

## Transcription for SGM HR Listening 10-22-19

**KAREN PARKER:** Good morning and welcome, everybody. My name's Karen Parker, and I'm the director of the Sexual and Gender Minority Research Office here at NIH. I want to welcome you to NIH's first listening session that's specifically focused on SGM health research since the inception of our Office. We are recording this session. So, for those in the room, anything that you say will be recorded, and we will also be posting the recording to our website. While folks on the phone cannot actively participate today, what they can do is submit comments, so for those of you on the phone, we are certainly interested in hearing from you, and so you can submit a comment to our office and you can email it to [sgmro@nih.gov](mailto:sgmro@nih.gov). Please do so by November 1st if you have comments related to this session. So, we invited folks here today with two goals in mind. One is we want to offer you a platform to voice your comments, your concerns, your suggestions in regards to SGM-related health research and related activities that are linked to the NIH mission. And we also will be using these comments as we work to develop our next NIH SGM strategic plan, which will cover FYs 2021 through 2025. So, in the room, we have representatives from across NIH's Institutes, Centers, and Offices, and we are all ready to listen. As a reminder, please be sure that you keep your comments brief, so we're looking for about 3–5 minutes. We do have a timekeeper sitting to my right who will alert you when you have 1 minute left and when we would like you to wrap up your comments. And I would just like to reiterate that this session is not about NIH answering questions, it's not about responding to comments. It's really about listening. And so, it's about you all having an opportunity to tell us what is on your mind about SGM-related health research. So, before we begin, I would like to introduce the NIH Associate Deputy Director, Dr. Tara Schwetz, who will provide opening remarks.

**TARA SCHWETZ:** Thanks, Karen. I hope you guys can hear me. If not, I'll just speak loud, but for those on the phone, I want to make sure that I'm close to the mic. So, first and foremost, I want to thank you all for joining us here today. I'm happy to see all of you and, hopefully, even get a second or two to meet you all. But I do want to reiterate that NIH is deeply committed to and supportive of the LGBT community and their health and well-being, and I personally am committed to this work, as well. For several years behind the scenes, I've been working on this effort, and in my new role as Associate Deputy Director, I work very closely with Karen and some of her folks to ensure that the SGMRO office has the resources needed to implement its mission and strategic plan. But since the IOM report in 2011, there have been a few key policies that have been put into place to help NIH move forward with programs and activities, and I'll just very briefly talk about one or two of them. In October of 2016, the National Institute of Minority Health and Health Disparities in collaboration with AHRQ—the Agency for Healthcare Research and Quality—announced the official designation of SGM populations as health disparity populations for both NIH and AHRQ, which is a big step, a positive step that we saw in the right direction in terms of advancing research in this space. In December 2016, the 21st Century Cures Act was signed into law, and as I'm sure most of you know, it calls for NIH to encourage efforts to improve research related to SGM populations, and SGMRO has been working with all of the Institutes at NIH. Across NIH, we have 27 Institutes, Centers, and then the Office of the Director—so the OD Office—and they have been working to implement their 2015–2020 [2016–2020] sexual and gender minority strategic plan. And over the last several years, they've made really some significant strides that we're really proud of, and I will highlight a few of them. So, they have expanded their Office by hiring three new staff members, and I don't know if the folks in the SGMRO office want to just all raise their hand so that everyone knows who they are? So, there are a few folks over here, so you guys can see—and that's the table—so that way if you want to track them down after this meeting, they're the ones, along with Karen, who are doing the bulk of the work here in this space to help promote this across the OD and help supporting

the NIH ICs and their works, as well. The SGMRO is preparing to launch the FY 2020 FOA for Administrative Supplements for Research on Sexual and Gender Minority Populations, and this is going to be its fifth year, so we've doing this for quite some time. The SGMRO has successfully held several regional and scientific workshops over the last few years to enhance capacity building, and one was just held at Thomas Jefferson University a few weeks ago—October 11th. And in September 2019, NIH recognized the following investigators who have made significant contributions to sexual and gender minority health research—and I know I was at that, or at least part of, the awards ceremony, which was really fun—Katie Biello and Lindsay Talaferro...Taliaferro (I knew I was going to botch her name; I'm so sorry, Lindsay) as early-stage investigators and Karen Fredricksen Goldsen as a distinguished investigator. And then last month, the SGMRO hosted a Bisexual Health Workshop. So, that's just a little bit of a taste of some of the activities that we've been conducting across NIH, and today we've invited you here because we actually really want to hear from you. So just to reiterate what Karen said, this is not an opportunity for us to tell you all about the things that we're doing in this space, but we want to hear from you guys. And so, I am joined here by some other leaders across NIH, which I'll go through. I don't know if Robin is going to join us later, but Robin Kawazoe, who's the Deputy Director of an Office that we lovingly call DPCPSI [laughs]; it's probably the best acronym, maybe, we have at NIH. It's the Division of Program Coordination, Planning, and Strategic Initiatives. Then, I'll just sort of go down the line. The Chief of Staff at the National Institute of Minority Health and Health Disparities, Dr. Courtney Aklin, is here as well, and the Senior Advisor to the Chief Officer for Scientific Workforce Diversity, Dr. Charlene Le Fauve, is here to my right. I will say I will stay, probably, for the next 15–20 minutes, but unfortunately, I had a prior commitment so I'm going to have to leave, but my special assistant, Dr. Courtney Coombes, is over there, and she's going to be here for the whole session. And I'll get a download from her on some of the feedback that you guys discussed today. So, I look forward to hearing at least part of the discussion and continuing to support NIH sexual and gender minority research efforts. So, I'll turn it back over to Karen.

