



The highest priority needs, and emerging areas of opportunity related to SGM health research at NIH:

Sexual and gender minority (SGM) populations have always included autistic people & those with intellectual and developmental disabilities (IDD), yet our existence is not adequately reflected in SGM health research. Instead, autistic SGMs, particularly those of color, are excluded from & mistreated in clinical & research settings, resulting in adverse health outcomes. Autism, alone, does not create these disparities. To start closing the gaps, NIH's strategic plan for SGM health research must replace the euphemistic "ability status" with the more precise "disability status." The plan must also expand its "sexual and gender minority subpopulation" to include SGM's with IDD & SGM's of color with IDD.

Clinical SGM health research needs to reflect the known co-occurrence of gender dysphoria & autism (Van Der Miesen, 2016). In particular, large-sample quantitative research, which often impacts policy, should include autistic SGM experiences, especially of multiply-marginalized SGM autistics and those outside the binary. Our inclusion in research is of vital importance because access to gender-affirming care is under attack at the federal & state level (Trans Formation Project, 2024). To help mitigate the damage, there needs to be research about the adverse health outcomes of anti-trans policies on autistic SGMs. This includes but is not limited to the adverse health outcomes associated with barriers to accessing care, such as the predication of access to gender-affirming care on unnecessary screenings for ASD and other similarly unrelated conditions. Such screenings perpetuate the discriminatory and inaccurate myth that autistic people are "too disabled" to know ourselves.

The FY21-25 strategic plan correctly identifies the necessity of collecting research participants' SOGI data, increasing the capacity of researchers, & expanding data repositories. However, more explicit changes must be made in order to increase enrollment & retention of disabled SGMs, particularly SGMs with IDD. One major issue is that SGM health clinicians & researchers lack basic competence of autism, resulting in traumatic healthcare experiences for autistic people wherein our medical needs are ignored or dismissed. These negative experiences disincentivize autistics from seeking care, which leads to worsening health outcomes, even death (Doherty, 2021). For example, autistic children are less likely to receive preventive healthcare (Lindly, 2019). There needs to be health services research on how to best educate those who work in medicine and research about the range of autism's presentations, co-occurring conditions, & support needs across the lifespan, as well as research on how to reduce the systemic barriers SGM disabled people face. NIH's strategic plan must list disability competency as one of its operational objectives.

Much of the existing SGM health research excludes autistics, both through arbitrary exclusion from eligibility criteria & through inaccessible study design. Disability status, ASD or IDD diagnoses & racially biased metrics like IQ scores should not be grounds for exclusion. In fact, these populations are in most need of clinical SGM health research. For solutions to inaccessible study design, see our response to question #2.

For the remainder of our response to question #1, see question #3.

Actions that NIH should prioritize to advance SGM health-related research:

Research Topics:

- Impact of individuals' gender/sex & race/ethnicity on accessing an autism diagnosis & autism services & supports. While research is starting to grasp the gender disparities in accessing an autism diagnosis, there is little discussion about accessing an autism diagnosis for trans & gender-non-conforming people, & even less focus on the intersectional experiences of SGM people of color in this context. Closing equity gaps in access to diagnosis is essential because diagnosis is often a gateway to services & supports.
- Impact of racial & ethnic disparities on SGM autistic people's access to health care, including primary, speciality, & preventative.
- Improving clinical research & health care experiences for SGM disabled people who use alternative & augmented communication (AAC); research on incorporating vocabulary on AAC devices that SGM users find useful in healthcare settings.
- The impact of Long Covid on autistic SGM people: There is little research on the incidence of Long Covid among SGM autistics or how it impacts their lives.
- Strategies for improving reproductive health in SGM autistics, including research on pregnancy outcomes, menopause, HIV/AIDS, & experiences with accessing abortion and contraception.
- Strategies for expanding the number & quality of sexual & reproductive health providers available through Medicaid/Medicare Home & Community Based Services (HCBS): The Council on Quality & Leadership found in 2023 that just 10% of HCBS recipients with IDD received sexual health services. Research on how to expand comprehensive, accessible sexual health services for this population is vital.
- Autistic experiences of standard puberty, particularly how it impacts all spheres of life (internal/external body, social/family dynamics, etc.).

