



# Health Care Bias and Discrimination Experienced by Lesbian, Gay, Bisexual, Transgender, and Queer Parents of Children With Developmental Disabilities: A Qualitative Inquiry in the United States



Emilee I. Coulter-Thompson, DrPH, LMSW, Derrick D. Matthews, PhD, Julia Applegate, MA, MPH, Sarabeth Broder-Fingert, MD, MPH, & Karine Dubé, DrPH, MPhil

## ABSTRACT

**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 disabilities in the United States, including the timing of developmental screening and diagnosis.

Emilee I. Coulter-Thompson, Manager, Research, Education, and Career Development, University of Michigan Institute for Healthcare Policy and Innovation, Ann Arbor, MI

Derrick D. Matthews, Assistant Professor, University of North Carolina at Chapel Hill, Gillings School of Global Public Health, Chapel Hill, NC

Julia Applegate, Senior Lecturer, the Ohio State University, Columbus, OH

Sarabeth Broder-Fingert, Associate Professor, University of Massachusetts Chan Medical School, Worcester, MA

Karine Dubé, Assistant Professor, University of North Carolina at Chapel Hill, Gillings School of Global Public Health, Chapel Hill, NC

Conflicts of interest: 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 her Doctor of Public Health (DrPH) dissertation research at the University of North Carolina Gillings School of Global Public Health. In 2020, she received a speaker honorarium

for presenting the literature review. Finally, 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 have no conflicts of interest to disclose.

Correspondence: Emilee I. Coulter-Thompson, DrPH, LMSW, University of Michigan Institute for Healthcare Policy and Innovation, 2800 Plymouth Rd., North Campus Research Complex, Bldg. 16, Ann Arbor, MI 48109.; e-mail: [eit@umich.edu](mailto:eit@umich.edu). *J Pediatr Health Care.* (2023) 37, 5-16

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**Method:** We conducted semistructured interviews with 16 LGBTQ parents of children with developmental concerns or disabilities recruited through a prior national survey. Interviews were transcribed and analyzed using a combined inductive and deductive approach.

**Results:** Discrimination types reported included noninclusive forms, disclosure challenges, and providers dismissing nongestational parents and diverse families. Few parents reported screening and diagnosis delays. Parents' recommendations included: avoiding assumptions, honoring family diversity, increasing LGBTQ family support, improving HC forms, increasing antibias training, and convening a learning community.

**Discussion:** Our study advances the knowledge around HC bias and discrimination among LGBTQ parents of children with disabilities. Findings highlight the need for increased LGBTQ-affirming family support and research representing LGBTQ family diversity in U.S. health care. *J Pediatr Health Care.* (2023) 37, 5–16

## KEY WORDS

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

## INTRODUCTION

Lesbian, gay, bisexual, transgender, and queer (LGBTQ) parents experience structural bias and discrimination when accessing care for their children in health care (HC) and early childhood systems (Coulter-Thompson, 2022). For children with developmental disabilities (DD) in LGBTQ families, this bias and discrimination may increase barriers to care (i.e., delayed developmental screening, diagnosis, and early intervention). Early identification and treatment of DDs are important for improving health outcomes and school

readiness because young children's brains develop rapidly from birth to 5 years old, and early childhood represents the optimal timing for transformative treatment (Shonkoff, Boyce, & McEwen, 2009). Timely screening, diagnosis, and intervention are critical for optimizing children's long-term health outcomes and reducing avoidable HC costs (U.S. Department of Health and Human Services and U.S. Department of Education, 2016).

