

# Survey of Lesbian, Gay, Bisexual, Transgender, and Queer Parents' Experiences Accessing Health Care for their Children With Developmental Disabilities

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**Introduction:** This study explored the impact of health care (HC) bias and discrimination on lesbian, gay, bisexual, transgender, and queer (LGBTQ) parents and their children with developmental disabilities.

**Method:** We conducted a national online survey of LGBTQ parents of children with developmental disabilities using social media and professional networks. Descriptive statistics were

compiled. Open-ended responses were coded using inductive and deductive approaches.

**Results:** Thirty-seven parents completed the survey. Most participants identified as highly educated, White, lesbian or queer, cisgender women and reported positive experiences. Some reported bias and discrimination, including heterosexist forms, LGBTQ disclosure challenges, and, because of their LGBTQ identity, feeling

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The University of North Carolina Institutional Review Board approved all study procedures (study no. 20-2988).

Conflicts of interest: This work was completed during Emilee I. Coulter-Thompson's Executive Doctoral Program in Public Health Leadership (DrPH) at the University of North Carolina at

Chapel Hill. Emilee I. Coulter-Thompson volunteered with the National Maternal and Child Health Workforce Development Center's Health Equity Committee from 2020 to 2021 while conducting this dissertation research. In 2020, Emilee I. Coulter-Thompson received a speaker honorarium for presenting the literature review. In 2021, she received a fee for consulting with the Health Equity Committee not related to this research. These were paid by the Association of Maternal and Child Health Programs in coordination with the Workforce Development Center. The remaining authors reported no conflicts of interest.

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mistreated by their children's providers or being refused needed HC for their child.

**Discussion:** This study advances knowledge around LGBTQ parents' experiences of bias and discrimination while accessing children's HC. Findings highlight the need for additional research, policy change, and workforce development to improve HC for LGBTQ families. *J Pediatr Health Care.* (2022) XX, 1–11

## KEY WORDS

Discrimination, health care, sexual and gender minority, developmental disability, developmental screening

## INTRODUCTION

An estimated two to three million U.S. children aged < 18 years have a parent identifying as lesbian, gay, bisexual, trans, or queer (LGBTQ; [Gates, 2015](#)). Moreover, the number of LGBTQ families is projected to increase further ([Family Equality Council, 2019](#)). Few U.S. studies have examined the experiences of LGBTQ parents accessing health care (HC) for their children ([Coulter-Thompson et al., 2023](#); [Perrin, 1996](#); [Perrin & Kulkin, 1996](#)). Studies have shown that LGBTQ adults experience discrimination and systemic barriers to accessing their HC ([Buchmueller & Carpenter, 2010](#); [Jennings et al., 2019](#); [Mirza & Rooney, 2018](#); [Romanelli & Hudson, 2017](#)). LGBTQ parents may encounter systemic barriers and provider bias when accessing care for their children.

Approximately one in six U.S. children have a developmental disability (DD), such as autism or attention deficit hyperactivity disorder ([Zablotsky et al., 2019](#)). Children with DDs are common among all family types, regardless of parents' sexual orientation and gender identity ([Zablotsky et al., 2019](#)). However, children who are adopted have high rates of special HC needs (one study showed 39%), including DDs ([Vandivere et al., 2009](#)). Same-sex couples are nearly three times as likely as heterosexual couples to be raising adopted or foster children ([Gates, 2015](#); [Goldberg & Conron, 2018](#)). Given the high proportion of LGBTQ parents who adopt and foster children, there are likely many LGBTQ parents raising children with DDs.

Families marginalized by race, ethnicity, and language are at higher risk of disparate outcomes when accessing HC for their children's DDs, including delayed screening and diagnosis ([Bishop-Fitzpatrick & Kind, 2017](#); [Kendall & Hatton, 2002](#)). For children of LGBTQ parents, anti-LGBTQ structural bias and discrimination in HC systems may delay the early identification of DDs and interfere with families obtaining timely and culturally effective interventions, which is critical for optimizing long-term health outcomes and reducing avoidable HC costs ([U.S. Department of Health and Human Services & U.S. Department of Education, 2016](#)).

The experience of LGBTQ parents accessing HC for their children with DDs in the United States remains unknown. This study aimed to document how HC bias and discrimination affect LGBTQ parents and their children

with DDs in the United States, including parents' perceptions of how bias and discrimination affect their children's screening and diagnosis for DDs.

