

Qualitative Assessment of the NIH Behavioral and Social Sciences Research Portfolio— Interviews with Institute Staff and Personnel from Selected Professional Societies

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A. Introduction

The Office of Behavioral and Social Sciences Research (OBSSR) of the National Institutes of Health (NIH) coordinates behavioral and social sciences research (BSSR) across NIH Institutes and Centers (ICs) in support of its mission to stimulate crosscutting research on the role that behavioral and social factors play in the causes, treatment, and prevention of disease and in the promotion of health and quality of life.

In September 2011, the OBSSR contracted with the IDA Science and Technology Policy Institute (STPI) to document and evaluate the BSSR portfolio for fiscal year (FY) 2006 through FY 2010 across NIH's 24 ICs that fund and manage extramural research. Upon mutual agreement, the range was subsequently changed to FY 2007 through FY 2011. A team of STPI researchers conducted qualitative assessments of the NIH BSSR portfolio from 11 NIH ICs that participated in the pilot study, and delivered the results of these assessments on November 2, 2012, in a memorandum to the director of the OBSSR.

In response to this memorandum, the director requested that we obtain additional qualitative perspectives from the remaining ICs that fund extramural BSSR but did not participate in the pilot study. He also requested that we seek perspectives on the current state and future trends in BSSR from experts outside the NIH. Between January and May 2013, we interviewed representatives from 12 ICs and 7 professional societies. This report summarizes the results of these interviews.

B. Interviews of Researchers at NIH Institutes and Centers

1. Methodology

We used semi-structured, in-person, and telephone interviews to gather information about BSSR and basic BSSR (bBSSR) portfolios of NIH ICs. Between January and March 2013, we interviewed 29 individuals across 12 ICs. (See Table 1 for a list of ICs and interviewees.) A list of abbreviations at the end of the report explains acronyms used in the table and elsewhere in the report. By mutual agreement of NIH and the STPI team, the National Center for Advancing Translational Sciences (NCATS) was excluded from the study as it was created in December 2011. The interview protocol included questions about the experts' individual definitions of the five categories explored in the pilot study, research trends in these areas, and stakeholders for the research. A separate protocol was developed for the Center for Scientific Review (CSR) given the different nature of its work relative to that of grant-making ICs. The CSR protocol addressed the representation of behavioral and social science researchers on study sections and other issues related to the proposal review process. The interview protocols for both the CSR and the grantmaking ICs are provided in Appendix A.

IC	Name	Title	Program, Office, Branch, or Division
CSR	Thomas Drgon	Scientific Review Officer	Biostatistical Methods and Research Design (BMRD) Study Section
	Wenchi Liang	Scientific Review Officer	Community Influences on Health Behavior (CIHB) Study Section
	Suzanne Ryan	Scientific Review Officer	Social Sciences and Population Studies A (SSPA) Study Section
	Delia Olufokunbi Sam	Scientific Review Officer	Health Disparities and Equity Promotion (HDEP) Study Section
	Jane Doussard-Roosevelt	Scientific Review Officer	Child Psychopathology and Developmental Disabilities (CPDD) Study Section
	Gabriel Fosu	Chief	Healthcare Delivery and Methodology Integrated Review Group
	Rebecca Henry	Scientific Review Officer	Health Literacy Study Section
FIC	Joshua Rosenthal	Acting Director	Division of Training and Research, Extramural Division
	Farah Bader	Public Health Analyst	Division of International Training and Research
NHGRI	Jean McEwen	Program Director	Ethical, Legal, and Social Implications (ELSI) Research Program
	Joy Boyer	Program Analyst	Ethical, Legal, and Social Implications (ELSI) Research Program
NIAID	David Burns	Branch Chief	Clinical Prevention Research Branch, Division of AIDs
	Phillip Renzullo	Deputy Branch Chief	Vaccine Clinical Research Branch, Division of AIDs
	Carolyn Williams	Branch Chief	Epidemiology Branch, Division of AIDs
NIAMS	William Tonkins	Health Science Administrator	Division of Skin and Rheumatic Diseases
NIEHS	Symma Finn	Health Science Administrator	Susceptibility and Population Health Branch
	Liam O'Fallon	Program Analyst	Susceptibility and Population Health Branch
	Claudia Thompson	Branch Chief	Susceptibility and Population Health Branch
NIBIB	William Heetderks	Director	Extramural Science Programs
	Mary Rodgers	Professor	University of Baltimore School of Medicine
NIDCR	Melissa Riddle	Director	Behavioral and Social Science Research Branch
	David Clark	Health Science Administrator	Behavioral and Social Science Research Branch
NIGMS	Juliana Blome	Chief	Office of Program Analysis and Evaluation
	Stephen Marcus	Program Director	Division of Biomedical Technology, Bioinformatics, and Computational Biology
NIMHD	Francisco Sy	Director	Extramural Research Administration
	Jennifer Alvidrez	Program Officer	Division of Scientific Programs
NINDS	Courtney Ferrell Aklin	Program Director	Office of Special Programs in Diversity
NINR	Linda Weglicki	Chief	Division of Extramural Programs
	Donna Joe McCloskey	Program Director	Women's Health and Self-Management

Table 1. Institute Interviewee List

We asked interviewees of grant-making ICs five sets of questions related to BSSR and bBSSR at their IC:

- 1. Description of the portfolio
- 2. Organization of the portfolio
- 3. Current research in five sub-categories: prevention, decision science, social epidemiology, mobile health (mHealth), and measurement development
- 4. Future trends in the portfolio
- 5. Related stakeholders

Using notes, transcripts, and audio recordings from interviews as well as supplemental materials, we created a summary write-up for each IC. (See Appendix B through Appendix M.) We then located common themes across write-ups, which were developed into research findings. Eighteen findings resulted from expert interviews, some of which repeated themes that emerged from the pilot study interviews. The following section discusses these research findings.

2. Findings

This round of interviews echoed eight findings from the pilot study with ten new perspectives being raised by several of the interviewees. A finding is presented here if representatives from more than one IC raised the issue. We emphasize that these are the perspectives of individuals and may not represent official policies or positions of the IC as a whole. Findings from the CSR interviews are presented separately. Additional perspectives are highlighted in the Appendixes.

a. New Findings

These findings emerged from the second round of interviews. We separate these findings into those that address how the current portfolio is handled and those that identify anticipated future trends.

1) Current Portfolio

IC reorganizations provide opportunities to institutionalize support for BSSR. Some ICs have created new divisions and offices that will house more of the IC's BSSR. For example, the National Human Genome Research Institute (NHGRI)'s Genomic Medicine Branch has become a full division and will support more clinical research with BSSR components. NIDCR has a dedicated BSSR branch, and NINDS created an Office of Clinical Research, which houses more of its behavioral research.

Engagement in BSSR depends on the IC's mission. Five of the 11 ICs interviewed have missions that could be characterized as disease-specific: supporting research on the

causes, prevention, and treatment of disease. These ICs support a range of BSSR, whereas ICs such as NGHRI, the National Institute of Biomedical Imaging and Bioengineering (NIBIB), and the National Institute of General Medical Sciences (NIGMS) have specialized missions for which BSSR plays a targeted role in the portfolio. For example, NIBIB develops biomedical technologies and supports research on mHealth and technology usage and uptake, NHGRI is a resource development IC and supports research on decision science and genomic information, and NIGMS focuses on basic and foundational research and much of its BSSR is basic.

Program Officers support grantees in improving the quality of BSSR proposals. As BSSR directions evolve and change within an IC and in the external research community, Program Officers (POs) work to improve the quality of BSSR proposals. For example, NIDCR may hire consultants such as survey methodologists and scientometrics experts to help grantees incorporate newer methodologies into proposals to meet requirements of rigorous review. NHGRI grantees often do not have BSSR backgrounds but have begun including empirical components in their proposals, at the PO's urging.

ICs support training of the new BSSR workforce. Along with funding BSSR, many ICs focus on increasing BSSR capacity within the IC and the greater research community. For example, FIC plans to train BSSR scientists to operate in multidisciplinary research settings. The National Institute on Minority Health and Health Disparities (NIMHD) is focused on increasing the number of scientists studying health disparities and the number of minority scientists studying health.

BSSR appears in ICs' Strategic Plans. BSSR is mentioned peripherally, if not emphasized, in most ICs' strategic plans.

ICs partner in inter-IC and trans-NIH BSSR initiatives. For some ICs, especially the smaller ones or those that fund less BSSR, partnering with other ICs in inter-IC or trans-NIH initiatives provides leverage for their more limited dollars. For larger ICs and those that fund more BSSR, these initiatives allow them to extend into new areas of research.

2) Future Directions

ICs are shifting toward studies integrating biomedical and BSSR approaches. ICs identified combined biomedical and behavioral research as a future trend. The National Institute of Allergy and Infectious Diseases (NIAID) is working to understand how BSSR can improve Acquired Immune Deficiency Syndrome (AIDS) outcomes, as a biomedical cure remains elusive. NIBIB aims to understand how BSSR can aid in biomedical technology adoption and uptake. The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) is showing increased interest in studies using complementary and alternative medicine methodologies. NIMHD is integrating BSSR with epigenetics.

ICs are increasingly focused on implementation sciences and translational, population-level BSSR. ICs with specific missions such as National Institute of Environmental Health Sciences' (NIEHS) mission to understand the effects of environment on health, FIC's mission to facilitate global health, and NIMHD's mission to improve minority health and eliminate health disparities often support communitylevel research, translational, and applied research in behaviors in a cultural context. With respect to implementation science, previous studies at NIAID have shown that biomedical interventions are effective for HIV prevention, and will support more research on interventional research at the community level.

ICs see increased focus on data sciences and big data. Studies are increasingly using layered data such as family, community, and systems-level data in addition to individual data, as is the case with community-based research supported at FIC and NIMHD. With this came a focus on developing computational methods to study larger and more complex data sets, with a focus on creating large-cohort data sets. Moreover, many studies aim to increase the capacity to integrate data sets to ask broader, systems-level questions.

ICs will expand research on mHealth and e-health. ICs expect to increase research supporting mHealth and e-health. For example, NIAMS is interested in understanding electronic applications of Cognitive-Behavioral Therapy through mobile applications and CD-ROMs. NIEHS is developing personal sensors and mobile applications to increase environmental health education and community participation, and NIBIB is using mHealth to bridge the gap between BSSR and technology development.

b. Findings that Emerged from Both Sets of Interviews

ICs generally support the Basic Behavioral and Social Science Opportunity Network (OppNet), and most receive OppNet funding. All ICs reported enthusiastic support for OppNet, with only a few ICs indicating that their grants do not meet the OppNet funding criteria.

Leadership affects BSSR support and priorities. Leadership can influence research directions and types of BSSR funded by the IC, by creating more visibility and in some cases elevating BSSR as a whole within an IC. Specific examples include the Fogarty International Center (FIC) director's interest in mHealth, the previous National Institute of Dental and Craniofacial Research (NIDCR) director's creation of a separate BSSR branch, and the National Institute of Neurological and Communicative Disorders and Stroke (NINDS) director's creation of more visibility for traumatic brain injury in the external community.

ICs manage and fund prevention research on a variety of intervention levels, diseases, and conditions. This agrees with our previous work showing that prevention is the most prevalent of the five pilot subcategories.

Decision science at NIH includes a wide range of research activities, making it very broad for purposes of categorization. The fact that this finding emerged again suggests that NIH should consider refining and narrowing the category by, for example, splitting out behavioral economics into its own category.

Traditional social epidemiology and measurement development are not prioritized across NIH. OBSSR should consider exploring the role and status of social epidemiology and measurement development research in contributing to NIH's mission.

mHealth is widely supported across ICs and, though small, is growing. This is an area that bears watching and OBSSR should consider its role in supporting BSSR as it relates to mHealth.

c. Findings from the Center for Scientific Review

We were asked to interview CSR because of its unique perspective on scientific trends among the NIH ICs. Because CSR Scientific Review Officers (SROs) handle all proposals that are submitted to the NIH, CSR is positioned to see what topics, methods, and fields drive the scientific community in BSSR. Moreover, SROs can recognize when the scientific community has moved on from a particular topic or methodology, and what new topics are trending in its place. SROs can see applications that have the potential to influence and change the research landscape, and inform the OBSSR on why applications showing promise might not score well in review.

STPI researchers interviewed seven CSR SROs on two dates. In the first interview, we spoke with Dr. Tomas Drgon, Dr. Wenchi Liang, and Dr. Suzanne Ryan, who manage the Biostatistical Methods and Research Design (BMRD), Community Influences on Health Behavior (CIHB), Social Sciences and Population Studies A (SSPA) study sections, respectively. In the second interview, STPI spoke with Dr. Jane Doussard-Roosevelt, Dr. Gabriel Fosu, Dr. Rebecca Henry, and Dr. Delia Olufokunbi Sam, who manage the Child Psychopathology and Developmental Disabilities (CPDD), Risk, Prevention and Intervention for Addictions (RPIA), Health Literacy, and Health Disparities and Equity Promotion (HDEP) study sections, respectively. Findings from both interviews are described below. We emphasize that, as with the IC interviews, these interviewees are a small subset of CSR SROs, and their viewpoints do not necessarily paint a complete picture of the IC.

Scientific Review Officers are seeing a rise in the number of BSSR applications, specifically those that include biological components, mixed methodologies, and interdisciplinary topics. BSSR proposals are becoming increasingly interdisciplinary, including components of genetics, neuroscience, and imaging. No quantitative data were provided to substantiate this perception.

Scientific Review Officers are seeing an increase in each of the five subject categories, especially in mHealth and decision science. No quantitative data were provided to substantiate this perception.

Proposals in health disparities are increasing, which touches on each of the five subject categories. No quantitative data were provided to substantiate this perception.

The content of a proposal is driven by two factors: Trends in the scientific community and as a response to NIH funding announcements. The number of BSSR proposals that CSR receives has increased in the past few years, but it is unclear if investigators are submitting proposals in response to an NIH funding announcement implying that NIH is driving the research in a particular direction—or if the increase is emerging organically from the scientific community. SROs believe both have been a factor in the increase in BSSR proposals.

Scientific Review Officers ensure that reviewers have the right mix of expertise to comprehensively review a proposal. When CSR receives proposals that are more interdisciplinary or are using mixed methods, SROs invite specialists to participate on the study section as ad hoc reviewers or as mail reviewers so that the contents of a proposal will be well understood before scoring.

Proposals for data collection score better in review than proposals that test hypotheses based on an already existing data set. As budgets have become tighter, reviewers are prioritizing proposals that can create new data sets, which will then be available for other researchers vs. funding a grant that analyzes an existing data set.

C. Interviews with Personnel at Behavioral and Social Science-Related Professional Societies

1. Methodology

To gain perspectives on BSSR trends from stakeholders outside the NIH, we interviewed representatives from eight professional societies (Table 2). At the request of Dr. Kaplan, societies were chosen from the governing members of the Consortium of Social Science Associations (COSSA) with the exception of the Society for Behavioral Medicine. We chose organizations whose research disciplines aligned with the biomedical and health-related mission of the NIH and contacted the president and publisher of each society's flagship publication asking them, or someone within the organization, to contribute to the study.

Organization	Interviewees
American Educational Research Association (AERA)	William Tierney, President Felice Levine, Executive Director
American Psychological Association (APA)	Steve Breckler, Executive Director for Science Gary VandenBos, Publisher
Association for Psychological Science (APS)	Alan Kraut, Executive Director Erich Eich, Editor <i>Psychological Science</i>
American Sociological Association (ASA)	Cecilia Ridgeway, President Debra Umberson, Editor <i>Journal of Health and</i> <i>Social Behavior</i>
American Statistical Association (ASA)	Marie Davidian, President Leonard Stefanski, Chair of Committee on Publications
Linguistics Society of America (LSA)	David Lightfoot, Past President 2010-2011 Doug Whalen, Nominating Committee
Society of Behavioral Medicine (SBM)	Alan Christensen, President Amy Stone, Executive Director
Society for Research in Child Development (SRCD)	Ann Masten, President Jeffrey Lockman, Editor <i>Child Development</i> Lonnie Sherrod, Executive Director

Table 2. Professional Societies Interviewee List

We conducted one-hour, semi-structured interviews around five topical areas: organization of the society, conference proceedings, the society's publications, emerging trends, and interactions with the National Institutes of Health and OBSSR. The interview guide used for the semi-structured interviews is found in Appendix N. The guide was designed to elicit perspectives on how the organizations operate, how they identify and account for changing research priorities, how they perceive NIH and OBSSR's role in identifying and influencing research priorities, and how they interact with NIH and OBSSR. The following sections discuss common themes that arose from this study. For more detailed information pertaining to each organization, please refer to the compiled notes from each interview located in Appendix O through Appendix V.

2. Method for Identifying Trends in BSSR

All interviewees indicated that their society's leadership is cognizant of changing and emerging research trends and priorities; however, no organization, with the exception of the American Educational Research Association (AERA), stated that they engage in formal trend identification analyses (e.g., bibliometric analyses to determine emerging research topics). AERA has provided \$250,000 per year for the next 4 years for a conference initiative aimed at identifying and accepting papers in nascent educational science research topics.

Interviewees responded that publications, conference papers, abstracts and proceedings, and grant applications are the primary venues for identifying emerging trends. Conferences are particularly useful for trend identification because research presented at conferences can be at an earlier stage than research submitted for journal publication and therefore topics represented at conferences may include emerging research areas. The Society for Research in Child Development (SRCD) targets emerging topic areas through special topic meetings, invited conference sessions and lectures, and special journal sections and issues. LSA and AERA also indicated that conference sessions and lectures may include emerging topic areas; however, they also indicated such conference sessions tend to focus on the center of the field and established research topics.

As a strategy for identifying emerging trends, interviewees asserted that it is important to analyze submissions to conferences, journals, and funding agencies, rather than analyzing only funded grant applications and publications. Such analysis would provide a more complete view of current research, and, as SBM noted, would give more insight into emerging research. SBM interviewees noted that some unpublished manuscripts and unfunded grant applications may represent research that is too new and underdeveloped to pass the review process but that is breaking from core research into new and possibly fruitful research areas. One weakness of this analysis, however, is that it is unclear whether agencies react to research trends or create them through funding priorities. While program announcements may be created based on community input as to which areas require more funding, they may also be influenced by other priorities to drive research in specific directions.

3. BSSR Trends

One common topic that emerged from the interviews was that of "big data" and data-intensive research projects. Five of the organizations specifically mentioned the increasing role of big-data analytics in their respective fields' research practices. Some organizations, such as LSA, suggested that research is beginning to focus more on computational research, while others, such as SRCD, offered that its community's research is incorporating big-data analytics into mixed methodologies research. AERA interviewees specifically noted incorporating and analyzing multiple large data sets (e.g., local, State, and Federal educational records) to answer new, unique research questions. Investigators need more training in data development, measurement, mixed-type databases, and data analytics.

Also apparent in several of the discussion topics and specifically noted by the Association for Psychological Science (APS) and AERA interviewees is the trend toward more interdisciplinary collaboration for behavioral and social science research projects. They assert that BSSR requires input from multiple disciplines in order to answer emerging research questions in biomedical sciences. The AERA interviewees noted that health education issues cannot be addressed only through research on teaching, but must also incorporate socioeconomic, health, and development research. Such inquiries require expertise in education, psychology, development, economics, and other research areas. The APS interviewees noted that even within the field of psychology, research teams are becoming more interdisciplinary. In order to successfully pursue psychological BSSR, a research team may need expertise in clinical psychology, developmental psychology, cognitive science, and neuroscience. Research teams are incorporating many different BSSR perspectives and questions to gain a more complete understanding of different phenomena, as opposed to the more narrowly focused research questions previously addressed.

Big data and the increasingly interdisciplinary nature of BSSR have also contributed to the increasing use of mixed methodology research. As research teams become more interdisciplinary, different methodologies are employed to supplement one another and provide a more complete answer to the research questions. In sociology, for example, quantitative methods are still the primary technique, however, qualitative interviews and behavioral experiments are used more often to supplement and cross-validate findings. In developmental psychology, studies may bring together multiple levels of analysis, from genetic to environmental to social influences on development, to answer research questions. Animal, human, and population-level studies may be conducted in conjunction with one another in order to understand how basic biological factors along with societal factors influence the development and educational performance of a child. Longitudinal studies may be included to understand how development at an early stage of life affects outcome in early adult or later periods in life. Such mixed methodologies have also coincided with the resurgence in qualitative analyses that complement the quantitative big-data analytics. These analyses include ethnographies, individual interviews, and other techniques that provide unique data points that provide further insight into the aggregated quantitative data.

For specific topic trends please refer to the *Trends in BSSR—Topics* sections of the individual interview notes in Appendix O through Appendix V.

4. Comments and Recommendations for NIH and OBSSR

Several interviewees acknowledged that NIH is starting to focus more on the role of large, complex, and diverse data sets in biomedical research, and recommended the NIH continue to increase its efforts in this area. The LSA interviewees suggested more collaboration between NIH researchers and researchers from fields with established experience in big-data analytics, such as astronomy and physics, in order to learn best practices and techniques for training and integrating big data with biomedical research. The National Science Foundation (NSF)'s activities may serve as an example, as the foundation has already engaged with those communities, has increased training for data scientists, and has provided significant funding for cyberinfrastructure.

Interviewees also discussed the NIH's peer review process and suggested that CSR SROs should focus on inviting more BSSR scientists to review grant proposals. Interviewees shared the perception that BSSR may have a more difficult time succeeding during the review process not because of lack of merit but because reviewers may not completely understand the research methods and their application to the NIH mission. Interviewees from ASA stated that sociologists are rarely involved with the scientific review process at NIH, a factor which may tie into their observation that NIH does not examine issues in the larger sociological contexts in which they exist. The perceptions of these external stakeholders do not align with those of the CSR interviewees who assert that SROs are able to get experts with the appropriate backgrounds to review BSSR proposals (see Section 1.B.2.c, Findings from the Center for Scientific Review).

The interviewees recognized the importance of the office in encouraging BSSR within the NIH. Several recommendations emerged for improving OBSSR's role within the NIH. Several interviewees thought that OBSSR's role was appropriate but suggested the office receive more funding in order to carry out its current initiatives and provide more specific funding for grant applications. Interviewees also stated that OBSSR should focus more on engagement with individual ICs. While it is important to bring together ICs through coordinating committee meetings, they suggested it may be more effective to engage individually with IC program officers and leadership. While bringing together ICs for joint BSSR funding opportunities is important, individual engagement with ICs may help the ICs realize how BSSR fits into their existing missions and funding opportunities. This would address the issue of BSSR grant applications that make it through review but

are left unfunded because ICs do not believe them to be closely aligned with their core institutional mission. The LSA interviewees specifically noted that through such engagement, OBSSR can stress how small investments in BSSR can lead to big payoffs. They argued that the return on small investments for BSSR is greater than much of the other research funded through the NIH. SRCD interviewees also suggested that OBSSR engage more with external stakeholders through regular meetings with or newsletters for professional organizations.

The last theme that emerged from multiple interviews related specifically to the National Institute of Mental Health (NIMH) and its shift in focus from mental health to mental illness. Several interviewees asserted that the NIMH's increased focus on disease genetics and translational science over general mental function and health has resulted in a behavioral and social science gap for basic research investigating environmental, societal, and other factors affecting mental health and function. The LSA interviewees stated that NIMH still provides some funding for basic cognitive neuroscience and language disorder research but far below pre-2003 levels, when the strategy of the IC shifted focus. The National Institute of Child Health and Human Development (NICHD) has funded some of the projects within these fields but does not provide substantial enough awards to close the funding gap.

Appendix A. Interview Guides for Experts at 12 NIH Institutes and Centers

Interview Guide for the Center for Scientific Review (CSR)

Informed Consent

The NIH Office of Behavioral and Social Sciences Research (OBSSR) asked the Science and Technology Policy Institute to conduct a study on behavioral and social sciences research (BSSR) at NIH. We will ask you some questions about your Institute or Center (IC) and position as it relates to BSSR at NIH. Our conversation will <u>be audio-recorded</u>, but if you'd like to tell us something that is off the record, feel free to do so. We will stop recording and writing until you tell us that we can start again.

