Office of Science and Technology Policy and Office of Information and Regulatory Affairs
The White House
1600 Pennsylvania Ave NW
Washington, DC 20500

Submitted via email to: equitabledata@ostp.eop.gov

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RE: Public Request for Information; Advancing Equity with Community Data Partnerships: We Need to Hear From You

Justice in Aging appreciates the opportunity to comment on the above referenced public request for information.

Justice in Aging is an advocacy organization with the mission of improving the lives of low-income older adults nationwide. We use the power of the law to fight senior poverty by securing access to affordable health care, economic security, and the courts for older adults with limited resources—particularly populations that have been marginalized and excluded from justice, such as older adults of color, older adults with disabilities, LGBTQ older adults, and older adults with limited English proficiency. We have decades of experience with programs and services established by federal agencies, including the Centers for Medicare & Medicaid Services, Social Security Administration, and the Administration for Community Living.

We also have experience with state and local agencies and programs that impact the lives of older adults. Justice in Aging administers the National Center on Law and Elder Rights (NCLER) on through our contract with the Administration for Community Living. Through NCLER, we connect with front-line advocates at legal and aging services throughout the country who work directly with older adults to access State and local programs.

Our comments focus on policies and practices that can improve equitable data sharing and collection to advance equity for older adults with marginalized identities.

I.   **What are examples of successful collaborations between the Federal government and (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data?**

We offer two examples of successful collaborations to share equitable data specific to the context of services and programs for older adults.

a.   *The National Adult Maltreatment Reporting System (NAMRS)[1]*

NAMRS is a data reporting system used to understand adult maltreatment in the U.S.; it is operated by the Administration for Community Living (ACL) and the data is collected and submitted by adult

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[1] Administration for Community Living, National Adult Maltreatment Reporting System, https://namrs.acl.gov/ (last visited Sept. 29, 2022).

protective services (APS) programs in every state, the District of Columbia, and the territories.[2] While APS programs operate within the same statutory framework of services, there is great variation across programs in the populations they serve and their policies and practices. NAMRS is a comprehensive reporting system established by ACL—the federal agency that oversees APS programs—that provides insight into adult maltreatment at the client level and the supports needed to prevent it. The APS Technical Resource Center (APS TARC), also funded by ACL, provides training and technical assistance to states regarding NAMRS requirements.

NAMRS collects de-identified data from over one million reports of adult maltreatment annually,[3] and collects both quantitative and qualitative data on APS policies and outcomes of maltreatment investigations.[4] The collected client-level data includes data points that are directly relevant to APS's impetus, such as clients' and victims' age, disabilities, and residence. Additionally, the majority of states also report gender, race, and ethnicity data on some, but not all, APS clients and victims.[5] Less than half of state APS programs also report demographic information (age and gender) regarding the perpetrators of adult maltreatment.[6]

NAMRS data has been useful to advocates, policymakers, and service providers in understanding of the types of maltreatment experienced by different populations and identifying risk factors. It has also been useful in understanding maltreatment reports during the COVID-19 pandemic, during which social isolation and increased dependency on others for daily activities potentially increased exposure to maltreatment.[7]

b. *Title III Older Americans Act State Performance Report (SPR)*

The Older Americans Act (OAA) authorizes services through a national network of state agencies; local area agencies on aging; and American Indian, Alaskan Native and Native Hawaiian organizations to promote the rights of older adults. The State Performance Report (SPR) effort fulfills a requirement of the OAA, which requires "collection of statistical data regarding the programs and activities carried out with funds provided under the OAA" and reporting this data to the federal agency. Not only does SPR indicate how the national aging network and state agencies on aging use OAA funds, it now also provides information on the characteristics of the people serviced. The demographic information collected includes data points such as race, ethnicity, age, gender, and poverty status.[8]

While the new addition of demographics of OAA service recipients has not yet been reported publicly, this data will be aggregated at the state-level and de-identified where appropriate. The collection of

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[2] Adult Protective Services (APS) are federally mandated State-level programs that investigate reports of abuse, exploitation, neglect, and self-neglect relating to older adults and adults with disabilities.

[3] *Supra* note 1.

[4] Administration for Community Living & Administration on Aging, Adult Maltreatment Report 3 (2020), https://namrs.acl.gov/getattachment/Learning-Resources/Adult-Maltreatment-Reports/2020-Adult-Maltreatment-Report/2020_NAMRS_Report_ADA-Final.pdf.aspx?lang=en-US.

[5] *Id*. at 18. NAMRS also collects data relating to the practices of the investigation, such as the length of the investigation, reasons for case closure, and prior reports of maltreatment.

[6] *Id.* at 22.