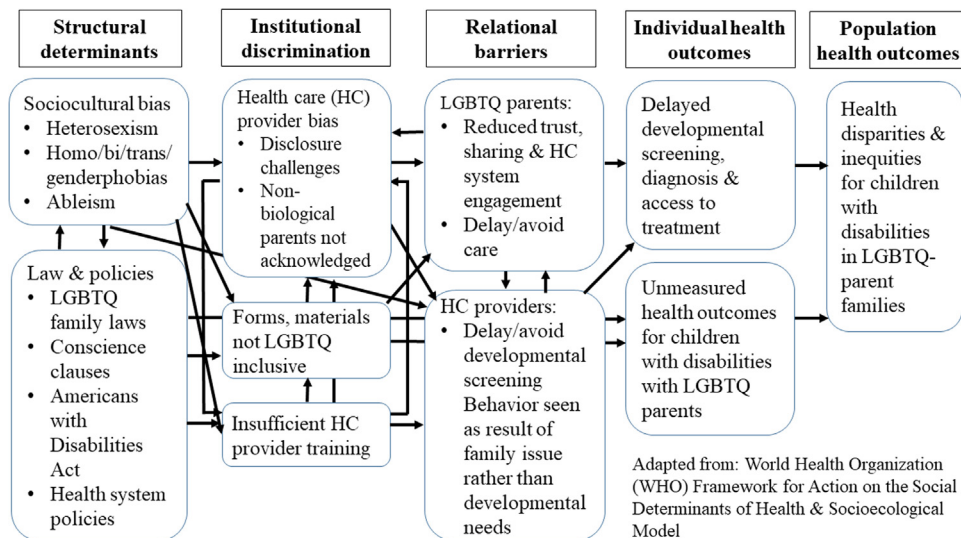
## METHODS

This study employed a transformative worldview with the goal of giving a voice to marginalized populations ([Creswell & Creswell, 2018](#)). The study design and methodology were informed by a conceptual model on the basis of the World Health Organization (Geneva) framework for action on the social determinants of health and the socioecological model ([Figure 1](#); [Centers for Disease Control and Prevention, 2019](#); [Solar & Irwin, 2010](#)). This model illustrates how structural determinants and institutional discrimination influence relational barriers between parents and providers, which may lead to negative health outcomes ([Figure 1](#); conceptual model of study).

## Survey Instrument

The principal investigator created a 45-item survey instrument administered online through Qualtrics. The University of North Carolina (UNC), Institutional Review Board, approved all study procedures (study no. 20-2988). The survey was pilot tested with LGBTQ parents and stakeholders with expertise on the topic and questionnaire design before launch. Participants completed an informed consent form embedded in the survey. Survey access was granted after participants self-identified as LGBTQ parents with at least one child with developmental concerns (DCs) or DDs living in the United States.

The survey measured LGBTQ parents' perceptions of bias and discrimination while seeking HC for their children and its impact on the timing of their children's developmental screening and diagnosis. The survey was designed for families to complete one survey per family. If the family had more than one child with disabilities, they were instructed to answer the questions on the basis of their child who was first identified to have DCs or DDs (to reflect their first experience navigating the HC system for their child's disability care). Questions to identify children's disability status were based on the National Survey on Children's Health and the National Health Interview Survey (e.g., Has a doctor or health professional ever told you that your child had a disability or delay?; [U.S. Department of Health and Human Services, 2018](#); [Zablotsky et al., 2015](#)). A series of quantitative and qualitative questions were adapted from multiple sources ([Goldberg & Smith, 2014](#); [Harless et al., 2019](#); [Lambda Legal, 2010](#); [Perrin, 1996](#); [Stanford University School of Medicine, 2020](#)). Questions focused on themes from the literature (e.g., LGBTQ-parent disclosure to providers, noninclusive paperwork, and providers' recognition of nonbiological parents and diverse family structures; [Andersen et al., 2017](#); [Bennett et al., 2017](#); [Chapman et al., 2012](#); [Gibson, 2018](#); [McNair et al., 2008](#); [Mikhailovich et al., 2001](#); [Perrin, 1996](#)) and the timing of their children's developmental screening and diagnosis. For example, the survey asked LGBTQ parents whether they think anti-LGBTQ

**FIGURE 1. Study conceptual model. LGBTQ, lesbian, gay, bisexual, trans, or queer.**

Data from Coulter-Thompson et al. (2023).

bias among their child's HC providers contributed to a delay in their child being screened for or diagnosed with their disability. The survey asked if participants would be interviewed (interview results reported separately; Coulter-Thompson et al., 2023). The survey concluded with questions on demographics (language, race, ethnicity, education, and geography), family formation, and family constellation.