STPI Project Overview (10 minutes)

- Goals of project
 - To uncover trends in BSSR important to NIH.
 - To better estimate the percentage of total NIH funding going toward BSSR.
 - To analyze categories of BSSR in NIH portfolio without relying on Research, Condition, and Disease Categorization (RCDC).
- Description of recent project activities
 - To reach the third goal, we performed a pilot on five categories: mHealth, prevention, social epidemiology, decision sciences, and measurement development with input from 11 ICs that fund varying amounts of BSSR.
 - Developed an algorithm based on funded grant applications (FGAs) highly representative of each of the five categories.
 - Validated this algorithm with the 11 ICs.
 - We also interviewed these ICs about the structure of their BSSR portfolio and trends in BSSR as it relates to their IC.
- Your participation
 - Goals of this interview are to understand:

- o CSR's grant review process.
- How CSR reviews and scores BSSR grant proposals in general, and as they relate to the five categories.
- Trends in BSSR grant proposals coming into NIH, and types of BSSR proposals that do and do not get funded.
- Questions?

CSR BSSR Portfolio (35 minutes)

- Introductions—Please state your name, your academic background, and how long you have been an SRO. What do you do in your day-to-day job?
- How are BSSR grants distributed among the seven divisions of CSR? Do BSSR grant applications fall under more than one division? Are they organized by study sections within each division, within CSR Integrated Review Groups (IRG), or across CSR?
- Describe the process NIH uses to assemble study sections.
 - How often do they meet?
 - How do you find reviewers and people? Are BSSR proposals mixed in with ones with a bio focus?
- Describe the review lifespan of a grant application—starting from grant submission to final scoring.
- What are the criteria for scoring of BSSR grant applications—new methodologies, high risk, interdisciplinarity? (e.g., NIMH funds grants that include imaging components)
 - How does a study section determine the scientific merit of a particular topic or methodology, or whether a proposal is outdated?
- Why might a BSSR grant score poorly in review?
- How do you stay current with developments in BSSR fields? Do you reach out to external stakeholders?
 - If so, who are they? Are there particular organizations? Particular extramural researchers?
- Do you attend BSSR conferences and hold workshops?

BSSR Trends (25 minutes)

- Do you see any future BSSR trends that would impact the quantity and kinds of applications coming into NIH?
- Have you seen a surge or decline in applications for BSSR?
- What future trends in BSSR do you see that are specific to the five categories?
 - mHealth?
 - Prevention?
 - Social epidemiology?
 - Decision sciences
 - Measurement development?
 - Are any of these five topics underfunded? Why do you say this?

Final Questions (5 minutes)

- Do you have any questions related to this interview or the analysis of BSSR categories?
- Do you have any comments that you would like passed to OBSSR?

Thank You

- We greatly appreciate your participation in interviews. It was extremely important to get your IC's feedback.
- Thank you!

Interview Guide for Grant-Making Institutes and Centers

Informed Consent

The NIH Office of Behavioral and Social Sciences Research (OBSSR) asked the Science and Technology Policy Institute to conduct a study on behavioral and social sciences research (BSSR) at NIH. We will ask you some questions about your Institute or Center (IC) and position as it relates to BSSR at NIH. Our conversation will <u>be audio-recorded</u>, but if you'd like to tell us something that is off the record, feel free to do so. We will stop recording and writing until you tell us that we can start again.

STPI Project Overview (10 minutes)

- Goals of project
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- To better estimate the percentage of total NIH funding going toward BSSR.
- To analyze categories of BSSR in NIH portfolio without relying on Research, Condition, and Disease Categorization (RCDC).
- Description of recent project activities
 - To reach the third goal, we performed a pilot on five categories—mHealth, prevention, social epidemiology, decision sciences, and measurement development—with input from 11 ICs that fund varying amounts of BSSR.
 - Developed an algorithm based on funded grant applications (FGAs) highly representative of each of the five categories.
 - Validated this algorithm with the 11 ICs.
 - We also interviewed these ICs about the structure of their BSSR portfolio and trends in BSSR as it relates to their IC.
- Your participation
 - Goals of this interview are to understand:
 - Your IC's BSSR portfolio overall.
 - Your IC's BSSR as it relates to the five categories.
 - Trends in BSSR research as it relates to your IC.
- Questions?

IC BSSR Portfolio (35 minutes)

- Introductions and job titles (indicate that these are IC-specific questions that the group will answer one IC at a time).
- Are there specific program officials or officers dedicated to BSSR at your IC?
 - If so, how many?
 - If so, how do they organize and manage their BSSR portfolios? Please provide examples.
- Does your IC organize BSSR under specific topics?
 - Target populations?
 - Disease prevalence?
 - Funding mechanism
 - NIH directives?
- Specific announcements? (e.g., intra-IC, across-IC, and OBSSR announcements)

- Other topics?
- Why do these topics exist, and why do you manage your research under these topics?
- Does your IC organize basic BSSR (bBSSR) separately from BSSR?
 - Has your IC ever received OppNet funding?
- Does your IC manage to certain percentages of funding dollars or funding rates?
 - Does your IC take outside funding (e.g., NGOs or other ICs) to support its BSSR?
- Have changes affected how you organize your BSSR? Please provide examples.
 - Changes in leadership?
 - New funding mechanism?
 - New NIH initiatives or directives?
 - New policies and legislation?
 - Other changes?
- Does your IC have specific stakeholders related to BSSR?
 - If so, who are they? Are there particular organizations? Particular extramural researchers? Do you have a published list of stakeholders?
 - How does their involvement influence your research?
 - Does your IC have specific stakeholders related to BSSR in any of these five categories?

IC BSSR Related to Categories (15 minutes)

• What current research does your IC fund in these five categories? Please provide examples.

IC BSSR Trends (25 minutes)

- Indicate that the following questions are posed to the group as a whole.
- Do you see any future BSSR trends that would impact research funded by your IC? Please provide examples.
- Do you think any BSSR areas relevant to your IC are currently not funded or underfunded?
 - If so, what are they?

- What future trends in BSSR do you see that are specific to the five categories?
 - mHealth?
 - Prevention?
 - Social epidemiology?
 - Decision sciences?
 - Measurement development?
 - Are any of these five topics underfunded? Why do you say this?

Final Questions (5 minutes)

- Do you have any questions related to this interview or the analysis of BSSR categories?
- Do you have any comments that you would like passed to OBSSR?

Thank You

- We greatly appreciate your participation in interviews. It was extremely important to get your IC's feedback.
- Thank you!

Appendix B. Center for Scientific Review (CSR)

The Science and Technology Policy Institute (STPI) interviewed seven CSR Scientific Review Officers (SROs) on two dates. In the first interview, STPI spoke with Dr. Tomas Drgon, Dr. Wenchi Liang, and Dr. Suzanne Ryan, who manage the Biostatistical Methods and Research Design (BMRD), Community Influences on Health Behavior (CIHB), Social Sciences and Population Studies A (SSPA) study sections, respectively. In the second interview, STPI spoke with Dr. Jane Doussard-Roosevelt, Dr. Gabriel Fosu, Dr. Rebecca Henry, and Dr. Delia Olufokunbi Sam, who manage the Child Psychopathology and Developmental Disabilities (CPDD), Risk, Prevention and Intervention for Addictions (RPIA), Health Literacy, and Health Disparities and Equity Promotion (HDEP) study sections, respectively. Findings from both interviews are aggregated into a single document below.

Highlighted Findings

- BSSR is handled by CSR in several different ways:
 - Special announcements from OBSSR may result in a special review study section.
 - Proposals submitted through Program Announcements and Program Announcements with Special Review from ICs may be sent to a standing study section or a special review study section depending on circumstances.
- Study sections are organized according to expertise, including both content specific and methodological expertise and BSSR proposals are assigned according to the primary focus of the application, not just according to discipline.
- Study sections will invite ad hoc reviewers or mail reviewers to bring expertise for specific proposals that may contain content outside the expertise of standing members.
- There is a split between quantitative and qualitative mindsets on review panels, which may result in mixed-method proposals being poorly understood by the panel.

CSR Mission Statement

"Since 1946, we have worked to see that NIH grant applications receive fair, independent, expert, and timely reviews—free from inappropriate influences—so NIH can fund the most promising research."¹

Interviewees

Dr. Tomas Drgon is the SRO for the Biostatistical Methods and Research Design Study Section (BMRD). His background is in molecular biology, genetics, statistics, and systems science. He reviews Program Announcements (PAs) for systems sciences and last year reviewed the OBSSR PA on methods and measurements in BSSR. He has been at CSR for 3 years, and has previously worked as a fellow at the National Institute on Drug Abuse (NIDA) doing intramural research.

Dr. Wenchi Liang is the SRO for the Community Influences on Health Behavior (CIHB) study section, which focuses on primary prevention in obesity and substance abuse. She has been at CSR for 3 years and was previously an assistant professor at Georgetown conducting cancer prevention research.

Dr. Suzanne Ryan is the SRO for the Social Sciences and Population Studies A (SSPA) study section. She has been at CSR for 4 years and is trained as a demographer and sociologist in family demography. Prior to coming to NIH, she worked at a nonprofit research organization called Child Trends.²

Dr. Delia Olufokunbi Sam is the SRO for Health Disparities and Equity Promotion (HDEP) in the Healthcare Delivery and Methodologies Integrated Review Group (IRG). She earned a PhD in clinical and health psychology and received postdoctoral training in mental health services research and policy. She is trained as a nurse anthropologist and has been at CSR for a few years.

Dr. Jane Doussard-Roosevelt is an SRO in the Child Psychopathology and Developmental Disabilities (CPDD) Study Section and Biobehavioral and Behavioral Processes IRG. Dr. Doussard-Roosevelt is a developmental psychologist with postdoctoral training in psychophysiology and psychopathology.

Dr. Gabriel B. Fosu is the Chief of the Healthcare Delivery and Methodology IRG. Previously, he was an SRO in the Risk, Prevention and Intervention for Addictions (RPIA) study section and the Risk, Prevention and Health Behavior IRG. He received his

¹ The CSR mission statement is from <u>http://public.csr.nih.gov/aboutcsr/Pages/default.aspx</u>.

² Child Trends is a non-profit research organization that aims to improve the health of children. More information can be found at <u>http://www.childtrends.org/</u>.

PhD in sociology from Brown University. His research has been in the areas of demography, social epidemiology, health-related behaviors, and applied research and evaluation methods.

Dr. Rebecca R. Henry manages the Health Literacy study section, is trained as a nurse anthropologist, and has been at CSR for a few years. She received her PhD in anthropology and her BA in nursing. Prior to coming to NIH she designed and oversaw a diverse portfolio of international qualitative research for the Demographic and Health Research group. Her interests include health provider practice; client-provider interaction; social construction of the body, experience and illness; gender analysis; Southeast Asia, immigrants, refugees and transnational communities.

CSR Organizational Structure

CSR is divided into seven divisions: The Division of Management Services (DMS), the Division of Basic and Integrative Biological Sciences (DBIB), the Division of Neuroscience, Development, and Aging (DNDA), the Division of Receipt and Referral (DRR), the Division of AIDS, Behavior and Population Sciences (DABP), Division of Physiological and Pathological Sciences (DPPS), and the Division of Translational and Clinical Sciences (DTCS).

Role of the Scientific Review Officer

SROs coordinate the review of proposals and assignment of proposals to ICs. They review about 300 applications annually, and based on the content of the proposal, they assign proposals to a standing study section, determine the relevant expertise needed to appropriately review the application, and facilitate the review and scoring process. SROs also recruit standing review members, ad hoc reviewers, and mail reviewers for standing study sections, and create new sections or special panels as needed, based on the set of applications they receive each round. Additionally, SROs provide training for less experienced reviewers prior to their meetings and network with reviewers informally to learn each other's backgrounds and expand upon topics that are not understood by everyone on the panel, and to provide tutorials for new concepts that are brought up in meetings.

Assembling Study Sections and Grant Assignment for Review

There are a few ways that a BSSR grant can flow through to CSR. If OBSSR puts out an announcement on a special topic such as systems science, they coordinate with CSR to have a special review. An IC can put out a Program Announcement (PA) or Program Announcement with special review (PAR) and the applications for that announcement can go to any study section. Finally, an investigator can write an application that goes to NIH's Division of Receipt and Referral, and can then go to any study section at the SRO's discretion. CSR does not have any IC-specific study sections, and no sections dedicated to BSSR. Study sections have been established, and CSR follows guidelines that set parameters for what types of topics the study section can review. Standing members serve in the study sections from four to 6 years. In the case that OBSSR releases a PAR, CSR will organize a special review panel within a standing study section. CSR recruits reviewers for special emphasis panels for four- to 6-year periods. These special emphasis panels are created only in established areas of science. SROs have flexibility in inviting reviewers, and based on the topics needing review, SROs invite reviewers for every round of review. Most of the review for BSSR has been done through special panels.

An application may score better or worse depending on the study section, but based on the content of the proposal, SROs will place applications in the study section with the most relevant expertise. For example, in the BMRD section, the core criterion is not content, but methodology; an application that has a BSSR content focus may do well in another study section slanted towards the content. If an investigator has requested a study section, this is taken into account and usually honored by CSR. The investigator may talk to an IC before sending the proposal to gauge interest, and the IC can help them word the grant to align with the IC mission and interests. For grants that may be applicable to more than one IC, CSR assigns a secondary IC. IC assignment occurs independently of the review, and does not affect the score in any way.

In addition to standing study sections and special panels within these sections, CSR has IRGs, similar groups of study sections clustered around a broad scientific area. Applications are first assigned to an IRG and to a specific study section within the IRG, and the IRG chief approves all assignments and can redistribute and reapportion grants. The main reason for IRGs is administrative size, so there is review coverage on two levels. The DABP has three or four IRGs that cover behavioral grants. Examples of IRGs that review BSSR include the Biobehavioral and Behavioral Processes IRG (BBBP), AIDS and Related Research IRG (AARR), Population Sciences and Epidemiology IRG (PSE), Healthcare Delivery and Methodologies IRG (HDM), Biology of Development and Aging IRG (BDA), and the Risk, Prevention and Health Behavior IRG (RPHB).

The Fogarty International Center has its own review panel with a different focus. Their study section is called Non-Communicable Chronic Disease, as the international global health community regards chronic disease as more of a threat to global health than infectious disease.

CSR also receives applications for funding announcements from other funding agencies. For example, the Congress funded the Food and Drug Administration (FDA)

for tobacco-related research, and many applications that were submitted to the Patient Centered Outcomes Research Institute (PCORI)³ came first to NIH for review.

Scoring and Reviews

Each grant is assigned three or four reviewers within the panel, and SROs try to ensure that reviewers have the right mix of expertise to score a proposal. For topics outside of a reviewer's expertise, the reviewer will defer to a specialist reviewer. These three reviewers have read and reviewed the proposal and lead the discussion during the study section. Their scoring weighs more than that of the other panel members, as these reviewers have expertise in the subject area. This score sets the range of the final score, but if there is strong disagreement within the rest of the panel, then panelists may vote outside of that range.

Scoring criteria are dependent on the study section. For example, in BMRD, studies that create data sets or large new survey collection endeavors do best in review, especially when compared to a hypothesis-driven research question. Reviewers are told to judge the overall impact of the application, and whether it will have a sustained and powerful influence on the field. In BMRD, for example, a proposal that can create a new data set does better than one that uses an already established data set to explore a hypothesis about a topic.

An application might score poorly in review because investigators have not developed the application very well. CSR does not see many applications that are strictly behavioral, but they fare well in review, so there is no bias against BSSR applications in review.

One problem that occurs during review is that, with the diversity in expertise represented in the panel, sections run into a problem of having a split between the quantitative and qualitative mindsets and not knowing how to take other's perspective into account when scoring grants. When CSR receives cutting edge applications using mixed methods, those proposals are often not well understood by reviewers. Additionally, there is sometimes tension between panelists who value approaches that describe a phenomenon vs. intervention studies and vice versa. The difficulty lies in finding the balance between these two differing thought processes.

³ Congress established PCORI to conduct research that would enable more effective medical decision making between patients and health care providers. More information is available at http://www.pcori.org/.

Mail Reviewers and Ad Hoc Reviewers

If a section receives a set of proposals in a new topical area, SROs will invite ad hoc reviewers or mail reviewers, and as this topic trends, the reviewers can become permanent standing members.

In the case that SROs need to review a set of small applications on a specific topic, they may ask for participation by a mail reviewer, who reviews an application and provides a written critique that is then read and discussed when the panel meets. Panelists review this critique in advance, and having this specific topic area expertise allows panelists to be confident in their review to the entire section. If panelists need more information, they discuss the application with the mail reviewer on the phone. Mail reviewers do not provide a numerical score, but their critique is incorporated into the review.

Ad hoc reviewers are asked in the case where there are more than a few grants in that area. For example, a study section that receives one imaging grant will recruit a mail reviewer, but a section that receives three population environment grants will ask an ad hoc member to review them.

Study Sections

STPI interviewed SROs from six study sections and two IRGs, all described below.

The **Biostatistical Methods and Research Design (BMRD)** study section reviews applications with a focus on methodology, rather than on specific content area. After a recent OBSSR PA, BMRD saw applications on methods and measurements in BSSR. The systems science special emphasis panel reviews proposals with four specific methodologies: agent-based models, systems dynamics models, social network analysis, and content-based data analysis such as looking at models of obesity, models of cities, looking at where people walk and where collisions occur, and models of enzyme kinetics. Few social sciences proposals are reviewed in this section.

Reviewers in the **Community Influence on Health and Behavior (CIHB)** section are behavioral scientists. Since they are getting more multidisciplinary work that includes biological mechanisms, they will invite a temporary reviewer with expertise in that area. Some examples of these studies include a diabetes study looking at biological markers, a tobacco study that combines toxicity and behavior, and environmental health sciences looking at soil and asthma control.

Reviewers in the **Social Sciences and Population Studies A** (**SSPA**) study section are sociologists, economists, and social epidemiologists, and will be including a clinician because grants in mechanisms of chronic heart disease, cancer risk, and social epidemiology are becoming more important in this panel. The Health Disparities and Equity Promotion (HDEP) study section reviews proposals in different content areas, disease states, cancer disparities, child pediatric disparities, and cardiovascular health, and captures different methodologies and content areas focused on health disparities. This section receives grants from NIDA, NIMH, NCI, and NIMHD. Health disparities was a special panel until OBSSR released a PAR on health disparities, which increased the number of proposals submitted in this area, resulting in the creation of a standing study section. Applications for this PAR included topics in mHealth, prevention, and social epidemiology with biological, social, and genetic components. Reviewers in this section have underlying expertise in health disparities, and their specific expertise cuts across many areas such as behavior and cancer.

The **Healthcare Delivery and Methodologies (HDM) IRG** focuses on health services research in a number of different content areas such as addiction, behavioral health, and primary care intervention.

Reviewers in the **Child Psychopathology and Developmental Disabilities** (**CPDD**) study section are split between university professors and medical center researchers. The panel is currently recruiting neuroscientists and imaging reviewers. Nearly half of the panel members have a background in imaging, psychophysiology, and electroencephalograms (EEGs), and a few are behaviorists. This section is seeing more proposals on reward processing, autism, Attention Deficit Hyperactivity Disorder (ADHD), and anorexia.

Biobehavioral and Behavioral Processes (BBBP) IRG—All applications that come into the Division of Aids, Behavioral and Population Sciences have a BSSR component, and there is overlap within the division and the BBP IRG. A child psychology proposal may go to the adult subjects study section if it includes a disease like ADHD that starts in childhood or schizophrenia that starts in early adulthood. When applications border between neuroscience and behavioral science, they go to a different study section.

The **Risk**, **Prevention and Health Behavior (RPHB) IRG** covers risk, interventions, and prevention, with some applications focusing on risk factors. There are a few emerging areas in this section including behavioral economics, and many applications are including components of neuroscience, genetics, and quantitative methodologies. They are also seeing more proposals in mHealth and wireless and webbased interventions. SROs intend to divide this study section into two sister sections.

The **Health Literacy** study section is not yet a standing study section. OBSSR has just renewed a health literacy funding opportunity announcement (FOA), and this section reviews R01s, R03s, and R21s that cover broad topic areas in health literacy such as access to healthcare. Reviewers are a mix of professionals who have worked in the field,

doctors, nurses, special education professionals, and other specialists, depending on the kinds of applications received in a particular round. Examples of other specialists include those in dietetics, communications, health communications, sociologists, anthropologists, and psychologists.

CSR and the Scientific Community

As NIH leadership is dedicated towards training and professional development, SROs are encouraged to attend two conferences or scientific meetings annually, one local and one outside Washington, D.C. This has declined recently due to budget constraints and Federal sequestration. This raises concern, as many sections are diverse and review grants for multiple ICs. Conference attendance allows SROs to gain exposure to different topical areas, and get to know the grantee population in terms of who is writing similar proposals and who can be potential reviewers. Through networking with senior researchers, SROs can learn about up-and-coming researchers or find a reviewer in a specific topic area, for both standing and ad hoc study section members.

SROs also stay current in their fields by reading applications and journal articles, through involvement in OppNet, and taking advantage of NIH-archived videos as well as seminars and presentations in Washington, D.C., and on the NIH campus. SROs indicated that NIH seminars in mixed methods and translation and implementation have been particularly useful.

Trends in BSSR according to CSR

General Trends

CSR has been seeing an increase in BSSR applications in the past few years, although it is difficult to tell whether this change is in response to a PAR or because the scientific community is trending towards these topics. Similarly, SROs do not know if declining topics are in response to declining funding or lack of interest from researchers, but SROs believe both have an influence. For example, after the Congress pushed for funding comparative effectiveness research⁴ through the Affordable Care Act, NIH received many applications. Moreover, health literacy is increasing in response to government policies, and specifically, those aimed at early intervention training.

In addition, SROs are seeing a rise in the number of interdisciplinary applications they are receiving. However, interdisciplinarity does not guarantee that an application

⁴ Comparative effectiveness research refers to studies aimed at defining effective strategies to prevent and treat health conditions under a variety of specific circumstances. Go to <u>http://www.nlm.nih.gov/hsrinfo/cer.html for more information</u>.

will score well in review. Moreover, ICs are increasingly funding centers working together on a topic vs. a single principal investigator (PI).

Section-Specific Trends

The CIHB study section has seen a number of changes in the kinds of BSSR applications it is receiving. Mixed methods research is a small trend in this section. Since reviewers need to ensure that the research is innovative, reviewers of many different backgrounds come together to score these proposals. Recently, the National Institute on Aging (NIA) released an announcement on preparing the elderly in case of disaster. More applications are being submitted on the study of behavior and challenges in the lesbian, gay, bisexual, and transgender (LGBT) population. A PA on behavior and prevention of obesity through understanding the built environment, global positioning systems (GPS), and Ecological Momentary Assessment (EMA) is receiving applications with the goal of understanding how people are moving in their environment, to see if people are going to parks as opposed to the grocery store, and looking at the alcohol outlets density in a neighborhood and combining movement behavior.

Some proposals that have been decreasing include cancer screening studies because they involve interventions and CIHB reviews mostly non-intervention studies. Additionally, there are fewer international studies because panels are asking whether international comparisons are necessary to get new knowledge for what is already known.

The SSPA has seen increased emphasis on developmental origins of health and disease (DOHaD)⁵. These types of studies include those looking at early life environments and health risk of the mothers and how that affects outcomes for children as they age. Additionally, many applications have started to incorporate biomarkers and genetics linked with larger population surveys such as NIA's Health and Retirement Study⁶ that has epigenetic biomarkers. Moreover, this section is seeing an increase in topics of chronic heart disease, cancer risk, and social epidemiology research. Retirement economics is one topic that is declining.

As the BMRD study section focuses mostly on methodology and data collection instead of content and disease area, they are seeing trends in data integration. For example, studies can combine readily available Medicare data with demographic data on how far people walk to restaurants and stores. Additionally, research in modifying computational methodologies to apply to complex data sets, such as in longitudinal brain

⁵ More information on DOHaD is available at <u>http://www.dohad2013.org/</u>.

⁶ More information on NIA's Health and Retirement Study can be found at <u>http://www.nia.nih.gov/health/publication/growing-older-america-health-and-retirement-study.</u>

imaging studies, is increasing. Disaster preparedness and logistics modeling research is increasing due to increase in public awareness of infectious diseases, and NIH is modeling the spread of infectious disease. Obesity is trending in the systems sciences panel. The panel is also receiving fewer grants on straightforward genetics or behavioral genetics or simple longitudinal studies of cancer; applications are more complex because simpler applications do not score well in review since methodologies are simpler and less cutting edge.

The RPIA study section is has noticed an increase of applications with components of behavioral economics, neuroscience, and genetics. Many are including mobile, Internet, and web applications for prevention and intervention. There is also a PAR in development on substance abuse among military families and this is an area that will likely expand in the near future; OBSSR should focus on that in terms of prevention and intervention for veterans and their families.

