma-related health problems requires the participation of investigators across a broad range of biomedical and non-biomedical fields. Interdisciplinary studies are needed which use current behavioral, social and biomedical approaches to elucidate the etiology of stigma in relation to health as well as develop and test interventions to mitigate the negative effects of stigma on health outcomes. Finally, researchers must better understand the policy-making process so they can work to ensure that research results have an impact.

Understanding the causes, consequences and effective interventions for stigma-related issues and problems has the potential to significantly improve treatment and care particularly for public health problems of global importance. In the same way that the effects of stigma magnify the personal and societal problems related to such diseases and disorders, preventing or mitigating stigma and its effects can profoundly improve the lives of individuals and, by extension, their families and the larger society.

The public health community has demonstrated increasing awareness of the role of stigma in many diseases and disorders. Recent conferences have focused on the role of stigma in mental illnesses including depression and schizophrenia, HIV/AIDS and epilepsy. These conferences were convened by organizations including the Health and Development Networks with UNAIDS, the United States Substance Abuse and Mental Health Services Administration, the World Health Organization, and the World Psychiatric Association.

This RFA is informed as well by the recent U.S. National Institutes of Health International Conference on Stigma and Global Health: Developing a Research Agenda (www.stigmaconference.nih.gov). This conference was convened by the Fogarty International Center of the NIH in partnership with various other NIH institutes and offices along with other U.S. agencies, and domestic and international organizations. More than 250 participants from 30 nations, including 23 developing countries, discussed stigma associated with a variety of illnesses and conditions including HIV/AIDS, mental health, epilepsy, physical anomalies, alcohol and drug abuse, physical and sexual abuse, genetics, race and gender. Scientists and other experts encompassing the

health, social and behavioral sciences, media, law, politics and economics focused on stigma as it relates to global public health. They examined both what is known about the causes and consequences of stigma and what can be done to prevent or minimize its negative effects on the health of individuals and societies.

One outcome of the conference was a set of research recommendations for stigma and its relationship to a variety of global public health problems. The recommendations include research to:

- Further elucidate the etiology of stigma,
- Investigate the health consequences of stigma,
- Develop methodology for studying stigma with respect to health,
- Evaluate and develop new effective interventions to deal with stigma,
- Lay the groundwork for guidelines on ethical conduct of studies on stigmatized individuals and groups who may face further negative effects, including physical violence or social isolation, because of their participation in such studies.

Research Topics

Studies of stigma are encouraged across physical and mental health conditions (including addictions), care settings, groups, outcomes and interventions, including research on the social, economic, cultural and political factors in both creating and intervening in stigmatization of health conditions. This RFA encourages interdisciplinary studies throughout whenever appropriate to the research question. Ethnographic and other areas of social science research in particular will be necessary to fully understand the role of stigma within a given society or group and to design appropriate interventions. The ways stigma is applied, perceived and measured in other cultures are relevant avenues of inquiry and ethnographic and comparative studies are encouraged alone or as components of other studies.

Other relevant research topics include but are not limited to the following:

1. The role of stigma in specific public health problems, diseases or disorders, and its implications for issues from etiology to interventions and public policy,
2. The implications of stigma for access to care and treatment, and how stigma affects outcomes across health conditions,
3. Systematic studies to determine psychological, social, economic, cultural and political factors that operate in the creation of stigma and how they link to stereotypes, discrimination and mistreatment in the context of health problems and health care systems,
4. Approaches to ensure that medical advances, which can be used to treat or prevent stigmatized conditions, effectively reach appropriate populations,
5. Development of tools to study and document stigma and its impact on accurate determination of incidence and prevalence of health conditions, and to estimate the risk for over- or under-diagnosis as a result of stigma-related influences,
6. Evaluation of which interventions work for stigma-related health problems, the characteristics of successful interventions, demonstration of successful interventions that can be scaled up or generalized to other stigmatized public health problems and/or to other populations and cultures,
7. The role of stigma in provision of health care including, quality and extent of available treatment and care, the quality of the patient/health care practitioner relationship, the role of the provider's attitude in perpetuating stigma and the role of stigma in disclosure of disease status during medical visits,

8. The role of disclosure of disease in an individuals' personal or professional life and its relationship to perceived stigma,
9. Identification of methods to minimize (or eliminate) the consequences of stigma/stigmatization on the recognition and diagnosis of health conditions and on options for treatment and/or rehabilitation,
10. Social, cultural and environmental influences on perceptions of and reactions to stigma/discrimination among individuals, families and communities, and on the resources available for coping with or ameliorating its negative health consequences,
11. The interaction of social systems including gender, culture, politics, economics and the law in creating stigmas and the examination of the interplay between different kinds of stigmas as well as the combined impact on individuals, families, and groups,
12. The involvement of social, political, economic and legal systems in creating appropriate, effective and culturally sensitive interventions to combat stigma and the negative effects of stigma,
13. The actual and potential roles of media in creating, disseminating and intervening in stigma-related attitudes and actions,
14. The relationship between attributions about the causes/etiologies of particular diseases and disorders and the degree to which those with, or at risk for, the disorder are stigmatized. For example: does the public view a disease or disorder as more or less stigmatizing when it may be associated with a specific genetic predisposition, is this perception different for different diseases and disorders, for example diseases such as cancer, neurological and neuropsychiatric disorders such as epilepsy, movement disorders, schizophrenia and bipolar disorder, or conditions in which there is a clear behavioral component (e.g. drug abuse, obesity)?

Specific Research Areas of Interest to Stigma and Global Health RFA Sponsors:

The FIC is interested in applications on stigma and health topics relevant to and involving low to middle income countries of the developing world. Special consideration will be given to meritorious interdisciplinary applications from, or in collaboration with, developing country investigators.

NCMHD would like to encourage applications that have minority health or health disparity focus.

NIAAA is interested in supporting applications that address the association of stigma with the detection, prevention and treatment of alcohol use disorders. Of particular interest are applications that address alcohol abuse and addiction in populations that bear a greater burden of stigma (i.e. pregnant women) and alcohol related birth defects (such as Fetal Alcohol Syndrome). Applications that address the stigma associated with alcohol and other health conditions, such as HIV AIDS, will also be considered. Studies on the role of stigma in the development of alcohol-related policies and the delivery of services are also encouraged.

NIAID encourages applications addressing the impact of stigma on control and treatment of infectious diseases. Of particular interest is research to develop and evaluate strategies to prevent or minimize the negative physical, cognitive, and social consequences of HIV infection, including the stigmatization of persons with or at risk for HIV infection. NIAID is particularly interested in applications with an international/developing country focus.

NIDA is interested in supporting applications that address the causes and consequences of stigma in drug abusing and addicted individuals and populations, including the impact on stigma on the availability and provision of treatment and prevention services. Studies on interventions directed at reducing stigma in these populations are encouraged as well.

NIDCR is interested in supporting research to identify, prevent, or ameliorate consequences of stigma related to socially perceived variations or changes in orofacial appearance or function. Such changes may, for

example, result from orofacial injuries or from congenital craniofacial anomalies, such as cleft lip and palate, disfiguring infectious diseases such as noma, oral facial cancers or ablative cancer surgeries affecting orofacial structures, edentulousness, malocclusion, or other orofacial diseases/ conditions.

NHGRI would like to encourage applications on stigma-related issues related to genetic disorders.

NIMH encourages research on stigma related to neuropsychiatric disorders and research on AIDS stigma and prevention of HIV transmission and its consequences including descriptive cross-sectional studies of stigma, longitudinal research studies and intervention studies.

NINDS encourages research on stigma related problems across the spectrum of neurological disorders to reduce the burden of neurological disease borne by every age group and segment of society all over the world.

OAR is interested in supporting applications that address the role of stigma and discrimination in the HIV/AIDS pandemic. This includes basic research on the causes and consequences of HIV/AIDS-associated stigma and discrimination, as well as intervention research to ameliorate them.

ORWH would like to encourage applications, across the spectrum of possible research topics, which include in the research design scientific analyses aimed at delineating sex/gender differences. The results of such analyses are expected to be particularly important when designing and testing appropriate interventions to have the best possible outcomes.

The HIV/AIDS Bureau, HRSA, is interested in supporting the evaluation of interventions to reduce stigma as a barrier to the care and treatment of those living with HIV/AIDS. Examples of potential interventions include training of health care providers, community involvement in HIV program planning, and the inclusion of people living with HIV/AIDS in program planning and as staff or volunteers in care and support programs. Programs that tie decreases in stigma to increased access to care and improved quality of care are of particular interest.

The Institute of Neurosciences, Mental Health and Addiction (INMHA) of the Canadian Institutes of Health Research (CIHR) is interested in supporting applications from Canadians or, in collaboration with the Canadian International Development Research Center (IDRC), in co-sponsoring proposals originating in and responding to priorities of developing countries and with a Canadian component. Eligible applications for CIHR/INMHA include those dealing with research on stigma related to neurological disorders, mental illnesses and addictions which are aimed at finding innovative, effective and evidence-based means to reduce discrimination, improve access to services and to raise public awareness through education.

Contact the representatives of the participating Agencies, Institutes or Centers (ICs) listed in the "Where to Send Inquiries" section of this RFA or visit individual Agency and IC websites for more information about topics of interest to each. Additional research questions and other information of specific interest to individual participating Agencies and ICs in the context of this RFA can be found at:

<http://www.nih.gov/fic/programs/stigma.html>.

MECHANISM OF SUPPORT

This RFA will use the National Institutes of Health (NIH) research project grant (R01) and the developmental/exploratory grant (R21) award mechanisms. Note that the R21 mechanism is specifically intended to support innovative ideas where preliminary data as evidence of feasibility are sparse or do not exist. R21 grants are not intended for large-scale undertakings or to support or supplement ongoing research. Rather, R21-supported projects are intended to serve as a basis for planning and strengthening future research project grant applications (R01).

This RFA also uses just-in-time concepts and the modular grant format (see <http://grants.nih.gov/grants/funding/modular/modular.htm>). Specifically, if you are submitting an application with direct costs in each year of \$250,000 or less, use the modular format (modules of \$25,000). Otherwise follow the instructions for non-modular research grant applications.

Applications submitted by foreign institutions can request facilities and administrative (F&A) costs up to a maximum of eight percent. Please see the web site <http://grants.nih.gov/grants/guide/notice-files/NOT-OD-01-028.html> for more information on allowable F&A costs for foreign grants and domestic grants with foreign components.

This RFA is issued for fiscal year (FY) 2003 and the anticipated award start date is July 2003. Applications submitted in response to this RFA may have a project period of up to five years for R01 and up to three years for R21 grant applications. As an applicant you will be solely responsible for planning, directing, and executing the proposed project.

At this time, it is not known if this RFA will be reissued. Any future unsolicited competing continuation applications based on this project may compete with all NIH investigator-initiated applications and be reviewed according to the customary peer review procedures.

FUNDS AVAILABLE

The participating ICs intend to commit approximately \$2.5 million in FY 2003 to fund up to 12 new competitive grants in response to this RFA.

R21 grant applicants may request a project period of up to three years with a total direct cost of \$100,000 per year.

R01 grant applicants may request a project period of up to five years. An applicant may request a budget up to 1) \$500,000 direct costs per year for applications in which comparative or intervention studies at two or more international sites are planned, and which involve an international team of investigators. No one site may be allocated more than half the budget. 2) \$200,000 direct costs per year for all other projects (i.e. those that will take place only in a single country, do not propose comparative or intervention studies, do not involve an international collaboration).

Because the nature and scope of the proposed research will vary from application to application, it is anticipated that the size and duration of each award will also vary, with multidisciplinary collaborative, international applications requiring more funding and time. Although the financial plans of the IC(s) provide support for this program, awards pursuant to this RFA are contingent upon the availability of funds and the receipt of a sufficient number of meritorious applications. Each award will be administered by one of the participating NIH ICs or other participating agencies although several may participate in funding of any given application.

The Canadian Institute for Health Research (CIHR) along with the Canadian International Development Research Centre (IDRC) will consider meritorious applications, relevant to their missions, from Canadian applicant institutions. CIHR will make the award of grants for meritorious applications of interest to them. Applicants who wish to have their projects considered for funding by CIHR should include with their application a letter stating that their application and summary statement may be shared with CIHR and IDRC.

ELIGIBLE INSTITUTIONS

You may submit (an) application(s) if your institution is in one of the following categories:

- For-profit or non-profit organizations
- Public or private institutions, such as universities, colleges, hospitals, and laboratories
- Units of State and local governments
- Agencies of the Federal government
- Domestic or foreign institutions or organizations
- Faith-based organizations

INDIVIDUALS ELIGIBLE TO BECOME PRINCIPAL INVESTIGATORS

Any individual with the skills, knowledge, and resources necessary to carry out the proposed research is invited to work with their institution to develop an application for support. Individuals from underrepresented racial and ethnic groups as well as individuals with disabilities are always encouraged to apply for NIH programs.

SPECIAL REQUIREMENTS

Two meetings of grantees of these awards will be held in the Washington, D.C. area (one in the second year and one in the fourth year of the grant period) to share information and discuss new insights on stigma and health, in particular, stigma intervention strategies. For these meetings, funds should be budgeted for travel by the PI and/or other relevant individuals with significant day-to-day involvement in the activities performed under this award.

WHERE TO SEND INQUIRIES

We encourage inquiries concerning this RFA and welcome the opportunity to answer questions from potential applicants. Inquiries may fall into three areas: scientific/research, peer review, and financial or grants management issues.

GENERAL INQUIRIES regarding the scope and content of this Request for Applications should be directed to:

Kathleen Michels, Ph.D.
Program Director
Division of International Training and Research
Fogarty International Center
Building 31, Room B2C39
31 Center Drive, MSC 2220
Bethesda, MD 20892-2220
Telephone: 301-435-6031
Fax: 301-402-0779
Email: Michelsk@nih.gov

Direct your questions about SCIENTIFIC/RESEARCH ISSUES to the contacts below (additional specific research questions of interest to participating ICs can be found in the "Research Topics" section of this RFA and at <http://www.nih.gov/fic/programs/stigma.html>):

CANADA:

CANADIAN INSTITUTES OF HEALTH RESEARCH and INTERNATIONAL DEVELOPMENT RESEARCH CENTER

Astrid Eberhart

Institute Liaison
Institute of Neurosciences, Mental Health and Addiction
Canadian Institutes of Health Research
410 Laurier Avenue W., 9th Floor
Address Locator 4209A
Ottawa, ON K1A 0W9
Telephone: 613-941-4643
Fax: 613-941-1040
Email: aeberhart@cihr.ca

UNITED STATES:

HEALTH RESOURCES AND SERVICES ADMINISTRATION

Laura Cheever, M.D., Sc.M.
Chief, HIV Education Branch
Health Resources and Services Administration
Parklawn Building, Room 7-29
5600 Fishers Lane
Rockville, MD 20857
Telephone: 301-443-3067
Fax: 301-443-9887
Email: LCheever@HRSA.gov

NATIONAL INSTITUTES OF HEALTH:

FOGARTY INTERNATIONAL CENTER

Kathleen Michels, Ph.D.
Program Director
Division of International Training and Research
Fogarty International Center
Building 31, Room B2C39
31 Center Drive, MSC 2220
Bethesda, MD 20892
Telephone: 301-435-6031
Fax: 301-402-0779
Email: Michelsk@nih.gov

NATIONAL HUMAN GENOME RESEARCH INSTITUTE

Jean E. McEwen, J.D., Ph.D.
Program Director
Ethical, Legal, and Social Implications Program
National Human Genome Research Institute
National Institutes of Health
Building 31, Room B2B07
31 Center Drive, MSC 4997
Bethesda, MD 20892-2033
Telephone: 301-402-4997
Fax: 301-402-1950
Email: jm522n@nih.gov

NATIONAL INSTITUTE OF ALCOHOL ABUSE AND ALCOHOLISM

Margaret M. Murray, M.S.W.
Chief, International and Health Education Programs Branch
National Institute on Alcohol Abuse and Alcoholism
National Institutes of Health
6000 Executive Boulevard, Suite 302
Rockville, MD 20852
Telephone: 301-443-2594
Email: pmurray@mail.nih.gov

NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES

Rodney Hoff, D.Sc., MPH
Vaccine and Prevention Research Program
Division of AIDS, NIAID/NIH
6700B Rockledge, Room 4157, MSC 7620
Bethesda, MD 20892-7620
Telephone: 301 496 6179
Email: rh25v@nih.gov