### Participant Recruitment

The survey was distributed on Facebook (including LGBTQ and disability parent groups), Twitter, LinkedIn and via e-mail to organizational contacts in public health, early childhood, social justice, disability, and LGBTQ health. Participants could enter a prize drawing (one \$25 VISA gift card for every 25 survey participants) if they shared their contact information. The survey launched on March 29, 2021 and closed on June 6, 2021. It was fielded for 65 days with pauses because of multiple instances of internet trolls and bots submitting fraudulent responses. After the first survey pause, Qualtrics settings were adjusted to add additional security protections. To assess validity, responses were checked for their date and time of submission (e.g., several responses submitted within minutes of each other) and the responses to open-ended questions, demographics, and contact information (e.g., whether it made sense, were an exact duplicate of other responses, or included offensive or unusual content).

### Data Analysis

Descriptive statistics were compiled for the quantitative questions, and responses were grouped and converted to categorical measures. To test the relationships between participants' sexual orientation and each dependent variable and participants' gender identity and each dependent variable,

mediation analyses were conducted using the PROCESS macro in SPSS Statistics (Version 28, IBM, Armonk, NY) (Hayes, 2017). State of residence was the mediating variable between sexual orientation (or gender identity) and each dependent variable. Open-ended questions were coded using a combination of inductive and deductive approaches (Creswell & Creswell, 2018). Numeric identifiers were assigned to each participant. Personal identifiers were removed from surveys and destroyed after the analysis was completed. The principal investigator worked with the UNC Odum Institute to assess and eliminate fraudulent responses. Qualtrics scores for relevant ID, duplicates, fraud, IP address, and response type were analyzed.

### RESULTS

Thirty-seven surveys were ascertained to be valid, complete responses from LGBTQ parents. Participant demographics are shown in Table 1. The results of the moderated mediation analysis are not reported because they were not significant.

### Demographics

Most participants identified as cisgender women (68%). Five participants (14%) selected multiple gender identities (e.g., nonbinary, genderqueer, and gender nonconforming). One participant identified as a transgender man, whereas no one identified as a transgender woman or intersex.

Most participants identified as lesbian (43%). Six participants (16%) selected multiple identities: four selected lesbian and queer; one selected gay, lesbian, and queer; and one selected lesbian, queer, and another orientation not listed (demisexual). One participant identified with a sexual orientation not listed (pansexual).

TABLE 1. Survey descriptive statistics (online survey, 2021)

Variable	n (%)	Response options					
Parent sexual orientation and gender identity		Asexual	Bisexual	Gay	Lesbian	Queer	Multiple identities or another identity not listed
Parent sexual orientation	37 (100)	1 (3)	5 (14)	3 (8)	16 (43)	5 (14)	7 (19)
Parent gender identity	37 (100)	Cis-Male 4 (11)	Cis-Female 25 (68)	Trans-Male 1 (3)	Trans-Female 0 (0)	Multiple identities 5 (14)	A gender not listed 2 (5)
Assigned sex at birth	37 (100)	Female 33 (89)	Male 4 (11)	Intersex 0 (0)			
Child DD or delay		Yes	No				
Believe your child has a DD?	37 (100)	34 (92)	3 (8)				
Believe your child has a developmental delay?	37 (100)	27 (73)	10 (27)				
Have you spoken to your child's doctor/PCP about these concerns?	37 (100)	36 (97)	1 (3) <sup>a</sup>				
Has a doctor or health professional ever told you your child has a DD?	37 (100)	31 (84)	6 (16)				
Has a doctor or health professional ever told you your child has a developmental delay?	37 (100)	24 (65)	13 (35)				
Family demographics		Carried	Partner carried	Marriage/step-parent	Foster parent	Adoptive parent	Specify: foster care to adoption
How became a parent	35 (95)	15 (41) 1 child	3 (8) 2 children	0 (0) 3 children	8 (22) > 3 children	7 (19)	2 (5)
No. of children	37 (100)	15 (41)	15 (41)	6 (16)	1 (3)		
Household language	35 (95)	English 35 (95)	Spanish 0 (0)	Specify 0 (0)			
Hispanic, Latino or of Spanish origin	34 (92)	No 32 (86)	Yes 2 (5)				
Parent race	35 (95)	AI/AN 0 (0)	Asian 0 (0)	Black or AA 1 (3)	NH/PI 0 (0)	White 32 (86)	Multiracial/biracial 2 (5)
Child race	35 (95)	0 (0)	0 (0)	7 (19)	0 (0)	21 (57)	7 (19)
Education	35 (95)	< HS 0 (0)	HS graduate 1 (3)	Some college 1 (3)	UG degree 7 (19)	≥ GD 26 (70)	Prefer not to answer 0 (0)
Twelve states represented by six regions		MA	MW	NE	NW	SE	SW
Region of the United States	37 (100)	3 (8)	10 (27)	3 (8)	14 (38)	6 (16)	1 (3)
Willing to be interviewed	35 (95)	Yes 29 (78)	No 6 (16)				
Multiple-choice questions		Always	Sometimes	Rarely	Never	Blank	
I feel comfortable openly discussing my sexual orientation and gender identity with my child's HC providers	37 (100)	19 (51)	14 (41)	3 (8)	0 (0)	0 (0)	
I think HC providers in my community are able to provide quality medical care to LGBTQ-parent families with children with disabilities	37 (100)	12 (32)	22 (59)	2 (5)	0 (0)	1 (3)	

