Elements for Success: Guidelines for Organizations that are Implementing Research Advisory Boards

Engaging diverse voices into the research process, or learning to provide your voice to research requires time, patience, and flexibility. This document is a set of guidelines for organizations that are working to implement research engagement programs similar to the Bureau of Sages into their communities. Whether you are a researcher, a provider organization, or if you already have a strong partnership, there are many elements to consider as you begin this process.

These materials were developed based on our experiences building, operating, and evaluating the Bureau of Sages, as well as the literature. They were enhanced with input from a variety of stakeholders including patients/persons, researchers, and health care providers. This was designed to be a *quick and easy* guide on the elements that should be considered when developing an advisory board. More information and resources can be found on our [webpage](#).

The list below outlines the four elements we found to be most important to thoughtfully plan for when working to create and sustain a new advisory board. Those elements include: 1) advisory board members (the voices that you want to pull into research, for the Bureau of Sages, we focused on long-term services & supports (LTSS) recipients); 2) the research organization and researchers; 3) the provider organization and support staff to help maintain the infrastructure; and 4) (a) strong research coach(es) to run the group and 5) champion(s) at either organization to ensure commitment and sustainability. If any of these elements are weak or missing, sustainability will be difficult.

A crucial factor tying together the above components is a **strong organizational partnership**. We recommend that organizational partnerships include one organization that houses researchers and one that houses advisory board members (outside of some unique organizations which house both of these personnel). Research organizations are typically a university or research institute where researchers are based. Provider organizations may be long-term care settings, home care agencies, advocacy groups, or any other organization that can connect researchers with persons with lived experience.

A strong partnership and good relationships are the backbone of any research advisory board. Oftentimes, these partnerships take many years to develop through patience, understanding and establishment of trust.

Thus, we recommend either prior collaborations between partners (e.g. interns, research studies, shared programs) *or* the time and ability to forge effective connections, as well as well-defined communication mechanisms, governance structure and feedback

loops between organizations throughout the duration of the partnership. For more resources on building strong partnerships, see our resources list at the end of this document.

1. Advisory board members

Members are those who have lived expertise. Members may need to receive training that maximizes their ability to give input to researchers. Once trained, they make group decisions about the extent of the advisory board's engagement role and how it will be sustained.

The guidelines below outline characteristics to consider when recruiting advisory board members:

- ✓ Enjoy intellectual stimulation and have an interest in topics addressed by advisory board (health & wellness/care/quality of life)
- ✓ Value being part of a group of peers and feel comfortable expressing self in small group discussions (this can come with time and support)
- ✓ Time to commit to group meetings and other possible events

> *For those who are not able to meet in a group setting, alternatives need to be considered. For the Bureau of Sages, we held meetings virtually with participants who were open to using technology to communicate and who had the ability to be patient with technological challenges that occurred along the way.

2. Research organizations & researchers

The research organization in the partnership should be able to provide researchers to engage with the advisory board, the researchers, in turn, need to commit time needed to make engagement meaningful. Before meeting with the advisory board, researchers will be trained on the most effective ways to present to and engage with the population. There can also be researchers involved in the inception of the advisory board, who should be willing to take a smaller or larger role as determined by consensus.

Guidelines for research organizations and researchers are listed below.

- ✓ Ability to demonstrate that they are ethical and explain their reason for engaging; ensure confidentiality if needed
- ✓ Willingness to engage and give voice to non-researchers, including adapting verbal and visual communication and possibly having opinions challenged
- ✓ Understanding of the advisory board's purpose: to engage with members as colleagues, not to incorporate stakeholders into research as participants
- ✓ Networks to attract a consistent flow of researchers seeking input from the advisory board, as well as students to potentially serve as research coaches, note takers, or evaluators

> **An engaging research presentation**: Researchers that come to advisory board sessions prepared will get the most out of the session. Reviewing guidelines, preparing brief talking points without research jargon, and creating a lay biosketch/reviewing the advisors' biosketches are all things that a successful researcher will do to be ready for the session.

3. Provider organizations & support staff

Support staff at the provider organization will typically be the ones maintaining ongoing logistics of the advisory board, and what this looks like in practice can differ greatly depending on the type of organization. Relevant staff will be trained on what an advisory board is and how they work, but there is room for operational creativity from site to site.