NATIONAL INSTITUTE OF DENTAL AND CRANIOFACIAL RESEARCH

Patricia S. Bryant, Ph.D.
Director, Behavioral and Social Science Research
Division of Population and Health Promotion Sciences
National Institute of Dental and Craniofacial Research
National Institutes of Health
Building 45, Room 4AN24E, MSC 6402
Bethesda, MD 20892-6402
Telephone: 301-594-2095
Fax: 301-480-8318
Email: BryantP@de45.nidr.nih.gov

NATIONAL INSTITUTE ON DRUG ABUSE

Minda R. Lynch, Ph.D.
Branch Chief
Behavioral and Cognitive Sciences Research Branch
Division of Neuroscience and Behavioral Research
National Institute on Drug Abuse
National Institutes of Health
6001 Executive Boulevard, Room 4282, MSC 9555
Bethesda, MD 20892
Telephone: 301-435-1322
Fax: 301-594-6043
Email: mlynch1@nida.nih.gov

Leslie C. Cooper, Ph.D., M.P.H., B.S.N., R.N.
Research Program Director for the Epidemiology, Etiology and Consequences of Drug Abuse in Special Populations and Health Disparities.
Captain/USPHSCC
Nurse Epidemiologist
NIH/NIDA/DESPR
6001 Executive Boulevard, Room 5167, MSV 9589
Bethesda, MD 20892-9589

Telephone: 301-402-1906
Fax: 301-480-2543
Email: lc58q@nih.gov

NATIONAL INSTITUTE OF MENTAL HEALTH

Emeline Otey, Ph.D.
Division of Mental Disorders, Behavioral Research and AIDS
National Institute of Mental Health
6001 Executive Boulevard, Room 6186, MSC 9625
Bethesda, MD 20892-9625
Telephone: 301-443-1636
Fax: 301-443-4611
Email: eotey@nih.gov

Christopher M. Gordon, Ph.D.
Division of Mental Disorders, Behavioral Research, and AIDS
National Institute of Mental Health
6001 Executive Boulevard, Room 6204, MSC 9619
Bethesda, MD 20892-9619
Telephone: 301-443-1613
Email: cgordon1@mail.nih.gov

NATIONAL INSTITUTE OF NEUROLOGICAL DISORDERS AND STROKE

Margaret P. Jacobs
Program Director, Epilepsy Research
National Institute of Neurological Disorders and Stroke, NIH
Neuroscience Center
6001 Executive Boulevard, Room 2138, MSC 9523
Bethesda, MD 20892-9523
Telephone: 301-496-1917
Fax: 301-480-2424
Email: mj22o@nih.gov

OFFICE OF THE DIRECTOR, NIH:

OFFICE OF AIDS RESEARCH

Paul A. Gaist, Ph.D., M.P.H.
Health Scientist Administrator
Office of AIDS Research
Office of the Director
National Institutes of Health
Building 31, Room 4C06
31 Center Drive
Bethesda, MD 20892
Telephone: 301-402-3555
Fax: 301-496-4843
E-mail: gaistp@nih.gov

OFFICE OF RESEARCH ON WOMEN'S HEALTH

Joyce Rudick
Director, Programs and Management

Building 1, Room 201
9000 Rockville Pike, MSC 0161
Bethesda, MD 20892-0161
Telephone: 301-402-1770
Fax: 301-402-1798
Email: Joyce.Rudick@nih.gov

Direct your questions about peer review issues to:

Mariela C. Shirley, Ph.D.
Risk, Prevention, and Health Behavior IRG
Center for Scientific Review
National Institutes of Health
6701 Rockledge Drive, Room 1102, MSC 7848
Bethesda, MD 20892-7848
Bethesda, MD 20817 (For express/courier service)
Telephone: 301-435-3554
Fax: 301-480-3962
Email: Shirleym@csr.nih.gov

Direct your questions about financial or grants management matters to:

FOGARTY INTERNATIONAL CENTER

Bruce Butrum
Grants Management Officer
Grants Office
Fogarty International Center
Building 31, Room B2C29
31 Center Drive, MSC 2220
Bethesda, MD 20892-2220
Telephone: 301-496-1670
Fax: 301-402-0779
Email: butrumb@mail.nih.gov

NATIONAL INSTITUTE OF DENTAL AND CRANIOFACIAL RESEARCH

H. George Hausch, Ph.D.
Division of Extramural Activities
National Institute of Dental and Craniofacial Research
National Institutes of Health
Building 45, Room 4AN-44K, MSC 6402
Bethesda, MD 20892-6402
Telephone: 301-594-2904
Fax: 301-480-8303
Email: George.Hausch@nih.gov

LETTER OF INTENT

Prospective applicants are asked to submit a letter of intent that includes the following information:

- Descriptive title of the proposed research
- Name, address, and telephone number, of the Principal Investigator
- Names of other key personnel

- Participating institutions
- Number and title of this RFA

Although a letter of intent is not required, is not binding, and does not enter into the review of a subsequent application, the information that it contains allows IC staff to estimate the potential review workload and plan the review.

The letter of intent is to be sent by the date listed at the beginning of this document. The letter of intent should be sent to:

Kathleen Michels, Ph.D.
 Program Director
 Division of International Training and Research
 Fogarty International Center
 Building 31, Room B2C39
 31 Center Drive, MSC 2220
 Bethesda, MD 20892-2220
 Telephone: 301-435-6031
 Fax: 301-402-0779
 Email: Michelsk@nih.gov

SUBMITTING AN APPLICATION

Applications must be prepared using the PHS 398 research grant application instructions and forms (rev. 5/2001). The PHS 398 is available at <http://grants.nih.gov/grants/funding/phs398/phs398.html> in an interactive format. For further assistance contact GrantsInfo, Telephone (301) 435-0714, Email: GrantsInfo@nih.gov.

SUPPLEMENTAL INSTRUCTIONS:

Description section: If a country other than the home country of the applicant institution is involved in the application, please include the name of the other country or countries in your description.

Canadian Applicants: Applicants who wish to have their projects considered for funding by CIHR and IDRC must include with their application a letter stating that their application and summary statement should be shared with CIHR and IDRC.

R21 applications: limit of 20 pages for the Research Plan (sections a-d).

SPECIFIC INSTRUCTIONS FOR MODULAR GRANT APPLICATIONS: Applications requesting up to \$250,000 per year in direct costs must be submitted in a modular grant format. The modular grant format simplifies the preparation of the budget in these applications by limiting the level of budgetary detail. Applicants request direct costs in \$25,000 modules. Section C of the research grant application instructions for the PHS 398 (rev. 5/2001) at <http://grants.nih.gov/grants/funding/phs398/phs398.html> includes step-by-step guidance for preparing modular grants. Additional information on modular grants is available at <http://grants.nih.gov/grants/funding/modular/modular.htm>.

USING THE RFA LABEL: The RFA label available in the PHS 398 (rev. 5/2001) application form must be affixed to the bottom of the face page of the application. Type the RFA number on the label. Failure to use this label could result in delayed processing of the application such that it may not reach the review committee in time for review. In addition, the RFA title and number must be typed on line 2 of the face page of the application form and the YES box must be marked. The RFA label is also available at: <http://grants.nih.gov/grants/funding/phs398/label-bk.pdf>.

SENDING AN APPLICATION TO THE NIH: Submit a signed, typewritten original of the application, including the Checklist, and four signed photocopies, in one package to:

Center For Scientific Review
National Institutes of Health
6701 Rockledge Drive, Room 1040, MSC 7710
Bethesda, MD 20892-7710
Bethesda, MD 20817 (For express/courier service)

At the time of submission, one additional copy of the application must be sent to:

Kathleen Michels, Ph.D.
Program Director
Division of International Training and Research
Fogarty International Center
Building 31, Room B2C39
31 Center Drive, MSC 2220
Bethesda, MD 20892-2220
Phone: 301-435-6031
Fax: 301-402-0779
Email: Michelsk@nih.gov

APPLICATION PROCESSING: Applications must be received by the application receipt date listed in the heading of this RFA. If an application is received after that date, it will be returned to the applicant without review.

The Center for Scientific Review (CSR) will not accept any application in response to this RFA that is essentially the same as one currently pending initial review, unless the applicant withdraws the pending application. The CSR will not accept any application that is essentially the same as one already reviewed. This does not preclude the submission of substantial revisions of applications already reviewed, but such applications must include an Introduction addressing the previous critique.

PEER REVIEW PROCESS

Upon receipt, applications will be reviewed for completeness by the CSR and responsiveness by the participating Institutes and Centers. Incomplete applications will be returned to the applicant without further consideration. If the application is not responsive to the RFA, CSR staff may contact the applicant to determine whether to return the application to the applicant or submit it for review in competition with unsolicited applications at the next appropriate NIH review cycle.

Applications that are complete and responsive to the RFA will be evaluated for scientific and technical merit by an appropriate peer review group convened by the CSR in accordance with the review criteria stated below. As part of the initial merit review, all applications will:

- Receive a written critique
- May undergo a process in which only those applications deemed to have the highest scientific merit, generally the top half of the applications under review, will be discussed and assigned a priority score
- Receive a second level review by the National Advisory Council of the relevant participating IC or Board.

REVIEW CRITERIA

The goals of NIH-supported research are to advance our understanding of biological systems, improve the control of disease, and enhance health. In the written comments, reviewers will be asked to discuss the following aspects of your application in order to judge the likelihood that the proposed research will have a substantial impact on the pursuit of these goals:

- Significance
- Approach

- Innovation
- Investigator
- Environment

The scientific review group will address and consider each of these criteria in assigning your application's overall score, weighting them as appropriate for each application. Your application does not need to be strong in all categories to be judged likely to have major scientific impact and thus deserve a high priority score. For example, you may propose to carry out important work that by its nature is not innovative but is essential to move a field forward.

- (1) **SIGNIFICANCE:** Does your study address an important problem related to stigma and health? If the aims of your application are achieved, how do they advance scientific knowledge? What will be the effect of these studies on the concepts or methods that drive this field?
- (2) **APPROACH:** Are the conceptual framework, design, methods, and analyses adequately developed, well integrated, and appropriate to the aims of the project? Do you acknowledge potential problem areas and consider alternative tactics? Do your project use multidisciplinary tools, techniques and expertise to address stigma and health at various levels?
- (3) **INNOVATION:** Does your project employ novel concepts, approaches or methods? Are the aims original and innovative? Does your project challenge existing paradigms or develop new methodologies or technologies?
- (4) **INVESTIGATOR:** Are you appropriately trained and well suited to carry out this work? Is the work proposed appropriate to your experience level as the principal investigator and to that of other researchers (if any)?
- (5) **ENVIRONMENT:** Does the scientific environment in which your work will be done contribute to the probability of success? Do the proposed experiments take advantage of unique features of the scientific environment or employ useful collaborative arrangements? Is there evidence of institutional support?

ADDITIONAL REVIEW CRITERIA: In addition to the above criteria, your application will also be reviewed with respect to the following:

SPECIFIC R21 REVIEW CRITERIA:

- Innovation of the project and potential significance of the proposed research will be the major considerations in the evaluation of the R21 exploratory grant mechanism. Because the R21 is designed to support innovative ideas, preliminary data as evidence of feasibility of the project are not required. However, the applicant is also responsible for presenting the background literature that provides some basis for the approach and for developing a rigorous research plan. Relevant pilot data should be cited when available.
- **PROTECTIONS:** The adequacy of the proposed protection for humans, animals, or the environment, to the extent they may be adversely affected by the project proposed in the application.
- **INCLUSION:** The adequacy of plans to include subjects from both genders, all racial and ethnic groups (and subgroups), and children as appropriate for the scientific goals of the research. Plans for the recruitment and retention of subjects will also be evaluated. (See Inclusion Criteria included in the section on Federal Citations, below)
- **DATA SHARING:** The adequacy of the proposed plan to share data.
- **BUDGET:** The reasonableness of the proposed budget and the requested period of support in relation to the proposed research.

RECEIPT AND REVIEW SCHEDULE

Letter of Intent Receipt Date: October 14, 2002
Application Receipt Date: November 14, 2002
Peer Review Date: February 2003
Council Review: May 2003
Earliest Anticipated Start Date: July 1, 2003

AWARD CRITERIA

Award criteria that will be used to make award decisions include:

- Scientific merit (as determined by peer review)
- Availability of funds
- Programmatic priorities

REQUIRED FEDERAL CITATIONS

MONITORING PLAN AND DATA SAFETY AND MONITORING BOARD:

Research components involving Phase I and II clinical trials must include provisions for assessment of patient eligibility and status, rigorous data management, quality assurance, and auditing procedures. In addition, it is NIH policy that all clinical trials require data and safety monitoring, with the method and degree of monitoring being commensurate with the risks (NIH Policy for Data Safety and Monitoring, NIH Guide for Grants and Contracts, June 12, 1998: <http://grants.nih.gov/grants/guide/notice-files/not98-084.html>).

INCLUSION OF WOMEN AND MINORITIES IN CLINICAL RESEARCH: It is the policy of the NIH that women and members of minority groups and their sub-populations must be included in all NIH-supported clinical research projects unless a clear and compelling justification is provided indicating that inclusion is inappropriate with respect to the health of the subjects or the purpose of the research. This policy results from the NIH Revitalization Act of 1993 (Section 492B of Public Law 103-43).

All investigators proposing clinical research should read the AMENDMENT "NIH Guidelines for Inclusion of Women and Minorities as Subjects in Clinical Research - Amended, October, 2001," published in the NIH Guide for Grants and Contracts on October 9, 2001 (<http://grants.nih.gov/grants/guide/notice-files/NOT-OD-02-001.html>), a complete copy of the updated Guidelines are available at http://grants.nih.gov/grants/funding/women_min/guidelines_amended_10_2001.htm

The amended policy incorporates: the use of an NIH definition of clinical research, updated racial and ethnic categories in compliance with the new OMB standards, clarification of language governing NIH-defined Phase III clinical trials consistent with the new PHS Form 398, and updated roles and responsibilities of NIH staff and the extramural community. The policy continues to require for all NIH-defined Phase III clinical trials that: a) all applications or proposals and/or protocols must provide a description of plans to conduct analyses, as appropriate, to address differences by sex/gender and/or racial/ethnic groups, including subgroups if applicable, and b) investigators must report annual accrual and progress in conducting analyses, as appropriate, by sex/gender and/or racial/ethnic group differences

INCLUSION OF CHILDREN AS PARTICIPANTS IN RESEARCH INVOLVING HUMAN SUBJECTS: The NIH maintains a policy that children (i.e., individuals under the age of 21) must be included in all human subjects research, conducted or supported by the NIH, unless there are scientific and ethical reasons not to include them. This policy applies to all initial (Type 1) applications submitted for receipt dates after October 1, 1998.

All investigators proposing research involving human subjects should read the "NIH Policy and Guidelines" on the inclusion of children as participants in research involving human subjects that is available at <http://grants.nih.gov/grants/funding/children/children.htm>.

REQUIRED EDUCATION ON THE PROTECTION OF HUMAN SUBJECT PARTICIPANTS: NIH policy requires education on the protection of human subject participants for all investigators submitting NIH proposals for research involving human subjects. You will find this policy announcement in the NIH Guide for Grants and Contracts Announcement, dated June 5, 2000, at <http://grants.nih.gov/grants/guide/notice-files/NOT-OD-00-039.html>.

PUBLIC ACCESS TO RESEARCH DATA THROUGH THE FREEDOM OF INFORMATION ACT: The Office of Management and Budget (OMB) Circular A-110 has been revised to provide public access to research data through the Freedom of Information Act (FOIA) under some circumstances. Data that are (1) first produced in a project that is supported in whole or in part with Federal funds and (2) cited publicly and officially by a Federal agency in support of an action that has the force and effect of law (i.e., a regulation) may be accessed through FOIA. It is important for applicants to understand the basic scope of this amendment. NIH has provided guidance at http://grants.nih.gov/grants/policy/a110/a110_guidance_dec1999.htm.

Applicants may wish to place data collected under this RFA in a public archive, which can provide protections for the data and manage the distribution for an indefinite period of time. If so, the application should include a description of the archiving plan in the study design and include information about this in the budget justification section of the application. In addition, applicants should think about how to structure informed consent statements and other human subjects procedures given the potential for wider use of data collected under this award.

URLS IN NIH GRANT APPLICATIONS OR APPENDICES: All applications and proposals for NIH funding must be self-contained within specified page limitations. Unless otherwise specified in an NIH solicitation, Internet addresses (URLs) should not be used to provide information necessary to the review because reviewers are under no obligation to view the Internet sites. Furthermore, we caution reviewers that their anonymity may be compromised when they directly access an Internet site.