(continued on next page)

TABLE 1. (Continued)

Variable	n (%)			Response options		
My child's HC organizations use forms that allow families to identify themselves in a way that they choose (e.g., the form says parent(s) rather than mother and father)	37 (100)	4 (11)	26 (70)	3 (8)	3 (8)	1 (3)
I am willing to share sensitive information with my child's HC providers	37 (100)	20 (54)	16 (43)	1 (3)	0 (0)	0 (0)
I have to educate HC providers about my LGBTQ-parent family while getting care for my child with DC/DD	37 (100)	5 (14)	10 (27)	12 (32)	9 (24)	1 (3)
I have felt that HC providers treated my child differently because my child's parent(s) is(are) LGBTQ.	37 (100)	0 (0)	6 (16)	9 (24)	22 (59)	0 (0)
I have felt mistreated by my child's HC providers because I am an LGBTQ parent	37 (100)	0 (0)	5 (14)	8 (22)	24 (65)	0 (0)
HC providers have blamed me for my child's health status (i.e., blamed me for my child having a DC/DD) because I am an LGBTQ parent	37 (100)	0 (0)	1 (3)	4 (11)	32 (86)	0 (0)
I believe that I have been refused needed HC for my child with DC/DD because of my sexual orientation or gender identity	37 (100)	0 (0)	2 (5)	1 (3)	34 (92)	0 (0)
I trust my child's HC providers	37 (100)	20 (54)	17 (46)	0 (0)	0 (0)	0 (0)
I have fears (or I have had fears in the past) about letting my child's HC providers know about my sexual orientation, gender identity, and/or family constellation	37 (100)	0 (0)	13 (35)	6 (16)	18 (49)	0 (0)

Note. DCs, developmental concerns; DDs, developmental disabilities; PCP, primary care provider; AI, American Indian; AN, Alaska Native; AA, African American; NH, Native Hawaii; PI, Pacific Islander; HS, high school; UG, undergraduate; GD, graduate; MA, Mid-Atlantic; MW, Midwest; NE, Northeast; SE, Southeast; SW, Southwest; HC, health care; LGBTQ, lesbian, gay, bisexual, trans, or queer.  
<sup>a</sup>Child does not have a PCP.

**TABLE 2. Child age at parents' first concern, screening, and diagnosis (online survey, 2021)**

First, concerned about child	Child first screened, years				Child first diagnosed, years			
	NS	0–5	6–10	> 10	ND	0–5	6–10	> 10
0–5 years	2 (5)	27 (73)	5 (14)	0	5 (14)	21 (57)	7 (19)	1 (3)
6–10 years	0	0	3 (8)	0	0	0	3 (8)	0

Note. Total sample size (n = 37). NS, not screened; ND, not diagnosed.

Most participants had a graduate (70%) or undergraduate (19%) degree and were White (86%), non-Hispanic (86%), and primarily English-speaking (95%). Their children were more racially diverse. Seven participants (19%) reported that their children were Black or African American, and seven (19%) reported that they were multiracial or biracial. The reported current age of the child who was first identified to have DCs or DDs ranged from 2–33 years. Twenty participants (54%) reported that their child was aged  $\leq 10$  years.