**KAREN PARKER:** Great. Thanks, Tara. And I think Tara's remarks really outline sort of the support that we've been getting from the NIH leadership from the very beginning, so thank you to folks in the NIH leadership. So now, we're just going to get started with comments, and so I thought that we would start with Sandy. Again, you have about 3–5 minutes, and as we go around the table, you can just take your turn, introduce yourselves, and please be sure that you're using the microphone for those who are listening. Thank you so much. Go ahead, Sandy.

**SANDY JAMES:** Hello. Well, thank you for inviting me here today. My name is Dr. Sandy James. I am currently the chair of the board of directors of Whitman-Walker Health, a community health center based in Washington, DC. In my day job, I'm also a staff attorney at FreeState Justice, where we serve LGBTQ people throughout the state of Maryland, and so I can bring both of those to bear on my comments today. Most of you know Whitman-Walker as a health center that serves and has cultural competency and expertise in LGBTQ health care and HIV care, but Whitman-Walker also conducts robust research. Part of that is done to fill the gaps in the disparity we have in research for the populations that we primarily are serving; at this time, we do need more information on health disparities, in particular, and it's something that certainly the NIH could weigh in on with their expertise. I'd certainly like to highlight that we are increasingly serving the transgender people, and there is a dearth of information about transgender people. I should also say that I formerly worked with the National Center for Transgender Equality and ran a large research project there—the U.S. Transgender Survey, another gap-filling measure, I would say, in terms of collecting research about the health disparities of certain populations. So, in order to be able to conduct our work at Whitman-Walker Health and to be able to really have the correct interventions, we should say some positive

interventions, for our populations, which are often lower income who are dispersed throughout the District of Columbia and Maryland and Virginia and from other neighboring states. It is really important for us to have information about disparities that are specific to our population, and we are asking here, since we have been invited, to have NIH contribute to that. There has been a lack in the past of research that is focused on the issues, the unique issues that LGBTQ populations face, and with this new Office here—well, not quite new at this point—there's a phenomenal opportunity to be able to fill some of the gaps that we have been facing, in terms of the data that will allow us to make the proper interventions—whether that be on not only HIV prevention, but eradication—sometime in the near future, hopefully, but also to be able to provide the best level of care we can to our transgender patients. We also have a legal services department, and that's important because, as we all know, that health care is not just about what happens in the human body; it's about all of our...it's about environment. It's about all of the social determinants of health we all talk about, but it is incredibly important for us to have specific data that teaches us and tells us about the unique health outcomes that LGBTQ people—and, in particular, transgender people—are facing so that we can make the correct interventions and make the shifts in the ways in which we deliver care. So, I'm just asking that NIH does all they can to help us to fill some of those gaps to identify those health disparities. Thank you.

**JULIANNA GONEN:** Is this working? Alright. Good morning. My name is Julie Gonen. I'm the policy director at the National Center for Lesbian Rights. We are based in San Francisco. We were formed in the late '70s, and we are a legal organization, primarily. We have a small policy team here in DC; I'm half of it. Even though our name is National Center for Lesbian Rights, we represent the interest of the entire community, the entire LGBTQ population. In the late 1970s, we were focusing on issues that were particularly impacting lesbians, particularly coming out of marriage and losing custody of their children because being lesbian was considered...made someone, per se, unfit to be a parent. But now we represent the full spectrum of our community, particularly those who are most marginalized, and I do appreciate the invitation to be here and talk to you today. I was looking back at the comments that we submitted when you were getting ready to implement your last strategic plan, and our comments fell into really two buckets, and I think they're still pretty relevant today; and then I'll go ahead and add a third. One area that we focus a lot on is conversion therapy and related issues of family rejection or, the flip side, family acceptance. We've had in place for a number of years now a campaign called Born Perfect, which is...the goal was to eradicate conversion therapy, I think, by this year or next, so we're not quite there yet, but we've had a lot of progress working with a lot of partners, including some in this room. I think that there's always a need for more information on how harmful conversion therapy is, even though all major medical associations agree now that it's not only not effective but extremely harmful, particularly to young people, but also to adults. More information on how harmful it is can only be helpful. And I do tend to see these issues, of course, through a policy lens as we're trying to get more bans on this practice enacted. We are encountering pushback, including even litigation over some of these bans, so the more we can document the harms, I think, the better it is to be able to show that this is just something that should never happen to young people. Relatedly, additional research on, again, the harms of family rejection and the benefits of family acceptance I think would be incredibly useful, particularly evidence about interventions that help families with family acceptance, because what we know is that, although it seems very cruel to subject someone to conversion therapy, a lot of times parents actually think they're doing the right thing for their child, and the more we can help parents understand that they're not and how they can come to actually accept their children as they are—hence, the name of our campaign, Born Perfect—I think that would be particularly helpful. And we're actually seeing recently an uptick in custody disputes around...involving transgender youth. And so, it'll be helpful also for courts to help evaluate...to show that the affirming parent is actually