In health literacy, there is an intellectual siloing trend in which applications are scoring poorly when they do not include field-developed health literacy measures. Computer and human interactions are becoming more important. There was a rise in applications in response to a PAR focused on medication, labeling, and drug adherence and creating accessibility to different groups. More social scientists are submitting applications to the health disparities PAR and there is more diversity in the applications, researchers, and in the review panel. Descriptive studies are being discouraged through PAR language, and CSR is receiving many of the same topics in the last 2 years.

In the CPDD study section, the number of applications in autism has increased, as it has received media attention. Researchers feel as if they are at a disadvantage if they are not submitting proposals on autism or adolescent mood. There is also a decrease in Down syndrome research. Imaging grants are on the rise but may not score well if there is no clinical impact. This change is driven by reviewers trying to select the best research with a limited funding payline.

The HDEP study section has seen a rise in implicit bias studies, systems science, network analysis and agent-based modeling, and the Human Papillomavirus (HPV). Applications on American Indian issues have decreased but NIDA is attempting to reinvigorate this portfolio. Studies on LGBTI are on the rise. NIH is creating an LGBTI coordinating committee and promoting FOAs on LGBTI studies and encouraging LGBTI researchers as well.

Subject Category Trends

CSR sees an increasing trend in each of the five BSSR categories. Health disparities research is on the rise, cutting across the five categories. In decision science, economics

and medical decision making studies are increasing. There is an increase in mHealth and medical decision making in CSR's Small Business Innovation Research (SBIR) section.

There are fewer treatment studies on child psychopathology because those studies are conducted intramurally by NIMH. There are more mHealth applications, particularly in developing children's iPod apps. Other mHealth proposals include creating prostate cancer decision making dashboards for quality of life for providers and patients and using crowdsourcing as a method for data collection.

Additional Comments

Role of OBSSR

SROs believe that OBSSR has a role in distinguishing between the two drivers of research at NIH:

- Researchers have an idea and new methodology makes this research possible. For example, researchers would previously choose one data set out of many to study, but with advanced computational methodology, researchers can extract information from different data sets.
- The perception of what is trending often influences proposals. Labs that are on the cutting edge may incorporate trending topics to get funding at the cost of doing innovative science. For example, when the FDA released a tobacco-related PA, the visibility was raised in the community and investigators began to submit more applications to the National Cancer Institute (NCI)'s Tobacco Control Research Branch.

SROs indicated that often the most valuable grants are investigator imitated grants, where there is as little influence as possible from what NIH, or a limited number of experts at NIH, thinks is important. Keeping in mind that NIH has accountability to taxpayers and public thought, the scientific thought may be contaminated by trends that are artificially added. The investigator should not be encouraged to look at content that is fashionable, but something that would lead to groundbreaking and innovative research. The systems science request for application (RFA) is a good example because it focuses on development of methods and the content is not narrowly defined. If OBSSR can distinguish that, that would elicit more innovative research.

SROs also struggle with knowing in advance that a certain grant will do better than another, and do not know if scoring reflects IC and OBSSR priorities. For instance, does NIH want to fund more data collection or hypothesis-driven research using existing data? The former scores better in review than the latter. OBSSR should be aware of the fact that applications receiving high scores in review are those creating a public good such as new databases. Additionally, OBSSR should be a catalyst in spearheading and developing areas such as health disparities and doing large-scale coordination of research among the ICs. OBSSR can provide a driving vision for ICs considering a topic area that do not have buy-in within their Institute, and should move BSSR forward within NIH because BSSR is not a huge priority within the ICs. Coordinating committee meetings are a good vehicle to convene OBSSR and ICs together to share cross-cutting ideas and facilitate greater buy-in of BSSR.

SROs would like to focus on more health disparities research across ICs, along with LGBT and systems science research. Most research at NIH receives funding when it has a direct health outcome, so oftentimes basic BSSR is not funded even when scoring well in review.

Innovation

Review criteria and scoring influence which grants are funded by ICs, and the question of scoring outlier or emerging trend in BSSR is difficult. SROs indicated that ideas no longer occur in isolation, and when new ideas and thoughts are propagated, they emerge from many areas at once. For instance, a conference or meeting may provide ideas about solutions to a particular topic or problem, which may result in many proposals arising from different labs.

Appendix C. Fogarty International Center (FIC)

Highlighted Findings

- FIC frequently participates in OppNet funding opportunities and co-funds BSSR with other ICs.
- FIC's research portfolio includes prevention, decision science, social epidemiology, and measurement development; FIC is planning to fund non-commercial applications of mHealth, which is broadly highlighted in the strategic plan.
- FIC has several programs heavy in BSSR, including the Fogarty International Research Collaboration Behavioral, Social Sciences (FIRC-BSS).
- Global health is trending towards issues closer to delivery of healthcare and prevention (as opposed to the basic research on which much of NIH research focuses), including associated behavioral issues and risk decision making.

FIC 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."¹

Interviewees

Dr. Joshua Rosenthal is the acting director of the Division of Training and Research in the Extramural Division. He is an ecologist by training, and has worked in plant and insect interactions with an emphasis on complex systems. He has been with FIC for 18 years.

Farah Bader is a public health analyst in the Division of International Training and Research where she conducts program analyses and reporting activities. Ms. Bader has an

¹ The FIC mission statement is from <u>http://www.fic.nih.gov/About/Pages/mission-vision.aspx</u>.

MA in public health and public mental health research, with a BA in neuroscience and behavioral neurobiology. She has been at FIC for 4 years.

FIC BSSR Portfolio

Organizational Structure

The FIC is divided into four divisions: The Division of International Relations; the Division of International Epidemiology and Population Studies; the Division of International Science Policy, Planning, and Evaluation; and the Division of International Training and Research.

Funding

FIC received 0.2 percent of the total NIH-appropriated funding in 2012. According to RCDC, FIC's average portion of the BSSR and bBSSR portfolios for the combined years 2008–2011 is, 0.3 percent and 0.2 percent, respectively.

General Research

FIC has a blended portfolio of behavioral and social sciences with 10 program officers and one social scientist. Most of its portfolio is not clinical, although its director, Dr. Roger Glass, is focused on clinical endpoints. Research funding has focused on low and middle income countries with over 30 percent of funding going to HIV/AIDS research, particularly in Africa. Staff provided a list of FIC's BSSR programs, which include:

- Behavioral and Social Sciences—Fogarty International Research Collaboration— Behavioral, Social Sciences (FIRCA-BSS)
- Brain Disorders Brain Disorders in the Developing World: Research Across the Lifespan (BRAIN)
- Systems Science Systems Science Methodologies to Protect and Improve Population Health (SYSMETH)
- AIDS AIDS International Training and Research Program (AITRP)
- Trauma Fogarty International Collaborative Trauma and Injury Research Training Program (TRAUMA)
- Training Global Research Initiative Program for New Foreign Investigators (GRIP); Fogarty International Clinical Research Scholars and Fellows (*Scholars*), International Research Scientist Development Award (IRSDA)

The Stigma program is currently inactive but a newer version is being regenerated by OppNet through an R01 called Revision Applications for Basic Social and Behavioral
Research on the Social, Cultural, Biological, and Psychological Mechanisms of Stigma. FIC frequently partners with OppNet and other ICs to co-fund programs.

A few small grants in BSSR have been terminated due to the granting system; grants were funding projects in countries that were low-priority for FIC, but are now funding more population skills and health systems research, which includes trauma, tobacco, mental health, systems approaches to health services delivery and adherence to protocols, and indoor air pollution.

FIC submitted a new RFA in 2006 called the International Training and Research in Environmental and Occupational Health (ITREOH)² to develop hubs in research and training in the developing world to broadly support environmental occupational health decision-making and policy, including climate change and indoor air pollution and traditional toxicology and pollution analyses. Additionally, FIC and NCI have partnered on the Global Alliance for Clean Cookstoves,³ to support research on decision-making on cooking and heating homes.

FIC does not have targeted dollar amounts allocated to BSSR, but its program lines grow depending on the quality of grants received and co-funding available.

Current BSSR at FIC

Ms. Bader assembled a list of grants fitting into the five pilot categories using the NIH RCDC categorization system and feeding FIC grants through a categorization and evaluation software called IN-SPIRE.⁴ Below are selected examples she described during the interview.

Prevention

Two examples of prevention studies include Hope for the Future: A School-Based HIV Prevention Program for Youth in Malawi, which aims to create an intervention to teach HIV prevention strategies using Social Cognitive Behavioral Theory, Theory of Possible Selves, and Resilience Theory; and Examining Human Behavior in Dengue Prevention Efforts in Iquitos, Peru, which will evaluate movement patterns and human behavior in dengue prevention efforts.

² The ITREOH program ended in 2011. <u>http://grants.nih.gov/grants/guide/notice-files/NOT-TW-11-020.html</u>.

³ More information on the Global Alliance for Clean Cookstoves can be found at <u>http://www.cleancookstoves.org/</u>.

⁴ More information on IN-SPIRE can be found at <u>http://in-spire.pnnl.gov/</u>.

Social Epidemiology

Grants identified as having components of social epidemiology include Syphilis Social Epidemiology in the People's Republic of China, which evaluates the impact of a World Health Organization (WHO) program offering free rapid syphilis testing on a patient's decision to consent to both a syphilis and HIV test. Additionally, the Social and Neighborhood Predictors of Obesity in Belo Horizonte project will clarify the role of socioeconomic and community factors in shaping obesity and related behaviors.

Decision Science

Example grants for decision sciences include Social Interactions and Malaria Preventive Behaviors in Sub-Saharan Africa, which hopes to understand the importance of social interactions with neighbors in the adoption and spread of malaria preventative technologies; and Examining Policy Resistance and Infectious Diseases within Dynamic Network conditions, which will use innovative combinations of epidemiological modeling, behavior modeling, and institutional modeling to understand feedback processes among individuals and institutions that influence the effectiveness of public health policy toward infectious diseases at international borders.

mHealth

FIC's director, Dr. Roger Glass, is interested in mHealth research and in creating systems that are useful rather than being driven by commercial applications. There are research questions at the individual level, as well as systems-level questions on how to create large data cohorts to answer questions such as whether adherence to a particular drug regimen is useful. mHealth will be broadly highlighted in the FIC strategic plan.

Grants exemplifying mHealth include SMS Turkey: Harnessing the power of TXT messaging to promote smoking cessation and Evaluation of a computer-based system using cell phones for HIV people in Peru.

Measurement Development

FIC highlighted two projects as examples of measurement development. The Vanderbilt-Zambia network for innovation in global health technologies, led by Flora Katz, Deputy Director of the Division of International Training and Research, will develop and implement innovative solutions for malaria detection in a multidisciplinary environment. The Measuring Health, Media, Computer, and Digital Literacy Among Senegalese Youth project will develop standardized scales and indicators of health literacy, e-health literacy, media, and computer literacy.

Trends in BSSR at FIC

In the last decade, global health discussion has moved to focus more on downstream issues closer to delivery of health services than the kinds of basic science that NIH supports. Dr. Glass encourages asking questions that relate to access to care and training young scientists to do a wide range of research, especially clinical.

Opportunities for growth in FIC include systems science and tobacco. FIC has been co-funding tobacco-related grants with the NCI for the past 10 years through the International Tobacco and Health Research and Capacity Building Program. The research shows that tobacco drives the largest disease burden in terms of life-years. The tobacco program was designed to support research on policy change, but future directions show more of a focus on behavior, which is also the case for other non-communicable diseases such as heart disease and obesity.

Traditionally, global health has focused on infectious disease, malaria, tuberculosis, and now AIDS, but is now moving towards social and behavioral issues such as clean water, vaccinations, mental health, and systems approaches to health services.

Other areas where FIC would like to see more applied research are in risky behaviors and risk-evaluating decision-making in a cross-cultural context (such as riding motorcycles without helmets, drinking behaviors and violence, and smoking). FIC highlighted the need for behavioral and social scientists trained to integrate research in a multi-disciplinary community and for scientists with the ability to understand the range from complex disease systems to developing interventions and implementation science. The field of implementation science is moving forward and is also seeing an increasing trend of using a systems approach to think about complex systems that drive health. Additionally, data sciences are receiving a push from the director's office, and OBSSR can be involved to help support data sharing. Finally, topics in mHealth, specifically in the interaction of electronic devices and social media, are growing.

Stakeholders

- Consortium of Universities for Global Health
- American Thoracic Society

Medical Anthropology groups are missing from the discussion and are needed.

Appendix D. National Human Genome Research Institute (NHGRI)

Highlighted Findings

- NHGRI participates in BSSR Coordinating Committee meetings but has not funded OppNet grants.
- NHGRI's research portfolio includes decision science and measurement development as part of larger interdisciplinary grants.
- The Genomic Medicine Branch is now a full division of NHGRI, resulting in more clinical research with BSSR components.
- NHGRI is receiving more quantitative decision science proposals and proposals with empirical component (however, such proposals usually do not do well in review because the submitting PIs are not trained in BSSR).

NHGRI Mission Statement

"NHGRI supports the development of resources and technology that will accelerate genome research and its application to human health. A critical part of the NHGRI mission continues to be the study of the ethical, legal and social implications (ELSI) of genome research. NHGRI also supports the training of investigators and the dissemination of genome information to the public and to health professionals."¹

Interviewees

Dr. Jean McEwen is the Program Director of the Ethical, Legal, and Social Implications (ELSI) of Genomics Research Division. Previously, she managed ELSI grants on genetic variation in complex traits and behavioral genetics, especially as such issues relate to law and social policy.

Dr. Joy Boyer is a Program Analyst in the ELSI Program. She is a social scientist with a BS in religion and has been at NHGRI since 1996 and in this role for a majority of that time.

¹ The NHGRI mission statement is from <u>http://www.genome.gov/10001022</u>.

Organizational Structure

NHGRI's extramural research program is divided into four divisions: the Division of Genome Sciences, the Division of Genomic Medicine, the Division of Genomics and Society, and the Division of Extramural Operations. In the Division of Genomics and Society, the ELSI Research Program is responsible for conducting basic and applied research on the ethical, legal, and social implications of genetic and genomic research.

The Division of Intramural Research has seven branches: the Cancer Genetics Branch, the Genetic Disease Research Branch, the Genetics and Molecular Biology Branch, the Genome Technology Branch, the Inherited Disease Research Branch, the Medical Genetics Branch, and the Social and Behavioral Research Branch (SBRB).

Funding

NHGRI ranks 16th among NIH's Institutes and Centers in terms of funding, receiving 1.7 percent of the total NIH appropriated funding in 2012. According to RCDC, NHGRI's average portion of the BSSR and bBSSR portfolios for the combined years 2008–2011 are 0.4 percent and 0.4 percent, respectively.

General Research

The NHGRI differs from most other ICs in that its research does not focus on specific diseases, even those with a strong genetic component. Instead, interviewees considered NHGRI more of a resource development institute, having developed the Human Genome Project. ELSI is a significant component of NHGRI, having been built into the Human Genome Project from the beginning. While one might expect the ELSI program to be a natural place for BSSR to fit within NHGRI, ELSI staff are not BSSR-focused. ELSI researchers have backgrounds in philosophy, social psychology, and law, and the research they support is more grounded in the humanities than in the behavioral or social sciences. The little funding there is for BSSR mostly supports broader ethical questions, although ELSI has a clinical integration portfolio that funds a few large grants with BSSR components. Funding levels are determined by proposal merit, and not managed to specific funding percentages. ELSI comprises 5 percent of NHGRI's research budget, only a small portion of which supports BSSR.

Grants that are purely BSSR look at the psychosocial reactions to learning genetic information. For example, the Risk Evaluation and Education for Alzheimer's Disease (REVEAL)² grants look at families with a history of Alzheimer's and study the effect on relatives of receiving the genetic probabilities that they will also have Alzheimer's.

² More information on the REVEAL grants can be found at <u>http://www.aging.senate.gov/award/nih65.pdf.</u>

Another type of BSSR supported at NHGRI is clinical sequencing exploratory research, which studies the impact of providing genetic information on clinicians and the greater healthcare system.

NHGRI is involved in the OppNet coordinating committee, but has not been assigned any OppNet grants.

Current BSSR at NHGRI

Prevention

NHGRI does very little in prevention research.

Social Epidemiology

NHGRI does very little in social epidemiology research.

Decision Science

Some of NHGRI's grants may fall loosely into this category, but do not use strict decision science methodologies. Rather, decision sciences is a small component of larger, multidisciplinary grants.

Mhealth

NHGRI does not do mHealth research.

Measurement Development

Measurement development is also included as a small component of a larger grant.

Trends in BSSR at NHGRI

The 2012 reorganization of the Genomic Medicine Branch into a full division³ has been the biggest change affecting BSSR. The Genomic Medicine Division will support more clinical research, which is expected to involve a greater emphasis on BSSR, especially in the area of testing interventions to observe impacts on behavior. Before this, BSSR tended to be collaborative across NHGRI. Any changes in NHGRI's BSSR were at the program level and not at the Institute level.

Program Officers have been seeing a rise in the number of ELSI proposals received. They are also seeing an increase in quantitative decision science grants. Additionally,

³ More information on the NHGRI reorganization can be found at <u>http://www.genome.gov/27546599</u>.

philosophers and legal scholars are increasingly including empirical components in research proposals, but since PIs are not trained in BSSR, these grants do poorly in review. POs help PIs with grant-writing to improve peer review outcomes.

Program Officers emphasize that there is a proliferation of BSSR committees and meetings and that NHGRI does not have the staff to cover them all. NHGRI's interests are different from those of OBSSR, and while BSSR is important to ELSI POs, they should not be directing BSSR because their focus is on humanities.

Stakeholders

• Research community

Appendix E. National Institute of Allergy and Infectious Diseases (NIAID)

Highlighted Findings

- NIAID does not support OppNet because its mission is focused on applied research instead of basic research.
- NIAID's research portfolio includes prevention, decision science, measurement development, and some social epidemiology and mHealth.
- NIAID does not have a centralized office or dedicated program officers for BSSR; however it partners closely with NIMH for prevention and behavioral research.
- Research on HIV/AIDS is becoming more behavior-focused, as researchers seek to understand behaviors associated with HIV treatment and prevention.

NIAID Mission Statement

"The National Institute of Allergy and Infectious Diseases (NIAID) conducts and supports basic and applied research to better understand, treat, and ultimately prevent infectious, immunologic, and allergic diseases."¹

Interviewees

Dr. David Burns is the Branch Chief for the Clinical Prevention Research Branch in the Prevention Sciences Program in the Division of AIDs. He has an MD and an MPH in epidemiology and previously practiced internal medicine in infectious diseases. He has been at NIAID for 7 years and at NIH for 18 years.

Dr. Phillip Renzullo is the Deputy Branch Chief of the Vaccine Clinical Research Branch in the Vaccine Research Program in the Division of AIDs. He has a PhD in infectious diseases and an MPH in public health and epidemiology. Dr. Renzullo manages the NIAID/HIV clinical trials network, the HIV Vaccine Trials Network (HVTN), as well as NIAID's portfolio with the military's HIV research program.

¹ The NIAID mission statement is from <u>http://www.nih.gov/about/almanac/organization/NIAID.htm</u>.

Dr. Carolyn Williams is the Branch Chief of Epidemiology in the Division of AIDs studying observational data cohorts and large data cohorts. She received her PhD in infectious diseases and has an MPH. She has worked in the Federal Government for 17 years and has spent the last few years at NIH.

Organizational Structure

NIAID is divided into five divisions and one center: the Division of Acquired Immunodeficiency Syndrome (DAIDS); the Division of Allergy, Immunology, and Transplantation (DAIT); the Division of Microbiology and Infectious Diseases (DMID); the Division of Clinical Research (DCR); the Division of Intramural Research (DIR); and the Vaccine Research Center (VRC).

Funding

NIAID ranks second among NIH's Institutes and Centers in terms of greatest funding, receiving 14.6% of the total NIH-appropriated funding in 2012. According to RCDC, NIAID's average portion of the BSSR and bBSSR portfolios for the combined years 2008–2011 are, 2.1% and 0.3%, respectively.

General Research

Behavioral research is an important component of NIAID's work in understanding and preventing HIV transmission. Rather than having deep behavioral expertise in-house, NIAID partners closely with NIMH on which it relies to support its work in research on behavior and change models.

NIAID does not have a centralized office dedicated to BSSR and the research is not siloed or partitioned off in any one division. While there are no Program Officers (POs) dedicated to BSSR, there are a few POs with BSSR backgrounds, and colleagues in their HIV Vaccine Trials Network (HVTN) clinical trials network are trained in BSSR as well.

The Institute has signed onto some Funding Opportunity Announcements (FOAs) in measurement development and decision science, and is starting to co-fund an initiative with NIHM which combines prevention, behavioral, and biomedical sciences. NIAID does not administer OppNet-supported basic BSSR since its work is more applied.

Current BSSR at NIAID

Prevention

All of NIAID's BSSR includes a behavioral prevention component and Program Officers work with NIMH on a majority of their projects.

The Methods for Prevention Packages Program (MP3) focuses on developing optimal prevention packages for specific populations and settings.

Social Epidemiology

NIAID does not do much research in this area except in understanding social and behavioral influences on a general population. One example of this is a combination prevention² study called PopART³ in Zambia and South Africa looking at the influence of stigma on uptake of an intervention.

Decision Science

Studies in decision science include components of behavioral economics, in which patients are given financial incentives for drug adherence. Some studies include research on implementation science, understanding the uptake of behavioral interventions.

Mhealth

Research in mHealth is limited to studies on electronic men's caps,⁴ which monitor whether patients have taken the cap off their medication, and the use of cell phones to interact with high-risk patients.

Studies in the HVTN are trying to understand why people make or miss their appointments and what behaviors they engage in between visits using texting and SMS in cell phones in South Africa.

Measurement Development

There is an effort to standardize behavioral data collection and analysis, putting together a catalog of procedures and activities to be used within the six clinical trial networks in NIAID.⁵ Additionally, while NIAID projects do not have the aim of

² Combination studies refer to those studying the effect of a combination of interventions. The PopART trial will use a combination of counseling, voluntary testing, and antiretroviral (ART) therapy.

³ More information on the PopART trial can be found at <u>http://www.hptn.org/web%20documents/IndexDocs/071StudyAnnouncement14Sep11.pdf</u>.

⁴ These electronic men's caps provide real-time monitoring of patients to see if they have taken the caps off their medication. A remote sensing technology transmits a report back to the healthcare facility to see if an intervention is necessary if adherence has dropped.

⁵ NIAID's six clinical trial networks include the AIDS Clinical Trials Group (ACTG), the HIV Prevention Trials Network Group (HPTN), the HIV Vaccine Trials Network (HVTN), the International Maternal Pediatric Adolescent AIDS Clinical Trials (IMPAACT), the International Network for Strategic Initiatives in Global HIV Trials (INSIGHT), and the Microbicide Trials Network (MTN). More information on these networks can be found at http://www.niaid.nih.gov/about/organization/daids/networks/pages/daidsnetworks.aspx.

developing new measurement tools, NIAID uses different measurement tools to assess depression and other behavioral issues.

Trends in BSSR at NIAID

As an effective vaccine for HIV remains elusive, more researchers are directing their efforts at understanding the behavioral factors that influence the treatment and prevention of HIV. As a result, NIAID POs have seen a dramatic uptick in the collection of behavioral data. The interviewees believe this trend will continue in the near future, raising the prominence of behavioral research within the institute.

The NIH portfolio is shifting from doing initial behavioral efficacy research to looking at implementation science⁶. Additionally, NIAID is seeing more proposals to scale up initial intervention efficacy studies using multipronged approaches which are more complicated and require more assessment. In the past 5 years, funding of network studies and individual randomized clinical trials has increased and has yielded results that indicate that biomedical interventions are effective for prevention. Current research is moving towards using combination behavioral and biomedical studies to understand whether these interventions will work outside of a clinical trial setting, at the community and population level. In the absence of a vaccine or microbicide for preventing HIV transmission, NIAID is increasing its focus on behavioral modification approaches. Another trend in the past few years is the increase in aggregation of large databases at the population level.

In order to stay current with trends, POs usually attend annual scientific meetings, but this has decreased due to budget restrictions. Instead, POs keep in touch with research community electronically.

Additional Comments

As NIAID is starting to focus more in individual behavior for prevention of transmission and uptake of HIV, they are interested in expanding their research by working with other ICs and signing onto FOAs from other groups. The interviewees were not sure who the NIAID representative to the BSSR coordinating committee is, nor what contributions the committee make to NIAID's work.