Participants reported residing in 12 states: Connecticut, Kentucky, Maryland, Massachusetts, Michigan, North Carolina, New Jersey, Ohio, Oregon, Texas, Washington, and Wisconsin. All U.S. regions were represented except the West.

Parents built their families through a parent or co-parent giving birth (49%) or foster care and adoption (46%). Many participants reported being in two-parent relationships or marriages. Eight participants described being single parents. Several participants described building their families with unknown and known donors. A few participants described their children being conceived in heterosexual relationships before forming their current LGBTQ-parent family.

Most parents indicated that they believe their child has a DD (92%; Table 1), and most had spoken to their child's doctor/primary care provider (PCP) about these concerns. All parents, except three, were told by a doctor or health professional that their child had a DD (91%). Slightly fewer (73%) reported believing their child to have a developmental delay, and all of them, except four, had spoken to their child's doctor/PCP and were told by a doctor or health professional that their child had a developmental delay (85%). Only one participant reported that they did not believe their child had a DD or delay. That same participant was the only parent who reported not having spoken to their child's doctor or PCP about their concerns and that their child does not have a PCP.

Participants reported the age at which they were first concerned about their child's development and when their child was first screened and diagnosed (if applicable) for DDs (Table 2). Most parents reported that their child was first screened (73%) or diagnosed (57%) for DDs at  $\leq 5$  years old.

### Parents' Experiences

Parents responded to 11 multiple-choice questions describing their experiences accessing care for their children (Table 1). Overall, parents' responses indicated positive experiences. Most parents reported always or sometimes:

feeling comfortable openly discussing their sexual orientation and gender identity with their child's providers, being willing to share sensitive information with their child's providers, and thinking that their community's providers were able to provide quality medical care to LGBTQ-parent families with children with disabilities. All parents reported trusting their child's HC providers always or sometimes. Most parents (92%) reported they believe they have never been refused medical care for their child with DCs/DDs because of their sexual orientation and gender identity.

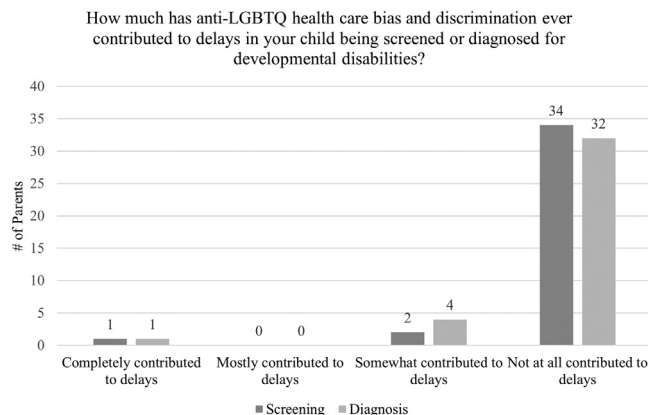
Survey responses indicated experiences of bias and discrimination. Six parents (16%) reported that their child's HC organizations rarely or never use forms that allow families to identify themselves in a way that they choose (e.g., form saying parent(s) rather than mother and father; 26 [70%] reported that forms were sometimes inclusive, and only 4 [11%] said the forms were always inclusive). Fifteen parents (41%) reported having to educate HC providers about their LGBTQ-parent family (always 15% and sometimes 27%) while getting care for their child with DCs/DDs. Six parents (16%) reported feeling that HC providers sometimes treated their child differently because their child's parents are LGBTQ, and nine parents (24%) reported feeling this way rarely (no one reported feeling this way always). Five parents (14%) reported feeling mistreated by their child's HC providers because they are LGBTQ parents, and eight (22%) reported feeling this way rarely. One parent (3%) reported that HC providers had sometimes blamed them for their child's health status (i.e., blamed them for their children having DCs or DDs) because they are an LGBTQ parent (four parents [11%] reported rarely). Three parents (8%) indicated they believe they have been refused needed HC for their child with DCs/DDs because of their sexual orientation or gender identity (two [5%] sometimes, one [3%] rarely). One-third of parents (35%) reported having fears (or having fears in the past) about letting their child's HC providers know about their sexual orientation, gender identity, and/or family constellation.

Very few parents believed that anti-LGBTQ HC bias and discrimination had contributed to delays in their child being screened or diagnosed for DDs. Most parents indicated that it did not at all contribute to delays in screening (92%) and diagnosis (86%; Figure 2).

