



Nothing about us without us!

Thank you for the opportunity to submit written comments for the IACC's public meeting on January 19th, 2022. In prior comments in November, ASAN emphasized the importance of addressing diagnostic disparities in autism, as well as the need for more lifecourse-focused measures of autistic outcomes. As the IACC continues to develop its strategic plan for 2021-22, we wish to expand upon these previously discussed matters.

On December 2nd of this past year, the Centers for Disease Control released new autism prevalence numbers through its Autism and Developmental Disabilities Monitoring (ADDM) Network report. This report demonstrates what we have long anticipated- that improved knowledge of autism and improving access to diagnostic screening have led to more early detection and diagnosis, leading to greater prevalence numbers. To be clear, there is little evidence to support any claims that this increase is due to a true increase in the prevalence of autism, but rather, all evidence suggests that it is due to improvements in the effectiveness and availability of diagnostic screening.

While this news is encouraging, as are the signs that some historic gender and racial disparities have begun to close, there is also ample evidence that substantial disparities continue to exist in autism diagnosis, and that these disparities lead many marginalized groups, such as individuals assigned female at birth and people of color, to be underdiagnosed or misdiagnosed, with many such individuals not receiving diagnosis until adulthood, if at all.

In light of this fact, it is imperative that IACC's strategic plan center efforts to reach and support underserved populations as a substantial priority. One element of this is recognizing that the path to diagnosis and support may differ substantially for underserved groups. Recognizing the importance of early identification for matching autistic individuals to supports, it follows therefore that those who are diagnosed later are more likely to have unmet support needs, and more likely to experience additional downstream impacts from these unmet needs. Where underserved communities are underserved due to lack of access to services and supports, this lack of access is likely to additionally manifest elsewhere in their lives, creating additional challenges around co-occurring diagnoses and health burdens.

All of this also highlights the importance of an improved access to diagnosis and support for autistic adults. Expanding access to diagnosis for adults is critical to ensure that under-served and underdiagnosed populations are able to receive needed supports. As these unmet support needs can also lead to worse life outcomes including housing and food insecurity, unemployment or underemployment, and greater risk of illness, injury and justice involvement, it is important to ensure that unidentified autistic adults have access to screening and supports as well. This is also important for expanding our understanding of autism, including its true overall prevalence in society, and for a fuller appreciation of the impacts of missed or misdiagnosis on the lifecourse of autistic individuals.

Finally, while the news that some of the diagnostic gaps in autism have begun to shrink is encouraging, it remains the case that significant gaps still exist, and that more progress needs to be made in ensuring that underserved populations are able to access providers and services that help them. Therefore, IACC must also be sure to focus on strategies to close this gap and ensure that underserved and underrepresented populations, including Black and Hispanic populations, as well as children assigned female at birth, have fuller access to diagnosis and services. In many places, this also means considering broader social and economic contexts. The CDC's ADDM report

populations, including Black and Hispanic populations, as well as children assigned female at birth, have fuller access to diagnosis and services. In many places, this also means considering broader social and economic contexts. The CDC's ADDM report noted substantial variance in diagnosis rates by geography, for example. This suggests that some of the continued diagnostic gaps are a product of community-by-community variance in access to services and supports. Addressing these broader sources of care inequality are critical for continuing to address these gaps. Similarly, our knowledge-base concerning autistic English language learners, including their barriers to diagnosis and supports, remains woefully sparse. Ensuring that the English learner population is well understood, identified, and supported should be a priority for the IACC alongside other underserved populations.

We thank the IACC for inviting stakeholders to comment and help the IACC identify strategic priorities for the coming year. For more information on ASAN and the autistic community's research priorities, please contact Julia Bascom, our Executive Director, at jbascom@autisticadvocacy.org.