⁶ Implementation science refers to the uptake of initial behavioral and biomedical research; the implementation of procedures and behaviors based on prior research.

Appendix F. National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

Highlighted Findings

- NIAMS participates in BSSR Coordinating Committee meetings but has not funded any OppNet grants; however they co-fund BSSR with other ICs.
- NIAMS's research portfolio includes primary and secondary prevention, decision science, mHealth, measurement development, and some social epidemiology.
- NIAMS has recently increased its research into alternative interventions (e.g., yoga) and uses for the Patient Reported Outcomes Measurement Information System (PROMIS).

NIAMS Mission Statement

"The mission of the National Institute of Arthritis and Musculoskeletal and Skin Diseases is to support research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases; the training of basic and clinical scientists to carry out this research; and the dissemination of information on research progress in these diseases."¹

Interviewees

Dr. William (Phil) Tonkins is the Program Director and Health Sciences administrator at NIAMS and manages the behavioral and biopsychosocial portfolio of the Division of Skin and Rheumatic Diseases. He has a PhD in public health with a background in exercise physiology and sports medicine. He has worked at NIH for 6 years and at NIAMS for the past 4 years.

¹ The NIAMS mission statement is from <u>http://www.niams.nih.gov/About_Us/Mission_and_Purpose/mission.asp.</u>

Organizational Structure

NIAMS is divided into three divisions and one Intramural Research Program. The research divisions are the Division of Extramural Research Activities, the Division of Musculoskeletal Diseases, and the Division of Skin and Rheumatic Diseases.

Funding

NIAMS ranks 17th among NIH's Institutes and Centers in terms of funding, receiving 1.7% of the total NIH-appropriated funding in 2012. According to RCDC, NIAMS's average portion of the BSSR and bBSSR portfolios for the combined years 2008–2011 is, 0.6% and 0.2%, respectively.

General Research

NIAMS supports disease-specific research with a mix of both behavioral and social science. BSSR is categorized by funding mechanism and by type of methodology or intervention proposed in the research grant.

Many projects are based on Cognitive-Behavioral Therapies (CBT) Internet-based therapies and intervention. The Division of Skin and Rheumatic Diseases and the Division of Musculoskeletal Diseases support research on behavioral interventions and psychosocial research, specifically in intervention for fibromyalgia pain.

NIAMS collaborates with other ICs to co-fund grants. Currently NIAMS and NCCAM co-manage the Patient-Reported Outcomes Measurement Information System (PROMIS).² NIAMS attends OppNet coordinating committee meetings but has not had any grants that have met OppNet funding criteria.

While there may be a few BSSR grants spread across other divisions, Dr. Tonkins oversees most of the BSSR portfolio at NIAMS.

Current BSSR at NIAMS

Prevention

Prevention at NIAMS is a mix of primary and secondary, with CBTs used to prevent the progression of arthritis and fibromyalgia.

² The Patient Reported Outcomes Measurement Information System (PROMIS) is a set of measurement tools that allows patients to self-report on their physical, mental, and social well-being. See <u>http://www.nihpromis.org/ for additional information</u>.

Social Epidemiology

NIAMS has few grants in this category, but some focus on how drug advertisements influence interaction between physicians and patients in terms of what the patient requests for treatment options.

Decision Science

Dr. Tonkins indicated that decision science is an area supported within the BSSR portfolio. One example is a study looking at patient-provider interactions when making drug treatment decisions.

Mhealth

Grants on mHealth focus on mobile app development.

Measurement Development

NIAMS has a funding announcement for arthritis-specific applications using PROMIS to validate the instrument within the arthritic population.

Trends in BSSR at NIAMS

NIAMS is seeing increased interest in research on interventions involving alternative exercises such as yoga. Many of these studies were previously supported by NCCAM.

Another trend is using PROMIS to assess an individual's health and document patient reported outcomes using mobile technologies and applications such as laptops, iPads and smartphones.

There is increasing interest in understanding the electronic application of CBT through CD-ROMs and mobile applications. Examples of this type of research at NIAMS include research to design interventions for pain management and grants that explore social dimensions such as the patient-family interaction. Some of this research is in pediatrics helping children cope with disease in terms of symptoms and quality of life. Dr. Tonkins anticipates that future research will focus more across the lifespan.

Dr. Tonkins would like to see more research using imaging to validate the use of other interventions, such as using functional magnetic resonance imaging (fMRI) and CBT to validate a measureable outcome.

Stakeholders

- Grantees
- Society of Behavioral Medicine (SBM)

- American College of Rheumatology
- BSSR scientists in the American College of Radiology (ACR)

Additional Comments

Dr. Tonkins sees a distinct role for OBSSR to play in funding the development of pilot data on the effectiveness of BSSR interventions, to include determining methodologies for applying therapies. The ICs could focus on funding more specific science related to implementation of these interventions and therapies within their diseases rather than the IC funding the entire process of method development, piloting, and application.

Appendix G. National Institute of Environmental Health Sciences (NIEHS)

Highlighted Findings

- NIEHS has funded a few OppNet grants and participates in NIH-wide BSSR announcements, such as health literacy.
- NIEHS's research portfolio includes prevention, decision science, social epidemiology, mHealth, and measurement development.
- NIEHS focuses on applied and translational BSSR, divided into outreach and community engagement
- The Director of NIEHS increased the focus on community engagement and there is a new plan for increasing support for BSSR.
- NIEHS has pushed for increased community awareness of environmental health issues, and there has been an increase in e-health, personal sensors and mobile applications, and new technologies to address mental health disparities and to increase diversity in the research workforce.

NIEHS Mission Statement

"The mission of the National Institute of Environmental Health Sciences is to discover how the environment affects people in order to promote healthier lives."¹

Interviewees

Dr. Symma Finn is the Health Science Administrator in the Susceptibility and Population Health Branch. She received her PhD in medical anthropology from the University of Florida in 2008 and MA from the University of Miami in environmental anthropology.²

¹ NIEHS 2012–2017 Strategic Plan <u>http://www.niehs.nih.gov/about/strategicplan/index.cfm#a224822</u>.

² More information on Dr. Finn can be found at <u>http://www.niehs.nih.gov/research/supported/dert/sphb/staff/thompson/index.cfm.</u>

Dr. Liam O'Fallon is a Program Analyst in the Susceptibility and Population Health Branch, specifically coordinating the Partnerships for Environmental Public Health program and the Community Outreach and Engagement Program (COEP).³

Dr. Claudia Thompson is the Branch Chief of the Susceptibility and Population Health Branch. She received her Ph.D in biochemistry and nutrition from the University of North Carolina at Chapel Hill and BS in biology from Bradley University. She was responsible for building the grant portfolio in the scientific areas of biomarker development, metabolic toxicology, chemical mixtures research and molecular mechanisms of metal toxicity and carcinogenicity. Additionally, she provides leadership to the Deepwater Horizon Disaster Academic-Community Research Consortium.

Organizational Structure

NIEHS is divided into four main research divisions: the Division of Intramural Research, the Office of Translational Research, the Division of National Toxicology Program, and the Division of Extramural Research and Training with the Susceptibility and Population Health Branch housing most of the social science research and the Cellular Organ Systems Pathology Branch (COSPB) housing most of the behavioral research at NIEHS.

Funding

NIEHS ranks 13th among NIH's Institutes and Centers in terms of funding, receiving 2.5% of the total NIH-appropriated funding in 2012. According to RCDC, NIEHS's average portion of the BSSR and bBSSR portfolios for the combined years 2008–2011 are, 1.2% and 1.2%, respectively. NIEHS has also received funding from the Avon Foundation to support community partnering activities.

General Research

NIEHS uses specific criteria for labeling a research grant as BSSR. The grant must have BSSR as one of its core aims, and not just a peripheral element of the research. BSSR at NIEHS falls on the applied and translational side, rather than basic. Program officers identified 54 social science projects from 2008–2012 with topics including the built environment, capacity building, community-based participatory research (CBPR), climate change, Ethical, Legal and Social Implications of Genomic Research (ELSI), environmental justice, socioeconomic status (SES), and sociology. CBPR is further divided into projects that are simply outreach compared to those that involve community

³ More information on Dr. O'Fallon can be found at <u>http://www.niehs.nih.gov/research/supported/dert/sphb/staff/thompson/index.cfm</u>.

engagement by directional communication. Additionally, they identified twenty-one behavioral research projects dealing with autism and neuro-behavioral and neurological development. The majority of the social science research is housed in the Susceptibility and Population Health Branch, whereas behavioral research is mainly in the Cellular Organ Systems Pathology Branch (COSPB). An additional thirty to forty projects contained BSSR as elements in the research, with topics on community cores and educational outreach activities.

NIEHS participates in the NIH-wide health literacy announcement as well as the HHS Environmental Justice Implementation. NIEHS also participates in OppNet funded research opportunities, specifically for community-based research projects for the medically underserved, but on the whole, OppNet has not had a large influence at NIEHS.

Currently, NIEHS is working on revising its 5-year strategic plan and several teams are focusing specifically on BSSR topics such as health disparities, communications, knowledge management, and science and education training.

Most of the NIEHS budget goes to fund environmental health disparities research and environmental justice as a research component, with social/behavioral sciences embedded in larger programs such as the Deepwater Horizon Research Consortia⁴ and children's centers that NIEHS supports. As part of their Partnerships for Environmental Public Health initiative, NIEHS has created smaller projects that focus more on behavioral and social elements.

The leadership of NIEHS director Dr. Linda Birnbaum has increased the focus on community engagement, environmental public health, and working in partnership with communities. Previous NIH program announcements in built environment and climate change and human health, and research integrity have influenced research supported by NIEHS.

Current BSSR at NIEHS

Prevention

Prevention is included in NIEHS's mission statement and primary prevention comprises most of the portfolio with projects on identifying exposures, education,

⁴ The Deepwater Horizon Research Consortia created community partnerships to address health effects stemming from the 2010 Deepwater Horizon Gulf oil spill. More information is available at https://www.niehs.nih.gov/research/supported/dert/sphb/programs/gulfconsortium/index.cfm.

outreach, and the use of sensors for local risk assessment, although some projects do target secondary prevention.

Social Epidemiology

A variety of NIEHS's BSSR falls under social epidemiology, including built environment, CBPR, SES, and ELSI projects.

Decision Science

NIEHS looks at decision outcomes but not particularly at the science of decisionmaking.

MHealth

MHealth research at NIEHS relates to capacity building, which includes any technological development that provides people with the ability to assess environmental risk locally. One project called the Ubiquitous Mobile Multimedia for Environmental Public Health Outreach is building sustainable community-based research infrastructure. Some mHealth projects may be housed in NIEHS's SBIR/STTR portfolio.

Measurement Development

Elements of measurement development are present in behavioral projects and capacity building projects.

NIEHS has developed its own categorization system for BSSR grants. These categories are built environment, capacity building, CBPR, climate change, ELSI, environmental justice, SES, sociology, and behavioral.

Trends in BSSR at NIEHS

In the past few years, the public has become more aware of environmental issues such as fracking, indicating that NIEHS's support of outreach and communication efforts has begun to bear fruit. The 2012 HHS Environmental Justice Strategy and Implementation Plan⁵ has had a huge influence on NIEHS research, and the coalescence of the field of environmental health literacy under health literacy is a development that NIEHS has been noticing. Environmental health literacy is distinct from health literacy with the latter focusing on clinical and health professional communication with patients,

⁵ The HHS Environmental Justice Strategy and Implementation Plan provides strategies and direction to guide environmental justice for minority and low-income populations. More information can be found at <u>http://www.hhs.gov/environmentaljustice/strategy.pdf</u>.

with environmental health literacy focusing more on prevention—to increase awareness of exposures and how to mitigate and prevent them. Other trends include an increase in ehealth and the development of technologies: personal sensors and mobile apps that increase education and community engagement to both adults and youth organizations. Additionally, new technologies will address mental health disparities and increase diversity of the research workforce, which are goals under the NIEHS strategic plan.

The concept of citizen science has contributed to moving CBPR, which was usually done by individual investigators reaching out to participants, to full community engagement, or community-owned and managed research. In 1999, CBPR was a novel concept at NIH. CBPR used to be the endpoint for community engagement, but now NIEHS awards R01s to the community-based organization, which is a big change from the early 2000s. For the last decade, various materials have been produced from this research such as environmental health messages for community groups and health care professionals. Future studies will focus on understanding the behavioral uptake of community messages. The cultural movements coming from the outside community affect how NIEHS research is perceived by the general public and may have increased participation in such research.

Evaluation of community-engaged projects is a topic that has been evolving beginning with the Partnerships for Environmental Health. In response, NIEHS developed an Evaluation Metrics Manual.⁶

POs stay current in the field in two ways: by attending regional meetings and conferences and conducting literature searches. For example, trends in environmental health literacy after conducting a literature review and found that additional search terms need to be identified because the field is coalescing with health literacy. Program officers also attend meetings and conferences and assemble workshops around particular topic areas, bringing in experts to understand emerging areas as well as drawing from community partners and the community of researchers to understand what their needs are and what issues coming to the surface.

Stakeholders

- Breast cancer advocates
- Deepwater Horizon Disaster Academic-Community Research Consortium
- Community organizations tied to community academic partnerships

⁶ The Partnerships for Environmental Public Health Evaluation Metrics Manual can be found at <u>http://www.niehs.nih.gov/research/supported/assets/docs/a c/complete peph evaluation metrics manua 1.pdf</u>.

- Alaskan Community Action Toxins
- Native American Tribal Groups
- Generally, communities that deal with geographic-based issues of exposure

Appendix H. National Institute of Biomedical Imaging and Bioengineering (NIBIB)

Highlighted Findings

- NIBIB participates in OppNet funding and co-funds BSSR with NIMHD.
- NIBIB's research portfolio includes decision science, mHealth, and prevention through mHealth applications.
- Research at NIBIB is categorized according to technology type, so BSSR is spread across the portfolio.
- Research at NIBIB is trending towards mHealth (a recent major focus for the IC) and towards chronic care as opposed to acute care.

NIBIB Mission Statement

"The mission of the National Institute of Biomedical Imaging and Bioengineering (NIBIB) is to improve health by leading the development and accelerating the application of biomedical technologies. The Institute is committed to integrating the physical and engineering sciences with the life sciences to advance basic research and medical care. This is achieved through: research and development of new biomedical imaging and bioengineering techniques and devices to fundamentally improve the detection, treatment, and prevention of disease; enhancing existing imaging and bioengineering modalities; supporting related research in the physical and mathematical sciences; encouraging research and development in multidisciplinary areas; supporting studies to assess the effectiveness and outcomes of new biologics, materials, processes, devices, and procedures; developing technologies for early disease detection and assessment of health status; and developing advanced imaging and engineering techniques for conducting biomedical research at multiple scales."¹

¹ NIBIB mission statement is from <u>http://www.nibib.nih.gov/About/MissionHistory</u>.

Interviewees

Dr. William Heetderks, MD, PhD, is the Director of Extramural Science Programs at NIBIB. He received his PhD in 1976 in bioengineering with a focus on neuroscience from the University of Michigan. He joined NIH in 1986 as the Program Director of the Repair and Plasticity Cluster at the National Institute of Neurological Disorders and Stroke, where he focused on spinal cord injury. He joined NIBIB in 2002 in his current position.

Dr. Mary Rodgers is currently doing research with NIBIB through the Intergovernmental Personnel Act (IPA). She works in the Department of Physical Therapy and Rehabilitation Sciences at the University of Baltimore School of Medicine.

Organizational Structure

The NIBIB is divided into the Office of Research Administration, the Office of Administrative Management, the Extramural Science Program, and the Intramural Science Program.

Funding

NIBIB ranks 20th among NIH's Institutes and Centers in terms of funding, receiving 1.1% of the total NIH-appropriated funding in 2012. According to RCDC, NIBIB's average portion of the BSSR and bBSSR portfolios for the combined years 2008–2011 are, 0.1% and 0.0%, respectively.

General Research

NIBIB functions as the technology institute for the NIH. Its main focus is on supporting the development of medical technologies and it categorizes its research portfolio in terms of technologies such as magnetic resonance imaging, ultrasound, tissue engineering, and biomaterials. There has been increasing recognition that NIBIB needs to support the social sciences to address the issue of technology adoption—understanding how patients are interacting with medical technologies and the degree to which patients are responding to them. Social sciences are relevant to two broad areas of interest to NIBIB: low-cost medical devices, which fit within the Point-of-Care Technologies Research Network² and the Small Business Innovation Research (SBIR) program; and mobile health, which includes development of technology for home health care and

² Point of care refers to the development of technologies that will increase access to medical care and support earlier diagnosis at the initial point of contact with a health care professional. More information on the Point-of-Care Technologies Research Network can be found at <u>http://www.nibib.nih.gov/Research/POCTRN</u>.

design of technology for a changing U.S. healthcare system. NIBIB supports research on how technology impacts healthy independent living through its Program Announcements with Review (PARs) and has partnered with other institutes to fund R01 and R21 grants in this area. Additionally, NIBIB receives some OppNet funding. BSSR grants are spread across program officers at NIBIB rather than being organized within a particular unit.

Behavioral research is becoming increasingly important as there are many behavior changes that are relevant to technology adoption and use. An example of a behavioral grant is an SBIR grant co-funded with the National Institute of Minority Health and Health Disparities (NIMHD), focusing on partnering with community clinics to develop technologies not just for hospital settings, but for underserved community settings.

NIBIB is currently working with four other ICs to develop a Common Fund initiative for mHealth. NIBIB participates in inter-IC announcements in the Point-of-Care Technologies Research Network and the NIBIB-India joint initiative, which have BSSR components. The NIBIB-India initiative supports the development of low-cost technologies with the recognition that healthcare is becoming a global problem requiring global solutions. NIBIB also participates in the Smart and Connected Health Initiative³ with NSF.

Current BSSR at NIBIB

Prevention

NIBIB does not have specific programs in prevention, but prevention research relates to mHealth, which is supported by the institute. For its NIBIB-India joint initiative, grants focus on increasing hypertension awareness and developing low-cost methods for blood pressure screening for hypertension. The aim of these studies is to increase prevention activities in the long-term in India.

Social Epidemiology

NIBIB does not support research in this category.

Decision Science

An area that is of great interest to NBIBI is clinical decision support, which involves decision support for the health provider when ordering and planning expensive imaging

³ The goal of the Smart and Connected Health Program is to expedite the development of new approaches blending technology-based and biobehavioral-based research to transform health care. More information can be found at <u>http://www.nsf.gov/pubs/2013/nsf13543/nsf13543.htm</u>.

tests. Most of this research is funded through the American Recovery and Reinvestment Act.⁴

Mhealth

NIBIB supports a variety of research initiatives in mHealth, including the NIBIB-India joint initiative and the Point-of-Care Technologies Research Network. Additionally, NIBIB uses mHealth research as a bridge between technology research and BSSR, supporting research on the technology side of BSSR.

Measurement Development

NIBIB does not support research in this category.

Trends in BSSR at NIBIB

The rise of mHealth is raising the significance of BSSR within NIBIB, which is a major shift for the institute. NIBIB is also seeing a shift from acute care to chronic disease management for a range of diseases including obesity, hypertension, and diabetes. The U.S. medical system has previously focused more on acute care because BSSR has not figured prominently in care. Since many problems surrounding chronic disease management are behavioral, BSSR is becoming more important to NIBIB.

Another new area that is emerging is that of clinical decision support. New technologies are increasingly more expensive, and clinical decision support aims at looking critically at the evidence base for ordering a test for a patient.

Stakeholders

Imaging stakeholders:

- Radiological Society of North America
- American College of Radiology

Engineering stakeholders:

- American Institute of Medicine and Bioengineers
- Biomedical Engineering Society (BMES)
- Institute of Electrical and Electronics Engineers' (IEEE) biomedical program

Web Media

⁴ ARRA funds have been depleting, and so there is less support for this type of research at NIBIB.

Additional Comments

OBSSR should keep a level of independence separate from the other ICs, and OBSSR could be an additional source for BSSR funding.

Appendix I. National Institute of Dental and Craniofacial Research (NIDCR)

Highlighted Findings

- NIDCR participates in OppNet funding and engages in inter-IC BSSR funding opportunities and activities.
- NIDCR's research portfolio includes prevention, decision science, measurement development and e-health.
- NIDCR's Division of Extramural Research includes the Behavioral and Social Sciences Research Branch, and the IC's strategic plan has four goals with strong BSSR components.
- NIDCR actively works to increase the scientific rigor of BSSR through greater in-house BSSR expertise and more intensive review of proposals.

NIDCR Mission Statement

"The mission of the National Institute of Dental and Craniofacial Research (NIDCR) is to improve oral, dental and craniofacial health through research, research training, and the dissemination of health information. We accomplish our mission by: Performing and supporting basic and clinical research; Conducting and funding research training and career development programs to ensure an adequate number of talented, well-prepared and diverse investigators; Coordinating and assisting relevant research and research-related activities among all sectors of the research community; Promoting the timely transfer of knowledge gained from research and its implications for health to the public, health professionals, researchers, and policy-makers."¹

Interviewees

Dr. Melissa Riddle has been the Director of the BSSR branch at NIDCR for the past 5 years, and has been at NIH for the past 12 years. Her research portfolio covers child,

¹ The NIDCR mission statement is from <u>http://www.nidcr.nih.gov/AboutUs/MissionandStrategicPlan/MissionStatement/</u>.

adolescent parenting and family oral health interventions; stress and oral health; and managing serious or chronic oral or craniofacial conditions.

Dr. David Clark has been in the BSSR branch of NIDCR for the past $3\frac{1}{2}$ years and at NIH for the past $4\frac{1}{2}$ years. His research portfolio covers the following topics: behavioral economics and oral health; Screening, Brief Intervention, and Referral to Treatment (SBIRT)² for tobacco; brief intervention and referral to treatment in dental settings; sustainability of oral health behavioral and social interventions; health services research; technology and the behavioral and social aspects of oral health.

Organizational Structure

The NIDCR is divided into three divisions and six offices: the Office of the Director, the Office of Administrative Management, the Office of Information Technology, the Office of Science Policy and Analysis, the Office of Clinical Trial Operations and Management, the Office of Communications and Health Education, the Division of Extramural Research, the Division of Intramural Research, and the Division of Extramural Activities. NIDCR's Division of Extramural Research is divided into four branches: Integrative Biology and Infectious Diseases Branch, the Translational Genomics Research Branch, the Center for Clinical Research, and the Behavioral and Social Sciences Research Branch.³

Funding

NIDCR ranks 19th among NIH's Institutes and Centers in terms of funding, receiving 1.3% of the total NIH appropriated funding in 2012. According to RCDC, NIDCR's average portion of the BSSR and bBSSR portfolios for the combined years 2008-2011 is, 0.7% and 0.6%, respectively.

General Research

The BSSR branch supports both basic and applied research promoting oral health and preventing oral diseases. The program draws on expertise from multiple disciplines including those that focus on basic and clinical health, and encourages the use of various methodologies such as randomized clinical trials, single-case, within-subjects, historical control, microanalytic change process, and other designs. Specific research areas of

² SBIRT uses a three-pronged approach of using early screenings, behavioral interventions, and treatment referrals to treat patients with substance abuse disorders. More information on SBIRT can be found at <u>http://www.samhsa.gov/samhsanewsletter/Volume 17 Number 6/SBIRT.aspx</u>.

³ More information on NIDCR's BSSR branch can be found at <u>http://www.nidcr.nih.gov/Research/DER/BSSRB.htm</u>.

interest include: health behaviors research, stress and health research, pain research, health communication research, research on managing serious and chronic illness, and health disparities research.

NIDCR's BSSR branch was created five years ago, and includes the Center for Clinical Research, which funds mostly health disparities research with a BSSR emphasis. BSSR is also supported in various other branches of the extramural division, and decisions about the assignment of a BSSR grant into a particular branch are made by Program Officers (POs).

NIDCR's portfolio is often organized by age, target population, and basic vs. applied BSSR. The research is organized by how the community sees the application of BSSR to dentistry. The nature of the NIDCR research community, which includes both researchers and dental practitioners, poses some challenges to research practice that the Institute directly addresses through its programming. Dental practitioners often have little research training but are pulled into the research enterprise in leadership roles that require more experience and training. Researchers usually have MPH and DDS degrees but their training does not always prepare them with the skills needed to perform research in behavioral interventions. NIDCR's training branch focuses on the challenge of ensuring that there is a good match between the research that applicants are proposing and their training and skills.