acting in the best interest of the child. So, that would be sort of one bucket: the conversion therapy and family acceptance. The other bucket that we had in our last letter was sort of broad. It was research on the transgender community, because there has been such a dearth of that, and NIH, of course, has been involved in this groundbreaking 5-year study on the effects of certain kinds of hormone therapy on transgender youth. And my understanding is that there's an interest in continuing that study for another 5 years so that we can get even more longitudinal data, and we think that would be tremendously helpful. It sort of even circles back to the first bucket, because, again, if affirming parents are providing care that is the standard of care to their kids, it's helpful to have data to show that they are, in fact, doing the right thing for their children. I think the third bucket I would add is—and this is kind of broad—the health effects of discrimination on the LGBTQ community. We saw some gains in the last administration in trying to advance nondiscrimination protections. Those are, I'll just say, a little bit at risk right now, and we have good data from, for example, the National Transgender Survey. The Center for American Progress has done good research. Lambda Legal has a study, but it's a little bit old now, and I think having data from NIH to document how harmful discrimination is would be tremendously helpful to supplement the work that's being done by some of our colleagues. We know anecdotally and through some of these studies that sometimes LGBTQ people just stay away from the health care system entirely because they're afraid of what they're going to experience when they get there, either being misgendered or abused or turned away at the door. And we have anecdotal examples of those things happening, but it would be helpful to have solid research to show that if you...we're not just talking about people's feelings getting hurt. Like, if people don't seek care or if they're mistreated in the health care system, it has devastating health impacts. Another program that we have is one called Rural Pride, where we go into rural communities to talk with people in our community who are living in rural spaces. The issue with health care access comes up over and over again, and we hear heartbreaking stories of people saying, "Yeah, we tried to go to the doctor, and we were told 'we don't serve people like you; we don't treat people like you.'" And we know that that's devastating just because of the dignitary harm, but we also need to know more about the health care effects of that kind of treatment. So again, thank you for being here, and I'm going to stop right when the sign comes up. [laughter] Thank you.

**TARI HANNEMAN:** Good morning. My name is Tari Hanneman. I'm the director of the Health and Aging Program at the Human Rights Campaign Foundation. I use she/her pronouns. Thank you for hosting this, and thank you for inviting the Human Rights Campaign, which is the nation's largest LGBTQ civil rights organization. We have over 3 million members and supporters, so I'm happy to speak briefly on behalf of them today, but we have so many tremendous advocates and providers in this room who I think are going to add a lot more to this conversation. I really...my husband said there's been some progress since the IOM report, but we're also still talking about a lot of the same things—we need more money, we need more research. We know that there are significant health and well-being disparities that LGBTQ people face across their lifespan from coming out: victimization; family rejection; depression; suicide; unemployment; unstable housing; HIV risk, etc.; a huge epidemic of violence among transgender women; and overall reduced access to culturally competent care. So, what we would...in addition to having studies that are SGM-focused, we'd really love to see more inclusion of SOGI data collection across all research to better understand how our experiences are similar and different from others, and we want to be able to identify the factors that lead to healthier outcomes, resilience, so that...we don't know enough about the solutions to these ongoing disparities, so that kind of research would be very helpful. So, we encourage you to continue your efforts to support researchers to incorporate SOGI data collection and SGM-relevant questions into their existing planned research activities across all areas of health. We'd also like to commend this office for their recent workshop on bisexual health. The bisexual

population is the single largest group within the LGBT community, and yet there is not enough research being done. Similarly, there's not enough research being done on our transgender community. I think these two communities are often invisible. I went to...I work with hospitals and health care providers, and I was in Jackson, Mississippi talking to some leaders of hospitals, and I had an executive from the Delta area tell me that, well, they have some of those "Ls" and "Gs" but none of those "Bs" and "Ts." So, I think they're ignored in health care settings and in research all too often. So, we'd love to see more research on these populations, as well as the aging LGBT population, which I'm sure my neighbor next door will speak more about in a second. And then on the other end of the age spectrum, we really encourage you to continue to fund important studies on the impact of early medical treatment for transgender youth and to reject the politically based anti-science attacks on this type of research.

**PORSHA HALL:** Good morning. Thank you for inviting SAGE to this conversation and for having this gathering. My name is Porsha Hall, and I am the director of quality and innovation at SAGE. We were founded in 1978 in New York City, and we're the nation's oldest and largest organization dedicated to serving and advocating for LGBT older adults. In order to ensure the quality of life needs of LGBT older adults are adequately met, more research studies evaluating their diverse needs should be funded, and sexual orientation and gender identity information should be collected from all research studies exploring the health needs of older adults, in general. LGBT older adults comprise 2.5 and...between 2.5 and 4 million of the United States population, and this estimate is predicted to double by 2030, so there's a lot of LGBT older adults. A lifetime of experiencing discrimination, stigma, and isolation have negatively impacted the health and well-being of LGBT older adults, and LGBT older adults are more likely to acquire disabling chronic conditions, such as heart disease, diabetes, gynecological cancers, HIV/AIDS, and depression, than their heterosexual peers. Yet, one of the greatest challenges to addressing the needs of LGBT older adults continues to be the lack of valid data, especially among the group's more marginalized members: older adults of color and those who identify as transgender and bisexual. Thus, SAGE advocates that the NIH fund more research projects which center the diverse circumstances of LGBT older adults and specifically assess health disparities among older adults of color and individuals who identify as transgender and bisexual. Further, we advocate that the collection of sexual orientation and gender identity information be a requirement in all research projects being supported by NIH in order to further identify LGBT health disparities. Thank you.

