LGBTQ parents' experiences accessing health care for their children with disabilities

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Background

- An estimated 2-3 million U.S. children under the age of 18 have LGBTQ parents.¹
- Approximately 1 in 6 U.S. children has a developmental disability.²
- LGBTQ parents' experiences accessing health care for their children with developmental disabilities (DDs) in the U.S. remain unknown.
- Anti-LGBTQ health care bias and discrimination may delay screening and diagnosis of DDs and access to early interventions.

Methods

- National online survey of LGBTQ parents of children with DDs (March June 2021).
- Descriptive statistics compiled.
- Semi-structured interviews with a subset of LGBTQ parents (September – October 2021).
- Interviews transcribed and analyzed with a combined inductive and deductive approach.

References:

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- 3. Coulter-Thompson, E. I. (2022). The Impact of Health Care Discrimination Against LGBTQ Parents on the Screening and Diagnosis of Their Children with Disabilities. ProQuest Dissertations. (28968399)
- 4. Coulter-Thompson, E.I. et al. (2022). Health Care Bias and Discrimination Experienced by LGBTQ Parents of Children with DDs. J of Pediatric Health Care. https://doi.org/10.1016/j.pedhc.2022.09.004.

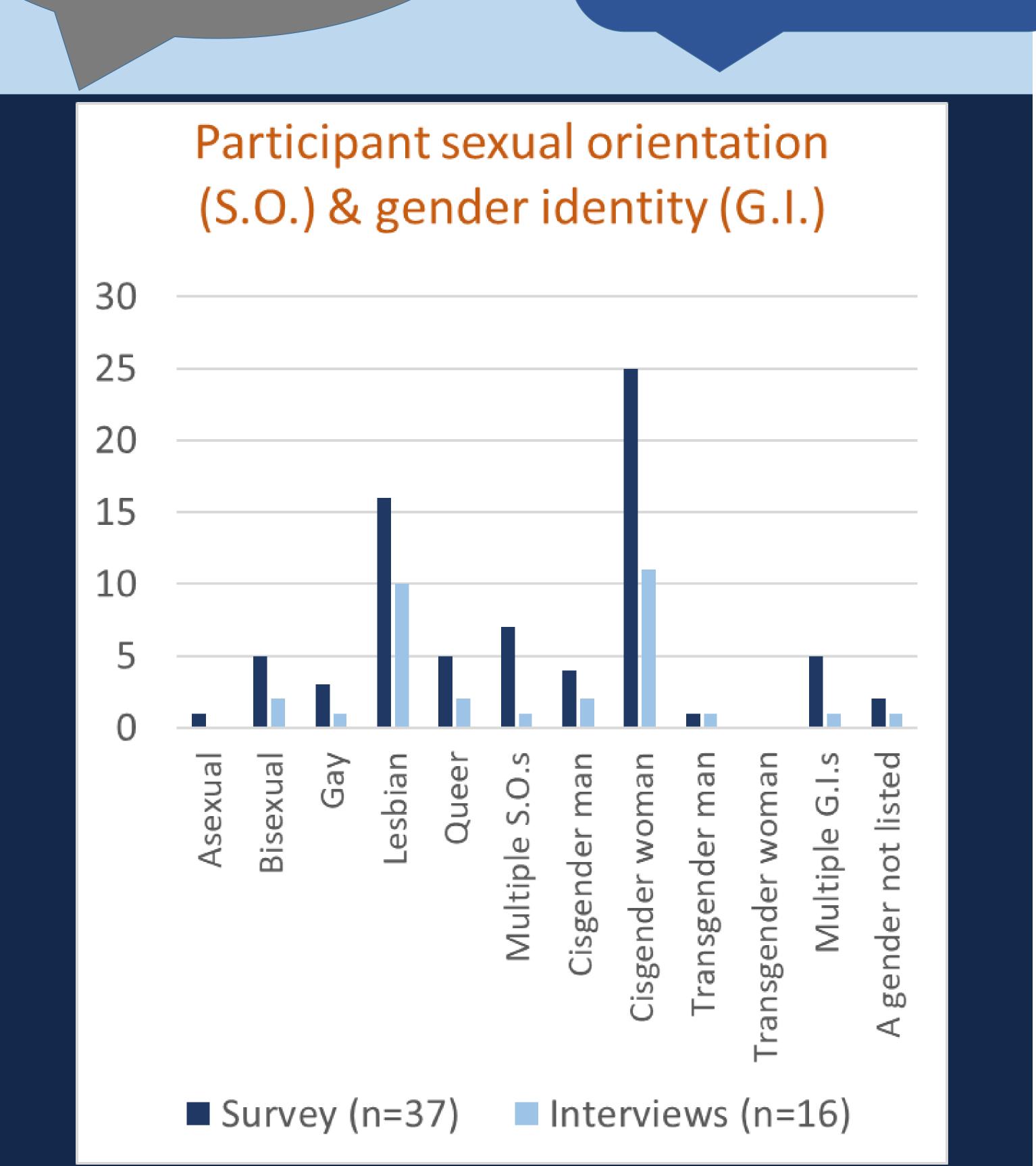
LGBTQ parents' voices:

"I think [anti-LGBTQ bias and discrimination] has been the primary force behind the way [our son was] evaluated [for developmental disabilities]. (Alice)

"... Do [clinicians believe] that there's something wrong with me or that I'm not a good parent? Does that affect what's happening? I worry about it, and I have for years." (Cassie)

"Do I need to hide who I am so that I can get the best [health care] for my kids?" (Mona)

"... doctors have been great, but **forms that are antiquated** don't account for families that are outside of the heterosexual norm." (Anthony)



Results

- Several LGBTQ parents reported experiencing discrimination when accessing care for their children with DDs.
- Discrimination types: non-inclusive forms, disclosure challenges, providers dismissing non-gestational parents and diverse families, being refused needed care.
- Few parents reported screening and diagnosis delays.
- Parents recommended: honoring family diversity, avoiding assumptions, increasing LGBTQ family support, improving forms, increasing anti-bias training.

Conclusion & Implications

- Further research is needed to systematically measure health discrimination against LGBTQ parents of children with DDs.
- Revise health care forms, electronic records, and materials to include LGBTQ families.
- LGBTQ-specific health professions education and workforce development are needed.

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