HEALTHY PEOPLE 2010: The Public Health Service (PHS) is committed to achieving the health promotion and disease prevention objectives of "Healthy People 2010," a PHS-led national activity for setting priority areas. This RFA is related to one or more of the priority areas. Potential applicants may obtain a copy of "Healthy People 2010" at <http://www.health.gov/healthypeople>.

AUTHORITY AND REGULATIONS: This program is described in the Catalog of Federal Domestic Assistance No. 93.989. Awards are made under authorization of sections 301 and 405 of the Public Health Service Act as amended (42 USC 241 and 284) and administered under NIH grants policies and Federal Regulations 42 CFR 52 and 45 CFR Parts 74 and 92. This program is not subject to the intergovernmental review requirements of Executive Order 12372 or Health Systems Agency review. The PHS strongly encourages all grant recipients to provide a smoke-free workplace and discourage the use of all tobacco products. In addition, Public Law 103-227, the Pro-Children Act of 1994, prohibits smoking in certain facilities (or in some cases, any portion of a facility) in which regular or routine education, library, day care, health care, or early childhood development services are provided to children. This is consistent with the PHS mission to protect and advance the physical and mental health of the American people.

Appendix C: FIC Mission Statement and Summary of Strategic Plan Goals and Strategic Priorities

Mission Statement

The Fogarty International Center is dedicated to advancing the mission of the National Institutes of Health by supporting and facilitating global health research conducted by U.S. and international investigators, building partnerships between health research institutions in the U.S. and abroad, and training the next generation of scientists to address global health needs.⁴⁷

Strategic Plan 2008-2012 – Goals and Strategic Priorities⁴⁸

Goals	Strategic Priorities
I: Mobilize the scientific community to address the shifting global burden of disease and disability.	<p><i>Expand Fogarty’s investment in noncommunicable diseases research and research training.</i></p> <p><i>Continue to invest in infectious diseases research and research training.</i></p>
II: Bridge the training gap in implementation research.	<p><i>Support and expand the development of research training programs for implementation science research.</i></p> <p><i>Support the application of implementation research to the recommendations from the Disease Control Priorities Project.</i></p>
III: Develop human capital to meet global health challenges.	<p><i>Expand programs to provide early global health research experiences for U.S. health science students and junior faculty.</i></p> <p><i>Sustain research training for future generations of foreign health scientists.</i></p> <p><i>Expand research support for foreign researchers to promote pathways to independence.</i></p>
IV: Foster a sustainable research environment in low- and middle-income countries.	<p><i>Support the development of research hubs in low- and middle- income countries.</i></p> <p><i>Bolster the development of expertise and use of information and communication technologies (ICT) in support of research and research training programs.</i></p> <p><i>Sponsor the development of Fogarty alumni networks.</i></p>
V: Build strategic alliances and partnerships in global health research and training.	<p><i>Forge partnerships based on mutual interest and complementary strengths</i></p>

⁴⁷ NIH, Fogarty International Center, “About Fogarty,” <http://www.fic.nih.gov/about/index.htm>.

⁴⁸ NIH, Fogarty International Center, “Pathways to Global Health Research; Strategic Plan: 2008-2012,” http://www.fic.nih.gov/about/plan/strategicplan_08-12.htm.

Appendix D: Glossary of Key Terms

R01 - NIH Research Project Grant Program

- Used to support a discrete, specified, circumscribed research project
- NIH's most commonly used grant program
- No specific dollar limit unless specified in FOA
- Advance permission required for \$500K or more (direct costs) in any year
- Generally awarded for 3 -5 years
- All ICs utilize

R21 - NIH Exploratory/Developmental Research Grant Award

- Encourages new, exploratory and developmental research projects by providing support for the early stages of project development. Sometimes used for pilot and feasibility studies.
- Limited to up to two years of funding
- Combined budget for direct costs for the two year project period usually may not exceed \$275,000.
- No preliminary data is generally required
- Most ICs utilize

Program Announcement (PA)

- Identifies areas of increased priority and/or emphasis on particular funding mechanisms for a specific area of science
- Applications usually accepted on an on-going basis
- Remains active for three years from date of release unless the announcement indicates a specific expiration date or the NIH Institute/Center (IC) inactivates sooner

Request for Application (RFA)

- Identifies a more narrowly defined area for which one or more NIH institutes have set aside funds for awarding grants
- Usually has a single receipt (received on or before) date specified in the RFA announcement
- Applications usually reviewed by a Scientific Review Group convened by the issuing awarding component

Appendix E: CRISP Terms Associated with Awarded Stigma and Global Health Projects

CRISP Term	Primary	Secondary	Tertiary
Psychosocial separation	18	0	0
Mental Health	5	1	0
culture	4	4	0
health care quality	4	2	0
social psychology	4	1	0
AIDS	4	0	0
prejudice	3	3	0
attitude	3	3	0
gender difference	3	2	0
Africa	3	1	1
health care service utilization	3	1	0
HIV infection	3	1	0
epidemiology	2	2	0
substance abuse	2	1	0
depression	2	1	0
human immunodeficiency virus	2	0	0
patient care personnel relations	2	0	0
tuberculosis	2	0	0
adolescence (12-20)	2	0	0
African	2	0	0
mental disorder	2	0	0
migrant	2	0	0
perception	1	5	0
socioeconomics	1	2	0
health care personnel	1	2	0
mental health service	1	2	0
quality of life	1	2	0
therapy compliance	1	2	0
United States	1	1	0
AIDS education /prevention	1	1	0
education evaluation /planning	1	1	0
geographic difference	1	1	0
mental health epidemiology	1	1	0
low income	1	1	0
stress	1	1	0
India	1	0	1
epilepsy	1	0	0
China	1	0	0
immigrant	1	0	0
Mental Health education	1	0	0
African American	1	0	0
body movement	1	0	0
Caribbean island	1	0	0

CRISP Term	Primary	Secondary	Tertiary
Chinese	1	0	0
comorbidity	1	0	0
educational psychology	1	0	0
health administration	1	0	0
health behavior	1	0	0
health care service organization	1	0	0
major depression	1	0	0
neuropsychology	1	0	0
Parkinson's disease	1	0	0
patient care personnel attitude	1	0	0
posttraumatic stress disorder	1	0	0
Puerto Rico	1	0	0
schizophrenia	1	0	0
social change	1	0	0
high risk behavior /lifestyle	1	0	0
school	1	0	0
sex behavior	1	0	0
belief	0	6	0
outcomes research	0	6	0
psychometrics	0	6	0
racial /ethnic difference	0	4	0
experience	0	3	0
health care policy	0	3	0
health care service availability	0	3	0
health care service evaluation	0	3	0
data collection	0	2	1
community health service	0	2	0
coping	0	2	0
data collection methodology /evaluation	0	2	0
family structure /dynamics	0	2	0
health disparity	0	2	0
medically underserved population	0	2	0
New Zealand	0	2	0
rural area	0	2	0
self concept	0	2	0
sexual orientation	0	2	0
social model	0	2	0
social perception	0	2	0
social support network	0	2	0
child behavior disorder	0	1	0
urban area	0	1	0
AIDS /HIV test	0	1	0
allied health personnel	0	1	0
alternative medicine	0	1	0
Bangladesh	0	1	0
behavior therapy	0	1	0
bipolar depression	0	1	0
Brazil	0	1	0

CRISP Term	Primary	Secondary	Tertiary
child psychology	0	1	0
communicable disease control	0	1	0
diagnosis quality /standard	0	1	0
drug abuse therapy	0	1	0
drug resistance	0	1	0
environmental stressor	0	1	0
ethnic group	0	1	0
experimental design	0	1	0
face expression	0	1	0
fear	0	1	0
Germany	0	1	0
health care facility	0	1	0
hospital personnel	0	1	0
human migration	0	1	0
impression	0	1	0
interpersonal relations	0	1	0
Japan	0	1	0
longitudinal human study	0	1	0
method development	0	1	0
nurse	0	1	0
nurse patient relations	0	1	0
nursing personnel	0	1	0
perceptual masking	0	1	0
Philippines	0	1	0
physician	0	1	0
politics	0	1	0
psychopathology	0	1	0
religion	0	1	0
Scandinavian country	0	1	0
sex role	0	1	0
social group process	0	1	0
South America	0	1	0
Taiwan	0	1	0
behavioral /social science research tag	0	0	18
clinical research	0	0	17
human subject	0	0	17
interview	0	0	9
health services research tag	0	0	6
questionnaire	0	0	4
health survey	0	0	3
behavior test	0	0	2
adult human (21+)	0	0	1
handbook	0	0	1
human data	0	0	1
patient oriented research	0	0	1
psychological test	0	0	1
southeast Asia	0	0	1
videotape /videodisc	0	0	1

Appendix F: Results of Search for Awards whose Abstracts use “Stigma”, 2001–2008

1. Award Number: 1F31MH012836-01A1(NIMH). PI: BEALS, KRISTIN. Title: Stigmatized Identity, Psychological and Physical Health. FY First awarded: 2001
2. Award Number: 1Z01HG000166-02(NHGRI). PI: BIESECKER, BARBARA. Title: Stigma/culture/genetics of schizophrenia--Family perspec. FY First awarded: 2001
3. Award Number: 1R01DA015269-01(NIDA). PI: BOCKTING, WALTER. Title: Gender Identity and HIV Risk. FY First awarded: 2001
4. Award Number: 1R21MH062135-01A1(NIMH). PI: GLYNN, SHIRLEY. Title: Online Family Support and Education for Schizophrenia. FY First awarded: 2001
5. Award Number: 1Z01HG000188-01(NHGRI). PI: HADLEY, DONALD. Title: How Does Mode of Inheritance of a Genetic Condition Infl. FY First awarded: 2001
6. Award Number: 1F30DA014458-01(NIDA). PI: HORWITZ, RUSSELL. Title: DRUG ABUSE AND CONSENT FOR MEXICAN IMMIGRANT HIV TESTING. FY First awarded: 2001
7. Award Number: 1R01MH062966-01A1(NIMH). PI: MARTIN, DAVID. Title: Working with HIV/AIDS: A Mixed Modality Intervention. FY First awarded: 2001
8. Award Number: 1R01HD039117-01A2(NICHHD). PI: NACHTIGALL, ROBERT. Title: The Disclosure Decision after the Use of Donor Gametes. FY First awarded: 2001
9. Award Number: 1R01MH062981-01(NIMH). PI: PRESTON, DEBORAH. Title: EFFECTS OF STIGMA ON RISK BEHAVIOR OF RURAL MEN. FY First awarded: 2001
10. Award Number: 1R03MH061710-01A1(NIMH). PI: SANTOS, DOUGLAS. Title: MENTAL HEALTH OF WOMEN WITH HIV/AIDS IN PUERTO RICO. FY First awarded: 2001
11. Award Number: 1F31MH012816-01A1(NIMH). PI: SANTUZZI, ALECIA. Title: PREDOCTORAL FELLOWSHIP PROGRAM (DISABILITY). FY First awarded: 2001
12. Award Number: 1R03MH063142-01(NIMH). PI: SIREY, JO. Title: Barriers to Mental Health Treatment in Primary Care. FY First awarded: 2001
13. Award Number: 1R01MH066767-01(NIMH). PI: ALLEN, SUSAN. Title: Couples HIV Counseling & Testing in two African capitals. FY First awarded: 2002
14. Award Number: 1F31MH065776-01(NIMH). PI: BERGSTRESSER, SARA. Title: Community Mental Health Care: An Ethnographic Case Study. FY First awarded: 2002
15. Award Number: 1R01MH066806-01(NIMH). PI: EARLS, FELTON. Title: Ecology of HIV /AIDS and Child Mental Health in Tanzania. FY First awarded: 2002
16. Award Number: 1R24HD043558-01(NICHHD). PI: JEFFERY, BRIDGET. Title: Building Capacity for AIDS research in South Africa. FY First awarded: 2002
17. Award Number: 1R03MH064317-01A1(NIMH). PI: KAHNG, SANG. Title: Stigma and the Two Dimensions of Self-esteem. FY First awarded: 2002
18. Award Number: 1R01HG002431-01(NHGRI). PI: KLITZMAN, ROBERT. Title: Views of Privacy of Genetic Information. FY First awarded: 2002
19. Award Number: 1K02MH065330-01(NIMH). PI: PHELAN, JO. Title: Understanding and Reducing the Stigma of Mental Illness. FY First awarded: 2002
20. Award Number: 1F31MH067535-01(NIMH). PI: PURDIE, VALERIE. Title: Minority Predoctoral Fellowship Program. FY First awarded: 2002
21. Award Number: 1R03MH063913-01A1(NIMH). PI: RICHESON, JENNIFER. Title: Stigma versus Situational Status in Dyadic Interactions. FY First awarded: 2002
22. Award Number: 1R01AI050718-01A1(NIAID). PI: SCHWEBKE, JANE. Title: Control of Trichomoniasis -A Paradigm for STD Control. FY First awarded: 2002
23. Award Number: 1R01HD042970-01(NICHHD). PI: SHEDLIN, MICHELE. Title: New Hispanic Communities and HIV Risk. FY First awarded: 2002

24. Award Number: 1K23MH066381-01(NIMH). PI: SIREY, JO. Title: Improving Antidepressant Adherence in Older Adults. FY First awarded: 2002
25. Award Number: 1F31HD041928-01(NICHD). PI: TRUJILLO, LEA. Title: Minority Predoctoral Fellowship Program. FY First awarded: 2002
26. Award Number: 1R03MH065159-01(NIMH). PI: VARAS-DIAZ, NELSON. Title: Exploring AIDS related stigma in Puerto Rico. FY First awarded: 2002
27. Award Number: 1R01HD041723-01A1(NICHD). PI: WELLE, DORINDA. Title: LGBTQ Youth: Developmental Complexity In The Age Of HIV. FY First awarded: 2002
28. Award Number: 1R01DA015623-01(NIDA). PI: WONG, FRANK. Title: Sexuality, HIV/Drug in 3 Groups of Asian/Gay/Bi Men/MSM. FY First awarded: 2002
29. Award Number: 1U19AI051915-010002(NIAID). PI: WU, ZUNYOU. Title: Behavioral Intervention. FY First awarded: 2002
30. Award Number: 1R24MH068180-01(NIMH). PI: AIRHIHENBUWA, COLLINS. Title: CAPACITY BUILDING FOR RESEARCH ON HIV STIGMA IN S AFRICA. FY First awarded: 2003
31. Award Number: 1R21MH070259-01(NIMH). PI: ALVIDREZ, JENNIFER. Title: Stigma Psychoeducation for Black Mental Health Clients. FY First awarded: 2003
32. Award Number: 1R21NS048060-01(NINDS). PI: BIRBECK, GRETCHEN. Title: Epilepsy-associated stigma in Zambia. FY First awarded: 2003
33. Award Number: 1U01MH066687-01A1(NIMH). PI: CELENTANO, DAVID. Title: Community-Based VCT: Thailand. FY First awarded: 2003
34. Award Number: 1U01MH066701-01A1(NIMH). PI: COATES, THOMAS. Title: Community-Based HIV VCT: South Africa. FY First awarded: 2003
35. Award Number: 1R01TW006320-01(FIC). PI: COREIL, JEANNINE. Title: Stigma and Tuberculosis in Haitian Populations. FY First awarded: 2003
36. Award Number: 1R01AA014842-01(NIAAA). PI: CORRIGAN, PATRICK. Title: Stigma & Behav Hlth in Urban Employers from China & US. FY First awarded: 2003
37. Award Number: 1R21MH066059-01A1(NIMH). PI: CORRIGAN, PATRICK. Title: The Paradox of Self Stigma in Serious Mental Illnes. FY First awarded: 2003
38. Award Number: 1R21AA014855-01(NIAAA). PI: DOHAN, DANIEL. Title: Poverty, Substance Use, and Stigma in Four Organizations. FY First awarded: 2003
39. Award Number: 1R01TW006314-01(FIC). PI: EKSTRAND, MARIA. Title: AIDS Stigma & Gender: Health Consequences in Urban India. FY First awarded: 2003
40. Award Number: 1R21MH070261-01(NIMH). PI: ELLIS, BEVERLEY. Title: Stigma and PTSD in Refugee Adolescents. FY First awarded: 2003
41. Award Number: 1R03MH069334-01(NIMH). PI: EMLET, CHARLES. Title: HIV Stigma in a population of adults age 50 and over. FY First awarded: 2003
42. Award Number: 1F31MH066492-01A1(NIMH). PI: ERB, CHRISTOPHER. Title: State Mental Health Policy-Making under Managed Care. FY First awarded: 2003
43. Award Number: 1R01TW006395-01(FIC). PI: HOLZEMER, WILLIAM. Title: Perceived AIDS Stigma: A Multinational African Study. FY First awarded: 2003
44. Award Number: 1R21NS048839-01(NINDS). PI: JACOBY, ANN. Title: Developing Approaches to Reducing Stigma of Epilepsy. FY First awarded: 2003
45. Award Number: 1R21DA017644-01(NIDA). PI: KOHLENBERG, BARBARA. Title: Reducing Felt Stigma in SUD. FY First awarded: 2003
46. Award Number: 1R01MH070931-01(NIMH). PI: LI, LI. Title: HIV Related Stigma among Service Providers in China. FY First awarded: 2003
47. Award Number: 1R21TW006375-01(FIC). PI: LI, XIAOMING. Title: Social Stigma/Mental Health Symptoms in Migrant Workers. FY First awarded: 2003
48. Award Number: 1R03AA014595-01(NIAAA). PI: MCKELLAR, JOHN. Title: Behavioral Economics of Help-seeking in AUD. FY First awarded: 2003