[7] *Id.* at 24 (reporting that APS reports dropped in the early months of the pandemic and rose above normal levels after the initial shut-down period).

[8] Other data points include geographic distribution (i.e., rural/non-rural), household status, minority status, and number of functional limitations, and nutritional risk.

demographic data for SPR purposes will allow for a better understanding of the older adults who are impacted by OAA funded programs—which statutorily requires that some programs target services to older adults with the greatest social and economic need. For example, pro-bono legal assistance providers that represent older adults using OAA funding will report de-identified, aggregated demographic and other information related to their clients and cases which will be useful to both the federal government and the providers in identifying unmet needs in different communities.

II. **What policies, resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) around equitable data?**

a. *Data Collection as Standard Practice and Improved Data Points.*

A current barrier in gaining perspective on the impact of government-funded social services programs that are administered at the state or local level is inconsistencies in reported data points. Policies that define universal data points in federally-funded programs will facilitate cross-county and cross-state comparisons and provide a better perspective on the impact of social services programs nationally. This is particularly true for programs that are federally funded, but have state-by-state variations in implementation and impact, such as Medicaid-funded home- and community-based services and OAA funded legal and aging services.

These policies should emphasize the standard collection of demographic data, including race, ethnicity, sexual orientation and gender identity, age, disability, and languages spoken. Additionally, while many state and local programs gather some demographic information, the data points can be improved. For example, most self-reported accounts of race and ethnicity do not ask about Middle Eastern and Northern African (MENA) heritage.[9] Similarly, programs vary in how they collect information on sexual orientation and gender identity (SOGI). Traditional self-reported demographics questions that only allow one to identify as female or male "do[] not necessarily capture information on transgender or gender non-conforming individuals."[10] We encourage OIRA and OSTP to connect with trusted advocates from impacted communities to develop uniform standards for the type of information that should be collected by localities and states and these specific considerations for each type of data.

States and localities would benefit from resources and guidance on collecting this data, for example: Internet-based tools; trainings on gathering, and de-aggregating and de-identifying data; and targeted assistance in engaging impacted communities and improving data collection where it has historically been lacking. Resources on how to ask about demographic information in a culturally appropriate and sensitive manner are critical (addressed further in subsection(b)). Additionally, programs at all levels of government would benefit from resources on evaluating disparaties and intervention impacts on populations with intersecting marginalized identities.

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[9] The Federal government categorizes people with MENA origins as White, despite the fact that many such individuals do not self-identify as White and may experience different health and social outcomes than White populations. *See* Neda Maghbouleh et al., *Middle Eastern and North African Americans may not be perceived, nor perceive themselves, to be White* (2022), https://www.pnas.org/doi/10.1073/pnas.2117940119. While some government forms allow individuals to self-identify as "Other" on government forms and occasionally write in a response, there is no uniform policy for how these selections are reported.

[10] NATIONAL RESOURCE CENTER ON LGBT AGING, INCLUSIVE SERVICES FOR LGBT OLDER ADULTS 8 (2018), https://www.sageusa.org/wp-content/uploads/2018/05/sageusa-welcoming-agency-guide-inclusive-services-for-lgbt-older-adults.pdf.

b. Best Practices for Data Collection.

As uniform data reporting standards develop, so should standards of practice for data collection. Sharing one's detailed demographic information on race, ethnicity, SOGI, language, disability, and age is a sensitive matter, and many individuals may rightly feel hesitant to share this information due to perceived or lived experiences of bias and danger.[11] These hesitancies can be barriers to accurate and reliable data collection, which impacts data sharing across levels of government and limits our ability to draw relevant conclusions about the success of interventions that advance equity.

States, localities, Tribes, and territories would benefit from resources that are derived from input from impacted communities on how to collect, store, and report this information to build and maintain trust with self-identifying individuals. This includes, but is not limited to, guidance on framing culturally competent and trauma-informed questions; communicating confidentiality and privacy measures; and creating safe spaces to self-report data.[12]

c. Tools and Resources.

Another barrier to gaining equitable data is the administrative burden data collection places on the frontline service providers who work directly with clients from impacted communities. Because social services and government systems at the local, state, territorial, and Tribal level already gather some demographic information during intake procedures, resources to incorporate improved data points in providers' existing intake procedures—such as by facilitating case management and intake systems to collect this information—may reduce the burden of data reporting.

Another barrier in equitable data sharing is that the tools to compile and compare data between different levels of government is lacking. For example, courts in every state oversee guardianship proceedings for adults with diminished capacity, and all courts monitor issues such as the financial security and health of the adult through regular reporting requirements. However, there is no mechanism to compare the demographics and outcomes of adults under guardianship because states use different methods to record this information—ranging from Internet-based tools to paper records—and there are variances in the type of information that is collected.[13] While some federally-funded programs have national data reporting requirements and systems (including NAMRS and SPR), one ongoing challenge is that these mechanisms are not available for all social services programs.