**SAM BRINTON:** Good morning, everyone. My name is Sam Brinton. I use they and them as my pronouns, and I serve as the head of Advocacy and Government Affairs for the Trevor Project. The Trevor Project, as many of you know, is the world's largest organization providing crisis intervention and suicide prevention services to LGBTQ youth every single day. We are currently serving more youth than we have ever served before, with more than 10,000 youth contacting us every single month and that number growing by a significant percentage every single year. At the same time, we recognize that we are not serving all of the LGBTQ youth who are in crisis, as we estimate...thanks to some federal surveys, we estimate that there are over 1.5 million LGBTQ youth seriously attempting or considering suicide every single year. So we have much work left to be done, and that's where you come in. So, just like my partner from NCLR, I'm going to have to duplicate in this work. Our first request is a funded study on the harms of conversion therapy. I myself am a survivor of conversion therapy, and with our partners at NCLR, we lead some of the world's largest organizations working to end conversion therapy, with 13 laws being passed in the last 30 months—a.k.a., a bill every other month. That is only because we can prove the harm. At the Trevor Project, we hear from survivors of conversion therapy every single day, whether they are in conversion therapy, about to be put into conversion therapy, or just got out of conversion therapy. Our surveys that we did of

34,000 youth found that two out of three LGBTQ youth said someone was trying to change their sexual orientation, and that transgender youth who have received conversion therapy--or 60 percent of transgender youth who had received conversion therapy will attempt suicide this year alone. We are in a crisis, and we need research on the health disparities and harms of conversion therapy. Following off of that work, I also did want to also duplicate what my partners from HRC also said, which is we need more data in more surveys. So, the Trevor Project is working both with the CDC and others to make sure that sexual orientation and gender identity for youth who use a variety of different terms for their sexual orientation and gender identity are actually captured. In our recent survey, more than 100 different terms were used by the youth to self-identify. We recognize that this will not be something that the NIH necessarily does, is to try to capture 100 different terms, but maybe we could expand it beyond LGB and T. This is our work to make sure that every youth is seen and heard as they are. I wanted to also move us...and I'll be moving quickly, so that we can get through all of this. I wanted to move us also into the connections between policies and positive outcomes. We currently operate the world's largest database of suicide prevention policies in schools, and we have found that as schools have more inclusive LGBTQ suicide prevention policies, health disparities have been able to be dropped. Well, yes, the disparities have been dropped—a.k.a., it gets better—and we want to make sure that these types of disparities and the policies that remove them are actually captured in NIH data. Last but not least, I do want to make sure that we include sexual and gender minorities in what would be considered fatality data, mortality data. We are really at a loss. It is commonly referred to the 20—22, now—random...22 transgender women of color who have died this year, but we very clearly recognize that is not the entire number, because we are not capturing this information. An NIH study capturing SOGI mortality data and how those medical examiners and death investigators could be better trained to make sure that LGBTQ youth are actually being captured in these statistics would be revolutionary. So, these are the things that I ask: a study on conversion therapy, a recognition of our multiple identities, the definition of how our disparities are making sure...are being removed by good policies, and actually capturing our information at the time of death. These are the things I request of you, and I appreciate your time.

**KAREN PARKER:** May I just say one thing? If you're on the phone, can you please make sure your phone is muted, because there is some interference that's happening for other folks on the audio line. So, thank you.

**KHADIJA KHAN:** Good morning, everyone. My name is Khadija Khan, and I'm here with Advocates for Youth. I'd like to say thank you to Sam and my previous panelists for sharing important information. It's really special that we're all here in the room today. Advocates for Youth is a DC-based youth-serving and youth-centered organization that works to support the sexual health and reproductive rights of young people. We work mostly domestically, but internationally as well, and we started back in 1980 doing a lot of the groundbreaking work on developing sex ed curriculums called the "3Rs." Over the past couple of decades, we've transformed to become a more intersectional organization, and now we work specifically with youth groups such as Young Women of Color [Leadership] Council, the first-ever council for youth living with HIV; a council for folks on Know Your IX, or Title IX; and I run a program for queer Muslim youth. And so, I'm here to advocate today for research not only on LGBTQ youth, in general, but specifically for LGBTQ Muslim youth. So, the program of Advocates for Youth that I run is called the Muslim Youth Leadership Council, and it is a group of 20 young queer Muslims from all across the United States, and we're entering our third year of the program. This has been a big feat to even be able to create a youth group like this. It's taken decades and decades of activism by Muslim elders in order to get us to a place where this is able to exist, so we recognize that. The Muslim Youth Leadership Council works on four different bucket areas.

The first is countering Islamophobia, specifically gendered Islamophobia, and how often queer people sit at the intersections of Islamophobia and gender inequality. Second is sexual health and reproductive rights for Muslim American communities. Often...well, what I'll go into next—and there's not enough research about this—but we know through our lived experiences that young people and Muslims, in general, are not getting culturally competent and responsive sex ed and maybe aren't even getting access to sex ed, in general. And then the third bucket area is LGBTQ rights and building a community of young queer Muslims. The fourth is countering racism and anti-blackness within the Muslim community. So, the American Muslim community makes up about 1–2 percent of the American population, and it's rapidly growing, and within that, about 30 percent of American Muslims identify as African American, and those populations are often even more underrepresented in our work, so that is something that we are working to bring visibility towards. And so like I said, we understand that there are issues and there are specific needs that young queer Muslims face, but we have similarly very stark gaps of research to be able to justify it. And we understand it as our lived reality, but there is absolutely no data and no research out there specifically about LGBTQ Muslim youth. We undertook a research project last summer to try and bridge some of these gaps. Actually, we just mostly did, like, a desk review to see what was out there, and what we saw is that there is research for women who are Muslim who are in need of access to sexual and reproductive health care, and then there's absolutely nothing on Muslim youth; and we were trying to bridge the intersections between LGBTQ youth data and Muslim data, and it just absolutely didn't work. So, like I said, I'm here today to advocate for some of the foundational research and data that we need on queer and trans Muslim American youth, and we know that there are...not only is it general American Islamophobia and the cultural barriers that are brought into our community, in general, in living in a post-9/11 world and service providers not always being culturally competent or having the necessary tools to reach the populations that they need to, but that having both the LGBTQ Muslim youth issues...or LGBTQ youth issues compounded with the issues that come from facing discrimination in America today compound to lead to health disparities. And so, we're looking for data, not only on the personal effects of being a LGBT Muslim youth—whether that's family acceptance or so on—but also the structural and cultural issues that face this community, as well, and the intersections of the current political environment. Ultimately, I would just like to conclude by saying that we are rapidly a more visible population and that this work is growing not only in the U.S., but internationally, as well, and if we were able to have some foundational data that would be able to, like my partners have said, justify and make cases for how this work needs to be funded and continued for future groups of queer Muslim youths. So, thank you so much, and I look forward to being in contact with you all.