Methodology:

- All materials required for research participation must be in Plain Language & Easy Read (PL/ER) formats for cognitive accessibility.
- Findings must be communicated in PL/ER to be accessible; academic language is inaccessible to most of the public, especially those with disabilities that impact language processing or for whom English is not a primary language. For research findings to be translatable, they need to be communicated in accessible formats.
- Findings, particularly related to public health, must be shared via non-web-based communications to ensure people in institutions or without internet access have access.
- Data collection should be responsive to the communication needs of its participants, ranging from phone interviews to pen-&-paper responses. Researchers should exhibit basic competency in Augmented and Alternative Communication (AAC) devices to include people with a wider range of communication needs in research.
- There must be consideration for barriers to research participation, like lack of transportation access, internet connectivity issues, & language barriers for non-English speakers. Research grants should account for the funds needed to reduce these barriers.

- Autistic people should be involved as researchers & advisors in SGM research, not just limited to participant/subject status.
- Research should be informed by a participatory research advisory board to ensure that research methods are aligned with the priorities of the most impacted communities. It is not enough for participatory advisory boards to exist; researchers must also heed the recommendations.
- Provide alternative consent processes to individuals requiring proxy consent, while still presuming competence; don't assume all individuals with IDD cannot consent.

Partnerships NIH should pursue, both inside and outside of government, to advance SGM health-related research.

Continuing Question #1—

SGM health research must include research about best practices on comprehensive and accessible sex education for disabled and autistic youth. Autistic youth & those with IDD are often excluded due to discriminatory & inaccurate presumptions of incompetence. Bodily autonomy is a human right disabled people are often denied. Disabled people are often targeted for sexual assault, so sex ed for youth is important to help them know both how to recognize abuse & where to seek help.

Starting Question #3 —

NIH should prioritize collaboration with organizations that have wide & diverse networks of potential research participants by ensuring calls for engagement & feedback are well-advertised to these groups.

The Autistic Self Advocacy Network (ASAN): a policy advocacy nonprofit created by & for autistic people. We have many people who identify as SGMs on staff & have frequently engaged in advocacy for SGM autistics, including speaking out against anti-trans health care bans & creating Plain Language & Easy Read resources on gender & sexuality topics.

The Autistic Women & Nonbinary Network (AWN): a nonprofit committed to disability justice, gender & racial equity, neurodiversity & trans liberation with a focus on transformative & restorative justice in disability spaces. They provide community support & financial aid to a large network of SGM autistics.

The Autistic People of Color Fund (APOCF): exists to provide direct support, mutual aid, & reparations by & for autistic people of color. They have a unique perspective on the needs of racialized autistics & many in their network are SGMs.

The Drexel Autism Institute: founded 10 years ago as the first autism research center in the US to focus on public health research in autism. ASAN continues to collaborate with them in producing the Autism Research for Us Symposium, an annual research conference that centers autistic researchers & the research priorities of the autistic community.

The Center for American Progress Disability Justice Initiative (CAP DJI): promotes policies to ensure disabled people of color & those most marginalized by ableism & other forms of oppression can participate in the economy & democracy. They have produced & collaborated on policy research that centers disabled SGMs.

The Association of University Centers on Disability (AUCD): a network of disability research centers housed at public universities in every U.S. state. These centers research important disability issues related to public health, housing, employment, services, & more.

We encourage greater coordination between NIH and the Interagency Autism Coordinating Committee (IACC) on matters related to SGM health.

Any other relevant topics that NIH should consider when developing the next NIH-Wide strategic plan for SGM health research. *(Side note from ASAN: our response here was constrained by the extremely limited character count that was permitted for this question).*

Desilo SGM research from disability research