49. Award Number: 1R01MH066058-01A1(NIMH). PI: MEYER, ILAN. Title: Stress, Identity, and Mental Health. FY First awarded: 2003
50. Award Number: 1R01MH070260-01(NIMH). PI: MIRANDA, MARTHA. Title: Clinical Implications of Depression-Based Stigma. FY First awarded: 2003
51. Award Number: 1R03MH068255-01(NIMH). PI: MORADI, BANAFSHEH. Title: Examining Minority Stress & Mental Health. FY First awarded: 2003
52. Award Number: 1U01MH066702-01A1(NIMH). PI: MORIN, STEPHEN. Title: Community-Based HIV VCT: Zimbabwe. FY First awarded: 2003
53. Award Number: 1R01TW006374-01(FIC). PI: PESCOLIDIO, BERNICE. Title: Stigma and Mental Illness in Cross-National Perspective. FY First awarded: 2003
54. Award Number: 1R01DA017979-01(NIDA). PI: SAEWYC, ELIZABETH. Title: Enacted Stigma, Gender & Risk Behaviors of School Youth. FY First awarded: 2003
55. Award Number: 1R03MH067124-01(NIMH). PI: SCOTT, LIONEL. Title: Young African American Males' Readiness to Seek Help. FY First awarded: 2003
56. Award Number: 1R21TW006329-01(FIC). PI: SOLOMON, SUNITI. Title: Stigma in Health Care Settings in South India. FY First awarded: 2003
57. Award Number: 1U01MH066688-01A1(NIMH). PI: SWEAT, MICHAEL. Title: Community-Based VCT: Tanzania. FY First awarded: 2003
58. Award Number: 1R01NS048059-01(NINDS). PI: TICKLE-DEGNER, LINDA. Title: Culture, Gender, and Health Care Stigma in Parkinsonism. FY First awarded: 2003
59. Award Number: 1R21TW006347-01(FIC). PI: VAN RIE, ANNELIES. Title: Social Stigma of the New Tuberculosis. FY First awarded: 2003
60. Award Number: 1R21DA017643-01(NIDA). PI: VARAS-DIAZ, NELSON. Title: AIDS stigma and health professionals in Puerto Rico. FY First awarded: 2003
61. Award Number: 1R01MH065880-01A1(NIMH). PI: WAHL, OTTO. Title: Mental Illness in Children's TV. FY First awarded: 2003
62. Award Number: 1U54RR019507-01(NCRR). PI: ZORRILLA, CARMEN. Title: Puerto Rico Comprehensive Center for HIV Disparities. FY First awarded: 2003
63. Award Number: 1R36MH071135-01(NIMH). PI: ALMAZAN, ELBERT. Title: Stigma, Social Structure, and Adolescent Mental Health. FY First awarded: 2004
64. Award Number: 1R03HD046371-01A1(NICHHD). PI: ARMISTEAD, LISA. Title: HIV-infection and Parenting in South African Mothers. FY First awarded: 2004
65. Award Number: 1R36MH071117-01(NIMH). PI: CHANDRA, ANITA. Title: Teens Addressing Mental Health Services. FY First awarded: 2004
66. Award Number: 1R21DA018072-01(NIDA). PI: CLATTS, MICHAEL. Title: HIV Risk & Migration -Young Yi Minority - Sichuan China. FY First awarded: 2004
67. Award Number: 1F31MH072549-01(NIMH). PI: LINDNER, GRETCHEN. Title: HIV and Psychological Functioning in South African Women. FY First awarded: 2004
68. Award Number: 1F31MH071179-01A1(NIMH). PI: PANTALONE, DAVID. Title: Intimate Partner Violence Among HIV-Infected Outpatients. FY First awarded: 2004
69. Award Number: 1R01DE015860-01(NIDCR). PI: PATRICK, DONALD. Title: Stigma & Quality of Life of Youth w/Facial Differences. FY First awarded: 2004
70. Award Number: 1R01MH065950-01A2(NIMH). PI: PESCOLIDIO, BERNICE. Title: Social Network & Media Effects on Mental Illness Stigma. FY First awarded: 2004
71. Award Number: 1P30MH068579-01A1(NIMH). PI: PROCTOR, ENOLA. Title: Center for Research on Mental Health in Social Services. FY First awarded: 2004
72. Award Number: 1R01MH071749-01(NIMH). PI: SCHMADER, TONI. Title: Stereotype Threat as a Stress Induced Cognitive Deficit. FY First awarded: 2004
73. Award Number: 1R01MH066848-01A2(NIMH). PI: SOLOMON, SONDRRA. Title: Rural Ecology and Coping with HIV Stigma. FY First awarded: 2004

74. Award Number: 1R01MH069864-01(NIMH). PI: VON KORFF, MICHAEL. Title: Social Role Disability and Mental-Physical Co-Morbidity. FY First awarded: 2004
75. Award Number: 1R01HD041716-01A2(NICHD). PI: WINGOOD, GINA. Title: National Survey on HIV Risk for African-American Women. FY First awarded: 2004
76. Award Number: 1R34MH073073-01(NIMH). PI: ADDIS, MICHAEL. Title: Men's Service Use for Depression and Anxiety Disorders. FY First awarded: 2005
77. Award Number: 1F31MH073442-01A1(NIMH). PI: ANDRINOPOULOS, KATHERINE. Title: Stigma as a Barrier to HIV Testing for Inmates, Jamaica. FY First awarded: 2005
78. Award Number: 1R21NR009362-01(NINR). PI: AYRES, LIONESS. Title: Persons with Impaired Mobility: Transition to Adulthood. FY First awarded: 2005
79. Award Number: 1R21MH073495-01A1(NIMH). PI: GALLETLY, CAROL. Title: Exploring the Impact of Criminal HIV Disclosure Law. FY First awarded: 2005
80. Award Number: 1R01DA017868-01A1(NIDA). PI: HAYES, STEVEN. Title: Stigma and Burnout in Addiction Counselors. FY First awarded: 2005
81. Award Number: 1R01TW007298-01(FIC). PI: HE, NA. Title: Community-based VCT for HIV in Rural Migrants in China. FY First awarded: 2005
82. Award Number: 1R01CA107305-01A1(NCI). PI: HEINEY, SUE. Title: Teleconference Group: Breast Cancer In African Americans. FY First awarded: 2005
83. Award Number: 1K23AI063998-01A1(NIAID). PI: IVERS, LOUISE. Title: Identifying HIV and related stigma in rural Haiti. FY First awarded: 2005
84. Award Number: 1R03MH072638-01A1(NIMH). PI: JAYASINGHE, NIMALI. Title: Barriers to treatment in WTC attack disaster workers. FY First awarded: 2005
85. Award Number: 1R34MH072382-01A1(NIMH). PI: MCKAY, MARY. Title: CHAMP+: Supporting HIV-infected youth and families. FY First awarded: 2005
86. Award Number: 1R21MH076447-01(NIMH). PI: MUKHERJEE, JOIA. Title: Psychosocial Intervention in HIV-Affected Children in Haiti. FY First awarded: 2005
87. Award Number: 1R21AA015397-01A1(NIAAA). PI: MULIA, NINA. Title: Race, Stressors, and Alcohol-related Health Disparities. FY First awarded: 2005
88. Award Number: 1R01MH074985-01(NIMH). PI: PESCOSOLIDO, BERNICE. Title: Assessing Change in Mental Illness Stigma Over A Decade. FY First awarded: 2005
89. Award Number: 1R01NR009922-01(NINR). PI: ROTHERAM-BORUS, MARY. Title: Family-to-Family: Psychoeducation to Improve Children's Outcomes in HIV+ Families. FY First awarded: 2005
90. Award Number: 1R01MH071307-01A1(NIMH). PI: SAINT ARNAULT, DENISE. Title: Mixed-Method Analysis of Depressed Japanese Women. FY First awarded: 2005
91. Award Number: 1F31MH075497-01(NIMH). PI: SHAPIRO, JENESSA. Title: Reducing The Consequences Of Mental Illness Stigma. FY First awarded: 2005
92. Award Number: 1U01MH070018-01A2(NIMH). PI: SHERBOURNE, CATHY. Title: CALM: IMPROVING PRIMARY CARE ANXIETY OUTCOMES. FY First awarded: 2005
93. Award Number: 1Z01HD008741-04(NICHD). PI: SIMONS-MORTON, BRUCE. Title: Research On Family Management Of Childhood Disease. FY First awarded: 2005
94. Award Number: 1U01MH070022-01A2(NIMH). PI: SULLIVAN, JAN. Title: CALM: Improving Primary Care Anxiety Outcomes. FY First awarded: 2005
95. Award Number: 1R01MH071781-01A1(NIMH). PI: THOMAS, CSORDAS. Title: Navajo Youth and the Experience of Psychiatric Treatment. FY First awarded: 2005
96. Award Number: 1R01HD050180-01(NICHD). PI: WAWER, MARIA. Title: ARV effects on HIV epidemiology & behaviors Rakai Uganda. FY First awarded: 2005
97. Award Number: 1R21DA019394-01(NIDA). PI: WILLIAMS, MARK. Title: Tanzania Injection Drug Use/HIV Prevention Project. FY First awarded: 2005
98. Award Number: 1K01MH073034-01(NIMH). PI: YANG, LAWRENCE. Title: EE and Stigma among Chinese-Americans with Schizophrenia. FY First awarded: 2005

99. Award Number: 1D71TW007548-01(FIC). PI: BALABANOVA, YANINA. Title: Development of research capacity for AIDS and TB in Samara Oblast, Russia. FY First awarded: 2006
100. Award Number: 1K23AI068458-01(NIAID). PI: BASSETT, INGRID. Title: The Efficacy and Impact of Routine HIV and TB Testing in Durban, South Africa. FY First awarded: 2006
101. Award Number: 1R01MH077574-01(NIMH). PI: CADDELL, JUESTA. Title: Randomized Trial of a Self-Management Early Intervention for Combat-Related PTSD. FY First awarded: 2006
102. Award Number: 1R34MH078874-01(NIMH). PI: ENGEL, CHARLES. Title: Randomized Trial of an Online Early Intervention for Combat PTSD in Primary Care. FY First awarded: 2006
103. Award Number: 1K01DA020774-01(NIDA). PI: FRYE, VICTORIA. Title: Informal Social Control of Partner Violence in Drug Users. FY First awarded: 2006
104. Award Number: 1R21MH073002-01A2(NIMH). PI: KALES, HELEN. Title: Racial Differences in Geriatric Antidepressant Adherence. FY First awarded: 2006
105. Award Number: 1T32MH074387-01A1(NIMH). PI: KALICHMAN, SETH. Title: Training in Social Processes of HIV/AIDS. FY First awarded: 2006
106. Award Number: 1R21MH074996-01A1(NIMH). PI: LINK, BRUCE. Title: Stigma and Psychosis: A Prospective Study. FY First awarded: 2006
107. Award Number: 1R01DK073835-01(NIDDK). PI: MCGRAW, SARAH. Title: Beneath the Urologic Iceberg: A Qualitative Study. FY First awarded: 2006
108. Award Number: 1R01MH072649-01A2(NIMH). PI: MCKAY, MARY. Title: Family Groups to Reduce Youth Behavioral Difficulties. FY First awarded: 2006
109. Award Number: 1R21TW007554-01(FIC). PI: MIRZA, ILYAS. Title: Community management of mental retardation in Pakistan: An exploratory study. FY First awarded: 2006
110. Award Number: 1F31MH076743-01A1(NIMH). PI: NAMBIAR, DEVAKI. Title: Minority Predoctoral Fellowship Program. FY First awarded: 2006
111. Award Number: 1F31HD054022-01(NICHD). PI: NOBLES, RICHARD. Title: MINORITY PREDOCTORAL FELLOWSHIP PROGRAM. FY First awarded: 2006
112. Award Number: 1R01HD053268-01(NICHD). PI: OBERMEYER, CARLA. Title: Testing and Counseling for HIV: A Multi-Site Study. FY First awarded: 2006
113. Award Number: 1R01DA018621-01A2(NIDA). PI: OPERARIO, DON. Title: Gender, Relationship Dynamics, and HIV Risk. FY First awarded: 2006
114. Award Number: 1R01HG003380-01A1(NHGRI). PI: PHELAN, JO. Title: Genetics and Stigma: The Role of Mass Media. FY First awarded: 2006
115. Award Number: 1R01HD050147-01A1(NICHD). PI: RANKIN, SALLY. Title: Malawi Christians and Muslims HIV Prevention and Care. FY First awarded: 2006
116. Award Number: 1Z01HD008741-05(NICHD). PI: SIMONS-MORTON, BRUCE. Title: Research On Family Management Of Childhood Disease. FY First awarded: 2006
117. Award Number: 1F31MH077558-01(NIMH). PI: TALLEY, AMELIA. Title: HIV-stigma and Depression: Daily Reports from Couples. FY First awarded: 2006
118. Award Number: 1U01MH070016-01A2(NIMH). PI: WILSON, DANIEL. Title: Relapse Prevention: Long-Acting Atypical Antipsychotics. FY First awarded: 2006
119. Award Number: 1R21AA015972-01(NIAAA). PI: ZEMORE, SARAH. Title: Acculturation and Alcohol among U.S. Latinas. FY First awarded: 2006
120. Award Number: 1R24MH082471-01(NIMH). PI: AMIRKHANIAN, YURI. Title: Fostering an AIDS Research and Training Center Infrastructure in Russia. FY First awarded: 2007
121. Award Number: 1R03DA019860-01A2(NIDA). PI: BALDWIN, MARJORIE. Title: Labor Market Discrimination and Substance Use Disorders. FY First awarded: 2007
122. Award Number: 1R03DA022128-01A1(NIDA). PI: BOWEN, ANNE. Title: Wyoming Meth Use and AIDS Risk: Exploring Rural Culture and Context (WyMAR). FY First awarded: 2007
123. Award Number: 1R01HL086830-01(NHLBI). PI: CHANG, VIRGINIA. Title: Dynamic relationship of BMI and SES over the life cycle and between generations. FY First awarded: 2007

