Cross-Cutting Objective – Reducing Disparities and Promoting Equity

The Committee supports the concepts of diversity, equity, inclusion, and accessibility within and for the autism community and the reduction of disparities in access to opportunities, services, and positive outcomes in health and well-being. People with disabilities, including autism, are both a part of our society's diversity and often experience disadvantages, disparities, and discrimination. The work of the IACC has raised the profile of autism and increased autism awareness in an effort to foster inclusion and acceptance of autistic people. The IACC has also supported efforts toward reducing disparities that occur at the intersection of race/ethnicity and autism since the first *IACC Strategic Plan* was issued in 2009. The topic of reducing disparities for underrepresented and underserved populations is mentioned in several chapters of this 2021-2022 edition of the *Strategic Plan.* At this time, with increased momentum from sources ranging from federal agencies to private organizations, more opportunity exists than ever before to address issues of creating equity and reducing disparities and the Committee renews its commitment to this effort.

Underrepresented and underserved populations, as defined in the *Strategic Plan*, may include various groups identified by demographic factors (e.g., sex/gender presentation, race, ethnicity, age, language preference, socioeconomic status, urban/rural, etc.). The intersection between these underserved populations and autism often enhances disparities in health, social and economic well-being, and opportunities. The Committee recognizes that reducing disparities in underrepresented and underserved populations is an important topic across all Questions of the *Strategic Plan*. As a result, this topic has been selected as a Cross-Cutting Objective. This will enable the Committee to track the critical research and services in this area across the *Strategic Plan* while also identifying this topic as a priority for funders.

Disparities among underrepresented and underserved populations with autism are evident across many research and service domains, including access to early assessment, diagnosis, and therapeutic interventions. For example, although the prevalence of autism has been found not to differ across racial and ethnic groups, studies have found that White children and those of higher socioeconomic status are more likely to be diagnosed with autism and at an earlier age compared to Black, Latinx, and Asian children and children from low-income families.[1-3] In addition, missed diagnosis or misdiagnosis is more common among Black and Latinx children.[4, 5] The delays in diagnosis observed in some underrepresented groups may then lead to further delays in access to early intervention services for children on the autism spectrum, particularly during important periods in child development. Subsequently, across the lifespan, these disparities may compound, resulting in disparate negative health outcomes typically seen in underrepresented and underserved populations as they progress to and through adulthood.[6] Addressing the causes of these disparities will also involve examining the effect of bias, cultural differences, and various social determinants of health (e.g., housing, educational and employment opportunities, geographic proximity to providers/specialists, crime and victimization, etc.) on the lifelong outcomes of autistic individuals. For example, for populations in rural settings, there are noted disparities in access to transportation, stable and reliable internet access, and access to appropriate healthcare services. These social determinants of health are key to providing a holistic view of how best to reduce disparities.

Despite the heterogeneity of autism presentation and support needs, much of the autism research in previous decades had been conducted in mostly White, male, middle- to upper-class children with higher cognitive and language abilities. As more intersectional approaches are developed in the investigation of autism disparities, researchers, educators, and care providers have begun embedding aspects of cultural competency and cultural humility into their respective practices. Cultural humility training encourages providers to reflect on their own beliefs, values and biases—explicit and implicit—through introspection, thus revealing the impact of their own culture on patients.[7] Therefore, as opposed to cultural competency trainings, which are more content-oriented and aim to increase provider knowledge, confidence, and self-efficacy in communicating with diverse patients, cultural humility trainings are more process-oriented and aim to enhance provider capability to deliver patient-centered care. Given that some autism-related disparities arise from barriers at the familial, cultural, and structural levels,[8] the utilization of culturally competent and humble approaches are key in enhancing the ability of the workforce to provide optimal care, ideally leading to positive outcomes in the autism community.

On his first day in office, President Biden signed Executive Order 13985, Advancing Racial Equity and Support for Underserved Communities Through the Federal Government,[9] encompassing efforts to improve opportunities and outcomes for communities of color, Tribal communities, rural communities, LGBTQI+ communities, people with disabilities, women and girls, and communities impacted by persistent poverty. The Executive Order directed the Federal Government to advance an ambitious government-wide equity agenda that has resulted in equity activities across every federal agency. One example of an initiative that has targeted heath disparities is the Department of Health and Human Service's Office of Minority Health's National Culturally and Linguistically Appropriate Services (CLAS) Standards, a set of 15 action steps intended to advance health equity, improve quality, and help eliminate health care disparities by providing a blueprint for individuals and health and health care organizations to implement culturally and linguistically appropriate services. Another example is the Health Equity Framework, released by the National Council on Disability in 2022, that lays out a set of goals to create health equity for individuals with disabilities. In addition to federal agency efforts on equity, many state agencies, private organizations, and academic institutions are also supporting research, services, and policy initiatives to address equity and disparities within the autism community. For example, Drexel University's Policy Analytics Center and Life Course Outcomes Program published a National Autism Indicators Report in 2022: *The Intersection of Autism, Health, Poverty, and Racial Inequity* that describes social determinants that influence health and well-being for individuals on the autism spectrum, and they propose that programs addressing these determinants are needed in order to close the gaps in health for these intersectional populations. Overall, the ripple effects of many different federal equity-related initiatives, including those that may address intersectionality across multiple underserved groups will provide new opportunities to improve the health and well-being of individuals on the autism spectrum.