The POs often play a role in navigating between supporting the right research and having the right researchers on grants. To address gaps in research expertise, NIDCR frequently hires survey methodologists and scientometrics experts as consultants to help grantees develop surveys and incorporate emerging and progressive methodologies and approaches into their research design.

As NIDCR is a smaller institute, it participates in a number of inter-IC initiatives such as the Systems Science and Health in the Behavioral and Social Science, the Science of Behavior Change, the Health Economics Common Fund, and Health Disparities. A few of NIDCR's BSSR initiatives include a Request for Applications (RFA) for complex models, an OppNet funded mid-career training program in genomics and BSSR, and a R34 grant called NIDCR Behavioral or Social Intervention Planning and Pilot Data Grant which collected pilot data for large clinical trials.

NIDCR also supports research in two major areas: systems science and health disparities. Systems science is a big funding area for NIDCR, and experts in systems science are now applying for grants in oral health. Health disparities is an up-and-coming topic that contains research within all five pilot categories of prevention, social epidemiology, decision science, mHealth, and measurement development. The 2009-

2013 NIDCR Strategic Plan⁴ describes four goals, each emphasizing BSSR. For example, two goals include increasing the rigor of oral health research, which emphasizes increasing the Institute's commitment to research in BSSR; and supporting health disparities research, which includes BSSR components.

Since 2008, NIDCR has had two directors, Dr. Lawrence Tabak, and the current director, Dr. Martha Somerman. BSSR was a top priority for Dr. Tabak, and the BSSR branch was created under his leadership. The current structure of NIDCR has remained unchanged under Dr. Somerman's leadership who consults with Dr. Tabak in matters of BSSR. While she tends to think of BSSR research relating to her background in bone biology, Dr. Somerman listens to the suggestions of all internal and external stakeholders, and supports BSSR initiatives based on this feedback.

Due to an internal policy, NIDCR only accepts U01 proposals for R01 intervention development studies which may prevent NIDCR from signing on to some R01-funded Common Fund initiatives. Researchers may still try to submit R01 proposals to NIDCR through the Common Fund Initiative, and NIDCR will be unable to fund that research. In some cases, POs may help the researcher convert the R01 to a U01, or they will try to find other places for investigators to submit grant proposals.

Current BSSR at NIDCR

Prevention

NIDCR supports a significant amount of prevention research, particularly in children, and supports research in a variety of secondary target areas such as early nutrition, oral hygiene, teen drug abuse (including smoking and alcohol), helmet wearing, domestic violence and child abuse, periodontal disease and tooth loss, autism and regular care and other special needs characteristics.

Social Epidemiology

NIDCR does not support any research in this category since investigators are not submitting proposals in this area but POs would like to see this increase in the future.

Decision Science

NIDCR supports a number of decision science grants including grants to develop diagnostic terminology leading to treatment decisions, grants that explore patient safety

⁴ The NIDCR Strategic Plan can be found at <u>http://www.nidcr.nih.gov/Research/ResearchPriorities/StrategicPlan/.</u>

issues, grants that explore decision-making in treatment options, and grants that aim to maximize the use of electronic dental records.

Mhealth

NIDCR does not have any pure mHealth research but does support some e-health⁵ grants. One SBIR grant involves having a decision support system to quit smoking as a smart phone or tablet application. Other grants focus on electronic medical records—to develop diagnostic terminology that is user friendly and useful with current terminology standards and diagnosis dictating treatment, which also has a component of decision science research.

Measurement Development

All NIDCR program announcements encourage measurement development. NIDCR is trying to understand how to introduce new measurements and techniques such as factorial design, since existing behavioral measures in oral health are unsatisfactory.

Trends in BSSR at NIDCR

POs are working to increase the rigor of BSSR by improving in-house expertise for more intensive review of projects before funding and conducting site monitoring visits; they are supported by the Institute in this endeavor. Additionally, POs are working to build stronger relationships with their grantees, especially since they themselves are not dentists and are working to fill the knowledge gap between researchers and practitioners with respect to conducting BSSR.

POs are also looking for new methodologies to improve the scientific rigor of grants; the quality of scientific work is limited when using outdated methodologies and sometimes results in duplication of effort. There is a chasm between dental practice and research in that dentists within community practice are not motivated to change their practice and new ideas do not get traction unless practitioners work in community health centers, large practices, or dental schools. POs endeavor to bring dental researchers up-to-date, but the challenge is that mediocre grants are funded due to less rigorous review, resulting in researchers repeating outdated methodologies and studies.

POs actively reach out to researchers and practitioners at dental schools, at conferences, and through meetings in-person or over the phone to talk about future funding directions, especially since POs recognize a need for psychologists and social workers to be brought into dentistry-related BSSR.

⁵ In this context, e-health refers not only to mobile health, but all technology-related applications.

Other factors have played a role in the push for BSSR at NIDCR; Dr. Pamela McKinnis, the Director of Extramural Research, also sees BSSR as a priority. Additionally, NIDCR's participation in trans-NIH initiatives such as the Science of Behavior Change and Health Economics has been beneficial to researchers even if they are not funded through these mechanisms.

Stakeholders

- Dental schools
- Clinicians that are part of networks
- American Dental Association (ADA)—large advocates on the hill and elsewhere
- American Dental Educational Association (ADEA)
- Society for Behavioral Medicine—NIDCR is trying to establish themselves with SBM
- Friends of NIDCR⁶
- American Association of Public Health Dentistry (AAPHD)
- Public Health Dentistry List serves
- Association for Psychological Science (APS)

Additional Comments

POs indicated that interactions with OppNet and BSSR Coordinating Committee have been beneficial, but they are concerned that they learn about other ICs' initiatives through back channels and not firsthand, and so they recommend having more roundtable discussions to update what other ICs are doing in terms of their BSSR initiatives.

⁶ For more information on Friends of NIDCR, to go <u>http://www.fnidcr.org/index.html</u>.

Appendix J. National Institute of General Medical Sciences (NIGMS)

Highlighted Findings

- NIGMS was heavily involved in the founding of OppNet, but has played a lesser role in recent years; however, it continues to fund OppNet research.
- NIGMS's research portfolio includes some mHealth and some measurement development through methods development research.
- NIGMS's strategic plan mentions BSSR as a broad goal, and funds BSSR across its portfolio rather than through a specific office or division.
- An emerging trend in NIGMS research is that of big data and computational approaches.

NIGMS Mission Statement

"The mission of the National Institute of General Medical Sciences (NIGMS) is to support research that increases understanding of life processes and lays the foundation for advances in disease diagnosis, treatment and prevention. NIGMS-funded researchers seek to answer important scientific questions in fields such as cell biology, biophysics, genetics, developmental biology, pharmacology, physiology, biological chemistry, biomedical technology, bioinformatics, computational biology, selected aspects of the behavioral sciences and specific cross-cutting clinical areas that affect multiple organ systems. To assure the vitality and continued productivity of the research enterprise, NIGMS also provides leadership in training the next generation of scientists as well as in developing and increasing the diversity of the scientific workforce."¹

Interviewees

Dr. Juliana Blome is the chief of the Office of Program Analysis and Evaluation in the Office of the Director. She is a sociologist by training and received her master's degree in public health and social work. She is on the BSSR coordinating committee and

¹ The NIGMS mission statement is from <u>http://www.nigms.nih.gov/About/</u>.

has a background in clinical work, applied behavioral methods and risky behaviors in adolescents.

Dr. Stephen Marcus is Program Director in the Division of Biomedical Technology, Bioinformatics, and Computational Biology. He is an epidemiologist who has spent half his career in health services and health policy and epidemiology and the other half in psychosocial epidemiology. His role includes creating and developing a new program in computational sciences modeling and specializes in a systems approach to doing basic BSSR.

NIGMS BSSR Portfolio

Organizational Structure

NIGMS is divided into six offices and six divisions. The divisions include: Division of Extramural Activities; the Division of Biomedical Technology, Bioinformatics, and Computational Biology; the Division of Cell Biology and Biophysics; the Division of Genetics and Developmental Biology; the Division of Pharmacology, Physiology, and Biological Chemistry; and the Division of Training, Workforce Development, and Diversity.

Funding

NIGMS ranks fourth among NIH's Institutes and Centers in terms of funding, receiving 7.9% of the total NIH-appropriated funding in 2012. According to RCDC, NIGMS's average portion of the BSSR and bBSSR portfolios for the combined years 2008-2011 are, 0.8% and 1.3%, respectively.

General Research

NIGMS has a small portfolio in BSSR because most of its research is basic, foundational research in genetics, pharmacology, and molecular biology. NIGMS's mission statement charges it to do behavioral and social science research related to basic sciences. NIGMS is also a training institution, which includes training behavioral scientists to do biomedical research and understanding the career patterns of women in science. Its portfolio is blended, and it does not have separate offices that support behavioral research. It also funds grants in modeling social behavior and programs in collaborative research for molecular and genomic studies of animal models. Additionally, NIGMS houses the Office of Emergency Care Research (OECR) which has a small portfolio on trauma and burns as well as racial and gender disparities in how people respond to treatment.

A 1998 Congressional mandate charged NIGMS to start doing basic BSSR. OppNet was created and co-led by NIGMS during Director Jeremy Berg's tenure² but after the leadership changed, NIGMS played a smaller role within OppNet. NIGMS participates in OppNet to fund systems science and health and behavioral sciences. In the past five years, OppNet has been a big change with regards to changing the direction of BSSR at NIGMS. It has helped coordinate ICs working together on basic BSSR and has provided a place to leverage funds to collaborate on different initiatives and programs.

Because of NIGMS's unique, basic research mission, it is unclear to POs how much of the portfolio basic BSSR should comprise. The 2008-2012 NIGMS Strategic Plan³ mentions behavioral and social science research as part of their broad goal toward more multidisciplinary research, but does not emphasize BSSR. While Dr. Berg championed support for the social and behavioral sciences, future directors may make different decisions about their role in the IC. NIGMS POs try to ensure that their funded grants have more behavioral components since there are behavioral aspects to all basic research. NIGMS does not have any targets for BSSR funding, but allocates funds depending on the quality of grants it receives.

BSSR at NIGMS

Interviewees indicated that none of their BSSR research falls wholly into the five pilot categories, but some grants have components of one or more categories. NIGMS is interested in methods development, which includes a measures component. There are a few mHealth grants, but the technology is applicable across many disease types and so the focus is not on mHealth *per se*, but rather on innovation in methods and technology such as concept mapping, word clouds, and natural language processing. Interviewees categorize their research in the following areas: modeling, systems approaches, and computation.

Dr. Marcus emphasized that other agencies such as DARPA and the DOD are supporting cutting edge BSSR to a greater extent than NIGMS.

Trends in BSSR at NIGMS

One emerging trend is in big data, studying data sciences as opposed to informatics. Dr. Marcus would like to see NIH embrace methods used in physics, engineering, and other disciplines to move towards more systems science approaches. Specifically,

² Dr. Jeremy Berg was Director of NIGMS form 2003 to 2011. OppNet was established in 2009.

³ The 2008-2012 NIGMS Strategic Plan "Investing in Discovery" can be found at <u>http://publications.nigms.nih.gov/strategicplan/strategicplan.pdf.</u>

NIGMS needs to move from experimental approaches to computational approaches, utilizing more mathematical, statistical, geological, and computer science methods. Additionally, POs would like to see health data geocoded in the future. Social media is another emerging area, especially in research to develop methodologies to reduce the signal to noise ratio on sites such as Twitter.

Stakeholders

Typical Stakeholders:

- Research scientists and grantees
- American Psychological Association
- Members of Congress pushing for more behavioral research
- Federation of American Societies for Experimental Biology (FASEB)
Appendix K. National Institute on Minority Health and Health Disparities (NIMHD)

Highlighted Findings

- NIMHD funds OppNet grants and OppNet is the IC's primary method for supporting basic research.
- NIMHD's research portfolio includes primary and secondary prevention, social epidemiology, mHealth, and some decision science.
- The majority of BSSR at NIMHD is part of the portfolio from the Office of Training and Capacity Building, where the portfolio is organized according to funding mechanism instead of content area; BSSR is spread throughout such mechanisms.
- Research has been trending on the social determinants of health, the integration of BSSR with laboratory science, the integration of multiple levels of data (from individual to community).

NIMHD Mission Statement

"The mission of NIMHD is to lead scientific research to improve minority health and eliminate health disparities. To accomplish this, NIMHD: Plans, reviews, coordinates, and evaluates all minority health and health disparities research and activities of the National Institutes of Health; Conducts and supports research in minority health and health disparities; Promotes and supports the training of a diverse research workforce; Translates and disseminates research information; Fosters innovative collaborations and partnerships."¹

Interviewees

Dr. Francisco Sy started as an NIH Program Officer (PO) in 2004 and has been the Director of Extramural Research Administration since 2007. He was recruited from the Centers for Disease Control and Prevention (CDC) to start the Office of Participatory

¹ The NIMHD mission statement is from <u>http://www.nimhd.nih.gov/about_ncmhd/mission.asp</u>.

Research. He is currently overseeing a portfolio in Community Based Participatory Research (CBPR), the Loan Repayment Program (LRP), and the Research Endowment Program.² He has an MD and MA in public health, with a focus in infectious disease epidemiology and HIV prevention. Dr. Sy has served as the editor of a journal called AIDS Education and Prevention.

Dr. Jennifer Alvidrez has been a PO at NIMHD for 2¹/₂ years. She manages the portfolio on social and behavioral R01s and resource related programs and cooperative agreements. She was trained as a clinical psychologist and worked on disparities and access to mental health care.

Organizational Structure

The NIMHD is divided in the Division of Data Management and Scientific Reporting (DDMSR), the Division of Intramural Activities (DIR), and the Division of Scientific Programs (DSP). The latter division includes the Office of Scientific Training and Capacity Building, which houses most of the BSSR at NIMHD.

Funding

NIMHD received 0.9% of the total NIH-appropriated funding in 2012. According to RCDC, NIMHD's average portion of the BSSR and bBSSR portfolios for the combined years 2008–2011 are, 1.8% and 2.1%, respectively.

General Research

The Office of Scientific Training and Capacity Building within the DSP is small, and Program Officers (POs) manage the portfolio by mechanism, rather than content area. NIMHD has the largest CBPR social science program portfolio at NIH. Previously, NIMHD funded all health disparities research, but as the IC has grown, the research has been split into biomedical and social and behavioral research. Research in BSSR has grown organically, not due to any targeted guidance from NIMHD.

² NIMHD has been congressionally mandated to focus on supporting three main activities: NIMHD's Centers of Excellence Program (COE), its Loan Repayment Program, and its Research Endowment Program. The COE program develops programs with the goal of improving health in underserved populations. The Research Endowment Program provides endowments to academic institutions to support minority health and health disparities research. The LRP includes two types of repayment: for any researcher doing health disparities research, and for minorities doing clinical research. Researchers have 2-year contracts to pay loans as long as investigators show progress in their research, such as publishing papers. More information on these programs can be found at http://www.nih.gov/about/almanac/organization/NIMHD.htm.

NIMHD is the only NIH IC that was created from a Congressional mandate. In its first ten years, NIMHD was mandated to focus on minority health, with three specific program goals: to grow its centers of excellence (COE), its Research Endowment Program and its Loan Repayment Program. NIMHD has the largest loan repayment program at NIH. The applicant pool of minority researchers is small but there is a larger applicant pool of investigators wanting to do health disparities research. However, legislation indicates that half of the loan repayment grants should go to racial/ethnic minorities.

BSSR at NIMHD spans a range of topics including diabetes, HIV/AIDS, sleep, and depression, as well as disease conditions disproportionately affecting minorities. NIMHD research on sleep focuses on its role as a non-specific factor that relates to poor health, and includes understanding the influence of the physical and social environment (specifically noise, stress, and violence) on sleep.

In its first few years, NIMHD funded research collaboratively with other ICs, but as it has grown, the focus has shifted towards funding its own programs; occasionally, NIMHD will participate in an OppNet grant. For example, NIMHD currently has three OppNet grants on sleep and is the host IC for the 2014 Basic Social and Behavioral Research on the Social, Cultural, Biological, and Psychological Mechanisms of Stigma (R01) grant. POs indicated that NIMHD does not have a mechanism to fund basic research, so OppNet-supported grants are the main way for NIMHD to conduct basic BSSR. NIMHD also funds many centers grants. In particular, NIMHD has a transdisciplinary collaborative center that supports research on social determinants of health, and one that focuses on health policy research.

Current BSSR at NIMHD

Prevention

CBPR is focused on primary and secondary prevention, specifically in community interventions. A few R01s focus on tertiary prevention such as diabetes management interventions, adherence promotion for HIV-positive patients, lifestyle intervention such as diet and exercise, and prevention through disease screening.

Social Epidemiology

NIMHD has many R01s on a range of topics such as the interaction with the physical and social environment, discrimination, segregation, and the effects of physical abuse and violence on immune function and mental health. These include grants at the community level, grants that use census data to explore population characteristics, and hybrid grants that combine individual and national data.

Decision Science

NIMHD has few grants supporting decision sciences research. These grants fund research on the impact of prejudice in clinical practice, and on medical decision making.

Mhealth

mHealth research is distributed among the other categories with grants that focus on using text messaging to check heart rate, or provide check-up reminders. There are mHealth grants for collecting heart rate or sleep data, and to conduct health assessments and deliver personalized health information.

Measurement Development

NIMHD does not have grants in this category, but does participate in the NIH Toolbox for the Assessment of Neurological and Behavioral Function, funded by the SBIR/STTR program, and has components of measurement development.

Trends in BSSR at NIMHD

Globally, there's a growing recognition in the biomedical field of the social determinants of health, and grantees are showing more interest in BSSR. In 2008 and 2012, NIMHD held summits entitled "The Sciences of Limiting Health Disparities" in which they received thousands of abstracts, many of them in social and behavioral sciences, indicating an increased interest in BSSR related biomedical research.

Additionally, there's been an integration of social and behavioral research with bench sciences such as epigenetics. The first wave of epigenetics focused on environmental exposure and how it causes physical illness. Research is moving towards studies on how epigenetic factors affect behavior, understanding the impact of genes on social environmental, and looking at behavior as an outcome of this gene expression.

Another trend is the shift from looking at individual level data to higher level viewpoints such as looking at the family and community level. Review panels should evolve to include reviewers able to assess the quality of this new kind of research, such as experts who can combine census data with ethnographic studies.

One of the biggest gaps is translating bench research to the community. Community research is often neglected by NIH due to its greater emphasis on biomedical science over social and behavioral research. OBSSR's and NIMHD's attention to community-based BSSR is not matched by NIH as a whole.

Program officials would like to see more research on translating CBPR as it is critical to the uptake of community level interventions. There needs to be a way to translate and disseminate what's learned through CBPR at a local level so that other localities can benefit from the research without repeating the study. Additionally, POs would like to see more health policy research but there are barriers to doing this type of research at NIH. NIH does not do policy research as it is not traditionally seen as being health research. However, POs argue that understanding the impact of policies on health outcomes becomes health research.

Stakeholders

Minorities Academicians Schools of Public Health Professional organization such as The National Kidney Foundation Disease Advocacy groups Colleges and Universities Racial/ethnic minority professional organizations

Members of Congress—specifically interested in kidney disease, prostate cancer, and obesity; Congress frequently communicates directly with grantees.

Appendix L. National Institute of Neurological Disorders and Stroke (NINDS)

Highlighted Findings

- NINDS participates in OppNet funding opportunities.
- NINDS's research portfolio includes prevention, mHealth, measurement development, as well as some social epidemiology and decision science.
- Most of the BSSR at NINDS is behavioral and is tied to the translational clinical research portfolio.
- There have been increased BSSR efforts in epilepsy, traumatic brain injury, Parkinson's disease, and neuroAIDS; such trends and other changes in the portfolio are often catalyzed by Congressional mandates and feedback from the research community.

NINDS Mission Statement

"The mission of NINDS is to reduce the burden of neurological disease—a burden borne by every age group, by every segment of society, by people all over the world."¹

Interviewees

Dr. Courtney Ferrell Aklin is the Program Director in the Office of Special Programs in Diversity (OSPD) and has been at NIH for the past 6 years. She received her PhD in clinical psychology from the University of Maryland at College Park. Dr. Ferrell also manages the Specialized Neuroscience Research Programs (SNRP) Funding Opportunity Announcement (FOA)² and Collaborative Neurological Sciences Award.³ Her portfolio supports studies on increasing minority participation in research.

¹ The NINDS mission statement is from <u>http://www.ninds.nih.gov/about_ninds/mission.htm</u>.

² The SNRP FOA provides funding to academic institutions to strengthen their neuroscience research programs. For more information, go to <u>http://grants.nih.gov/grants/guide/rfa-files/RFA-NS-13-004.html</u>.

³ The Collaborative Neurological Sciences Award is a joint award with NINDS and the National Institute on Alcohol Abuse and Alcoholism (NIAAA) to foster competitive neuroscience research programs at minority academic institutions.

Organizational Structure

NINDS is divided into five areas: the Division of Extramural Research, the Division of Intramural Research, the Office of Translational Research, the Office of Clinical Research, and the Office of Minority Health Research.

Funding

NINDS ranks sixth among NIH's Institutes and Centers in terms of funding, receiving 5.3% of the total NIH-appropriated funding in 2012. According to RCDC, NINDS's average portion of the BSSR and bBSSR portfolios for the combined years 2008–2011 are, 3.8% and 4.1%, respectively.

General Research

BSSR at NINDS is varied and includes research on diseases such as epilepsy, studies on drug adherence, disease progression, sleep rhythm, and epidemiological studies. Additionally, NINDS received \$10 million from the National Football League (NFL) to support research on Traumatic Brain Injury (TBI) deriving from athletic injuries. There are also studies on cognitive restructuring, which refers to any study of stroke or neuropsychological assessment.

NINDS has a flat structure, and does not have Program Officials dedicated to BSSR. Much of its BSSR is behavioral, but since most PIs are basic biological researchers, behavioral and social sciences are not commonly distinguished from one another within the Institute. Most of the funding in BSSR is tied to NINDS' clinical portfolio, which means very little work can be characterized as basic BSSR. Funding of BSSR depends on quality of proposals, as NINDS does not manage to any funding percentages. In the past three years, BSSR funding has been about 2-3% of the total NINDS budget.

NINDS participates in OppNet announcements, and funds neuroscience related research.

Current BSSR at NINDS

Prevention

NINDS funds prevention research on stroke, epilepsy, and TBI. In stroke, NINDS supports research on health disparities. Example projects are those developing programs

to get patients into the hospital sooner after an injury, and epilepsy programs such as the Centers Without Walls⁴ initiative.

Social Epidemiology

NINDS supports some research in this category.

Decision Science

NINDS supports some research in this category.

Mhealth

Mhealth is just beginning at NINDS with a new mHealth Program Director in the Office of Clinical Research. Mhealth initiatives include mobile app development within the Small Business Innovation Research (SBIR) program for delivery of medication reminders and research on stroke recovery.

Measurement Development

NINDS supports research on measurement outcomes for pediatric head injury, circadian rhythm measurement development, and partners with SBIR in measuring outcomes. Additionally, it has a growing portfolio in measuring cognitive differences in stroke recovery.

Trends in BSSR at NINDS

In the past 3 years, BSSR changes have been largely driven by Congressional mandates. Internal Institute practices may also drive BSSR funding. Due to pressure from Congress and the research community, an advisory group was tasked to evaluate the NINDS portfolio, resulting in the creation of the Office of Clinical Research.

With regards to stroke, NINDS receives a lot of attention and interest from Congress as stroke is a leading cause of death in the US.

Epilepsy research is increasing in response to the demands of strong and vocal advocacy groups and research funding from private foundations. In the late 90s, Congress mandated that NINDS create seven centers focused on epilepsy research, but then changed its directive to incorporate Centers Without Walls to have greater engagement

⁴ Centers Without Walls is an initiative that allows the external medical community to advance the understanding of causes and treatment of epilepsy by bringing together multidisciplinary scientific programs and research. More information can be found at <u>http://www.ninds.nih.gov/research/epilepsyweb/feedback.htm</u>.

with the external community. In 2012, NINDS funded the first of four epilepsy research centers that will collaborate with other research institutions with components across different countries. NINDS is reissuing center grants to meet this objective, but was not given additional funding from Congress, and so had to reallocate existing money from other areas such as sleep research.