**SEAN CAHILL:** Hi. I'm Sean Cahill. I'm director of health policy research at the Fenway Institute, and we thank you for this opportunity. I'm going to make recommendations in a number of topical areas. First, the impact of policies and services on LGBT health. Policies and services vary significantly across municipalities and states. More and more health organizations have adopted sexual orientation and gender identity nondiscrimination policies, or SOGI nondiscrimination, while some states and the federal government have adopted religious refusal policies that could increase anti-LGBT discrimination in health care and restrict access to care. Many states and cities have adopted targeted services for LGBT elders, LGBT youth, and other populations, as have federal agencies like the VA. Research on the impact of pro- and anti-LGBT policies that have targeted services on health and well-being is needed; that way we could know what policies and targeted services correlate with greater resiliency, health, and well-being. A second area is LGBT older adults. We need research to evaluate the effectiveness of group-level and community-level interventions to promote community and reduce social isolation. These include congregate meal programs, LGBT elder bereavement groups, LGBT-friendly congregate housing, and other interventions. We also need research to study the

experiences of LGBT elders and older adults living with HIV in senior service settings, where age peers are more likely than other age cohorts to hold homophobic views and to be misinformed about how HIV is transmitted. This research could inform interventions, changes to services, and best practices to ensure access to elder services. Research on transgender elders is especially needed. Trans elders can experience family rejection from children and often experience rejection from the LGBT community members. They often experience culturally incompetent care from elder service and health care providers. The next topic is lesbian and bisexual women's health. There's a dearth of research on health issues affecting cisgender, lesbian, and bisexual women. We need more disparities research and intervention research in chronic disease, including cardiovascular health; stroke; functional impairments; body mass index; asthma; cancer, including colorectal and lung cancer; and behavioral health. Some of these disparities, particularly cancer and cardiovascular disease, are especially pronounced among black and Latina women, and it's also important to understand the impact of discrimination on health and how that discrimination manifests. So, for example, we recently...I'm on the statewide LGBT Aging Commission in Massachusetts. We recently did a listening session in the Berkshires, the western part of the state, and learned that older lesbian and bisexual women are sometimes misgendered as a form of harassment—repeatedly misgendered. The next topic is prisoners and youth in the juvenile justice systems. We know that LGBT people experience much higher rates of sexual victimization in both adult and juvenile systems. The Prison Rape Elimination Act is being implemented to reduce this disparity—and then prison rape in general—yet former prisoners say that PREA is being misused to single out and hyper-police LGBT people's behavior, often resulting in their being sent to solitary confinement for no legitimate reason: for example, because a prisoner's leg brushes up against another prisoner's leg or because a prisoner is seen talking closely to another prisoner. So, collecting SOGI data, which is happening in corrections and juvenile systems, but we'd like to see that expanded and more research on the experiences of LGBT people in corrections in juvenile systems. LGBT youth—research is really needed on how best to promote parent-child conversations about sexual health and healthy dating, about HIV/STI pregnancy prevention, and about SGM identity and issues. Many SGM youth do not know that lubricant can improve the function of condoms. They're also worried that if they possess condoms, that they will be found out by siblings and/or parents and get in trouble, so it's really important to develop prevention interventions that involve both youth and parents that address these concerns. I'd also just flag issues of self-esteem, body image, and disordered eating. And also it's important to figure out how to develop sexual health education and figure out ways to promote that in rural and socially conservative districts. We encourage NIH to support a research network of community health centers and research hospitals to track an ongoing clinical cohort of LGBT patients. We also want to see more research on people with disabilities in our community. The Sexual and Gender Minority Research Office should encourage the Administration for Community Living to add SOGI questions to the Centers for Independent Living Annual Program Performance Report, as was planned in 2017 and then that was pulled off. And the last thing is vaping and e-cigarettes. We know that LGBT people, in Massachusetts at least, are three times as likely to vape. This has emerged as a dangerous behavior, and so we need more research to develop prevention and cessation efforts in that area. Thank you.

