National Alliance on Mental Illness

Collecting Race and Ethnicity Data:
Guidance for NAMI State Organizations and Affiliates

As NAMI advocates for improved mental health care for all, the organization is striving to include and provide support to members of diverse communities. A key component for the success of this effort is the systematic collection of race and ethnicity data. Uniformly tracking race and ethnicity data provides organizations with important tools for determining the success of efforts to be inclusive of diverse communities in their area and reaching diversity goals.

The analysis of collected data can help identify areas in need of improvement and can guide the development of targeted strategies to become more inclusive. Unfortunately, many organizations do not collect this data out of reluctance to ask people to identify their race/ethnicity since they may feel that asking this question is intrusive and that it may alienate people.

Several studies in the healthcare field have focused on race/ethnicity data collection since it is a key step towards improving quality of care for diverse communities. *Unequal Treatment*, an Institute of Medicine report, recommends data collection to address disparities of care. Studies also show that, contrary to a common concern, requesting race/ethnicity data does not necessarily deter people from accessing or staying in treatment. Researchers have found that explaining to the public why they are asked about their race and/or ethnicity increases a respondent's comfort in reporting. The Baker et al 2005 study of patient attitudes, 79.9% of participants somewhat or strongly agreed that hospitals and clinics should collect information on race and ethnicity.

What follows are important steps to consider in collecting race and/or ethnicity data:

- **Make sure your leadership and all involved staff recognizes the reasons for and the importance of tracking race/ethnicity data.**
- **Use consistent categories for data collection.** We recommend using the Office of Management and Budget's (OMB) *Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity* as a starting point. You may decide to use the exact categories identified by OMB or you may add additional (more specific) categories to make it more relevant to your community. For example, instead of an overall Asian category you may want to have categories for the major Asian communities in your area (Korean, Chinese, Japanese, Indian, etc.). Whatever you choose, the key is to be consistent across the organization.
- **To ease potential discomfort, tell people why you are asking for this information and how the data will be used.** Here is a sample script* you can use:

We want to make sure that all members of our community, regardless of race and/or ethnicity, are recognized and supported by NAMI. Please share information about your race and/or ethnicity so that we can track how well we are including all communities and whether or not everyone is receiving NAMI's quality education and support. Thank you!

Please select all that apply:

___American Indian or Alaska Native
___Asian American
___Black or African American
___Hispanic or Latino
___Native Hawaiian or Other Pacific Islander
___White
___Multiracial
___Other (please specify): _____

- **Gather the data directly from the people you are serving.** Make sure you have each person provide the information rather than having your staff/volunteers 'eyeball' a person's race/ethnicity. Eyeballing is less than desirable because it is collecting data based on assumptions, not fact, and is error prone.

- **Do not get discouraged.** While the majority of people will support your collection of race/ethnicity data, some may experience discomfort when asked for this information. This is OK and entirely within their rights. Explain why you are asking and give people the option of answering or skipping the question. You may be surprised about how many people do answer.

- **Make sure you use the data.** Systematic and uniform collection of race/ethnicity data will show you how well your organization is including diverse communities in your area. Compare this data with your area's census demographics and develop strategies to conduct targeted outreach to match the demographics of the population you serve. The data can also provide the basis of further investigation to offer insights into other areas of need, such as uncovering disparities. The results can help you plan how to meet specific identified needs of your constituents.

- **Share the data.** Make sure you share the data with the community (post the information on your website, share it in your annual report, etc.). This will demonstrate to the individuals sharing the information with you that you value it and that you are committed to be an inclusive organization. This data will also be very valuable when applying for funding since more and more funders are requiring information on how organizations meet the needs of diverse communities.

*****The sample demographic survey script provided should be expanded, or part of a larger survey, to include information beyond race and ethnicity to provide NAMI with necessary information on the population we serve such as age, sex/gender, sexual orientation, etc.

Questions? Contact us at MACenter@nami.org

References

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