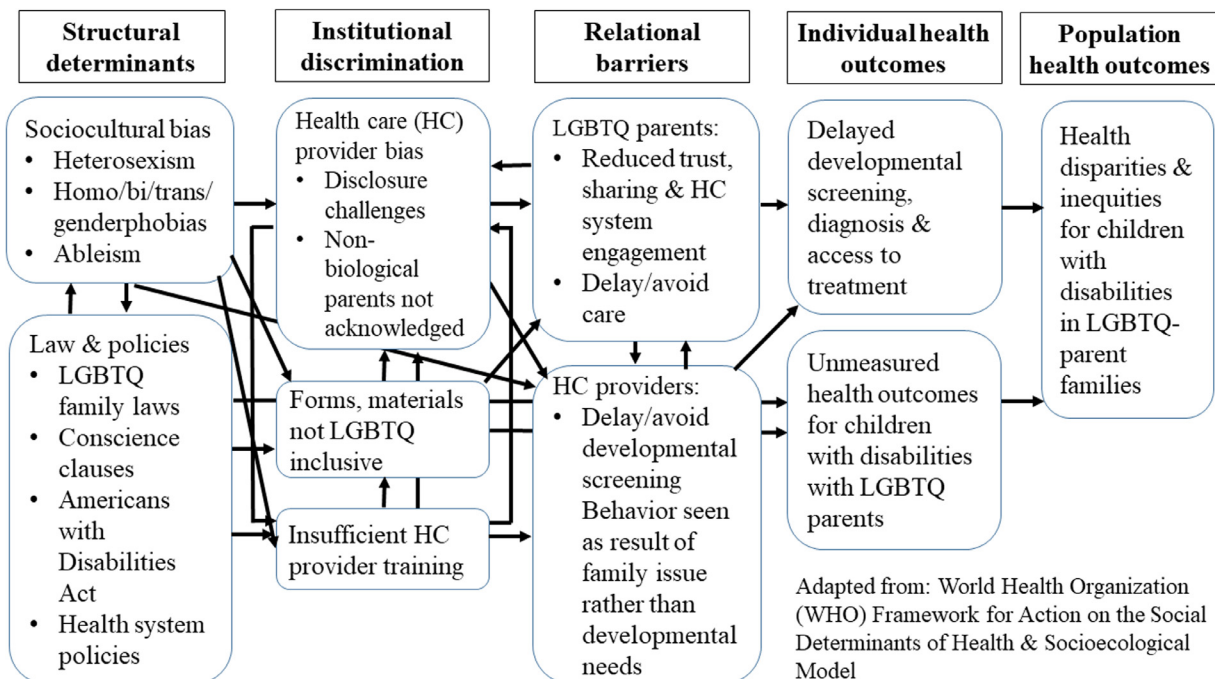
Among children in general, fewer than half of DDs are identified by the time of entering kindergarten, despite many children being in child care and preschools before entering school (Boulet, Boyle, & Schieve, 2009). Families marginalized by race, ethnicity, language, sexual orientation, or gender identity experience a higher risk of delays in their children's DD screening and diagnosis (Bishop-Fitzpatrick & Kind, 2017; Kendall & Hatton, 2002). Because of a paucity of research and limited HC data collected on sexual orientation and gender identity, the impact of bias and discrimination on children's health outcomes in LGBTQ-parent families remains unknown.

This study aimed to (1) explore the impact of HC bias and discrimination on LGBTQ parents and their children with disabilities in the United States, (2) explore parents' perceptions of how bias and discrimination affected their children's DD screening and diagnosis, and (3) identify parents' recommendations for change.

## METHODS

This study employed a transformative worldview to give voice to marginalized populations (Mertens, 2007). The study design and methods were inspired by a conceptual

**FIGURE 1. Study conceptual model**



model adapted from the World Health Organization Framework for Action on the Social Determinants of Health and the socioecological model (Figure; 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 HC providers, which may lead to negative health outcomes (Figure).

We administered a survey and interviews in 2 phases using a sequential, explanatory design (Creswell & Creswell, 2018). The University of North Carolina Institutional Review Board approved all procedures (study no. 20-2988). We first implemented a survey via Qualtrics (Provo, UT) measuring 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 (results reported separately). The survey was distributed using a convenience sample, online networks such as Facebook groups for LGBTQ parents, parents of children with disabilities, and listservs and newsletters from LGBTQ and disability organizations. To be eligible for the survey, participants had to self-identify as an LGBTQ-parent of at least one child with developmental concerns or disabilities living in the U.S. Survey participants completed informed consent embedded in the survey and indicated their willingness to participate in a separate interview by providing their contact information.

Survey results informed interview question development and recruitment. The interview guide (Supplementary Box) was refined and finalized on the basis of the survey results and tested with mock interviews with LGBTQ and heterosexual, cisgender parents of children with disabilities before launch (Supplementary Box). Semistructured individual interviews occurred in September and October 2021 and lasted 30–60 minutes. The principal investigator conducted all interviews in English using computer teleconference (Zoom). All interview participants completed a separate electronic informed consent form. Demographic data were extracted from the survey. The principal investigator introduced her positionality as a queer, cisgender parent and public health social worker with personal and professional experiences related to children with disabilities and health and early childhood systems. Participants were sent a brief resource list of support services after the interview.

### Data analysis

The qualitative data analysis was informed by Participatory Social Justice Theory and Queer Theory (Creswell & Creswell, 2018) and employed a combined deductive and inductive approach. Before coding the data, the principal investigator developed a priori codes on the basis of the aforementioned conceptual framework and themes from the literature.

Deidentified interview transcripts were analyzed using qualitative analysis software (MAXQDA) (VERBI Software, 2021, Berlin, Germany). The investigator applied the a priori codes to the first three transcripts and revised the list of codes accordingly as new themes emerged. The list of codes

was finalized after reviewing all 16 transcripts. A second researcher not involved in the interviews independently reviewed and recoded 10% of the transcripts to validate the coding with 95% interrater agreement. Discrepancies were resolved by discussion and consensus. The major themes were summarized, and direct quotes further illustrated the most common themes. All quotes were reported using pseudonyms to ensure participant confidentiality.

## RESULTS

### Participant Demographics

Of the 29 survey participants who indicated a willingness to be interviewed, 17 participants scheduled an interview, one participant canceled, and 16 (43% of the survey participants) completed an interview.

### Interview participant demographics

Interview participant demographics were similar to survey participant demographics (Table 1). Most parents were cisgender women (69%) who identified as lesbian (43%), queer (13%), or bisexual (13%). One participant identified as a gay male, and one identified as a transgender man. Parents resided in nine states: Kentucky, Maryland, Massachusetts, Michigan, North Carolina, Ohio, Oregon, Texas, and Wisconsin.