TBI has always been part of NINDS portfolio, but before receiving the NFL funding, it was scattered among various divisions. Now there is a dedicated TBI point person and NINDS is anticipating that BSSR on TBI will grow. The future of the TBI program is uncertain as the NFL money is a temporary boost to NINDS's budget. Additionally, TBI's visibility has increased due to the influence of NINDS Director, Dr. Story Landis.

With respect to Parkinson's disease, NINDS is working with the community to develop adherence and treatment models, and has created joint initiatives with different stakeholders to ensure funding. For example, NINDS is leading a large working group with the Michael J. Fox Foundation, but is unsure of the total funding provided by the foundation.

NINDS is growing its portfolio on NeuroAIDS research especially as it relates to global health, and will start to focus more on basic cognitive research in AIDs. Previously, AIDS research was underfunded at NINDS so that other ICs could maintain their AIDS portfolio.

NINDS will be growing its portfolio in a number of other areas including stroke, rare disease, and preclinical drug development, although the latter may not have a behavioral component.

Stakeholders

- Congress
- Disease-specific advocacy groups for Duchenne's Muscular Dystrophy, epilepsy, and Parkinson's disease.
- National Football League (NFL)—provided \$10 million in funding for Traumatic Brain Injury research.
- NINDS receives a lot of feedback from external stakeholders. They may help draft initiatives, review initiatives, and help with clinical trial outreach.

Additional Comments

Dr. Aklin-Ferrell was interested in understanding the difference between OBSSR and OppNet with regards to function and requests for funding. Since OppNet funds most behavioral research at NINDS, POs work directly with OppNet rather than OBSSR because there is a clear process of obtaining funding. These offices need more visibility to coordinate the BSSR portfolios across NIH.

Additionally, BSSR coordinating committee meetings are helpful to attend, but often overlap with the seminar series and are perceived to have little structure, follow-up, or take-home message.

Appendix M. National Institute of Nursing Research (NINR)

Highlighted Findings

- NINR funds OppNet research, works with FIC to fund social epidemiology research, and works with OBSSR on initiatives for medication adherence, multiple chronic disease management, community participation, and health disparities.
- NINR's research portfolio includes prevention, decision science, social epidemiology, measurement development and some mHealth.
- The majority of BSSR at NINR is behavioral, focusing on symptom management and self-management predominantly through the portfolios of the Bio-Behavioral Branch and the Symptom Management Branch of the Division for Intramural Research.
- NINR has recently focused efforts on self-management, symptom management, and palliative care, including the development of a Common Fund initiative for self-management strategy research.

NINR Mission Statement

"The mission of the National Institute of Nursing Research (NINR) is to promote and improve the health of individuals, families, communities, and populations. NINR supports and conducts clinical and basic research and research training on health and illness across the lifespan to build the scientific foundation for clinical practice, prevent disease and disability, manage and eliminate symptoms caused by illness, and improve palliative and end-of-life care."¹

Interviewees

Dr. Linda Weglicki has been at NIH since 2008 and is currently the Chief of the Extramural Programs in the Division of Extramural Programs. She manages funded studies such as the Study of Women's Health Across the Nation (SWAN) study.² Her

¹ The NINR mission statement is from <u>http://www.nih.gov/about/almanac/organization/NINR.htm</u>.

² For more information on the SWAN study, go to <u>http://www.swanstudy.org/investigators.asp</u>.

background is in tobacco, risky behaviors, adolescence and youth, air pollution and urban population.

Dr. Weglicki is heavily involved with OppNet. She is on the OBSSR executive committee and BSSR coordinating committee and is the co-chair of the OppNet Communications Working group and was instrumental in the design of the OppNet website. She is also the NINR representative to the OppNet Steering Committee on behalf of the NINR Deputy Director.

Dr. Donna Joe McCloskey has been at NIH since 1985 and previously worked at the NIH Clinical Center for 20 years doing deep vein thrombosis research. She has a PhD in nursing with a concentration on research methods and implementation. She worked as a Training Director at NCRR and as a Program Director at NINR and she oversees a portfolio of Center Grants and T32s on Women's Health and Self-Management.

Organizational Structure

The NINR is organized into four divisions: the Division of Management Services (DMS), the Division of Intramural Research (DIR), the Division of Extramural Activities (DEA), and the Division of Science Policy and Public Liaison (DSPPL).

The DEA has three offices: the Office of Extramural Programs, the Office of Review, and the Office of Grants Management.

The DIR has three branches: the Bio-Behavioral Branch, Symptom Management Branch, and Tissue Injury Branch. The Bio-Behavioral Branch supports research on understanding behavioral, biological, and environmental influences on health, and funds research in two areas: the Digestive Disorders Unit studies the biobehavioral relationship between inflammation and patient symptoms while the Clinical Neuroscience Unit studies the relationship between circadian rhythms and pain and fatigue symptoms across populations.

Funding

NINR ranks 23rd among NIH's Institutes and Centers in terms of funding, receiving 0.5% of the total NIH-appropriated funding in 2012. According to RCDC, NINR's average portion of the BSSR and bBSSR portfolios for the combined years 2008–2011 is 2.1% and 1.1%, respectively.

General Research

Eighty percent of NINR's BSSR is behavioral, specifically in the areas of symptom management and self-management. A few investigators conduct community-based participatory research, which is considered to be social science.

NINR collaborates with OBSSR on initiatives looking at medication adherence, multiple chronic conditions in a primary care setting, community participation, and research on reducing health disparities. NINR's community participation research looks specifically at medically underserved populations. NINR also collaborates with OBSSR in developing technological innovations for interdisciplinary research with the SBIR program. Recently, NINR was the lead on the initiative on Healthy Habits: Timing for Developing Sustainable Behaviors for Children and Adolescents.³

NINR is also heavily involved in OppNet, which support a number of their research grants.

NINR funds not only nurse investigators, but researchers across many areas of science to move the field of nursing forward.

There have been no major changes in NINR's BSSR portfolio in the past 5–10 years.

NINR funds grants based on application merit and whether a proposal fits into NINR's BSSR priorities rather than allocating toward specific target areas. The NINR council is instrumental in determining whether grants that score well in review fit NINR's priorities.

Current BSSR at NINR

Prevention

Prevention research is a priority for NINR, which couples prevention with health promotion. Most of its work focuses on person-centered healthcare decisions and using innovative technologies to promote clinical care and accelerate scientific discovery. NINR prevention research focuses on specific subpopulations such as patients with dementia, stroke, heart failure, HIV/AIDS, and diabetes. It aims to prevent further advancement of these diseases as well as the negative consequences of chronic comorbid conditions. NINR supports center grants and training programs in these disease conditions.

Another area important to prevention is providing palliative care and preventing further disease and disabilities that complicate quality of life toward the end of life. The Health Habits initiative covers primary, secondary, and tertiary prevention. Additionally, NINR supports tertiary prevention research through its Common Fund initiative for self-

³ More information on the Healthy Habits initiative can be found at <u>http://grants.nih.gov/grants/guide/pa-files/PA-11-327.html</u>.

care and the role of self-management in preventing further disease progression in chronic disease conditions.

Social Epidemiology

NINR has an HIV/AIDS portfolio and partners with the Fogarty International Center (FIC) and other ICs, the Office of Research on Women's Health (ORWH), and OBSSR to support their mission of improving population health, the health of individuals, families, and communities.

Decision Science

NINR considers decision science to be a core element in the areas of selfmanagement and symptom management. It funds behavioral economics research through its own initiative on cost effectiveness and by partnering on a Request For Applications (RFA) looking at comparative effectiveness research and a Program Announcement (PA) on behavioral economics. Program Officers (POs) have received applications on developing decision support systems through the Small Business Innovation Research and Small Business Technology Transfer Research (SBIR/STTR) programs. Tangential to decision sciences is research on patient-provider communication in areas such as palliative care or life-sustaining treatments as well as caregiver health. In particular, one study looks at the residence of healthcare providers in rural, urban, and suburban counties in palliative care and hospice care and the decision-making processes that physicians use to choose practice locations.

NINR has partnered with other ICs to support decision neuroscience RFAs in dementia and cognitive decline and Alzheimer's disease.

Mhealth

NINR has a small SBIR portfolio with technologies for health monitoring. Mhealth research often overlaps with measurement development research.

Measurement Development

NINR's measurement development research focuses on developing innovative strategies and technology to advance behavioral science, specifically using informatics research to prevent and manage symptoms. NINR does not have any announcements specifically measuring social science or behavior, but investigators receive grants for innovative methods in measuring behavior change. For example, one grant looks at different cryotherapy methodologies and technologies to treat ulcers. Other examples include using genomics methodologies and technology for infections and wound healing, particularly in complex wounds.

Trends in BSSR at NINR

NINR is focusing heavily on the area of self-management, symptom management, palliative care, and end of life. In the near future, POs are working to develop a common fund initiative for the development of self-management strategies. In July 2013, the Institute hosted an intensive boot camp focusing on teaching methods and measures and outcomes on fatigue and sleep research.

NINR regularly participates in OBSSR coordinating committee meetings, is engaged with OppNet, and keeps up with BSSR at NIH through communication with Dr. Kaplan, engagement with the Science of Behavior Change initiative, and participation in meetings. Dr. Kaplan has emphasized the importance of translational science, study replication, dissemination of research results and keeping costs down in BSSR across NIH, guidance that NINR follows. Additionally, NINR will focus on training in BSSR and understanding the gap between basic and behavioral and social science research. NINR keeps current in the field by conducting literature reviews and continuous contact with their external grantee community.

Stakeholders

NINR POs are in communication with the members of the IC's Council of Representatives about how to advance the IC's BSSR. NINR engages its extramural research community through yearly round table discussions, the outcome of which can sometimes drive NINR research agendas. Additionally, other specialty nursing professional groups such as the Academy of Nursing, Sigma Theta Tau, and the Oncology Nursing Society provide funding for more clinically focused research. NINR communicates with these groups but does not partner with them on funding.

American Academy of Nursing

Council for the Advancement of Nursing Science

Palliative and End of Life Research Communities

Additional Comments

NINR staff reported that they have a good working relationship with OBSSR.

Appendix N. Interview Guide for BSSR-Related Professional Societies

Informed Consent

The NIH Office of Behavioral and Social Sciences Research (OBSSR) tasked the Science and Technology Policy Institute to conduct a study on behavioral and social science research (BSSR), with one objective of the study to identify emerging research trends in BSSR. In this interview we will ask you some questions regarding health- and medicine- related BSSR in your respective areas of research and expertise. Our conversation will be audio-recorded, but if you would like to tell us something that is off-the-record, please let us know and we will stop the audio-recording and note-taking until you tell us we may continue.

STPI Project Overview (5 min)

- Goals of Project
 - To uncover trends in BSSR important to NIH
 - To better estimate the percentage of total NIH funding going towards BSSR
 - o To understand how NIH identifies and funds new BSSR areas
- Description of Project Activities
 - STPI interviewed NIH ICs about the structure of their BSSR portfolio and trends in BSSR as it relates to their IC
- Goals of this interview
 - To understand how professional societies organize and identify BSSR topics
 - To understand emerging trends in BSSR and the health applications of such research
- Questions?

Organization of the Society (15 min)

- Can you please introduce yourself, your role, and your background?
- Can you describe the membership of your organization?
 - o Academic researchers?
 - Private industry researchers?
 - o Government researchers?
 - Policy, media, others?
- How does your organization create member sections or interest groups?
 - How are these sections organized? By research area, by methodologies, or along another dimension?
 - What function do these sections serve for the members?
- We've identified the following sections related to health and medical BSSR:
 - [Read list of sections on note sheet]
 - Are there others?
 - What role do these sections play in your organization?
 - At conferences?
 - [if BSSR-related sections exist] Do these organizations maintain contact with NIH Program Officers in individual ICs and/or with individuals at OBSSR?

Conference Proceedings (5 min)

- Does your society hold conferences?
 - Annual and/or regional/topic-specific?
- Are there conference themes and how are they chosen?
 - Have there been themes related to BSSR?
- How do you choose keynote speakers or invited lecturers?
 - (Are they researchers who have focused on well-established areas or who have ventured into new areas recently?)

Society's Publication (15 min)

- What type of research is published in your journal?
 - Quantitative or qualitative?

- Basic or applied research?
- o Literature reviews?
- o Case studies and meta-analyses?
- o Methodologies?
- o Policy?
- How is the research funded? NIH?
- Authors
 - What types of institutions are authors affiliated with?
- Do you solicit for specific research topics?
 - o If so, examples?
 - If so, why do you solicit in these areas?
- Do you publish special issues?
 - o If so, examples?
 - o If so, how are the topic areas chosen?
- Are there research areas in which you receive a high volume of submissions?
 - Are there areas in which submission volume has decreased in the past few years?

Emerging Trends (15 min)

- What are the emerging areas in BSSR related to your organization?
 - How do you spot emerging trends?
 - Are these areas currently receiving primary funding or are they mostly pilot projects funded through other research areas?
- Are there BSSR emerging areas related to health and medicine?
 - If not, do these emerging areas have health applications? (For example, a socioeconomic population study used to inform community health practices and funding)
 - Are these areas currently receiving enough primary funding or are they mostly pilot projects funded through other research areas?

Other (5 min)

- Do program officers or other NIH employees regularly interact with your organization?
 - Attend conferences?
 - o Discuss areas in need of funding?
 - Are members or leaders in the organization?
- How can an organization like the NIH ensure it is prepared to respond with funding to emerging BSSR areas?
 - How can societies interact with NIH ICs and OBSSR to better identify emerging trends?

Appendix O. American Educational Research Association (AERA)

Highlighted Findings

- The three general trends in BSSR affecting education research are the increasing interdisciplinary nature of education research, the increasing reliance on big data analytics, and increasing research for informing educational reform.
- Specific education research topics currently trending include the relationship between prenatal care and later education; education and risk behaviors; health risks in the educational environment associated with minority sexual identity; violence in educational environment; and mitigating risk behaviors and violent behaviors in the educational environment.
- The NIH should provide more funding opportunities directly related to educational research and engage more with the educational research community to determine funding opportunities and help researcher navigate the NIH funding system.

Interviewees

William Tierney, PhD—President

Felice Levine, PhD—Executive Director

Dr. William Tierney is the President of American Educational Research Association (AERA) and is a professor at the University of Southern California. His PhD is in administration and policy analysis and he directs USC's Center for Higher Education Policy Analysis. His research concentrates on governance and administration in higher education. Dr. Tierney's full biography is available at the AERA website.¹

Dr. Felice Levine has been the Executive Director of AERA since 2002 and she focuses her work with AERA on science policy issues, research ethics, data access, scientific workforce, and higher education. Dr. Levine was involved in the establishment

¹ Dr. Tierney's webpage:

http://www.aera.net/AboutAERA/WhoWeAre/WilliamGTierneyPresidentElect/tabid/11941/Default.aspx.

of the NIH Office of Behavioral and Social Sciences Research (OBSSR). Her full biography is available at the AERA website.²

Organization Information

Members and General Description

AERA is the largest educational research association in the world with 25,000 members, 75-80% of whom are employed at universities. Dr. Tierney estimates that fewer than 20% of members receive external funding, which typically comes from NSF or the Department of Education. Most members are funded to perform their research by their host institution rather than granting agencies.

Special Interest Groups, Sections, etc.

AERA is organized into divisions that parallel the organization of university education departments. The Education in the Professions Division covers health and NIH-related issues for the AERA. Gale Sinatra may be a useful point of contact for this division.

Meetings and Conferences

The annual conference attracts about 15,000 attendees including non-members. The conference has themes, which have included theory of practice, education in poverty, and innovation. No themes have been directly related to NIH interests, but some sessions within a theme may be relevant. Sessions are organized by the divisions, and all abstracts are submitted to the divisions for approval within their session. The Education in the Professions Division would receive most NIH-relevant submissions.

Publication and Funding Information

Some, though not all, AERA members are aware of the importance of OBSSR in promoting BSSR as it relates to health, well-being, and education. NICHD funds the majority of NIH-sponsored educational research performed by AERA members and published in AERA journals, with some coming from NIA and NIGMS.

NIH support for training grants in the social sciences, which are perceived to be an important part of capacity building in educational research, has declined in recent years. NIMH support for BSSR, including training grants in social sciences, declined when its

² Dr. Levine's webpage:

http://www.aera.net/AboutAERA/WhoWeAre/ExecutiveDirectorofAERA/tabid/11378/Default.aspx.

focus shifted to support more research in mental illness, molecular sciences, and genetic research. NICHD and NIDA still do support some BSSR training grants.

Interactions with Funding Agencies and Foundations

Several topics in educational research are of importance to NIH; however, AERA members currently do not look to NIH for funding and NIH does not directly solicit ideas from the educational research community. There is greater potential for funding from NICHD than from other ICs, but the connection between NICHD and AERA members is not strong. One area where AERA has directly engaged with NIH is in the area of adolescent health. AERA and NICHD's Adolescent Health Survey team worked together on an education module to understand how education at a classroom and institutional level affects adolescent behavior and health, learning, achievement, and other outcomes linked to development.

Dr. Levine interacts directly with staff at OBSSR and indirectly through COSSA or the Federation of Associations in Behavioral & Brain Sciences (FABBS). COSSA helps promote BSSR in policy and funding and acts as a facilitator for interactions between its member organizations and OBSSR. AERA staff worked with OBSSR on two competitions to bring together an interdisciplinary group of investigators (economists, political scientists, etc.) to encourage attention to the importance of education and interdisciplinary research relevant to NIH.

Methods for Detecting Trends

Since 2009, AERA has provided \$250,000 per year for an initiative that seeks to advance and discover nascent topics in education and learning. They receive conference proposals on emerging topic areas as well as traditional topics where new theories, methods, and measurements might be needed. AERA is particularly interested in bringing together fields that have not traditionally worked together on education. The conference serves to convene people with diverse backgrounds and training to encourage innovative ideas across disciplines. These special conference sessions have included themes such as literacy and language development, self-identity, new methods for studying Science, Technology, Engineering, and Mathematic fields, and socializing intelligence through academic dialogue. The last theme brought together brain behaviorists, social psychologists, and educational researchers.

Trends in BSSR—General

Three broad trends have emerged in educational research: interdisciplinarity, "big data," and higher education reform.

Educational research is becoming more interdisciplinary as it draws upon development, sociology, and economics research. Educational issues cannot only be traced to teaching techniques, but rather to socioeconomic issues, health issues, and other problems currently researched in other disciplines.

The issue of "big data", or how to best take utilize large, publicly available data sets, is becoming more important in educational research. Training of investigators is needed in data development, measurement development, survey development for at-risk populations, mixed-data databases, and analyses of such large data sets. Analysis of large data sets could provide explanatory power for the impacts that health risk, resilience, and disease conditions have on education. In education, one important aspect of big data is incorporating district, State, and Federal longitudinal data and records into databases to enable expansive evaluation and analyses. The community needs to think through how to integrate health records and educational records to develop a better understanding of the intersections of human development, health, and education.

Much research is now focusing on higher educational reform, including: training graduate students and preparing them for tenure track faculty positions; incorporating research into graduate education; and how to judge academic skills throughout the K-12 and higher educational systems.

Trends in BSSR—Topics

Some current issues pertinent to AERA and NIH include: the effects of prenatal and early child care on later education; the education and wellbeing of the mother, family, and child; special education; learning and instruction; counseling; assessment and learning outcomes; language and literacy; and human development. More attention could be paid by NIH to these issues.

Trending topics include research connecting prenatal care to learning ability in a formal educational environment; the link between education level and risk behaviors, with current hypotheses suggesting that education can mitigate risky behavior and help develop resilience; counseling and prevention concerning bullying; health risks associated with minority sexual identity (safety, well-being, and security in educational environments); and violence in educational environments and communities. AERA held a special conference focusing on how interaction between peers and instructors has a sustained impact on academic performance, intelligence, brain capacity, and learning behavior.

NIH has not embraced important areas such as learning and human development or development in educational environments. NIMH used to fund some of the most important violence research through its center on Violence and Social Behavior but this type of research is no longer supported.

Comments and Recommendations for NIH and OBSSR

NIH should engage better with AERA organizational leadership, such as the executive director, as well as the research leadership, including the president and other elected governing members. Currently, it is difficult for research communities who are unfamiliar with the NIH funding system to enter it. NIH could actively educate interested AERA members on the application process and engage them through conferences or special meetings to learn about emerging research areas and areas in need of funding. COSSA and AERA may not be the best conduits for NIH to go through; NIH needs to reach out directly to AERA members by funding educational research and providing targeted funding opportunities. One technique may be to use social media platforms to reach out to new research communities that NIH may be interested in. There is great value for both NIH and the AERA community in engagement.

OBSSR has a role in coordinating BSSR efforts of the ICs and bringing to the forefront interdisciplinary BSSR areas as they relate to health and well-being. Their role should be to bring attention to such BSSR that may not fit directly within an ICs mission. OBSSR has been unable to stop the loss of BSSR funding, especially training grants, and this is representative of their limited influence. OBSSR has peaks and valleys of influence based on the director and his advisors. It is more difficult for an Office director to have influence on funding than it is for an IC director.

One concern Dr. Levine has is the growing absence of program officers in professional societies and at conferences. NIH should encourage career scientists and program officers to be actively engaged in the external scientific community. This will help them stay on top of trending research areas. One method may be to provide funding for 5-year convening programs in which the ICs or OBSSR brings together external stakeholders to determine underexplored, underfunded, and emerging areas for NIH research. The 5-year funding period would allow for long term planning of such events rather than ad hoc committees that NIH may use currently.

OBSSR has an important role in supporting investment in science policy around issues of big data, convening BSSR investigators, and training BSSR graduate students and early career scientists. OBSSR, as an office, can focus on these through convening the ICs through meaningful, strategically planned activities that do not just focus on the state of BSSR within the ICs.

Appendix P. American Psychological Association (APA)

Highlighted Findings

- The NIH portfolio reflects changing trends in psychological research, primarily because NIH funding opportunities direct the research.
- General trends in BSSR include the increasing link between methodology and content area (i.e., methodology-focused research is becoming less independent of the content to which the methodology is applied); and the increasing use of animal research to inform human health and behavior.
- Specific psychology research topics trending include neuroscience; child development and aging populations as they relate to human behavior and health; and how child development influences learning.
- OBSSR needs more resources to support funding opportunities and to effectively promote BSSR across ICs; it can be more effective if it does not have to rely mostly on ICs to contribute funds.

Interviewees

Steve Breckler, PhD-Executive Director for Science

Gary VandenBos, PhD—Publisher

Dr. Steve Breckler received his PhD in social psychology and he has served as Executive Director for Science at the America Psychological Association (APA) for 9 years. In this role, he manages the advanced training institutes, distinguished lecture series, and science advocacy groups run by APA. His profile is available from the APA website.¹

Dr. Gary VandenBos received his PhD in clinical psychology and he has served as Publisher for 29 years. As publisher he also serves as the Executive Director for the Office of Publications and Databases which, according to his APA profile produces 66 journals, five databases and 88 books per year.²

¹ Dr. Breckler's webpage: <u>http://www.apa.org/about/apa/senior-staff/breckler-bio.aspx</u>.

² Dr. VandenBos's webpage: <u>http://www.apa.org/about/apa/senior-staff/vandenbos-bio.aspx</u>.

Organization Information

Members and General Description

The APA has 135,000 members, the majority of whom are PhD-trained psychologists. Around 70% of members are licensed health care professionals while the other 30% are mostly university, private foundation, or government researchers. There is some overlap between those who provide health care, those who perform research, and those who train and educate. According to Dr. VandenBos, 75% of member report partaking in two of the three aforementioned professional activities. Dr. Breckler estimated that around 30,000 members are student members or affiliate members such as high school teachers, international associations, and others.

Special Interest Groups, Sections, etc.

There are 56 divisions that relate to content areas in psychology. About half of the APA's members belong to a division. Many of the divisions are relevant to NIH, such as the Rehabilitation Psychology, Neuropsychology, and Psychopharmacology divisions.

Meetings and Conferences

The annual conference attracts between 15,000 and 17,000 people. The divisions are involved in the planning of the annual conference and are assigned hours at the conference for programming such as poster sessions. There are also themes for each conference and divisions are encouraged to plan part of their programming related to the theme. The central programming committee handles about 2/3 of the programming while the rest of the programming relegated to each divisions programming committee. The divisions also have specialized meetings separate from the annual meeting.