### Open-Ended Comments

Twenty-three parents (62%) wrote general open-ended comments. Nine participants mentioned general factors that they

**FIGURE 2.** The extent to which bias and discrimination contributed to delays in screening and diagnosis. LGBTQ, lesbian, gay, bisexual, trans, or queer.



believed affected their care more than their own LGBTQ identity, including race (e.g., the child being of color and the parents being White), adoption, foster care, geography, non-monogamy, and kink. Two participants mentioned that accessing education was more challenging than HC. Two parents reported barriers on the basis of being nongestational parents.

Six participants reported that they believed their LGBTQ status had had no impact on their care.

“Nothing about my family status has ever played a part in my child’s care. They have always been welcoming.”

“It has never been an issue, and in most cases, it was never discussed.”

Survey responses included a mix of positive and negative experiences accessing HC for children with DDs.

## DISCUSSION

Although the numbers were small, the parents’ reported experiences of bias and discrimination while accessing care for their children are still noteworthy. Most concerning, some participants reported feeling that their HC providers treated their child differently or blamed them as parents for their child’s developmental concern or disability because they are LGBTQ parents. LGBTQ parents and their children with disabilities are at risk of increased societal stigma and being pathologized. In addition, it is very troubling that even a few participants believed they were refused needed HC for their child because of their LGBTQ identity. This study likely underestimates the extent of anti-LGBTQ bias and discrimination against parents because of the limited sample. If this study were replicated with a larger, more diverse sample with respect to parents’ sexual orientation, gender identity (particularly more transgender parents), education, income, race, ethnicity, language, citizenship status, and geography, then bias and discrimination may have been a larger issue.

LGBTQ parents’ reports of a mix of positive and negative experiences accessing care for their children with disabilities could indicate that the medical profession is progressing in providing LGBTQ-affirming and inclusive care. This may also reflect that the study participants were mostly non-Hispanic White, English-speaking, highly educated, cisgender female parents living in urban geographic areas, likely with access to a choice of LGBTQ-affirming providers.

It is possible that being an LGBTQ parent may be a protective factor for seeking care for children with disabilities. Given that many LGBTQ parents must engage in lengthy measures involving complex systems to form their families through insemination, foster care, or adoption and that LGBTQ parents may develop resiliency while advocating for their care (Prendergast & MacPhee, 2018), LGBTQ parents may be well versed and engaged in navigating systems and advocating for their children with disabilities.

## Impact on Screening and Diagnosis

One reason that so few parents indicated that being in an LGBTQ-parent family contributed to delays in their children’s developmental screening and diagnosis could be because this small sample was highly educated with access to LGBTQ-affirming providers. It could also be that parents were hesitant to label their experiences as biased and discriminatory, which is consistent with studies showing that marginalized groups tend to underreport discrimination (Mikhailovich et al., 2001; Perrin & Kulkun, 1996). For the few parents who indicated delays, because the limitations of this study are based only on parents’ self-reports, it remains unclear whether and to what extent the parents’ sexual orientation or gender identity contributed to the delays in their child’s screening or diagnosis, or whether those delays would have occurred anyway because of other system barriers. Developmental screening rates vary widely in the general population (Bethell et al., 2011; Hirai et al., 2018). Diagnosing a DD can be lengthy and involve waiting lists for families of any background. More research is needed on the timing

of screening and diagnosis among children in more diverse LGBTQ-parent families.

### Forms

HC forms not being inclusive of LGBTQ families is a persistent problem. Only four survey participants reported that their child's HC organizations always use forms that allow families to identify themselves as they choose. Parents of children with disabilities are required to fill out voluminous paperwork to complete developmental assessments, consult specialists, and receive ongoing care for their children. Experiencing repeated microaggressions of heterosexist, binary gender-centric forms may add minority stress and increase the allostatic load for parents during what often is a challenging, emotionally consuming process navigating care for children with DDs (Meyer, 2003). Updating forms is a basic change that could significantly create welcoming and affirming environments for LGBTQ families.

### Disclosure

Providing safe, affirming environments for LGBTQ parents of children with disabilities to openly disclose their identities and describe their families is critical to building strong, collaborative parent-provider relationships. Parents of children with disabilities need to be able to freely discuss vulnerable and sensitive information about their children's behavior and feel supported in navigating their children's care. Children with disabilities may also be highly attuned to consultation dynamics. Disclosure challenges can undermine the trust critical for establishing effective parent-provider and child-provider relationships (Ruben & Fullerton, 2018). Health professions education and workforce development, including curricula and provider training on LGBTQ-affirming care, are needed to ensure that LGBTQ parents have consistently positive experiences disclosing their identities and discussing their families in health settings.