Most parents had a graduate (81%) or undergraduate (13%) degree and were White (88%), non-Hispanic (94%), and English-speaking (100%). Their children were more racially diverse. Three parents (19%) reported that their children were Black or African American. Three (19%) reported that their children were Multiracial or Biracial. The current age of their child, who was first identified to have developmental concerns or disabilities, ranged from 4 to 33 years. Nine parents (56%) said their child was ≤ 10 years or younger. Most parents said their child was first screened (81%) or diagnosed (75%) for DDs at age ≤ 5 years (Table 2).

Although parents were not asked to report their profession or relationship status, 15 parents discussed their profession, and most discussed their relationship status. Professions included: three health researchers, three early childhood educators, two nurse educators/researchers, two teachers, two public health professionals, one social worker, one physician, and one policymaker. Eight parents were currently married or lived with a long-term partner. Four parents were single parenting. Seven parents were divorced or separated from the partner they were with when their children were conceived or adopted.

Themes are grouped by study aim and summarized in Table 3.

### Aim 1: Bias and Discrimination

Parents reported various experiences seeking HC for their children with disabilities, from LGBTQ-affirming care to blatant bias and discrimination. Parents also shared examples of feeling safe with and validated by their children's HC providers and inclusive encounters in which providers used

**TABLE 1. Participant demographics semistructured interviews (United States, 2021)**

Demographics	Survey participants (n = 37 unless otherwise listed)	Interview participants (n = 16)
Parent sexual orientation		
Asexual	1 (3)	0 (0)
Bisexual	5 (14)	2 (13)
Gay	3 (8)	1 (6)
Lesbian	16 (43)	10 (63)
Queer	5 (14)	2 (13)
Multiple identities or another identity not listed	7 (19)	1 (6)
Parent gender identity		
Cisgender man	4 (11)	2 (13)
Cisgender woman	25 (68)	11 (69)
Transgender man	1 (3)	1 (6)
Transgender woman	0 (0)	0 (0)
Multiple identities	5 (14)	1 (6)
A gender not listed	2 (5)	1 (6)
Assigned sex at birth		
Female	33 (89)	14 (88)
Male	4 (11)	2 (13)
Intersex	0 (0)	0 (0)
How became a parent		
Carried	15 (41)	8 (50)
Partner carried	3 (8)	1 (6)
Marriage/step-parent	0 (0)	0 (0)
Foster parent	8 (22)	2 (13)
Adoptive parent	7 (19)	4 (25)
Specify: Foster care to adoption	2 (5)	1 (6)
No. of children		
1	15 (41)	5 (31)
2	15 (41)	9 (56)
3	6 (16)	2 (13)
> 3	1 (3)	0 (0)
Household language	n = 35 (95)	
English	35 (95)	16 (100)
Spanish	0 (0)	0 (0)
Specify	0 (0)	0 (0)
Hispanic, Latino or of Spanish origin	n = 34 (92)	
No	32 (86)	15 (94)
Yes	2 (5)	1 (6)
Parent race	n = 35 (95)	
American Indian or Alaska Native	0 (0)	0 (0)
Asian	0 (0)	0 (0)
Black or African am.	1 (3)	1 (6)
Native Hawaiian or Pacific Islanders	0 (0)	0 (0)
White	32 (86)	14 (88)
Multiracial/biracial	2 (5)	1 (6)
Child race	n = 35 (95)	
American Indian or Alaska Native	0 (0)	0 (0)
Asian	0 (0)	0 (0)
Black or African am.	7 (19)	3 (19)
Native Hawaiian or Pacific Islanders	0 (0)	0 (0)
White	21 (57)	10 (63)
Multiracial/biracial	7 (19)	3 (19)
Education	n = 35 (95%)	
Less than high school	0 (0)	0 (0)
High school graduate	1 (3)	0 (0)
Some college	1 (3)	1 (6)
Undergraduate degree	7 (19)	2 (13)
Graduate degree	26 (70)	13 (81)
Prefer not to answer	0 (0)	0 (0)
U.S. Region	12 states represented	9 states represented
Mid-Atlantic	3 (8)	1 (6)
Midwest	10 (27)	6 (38)
Northeast	3 (8)	0 (0)

(continued)

**TABLE 1. (Continued)**

Demographics	Survey participants (n = 37 unless otherwise listed)	Interview participants (n = 16)
Northwest	14 (38)	6 (38)
Southeast	6 (16)	2 (13)
Southwest	1 (3)	1 (6)

Note. Values are n (%).

gender-neutral language and asked their pronouns. Parents described proactively selecting their child’s HC providers and ensuring their providers were LGBTQ-inclusive. Parents indicated that when they ventured beyond seeing their child’s primary care providers when referred to specialists for their child’s developmental concerns or visiting the emergency room, they were more likely to feel uncertain about providers’ levels of LGBTQ inclusivity and to encounter challenges in discussing their LGBTQ family and identities.

