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Mr. Adrian Shanker
Senior Advisor LGBTQI+ Health Equity
Office of the Assistant Secretary for Health
U.S. Department of Health and Human Services
Submitted via Regulations.gov

Re: **Notice for Advancing Health Equity for Intersex Individuals**

Dear Mr. Shanker:

Thank you for the opportunity to provide information on promising practices for advancing health equity for intersex individuals.

The Center to Advance Palliative Care (CAPC) is a national organization dedicated to ensuring that all persons living with serious illness have access to high-quality equitable care that addresses their symptoms and stresses, including access to specialty palliative care services. Palliative care specifically refers to specialized medical care for people living with a serious illness, focused on providing relief from the symptoms and stress of the illness. It is an added layer of support, working in partnership with other providers and can be provided along with curative treatment. A strong and consistent evidence base indicates that palliative care – delivered from the point of diagnosis – improves quality of life, reduces caregiver and clinician burden, and reduces avoidable utilization and spending.

We applaud the Office of the Assistant Secretary (OASH) for its work to reduce health inequities for lesbian, gay, bisexual, transgender, queer, and intersex individuals (also referred to as people with differences in sexual development, or DSD). As you know, LGBTQI+ people have a long history of inequity and discrimination within the health care system. This discriminatory care occurs across the lifespan, which erodes the trust these patients have in providers and institutions, and leads to delays in or avoidance of care. While this manifests as poorer health and health outcomes throughout life, **the impacts can be particularly pronounced as these patients experience serious illness and/or transition to end of life**. Unfortunately, there is a dearth of literature and other documented evidence concerning experiences, outcomes, and best practices in caring specifically for intersex individuals during these later stages.

That said, palliative care utilizes a person-centered approached that is grounded in a comprehensive assessment, which can help address the inequities that intersex and other LGBTQI+ patients face. As the OASH continues its work to improve health care for intersex individuals, we offer the following promising practices and highlight ongoing gaps as they pertain to the subset of this population living with serious illness and at the end of life.

Structures and Processes for Care

There are a number of structural and process changes that can be implemented to better support intersex individuals, which would also positively impact the care of other populations.

Standardized Requirements for the Electronic Medical Record (EMR) on Sexual Orientation and Gender Identity (SOGI). Many health care organizations across the country have updated their EMRs to reflect more nuanced information on SOGI. The act of making these additional options available – paired with comprehensive intake forms – can prompt or remind clinicians to take a more inclusive approach during visits, and signal that the clinical encounter is a safe space for the intersex individual to share their identity as they are comfortable to do so. Additionally, providing ongoing education and training to system administrative leaders and staff on best methodologies to collect these SOGI data will be essential. Updating the EMR to better capture this information also increases the visibility of patients receiving care in the institution who identify as LGBTQI+, which can highlight the need for and inform additional quality improvement initiatives. Unfortunately, the changes have not been universally adopted by health care organizations, which increases the likelihood of inequitable care depending on the institution.

Health Care Decision-Making, Visitation, and Other Policies and Procedures. There is a growing body of research supporting the necessity and protective factors of "families of choice" among LGBTQI+ populations. Institutional and governmental policies have not uniformly kept pace with this understanding, with decision-making still typically reverting back to biological families if the patient is incapacitated – regardless of whether they had good or strained relationships with blood relatives. Clearer universal standards are needed to ensure that patients can appoint their own proxies/decision-makers and that these appointments are documented and honored. Moreover, health care providers should partner with their intersex patients regarding goals of care pertaining to affirming medical and surgical therapies. An interprofessional team approach in the provision of high quality palliative care for intersex people living with serious illness is integral in ensuring a multidimensional, holistic, and humane approach to their medical care.

On a related note, institutions have come a long way in developing visitation policies that recognize the need to grant access based on patients' preferences and not just biological relationships. However, the COVID-19 pandemic complicated this landscape, and the consequences were particularly dire for people living with serious illness and at the end of life. Unfortunately the unique impacts of COVID-19 restrictions and care outcomes on this subset of LGBTQI+ patients has been understudied; this is something for the OASH to consider moving forward.

Beyond that, there must be a national push for health care institutions to comprehensively review their policies and procedures utilizing a health equity lens (again, the impact of this would be broader than intersex patients). Changes must include identifying and removing discriminatory policies and creating more inclusive ones that address training and antidiscrimination on the basis of SOGI (and beyond); and there should be clear mechanisms for patients, families, and staff to report discriminatory behaviors with an outlined plan for timely, and appropriate follow up. Additionally, institutions should adopt LGBTQI+-positive employment policies that include better recruitment and hiring practices, as well as equitable benefits for these employees. As part of the release of her book, LGBTQ-Inclusive Hospice and Palliative Care, Dr. Kimberly D. Acquaviva published free tools that hospice and palliative care organizations can use to audit their current policies and practices; these should be adapted for use across additional institutions.