Guidelines below are important for support staff:

> **Creativity with the process:** The Northwestern Medicine Mesulam Cognitive Neurology and Alzheimer's Disease Center partnered with CJE SeniorLife to start an advisory board of persons living with early-stage dementia. While CJE gave key personnel at the organization an initial overview, Northwestern decided the group would work best for them as an 8-week session that would then convene as needed as opposed to an ongoing group. They were able to assess their resources and population to edit the advisory board to better suit their needs.

- ✓ Administrative support and commitment to weaving advisory board into organizational culture and seeking diverse sources of expertise
- ✓ Past experience with running a group or knowledge or clear idea about how it would work logistically
- ✓ Resources and time to account for "soft costs," including legwork to recruit, time and materials to communicate with members and coordinate meetings, and annual review
- ✓ Ability to recruit members from the community with which they work
- ✓ Reliable accommodations, including technology, to accommodate any impairments or conditions of members
- ✓ Available and appropriate space (physical or virtual) with no distractions
- ✓ <u>For virtual advisory boards:</u> technology for meeting virtually, with individualized support to train members on technology

4. Research coaches (Facilitators)

Research coaches (advisory board facilitators) and champions could come from any one of the groups above (researcher, provider, or community member), and having at least one research coach and one champion within an advisory board's ecosystem is important. There needs to be a strong research coach to run the group, maintain interest, and support the development of members' skills.

No matter who they are, research coaches should possess the following characteristics:

Rely on students and volunteers: As the Bureau of Sages was being initiated, we published some press releases and let our community know of our efforts. We were fortunate that one of our committed volunteers heard about it and asked to get involved. After working with us and going through an orientation, she became the research coach for the Bureau. We prepared facilitation guides for her; she reviewed the guides each week and let us know if she had any questions. She then took notes to summarize the meetings. In addition, we often have students interested in observing, taking notes, or helping facilitate meetings.

- ✓ Experience in direct care field and comfort with working with people who are aging/have disabilities
- ✓ Ability to (or have the potential to be trained) foster trust, equalize exchange, and resolve conflicts
- ✓ Written and verbal communication skills and attention to detail
- ✓ Time to plan, talk with members individually, and follow up after meetings

5. Champions

Champions may also include stakeholders of any sort (researcher, provider, member, etc.), but they should be in a position that allows them to have some influence over the advisory board's continued existence and success. This is an informal role. The champion could be the facilitator or an additional person. Other guidelines for champions include:

- ✓ Passion for engaged research and the population with which the advisory board focuses and commitment to the advisory board's success.
- ✓ Ability to help maintain the vision and mission of the advisory board, whether up front or behind the scenes.
- ✓ Advocate for continued support for the sustainability for the board.
- ✓ Has strong connections with provider staff members.
- ✓ Continued/ongoing communication with provider staff and leadership about progress of the advisory board.

Additional Resources/References

Below are a list of additional resources related to facilitation, group dynamics, communicating with and presenting to older adults/persons with disabilities, and examples of positive engagement of nursing home residents or patients. These sources were also used to develop this tip sheet.

Communicating with and Presenting Information to Older Adults/Persons with Disabilities

Blind Foundation. How to help someone who is blind or has low vision. (2018.) Accessed Dec 6 2018 at https://blindfoundation.org.nz/how-we-can-help/carers-friends-and-family/advice-on-how-to-help-someone/

Cleveland Clinic Foundation. (1995-2015). Tips to Improve Communication when Talking with Someone with Hearing Loss. Accessed Feb 29 2016 at https://my.clevelandclinic.org/health/diseases_conditions/hic_Hearing_Loss_Communication_Strategies_for_Family_and_Friends/hic-tips-improve-communication-when-talking-someone-hearing-loss

Farage, MA, Miller, KW, Ajayi, F and Hutchins, D. (2014). Design Principles to Accommodate Older Adults. Global Journal of Health Science, 4, 2; 1-25. 2014. Doi: http://dx.doi.org/10.5539/gjhs.v4n2p2