**Health care forms**

All 16 parents cited examples of encountering forms not inclusive of LGBTQ-parent families or diverse family structures, including foster care, adoption, and multiracial or blended families:

Lots of times there’s just male or female or mother and father... there isn’t another option. That’s really hard because we don’t see ourselves reflected in the paperwork... I’m an afterthought... not good enough to make the template. (Mona)

Parents reported that forms ask for marital status but not the parents’ sexual orientation or gender identity. Some parents’ LGBTQ identities were invisible if they presented as single parents or with a partner who appeared to be of a different sex. A trans male parent with a female partner stated:

If my genderqueer identity were a little bit more prominent, or if I started using they/them pronouns... I would be up a creek. There’s no allowance for those identities on the forms that I’ve seen... we’re always assumed to be straight. Even my wife doesn’t identify as straight. (Darren)

Parents also discussed instances when providers did not read the paperwork and made incorrect assumptions about the sexual orientation, gender identity, or pronoun usage of a parent or child, which had to be corrected at the start of the visit, creating awkward first impressions.

**Disclosure**

Eleven parents discussed challenges disclosing or discussing their LGBTQ-parent identity with their children’s HC providers. Most parents reported being out and feeling comfortable discussing their identity with providers.

Eight parents described times when HC providers were noticeably uncomfortable when LGBTQ identity disclosure came up. For example, a gay father described being assumed as heterosexual by a pediatric specialist. When he corrected the provider:

He just turned red. You could see the discomfort... I’m here for my child. I don’t have the time to deal with your stuff. At the same time, I was having feelings about what just occurred. I needed to focus and be present for my child. We saw him two other times after that... He never did say, “Oh my goodness, I’m really sorry. I should not have made that assumption.” (Anthony)

Some parents discussed being selective in their disclosure with their children’s HC providers. “... it definitely is present to mind: Do I need to hide who I am so that I can get the best [care] for my kids?” (Mona)

Seven parents discussed proactively disclosing their identities with their children’s HC providers to assess providers’ LGBTQ inclusivity or informing providers about their families to prevent awkward encounters or ensure all parents were recognized.

**TABLE 2. Child ages of first concern, screening, and diagnosis (United States, 2021)**

n = 16 (Child age, years)	Child first screened				Child first diagnosed			
	Not screened	0–5	6–10	> 10	Not diagnosed	0–5	6–10	> 10
First concerned about child								
0–5	0	13 (81)	2 (13)	0	2 (13)	12 (75)	1 (6)	0
6–10	0	0	1 (6)	0	0	0	1 (6)	0

Note. Values are n (%).



**TABLE 3. Aims and themes from semistructured interviews (United States, 2021)**

Theme	Description	Representative quotes
Aim 1: the impact of health care (HC) bias and discrimination on LGBTQ parents and their children with disabilities in the United States Forms not inclusive	Forms were designed for heterosexual, cisgender parent families and did not allow space for LGBTQ-parent families to identify themselves without changing form fields	"I have to cross out things to fill this out accurately. . . at that point there's already tension and anxiety. . . the doctors have been great, but these forms that are antiquated don't account for families that are outside of the heterosexual norm." (Anthony)
Disclosure challenges	Parents experienced challenges disclosing or discussing their sexual orientation or gender identity with health care providers (HCPs), including providers' discomfort, proactive and selective disclosure approaches, and the impact of disclosure tension on their children	"[We've been] really upfront [in saying] 'We're a two-mom family, this is what we're looking for' . . . just so that if we got a weird vibe, it happened immediately, and so we didn't end up [working with that provider]." (Lila) "Unless I get an indication that there's some sort of allyship there, or that the person is LGBTQ themselves, I don't bother [disclosing]." (Darren)
Nongestational parents and family diversity dismissed	Nongestational parents, adoptive parents, and gender diverse parents reported being dismissed by providers or questioned about the legitimacy of their parental relationship with the child	"My wife was asked to leave visits a couple times because they said, 'it's really important that just the parents are here.' That was particularly difficult for her because she had tried to be a gestational parent a no. of times and was unsuccessful and, of course, when you're step-parenting it's always a little bit fraught with what is my relationship to these kids. . . It was infuriating for me, and it confused the kids." (Beth)
Discrimination overall	Some parents described examples of how anti-LGBTQ bias and discrimination affected the care they received for their children with disabilities and their fears of being discriminated against in HC settings	"I think (anti-LGBTQ bias and discrimination) has been the primary force behind the way (our son was) evaluated (for developmental disabilities), if at all, and their assessment of him, very clearly. (Alice) ". . . even if somebody is nice, do they have this belief that there's something wrong with me or that I'm not a good parent? And does that affect what's happening? I have no evidence of that. . . But I do worry about it, and I have for years." (Cassie)
Aim 2: Parents' perceptions of how bias and discrimination affected their children's screening for, and diagnosis of, developmental disabilities Perceived delays	Some parents believed that being an LGBTQ-parent family contributed to delays in their child's screening or diagnosis. Others did not think it contributed to delays	"It took us forever to have [our ten year old son] diagnosed with ADHD. I was advocating, saying 'this is not normal, something's wrong, what do we need to do?' . . . if we weren't a queer family, those concerns maybe would have been addressed sooner. . . maybe [the delays were due to] a combination of [me] being a [gay male parent] and someone who identifies as African American." (Anthony)
Aim 3: Parents' recommendations for improving care Avoid assumptions and honor family diversity	HCPs need to ask open-ended questions, believe and affirm LGBTQ parents, listen to LGBTQ families without judgment, and honor family diversity in many forms	"Families are different. So do not assume that you know there's a mother and a father, that that's the default, or that anything outside of that means there's something wrong, something's broken." (Anthony) "Believe what we tell you. When I tell you that these are my children, and this is my partner, there is no other question. I just told you what our reality is, and now it's your turn to take that and move on." (Mona)
Increase support for LGBTQ families		