Coverage Policies. Intersex individuals may receive hormone therapy for myriad reasons, and any care transitions can potentially disrupt access. These disruptions are particularly prevalent during the transition to hospice, when the directive is to discontinue "unnecessary" medications. In addition to ensuring adequate and continued coverage of appropriate hormone therapy, public and commercial health plans should review their coverage policies to ensure that the language is clear and does not unintentionally impede access to affirming treatment. On the clinical side, providers should have a clear conversation with patients receiving hormone therapies and only discontinue if doing so is consistent with the patient's wishes.

Beyond the LGBTQI+ population living with serious illness and at the end of life, it is important to observe that there is no universal coverage for gender-affirming hormone therapies. Rather, these policies are determined by the state in which a person resides and the type of medical insurance they have (both private and public). We urge the OASH to explore options to create a national standard.

Clinical Training and Care Delivery

At the clinician level, there are numerous opportunities to improve care for intersex individuals. The OASH should explore strategies that support a continuum of medical care that extends from infancy to serious illness and end of life (e.g., staffing clinics with members of different disciplines to create a seamless transition from pediatrics to adult medicine for intersex individuals). In order to scale these solutions, more training must be developed and made available across the health care system; and payment for clinical encounters must be adequate to cover the time and resources it takes to deliver complete care to this population.

Comprehensive Assessment including Financial Considerations and Other SDOH. As previously mentioned, the foundation of any palliative care encounter is built on a comprehensive assessment. This assessment informs the development of a customized plan that addresses physical, psychological, social, spiritual, cultural, and ethical and legal aspects of care. This approach is appropriate for the care of the intersex population and beyond, and should be adopted by other disciplines across the health system as appropriate. Special attention should be paid to financial issues, as many LGBTQI+ elders have faced economic marginalization that may inhibit their ability to afford medical costs associated with chronic or serious illness.

Staff Training. Even among well-meaning clinicians, there continues to be significant gaps in understanding about caring for LGBTQI+ individuals – particularly in the intersex/DSD population. These include distinctions in terminology, barriers to care, and history and consequences of victimization within the medical system due to homophobia, heterosexism, transphobia, cisgenderism, and other discrimination grounded in any other intersectional identities. More training is needed to promote health care worker sensitivity/competency, and should include examining any preconceptions or implicit biases, and strategizing how to overcome them. This training should be ongoing, with periodic updates and reassessments of knowledge base and skill sets. And it should be widely available to everyone, including clinicians at all levels, administrators, and any other professionals with whom the patients will interact.

Several national organizations, including the American Academy of Hospice and Palliative Medicine and the American Geriatrics Society, are developing training curricula that include best practices in the care of the wider LGBTQI+ population – especially transgender, gender diverse, and intersex individuals living with serious illness. As the curricula are completed, CAPC would be pleased to connect the OASH and/or any additional partners with these organizations so they can share this information.

Communication/Clinical Care Best Practices. There are several publications that provide excellent guidance on language and best practices for having person-centered, respectful conversations with LGBTQI+ patients (examples here, here, and here). Paramount to all effective communication is that patients should never have to self-identify as LGBTQI+ in order to receive inclusive care. Beyond this, commonly proposed strategies for these populations living with serious illness include:

- Including the use of the clinicians pronouns in any introduction
- Use of visible indicators of inclusion such as pronoun pins, rainbow stickers, Trans flags, gender neutral bathrooms, etc.
- Asking how the patient wants to be addressed, noting that names may be different than what is on their chart or legal documents
- Asking Chochinov's Dignity Question, "What do I need to know about you as a person to take the best care of you that I can?"
- If other people in the room, not making assumptions about their relations; instead, asking to be introduced and the nature of the relationship. If the patient is alone, asking them who the most important people in their life are
- Encouraging the selection and documentation of decision-making proxies; more broadly, conducting advance care planning as soon as possible
- Quickly correcting if the clinician misgenders the patient, apologizing, and practicing so as not to make the same mistake again
- Only examining what is relevant to the presenting issue; asking permission when doing an examination, explain what the clinician is doing and why they are doing it. If the examination must include genitalia, reproductive organs, or any other parts that may be considered private, again asking permission and getting buy-in – including asking how the patient wants the clinician to refer to their private parts

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Thank you for the opportunity to submit these comments. Please do not hesitate to contact me or Stacie Sinclair, Associate Director of Policy (stacie.sinclair@mssm.edu) if we can provide any further assistance.

Sincerely,

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