**MADDIE DEUTSCH:** Hi. Thank you. My name is Maddie Deutsch. I am the medical director for transgender care at UC San Francisco, and I'm an associate professor in family and community medicine, and I'm also the president-elect for the U.S. Professional Association for Transgender Health. I'm really glad to have been invited to come to this meeting, and I'm so inspired by everyone that I've seen. I think the first thing that I want to say right off the bat is a strong echoing of other comments about the need for support for longitudinal youth outcome studies, and UCSF is a site—our Child and Adolescent Gender Center is one of the enrollment sites for

the study that has been mentioned. In addition to some non-evidence-based kind of media coverage of some people who are in opposition to that research, I know that the investigator team and others involved in the study are being personally targeted to the extent that the PI of the study has changed her cell phone number and no longer posts her location updates on social media. So, I think it's important that we keep that in mind, that investigators are being targeted in some cases for doing this important work. I want to also echo the importance that several people have mentioned about the need to collect SOGI data universally. My particular interest in SOGI data and the research that I look at is the implementation science side. I think it's very important that we talk about including SOGI collection at every level. We also have to think about, how do we do that? One of the initiatives that I'm part of at UCSF is a health equity data workgroup, and we're looking at back-end data governance: developing data governance standards on the backend for data held in large databases, in our case clinical databases within the electronic health system. How are those data collected? Are they reliable? Are we asking questions in ways that make sense to people? We're in the midst of a study where we're using qualitative data to translate SOGI questionnaires into Spanish and are about to administer that to a number of patients in a clinic setting to get more understanding of how or what is the best way to ask these questions, and how do we get the most reliable data, and how do we ask them in ways that all people—not just sexual and gender minorities—are likely to answer the questions, and that the data that we have will be accurate. We also need to develop data governance standards to guide investigators who may not be 100 percent clear on what SOGI data is or how to categorize sexual/gender/minority populations so that people have clear understandings of how the data is organized and layered and how we can collect it. Another limitation that I think exists in this field is a lack of infrastructure. Often in your NIH proposal, you have to talk about preliminary...I mean, facilities and resources. And often that includes talking about prior studies in the field, and often investigators will leverage staff across multiple studies, and there's kind of a deep bench of experienced investigators and staff. But in the sexual and gender minority research field we have a limited pipeline of training for people to get into this field and for investigators, and we also have...because there's so much limited funding, often an institution doesn't really have any other things going on in this field, and so your preliminary studies and institutional experience sections are thin, and that can create a Catch-22 for investigators when applying. The same thing can happen with preliminary studies. If you have an institution that has not systematically collected SOGI data, or if there is just a general lack of data in the field—which, even though there's a growing body, there's still a significant lack of quality data—it can make the preliminary studies and preliminary data section of your proposal difficult. Again, a Catch-22 that can result in fewer funded studies and then a feed-forward problem. The need for longitudinal health outcomes, as has been mentioned, is essential, and it is absolutely essential, as well, to incorporate intersectionality at all levels of research along lines including race, ethnicity, language, immigration status, and disability status. Thank you again for this opportunity, and I'm honored to be here with you all.

**MARISSA MILLER:** Thank you so much for the invitation. Today, I sit and I represent the Southern AIDS Coalition. We are a movement; it's a really diverse community working across the political, religious, and geographic lines to end the HIV epidemic in the South. We are young and old. We are mothers and doctors and writers and CEOs. We are bus drivers and activists and sex workers and small-business owners. We are many things at once, and together we are the Southern AIDS Coalition. We are also a bridge...connection to each other's information, resources, and support needed to prevent new transmissions and build a better South for people living with HIV. "Be you, be bold, be brave" is the Southern AIDS Coalition, and I certainly appreciate the opportunity to be at the table. My passage to the table wasn't as easy as other individuals' passage to the table. I had to call a few times to request that somebody of the trans experience, somebody that is black and that is dying—not dying, being killed—be

invited to the table. I serve multiple hats for the Southern AIDS Coalition. Most of my work recently started when I was the lead organizer for the National Trans Visibility March, and our work was very intentional about what we were doing in the South, and I think the biggest thing that I would ask NIH is to help us figure out why our lives as black trans women are so indispensable, for NIH to help us to research, to not figure out how just to end the epidemic and how to put prevention measures in place, but how to add safety plans to our lives. Many of the trans community will remain in marginalized situations. Many of the black trans population will never have opportunities to be at these particular tables, but how do we save those lives? I ask NIH to look at the leadership training paradigm. Does it empower and add validity and equity and equality to black trans women's lives? Does it add value to have us at the table? Too often our voices are silenced in rooms that we sit in—not in rooms that we haven't been invited to, rooms that we sit in—our voices are silenced. I ask NIH to help develop a strategy. We know in the federal plan to end the HIV epidemic that the word "transgender" was not mentioned many times because of this particular administration. We entered into a relationship with the federal government with trust to take care of us while ending the epidemic. We ask NIH to figure out a way for us to be intentionally involved at the table. Too often we're brought to the tables as tokens and pawns to be pushed across a board of bureaucracy and hypocrisy, and we ask to be viewed as people today. And so, the work that we're doing in the Southern AIDS Coalition is certainly looking at what the workforce development plan looks like as it is related to ending the epidemic. How? Equity. Equity means money. Equity means opportunity. Equity doesn't mean that everybody gets some. Equity means that the person who needs it the most gets it the most, and I challenge NIH and my colleagues at the table to stop silencing the voices of trans people. How do we elevate the voices of the trans people? So, I ask for us to look at what the leadership paradigm looks like. I ask us to look at what human resources and diversity looks like in our workplaces. I ask us to look at how can we get through gatekeepers without academia, but we have subject matter expertise, and you call us when you need us, but how can that carry into saving our lives? Sam brought up a point about that. It wasn't the total number, but there have been 21 black trans women killed. I don't want to say trans women of color, because we take the focus off what is happening: Black trans women are being targeted across the country. And how can we as entities that talk about saving lives, that talk about prevention measures, that talk about research, and that talk about studies come into our work day in and day out, and black trans women's lives are disposable? I ask NIH to do research to determine and challenge why the lifespan of trans women is so low. Why is it 30–35? What can we do to change the lifespan? And those are some of the things that we've come to the table. We come to the table humbly, though. I talked to several of my sisters before I came. We come humbly, but we come determined to want answers and not just to be on the agenda as we have been for decades. Do you know we've been on the docket for decades? People asking us questions and seeking information, and information is given, and there are no changes. And so, I challenge NIH to make a difference, not just in the lives of others, but intentionally make a difference in the lives of black trans women whose lives are so disposable. And that's what I have to say.