(continued)

**TABLE 3. (Continued)**

Theme	Description	Representative quotes
Improve forms and materials	<p>LGBTQ-specific and LGBTQ-affirming services are needed to support parents throughout the life span, from their child's first diagnosis to transition to adulthood and to address intersectional support needs</p> <p>HC forms, program materials used for disability assessments and services, and marketing campaigns need to be more inclusive of LGBTQ family diversity</p>	<p>"My wife and I were distraught when our son was diagnosed, not because he had autism, but because it's another thing in his life that he has to explain or that he has to overcome because he already has two same-sex parents, he has one BIPOC [Black, Indigenous, Person of Color] parent, one White parent. And now he has to explain his autism on top of that. . . it's another challenge for him to own. Because we check all the boxes. . . Support is always good. Support is what keeps a family going." (Keisha)</p> <p>"There's just no reason for forms to make any assumptions about what the constellation of a family is, and if they really want to understand a family's functioning, if that's part of what the assessment is, then they need to do a full scan. . . if it was looked at as not just an accommodation of LGBTQ, but really trying to understand who parents kids and who needs information that has to do with the disability and in what context do they need it, after-school care, or whatever the thing is." (Paula)</p>
Increase antibias training and education	<p>Training and education could help HCPs to examine implicit biases, learn about LGBTQ family diversity, and improve care for LGBTQ families of children with disabilities</p>	<p>"Really work on any kind of internal bias. Prioritize using neutral language and valuing what that family relationship is, just how you treat all the families, the same. Take everybody's concerns as seriously, no matter what, or who it's coming from." (Cassie)</p>
Interest in learning about a multistakeholder learning community	<p>Parents shared whether they would be interested in learning more about a learning community of LGBTQ parents, HCPs and researchers to improve care for children with disabilities in LGBTQ families</p>	<p>"Connecting with others who have experienced these issues, barriers, complications, or frustrations is always good to know that you're not alone in it. . . I'm not sure that [HCPs] are always aware of [their biases]. I think it would be really powerful for them to hear our stories and to see where we interact with the systems and where we feel excluded." (Mona)</p>

"Because they don't have it on the forms, because [the forms are] not viewed at all, I'm going to inform them every time they walk in the room now." (Dawn)

Parents differed in the extent to which they felt disclosure was necessary or relevant to their children's care. Disclosure dynamics sometimes differed for each parent on the basis of their gender presentation, their partner's gender identity, or whether they went to their child's HC visits together or separately. Some parents described the impact on their children when disclosure conversations were stressful and the risks of disrupting care and upsetting their children if they confronted providers who referred to their families incorrectly.

### **Nongestational parents or diverse family constellations dismissed**

Ten parents described times when a nongestational parent or their family constellation was dismissed by HC providers. Some adoptive parents discussed having more challenges

surrounding the adoptive parent relationship and being questioned about whether they were the "real" parents. A provider asked one lesbian parent, "what's your relation?" to the child. When the parent responded that she was the child's adoptive mother, the parent could tell that there was:

... something [the provider] didn't like about it... [the provider was] making sure that I am authorized to do things, but I was really put off by that... I didn't like that more for the adoptive piece... it can be embarrassing to [my son] and it's kind of embarrassing to me. (Jenna)

One lesbian adoptive parent who identified as nonbinary/genderqueer/gender nonconforming stated: "[I've experienced discrimination] because I'm seen as a man or more man like. So, my opinions and my thoughts are not valid... I'm just dismissed." (Dawn)

Parents also cited sexism as a reason providers dismissed them (e.g., providers assumed gay fathers lacked parenting

knowledge or minimized queer women's concerns about their child's behavior).

### Discrimination overall

When asked if they thought being in an LGBTQ-parent family had affected the care they had received, if at all, for their child's developmental concerns or disability, 11 parents felt that their identity had affected the HC in some way, whereas five parents did not. Examples of how their identity had affected the care were consistent with the themes described above.