124. Award Number: 1R01HD054303-01A1(NICHD). PI: CHIN, JOHN. Title: Organizational Change toward HIV Involvement in Immigrant Religious Organizations. FY First awarded: 2007
125. Award Number: 1F31MH081476-01(NIMH). PI: CULLEN, SARA. Title: Impact of Maternal Psychotic Disorders on Pediatric Health Care Utilization. FY First awarded: 2007
126. Award Number: 1U01AI069486-01(NIAID). PI: DONASTORG, YEYCY. Title: Development of HIV Vaccine Clinical Trials Phase I-II-III in Dominican Republic. FY First awarded: 2007
127. Award Number: 1R01AG028469-01A1(NIA). PI: ECKERT, JOHN. Title: Stigma and the Cultural context of Residential Settings for the Elderly. FY First awarded: 2007
128. Award Number: 1R03MH077021-01A1(NIMH). PI: ELWY, ANASHUA. Title: Help Seeking for Depression by Primary Care Patients. FY First awarded: 2007
129. Award Number: 1R34MH076219-01A2(NIMH). PI: FLYNN, HEATHER. Title: Improving Psychosocial Treatment of Perinatal Depression. FY First awarded: 2007
130. Award Number: 1R01DA022962-01A1(NIDA). PI: GO, VIVIAN. Title: Prevention for Positives: A Randomized Controlled Trial Among Vietnamese HIV-Posi. FY First awarded: 2007
131. Award Number: 1R03MH077598-01A1(NIMH). PI: GUM, AMBER. Title: Depressed Older Adults? Attitudinal and Social Predictors of Mental Health Care. FY First awarded: 2007
132. Award Number: 1R24HD056670-01(NICHD). PI: HENDERSON, GAIL. Title: Partnership for Social Science Research on HIV/AIDS in China. FY First awarded: 2007
133. Award Number: 1R01MH079387-01A1(NIMH). PI: KRAVITZ, RICHARD. Title: Targeted and Tailored Messages to Enhance Depression Care. FY First awarded: 2007
134. Award Number: 1R01MH075837-01A1(NIMH). PI: LAX, AMY. Title: Evaluation of a middle school mental health education program. FY First awarded: 2007
135. Award Number: 1R01MH081778-01A1(NIMH). PI: LI, LI. Title: POL and Access Intervention to Reduce HIV Stigma among Service Providers in China. FY First awarded: 2007
136. Award Number: 1R01MH078770-01A1(NIMH). PI: MANTELL, JOANNE. Title: A Structural Intervention To Integrate Reproductive Health Into HIV Care. FY First awarded: 2007
137. Award Number: 1R03HD055107-01(NICHD). PI: MUNOZ-LABOY, MIGUEL. Title: Ethnography of Men Who Have Sex With Male-to-Female Transgender Individuals. FY First awarded: 2007
138. Award Number: 1R01MH077169-01A2(NIMH). PI: NELSON, ANN. Title: Reducing the Adverse Impact of Mental Illness Stigma Among Family Caregivers. FY First awarded: 2007
139. Award Number: 1R01MH077168-01A2(NIMH). PI: PERLICK, DEBORAH. Title: Reducing the Adverse Impact of Mental Illness Stigma Among Family Caregivers. FY First awarded: 2007
140. Award Number: 1R21HD055841-01(NICHD). PI: PFEIFFER, JAMES T.. Title: Pentecostalism & Utilization of HIV/AIDS Treatment Services in Central Mozambique. FY First awarded: 2007
141. Award Number: 1R01MH079162-01A1(NIMH). PI: PHELAN, JO. Title: Mental-illness stigma and status processes in interpersonal interactions. FY First awarded: 2007
142. Award Number: 1R34MH082654-01(NIMH). PI: REMIEN, ROBERT. Title: A Multimedia Social Support Intervention: Adherence to HIV Care in South Africa. FY First awarded: 2007
143. Award Number: 1R01AA017104-01A1(NIAAAA). PI: ROTHERAM-BORUS, MARY. Title: Neighborhood Alcohol & HIV Prevention in South African Townships. FY First awarded: 2007
144. Award Number: 1R03HD056059-01(NICHD). PI: SALVY, SARAH-JEANNE. Title: Peer Influence on Eating Behavior in Overweight and Normal Weight Youths. FY First awarded: 2007
145. Award Number: 1R01MH078992-01(NIMH). PI: SHELTON, JOSETTE. Title: Racial Bias and Mental Illness Stigma as Risk Factors for Mental Health Problems. FY First awarded: 2007
146. Award Number: 1R01MH079265-01A1(NIMH). PI: SIREY, JO ANNE. Title: Increasing Use of Mental Health Services by Community Dwelling Older Adults with. FY First awarded: 2007
147. Award Number: 1R21AA017136-01(NIAAAA). PI: SOBELL, LINDA. Title: Promoting Self-Change From Alcohol Problems: Mechanisms of Change in a Community. FY First awarded: 2007
148. Award Number: 1K01MH081777-01(NIMH). PI: TURAN, JANET. Title: The Effects of HIV/AIDS Stigma on Use of Services by Pregnant Women in Kenya. FY First awarded: 2007

149. Award Number: 1R01MH080694-01A2(NIMH). PI: VARAS-DIAZ, NELSON. Title: AIDS Stigma among Health Professionals in Puerto Rico. FY First awarded: 2007
150. Award Number: 1R01MH076093-01A1(NIMH). PI: WAHL, OTTO. Title: Evaluation of a middle school mental health education program. FY First awarded: 2007
151. Award Number: 1R01MH077515-01A1(NIMH). PI: WEINHARDT, LANCE. Title: Experimental Analysis of HIV Risk Assessment Reactivity in South African Clinics. FY First awarded: 2007
152. Award Number: 1R03HD054323-01A1(NICHHD). PI: WINSKELL, SAMANTHA. Title: HIV/AIDS through the eyes of young Africans: an analysis of fictional narratives. FY First awarded: 2007
153. Award Number: 1R21AA016286-01A1(NIAAA). PI: WITTE, SUSAN. Title: HIV/STI Prevention among Alcohol-Abusing Women in Mongolia. FY First awarded: 2007
154. Award Number: 1R01MH080662-01A1(NIMH). PI: YBARRA, MICHELE. Title: CyberSenga: Harnessing the power of the internet to prevent HIV in Ugandan youth. FY First awarded: 2007
155. Award Number: 1K23MH082126-01(NIMH). PI: ACHARYA, KRUTI. Title: The Ethics of Fragile X Genetic Screening and Testing Across the Lifespan. FY First awarded: 2008
156. Award Number: 1R21TW008224-01A1(FIC). PI: BASS, JUDITH. Title: HIV and Perinatal Depression in Brazil. FY First awarded: 2008
157. Award Number: 1R01NS061693-01(NINDS). PI: BIRBECK, GRETCHEN. Title: Epilepsy-associated stigma in Zambia: Evidence-based interventions and outcomes. FY First awarded: 2008
158. Award Number: 1R43MH083543-01A1(NIMH). PI: BRUSS, CATHERINE. Title: Psychiatric & Psychosocial Conditions of HIV/AIDS Patients: An e-Learning Course . FY First awarded: 2008
159. Award Number: 1R03NR010582-01(NINR). PI: BURGNER, SANDRA. Title: Examining Perceived Stigma in Persons with Dementia. FY First awarded: 2008
160. Award Number: 1R01DA022170-01A2(NIDA). PI: CLATTS, MICHAEL. Title: Diffusion of HIV-1 among Drug Using Men in SE Asia. FY First awarded: 2008
161. Award Number: 1K01MH079128-01A2(NIMH). PI: FLANAGAN PANTANO, ELIZABETH. Title: Stigma in mental health settings. FY First awarded: 2008
162. Award Number: 1F31MH083401-01(NIMH). PI: HATZENBUEHLER, MARK. Title: Mechanisms conferring risk for psychopathology in stigmatized groups. FY First awarded: 2008
163. Award Number: 1R21DA025252-01(NIDA). PI: HSER, YIH-ING. Title: Improving Methadone Maintenance Treatment Compliance and Outcomes in China. FY First awarded: 2008
164. Award Number: 1R21HD057832-01(NICHHD). PI: KURTH, ANN. Title: Reducing HIV Disparities: Sexual Concurrency Communication for HIV Prevention amo. FY First awarded: 2008
165. Award Number: 1R01HL089314-01A1(NHLBI). PI: LEVY, BECCA. Title: Racial Disparities in Heart Attack Recovery: Role of Stress and Stigma. FY First awarded: 2008
166. Award Number: 1R21MH080959-01A1(NIMH). PI: LIN, HAIQUN. Title: Assessing Intervention Effectiveness in Longitudinal Trials of Antipsychotic Medi. FY First awarded: 2008
167. Award Number: 1R24MD002812-01(NCMHD). PI: LLOYD, STEPHEN. Title: Colon cancer disparity elimination: a faith-based participatory partnership. FY First awarded: 2008
168. Award Number: 1R21CA129887-01A1(NCI). PI: MCMULLEN, CARMIT. Title: Intestinal ostomies and informal caregiving for colorectal cancer survivors. FY First awarded: 2008
169. Award Number: 1R34MH078922-01A2(NIMH). PI: MOHR, DAVID. Title: Integrated Telemental Health Intervention for Depression in Primary Care. FY First awarded: 2008
170. Award Number: 1R01MH082916-01A1(NIMH). PI: Multiple. Title: Predicting Psychological Distress for People with Concealable Stigmatized Identit. FY First awarded: 2008
171. Award Number: 1R03HD055107-01(NICHHD). PI: MUNOZ-LABOY, MIGUEL. Title: Ethnography of Men Who Have Sex With Male-to-Female Transgender Individuals. FY First awarded: 2008
172. Award Number: 1R43DA019723-01A2(NIDA). PI: NEMES, SUSANNA. Title: Lesbian, Gay, Bisexual, and Transgender - Treatment Issues for Providers. FY First awarded: 2008
173. Award Number: 1K23MH080021-01A1(NIMH). PI: PRATT, SARAH. Title: Individually Based Psychosocial Rehabilitation for Older People with SMI. FY First awarded: 2008

174. Award Number: 1K23MH084551-01(NIMH). PI: RAO, DEEPA. Title: Self Stigma Reduction for African Americans Living with HIV/AIDS. FY First awarded: 2008
175. Award Number: 1R01HD053637-01A2(NICHHD). PI: SANDBERG, DAVID. Title: Quality of Life in Intersexuality: A Pediatric Clinical and Research Tool. FY First awarded: 2008
176. Award Number: 1R03DA023438-01A1(NIDA). PI: WHITE, MARY. Title: Methamphetamine use in inmates: risk behaviors, health status and recidivism. FY First awarded: 2008
177. Award Number: 1R36MH080607-01A1(NIMH). PI: WONG, ROSE. Title: Depression as a Culture-Bound Syndrome: Adapting the CES-D for Screening Depressi. FY First awarded: 2008
178. Award Number: 1F31MH083584-01A1(NIMH). PI: WOODS, AMANDA. Title: Adherence in Adolescents with HIV: The Impact of Body Dissatisfaction. FY First awarded: 2008
179. Award Number: 1R34MH082161-01(NIMH). PI: YANOS, PHILIP. Title: Treating Internalized Stigma in Severe Mental Illness. FY First awarded: 2008
180. Award Number: 1R01HD057785-01A1(NICHHD). PI: ZEA, MARIA. Title: HIV PREVALENCE, SEXUAL BEHAVIOR, AND ATTITUDES TOWARD CIRCUMCISION AMONG COLOMBIA. FY First awarded: 2008
181. Award Number: 1R21MH084266-01(NIMH). PI: ZUNIGA DE NUNCIO, MARIA. Title: Barriers to Care & Treatment Practices in HIV+ Latinos in US-Mexico Border Region. FY First awarded: 2008

Appendix G: Results of Search for PAs and RFAs Using “Stigma”, 1992-2008

Year of Release Date	Issuing Organization	Title	What	Announcement Number
2008	NICHD	Meetings, Conferences, and Networks for Research Partnerships to Improve Functional Outcomes (R13)	PA	PAR-08-207
2008	NIA	Social Neuroscience of Aging (R01)	RFA	RFA-AG-09-006
2008	NIMH	Collaborative HIV/AIDS Studies in the Middle East and North Africa (R21)	PA	PAR-08-153
2008	NICHD	Gender, Youth and HIV Risk (R01)	RFA	RFA-HD-08-013
2008	NICHD	Gender, Youth and HIV Risk (R21)	RFA	RFA-HD-08-017
2008	NIMH	Prevention Research with HIV Positive Individuals (R01)	PA	PA-08-107
2008	NIMH	Prevention Research with HIV Positive Individuals (R03)	PA	PA-08-108
2008	NIMH	Prevention Research with HIV Positive Individuals (R21)	PA	PA-08-109
2008	FIC	Brain Disorders in the Developing World: Research Across the Lifespan (R01)	PA	PAR-08-112
2008	FIC	Brain Disorders in the Developing World: Research Across the Lifespan (R21)	PA	PAR-08-113
2008	NCI	The Effect of Racial and Ethnic Discrimination/Bias on Health Care Delivery (R01)	PA	PA-08-083
2008	NCI	The Effect of Racial and Ethnic Discrimination/Bias on Health Care Delivery (R21)	PA	PA-08-084
2008	NCI	The Effect of Racial and Ethnic Discrimination/Bias on Health Care Delivery (R03)	PA	PA-08-085
2008	NIDA	Screening, Brief Intervention and Referral to Treatment (SBIRT) for Drug Abuse in General Medical Settings (R01)	RFA	RFA-DA-08-021
2007	NIMH	Reducing Mental Illness Stigma and Discrimination (Collaborative R01)	PA	PAR-08-040
2007	NIDA	The Interaction of HIV, Drug Use, and the Criminal Justice System (R01)	RFA	RFA-DA-08-007
2007	Roadmap	Studies of the Ethical, Legal, and Social Implications (ELSI) of Human Microbiome Research (R01)	RFA	RFA-RM-08-006
2007	NHGRI	ELSI Regular Research Program (R01)	PA	PA-08-012
2007	NHGRI	ELSI Small Research Grant Program (R03)	PA	PA-08-013
2007	NIDA	Health Research with Diverse Populations (R01)	PA	PA-07-409
2007	NIAID	U.S.-India Bilateral Collaborative Research Partnerships (CRP) on the Prevention of HIV/AIDS (R21)	RFA	RFA-AI-07-031
2007	NINR	Reducing Health Disparities Among Minority and Underserved Children (R21)	PA	PA-07-391
2007	NIH	Reducing Health Disparities Among Minority and Underserved Children (R01)	PA	PA-07-392
2007	NICHD	Addressing the Role of Pregnancy in HIV Prevention (R01)	RFA	RFA-HD-07-020
2007	FIC	Framework Programs for Global Health (R25)	RFA	RFA-TW-08-001
2007	NICHD	Global Network for Women’s and Children’s Health Research (U01)	RFA	RFA-HD-07-016

Year of Release Date	Issuing Organization	Title	What	Announcement Number
2007	NIMH	HIV Treatment Adherence Research (R01)	PA	PA-07-338
2007	NIMH	HIV Treatment Adherence Research (R03)	PA	PA-07-339
2007	NIMH	HIV Treatment Adherence Research (R21)	PA	PA-07-340
2007	NIMH	HIV Treatment Adherence Research (R34)	PA	PAR-07-341
2007	NCHSTP	HIV/AIDS Risk Reduction Interventions for Heterosexually-Active African-American Men (UR6)	RFA	RFA-PS-07-002
2007	NIMH	Mental Health Consequences of Violence and Trauma (R03)	PA	PA-07-313
2007	NIMH	Mental Health Consequences of Violence And Trauma (R21)	PA	PA-07-314
2007	NIMH	Mental Health Consequences of Violence And Trauma (R34)	PA	PAR-07-315
2007	NIMH	Mental Health Consequences of Violence And Trauma (R01)	PA	PA-07-312
2007	NIDA	Drug Abuse Aspects of HIV/AIDS (R01)	PA	PA-07-307
2007	NIDA	Drug Abuse Aspects of HIV/AIDS (R03)	PA	PA-07-308
2007	NIDA	Drug Abuse Aspects of HIV/AIDS (R21)	PA	PA-07-309
2007	NIDA	Health Disparities in HIV/AIDS: Focus on African Americans (R21)	PA	PA-07-289
2007	NIDA	Health Disparities in HIV/AIDS: Focus on African Americans (R03)	PA	PA-07-290
2007	NIH	Research On Ethical Issues In Human Subjects Research (R01)	PA	PA-07-277
2006	FIC	Brain Disorders in the Developing World: Research Across the Lifespan (R01)	PA	PAR-07-268
2006	NIMH	Reducing Mental Illness Stigma And Discrimination (Collaborative R01)	PA	PAR-07-156
2006	NICHD	Men's Heterosexual Behavior and HIV Infection (R01)	PA	PA-07-147
2006	NICHD	Understanding Mechanisms of Health Risk Behavior Change in Children and Adolescents (R01)	PA	PA-07-148
2006	NIMH	Community-Based Participatory Research at NIMH (R01)	PA	PAR-07-133
2006	NICHD	Research on Pathways Linking Environments, Behaviors and HIV/AIDS (R01)	PA	PAR-07-143
2006	NIDA	Health Services Research on the Prevention and Treatment of Drug and Alcohol Abuse (R01)	PA	PA-07-119
2006	NIDA	Drug Abuse as a Cause, Correlate, or Consequence of Criminal Justice Related Health Disparities among African Americans (R01)	PA	PA-07-114
2006	NIDA	Health Disparities in HIV/AIDS: Focus on African Americans (R01)	PA	PA-07-116
2006	NIMH	Research on Rural Mental Health and Drug Abuse Disorders (R01)	PA	PA-07-103
2006	NINR	Chronic Illness Self-Management in Children and Adolescents (R01)	PA	PA-07-097
2006	NINR	Chronic Illness Self-Management in Children and Adolescents (R21)	PA	PA-07-099