Publication and Funding Information

American Psychologist is the organization's flagship journal and it publishes quantitative and qualitative research, basic and applied research, case studies, and opinion pieces. The publication is very broad so articles tend to cover larger issues centrally important to the field of psychology as a whole. This may also include policy and perspective pieces. Considering all publications, Dr. VandenBos estimates that 25% of funding for APA published research is provided through the NIH. The funding varies between the 66 journals, with around 95% of published articles in the *Journal of Health Psychology* receiving NIH funding. The more clinically-focused the journal, the more funding from NIH the published authors tend to receive.

Interactions with Funding Agencies and Foundations

In the APA Science Directorate they engage in advocacy on behalf of the research community through APA staff interactions with NIH researchers and administrators. APA invests time and effort into the "Friends of IC" advocacy organizations, such as Friends of NIDA, which advocate NIH and research priorities to Congress. Some researchers in the APA community also engage with NIH through the BSSR Coordinating Committee. APA has strong ties to OBSSR as well. The current CEO, Dr. Norman Anderson, was the first director of OBSSR and continues to maintain and build a strong relationship.

NIH participation in APA events varies and there has been a recent decline in attendance of small events by NIH program managers. There is always a strong presence at the annual conference and associated specialized meetings from NIH ICs, especially NIMH, NIDA, and NIAAA. NIDA and NCI administrators have also been involved in recent years.

Also in recent years, NCI has made a concerted effort to interact with various BSSR communities due to its leadership's recognition of the value of BSSR in diversifying and maintaining a strong portfolio.

Methods for Detecting Trends

The NIH portfolio reflects the changing trends in psychology, especially the integration of psychology and behavioral research into disease-specific research. Much of the trends are due to NIH funding priorities, so in effect the NIH is often driving the field. The NIH is also driving the trend towards interdisciplinary research not just within psychology but between psychology and other fields.

Trends in BSSR—General

Methodology-focused research is becoming more strongly tied to content area. There is less research in general methodology and statistical tool development. Methodologists and statisticians are becoming more grounded in psychology domain areas, and methodological skills are integrating with domain expertise rather than existing as a separate field of study.

Within the field of psychology and behavior, animal research is changing focus and purpose. There used to be a lot more research into animal behavior for the sake of understanding animal behavior, but now much of the animal research is conducted to understand human health and behavior. Many animal researchers with whom Dr. VandenBos is familiar are now focusing on animal models for stress, cancer, heart disease, and psychopharmacological effects on behavior.

Trends in BSSR—Topics

The biggest trend in general psychology is research incorporating neuroscience such as cognitive neuroscience, social neuroscience, and neuroeconomics.

Psychologists are now focusing on child development and aging populations as it relates to human behavior and psychology. Such research began in the 1960s and 1970s but, according to the interviewees, is only now reaching a critical mass in academia and clinical research. The research is especially focused in geriatric populations which are increasing as the Baby Boomer population ages.

Researchers in child development are focusing more on how development affects learning and can be leveraged in curriculum design.

The NIMH has pushed psychological research away from mental health and towards mental illness. Their focus on neuroscience and genomics naturally favors illness research over health research. NIMH no longer supports the behavioral and social components of psychological research.

Comments and Recommendations for NIH and OBSSR

Dr. VandenBos recommends that at least 10% of any health-relevant psychology research should be dedicated to behavioral components.

The interviewees recommended increasing BSSR scientists in the recruiting and search committees of NIH leadership positions. IC leadership is one of the most influential factors for how BSSR is promoted within the NIH, so input from OBSSR during the search and recruiting activity is critical.

In order to be more effective OBSSR needs more resources. It has always had very strong leadership but only do so much by promoting BSSR to the ICs. It needs its own resources and funding for larger programs to be truly effective. It does not necessarily need to be formed into an IC, but it should receive money to seed programs that they can then promote to the ICs. Currently they have to lobby ICs from money just to start major programs. BSSR benefits when the money is spread across ICs, but there needs to be a strong central office like OBSSR that has more substantial funding. Concentrating BSSR funding in a single BSSR funding would diminish the connectivity between disciplines through which BSSR thrives. With more funding OBSSR could better advocate BSSR and help BSSR grants pass review, especially in ICs that are more strongly focused in a specific disease or organ system.

Dr. Breckler thinks the review system may need to be revised if BSSR grants are doing poorly but offered no specific recommendations. He said that creating a BSSR IC would not be the proper solution. BSSR-oriented funding opportunities are poorly publicized and disseminated, including OppNet announcements. The windows of opportunity are two small and the announcement often change too quickly with the volatility of NIH priorities.

NIH needs to focus more on open data and replication of studies, especially to combat research fraud. Currently replication studies do not pass review but these are critical in the scientific process to not only confirm results but also combat fraud.

Appendix Q. Association for Psychological Science (APS)

Highlighted Findings

- One general trend in BSSR is the increasing interdisciplinary nature within research fields (e.g., between social psychology and clinical psychology) and between research fields (e.g., between psychology and economics).
- Trending psychology research topics include genomics, neuroeconomics, and classical psychology.
- The NIH needs to reorganize its programs and announcements to account for the increasing interdisciplinary nature of BSSR.
- The OBSSR Coordinating Committee's utility is limited because the IC representatives may not be fully aware of their ICs BSSR, nor can they effectively disseminate information from the committee to the appropriate people within their IC.

Interviewees

Alan Kraut, PhD-Executive Director

Erich Eich, PhD—Editor, Psychological Science

Dr. Erich Eich is the Editor in Chief for *Psychological Science* from 2012—2017. His background is in cognitive psychology and he is based at the University of British Columbia. His research focuses on the interplay between cognitive and emotional processes. His full profile is available at the UBC website.¹

Dr. Alan Kraut is a developmental psychologist and has been with APS since its founding in 1988.

Dr. Eich's webpageio:

http://www.psych.ubc.ca/faculty/profile/index.psy?fullname=Eich,%20Eric&area= Cognitive%20Science&designation=core.

Organization Information

Members and General Description

There are 25,000 members, approximately 80% of whom are employed at universities. The other members span multiple careers including government, clinical practice, and education.

Special Interest Groups, Sections, etc.

There are no special interest sections because APS is designed to attract individuals from all areas of psychology to provide a common forum on empirical psychological science. The organization's leadership believes special interest sections may prevent productive and unique collaborations from forming. The organization changed its name from the American Psychological Society to its present name to be more internationally inclusive. The APS is now 22-23% international by membership.

Meetings and Conferences

The conferences have tracks but these are general and do not divide between types of psychology. The themes do not control the conference and the program committee selects several plenary sessions independent of the president. NIH provides strong support for psychological health science-related sessions. At the 2013 conference there will be 5-6 special NIH posters identifying funding opportunities.

Publication and Funding Information

Psychological Science is an empirical journal that is primarily concerned with peer research rather than commentary. The journal publishes both basic and translational work. There are approximately 2,700 submissions annually from 80 countries though the majority of the submissions come from U.S.-based researchers. Primary U.S. funding sources include the NIH, Howard Hughes Medical Institute, NSF, DoED, and DOD. *Psychological Science* does not solicit specific topics but the topics with the most submissions are cognitive psychology, neuroscience, social psychology, and developmental psychology. *Perspectives on Psychological Science* is more conversational around specific topics, providing commentary on popular topics and emerging areas. In 2013 APS launched *Clinical Psychological Science* to focus specifically on clinical psychology research.

Interactions with Funding Agencies and Foundations

Dr. Bob Kaplan of OBSSR has been involved in APS conference sessions and symposia, and OBSSR and APS have had a close working relationship since the establishment of OBSSR. NIH in general is not integrated into APS decision making; however, an NIH scientist is currently running for a board position.

Methods for Detecting Trends

The topic of trend detection did not come up during this interview.

Trends in BSSR—General

Within psychology, barriers between psychology fields are being removed and the field is becoming more interdisciplinary both within psychology and with other disciplines. Thus to be a clinical psychology researcher, one also needs a background in multiple fields such as cognitive science, neural science, social psychology, or other psychology-related disciplines. Along with this trend, there is more of an interest in team science between disciplines such as psychiatry, public health, business, economics, and other fields.

There is also an interest within recent years in improving and developing research methods and reporting. The APS journals are starting to require the disclosure of more methodology information including: how sample sizes are determined; whether participants were excluded and why; whether independent variables were excluded and why; and whether any dependent variables were excluded due to failure. Dr. Eich stated that NIH has a huge role in encouraging the release of such information and raw data to improve practices through grant reporting requirements. These disclosures also contribute to the growing need for publically available data sets and big data.

Trends in BSSR—Topics

Genomics, neuroeconomics, and classical psychology (e.g. psychophysics) have previously been underrepresented in the journals and are now receiving more attention.

Comments and Recommendations for NIH and OBSSR

NIH needs to recognize that barriers between psychology subfields are being removed and needs to reorganize programs and announcements to account for and encourage this trend. The NIH is also not very sensitive to psychological issues and does not bring in psychologists on IPAs or visiting positions.

Dr. Kraut stated that the OBSSR coordinating committee is limited in its usefulness. The ICs do not have any internal mechanisms to handle BSSR across the ICs and therefore the representatives may not be fully aware of the IC BSSR portfolio. A new mechanism could be more useful if it is more IC focused, with OBSSR working closely with each IC to explore the breadth of BSSR at the IC. OBSSR may play a role in increasing BSSR representation during peer review process at the Center for Scientific Review (CSR).

Appendix R. American Statistical Association (ASA)

Highlighted Findings

- Conferences are important for detecting research trends, and a primary method useful to NIH program officers.
- General trends in BSSR include increased interest in large dataset analytics, longitudinal data, and mixed method data integration and analysis.
- Specific statistical research trends include variable and model selection, farce inference, health decision science, adaptive treatment and intervention, and agent-based modeling in health social sciences.
- The presence of BSSR statistics research within an IC depends on how proactive program managers are in attending conferences and maintaining contact with journal editors.

Interviewees

Marie Davidian, PhD—President

Leonard Stefanski, PhD-Chair of Committee on Publications

Dr. Marie Davidian received her PhD in statistics from UNC Chapel Hill and is a professor of statistics at the North Carolina State University. Her interests include statistical models and methods for analysis of longitudinal data, especially nonlinear mixed effects models; methods for handling missing and mismeasured data; methods for analysis of clinical trials and observational studies, including approaches for drawing causal inferences; pharmacokinetic and pharmacodynamic analysis; combining mechanistic mathematical and statistical modeling of disease progression to design treatment strategies and clinical trials; and statistical methods for estimating optimal treatment strategies from data. Her full bio is available at NCSU's website.¹

Dr. Leon Stefanski received his PhD in statistics from UNC Chapel Hill and is a professor of statistics at the North Carolina State University. His research interests include variable selection, measurement error models, generalized linear models,

¹ Dr. Davidian's webpage: <u>http://www4.stat.ncsu.edu/~davidian/</u>.

environmental statistics, and Trout distributions.² He was the former editor of the *Journal* of the American Statistical Association.

Organization Information

Members and General Description

There are over 18,000 members from 90 countries, approximately 40% of whom are academic, while the rest are individuals in government, financial industry, software industry, pharmaceutical industry, and other statistics-relevant industries.

Special Interest Groups, Sections, etc.

There are 26 sections that are formal entities with governing boards intended to provide for common member interests and undertake initiatives such as workshops, poster sessions, and conference sessions. The sections contribute to ASA conferences and the Joint Statistical Meeting, for which ASA is one of five contributing societies. Sections are free to organize their own session goals and agendas.

Sections may also sponsor webinars, continuing education activities, short courses, and career workshops.

Meetings and Conferences

For the Joint Statistical Meeting, there is a program committee with representatives from all interest sections, representatives from the 5 other societies, and external stakeholders. Each society determines their own invited paper program, and the program committee ensures there are many different topics covered. Each section referees its own program that directly receives paper submissions

Each year there is a conference theme and the sections usually organize at least one talk related to the theme from their respective interest focus. It is unlikely that BSSR-related topics would constitute a conference-wide theme.

ASA also sponsors smaller meetings, and it is possible that BSSR-related meetings could occur if there is enough interest from sections.

Publication and Funding Information

ASA journals of interest to NIH and OBSSR may include *Statistics in Biopharmaceutical Research* and the *Journal of Educational and Behavioral Statistics*.

² Dr. Stefanski's webpage: <u>http://www4.stat.ncsu.edu/~stefansk/</u>.

The latter is a joint journal with the American Educational Research Association (AERA).

The flagship journal, the *Journal of the American Statistical Association* (JASA), includes a theory and methods section and an applications and case studies section. The content is broad and not specific to health or behavior. Such specialty areas are usually covered by smaller, specialty journals. While editor of the methods section, Dr. Stefanski did not encounter many BSSR-related journal submissions. Most BSSR-related statistical research would probably be submitted to the applications section or the *Journal of Educational and Behavioral Statistics*.

The two main funders of JASA-published research are the NSF and NIH. In the methods section, there is a lot of work on big data techniques which may be relevant to genomics research funded by the NIH or analysis of other large databases and datasets produced by the NIH.

Submissions come from members and non-members in academia, government, and private industry. About 70% of submissions are from academia. The journal does retain associate editors who are qualified to review BSSR-related submissions. Of his 60+ associate editors, at least two would be qualified in social science statistical analyses.

Interactions with Funding Agencies and Foundations

There is no formal relation between ASA and OBSSR or NIH ICs.

ASA has a committee on funded research with NSF representatives.

Methods for Detecting Trends

The main method for emerging trend detection is NIH Program Officers attending conferences and interacting with the scientific community. Conferences are extremely important for trend detection.

Trends in BSSR—General

There is an increased interest in large dataset mining and analysis, longitudinal data analysis, mixed method data analysis, and data integration. Basic research in variable selection is increasing as well.

Trends in BSSR—Topics

There is an increase in variable selection and model selection research due to increased interest in big data analysis. Such large datasets contain detailed information on many individuals within a population and contain multiple variables. There is also recent interest in farce inference, or the detection of important information within a signal or
database. Such research may include detection of signal characteristics and artifacts in genomic sequence datasets.

Behavioral statistics is focusing more on decision making in health areas such as depression, substance abuse, chronic disorders, behavioral disorders, and the management of such disorders. Statistics is also critical for adaptive treatment and intervention strategies in which a patient's past treatment response is detailed and analyzed against a database that suggests further treatment routes. Such research is classified as decision science within statistics. There is an increased interest in sequential decision design for adaptive interventions, specifically Sequential, Multiple Assignment, Randomized Trials (SMART). Such research is funded through the NIH, specifically NIDA or NIAAA if more applied. There was a program announcement for Dynamic Treatment Regime research that may have encompassed statistical research

Agent-based modeling in health social sciences is also an area of interest.

Comments and Recommendations for NIH and OBSSR

BSSR statistics research varies across NIH ICs. Its presence within an IC depends on how proactive program managers are in attending conferences and maintaining contact with journal editors. Program officers are the conduit for identifying emerging trends in the research community and relaying this information to align funding sources.

Appendix S. American Sociological Association (ASA)

Highlighted Findings

- Analyzing funded and nonfunded NIH grant applications and published and unpublished conference papers may provide the most insight into research trends.
- One general trend in BSSR research is the growing legitimacy of qualitative research, especially as it becomes more integrated with mixed methodologies.
- Specific BSSR trends include understanding population level patterns of health behavior; identifying mechanisms of and correcting for social disparities in health; sexual minority health and disparities; social factors of genetic propensities in health; cumulative social disadvantages in health; adolescent behavior and health throughout the life course; and education and health.
- The NIH does not examine its research in the larger sociological context, and does not engage enough sociologists in scientific review groups.

Interviewees

Cecilia Ridgeway, PhD-President

Debra Umberson, PhD——Editor, Journal of Health and Social Behavior

Dr. Cecilia Ridgeway is a professor of sociology at Stanford. She has been involved with ASA for 35 years and her background is in sociology and social psychology. Her full bio is available on the Stanford website.¹

Dr. Debra Umberson is a professor of sociology at University of Texas, Austin. She has been involved with ASA for 25 years, over which she has had research funded by NIH. She has a master's degree in social work and a PhD in sociology.

¹ Dr. Ridgeway's webpage: <u>http://www.stanford.edu/dept/soc/people/cridgeway/index.html</u>.

Organization Information

Members and General Description

The organization is primarily academics from the United States and Canada.

Special Interest Groups, Sections, etc.

Special interest groups form through member interest and must have a minimum membership. The Health and Social Behavior was the largest interest group in the 1970s and split into the Medical Sociology and the Mental Health interest groups in the 1980s. Medical Sociology is one of the larger interest groups today with approximately 1,000 members. Mental Health has approximately600 members, many of whom also belong to Medical Sociology. Aging and the Life Course may also have NIH-relevant issues, but it extends beyond health issues such as social position of the elderly.

Meetings and Conferences

Conference programming is determined in three ways:

- Invited sections chosen by the program committee. The program committee is selected by the president. It is common for such sections to have health-related aspects.
- Regular sessions organized by the program committee based on contributed papers. It is common for such sections to have health-related aspects.
- Interest section sessions organized by the interest sections. Time is allotted based on interest section size. Medical Sociology has sessions every conference and these sessions often represent trends in their respective interest area.

Publication and Funding Information

The *Journal of Health and Social Behavior* publishes basic science research with 90% of the articles employing quantitative methods and 10% of the articles employing qualitative methods. The majority of research is funded by the NIH, with some funding from the Robert Wood Johnson Foundation and other private foundations. The content is driven by submissions, with the highest quality articles being published. There are no calls for special submission areas; however each issue and issue section is organized around thematic topics in areas like inequalities, social disparities, etc.

Interactions with Funding Agencies and Foundations

Dr. Ridgeway is aware of OBSSR but has no formal interaction with the office.

ASA sections interact with NSF program officers to discuss grant funding mechanisms. The NSF program officers attend the conference, with many of them from the psychology program within SBE Directorate.

There does not appear to be strong NIH program officer presence at the conference meetings and there is limited interaction with NIH program officers through ASA sections.

Methods for Detecting Trends

Analyzing funded and unfunded NIH grant applications would be the most effective method to detect emerging trends.

It is possible that the Medical Sociology maintains records of submissions and approved conference papers that could be analyzed for trends.

Trends in BSSR——General

While quantitative research is still dominant in sociology, qualitative research is growing in legitimacy. This has resulted in much more mixed methodology research, such as studies that incorporate quantitative surveys, qualitative interviews, and behavioral experiments to supplement and cross-validate findings

Trends in BSSR—**Topics**

Several areas trending in sociology are sexual minority (Lesbian, Gay, Bisexual, and Transgender) health and health disparities; genetics and social factors modifying genetic propensities for health outcomes; cumulative social disadvantages in health; and the relationship between education and health.

Within the realm of social inequalities and disparities research, there are increasing submissions attempting to identify and explain population level patterns of health behavior stemming from social disparities. There is also an increasing interest in identifying mechanisms of inequality and potential corrections for such inequalities by identifying origins and interlocking processes related to social disparities in health. Such inequalities may be researched through several modes including within institutions, within communities, over the life course, through economic processes, and within other social constructions.

Many sociology journals are receiving increased submissions in research on adolescent behavior and how that affects health throughout the life course.

Comments and Recommendations for NIH and OBSSR

NIH does not examine issues in the larger sociological contexts in which they exist. NIH has not realized that the myth of the individual being the only factor in health; the NIH needs to realize how social processes are created and affected in larger society and how this affects individuals' and communities' health.

Looking at most NIH grant application scientific review groups, there are usually no sociologists included. Without sociologists, the review groups may negatively affect how sociological research is reviewed and funded. It is difficult to determine if NIH is not inviting the sociologists or if NIH is inviting them but they are declining invitations. Sociologists, however, are involved in CDC research.

Appendix T. Linguistics Society of America (LSA)

Highlighted Findings

- Plenary sessions and lectures at conferences highlight research trends.
- The greatest general trend in linguistics is the focus on large and complex datasets through computational linguistics.
- Biolinguistics, including the genetics of language, is trending in linguistics research.
- The NIH is not focusing enough on cyberinfrastructure and big data analytics.
- OBSSR should provide more education to ICs on the importance of BSSR in health and wellness.

Interviewees

David Lightfoot, PhD—Past President 2010-2011; Chair, Publications Committee

Doug Whalen, PhD—Nominating Committee

Dr. David Lightfoot was President of the Linguistic Society of America for the 2010-2011 terms and currently serves as the Chair for the Publications Committee. He is also the society's delegate to the American Association for the Advancement of Science and the Consortium of Social Science Associations. He is a Professor of Linguistics at Georgetown University and his research focuses on syntactic theory, language acquisition, and historical changes in language. He received his PhD in linguistics and has been a member of LSA since the 1960s. His full biography is available at the Georgetown website¹.

Dr. Doug Whalen currently serves on the Nominations Committee of the LSA. He is the Vice President of Research at the Haskins Laboratory at Yale University and his research focuses on the production and perception of speech. He received his PhD in

¹ Dr. Lightfoot's webpage: <u>http://explore.georgetown.edu/people/lightd/?PageTemplateID=129</u>.

Linguistics and has been a member of the LSA for several years. His full biography is available at the Yale website².

Organization Information

Members and General Description

There are approximately 4,500 members, the majority of whom are academics.

Special Interest Groups, Sections, etc.

The society covers language research from all perspectives in areas such as social variation, language change, neurolinguistics, computational linguistics, sound systems, syntactic structures, and meaning systems. Biolinguistics and Clinical Linguistics special interest groups focus on issues that may be relevant to NIH and OBSSR.

Meetings and Conferences

LSA holds an annual conference with 1,200-1,500 attendees and a biennial summer institute. The institute is a continuing education event that incorporates lectures and workshops.

The annual conference has plenary sessions which may be of interest to NIH. Topics of past conferences included speech perception and cognitive neuroscience. The lectures often focus on new research trends and topics. There are many papers submitted to the regular sessions that are also of interest to the NIH, though applied research may be found at other conferences such as the Acoustical Society of America or the American Speech-Language-Hearing Association.

Publication and Funding Information

Certain topics will receive NIH funding, such as aphasia research (breakdown of language capacity) that is often funded through NIMH. NIMH also funds research on sign systems of the deaf and communication disorders; however, funding levels for such research have diminished since the NIMH began focusing more on genetics and translation research.

The journal *Language* tends to cover the inner core of the field, and it is unusual to see work on neuroscience and language. Such research tends to be published in specialty journals. There are a variety of health journals on autism, neuroimaging, and language pathology. Journals of interest include *Journal of the Acoustical Society of America*,

² Dr. Whalen's webpage: <u>http://www.haskins.yale.edu/staff/whalen.html</u>.

Journal of Speech, Language and Hearing Research, and Journal of Speech, Language and Hearing Disorders.

LSA is beginning specialty online-only journal sections in public policy, teaching linguistics, and possibly computational linguistics.

About half of the research published in *Language* does not receive Federal funding, as linguistics research does not require much equipment or research assistant support. This research is funded purely on academic appointment, but NSF and NIH fund the majority of the remaining research.

Interactions with Funding Agencies and Foundations

NSF usually sends a few program officers every year to the conference and holds a special session to discuss funding priorities and emerging areas of interest. It is rare to have NIH attendance at the annual conference.

Both Dr. Lightfoot and Dr. Whalen have had close interaction with OBSSR and Dr. Kaplan. There is no formal interaction between NIH or OBSSR and LSA.

Methods for Detecting Trends

Plenary sessions and lectures at the annual conferences usually focus on new research trends and emerging topics.

Trends in BSSR——General

The biggest change in linguistics research is the shift to analyzing large and complex datasets. Computational linguistics focuses on methods for analyzing large linguistics data sets resulting in new techniques through multidisciplinary collaboration with computer scientists. There is increased attention to language documentation for endangered, vanishing, dead, and extinct languages.

Trends in BSSR——Topics

There is an emerging paradigm over the past 10 years that language may be a branch of psychology and biology. Biolinguistics assumes that language derives from biological properties of the human species. Genetics is part of biolinguistics research, especially with research on the FOXP2 gene and research on unusual speech patterns not accompanied by other impairments. There is also an increase in the language of specific disorders, such as Williams Syndrome.

Comments and Recommendations for NIH and OBSSR

NSF used to be the major funder of cognitive linguistics until NIMH became the major funder in the 1980s. This has since changed again, as NIMH started to focus more on translation science as outlined in the 2003 roadmap. This change in priorities has resulted in a funding gap for cognitive neurosciences and language. However, there was a recent program announcement on multi-sensory perception, indicating NIH may be starting to look at basic cognitive neuroscience again. Unlike NSF, NIH is not shifting funding to cyberinfrastructure and big data analytics that are becoming critical for modern research. Dr. Lightfoot has chatted with Dr. David Abrams, former director of OBSSR, on this issue. There was one program, the Collaborative Research in Computational Neuroscience (CRCNS) that focused funds on big data analytics; however, this program has limited funds and is not sufficient enough to fulfill future needs.