When asked if they had ever experienced anti-LGBTQ bias or discrimination when getting HC for their children, 11 parents said no. Among the five parents who said yes, a few reported blatant examples of anti-LGBTQ bias and discrimination. A queer female parent from a Southern state reported accessing care at a rural pediatric practice whose founding physicians espoused homophobic beliefs about how gay couples should not raise children. A lesbian parent described the impact of discrimination on her children:

[Anti-LGBTQ discrimination did not prevent] me from accessing care, but in terms of feeling that our family is seen and recognized, yes... The issue of "who are your real parents?" became problematic for my kids because, like many autistic kids, they are very attuned to the emotional tenor of the room... one of the stereotypes that a lot of providers have for autistic kids is that they're oblivious to emotional tenor of the room, which is not in any way true...

One of my kids was so upset by [the question "who are your real parents?"] that she was actually not able to work effectively with the provider who had asked that. It's unfortunate because that was an SLP [speech language pathologist] who worked on pragmatic language skills which is hard to find. So, she was just not ever able to establish a therapeutic relationship with them, and when I asked her why later on, she said, well because she upset [my wife], and that was all she would say.

It's not just the harm that they're doing to my relationship with them as providers as their parents, it's also the harm they're doing to their own therapeutic relationship with my kid, and I don't think they get that at all. (Beth)

In addition, some parents described fears of being discriminated against for being LGBTQ.

### Aim 2 Themes: Impact on Screening and Diagnosis

Eleven parents reported that they did not think being an LGBTQ-parent family contributed to delays when their child was screened or diagnosed with DDs. Five parents believed that being an LGBTQ-parent family did contribute to delays in their child's screening or diagnosis. One lesbian mother (Alice) reported with certainty that she and her wife could not obtain an autism diagnosis for their son because of homophobic bias from the evaluators. The evaluators

told the parents that their son's anxiety was because the child was afraid of men because he did not have a father. The child's behavior was attributed to having two moms rather than a neurological condition that the mothers strongly believe their son has. The couple was never able to obtain a diagnosis after multiple attempts.

Another lesbian mother (Beth) believed "one hundred percent" that being an LGBTQ-parent family delayed her son's autism diagnosis. The parent reported that the evaluator said her son had an anxiety disorder because the mother was anxious from having recently divorced her son's father and married a woman. At first, the evaluator dismissed the mother's concerns about possible autism indicators. The mother persisted, and her son was eventually diagnosed with autism.

Parents shared a range of perceptions about the timing of their children's screening and diagnosis. A lesbian mother described wondering to what extent her queer identity influenced her son's diagnosis process:

It's hard. You don't know what you don't know. Maybe [providers] are not verbalizing that "we don't like you so we're not going to see you." I don't know why they kept telling us to wait [to get their son assessed for autism] when yet there's other kids that are diagnosed at a younger age. (Maria)

Among the parents who did not think being an LGBTQ-parent family contributed to delays, one parent (Cassie) said their concerns were "taken very seriously, and... [her son] had interventions very early." Another parent (Paula) who identified as lesbian and queer wondered if the process would have been faster if she had a heterosexual cisgender male co-parent: "You never know how that might have impacted things."

These parents' comments illustrate the subjectivity of the screening and diagnosis process, which depends on relative interpretations of children's behavior by providers and parents. Identifying clear trends is difficult because of the small sample size and only gathering the parents' perspectives.

### Aim 3: Parents' Recommendations to Improve Care

#### Avoid assumptions and honor family diversity

Twelve parents recommended HC providers avoid making assumptions about families, particularly around family structure and parents' sexual orientation and gender identity.

"Avoid assuming that every man and woman who comes through your door is a cisgender heterosexual couple." (Darren)

Nine parents discussed the importance of honoring family diversity in many forms, including families with two moms, two dads, children being raised by extended family members, and foster and adoptive families.



Parents also expressed wanting HC providers to believe what they share about their family. This came from parents' prior experiences of HC providers questioning their family structure in a way that the parents perceived as invalidating, challenging their parental relationship or role, or asking parents to prove the legitimacy of their relationships with their children.

### **Increase support to LGBTQ families with children with DDs**

Seven parents described the need for bolstering social and emotional support for LGBTQ-parent families with children with developmental concerns or disabilities throughout the child's lifespan, from the time of the first diagnosis to the child's transition into adulthood. Parents expressed wanting to join support groups specific to, or more inclusive of, LGBTQ parents and to meet families with similar experiences.

Some parents described discrimination in their families of origin that limited available support and necessitated more culturally-responsive resources. One gay father whose child required a full-time care provider stated:

[Having a child with disabilities] intensifies everything.. Family members can be judgmental because they don't understand the disability. They can blame... A lot of people need to blame somebody... So they might blame the problem the child is having on the LGBTQ relationship when they don't understand that the child would have this problem [regardless of the parents' relationship or family structure]. (Ken)

This parent recommended that HC systems provide increased support for families on receiving the child's diagnosis, especially if the child's developmental condition requires a high level of services.

It was really hard, because you just don't know what you're up against... education and access to immediate psychological and medical help in those first months and maybe years is critical for the health of the family, the individuals and everyone... It's treating the whole situation. Not just the child symptoms. Treating the environment, the parents, everyone around that. (Ken)

In addition, parents described that some of the existing supports for parents of children with disabilities are faith-based and not necessarily overtly inclusive of LGBTQ parents. One White queer mother who adopted an African American child shared challenges accessing support. She described applying to culturally-specific programs for foster children and not getting in.