Year of Release Date	Issuing Organization	Title	What	Announcement Number
2006	NINR	Chronic Illness Self-Management in Children and Adolescents (R03)	PA	PA-07-098
2006	NIMH	HIV/AIDS, Severe Mental Illness and Homelessness (R01)	PA	PA-07-090
2006	NIMH	Collaborative R01s for Clinical and Services Studies of Mental Disorders, AIDS and Alcohol Use Disorders (R01)	PA	PA-07-092
2006	NIMH	Research on The Reduction And Prevention of Suicidality (R01)	PA	PA-07-079
2006	NIMH	Women's Mental Health in Pregnancy and the Postpartum Period (R01)	PA	PA-07-081
2006	NIAAA	Structural Interventions, Alcohol Use, and Risk of HIV/AIDS(R01)	PA	PA-07-036
2006	OBSSR	Social and Cultural Dimensions of Health (R01)	PA	PA-07-045
2006	OBSSR	Research on Mind-Body Interactions and Health (R01)	PA	PA-07-046
2006	NIDDK	Research on Improving Health Care for Obese Patients (R01)	PA	PA-07-013
2006	NIAAA	Research on Alcohol and HIV/AIDS (R01)	PA	PA-07-028
2006	OBSSR	Methodology and Measurement in the Behavioral and Social Sciences (R01)	PA	PA-07-060
2006	NIAAA	Research on Alcohol and HIV/AIDS (R21)	PA	PA-07-063
2006	NIAAA	Research on Alcohol and HIV/AIDS (R03)	PA	PA-07-064
2006	NIAAA	Structural Interventions, Alcohol Use, and Risk of HIV/AIDS (R21)	PA	PA-07-005
2006	NIAAA	Structural Interventions, Alcohol Use, and Risk of HIV/AIDS (R03)	PA	PA-07-006
2006	NIMH	Community-Based Participatory Research at NIMH (R21)	PA	PAR-07-004
2006	NIDA	Field-Deployable Tools for Quantifying Exposures to Psychosocial Stress and to Addictive Substances for Studies of Health and Disease (U01)	RFA	RFA-DA-07-005
2006	NIA	Developmental Research on Elder Mistreatment (R21)	RFA	RFA-AG-06-009
2006	NIMH	NIMH Research Education Grants (R25)	PA	PAR-06-494
2006	NIMH	Research on Rural Mental Health and Drug Abuse Disorders (R01)	PA	PA-06-478
2006	NIMH	Research On The Reduction And Prevention Of Suicidality (R01)	PA	PA-06-438
2006	FIC	Brain Disorders in the Developing World: Research Across the Lifespan (R21)	PA	PAR-06-420
2006	FIC	International Tobacco and Health Research and Capacity Building Program (R01)	RFA	RFA-TW-06-006
2006	NIMH	Women's Mental Health in Pregnancy and the Postpartum Period (R01)	PA	PA-06-376
2006	NIMH	Women's Mental Health in Pregnancy and the Postpartum Period (R21)	PA	PA-06-377
2006	NIH	Research On Ethical Issues in Human Subjects Research (R03)	PA	PA-06-367
2006	NIH	Research On Ethical Issues in Human Subjects Research (R21)	PA	PA-06-368

Year of Release Date	Issuing Organization	Title	What	Announcement Number
2006	NIH	Research On Ethical Issues in Human Subjects Research (R01)	PA	PA-06-369
2006	NICHD	Global Partnerships for Social Science AIDS Research (R24)	RFA	RFA-HD-06-007
2006	OBSSR	Methodology And Measurement in The Behavioral And Social Sciences (R21)	PA	PA-06-343
2006	OBSSR	Methodology And Measurement in The Behavioral And Social Sciences (R03)	PA	PA-06-344
2006	NICHD	Men's Heterosexual Behavior and HIV Infection (R21)	PA	PA-06-353
2006	NICHD	Men's Heterosexual Behavior and HIV Infection (R03)	PA	PA-06-354
2006	NIDA	Health Services Research on the Prevention and Treatment of Drug and Alcohol Abuse (R21)	PA	PA-06-307
2006	NIDA	Health Services Research on the Prevention and Treatment of Drug and Alcohol Abuse (R03)	PA	PA-06-308
2006	NICHD	Understanding Mechanisms of Health Risk Behavior Change in Children and Adolescents (R21)	PA	PA-06-298
2006	NIAID	Centers for AIDS Research: D-CFAR, CFAR (P30)	PA	PAR-06-291
2006	NIMH	Rapid Assessment Post-Impact of Disaster (R03)	PA	PAR-06-252
2006	NIMH	Rapid Assessment Post-Impact of Disaster (R21)	PA	PAR-06-253
2006	NIMH	Collaborative R01s for Clinical and Services Studies of Mental Disorders, AIDS and Alcohol Use Disorders	PA	PA-06-154
2006	NIMH	Health Research with Diverse Populations (R01)	PA	PA-06-218
2006	NCHSTP	Opt-Out HIV Testing in Emergency Department Settings	RFA	RFA-PS-06-003
2005	NICHD	Research on Pathways Linking Environments, Behaviors and HIV/AIDS (R01)	PA	PAR-06-114
2005	NIDA	Drug Abuse as a Cause, Correlate, or Consequence of Criminal Justice Related Health Disparities among African Americans (R01)	PA	PA-06-068
2005	NIDA	Health Disparities in HIV/AIDS: Focus on African Americans (R01)	PA	PA-06-069
2005	FIC	Framework Programs for Global Health (R25)	PA	PAR-06-067
2005	NIMH	Health Behavior Change in Mental Disorders Modeled from HIV Interventions	RFA	RFA-MH-06-002
2005	NIMH	Intervention and Practice Research for Combat Related Mental Disorders and Stress Reactions	RFA	RFA-MH-06-004
2005	NIMH	NIMH Research Education Grants (R25)	PA	PAR-05-153
2005	NIAAA	Structural Interventions, Alcohol Use, and Risk of HIV/AIDS	PA	PA-05-146
2005	NIDA	Health Services Research on the Prevention and Treatment of Drug and Alcohol Abuse	PA	PA-05-139
2005	NICHD	Global Network for Women's and Children's Health Research	RFA	RFA-HD-05-025
2005	FIC	Brain Disorders in the Developing World: Research Across the Lifespan	PA	PAR-05-100
2005	OBSSR	Methodology and Measurement in the Behavioral and Social Sciences	PA	PA-05-090
2005	NIA	Developmental Research on Elder Mistreatment	RFA	RFA-AG-05-009

Year of Release Date	Issuing Organization	Title	What	Announcement Number
2005	FIC	Framework Programs for Global Health	PA	PAR-05-050
2004	NICHHD	Men's Heterosexual Behavior and HIV Infection	PA	PA-05-033
2004	OBSSR	Social and Cultural Dimensions of Health	PA	PA-05-029
2004	OBSSR	Research on Mind-Body Interactions and Health	PA	PA-05-027
2004	NIMH	Psychosocial Needs of Children Affected by AIDS in Low-Resource Countries	RFA	RFA-MH-05-008
2004	NIGMS	Pilot Projects for Models of Infectious Disease Agent Study (MIDAS)	RFA	RFA-GM-05-011
2004	NIAAA	Structural Interventions, Alcohol Use, and Risk of HIV/AIDS	RFA	RFA-AA-05-003
2004	NICHHD	Understanding Mechanisms of Health Risk Behavior Change in Children and Adolescents	PA	PA-04-121
2004	NICHHD	Religious Organizations and HIV	PA	PA-04-115
2004	NIMH	Reducing Mental Illness Stigma and Discrimination	PA	PAR-04-112
2004	NIDA	Cross-Disciplinary Translational Research at NIH	PA	PA-04-109
2004	NCI	Reducing Barriers To Symptom Management and Palliative Care	RFA	RFA-CA-05-013
2004	NICHHD	Research Partnerships for Improving Functional Outcomes	PA	PAR-04-077
2004	NIMH	Research on Rural Mental Health and Drug Abuse Disorders	PA	PA-04-061
2004	NINR	Improving Care for Dying Children and Their Families	PA	PA-04-057
2004	Roadmap	Meetings and Networks for Methodological Development in Interdisciplinary Research	RFA	RFA-RM-04-014
2004	NIDA	HIV/AIDS, Drug Use, and Highly Vulnerable Youth: Targeting Research Gaps	RFA	RFA-DA-04-012
2004	NHGRI	ELSI Regular Research Program (R01)	PA	PA-04-050
2004	NHGRI	ELSI Small Grant Research Program (R03)	PA	PA-04-051
2003	NIDA	Targeted Integrative Research in Drug Abuse and HIV/AIDS in Pregnancy	RFA	RFA-DA-04-010
2003	NIDA	Screening and Intervention for Youth in Primary Care Settings	RFA	RFA-DA-04-006
2003	Roadmap	Supplements for Methodological Innovations in the Behavioral and Social Sciences	RFA	RFA-RM-04-013
2003	NIMH	HIV/AIDS, Severe Mental Illness and Homelessness	PA	PA-04-024
2003	NIDA	Drug Abuse Aspects of HIV/AIDS and Other Infections	PA	PA-04-007
2003	NINDS	Reducing Disparities in the Treatment of Epilepsy	PA	PAS-03-164
2003	NIMH	Research on the Reduction and Prevention of Suicidality	PA	PA-03-161
2003	NINR	Chronic Illness Self-Management in Children	PA	PA-03-159
2003	OBSSR	Research on Mind-Body Interactions and Health	RFA	RFA-OD-03-008
2003	NIMH	Women's Mental Health in Pregnancy and the Postpartum Period	PA	PA-03-135
2003	NIMH	Research on Adherence to Interventions for Mental Disorders	PA	PA-03-111
2003	NIMH	Developing Disaster Mental Health Research Capacity Through Education (R25)	RFA	RFA-MH-03-009

Year of Release Date	Issuing Organization	Title	What	Announcement Number
2003	NIGMS	Pilot Projects for Models of Infectious Disease Agent Study (MIDAS)	RFA	RFA-GM-03-008
2003	OBSSR	Maintenance of Long Term Behavioral Change	RFA	RFA-OB-03-003
2003	NIDA	Drug Abuse and HIV Prevention in Youth	RFA	RFA-DA-03-012
2003	OBSSR	Mind-Body Interactions and Health: Research Infrastructure Program (R24)	RFA	RFA-OB-03-004
2003	OBSSR	Mind-Body Interactions and Health: Exploratory / Developmental Research Program (R21)	RFA	RFA-OB-03-005
2002	FIC	Brain Disorders in the Developing World: Research Across the Lifespan	RFA	RFA-TW-03-007
2002	NIAAA	Research on Alcohol-Related HIV/AIDS in Women	RFA	RFA-AA-03-004
2002	NICHD	Dynamic Health Assessments for Medical Rehabilitation Outcome	RFA	RFA-HD-02-024
2002	NIAAA	Services and Intervention Research with Homeless Persons Having Alcohol, Drug Abuse, or Mental Disorders	PA	PA-02-150
2002	NINR	Research to Improve Care For Dying Children and Their Families	RFA	RFA-NR-03-003
2002	NIMH	HIV Prevention in Treatment Settings: U.S. and International Priorities	RFA	RFA-MH-03-006
2002	NIMH	Rapid Assessment Post-Impact of Disaster	PA	PAR-02-133
2002	FIC	Stigma and Global Health Research Program	RFA	RFA-TW-03-001
2002	NIH	Research on Ethical Issues in Human Studies	PA	PA-02-103
2002	OBSSR	Methodology and Measurement in the Behavioral and Social Sciences	PA	PA-02-072
2002	NHGRI	Dissertation Research Grants for Underrepresented Minorities in the Ethical, Legal, and Social Implications (ELSI) of Genetics Research	PA	PA-02-048
2001	NIDA	New Approaches to Prevent HIV/Other Infections in Drug Users	RFA	RFA-DA-02-009
2001	OBSSR	Social and Cultural Dimensions of Health	PA	PA-02-043
2001	NIAAA	Research on Alcohol and HIV/AIDS	PA	PA-02-039
2001	FIC	Planning Grants to Organize Programs for International Clinical, Operational, and Health Services Research Training for Aids and Tuberculosis	PA	PA-02-022
2001	NIEHS	Environmental Justice: Partnerships to Address Ethical Challenges in Environmental Health	RFA	RFA-ES-02-005
2001	NHGRI	Studies of the Ethical, Legal, and Social Implications (ELSI) of Human Genetic Variation Research for Individuals and Diverse Racial and Ethnic Groups	RFA	RFA-HG-02-003
2001	NICHD	Partnerships for HIV/AIDS Research in African Populations	RFA	RFA-HD-02-003
2001	NIMH	HIV/STD Prevention Programs for Adolescents	RFA	RFA-MH-02-007
2001	NINR	The Management of Chronic Pain	PA	PA-01-115
2001	FIC	International Tobacco and Health Research and Capacity Building Program	RFA	RFA-TW-02-005

Year of Release Date	Issuing Organization	Title	What	Announcement Number
2001	NIMH	Behavioral, Social, Mental Health, and Substance Abuse Research with Diverse Populations	PA	PA-01-096
2001	NIMH	HIV Treatment Adherence Research	PA	PA-01-073
2001	NHLBI	Overcoming Barriers to Treatment Adherence in Minorities and Persons Living in Poverty	RFA	RFA-HL-01-005
2001	NIDA	Health Disparities: Drug Use and Its Adverse Behavioral, Social, Medical, and Mental Health Consequences	RFA	RFA-DA-01-008
2001	NIA	Planning Grants for HIV/AIDS Prevention and Treatment Intervention in Middle-Aged and Older Populations	RFA	RFA-AG-01-004
2000	NIDA	Drug Abuse Aspects of HIV/AIDS and Other Infections	PA	PA-01-023
2000	NICHD	The Influence of Gender on HIV Risk	RFA	RFA-HD-01-002
2000	NIMH	International Initiatives to Prevent HIV/STD Infection	RFA	RFA-MH-01-004
2000	NHGRI	Ethical, Legal, And Social Implications (ELSI) of Human Genetics And Genomic Research Small Grant Program	PA	PA-00-132
2000	NHGRI	Ethical, Legal, and Social Implications of Human Genetics and Genomic Research Regular Research Grant Program	PA	PA-00-133
2000	NHGRI	Ethical, Legal, and Social Implications of Human Genetics and Genomic Research Education Grant Program	PA	PA-00-134
2000	NIMH	Ancillary Studies to NIMH Multi-Site Clinical Trials	PA	PAR-00-095
2000	NIMH	Communications and HIV/STD Prevention	RFA	RFA-MH-01-003
2000	NIGMS	Pharmacogenetics Research Network and Knowledge Base	RFA	RFA-GM-00-003
2000	NIMH	Research on Mental Disorders in Rural and Frontier Populations	PA	PA-00-082
2000	NIMH	Integrating the Basic Behavioral Sciences and Public Mental Health	PA	PA-00-078
2000	NIMH	Family Interventions to Prevent And Adapt to HIV/AIDS	RFA	RFA-MH-00-009
2000	NIMH	HIV Preventive Interventions for the Severely Mentally Ill	RFA	RFA-MH-00-012
1999	NIMH	Research on Adherence to Interventions for Mental Disorders	PA	PA-00-016
1999	NHGRI	Studies of the Ethical, Legal and Social Implications of Research Into Human Genetic Variation	RFA	RFA-HG-99-002
1999	NIMH	Comorbid Mental Disorders and HIV/STD Prevention	RFA	RFA-MH-99-008
1999	NIA	NIA Pilot Research Grant Program	PA	PA-99-049
1998	NIGMS	Pharmacogenetic Research Network and Database	RFA	RFA-GM-99-004
1998	NIMH	Coping with Aids as a Chronic Long-Term Illness	PA	PA-99-026
1998	NIAAA	Preventing Fetal Alcohol Syndrome (FAS)	RFA	RFA-AA-99-002
1998	NIMH	HIV/AIDS and the Severely Mentally Ill	PA	PA-98-080
1998	NICHD	Cognition and Behavior in Down Syndrome	RFA	RFA-HD-98-007
1998	NIA	Methodology and Measurement in the Behavioral and Social Sciences	PA	PA-98-031
1997	NIMH	Mental Health and HIV/STD Prevention in Rural Settings	RFA	RFA-MH-98-004
1997	NIMH	Understanding and Improving Antiretroviral Regimen Adherence	PA	PA-97-070