**ARLENE BARATZ:** Thank you for this opportunity. Arlene Baratz. I'm representing the androgen insensitivity–differences of sex development AIS-DSD Support Group, which is the largest international group of intersex people, and Inter/Act Advocates for Intersex Youth. In addition to being an author of 20 publications on differences of sex development, I'm a practicing breast imaging radiologist, a mother of two adult intersex women, and advisor to affected families and adults for almost 20 years. Most treatment paradigms assume that diverse sex traits, especially genital variation, are inherently harmful to psychosocial and psychosexual health. Despite lack of convincing evidence, irreversible surgery during infancy is routinely recommended to prevent presumed negative outcomes, such as stigma. Although it has long been recognized that stigma and minority stress in SGM exist at multiple levels, their health

consequences have not been studied in variations of sex development. For example, whether children who do not have surgery to normalize intersex genitalia experience stigma or stress has been minimally investigated. Similarly, the claim that normalizing treatment will reduce stressor stigma has not been validated relative to no such intervention. For those of us in the community, this is extremely concerning, as adolescents and adults continue to experience stressful and even traumatic consequences of irreversible surgical and hormonal interventions, including medical stigma, psychosocial distress, urinary dysfunction, loss of sexual sensation, and incorrect gender assignment. Research focusing on the experiences of stigma and minority stress among intersex children, youth, adults, and families is essential to understanding effects not just of current medical treatment but of affirming practices. Affirming care for intersex modeled on affirming care for transgender people seeks to depathologize and destigmatize both sex and gender diversity using psychosocial support and interventions to promote thriving. In a 2016 study of affirming practice, Olson's group found no higher rates of mental health symptoms in trans children who were socially affirmed than in cisgender peers. Evaluation of affirming care in children with diverse sex traits could be modeled on this work. As in study of others in SGM, the way research is done is crucial. Community-based participatory research—CBPR—on intersex DSD is needed to determine patient-centered outcome measures. The most current research focuses on outcomes valued by clinicians, such as cosmetic results of surgery and short-term effects on parental distress. Furthermore, because these conditions exist at the intersection of SGM and rare conditions, recommendations for mixed-methods research from the International Rare Diseases Research Consortium should be implemented. They state that with use of initial narrative analysis to identify PCOM, subsequent mixed qualitative and quantitative research makes efficient use of data from small samples. In this way, Schweizer's group showed that across multiple diagnoses, 27 percent of adults with DSD have nonbinary gender identities. Similarly, in female-assigned children with 46,XX CAH, 13 percent did not identify as female and were from Pasterski's group. Use of scales that are not validated for intersex is a complicating issue. We are currently collaborating on intramural research with Veronica Gomez-Lobo, director of pediatric and adolescent gynecology, to develop a scale for sexual outcomes in androgen insensitivity syndrome. In other SGM populations studies, such as TransPop, using large probability samples have yielded tremendous insights into health. Given the diversity of conditions and identities, capturing data on intersex people remains a challenge. Community members are partnering an ongoing research with Jason Flatt of UCSF on development and validation of questions encouraging self-identification, with the goal of facilitating relevant data collection on people with intersex conditions. In summary, we hope that NIH can encourage meaningful research using methodologies informed by intersex people's lived experiences. Thank you again for this opportunity.

**NHAN TRUONG:** Good morning. My name is Nhan Truong, and I am a senior research associate at GLSEN, which is a national education nonprofit organization that aims to provide supportive and inclusive school environments for all students in K–12 despite their sexual orientation, gender identity, or gender expression. I wanted to talk about the school experiences of LGBTQ students, particularly in middle and high school, and provide recommendations for research specifically around LGBTQ-related supports and resources. We know that schools nationwide are a hostile environment for many LGBTQ students, the majority of whom experience high rates of anti-LGBTQ victimization, as well as anti-LGBTQ discriminatory school policies and practices. We know that these experiences of victimization and discrimination are related to lower mental health. In our 2017 National School Climate Survey, we found that experiencing high rates...experiencing anti-LGBTQ discrimination in school and anti-LGBTQ victimization has been related to lowered self-esteem and higher depression, but we also know that there are LGBTQ supports and resources in schools. Unfortunately, many LGBTQ students—secondary school students—do not have access to these resources. We know that

these...so, we have focused on four supports and resources in our research. Comprehensive anti-bullying and harassment policies and supportive and inclusive transgender and gender nonconforming policies, that's one; and the second is GSAs—or gender and sexuality alliances—and other similar clubs; a third is supportive school personnel such as school staff and educators and administration; and the fourth is having LGBTQ-inclusive curriculum—so, a curriculum that teaches positive representations of LGBTQ people, history, and events. So, the three buckets around these four resources that I would like NIH to be able to...for us to do research on...one is to look more in-depth into understanding the benefits of these four supports and resources. For instance, with GSAs, we know that they benefit LGBTQ students when there's access to GSAs at their school. We see less of a benefit—or, actually, very little benefit—in terms of participation. So, it would be good to understand more in-depth about, how do GSAs benefit LGBTQ students, as well as allies? The second bucket is around...and I know that some of the folks here have talked about the importance of looking at or examining longitudinal studies. So, how does...for instance, with GSAs, how do we sustain GSAs? What makes an effective GSA? And the third bucket of research around these resources is around the intersection...setting up an intersection of race, sexual orientation, gender identity, immigrant status, and disability. What are the different experiences that these students have in terms of access to these resources, as well as participation? Thank you.