### Limitations

This study provides a cross-sectional view of LGBTQ parents' experiences of HC bias and discrimination while accessing care for their children with disabilities in the United States. These methods cannot establish causal relationships between identity and HC experiences.

The survey convenience sampling method may have selection bias because the parents who self-selected to complete the questionnaire may have had more positive or negative experiences or may have differed in other ways (e.g., more likely to have internet access or be connected to LGBTQ or disability organizations or health research), compared with those who did not participate. The sample is limited in generalizability because it does not represent all LGBTQ parents of children with disabilities in the United States. Parents who identified as gay, bisexual, and trans were underrepresented. Parents who identified as intersex, asexual, or agender were not represented. Most participants were White, and all spoke English. The survey asked parents

to report their child's race but did not ask for their child's ethnicity, so it is unknown whether any of the children were Hispanic, Latinx, or of Spanish origin. This study did not ask participants to identify their child's specific disability. All research was conducted in English; thus, the results do not represent parents who experience language access biases and barriers. Parent participation may have been limited by the demands of caring for children with disabilities during the COVID-19 pandemic when the survey was fielded.

The survey disruption by internet trolls and bots may have limited the sample size because the survey was closed early, and the survey link changed midway through it being fielded. Future studies could use additional security measures (e.g., password protection or predetermined participant lists) to minimize these threats (Bybee et al., 2022; Griffin et al., 2022; Storozuk et al., 2020).

As a historically marginalized population with a documented history of mistreatment in HC systems and a lack of legal protections in society (Jennings et al., 2019; Romanelli & Hudson, 2017), LGBTQ parents may have hesitated to participate in research or share sensitive information. In addition, parents with older children may have had difficulty recalling earlier screening and diagnosis experiences.

### Implications for Future Research, Policy, and Practice

As one of the first studies on this topic, this study gathered evidence about and increased the visibility of a historically marginalized population facing intersecting inequities and barriers related to sexual orientation, gender identity, and disability. The results could help catalyze future research on LGBTQ-parent families, health equity, and access to care for children with DDs (Table 3).

More research is needed to examine the multifaceted experiences of diverse LGBTQ-parent families with respect to race, ethnicity, language, education, socioeconomic status, geography, citizenship, child disability, family constellation, sexual orientation, and gender identity. Studies could explore the factors that some study participants believed affected their care more than their own LGBTQ identity, including race; adoption or foster care; geography; parental role (e.g., being a nongestational parent); or nonmonogamy and kink. Similar studies could assess LGBTQ parents' experiences accessing education systems for their children with DDs.

Future research could compare the HC experiences of LGBTQ parents and heterosexual, cisgender parents accessing care for their children with DDs to identify health disparities and delays in screening and diagnosis. Studies could observe HC encounters or measure the knowledge, attitudes, and behaviors of HC providers to assess the dynamics of LGBTQ-parent-provider interactions. Studies could analyze provider and institutional-level factors contributing to LGBTQ-parent families reporting either no discrimination or positive experiences when accessing care for their children and explore how those affirming practices might be



