



SPAN & Family Voices NJ comments on Methods and Leading Practices for Advancing Equity and Support for Underserved Communities Through Government

July 6, 2021

Thank you for the opportunity to comment on the Request for Information (RFI) on the Methods and Leading Practices for Advancing Equity and Support for Underserved Communities Through Government. The SPAN Parent Advocacy Network (SPAN) is New Jersey's one-stop for families of children birth to 26 across systems; our special priority are children and families at greatest risk due to poverty, disability and special healthcare needs, discrimination based on race, ethnicity, immigrant or language status, or other special circumstances. Family Voices-NJ is the New Jersey affiliate for Family Voices, dedicated to supporting the family voice in children's healthcare. SPAN also serves as the Parent-to-Parent USA affiliate for NJ; the NJ Parent Training and Information Center and Family to Family Health Information Center; and the state affiliate of the National Federation of Families for Children's Mental Health. Our comments today are based on our extensive experience providing support to parents around education, healthcare, and family support including addressing disparities and inequities across systems. They reflect the experiences of our own staff, most of whom initially came to SPAN for help; our trained parent leaders; and the parents, youth and professionals we serve.

SUMMARY:

SUPPLEMENTARY INFORMATION:

I. Background

We understand and appreciate that comments are sought on barriers to enrollment, financial assistance, contracting, engaging vulnerable populations, available resources and most importantly addressing the underlying causes of inequities.

Information and Key Questions

We further understand that input is sought specifically on equity assessments/strategies, barrier and burden reduction, procurement/contracting, financial assistance, and stakeholder/community engagement. The focus on stakeholder/community engagement is at the heart of SPAN's work; our motto is, Empowered Families: Educated, Engaged, Effective!

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For Area 1 on equity assessments and strategies:

Implicit bias must be addressed. Public entities can utilize self-assessment tools such as those available from the National Center for Cultural Competence (<https://nccc.georgetown.edu/>). The NCC also provides excellent information on the foundations and conceptual frameworks underlying cultural and linguistic competence (<https://nccc.georgetown.edu/foundations/framework.php>). Policies could include training in culturally and linguistically appropriate approaches, as it is required of providers in our state.ⁱ Outreach to underserved populations and input as stakeholders could be utilized. Data already exists on inequities across the lifespan: black infant and maternal mortality and morbidity; delays in early intervention; diagnostic delays for developmental disabilities; unequal Response to Intervention (less time/less interventions), segregated settings, disproportion representation in classification, and discrimination in discipline all under education; adult services such as healthcare, housing, employment, etc.; and finally even end-of-life care discrepancies for hospice. While additional assessment can be productive to hone in on causes and solutions, taking action is critical.

For Area 2 on barrier and burden reduction:

Barriers already existed in access to programs and benefits with inequities based on race, ethnicity, language, and other characteristics of families who traditionally face discrimination and lack of/limited access. The NCCC summarizes the compelling need for cultural and linguistic competence (<https://nccc.georgetown.edu/foundations/need.php>), facts and contexts that must be understood in order to reduce barriers to access. These barriers were worsened due to anti-immigrant sentiment and the proposal to make the public charge more onerous. Families, even those that were eligible or mixed immigrant status families whose children were eligible, hesitate still to use programs or benefits for which they qualify. Other families may be unaware of programs, or information and applications aren't disseminated in their language. If families are hesitant to enroll in early intervention, special education, healthcare, etc. this exacerbates the impact of the social determinants of health, worsening outcomes. Eliminating these barriers, particularly for undocumented immigrants in healthcare, will improve outcomes. Here again underserved populations need nontraditional outreach (e.g. faith based and meet families where they are) and can provide stakeholder input. Vulnerable communities need to be assured of protection of privacy information. Demographic information shows that certain populations respond to surveys, etc. while others are underrepresented. We recommend approaches that enhance ease of determining eligibility and links to applications in multiple languages like the NJ 211 phone line and online portal.ⁱⁱ

For Area 3, on procurement and contracting and For Area 4, financial assistance:

We are aware of disparate outcomes in procurement and contracting, with entities led by and serving the most underserved communities receiving fewer and smaller contracts and grants. We would recommend reviewing the resources and approaches from the Government Alliance on Race and Equity and their Contracting for Equity Guide (https://belonging.berkeley.edu/sites/default/files/gare-contract_for_equity_0.pdf) (although race is not the only characteristic that must be analyzed – ethnicity, immigrant status, gender, etc. are all also important).

For Area 5, on stakeholder and community engagement:

As stated previously, nontraditional outreach is needed for underserved families. This will ensure that vulnerable families are reached and that stakeholders reflect the diversity of the families served. Finding

families where they are is essential; this includes outreach to churches, bodegas (Spanish grocery stores), laundromats, libraries, etc. Again, assuring confidentiality is key for success. Using cultural liaisons and community partners increases trust. Families will participate more if they see their input is heard, resulting in change. Outreach also needs to happen in the languages most commonly used in an area. Input methods must also be flexible such as in person, online, by phone etc. Families must be involved to know that there are opportunities for input. In addition, notices of opportunities to comment are complex. The language isn't family friendly, PDF's can't be highlighted to take notes, and many notices are unnecessarily lengthy and repetitive.

The best way to reach and engage stakeholders and communities is to partner with their trusted community based organizations and other organizations that are part of their "community." Every state and territory has at least one Parent Centre (funded by US Department of Education to help families of children ages birth to 26 with or at risk of inappropriate identification for disabilities in early intervention, special education, and transition to adult life) and a Family to Family Health Information Center (funded by the US Department of Health Maternal and Child Health Bureau to support families of children and youth with special healthcare needs), and most have a Federation of Families for Children's Mental Health affiliate; all of these entities are required to reach, engage, and serve/support families with a focus on the most underserved. The Parent Center network is currently engaged in a conversation about how to more effectively reach and serve the most underserved families, led by SPAN's Center for Parent Information and Resources, while the Family to Family network has been engaged in a year-long effort to understand and address racism in healthcare and other systems. Partnering with them on strategies to reach and engage families is an excellent starting place.

Thank you again for the opportunity to comment on the proposed RFI regarding equity.

Sincerely,



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ⁱ <https://www.njconsumeraffairs.gov/bme/Pages/Cultural-Competency.aspx>

ⁱⁱ <https://www.njhelps.org/>