Year of Release Date	Issuing Organization	Title	What	Announcement Number
1997	NIA	Social Cognition and Aging	PA	PA-97-065
1996	NIDA	Drug Use, Sexual Risk Behaviors, and HIV in Men	PA	PA-96-074
1996	NHGRI	Ethical, Legal, and Social Implications of Human Genetics Research	PA	PA-96-042
1996	NIAAA	Intervention Research to Prevent Alcohol-Related Problems	PA	PA-96-019
1995	NIMH	Women's Mental Health Research	PA	PA-95-061
1995	NIDA	Local Population/Area Epidemiologic Research on Drug Abuse	PA	PA-95-059
1995	NIMH	Family Interventions and HIV/AIDS	RFA	RFA-MH-95-002
1994	NIDA	Prescription Drug Use, Abuse, and Diversion	PA	PA-94-070
1994	NIMH	Basic Research in Emotion	PA	PA-94-059
1994	NHGRI	Studies of Genetic Testing and Counseling for Heritable Breast, Ovarian and Colon Cancer Risks	RFA	RFA-HG-94-001
1993	NIDA	Science Education Drug Abuse Partnership Award	PA	PAR-94-008
1992	NIMH	The Role of the Family in Preventing and Adapting to Human Immunodeficiency Virus Infection and Acquired Immunodeficiency Syndrome	RFA	RFA-MH-92-011
1992	NIMH	Implementation of Caring for People with Severe Mental Disorders	PA	PA-92-065
1992	NIH	Science Education Partnership Award	RFA	RFA-AD-92-001

Appendix H: Coding of Stigma Awards by Discipline and Disease Focus

PI	Discipline	Region	Disease Focus	Scope	Act. Code
Alvidrez	Psychology: Clinical	US	Mental health	Domestic	R21
Birbeck	Neurology	East Africa	Epilepsy	International	R21
Coreil	Anthropology	Latin America/ Caribbean	TB	International	R01
Corrigan	Psychology: Clinical	East Asia, US	Mental health, substance Abuse, HIV	International	R01
Dohan	Sociology	US	Substance abuse	Domestic	R21
Eckstrand	Psychology: Clinical	South East Asia	HIV/AIDS	International	R01
Ellis	Psychology: Clinical	US	Mental health	Domestic	R21
Holzemer	Community Health Systems	Southern Africa, East Africa	HIV/AIDS	International	R01
Kohlenberg	Psychology: Clinical	US	Substance abuse	Domestic	R21
Li, L	Sociology	East Asia	HIV/AIDS	International	R01
Li, X	Psychology: Educational	East Asia	Mental health	International	R21
Miranda	Psychology: Clinical	US	Mental health	Domestic	R01
Pescosolido	Sociology	Latin America/ Caribbean, Europe, US, East Asia, Oceania/ Australia	Mental health	International	R01
Saewyc	Nursing Sciences	US, Canada, Oceania/ Australia	Mental health	International	R01
Solomon	Not coded	South Asia	HIV/AIDS	International	R21
Tickle-Degnen	Psychology: Social and Occupational Therapy	East Asia, US	Parkinson's Disease	International	R01
Van Rie	Epidemiology and Medical Statistics	Southeast Asia	TB	International	R21
Varaz-Diaz	Psychology: Social	US	HIV/AIDS	Domestic	R21

Appendix I: Coding of Seniority of Investigators

PI Code	Activity Code	Terminal PhD/ Post-Doc	Seniority Coding	International/ Domestic?
PI A	R01	1989	Mid-career	I
PI B	R01	1999	Junior	I
PI C	R01	1988	Senior	D
PI D	R01	1992	Mid-career	I
PI E	R01	1988	Senior	I
PI F	R01	1988	Senior	I
PI G	R01	1979	Senior	I
PI H	R01	1982	Senior	I
PI I	R01	1975	Senior	I
PI J	R21	1997	Mid-career	D
PI K	R21	2002	Junior	D
PI L	R21	1994	Mid-career	D
PI M	R21	2001	Junior	D
PI N	R21	2002	Junior	D
PI O	R21	2006	Junior	I
PI P	R21	1973	Senior	I
PI Q	R21	2000	Junior	I
PI R	R21	1992	Mid-career	I

Appendix J: Bibliography of Publications Associated with Stigma Awards

1. Alvidrez J, Snowden LR, Kaiser DM. Involving consumers in the development of a psychoeducational booklet about stigma for black mental health clients. *Health Promotion Practice*, in press.
2. Alvidrez J, Snowden LR, Kaiser DM. The experience of stigma among Black mental health consumers. *J Health Care Poor Underserved*. 2008 Aug;19(3):874-93.PMID:18677076
3. Baskind R, Birbeck G. Epilepsy care in Zambia: a study of traditional healers. *Epilepsia*. 2005 Jul;46(7):1121-6.PMID:16026565
4. Baskind R, Birbeck GL. Epilepsy-associated stigma in sub-Saharan Africa: the social landscape of a disease. *Epilepsy Behav*. 2005 Aug;7(1):68-73. Review.PMID:15978874
5. Atadzhanov M, Chomba E, Haworth A, Mbewe E, Birbeck GL. Knowledge, attitudes, behaviors, and practices regarding epilepsy among Zambianclerics. *Epilepsy Behav*. 2006 Aug;9(1):83-8. Epub 2006 May 19.PMID:16713361
6. Birbeck GL, Chomba E, Atadzhanov M, Mbewe E, Haworth A. Zambian teachers: what do they know about epilepsy and how can we work with them to decrease stigma? *Epilepsy Behav*. 2006 Sep;9(2):275-80. Epub 2006 Jul 31.PMID:16877045
7. Chomba EN, Haworth A, Atadzhanov M, Mbewe E, Birbeck GL. Zambian health care workers' knowledge, attitudes, beliefs, and practices regarding epilepsy. *Epilepsy Behav*. 2007 Feb;10(1):111-9. Epub 2006 Oct 18.PMID:17055341
8. Mbewe E, Haworth A, Atadzhanov M, Chomba E, Birbeck GL. Epilepsy-related knowledge, attitudes, and practices among Zambian police officers. *Epilepsy Behav*. 2007 May;10(3):456-62. Epub 2007 Mar 23.PMID:17363333
9. Birbeck G, Chomba E, Atadzhanov M, Mbewe E, Haworth A. The social and economic impact of epilepsy in Zambia: a cross-sectional study. *Lancet Neurol*. 2007 Jan;6(1):39-44.PMID:17166800
10. Corrigan PW, Watson AC. How children stigmatize people with mental illness. *Int J Soc Psychiatry*. 2007 Nov;53(6):526-46.PMID:18181355
11. Tsang HW, Angell B, Corrigan PW, Lee YT, Shi K, Lam CS, Jin S, Fung KM. A cross-cultural study of employers' concerns about hiring people with psychotic disorder: implications for recovery. *Soc Psychiatry Psychiatr Epidemiol*. 2007 Sep;42(9):723-33. Epub 2007 May 23.PMID:17522747
12. Stuart Henderson, Clare Stacey, and Daniel Dohan. "Social Stigma and Dilemmas of Providing Care to Substance Users in a Safety-Net Emergency Department", in press.
13. Ellis BH, Fisher PA, Zaharie S. Predictors of disruptive behavior, developmental delays, anxiety, and affective symptomatology among institutionally reared romanian children. *J Am Acad Child Adolesc Psychiatry*. 2004 Oct;43(10):1283-92.PMID:15381896
14. Ellis BH, MacDonald HZ, Lincoln AK, Cabral HJ. Mental health of Somali adolescent refugees: the role of trauma, stress, and perceived discrimination. *J Consult Clin Psychol*. 2008 Apr;76(2):184-93.PMID:18377116
15. Ellis BH, Lhewa D, Charney M, Cabral H. Screening for PTSD among Somali adolescent refugees: psychometric properties of the UCLA PTSD Index. *J Trauma Stress*. 2006 Aug;19(4):547-51.PMID:16929510
16. Greeff, M., Uys, L.R., Holzemer, W.L., Makoae, L.N., Dlamini, P.S., Kohi, T.W., Chirwa, M.L., Naidoo, J., & Phetlhu, D.R. Experiences of HIV/AIDS stigma of PLWA and nurses from five African Countries, in press.
17. Naidoo, J.R., Uys, L.R., Greeff, M., Holzemer, W.L., Makoae, L., Dlamini, P., Phetlhu, R.D., Chirwa, M., & Kohi, T. Urban and rural differences in HIV/AIDS stigma in five African countries. *African Journal of AIDS Research*. 6(1): 17-23.
18. Uys, L.R., Holzemer, W.L., Chirwa, M.L., Dlamini, P., Greeff, M., Kohi, T.W., Makoae, L.N., Stewart, A.L., Mullan, J., Phetlhu, R.D., Wantland, D., Cuca, Y. & Naidoo, J. The development and validation of the HIV/AIDS Stigma Instrument- Nurse (HASI-N). *AIDS Care*, in press.

19. Holzemer WL, Uys LR, Chirwa ML, Greeff M, Makoae LN, Kohi TW, Dlamini PS, Stewart AL, Mullan J, Phetlhu RD, Wantland D, Durrheim K. Validation of the HIV/AIDS Stigma Instrument - PLWA (HASI-P). *AIDS Care*. 2007 Sep;19(8):1002-12. Review.PMID:17851997
20. Greeff M, Phetlhu R. The meaning and effect of HIV/AIDS stigma for people living with AIDS and nurses involved in their care in the North West Province, South Africa. *Curationis*. 2007 Jun;30(2):12-23.PMID:17703819
21. Holzemer WL, Uys L, Makoae L, Stewart A, Phetlhu R, Dlamini PS, Greeff M, Kohi TW, Chirwa M, Cuca Y, Naidoo J. A conceptual model of HIV/AIDS stigma from five African countries. *J Adv Nurs*. 2007 Jun;58(6):541-51. Epub 2007 May 1.PMID:17484748
22. Uys L, Chirwa M, Dlamini P, Greeff M, Kohi T, Holzemer W, Makoae L, Naidoo JR, Phetlhu R. "Eating plastic," "winning the lotto," "joining the www"...descriptions of HIV/AIDS in Africa. *J Assoc Nurses AIDS Care*. 2005 May-Jun;16(3):11-21.PMID:16433113
23. Makoae LN, Greeff M, Phetlhu RD, Uys LR, Naidoo JR, Kohi TW, Dlamini PS, Chirwa ML, Holzemer WL. Coping with HIV-related stigma in five African countries. *J Assoc Nurses AIDS Care*. 2008 Mar-Apr;19(2):137-46.PMID:18328964
24. Holzemer, W.L. & Uys, L. Managing AIDS Stigma. *Journal of Social Aspects of HIV/AIDS*. 1(3): 165-174.
25. Kohi TW, Makoae L, Chirwa M, Holzemer WL, Phetlhu DR, Uys L, Naidoo J, Dlamini PS, Greeff M. HIV and AIDS stigma violates human rights in five African countries. *Nurs Ethics*. 2006 Jul;13(4):404-15.PMID:16838571
26. Dlamini PS, Kohi TW, Uys LR, Phetlhu RD, Chirwa ML, Naidoo JR, Holzemer WL, Greeff M, Makoae LN. Verbal and physical abuse and neglect as manifestations of HIV/AIDS stigma in five African countries. *Public Health Nurs*. 2007 Sep-Oct;24(5):389-99.PMID:17714223
27. Greeff M, Phetlhu R, Makoae LN, Dlamini PS, Holzemer WL, Naidoo JR, Kohi TW, Uys LR, Chirwa ML. Disclosure of HIV status: experiences and perceptions of persons living with HIV/AIDS and nurses involved in their care in Africa. *Qual Health Res*. 2008 Mar;18(3):311-24.PMID:18235155
28. Wu, S, Li, L, Wu, ZY, Cao, HJ, Lin, CQ, Yan, ZH, Jia, MH, & Cui, HX. Universal precautions in the era of HIV/AIDS: Perception of health service providers in Yunnan, China. *AIDS Behavior*. 2008 Sep;12(5):806-14. PMID: 17641967
29. Li L, Wu S, Wu Z, Sun S, Cui H, Jia M. Understanding family support for people living with HIV/AIDS in Yunnan, China. *AIDS Behav*. 2006 Sep;10(5):509-17.PMID:16741672
30. Stein JA, Li L. Measuring HIV-related stigma among Chinese service providers: confirmatory factor analysis of a multidimensional scale. *AIDS Behav*. 2008 Sep;12(5):789-95. Epub 2007 Dec 7.PMID:18064554
31. Li L, Lin C, Wu Z, Wu S, Rotheram-Borus MJ, Detels R, Jia M. Stigmatization and shame: consequences of caring for HIV/AIDS patients in China. *AIDS Care*. 2007 Feb;19(2):258-63.PMID:17364408
32. Li L, Cao H, Wu Z, Wu S, Xiao L. Diffusion of positive AIDS care messages among service providers in China. *AIDS Educ Prev*. 2007 Dec;19(6):511-8.PMID:18190275
33. Li, L, Wu, ZY, Wu, S, Zhao, Y, Jia, MH, Yan, ZH. HIV-related stigma in health care settings: A Survey of service providers in China. *AIDS Patient Care and STDs*, 2007 Oct;21(10):753-62. PMID: 17949274
34. Li, L, Wu, Z.Y., Lin, C.Q., Lord, L., Jia, M.H., and Wu, S. To Tell or Not To Tell: HIV Disclosure to Family Members in China. *Developing World Bioethics*, in press.
35. Li L, Wu Z, Zhao Y, Lin C, Detels R, Wu S. Using case vignettes to measure HIV-related stigma among health professionals in China. *Int J Epidemiol*. 2007 Feb;36(1):178-84. Epub 2006 Dec 14.PMID:17175545
36. Li L, Wu Z, Wu S, Lee SJ, Rotheram-Borus MJ, Detels R, Jia M, Sun S. Mandatory HIV testing in China: the perception of health-care providers. *Int J STD AIDS*. 2007 Jul;18(7):476-81.PMID:17623506
37. Li L, Sun S, Wu Z, Wu S, Lin C, Yan Z. Disclosure of HIV status is a family matter: field notes from China. *J Fam Psychol*. 2007 Jun;21(2):307-14.PMID:17605553
38. Lin, CQ, Li, L, Wu, ZY, Wu, S, Jia, MH. Occupational exposure to Human Immunodeficiency Virus (HIV) among health care providers: A qualitative study in Yunnan, China. *Journal of the International Association of Physicians in AIDS Care*. 2008 Mar;7(1):35-41. PMID: 17641135

39. Nadeem E, Lange JM, Edge D, Fongwa M, Belin T, Miranda J. Does stigma keep poor young immigrant and U.S.-born Black and Latina women from seeking mental health care? *Psychiatr Serv.* 2007 Dec;58(12):1547-54.PMID:18048555
40. Saewyc E, Skay C, Richens K, Reis E, Poon C, Murphy A. Sexual orientation, sexual abuse, and HIV-risk behaviors among adolescents in the Pacific Northwest. *Am J Public Health.* 2006 Jun;96(6):1104-10. Epub 2006 May 2.PMID:16670224
41. Homma Y, Saewyc EM. The emotional well-being of Asian-American sexual minority youth in school. *J LGBT Health Res.* 2007;3(1):67-78.PMID:18029317
42. Sengupta S, Pungrassami P, Balthip Q, Strauss R, Kasetjaroen Y, Chongsuvivatwong V, Van Rie A. Social impact of tuberculosis in southern Thailand: views from patients, care providers and the community. *Int J Tuberc Lung Dis.* 2006 Sep;10(9):1008-12.PMID:16964792
43. Varas-Díaz N, Marzán-Rodríguez M. The emotional aspect of AIDS stigma among health professionals in Puerto Rico. *AIDS Care.* 2007 Nov;19(10):1247-57. *AIDS Care.* 2007 Nov;19(10):1247-57.PMID:18071968
44. Díaz NV, Rivera SM, Bou FC. AIDS stigma combinations in a sample of Puerto Rican health professionals: qualitative and quantitative evidence. *P R Health Sci J.* 2008 Jun;27(2):147-57.PMID:18616043
45. Li X, Zhang L, Stanton B, Fang X, Xiong Q, Lin D. HIV/AIDS-related sexual risk behaviors among rural residents in China: potential role of rural-to-urban migration. *AIDS Educ Prev.* 2007 Oct;19(5):396-407.PMID:17967110
46. Hong Y, Li X, Stanton B, Lin D, Fang X, Rong M, Wang J. Too Costly To Be Ill: Healthcare Access and Health-Seeking Behaviours among Rural-to-Urban Migrants in China. *World Health Popul.* 2006;8(2):22-34.PMID:18277099
47. Li X, Stanton B, Chen X, Hong Y, Fang X, Lin D, Mao R, Wang J. Health Indicators and Geographic Mobility among Young Rural-to-Urban Migrants in China. *World Health Popul.* 2006;8(2):5-21.PMID:18277098
48. Li X, Stanton B, Fang X, Lin D. Social Stigma and Mental Health among Rural-to-Urban Migrants in China: A Conceptual Framework and Future Research Needs. *World Health Popul.* 2006;8(3):14-31.PMID:18277106
49. Li X, Zhang L, Fang X, Xiong Q, Chen X, Lin D, Mathur A, Stanton B. Stigmatization experienced by rural-to-urban migrant workers in China: findings from a qualitative study. *World Health Popul.* 2007 Dec;9(4):29-43.PMID:18567950

Appendix K: Interview Guides

PI Guide

Application

1. How did you first learn of the Stigma in Global Health Program?

Probe:

- Did you learn from a colleague? Collaborator? Mentor?
- Did you learn from some kind of program announcement?
- Other?
- Why did you decide to apply?