**TABLE 3. Summary of research, policy, and practice implications**

Variables	Recommendations	Potential long-term impact
Research	<p>Additional research needed:</p> <ul style="list-style-type: none"> <li>• Identification of critical unmet needs and varied HC experiences among diverse LGBTQ families</li> <li>• Experiences of LGBTQ-parent families of children with disabilities accessing education systems</li> <li>• Comparison of children's screening and diagnosis experiences for LGBTQ and heterosexual, cisgender parents</li> <li>• Identification and evaluation of promising practices and interventions</li> <li>• Measurement of health discrimination with validated assessment tools</li> </ul>	<ul style="list-style-type: none"> <li>• Identification of health disparities</li> <li>• Identification of educational disparities</li> <li>• Identification of quality improvement and policy and system change opportunities</li> </ul>
Policy and practice	<ul style="list-style-type: none"> <li>• Improve HC forms and electronic health records to be inclusive of LGBTQ individuals and families</li> <li>• Improve measurement of health indicators for LGBTQ families</li> <li>• Require health professions education and workforce development on LGBTQ-affirming care</li> </ul>	<ul style="list-style-type: none"> <li>• Safer, more LGBTQ-affirming environments and care delivery for families</li> <li>• Improved patient data collection</li> <li>• Identification of health disparities and quality improvement opportunities</li> </ul>
Health professions education and workforce development	<p>Education and training topics:</p> <ul style="list-style-type: none"> <li>• Implicit bias related to heterosexism, cisgenderism, homo/bi/trans/gender phobias and intersectional oppression</li> <li>• How to proactively recognize and affirm LGBTQ parents and families during all aspects of HC visits</li> <li>• How to audit clinic intake forms, websites, educational materials, developmental screening, assessment and intervention forms and processes for LGBTQ-inclusive language and imagery</li> <li>• How to conduct LGBTQ-inclusive developmental screenings, assessments, and interventions</li> <li>• How to reexamine heterosexist, cisgendered assumptions about parenting roles and behaviors, especially related to caring for children with DDs</li> <li>• Understanding the impact of complex, historical trauma on LGBTQ-parent families</li> </ul>	<ul style="list-style-type: none"> <li>• Safer, more LGBTQ-affirming environments and care delivery for families</li> <li>• Enhanced trust, disclosure, information-sharing, and health system engagement from LGBTQ parents and their children</li> <li>• More thorough and accurate developmental screening, assessment, diagnosis, and intervention</li> <li>• Reduced health disparities</li> <li>• Improved HC and health outcomes</li> </ul>

Note. LGBTQ, lesbian, gay, bisexual, trans, or queer; HC, health care.

leveraged as interventions or improvement initiatives. In addition, studies could measure health discrimination with validated assessment methods.

As an increasing number of LGBTQ adults build families with children, health care, public health, education, and other child-serving systems need to prepare to understand and respond to the complex needs of these families. Improving forms and electronic records to include LGBTQ parents is urgently needed because these data will help identify health disparities and quality improvement opportunities to improve care for LGBTQ families. In addition, health professional education and workforce development related to LGBTQ-parent families is needed. HC clinic staff and providers need training on implicit bias, providing welcoming and affirming care to LGBTQ families, and culturally effective LGBTQ care for families of children with DDs. Curricula and trainings could include: how to proactively recognize and affirm same-sex parents and trans-parents from the moment the family walks in the door; how to ask open-ended questions about the family constellation that do not presume heterosexuality or cisgender identity; how to

audit clinic intake forms, websites, educational materials, and developmental screening, assessment, and intervention forms and processes for LGBTQ-inclusive language and imagery; how to conduct LGBTQ-inclusive developmental screenings, assessments, and interventions; how to reexamine heterosexist, cisgendered assumptions about parenting roles and behaviors, especially as they relate to caring for children with DDs; and understanding the impact of complex, historical trauma (associated with heterosexism, cisgenderism, homophobia, biphobia, transphobia, genderphobia and multiple, intersecting forms of oppression) on LGBTQ-parent families and how to provide and refer to culturally-specific support resources.

## Conclusions

This research challenges the maternal and child health field and its policies and programming for children and youth with special health care needs to expand beyond serving heterosexual, cisgender, feminine presenting mothers to serve LGBTQ parents who may benefit from public health services for their children with DDs. This study also challenges

the field of LGBTQ health, which historically has focused on sexual health, suicide, and substance use prevention for single adults and youth identifying as LGBTQ, to incorporate the perspectives of LGBTQ parents and conceptualize LGBTQ adults as part of families with their children. Furthermore, this study informs intersectional diversity, equity, and inclusion initiatives within health, education, public health, and other child-serving systems.

This study provides evidence that some LGBTQ parents believe they have experienced HC bias and discrimination at least some of the time when accessing care for their children with DDs. More research is needed to better understand the interplay of the many factors affecting LGBTQ families' experiences and to inform the development and implementation of culturally effective interventions and practice changes. Health professions education and workforce development are needed to advance LGBTQ-family health equity and improve care for LGBTQ families with children with disabilities.

### STATEMENT OF IMPACT

This is the first national study of lesbian, gay, bisexual, transgender, and queer parents' experiences accessing health care for their children with developmental disabilities in the United States. Documenting parents' experiences of bias and discrimination while accessing their children's health care will help to identify culturally-specific interventions to reduce and eliminate disparities in care, including possible delays in developmental screening, diagnosis, and early intervention services, which is critical for optimizing children's health outcomes and reducing avoidable health care costs.

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