NSF is inviting astronomers and researchers in other data-intensive fields talk about techniques with other disciplines that are starting to require big data analytics.

There needs to be an increased focus on basic science, especially in cognitive neuroscience.

NIH does not need to engage with professional society staff, but it needs to start interacting with the societies' leadership and members.

OBSSR needs to educate ICs on BSSR, especially how small investments in BSSR lead to large impacts. BSSR does not require as much money to have significant results, but current funds are too small.

Appendix U. Society of Behavioral Medicine (SBM)

Highlighted Findings

- Analyzing submissions to journals, rather than focusing only on publications, may the best indicator for trending research.
- General trends in BSSR include the increasing importance of qualitative research and increasing translational behavioral medicine research.
- Specific behavioral medicine research topics currently trending include cancer, smoking, physical activity, disease risk perception, health decision sciences, comorbidities, obesity, assessment tools, and health technology adoption behavior.
- OBSSR and NIH program officers have a strong connection with SBM.

Interviewees

Alan Christensen, PhD—President

Christopher France, PhD-Editor-in-Chief, Annals of Behavioral Medicine

Amy Stone, PhD-Executive Director

Dr. Alan Christensen is a Professor of Psychology and Internal Medicine at the University of Iowa and is the President of the Society of Behavioral Medicine (SBM). He holds a PhD in Clinical Psychology. According to his webpage¹, his research interests include: clinical health psychology, adjustment to chronic illness, medical regimen adherence, patient-provider interaction, health services research, and personality and health.

Dr. Christopher France is a Professor of Psychology at Ohio University and is the Editor-in-Chief of *Annals in Behavioral Medicine*. He holds a PhD in Clinical Health Psychology. He has been Editor-in-Chief for 3¹/₂ years and was an Associate Editor for 5 years before his current position. According to his webpage², his research interests

¹ Dr. Christensen's webpage: <u>http://www.psychology.uiowa.edu/people/alan_christensen</u>.

² Dr. France's webpage: <u>http://www.ohioupsychology.com/Faculty.php?p=737</u>.

include: pain and risk for hypertension, pain-related fear, nociceptive flexion reflex assessment, recruitment of blood donors, and retention of blood donors.

Amy Stone has been the Executive Director of SBM since 2008. She holds a Master's Degree in Health Communications. As Executive Director she helps ensure transfer of information and knowledge between officers of the society.

Organization Information

Members and General Description

There are approximately 2,200 members, 75% of whom are researchers in public health, nursing, medicine, and other related fields.

Special Interest Groups, Sections, etc.

Special interest groups are created on a volunteer basis and there are currently 18 interest groups. The interest groups communicate about scientific research, research planning, courses, and sessions for the meeting, though they do not organize conference sessions.

Meetings and Conferences

70% of SBM members along with non-members attend the conference. The annual themes are chosen by the president in conjunction with the program committee. This year's theme is health technologies, including topics like mHealth and behavioral health IT. The themes are often relevant to OBSSR and other NIH IC interests.

For keynotes and master speakers, the program committee seeks both established researchers and emerging researchers working on the edge of the field. Keynotes tend to be more established researchers who have worked on the core of the field or who worked on an emerging area that is now a core part of behavioral medicine. The master speakers may be concurrent with other sessions and these speakers present on topics either related to the conference theme or to another aspect of behavioral medicine.

There is a formal program planning committee consisting of the president, a chair, and other members. The group plans the meeting and picks independent reviewers for submissions.

Publication and Funding Information

SBM publishes Annals of Behavioral Medicine, Translational Behavioral Medicine: Practice, Policy, Research, and the Journal of Behavioral Medicine. Annals covers the breadth of psychosocial research and behavioral factors related to illness and treatment. It focuses on basic mechanisms of illness as well as treatments, intervention efficacy, and methodology. NIH funds the majority of the work while NSF and private foundations fund the other U.S.-based research. About 20% of publications are from international researchers who receive funding from their country's respective funding agencies and sources. Authors primarily work at research universities (some with hospital affiliations), NIH, other government agencies, and private research institutes.

Annals publishes special issues, with themes such as race or Lesbian, Gay, Bisexual, and Transgender (LGBT) issues. Every few years an organization may sponsor a special issue for which the purchasing organization works with the editorial board to select submissions for the special topic.

Interactions with Funding Agencies and Foundations

NIH program officers regularly attend and present at the SBM conference and there is a strong presence of NIH researchers in the SBM membership. The last two OBSSR directors have been SBM members.

Methods for Detecting Trends

Research submitted to the journal may be the best indicator of trend. Those seeking to uncover research trends should analyze submissions as opposed to publications, as new emerging areas may not be developed enough to pass the review process. Conversations through interest section electronic mailing lists may also indicate new trends as they tend to revolve around emerging research areas.

Trends in BSSR——General

More qualitative research is being produced but these studies have a harder time getting through review.

In the early 2000s NIH started to push for translational research so behavioral medicine research has followed suit, resulting in new research on the genetics of behavior and other translational areas. Additionally, researchers are becoming more interested in how the shift to translation affects public policy and funding.

Trends in BSSR——Topics

In terms of specific topics, cancer, smoking, physical activity, disease risk perception, health decision sciences, comorbidity and obesity are popular interests. Such topics as they relate to race and ethnicity are growing in focus and submission to the journal.

In technology areas, researchers focus on assessment tools in addition to intervention techniques. Additionally, researchers explore how behavior affects the adoption of new health technologies. Researchers still focus on specific diseases, so behavioral medicine plays limited role in some research circles. The field is not as interdisciplinary as it needs to be.

Comments and Recommendations for NIH and OBSSR

Recommendations specific to NIH and OBSSR were not discussed.

Appendix V. Society for Research in Child Development (SRCD)

Highlighted Findings

- Special topic meetings, invited conference sessions, and journal special sections highlight trending research topics.
- General trends in BSSR include the reliance on large datasets and the focus on translational research.
- Specific trends in developmental psychology include global issues and populations, the used of mixed-methodology analytics, mental health in immigrant and war-affected populations, the neuroscience of learning, and the mapping of early biological stress to long term development.
- NIH faces challenges in funding innovative interdisciplinary work when such research does not fit closely with a single IC's mission.

Interviewees

Dr. Ann Masten, PhD-President

Dr. Jeffrey Lockman, PhD-Editor, Child Development

Dr. Lonnie Sherrod, PhD—Executive Director

Dr. Ann Masten is the President of Society for Research in Child Development (SRCD) and is a professor at the University of Minnesota. She is a clinical psychologist by training, with expertise in the development of competence in high risk adverse environments, focusing on risk and resilience development. She maintains a clinical psychologist license. Full biographies can be found on the University of Minnesota¹ and PBS² websites.

Dr. Jeffrey Lockman is the Editor of SRCD's flagship journal, *Child Development*, and is a professor at Tulane University. He is a developmental psychologist with research

¹ Dr. Masten webpage: <u>http://www.cehd.umn.edu/icd/people/faculty/cpsy/Masten.html</u>.

² PBS webpage: <u>http://www.pbs.org/thisemotionallife/people/expert/ann-masten-phd/bio</u>.

interests in cognitive development and perceptual motor development. His biography is available at the Tulane University website.³

Dr. Lonnie Sherrod is the Executive Director of SRCD. Her research interests included civic engagement in minority youth. She has been Executive Director for 5 years. Prior to becoming Executive Director she was a professor at Fordham University.

Organization Information

Members and General Description

As of February 2013, SRCD has 4,984 members, 75% of whom have psychology backgrounds. SRCD is often a secondary affiliation for members whose primary discipline has its own professional society. The organization is expanding its international membership and outreach as this is necessary to accommodate the shift in research focus to global perspectives. U.S. researchers are currently focusing only on 5% of the world's child population.

Special Interest Groups, Sections, etc.

SRCD offers developmental psychologists a more focused professional society than other generalist psychological associations; however they do not offer special interest groups. There are committees around topics such as Equity and Justice, Ethnic and Racial Issues, Interdisciplinary, International Affairs, and others. These committees may organize conference sessions but are not required to do so.

Meetings and Conferences

SRCD has a biennial meeting that attracts approximately 7,000 individuals, only about half of whom are SRCD members. Sessions are proposed by members, either individually or from special topic meetings that occur throughout the year. These sessions go through the normal review process by the program committee.

SRCD puts out calls for special meetings for specific purposes such as writing books, organizing conference and pre-conference sessions, or discussing specific-interest topics and papers.

Additionally, SRCD has special topic meetings during the off-years of the biennial conference. These meetings are much more focused and on average attract approximately 300 attendees. In 2014 there will be four special topic meetings⁴: Developmental

³ Dr. Lockman'a webpage: <u>http://tulane.edu/sse/psyc/faculty-and-staff/faculty/lockman.cfm</u>.

⁴ <u>http://srcd.org/meetings/special-topic-meetings</u>.

Methodology; Strengthening Connections among Child and Family Research, Policy, and Practice; Positive Youth Development in the Context of the Global Recession; and New conceptualizations in the Study of Parenting-at-risk. These meetings often have a multi-disciplinary and international focus.

Publication and Funding Information

SRCD's main publication is *Child Development*, which publishes regular issues, special issues, and special sections. These special issues and sections may be requested by associate editors or SRCD members. They range in focus from molecular to macro level research, and often involve interdisciplinary research that connects the molecular or genetic level with the macro level. JL has published the following special sections while editor:

- Child Development in Developing Countries
- The Development of Children in Immigrant Families
- Developmental Social Cognitive Neuroscience
- Disasters and the Impact on Child Development
- Effects of Early Experience on Development
- The Genetic Sciences and their Role in Understanding Child Development

Child Development receives submissions from many other disciplines outside of developmental psychology but much of the published work is funded by NIH or derives from NIH-funded research (e.g. research that uses an NIH dataset). The major IC is NICHD, with funds also coming from NIDA, NIAAA, and NIMH. Some research has also been funded by NHLBI. Funding from NIMH has decreased significantly recently, as their focus has shifted from mental health to mental illnesses, such as depression, Dissociative Identity Disorder, etc. NSF is also a major Federal funder along with private foundations such as the Spencer Foundation. Universities may provide support to researchers through academic appointments. International submissions are funded by their home country's respective funding agencies.

Interactions with Funding Agencies and Foundations

SRCD has conducted meetings with Dr. Alan Guttmacher, Director of NICHD to discuss emerging research topics of interest. They also had meetings with Dr. Myron Guttman, NSF SBE Assistant Director. The SRCD Washington, D.C., office maintains contact with NIH and NSF, but NIH and NSF project officers that are SRCD members are the main connection between the organization and its funders.

There are at least sis agency sessions at the biennial conference, with NSF and NICHD as frequent presenters and attendees.

COSSA is important for SRCD contact with the Hill for legislative concerns and issues.

SRCD will have policy fellows at NIH and NSF. These individuals provide developmental science insight to the agencies and serve as a bridge between SRCD and the agency.

Methods for Detecting Trends

SRCD's special topic meeting, invited conference sessions, and *Child Development's* special sections and issues are intended to highlight emerging themes in the field that have reached an important critical mass. The organizers want to encourage further work in the highlighted research areas and the topics are intended to represent the fringe areas where child development field is headed. Most submissions to the journal and conferences represent the center of the field so special topic meetings, invited sessions, and special journal sections and issues are used to promote the edge of the field i.e. the emerging areas where the field should be heading.

Trends in BSSR—General

One trend is the reliance on large data sets collected by many PIs across multiple levels of analysis and disciplines. This trend is related to the one of multiple levels of analysis and mixed methodologies trend, such as using large data sets with small ethnographies.

Research is also becoming more translational (though basic science research still occurs) with researchers partnering with schools, communities, and state and Federal agencies. Researchers may be combining imaging or genetic studies with classroom or population studies. The goal for the Department of Education Institute of Education Sciences (IES) is to understand how basic biological development affects the classroom and education. Basic research in neurology and genetics is also being linked to clinical studies and implications, especially with young investigators.

Trends in BSSR—Topics

One trend in developmental psychology is a focus on global issues and populations, particularly in low income countries. Previously, research communities were internally focused on their own nation's populations, but it is becoming clearer that it is important to understand other populations, such as those in developing countries.

Another trend in developmental psychology is a focus on bringing together multiple levels of analysis, from neural and genetic development to social and environmental issues affecting development. This requires identifying animal models, human models, and population level analyses that are relevant to the research topic of interest. This may incorporate longitudinal studies that seek to identify early child development's effect on later development.

Along with the developing nation focus, there is an increase in mental health and physical health research, especially in immigrant and war-affected children populations.

Another research trend is mapping early biological stress to long term development. This is particularly relevant to longitudinal studies focusing on how early development affects later development.

There is also increased funding from the Department of Education IES for research on the neuroscience of learning and development interplay. This is related to a growing interest in prevention science and interventions designed to promote school success and brain development for higher function training.

Comments and Recommendations for NIH and OBSSR

Dr. Sherrod noted that behavioral and social science researchers in child development who are not focusing on neurological or genetic factors of child development may feel left in the dust by NIH. NIH needs to recognize that these individuals have very important research to contribute to development science.

Innovative multi-disciplinary work may fall through the cracks at NIH because it spans the mission of multiple institutes and it becomes difficult to find a home institution. For example, there may be research that explores development linkages to depression, heart disease, and cancer prevalence that cannot find a home IC. This is especially true for longitudinal studies that look at how early development links to later development, a trending topic in developmental research. Also, with increased funding limitations, ICs are more likely to fund center-of-the-field research that closely aligns with the IC mission as opposed to funding innovative multi-disciplinary research that may not be as closely related to the IC mission because it has components related to other ICs. This type of research is further set back due to cuts in private funding for multidisciplinary research. OBSSR may have a key role in advocating for such work and ensuring that ICs do not overlook this important, innovative research. Another option is to require interdisciplinary effort as a criterion for research proposal applications.

There is a need for more funding for international work due to the increasing interest in international populations. The NIH is starting to respond to this, as SRCD recently collaborated with NICHD, NSF, and the World Bank.

OBSSR could benefit from promoting itself more among external stakeholders, such as holding regular meetings to discuss research trends and funding issues. While

organization leaders are aware of OBSSR, the average member is not. Organizations would be more likely to inform members of OBSSR activities if OBSSR held regular meetings or newsletters for external organizations.

OBSSR should share the findings of this project with the external community.

Abbreviations

AAO	American Academy of Otolaryngology
AARR	AIDS and Related Research
ABMR	Academy of Behavioral Medical Research
ADA	American Diabetes Association
ADCS	Alzheimer's Disease Cooperative Study
ADGC	Alzheimer's Disease Genetics Consortium
ADHD	Attention Deficit Hyperactivity Disorder
ADNI	Alzheimer's Disease Neuroimaging Initiative
AERA	American Educational Research Association
АНА	American Heart Association
AHRQ	Agency for Healthcare Research and Quality
AIDS	Acquired Immune Deficiency Syndrome
AITRP	AIDS International Training and Research Program
AOA	American Osteopathic Association
APA	American Psychological Association
APS	Association for Psychological Science
ARP	AIDS Research Program
ARP	Applied Research Program
ASA	Acoustical Society of America
ASA	American Sociological Association
ASA	American Statistical Association
ASHA	America Speech-Language Hearing Association
BBBP	Biobehavioral and Behavioral Processes
BBPSB	Basic Biobehavioral and Psychological Sciences
	Branch
BBRB	Basic and Biobehavioral Research Branch
bBSSR	Basic Behavioral and Social Science Research
BCERP	Breast Cancer and the Environment Research Program
BDA	Biology of Development and Aging
BITB	Behavioral and Integrative Treatment Branch
BMRD	Biostatistical Methods and Research Design
BRAIN	Brain Disorders in the Developing World: Research
	Across the Lifespan
BRP	Behavioral Research Program
BSRT	Behavioral Sciences and Rehabilitative Technologies
BSSR	Behavioral and Social Science Research
CAM	Complementary and Alternative Medicine
CAP	Clinical Applications and Prevention branch
CBI	Combined Behavioral Intervention

CDB	Center for Mothers and Children's Child Development and Behavior Bhranch
CDC	Centers for Disease Control and Prevention
CIHB	Community Influences on Health Behavior
CIT	Center for Information Technology
	Chronic Lower Back Dain
CNID	Clinical Neuroscience Drench
	Combined Dearman action and Debaviarel
COMBINE	Combined Pharmacoinerapies and Benavioral
0000	Intervention
CUSSA	Consortium of Social Science Associations
CPDD	Child Psychopathology and Developmental Disabilities
CSR	Center for Scientific Review
CTN	National Drug Abuse Treatment Clinical Trials Network
DABPS	Division of AIDS Behavior and Population Sciences
DAIDS	Division of Acquired Immunodeficiency Syndrome
DAIT	Division of Allergy Immunology and Transplantation
DAR	Division of AIDS Research
DASH	Dietary Approaches to Stop Hypertension
	Division of Adult Translational Passarch and
DAIR	Treatment Development
	realment Development
DBDK	Division of Blood Diseases and Resources
DBIB	Division of Basic and Integrative Biological Sciences
DBNBR	Division of Basic Neuroscience and Behavioral
	Research
DBS	Demographic and Behavioral Sciences branch
DBSR	Division of Behavioral and Social Research
DCCPS	Division of Cancer Control and Population Sciences
DCNBR	Division of Clinical Neuroscience and Behavioral
	Research
DCR	Division of Clinical Research
DCVS	Divisions include the Division of Cardiovascular
	Sciences
DDN	Division of Digestive Diseases and Nutrition
DDTR	Division of Developmental Translational Research
DEM	Division of Diabetes, Endocrinology, and Metabolic
	Diseases
DER	Division of Extramural Research
DESPR	Division of Epidemiology, Services and Prevention
	Research
DGCG	Division of Geriatrics and Clinical Gerontology
DIR	Division of Intramural Research
DIRP	Division of Intramural Research Programs
DLD	Division of Lung Diseases
DMID	Division of Microbiology and Infectious Diseases
DMS	Division of Management Carvices
	Division of ivianagement services

DN	Division of Neuroscience
DNBBS	Division of Neuroscience and Basic Behavioral Science
DNDA	Division of Neuroscience, Development, and Aging
DOD	Department of Defense
DOHaD	Developmental Origins of Health and Disease
DPP	Diabetes Prevention Program
DPPS	Division of Physiological and Pathological Sciences
DRR	Division of Receipt and Referral
DS	Decision Sciences
DSIR	Division of Services and Intervention Research
DSM-5	Diagnostic and Statistical Manual of Mental Disorders
DSP	Division of Scientific Programs
DTCS	Division of Translational and Clinical Sciences
EEG	Electroencephalogram
ELSI	Ethical, Legal and Social Implications
EMA	Ecological Momentary Assessment
ERB	Epidemiology Research Branch
FDA	Food and Drug Administration
FGA	Funded Grant Application
FIC	Fogarty International Center
FIRCA-BSS	Fogarty International Research Collaboration—
	Behavioral, Social Sciences
FOA	Funding Opportunity Announcement
GEI	Gene Environment Interactions Project
GPS	Global Positioning System
GRIP	Global Research Initiative Program
GWU	George Washington University
HBRB	Health Behaviors Research Branch
HCIRB	Health Communications and Informatics Research
	Branch
HDEP	Health Literacy, and Health Disparities and Equity
	Promotion
HDM	Healthcare Delivery and Methodologies
HIV	Human Immunodeficiency Virus
HLAA	Hearing Loss Association of America
HMO	Health Maintenance Organization
HPV	Human Papillomavirus
HSA	Health Scientist Administrator
IBP	Individual Behavioral Processes branch
IC	Institute and Center
ICCFAS	Interagency Coordinating Committee on Fetal Alcohol
	Syndrome
IDD	Intellectual and Developmental Disabilities
IRDB	IMPAC II Reporting Database
IRG	Integrated Review Group
IRP	Division of Intramural Research

IRSDA	International Research Scientist Development Award
ITREOH	International Training and Research in Environmental
	and Occupational Health
KUH	Division of Kidney, Urologic, and Hematology
	Diseases
LBC	Laboratory of Brain and Cognition
LGBT	Lesbian, Gay, Bisexual, and Transgender
LSA	Linguistics Society of America
MADD	Mothers Against Drunk Driving
MBSR	Mindfulness-Based Stress Reduction
MCI	Mild Cognitive Impairment
MD	Measurement Development
MH	Mobile Health (mHealth)
MMBMB	Manual and Mind-Body Medicine Branch
MRI	Magnetic Resonance Imaging
NACA	National Advisory Council on Aging
NAD	National Association of the Deaf
NAMHC	National Advisory Mental Health Council
NAMI	National Alliance on Mental Illness
NCCAM	National Center for Complementary and Alternative
	Medicine
NCHS	National Center for Health Statistics
NCI	National Cancer Institute
NDCD	National Deafness and Other Communication Disorders
	Advisory Council
NEI	National Eye Institute
NHGRI	National Human Genome Research Institute
NHIS	National Health Interview Survey
NHLBI	National Heart, Lung, and Blood Institute
NIA	National Institute on Aging
NIAAA	National Institute of Alcohol Abuse and Alcoholism
NIAID	National Institute of Allergev and Infectious Diseases
NIAMS	National Institute of Arthritis and Musculoskeletal and
	Skin Diseases
NIBIB	National Institute of Biomedical Imaging and
	Bioengineering
NICHD	National Institute of Child Health and Human
	Development
NIDA	National Institute on Drug Abuse
NIDCD	National Institute on Deafness and Other
	Communication Disorders
NIDCR	National Institute of Dental and Craniofacial Research
NIDDK	National Institute on Diabetes and Digestive and
	Kidney Diseases
NIEHS	National Institute of Environmental Health Sciences
NIGMS	National Institute of General Medical Sciences

NIH	National Institutes of Health
NIMH	National Institute of Mental Health
NIMHD	National Institute on Minority Health and Health
	Disparities
NINDS	National Institute of Neurological and Communicative
	Disorders and Stroke
NINR	National Institute of Nursing Research
NOFAS	National Organization on Fetal Alcohol Syndrome
NSF	National Science Foundation
NSTC	National Science and Technology Council
OAD	Office of the Associate Director
OBSSR	Office of Behavioral and Social Sciences Research
OCS	Office of Cancer Survivorship
ODS	Office of Dietary Supplements
OppNet	Basic Behavioral and Social Science Opportunity
- FF- ····	Network
ORBIT	Obesity Related Behavioral Intervention Trials
ORDGMH	Office for Research on Disparities and Global Mental
	Health
ORWH	Office of Research on Women's Health
Р	Prevention
PA	Program Announcement
PAR	Program Announcement with Special Review
PCORI	Patient Centered Outcomes Research Institute
PI	Principal Investigator
РО	Program Officer
PRB	Prevention Research Branch
PRB	Prevention Research Branch
PROMIS	Patient Reported Outcome Measurement Information
	System
PSE	Population Sciences and Epidemiology
PSP	Population and Social Processes
PTSD	Post-Traumatic Stress Disorder
RCDC	Research, Condition, and Disease Categorization
RDoC	Research Domain Criteria project
REAP	Research Enhancement Awards Program
REVEAL	Risk Evaluation and Education for Alzheimer's Disease
RFA	Request for Application
RPHB	Risk, Prevention and Health Behavior
RPIA	Risk, Prevention and Intervention for Addictions
SABE	Society for the Advancement of Behavioral Economics
SAVP	Strabismus, Amblyopia, and Visual Processing
SBIR	Small Business Innovation Research
SBM	Society of Behavioral Medicine
SBRB	Social and Behavioral Research Branch
SCT	Society for Clinical Trials
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Social Epidemiology
Socioeconomic Status
Society for Prevention Research
Services Research Branch
Society for Research in Child Development
Scientific Review Officer
Science of Research and Technology Branch
Social Sciences and Population Studies A
Science and Technology Policy Institute
Small Business Technology Transfer
Support Vector Machines
Systems Science Methodologies to Protect and Improve
Population Health
Traumatic Brain Injury
Trauma and Injury Research Training Program
Transdisciplinary Research on Energetics and Cancer
Traumatic Brain Injury and Stroke Rehabilitation
University of California, San Francisco
Vaccine Research Center (VRC)
World Health Organization