I did often feel like we were being excluded from supports or conversely weren't a great fit for the support... It was hard to tell if it was because I was white, because we were queer, or because we were unchurched... the multiple layers of identity made it hard to feel like we found our people. (Paula)

### **Improve HC forms and materials to be more inclusive of LGBTQ families**

Six parents recommended improving forms, electronic health records, program materials, and marketing to be more inclusive of LGBTQ families. Multiple parents suggested that forms ask open-ended questions to allow families to describe themselves, including blended family relationships, sexual orientations and gender identities of the parents, caregivers, and children; how children refer to their parents and caregivers; foster care and adoption history, if applicable; and racial and ethnic backgrounds of the adults and children. One parent suggested reducing burdensome paperwork and repetitive storytelling about their child's history requested by parents of children with disabilities. Parents also mentioned the need for the program materials used during disability assessments and services, such as illustrated handouts, to reflect family diversity. One parent who is a HC provider emphasized the opportunity for HC organizations to do more inclusive marketing.

An LGBT parent already fears going to health care because of what they might face... A simple picture might provide reassurance to a parent, so [the health care organization] could bring them into this clinic or into this hospital and not delay their care... [Health care organizations] need to welcome the parent in order for the child to be seen. (Maria)

### **Increase antibias training and education**

In addition, some parents discussed the importance of HC providers doing their own work to examine internal biases regarding LGBTQ families. A few parents recommended that HC providers participate in training on implicit bias, LGBTQ family diversity, and how to work effectively with queer and trans parent families.

### **Learning community**

When asked if they would be interested in learning more about a learning community with other LGBTQ parents, HC providers, and researchers to help improve care for children with developmental concerns/disabilities who have LGBTQ parents, 10 parents said yes, four parents said maybe, and two parents said no. Several parents expressed high enthusiasm: "Of course. I need to advocate for my son as much as I possibly can. So, bring it on." (Keisha)

Parents who indicated maybe or no to learning about a learning community cited time constraints and having "bigger fires to put out."

### **Additional Themes**

Two additional themes emerged that were not part of the original study aims. Some parents, including parents of color and White parents of children of color, said that they felt race and racism impacted their HC experiences more than sexual orientation or gender identity.

Furthermore, 11 parents reported experiences of bias and discrimination in their children's education systems.

Some reportedly experienced more difficulties in education than HC.

## DISCUSSION

To our knowledge, this study provides the first insights into LGBTQ parents' experiences of bias and discrimination while accessing care for their children with DDs in the U.S., including instances contributing to delays in children's developmental screening and diagnosis (or nondiagnosis). The most commonly cited types of bias and discrimination were: (1) HC forms were not inclusive; (2) challenges disclosing or discussing family structure or identity, and (3) HC providers dismissing nongestational parents and diverse family constellations. These types of bias and discrimination are consistent with themes reported in prior studies of LGBTQ parents' experiences accessing HC for their children in and outside the U.S. (Andersen, Moberg, Bengtsson Tops, & Garmy, 2017; Bennett et al., 2017; Chapman et al., 2012; Chapman, Watkins, Zappia, Combs, & Shields, 2012; Chapman, Watkins, Zappia, Nicol, & Shields, 2012; Gibson, 2018; Kelsall-Knight & Sudron, 2020; Kerppola, Halme, Perala, & Maija-Pietila, 2019; McNair et al., 2008; Mikhailovich, Martin, & Lawton, 2001; Neville & Henrickson, 2009; Nicol, Chapman, Watkins, Young, & Shields, 2013; Perrin, Hurley, Mattern, Flavin, & Pinderhughes, 2019; Perrin & Kulkin, 1996; von Doussa et al., 2016). Similar barriers were first reported more than 25 years ago in a U.S. survey of gay and lesbian parents' experiences accessing children's HC (Perrin & Kulkin, 1996), indicating the slow pace of change. More recent qualitative studies with LGBTQ parents in Australia, England, Finland, and Sweden reported a similar mix of positive and negative HC experiences, including heteronormative HC provider attitudes and recommended provider training (Andersen et al., 2017; Chapman et al., 2012; Kelsall-Knight & Sudron, 2020; Kerppola et al., 2019; McNair et al., 2008).

This study's reported examples of providers misattributing children's developmental challenges to anxiety about their parent's sexual orientation are especially troubling and consistent with prior research with Canadian LGBTQ parents of children with disabilities that found "fatherless children" were pathologized (Gibson, 2018). Developmental evaluations are subject to the influence and biases of the HC providers conducting the evaluations (Zuckerman et al., 2017; Zuckerman, Lindly, & Sinche, 2015). If the trust between parents and providers or children and providers is inhibited by disclosure challenges, or parents feel obligated to continue seeing providers who are not fully inclusive (Gibson, 2018), then those dynamics could interfere with timely screening and diagnosis for the children of LGBTQ parents.