2. What kind of experiences did you have in the area of stigma and/or global health area before you decided to apply?

Probe:

- Any background research
- Background experiences that led to their attraction to this work.
- Any other stigma-related funding prior to your application? With whom?

3. Was research on the role of stigma and public health in domestic, cross-cultural, and international studies a new area of research for you?

Probes:

- Were you a well-established or independent researcher in your field prior to studying stigma?
- How long to become “independent” researcher in this area?
- How is “independence” defined?
- ...garnering sufficient funding and support?
- - ...establishing a sustainable funding level?

4. When you prepared the grant application, what amount of time did you budget for your role?

Probe:

- Amount of time in application:
- Amount of time reported in discussion
- Has it turned out that this level of effort was right?
- Why did it end up being more/less/no change?

5. Did foreign country stakeholders (researchers, community leaders, ministers) have any input into the shaping of your project? [Foreign NGOs may come up here.]

Probes:

- Have there been any benefits to the involvement of other counties that you believe would not have happened otherwise?
- Does the participation of foreign countries enhance the sustainability of the funded projects [their outputs]?
- Did foreign-country stakeholders have any impact on the objectives of your study?
- Did foreign-country stakeholders have any impact on the design or methodologies of your study?
- Any adaptations in procedures?
- Any adaptations to reflect a shared mission?
- Do you have any examples?
- Are there any challenges or costs to involving foreign country stakeholders?

Review & Management

6. Did you have any issues with the Stigma application and/or review process?

Probes:

- How were they received by the reviewers?
- Where they successful in guiding reviewers?
- Have the review criteria changed over time?

7. Did you receive any feedback from the review panel that impacted or changed the focus or concept of your study?

Probes:

- Any feedback that changed the design of or methodologies in your study
- Can you give examples?
- Was the feedback Stigma-specific?

8. Do you know of any delays in Stigma projects due to funds transfers, etc?

Probes:

- Have they impeded research?
- Do you know of any other barriers?
- How have these barriers been dealt with?

9. Did the award mechanism (R01s or R21s) end up being an appropriate length of time given the goals of your project?

Probes:

- Benefits of short-term vs. longer term funding
- Expected outcomes of each type
- Expected impact on career
- Did you consider the other type of mechanism?

Partnerships & Communication

10. [If a co-funded project] What has been your experience with running a co-funded project?

Probes:

- Have there been any benefits to the interagency involvement that you believe would not have happened otherwise?
- Do these partnerships enhance the sustainability of the funded projects [their outputs]?
- Do you have any examples?
- What are the challenges or costs to participation of program partners?

11. What other sources of support do you receive for your research?

Probes:

- Is it related to stigma or another topic?
- Is it complementary to you FIC Stigma grant?
- Is your funding sufficient?

12. Have you worked with or considered working with partnering organizations such as....?

Probes:

- Foreign or domestic agencies, MOHs, etc.?
- Foreign or domestic NGOs?
- WHO?

- EU?
- Other countries?
- Foundations? Gates, Global Health Council, etc
- CDC?
- OMHs?(Office of Mental Health)
- CMHPs? (Community Mental Health Programs?)
- Any others?
- For any current partnerships, how did they come about?
- How would such partnerships benefit the program or funded projects?
- How would partnerships with entities like these enhance the sustainability of the funded projects [their outputs]? What do you mean by “sustainability” in this context?
- Any potential disadvantages?

13. Apart from publications in scientific journals, were there any efforts to disseminate the research findings of your project?

Probes:

- Discussions with agencies or offices that work in official capacities? (Foreign and domestic)
- Websites/blogs
- Conferences – presentations, moderations
- Reviewing articles?
- Writing reviews.
- Being asked to serve as an expert on stigma.
- Direct communication with individuals? (When, where)
- Do you know of any efforts to link grantees with policymakers, or communicate their findings to the policy community?
- Do you know of efforts to encourage community participation in the research?
- Do you have any suggestions for data-sharing mechanisms (between researchers, with the wider research and public health community, etc)?
- [Other probes for other communication methods/tools].
- For the above examples, were they requested or proffered?
- For the above examples, any known impact?
- For the examples above, to they add anything to the sustainability of the funded project? What do you mean by “sustainability” in the context of transmitting research findings?

14. Were there any efforts to promote the translation and implementation of findings from the project?

Probes:

- Discussions with agencies or offices that work in official capacities? (Foreign and domestic)
- Websites/blogs
- Conferences – presentations, moderations
- Direct communication with individuals? (When, where)
- Do you know of any efforts to link grantees with policymakers, or communicate their findings to the policy community?
- Do you know of efforts to encourage community participation in the research?
- Do you have any suggestions for data-sharing mechanisms (between researchers, with the wider research and public health community, etc)?
- [Other probes for other communication methods/tools].
- For examples above, why were they “translation” or “implementation”
- For the above examples, were they requested or proffered?
- For the above examples, any known impact?
- For the examples above, to they add anything to the sustainability of the funded project? What do you mean by “sustainability” in the context of transmitting research findings?

15. To your knowledge, what funding sources, apart from FIC and the Stigma program, exist for biomedical and behavioral health scientists studying “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”?
(Probe for government support, other international support)

Probes:

- WHO?
- EU?
- Other countries?
- Foundations? Gates, Global Health Council, etc
- CDC?
- OMHs?(Office of Mental Health)
- CMHPs? (Community Mental Health Programs?)
- Others?
- Have received support from any of them?
- If so, how did the support come about?

16. Do you or have you interacted with other Stigma PIs?

Probes:

- If yes, how so? How often?
- Is there more that could be done in this area?
- What might be the advantages of FIC facilitation of interaction between PIs?
- Examples?
- Does the interaction between Stigma PIs enhance the sustainability of the funded work? Examples. What do you mean by “sustainability” in this context?
- Disadvantages of FIC facilitation? Examples

17. Do you mentor any students or junior colleagues?

Probes:

- Students – graduate or undergraduate? (Quantify.)
- Junior colleagues – in your department? (Quantify.)
- Colleagues abroad? (Quantify.)
- Is the arrangement formal or informal? (Quantify.)
- How often do you communicate and in what capacity? Example?
- What is your mentoring role in terms of grant writing? Example?
- What is your mentoring role in terms of Project planning? Example?
- Has your role changed [over the course of the Stigma grant] and why? Example?

18. Have you trained students or colleagues in stigma-related methods, projects, instruments, or implementation strategies

Probes:

- If foreign, at their home institutions?
- How many?
- Examples

19. Have international awardees developed stigma-relevant research resources (laboratories/capabilities) at their home institutions?

Probes:

- Curriculum
- Analysis frameworks
- Measures/metrics
- Training courses

Research Results & Outputs

20. Have you identified any "best practices" or lessons learned ...

a. ...in conducting research in inter-disciplinary research?

Probes:

- Working in/with a new discipline?
- Working in/with scientists of a different discipline?
- Examples?
- Have these been communicated either formally or informally?

b. ...in researching stigmatized populations? [Any ideas for probes?]

c. ... in conducting research in cross-cultural or international settings?

Probes:

- Examples?
- Have these been communicated either formally or informally?

21. Research outputs:

a. What have been the outputs of your Stigma research in terms of peer-reviewed journal publications?

- Noticed any changed in the pattern of your citations (instances of being cited)?

b. What have been the outputs in terms of new research collaborations?

- Noticed any changed in the pattern of your citations (instances of being cited)?
- Examples?

c. ...development of culturally-validated measures of stigma or other instruments?

- Examples?
- Are they still being used or further developed?

d. ...development of interventions to mitigate the negative effects of stigma on health outcomes?

- Examples?
- Are they still being used or further developed?
- Have any interventions developed by the stigma program been implemented?
- Are they successful?
- Scalable?
- Applicable to other contexts?

e. What have been the outputs in terms of continued research in the stigma field after completion of your grant?

- [Where applicable] Have R21 awardees successfully moved on to related R01 grants?
- Examples?

f. Others? (inventions, clinical protocols, etc.)!

22. What kind of impact has the Stigma funding had on your career?

Probes:

- Helped in obtaining additional funding?
- Has it led to prestige/promotion/career advancement?
- Helped them set up labs of their own?
- [If foreign] Allowed them to continue doing research in their own countries?
- Strengthened social networks in-country and in US?
- Strengthened collaboration with mentor?

Closing

23. Is there anything else you'd like to discuss regarding the Stigma in Global Health program, its award process, or results?

24. Do you have any suggestions for FIC on how to improve the Stigma in Global Health program?

25. Do you have any other questions?

Involvement in Shaping Program

1. Please tell me how involved were you in the shaping of the program?

Probes:

- Role in the process?
- Who else involved
- Changes in role over time?
- Planning process - initial conception/first hear of the program?
- Planning process - most recent PA?

2. What are the goals of the Stigma program, in your own words?

[Interviewer will paraphrase them.]

Probes:

- How did they evolve?
- Did you have a role in shaping them?
- Who else had input?

3. How was the need for the program identified?

Probes:

- Literature review to see what was/had been done?
- Contact anyone at Cochran Collaboration or look to Cochran reviews?
- Meetings/panel of experts?
- Planning exercises?
- Any other types of meta-analysis?

4. a. Did you have concerns from the beginning?

Probes:

- Were you supportive? Any reservations?
- What was your rationale?
- Would you say that you “bought in” to the project? What does that mean to you? What brought it about?
- Align with FIC’s strategic priorities?
- Did you solicit support from others?
- How has this changed over time? (if known.)

b. How do you think the Stigma program goals align with FIC’s strategic plan?

c. Those of NIH/other Institutes and Centers (ICs)?

Probes:

- Knowledgeable of other ICs participating in program?
- How did other ICs sign on to fund Stigma
- Did you experience or perceive any barriers or problems in finding partners?
- What role, if any, did partner ICs play in establishing the Stigma program goals over time? Please explain.
- What are ICs reasons for partnering with us?

5. Are the award mechanism for the Stigma in Global Health program (R01s & R21s) a good fit with the program’s goals?

Probes:

- Benefits of short-term vs. longer term funding?
- Benefits of offering the R21 mechanism?

- Expected outcomes of each type
- Expected impact on career
- Were other mechanisms or strategies considered?
- Does funding a Stigma grant under the R21 mechanism change the likelihood of awarding a subsequent R01 (under the Stigma program or otherwise)?

Program Management

6. Are you aware of which study section was used [if not, tell them.]

Probes:

- Are you aware of why this particular study section was used?
- Were the people appropriate for the topic or international orientation of the program?

7. Did you have any role in shaping the review criteria? Do you know what the review criteria have been?

Probes:

- What are their strengths and weaknesses?
- How were they received by the reviewers?
- Where they successful in guiding reviewers?
- Have the review criteria changed over time?

8. Were you aware of / knowledgeable of any of the feedback from the review panel to the Stigma applicants?

Probes:

- How would you characterize it?
- Were there any themes or commonalities in the feedback given?
- Do you feel that it was helpful or informative in terms of guiding the investigator to addressing the program's goals?

9. How would you describe your current level of involvement in Stigma as the program officer/planning officer?

Probes:

- How has this changed over time?
- How does this compare to your involvement relative to other R01/R21s programs?
- [Other probes for engagement with program.]

10. Do you know of any delays in Stigma projects due to funds transfers, etc?

Probes:

- Have they impeded research?
- Do you know of any other barriers?
- How have these barriers been dealt with?

11. What funding sources, apart from FIC and the Stigma program, exist for biomedical and behavioral health scientists studying “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”? (Probe for government support, other international support)

Probes:

- WHO?
- EU?
- Other countries?
- Foundations? Gates, Global Health Council, etc
- CDC?

- OMHs?(Office of Mental Health)
- CMHPs? (Community Mental Health Programs?)

Partnerships & Communication

12. How would you describe the level of involvement and role of interagency partnerships?

Probes:

- Have there been any benefits to the interagency involvement that you believe would not have happened otherwise?
- Do these partnerships enhance the sustainability of the funded projects [their outputs]?
- Do you have any examples?
- Is there a downside to participation by program partners?

13. For ICs or partners that chose to discontinue co-funding, what was the reason behind that decision?

Probes:

- What kind of impact did it have on the program?
- Do you have any examples?

14. Have foreign country stakeholders had any input into the shaping of the Stigma program? [Foreign NGOs may come up here.]

Probes:

- Have there been any benefits to the involvement of other counties that you believe would not have happened otherwise?
- Does the participation of foreign countries enhance the sustainability of the funded projects [their outputs]?
- Do you have any examples?
- Is there a downside to involving foreign country stakeholders?

15. Are there any potentially productive partnerships that you feel are lacking or that should be explored?

Probes:

- Foreign or domestic agencies, MOHs, etc.?
- Foreign or domestic NGOs?
- WHO?
- EU?
- Other countries?
- Foundations? Gates, Global Health Council, etc
- CDC?
- OMHs?(Office of Mental Health)
- CMHPs? (Community Mental Health Programs?)
- How would such partnerships benefit the program or funded projects?
- How would partnerships with entities like these enhance the sustainability of the funded projects [their outputs]? What do you mean by “sustainability” in this context?
- Any potential disadvantages?

16. On the program level, can you describe any efforts to disseminate research findings (apart from the publication in scientific journals)?

Probes:

- Discussions with agencies or offices that work in official capacities? (Foreign and domestic)
- Websites/blogs
- Conferences – presentations, moderations
- Direct communication with individuals? (When, where)

- Do you know of any efforts to link grantees with policymakers, or communicate their findings to the policy community?
- Do you know of efforts to encourage community participation in the research?
- Do you have any suggestions for data-sharing mechanisms (between researchers, with the wider research and public health community, etc)?
- For the above examples, how did you learn of these examples? PRs?
- For the above examples, were they requested or proffered?
- For the above examples, any known impact?

17. On the program and project level, can you describe any efforts to promote the translation and implementation of findings from the Stigma program?

Probes:

- Discussions with agencies or offices that work in official capacities? (Foreign and domestic)
- Websites/blogs
- Conferences – presentations, moderations
- Direct communication with individuals? (When, where)
- Do you know of any efforts to link grantees with policymakers, or communicate their findings to the policy community?
- Do you know of efforts to encourage community participation in the research?
- Do you have any suggestions for data-sharing mechanisms (between researchers, with the wider research and public health community, etc)?
- [Other probes for other communication methods/tools].
- For examples above, why were they “translation” or “implementation”
- For the above examples, were they requested or proffered?
- For the above examples, any known impact?
- For the examples above, do they add anything to the sustainability of the funded project? What do you mean by “sustainability” in the context of transmitting research findings?

18. [For POs only] Do you [FIC] facilitate interaction between Stigma PIs?

- If yes, would you consider your involvement more active or passive?
- Are the Stigma PIs interacting? How so? How often?
- Is there more that could be done in this area?
- What might be the advantages of FIC facilitation? Examples.
- Does the interaction between Stigma PIs enhance the sustainability of the funded work? Examples. What do you mean by “sustainability” in this context?
- Disadvantages of FIC facilitation? Examples

Closing

19. Is there anything else you’d like to discuss regarding the Stigma program, its award process, or results?

20. Do you have any suggestions for FIC on how to improve the Stigma in Global Health program?

21. Do you have any other questions?