III. What policies, resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?

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[11] For example, researchers have found that the way questions regarding sexual orientation are worded—"same sex attraction" versus "same-sex behaviors" and identifying as LBGTQ—impacts self-reported response rates. M.V. Lee Badget et al., *LGBTQ* Economics, 35 J. ECON. PERSPECTIVES 141, 144 (2021), https://pubs.aeaweb.org/doi/pdfplus/10.1257/jep.35.2.141.

[12] *See, e.g.*, NATIONAL RESOURCE CENTER ON LGBT AGING *supra* note 10 at 11-13 (discussing first impressions that demonstrate inclusivity); Badget, *supra* note 11 at 144 (noting differences in in-person versus computer-based data collection).

[13] While state courts are not federally funded, States can receive federal funding for guardianship-related efforts. *See, e.g.*, Administration for Community Living, Elder Justice Innovation Grants: Improving Guardianship (2022), https://acl.gov/grants/elder-justice-innovation-grants-improving-guardianship-fy2022.

        a.   *Publicizing Information*.

Universally, a major barrier in achieving health and social equity is lack of sufficient data around access to and outcomes of social programs for marginalized communities. Not having this information perpetuates structural disparities because government agencies and advocates are unable to accurately identify gaps in services and tailor solutions. Even when data are collected, it sometimes goes unreported or is reported in limited circumstances, such as being shared in a private meeting but not available publicly.

As data collection efforts are enhanced across federal and federally-funded programs, we encourage the agencies to report all collected data and stratify it by demographics. Additionally, intersectional data for all demographics should be reported as much as possible. While some data may be insufficiently large to include in analyses and trend reports, it should be publicized nonetheless in some format with the appropriate disclaimers.

IV.   **What policies, resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?**

As discussed in Section IV, we encourage policies surrounding publicizing data.

        a.   *Engage with Impacted Communities*.

As a general policy, we encourage engaging impacted communities at the onset of data collection efforts to help identify unmet needs, inform where to find the information, and develop community-informed equitable data practices. Additionally, we encourage keeping the community engaged during and post-data collection efforts, and sharing the results with the impacted communities.

Frequently, data-related efforts are often geared to the needs of the funders, and not the impacted community. It is vital that the outcomes of surveys, trend reports, and other data collection exercises are shared with community organizations that can use the information in making decisions regarding their programs.

One example from our experience of government accountability in data collection was in the recent COVID-19 context. California, like many other states, failed to report COVID-19 vaccine demographic data intersectionally. Instead, it reported uptake by race, gender, and age, but not at the intersection of any of those demographic characteristics. Therefore, it was virtually impossible to identify more precise trends among the older adult community because as a whole, it appeared that older Californians 65+ were embracing the vaccines. However, through efforts from Justice in Aging and others on the California Community Vaccine Advisory Committee, the state finally began reporting vaccine uptake for older adults by race, which revealed vacation rates among older adults in communities of color lagged behind white older Californians.[14] This led to more specific investments and outreach strategies tailored

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[14] More about the Community Vaccine Advisory Committee can be found on the California Department of Public Health's website at: https://www.cdph.ca.gov/Programs/CID/DCDC/Pages/COVID-19/Community-Vaccine-

to older adults of color.

V. **What policies, resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?**

As discussed in Section IV, we encourage policies surrounding publicizing data.

VI. **In which agencies, programs, regions, or communities are there unmet needs broken processes, or problems around participation and accountability that could be remedied through stronger collaborations and transparency round equitable data?**

    a. *Unmet Needs for Older Adults of Color and Older Adults with Other Marginalized Identities.*

While age is often a reported demographic data point, data on age and other intersecting identities (e.g., age and race, age and sexual orientation and gender identity) are not frequently reported. This was exemplified in the California vaccination example discussed in IV(a). Lack of data is a barrier that stymies efforts to advance equity at the policy and legislative level as well as the program level. Policies that uplift intersectionality in data collection across all sectors are necessary to advance equity in programs serving older adults.

VII. **Conclusion**

Thank you again for the opportunity to comment. If any concerns arise concerning submission, please contact Sahar Takshi at stakshi@justiceinaging.org.

Sincerely,

Denny Chan
Managing Director, Equity Advocacy

Advisory-Committee.aspx. The state's vaccine uptake data can be found on the COVID19.ca.gov webpage: https://covid19.ca.gov/vaccination-progress-data/#overview.