Another key step in advancing inclusion and equity in research, services, and reducing disparities involves diversifying the researcher and provider workforce, in addition to recruiting diverse research participants. Enhancing the workforce by diversifying its makeup and perspectives serves as a concerted effort to reduce the various biases contributing to disparities, such as structural, personally mediated, and internalized racism that affects the health and well-being of autistic stakeholders.[10] For example, although there is a shortage of pediatric specialists overall, a recent workforce survey showed that only 2% of developmental-behavioral or neurodevelopmental pediatricians are Black.[11] The diversity of the research workforce also needs to be more inclusive of other aspects of diversity, including autistic researchers who are working in the autism field. In 2020, the International Society for Autism Research (INSAR) launched its Autistic Researchers Committee to foster scientific career development for autistic autism researchers and add valuable autistic perspectives to research discussed within INSAR. Recruiting and effectively training a workforce that reflects the diverse populations served has been the target of recent mentorship and pipeline programs, although more funding is needed in this area. Regarding research participants, improving the diversity of participants will aid in improving the generalizability and applicability of research findings to broader populations of the autism community. For example, disparities have been noted in the lack of inclusion of research participants from female/gender minorites,[12] racial and ethnic minorites,[13] lower socioeconomic status,[14] rural,[15] and older adults.[16] As a result, their historic lack of inclusion in intervention and services research has resulted in notable gaps in the literature, limiting the ability of autism programs and funding from effectively reaching these underrepresented populations to reduce disparities.

In addition to acting as research participants, the diverse perspectives from autistic stakeholders should serve to guide the research agenda and priorities moving forward, to ensure that the research aligns with the needs and desires of those with lived experience. The development of culturally relevant, feasible, and acceptable interventions and services involves the direct feedback on challenges, perspectives, and preferences from community members.[17] Outreach efforts aimed at building trust within communities has been seen as the benchmark for building relationships for the purposes of informing research aims and increasing community knowledge on autism-specific information. For example, in Latinx communities, *promotores de salud* (i.e., community health workers; *promotores*) are becoming critical participants in the prevention, health promotion, and delivery of health care.[18] These workers are able to effectively complete outreach activities and aid in improving the participation from underrepresented populations due to the inherent trust they are afforded as members of their own community. Actively listening to the needs of these communities will serve to directly improve the disparities noted for these populations.

The effect of the COVID-19 pandemic on the research communities is discussed in greater detail in Question 7 and the COVID-19 chapters of the *Strategic Plan.* Despite the discontinuation of some in-person autism clinical trials for the initial lockdown phase of the pandemic,[19] there is evidence of aspects of resilience and resolve by the autism research community. For example, many investigators described how testing and clinical trials were rapidly converted from in-person to telehealth strategies.[20] Development of more efficient and technology driven assessment tools have also been fast-tracked due to the pandemic. The availability of telehealth and remote avenues for service provision and research participation could potentially have eliminated barriers to access for many underrepresented and underserved populations. Future evidence might shed light on the full potential benefits seen as a result of the adaptations to research processes enacted due to the pandemic.

In summary, increasing diversity, equity, inclusion, and accessibility, and addressing disparities remains an objective that informs numerous research projects and programs across the *Strategic Plan* Question areas. This Cross-Cutting Objective serves as a method to track the progress made to ensure that underrepresented and underserved populations receive appropriate research, education, and services in order to reduce the numerous disparities noted in the literature. While additional information on specific areas of disparities is expanded upon in each Question of the *Strategic Plan*, this section and the Cross-Cutting Objective outlined here serve as an indicator of the urgency felt by the Committee's to comprehensively address areas of disparities in research and services moving forward.

CC2. Support efforts toward diversity, equity, inclusion, and accessibility and foster advances in research and improvements in service access and delivery that reduce disparities for underrepresented, underserved, and intersectional populations.

Examples:

- Develop culturally competent and culturally humble research and service approaches aimed at building trust with historically underrepresented populations.
- Promote the inclusion of diverse research participants and researchers, including autistic researchers.
- Develop appropriate trainings for providers and caregivers in underserved communities.

- Support research on disparities and underserved or intersectional populations within the autism community.

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