In this study, the diversity and complexity among LGBTQ-parent families made it difficult to tease out the impact of anti-LGBTQ bias and discrimination from other factors influencing their children's care (e.g., relationship status, family formation (i.e., insemination, adoption, etc.), family structure, and parents' race, education, profession,

socioeconomic status, children's specific developmental concerns) that also may have influenced how parents were perceived and treated by HC providers. The results may reflect participants' high education and resource levels (i.e., all or most had health insurance and lived in geographic areas with a choice of LGBTQ-affirming providers) and HC system navigation and advocacy skills.

## Implications

This study identifies several necessary improvement opportunities to ensure equitable, affirming care for LGBTQ-parent families. First, health systems must make long overdue changes to update HC forms, electronic health records, and materials to be LGBTQ-inclusive. The cumulative burden of repeated microaggressions of heterosexist, binary gender-centric forms is especially acute for parents of children with DDs who must complete voluminous intake forms and assessments with multiple HC providers and specialists to support their children's developmental needs (Gibson, 2018). Entering a new HC facility can be anxiety-provoking for any new patient and especially challenging for families experiencing multiple layers of stigma related to sexual orientation, gender identity, and disability (Nyblade et al., 2019; Turan et al., 2019). Inclusive forms are an immediate, positive signal to LGBTQ families that they are safe and welcome.

Second, health systems must ensure that LGBTQ parents have safe, validating, and affirming HC environments to describe their families and their children's developmental needs, especially during developmental evaluations and diagnosis when family stress is heightened (Stuart & McGrew, 2009). Ideally, HC provider relationships can be a refuge for parents to be vulnerable and receive the support vital for meeting the complex, ongoing parenting demands associated with caring for children's developmental needs. HC provider assumptions and dismissiveness only interfere with establishing trust and have a harmful impact on children in addition to parents. LGBTQ-specific health professions education and workforce development are needed to improve HC providers' skills and abilities in providing LGBTQ-affirming care.

Third, a multistakeholder learning community comprised of LGBTQ parents of children with DDs, HC providers, and researchers could employ a learning health system (LHS) approach (Friedman et al., 2015; Friedman, Rubin, & Sullivan, 2017; Platt, Raj, & Wienroth, 2020; Smoyer, Embi, & Moffatt-Bruce, 2016) to collaboratively identify research questions, accelerate continuous improvement, and improve health outcomes. An LHS defining feature is the coproduction model of collaboration, which positions all learning community members as equal partners who share power while working toward a common purpose of improving care together (Batalden et al., 2016). The model's success hinges on a key driver of informed activated families as partners and decision-makers, which goes beyond family engagement (Murray et al., 2019). Multiple pediatric learning networks affiliated with Cincinnati Children's Hospital (Billett et al.,

2013) have successfully implemented this model, including the Autism Learning Health Network (Murray et al., 2019). An LHS learning community for LGBTQ parents of children with DDs could create a collaborative partnership to improve children's health and surface stories about how bias and discrimination have affected children's access to timely developmental screening, diagnosis, early intervention, and treatment. Through collaborative learning, members could coproduce innovative solutions to inform future research and improve system coordination and timely access to care.

### Limitations

We must acknowledge study limitations. Qualitative interviews with a small convenience sample of majority White, English-speaking, highly educated health and education professionals did not capture all possible experiences. Gay, bisexual, and trans parents were underrepresented. Intersex, asexual, and agender parents were not represented. Parent participation may have been limited by the demands of caring for children with disabilities during the COVID-19 pandemic. This study may have underestimated the extent of anti-LGBTQ bias and discrimination against parents because of the small sample and selection bias. LGBTQ parents may have hesitated to participate or share sensitive information given the history of HC mistreatment and marginalization in their communities (Jennings, Barcelos, McWilliams, & Malecki, 2019; Romanelli & Hudson, 2017). Bias and discrimination might present a larger problem if this study were replicated with a larger, more diverse sample.

### CONCLUSIONS

This study advances the knowledge around bias and discrimination experienced by LGBTQ parents while accessing care for their children with DDs. Parents' HC experiences reported ranged from affirming to outright discrimination. Although some LGBTQ parents reported that this anti-LGBTQ bias and discrimination contributed to delays in their children's developmental screening and diagnosis, most parents believed that it did not. Parents reported the need for more LGBTQ-inclusive forms and affirming care and emotional support services that honor multiple forms of family diversity. Future research should examine the HC and education experiences of LGBTQ families with larger samples (more diverse with respect to parents' sexual orientation, gender identity, race, ethnicity, language, citizenship status, education, income, and geography) and compare them with heterosexual, cisgender parents' experiences to identify disparities and improvement opportunities. Studies should evaluate the implementation of updating LGBTQ-inclusive forms and electronic health records and convening an LHS learning community and measure the impact of health professions education and workforce development among HC providers, including pediatric nurse practitioners, on the effectiveness of LGBTQ-inclusive care. Findings could inform tailored interventions to advance LGBTQ family health equity and improve the health of children with disabilities.

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### SUPPLEMENTARY MATERIALS

Supplementary material associated with this article can be found in the online version at <https://doi.org/10.1016/j.pedhc.2022.09.004>.

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