Gerontological Society of America. (2012). Communicating With Older Adults An Evidence-Based Review of What Really Works. Accessed Dec 11 2018 at https://www.geron.org/online-store?product_code_r=002_Communicating

Peninsula Agency on Aging. Senior Services Coalition. Tips for Communicating Successfully with an Older Audience. (No date.) Accessed Feb 29 2016 at http://www.paainc.org/wp-content/uploads/2015/10/SSC_2014_Tips_for_Communicating_Successfully_with_an_Older_Audience.pdf

U.S. Department of Health and Human Services. Office of Disease Prevention and Health Promotion. (Oct 2007). Quick Guide to Health Literacy and Older Adults. Accessed Feb 29 2016 at http://health.gov/communication/literacy/olderadults/literacy.htm

Example of Positive Ways to Engage Nursing Home Residents/Patients

Brédart, A., Marrel, A., Abetz-Webb, L., Lasch, K., & Acquadro, C. (2014). Interviewing to develop Patient-Reported Outcome (PRO) measures for clinical research: eliciting patients' experience. *Health and Quality of Life Outcomes*, *12*, 15. http://doi.org/10.1186/1477-7525-12-15

Moore, S.L., Susan E. Hall, S.E., Jackson, J. (2014). Exploring the experience of nursing home residents participation in a hope-focused group. *Nursing Research and Practice*, Vol. 2014, Article ID 623082, 9 pages, 2014. http://dx.doi.org/10.1155/2014/623082

Shura R, Siders RA, Dannefer D. (2011). Culture change in long-term care: Participatory action research and the role of the resident. Gerontologist 51(2):212-25. https://doi.org/10.1093/geront/gnq099

Group Facilitation

Community Tool Box.(2016). Section 2. Developing Facilitation Skills. Accessed 15 Nov from
http://ctb.ku.edu/en/table-of-contents/leadership/group-facilitation/facilitation-skills/main

Laurel and Associates. Ltd. (2010). How to Handle Difficult Participants. Accessed 12 Jan 2017 from http://laurelandassociates.com/whitepapersarticles/how-to-handle-difficult-participants/

The Sheridan Center for Teaching and Learning, Brown University. (2016). Tips on Facilitating Effective Group Discussions. Accessed Dec 11 2018 from https://www.brown.edu/sheridan/teaching-learning-resources/teaching-resources/classroom-practices/learning-contexts/discussions/tips

Partnership building

Cargo, M., & Mercer, S. L. (2008). The value and challenges of participatory research: strengthening its practice. *Annu. Rev. Public Health*, *29*, 325-350. https://doi.org/10.1146/annurev.publhealth.29.091307.083824

Castañeda, S. F., Holscher, J., Mumman, M. K., Salgado, H., Keir, K. B., Foster-Fishman, P. G., & Talavera, G. A. (2012). Dimensions of Community and Organizational Readiness for Change. *Progress in Community Health Partnerships : Research, Education, and Action*, *6*(2), 219–226. http://doi.org/10.1353/cpr.2012.0016

Christopher, S., Watts, V., McCormick, A. K. H. G., & Young, S. (2008). Building and maintaining trust in a community-based participatory research partnership. *American Journal of Public Health*, *98*(8), 1398-1406. DOI: 10.2105/AJPH.2007.125757

Corbie-Smith, G., Bryant, A. R., Walker, D. J., Blumenthal, C., Council, B., Courtney, D., & Adimora, A. (2015). Building capacity in community-based participatory research partnerships through a focus on process and multiculturalism. *Progress in community health partnerships: research, education, and action*, *9*(2), 261-273. doi: 10.1353/cpr.2015.0038.

Huang, Jennifer, Paula Darby Lipman, and C. Daniel Mullins. "Bridging the divide: building infrastructure to support community-academic partnerships and improve capacity to conduct patient-centered outcomes research." *Translational behavioral medicine* 7, no. 4 (2017): 773-782. doi: 10.1007/s13142-017-0487-z.

Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (1998). Review of community-based

      research: assessing partnership approaches to improve public health. *Annual review of*

      public health, *19*(1), 173-202.

      https://doi.org/10.1146/annurev.publhealth.19.1.173