**LAURA DURSO:** Hi everyone. My name is Laura Durso. I'm the vice president of the LGBTQ Research and Communications Project at the Center for American Progress. I use "she" and "her" pronouns. CAP is a multi-issue think tank back in DC, and it is really an honor to be here with you today. I want to first thank you for the work that you're already doing on behalf of SGM populations. The mere existence of the Office—the designation of LGBT people as a health disparities population—was a really incredible step forward in meeting the promise and the charge of the IOM report and to deepen our understanding of LGBTQ folks, so I'm honored to be here. I have the pleasure, I guess, of being last, so I can associate myself...I would like to associate myself with the comments made by all of my really incredible friends and colleagues across this table, and I hope to maybe reinforce and add a couple of things to close us out this morning. I first wanted to ask you to continue and really to grow the investments in the research process. That certainly is about some of the basic science and measurement and methodological research that is being done to help us even just identify LGBTQ people and keep up with, as Sam said, the many ways in which we identify ourselves. But that's also, I think, things like increasing the proportion of the mechanisms that are going to training and technical assistance, that are going to early-career investigators. I think if we're looking to really innovate in this space, I know that your portfolio reviews suggest that, really, the awards are going to well-established investigators, and I think a real concerted effort to increase the number of folks who are being given the opportunities to add significantly and then innovate would be really, really incredibly helpful. I'd like to see a greater diversity of disease states and health conditions being researched. Certainly, HIV and AIDS is an incredibly important marker of our community's health. It looks like the portfolio is going in the right direction: FY 2017—around 67 percent of the funds were going to HIV and AIDS. That's down from, I think, around 75 percent the year before. So, things—as Sean mentioned—like chronic conditions like cardiovascular disease and diabetes, these are important elements of the story that we still need a lot more data about. That said, we'd want to put in a plug for research that looks at resilience and coping, not only risk and disease, and this would include things like looking at and challenging our assumptions about what LGBTQ people are supposed to look like, what our health is supposed to look like, and really thinking deeply about the ways in which research is conducted to try and challenge those assumptions. So, for example, this is many years ago, but a funding opportunity went around to do behavioral weight loss intervention with lesbian, bi, and queer women, and the funding opportunity was really just sort of take cookie-cutter existing

behavioral weight loss treatments, apply them to a population, and see what happens. And it really, in my view, ignored some of the research evidence that we do have that, for example, different beauty standards and ways of thinking about body image within lesbian and queer women spaces might actually be beneficial to heterosexual women, to cisgender women, and we could look at those as interventions to help everyone, not just sort of apply old ideas to new populations. I'd love to see additional research on social determinants of health, in particular the structural stigmas that many of my colleagues here mentioned—and not only stigma as related to someone's sexual orientation, gender identity, or expression, but to things like structural racism and white supremacy—and thinking about how all of those add to our experiences and determine our health and wellness. We'd love to see more work connecting health to things like economic security or housing stability and see a holistic picture of our populations and how multiple things impact our health. Intervention research across the board, I think, is crucial. Providers need to know what works, and they're going to move ahead. It's a risk, actually, that that they do not move ahead at all and that they perceive a lack of tools and simply do not move ahead in working with our populations or, even worse, that they would do something that's unhelpful—if not outright harmful—so I think intervention research across the board. And if I can end with two thoughts about what the Office itself might do, not just NIH—not that you don't have enough work to do, Karen—but all of us are calling for more research. We also recognize that plenty of research exists and folks have a harder time connecting with it. So, are there ways in which the Sexual and Gender Minority Research Office can help us as advocates, in particular, know what's out there and be able to use it? The progress of science can be very slow, and the process of doing policy work can be very slow, until it is not, and I think advocates could really use pathways into knowing the great work that's already in existence at a range of institutions across the country for us to use. And finally, we think about, particularly with the *All of Us* Research Program being here, can this Office be a part of developing safeguards for the ethical use of data about LGBTQ people? Our population headlines talk about things like the “gay gene,” and what are the risks to those kinds of narratives and what are the ways in which we need to overcome skepticism and distrust of the medical establishments among LGBTQ populations, particularly among communities of color? I think this Office could be a way to help us combat the misuse of science to harm LGBTQ populations. So, thank you for the opportunity to speak with you today.

**KAREN PARKER:** Wow. Thank you very much. My hand is cramping from all the writing. So, this was really it. We just wanted to hear from you all, and I think I speak for all of my colleagues across the Agency when I say thank you for taking the time to be here. Thank you for sharing your thoughts. I assume that folks in this room and folks on the phone know that we're always interested in hearing from people. I take the job as a public servant very seriously, and so we're here to serve the public. And so, please reach out if other things come to mind that you'd like us to know about. As has been mentioned, we are going through a strategic planning process right now for NIH's next SGM research strategic plan. We will be putting out an RFI most likely in December—a Request for Information—to get public comment, and so we hope that those sitting around the table and on the phone will help us disseminate that broadly so that we can make sure that anybody who would like to provide a comment on that has the opportunity to do so. So, with that, I'd just like to thank everybody in the room and on the phone for being here today. [applause]