Treat Us Like Humans: Lived Experience Solutions to Improve Health Care for Multiply Marginalized Children with Disabilities

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ABSTRACT

OBJECTIVE: Multiply marginalized children with disabilities experience discrimination and inequity and consequently disparities in access to health care, health outcomes, and mortality. We gathered information about the health care experiences of multiply marginalized children with disabilities to describe lived experience-based solutions for improving health care and outcomes for this population.

METHODS: A qualitative exploratory study using focus group and individual interviews with multiply marginalized young adults with disabilities and the caregivers of multiply marginalized children with disabilities in the United States and territories. We asked how services could be changed to better support their health and well-being using an initial deductive approach combined with ongoing inductive thematic analysis.

RESULTS: The study team conducted 5 focus groups and 4 individual interviews with 33 young adults and caregivers in English, Spanish, and ASL. Negative health care experiences include biased and discriminatory professional behavior, barriers to access, and the necessity and burden of advocacy. Proposed solutions focused on professional growth, mental health, disability-centered design, and lived experience leadership. An underlying sentiment was the desire for equitable treatment.

CONCLUSION: Advancing health equity for multiply marginalized children with disabilities is within reach. Starting points for health care professionals and system leaders include addressing biases and developing reflective and empathic practices and systems, including child and family mental health in care, and using disability-centered design to proactively and flexibly support access. Implementation should be done with lived experience leadership and the centering of human dignity for multiply marginalized children with disabilities and their families.

KEYWORDS: Children with disabilities; Health disparity; Health equity; Intersectionality; Marginalized populations; Multiply marginalized

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WHAT'S NEW

A diverse group of multiply marginalized young adults with disabilities and caregivers of multiply marginalized children with disabilities describe their health care experiences and the solutions they believe would improve health care and outcomes for multiply marginalized children with disabilities.

Health disparities are preventable differences in health outcomes that result from the many intersecting layers of inequity and discrimination that marginalized groups experience.[1] They are observed across populations, including but not limited to those marginalized by disability; race or ethnicity; socioeconomic status;

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immigration status; or sexual and gender identities.[2–5] The body of literature demonstrating health disparities for individuals with marginalized identities is growing, along with calls to address the causal mechanisms.[6–11]

Children with one or more marginalized identity in addition to disability, hereafter referred to as multiply marginalized children with disabilities, experience compounded marginalization due to discrimination and inequity associated with each identity, exacerbating health disparities.[4,8,12,13] Across pediatric settings, multiply marginalized children with disabilities experience disparities in access to health care, care quality, health outcomes, and mortality.[2,8,14–17]

Despite these deeply impactful disparities, there is limited research on interventions specific to improving the health of multiply marginalized children with disabilities. A global scoping review of health care for individuals with disabilities found that multiply marginalized groups were examined in over half of the studies on barriers (54.2% of 83 studies) but were not similarly represented in intervention studies (25.3% of 99 studies).[18] Respecting the "Nothing about us without us" tenet of disability advocacy, input from multiply marginalized individuals with disabilities is vital to designing interventions, policies, and programs that address the key issues influencing their health. As such, this study's objective was to gather information about the health care experiences of multiply marginalized children with disabilities and to describe lived experience-based solutions for improving health care and outcomes for multiply marginalized children with disabilities.

METHODS

This qualitative exploratory study used semi-structured focus group and individual interviews to collect young adult and caregiver solutions for improving health care and related services for multiply marginalized children with disabilities. The multidisciplinary research team included health care professionals (HCPs), academic researchers, individuals with disabilities, and caregivers. The team was deliberately constructed to include and center the lived experience perspectives of members with disabilities and other marginalized identities or circumstances.

Participants were 18 years of age or older, living in the United States and territories, able to communicate in English, Spanish, or American Sign Language (ASL), and self-identified as either the parents or caregivers of multiply marginalized children with disabilities (under age 26) or a multiply marginalized young adult with disabilities (age 18–26). The study was advertised with community organizations, HCPs, professional listservs, and social media groups that focus on pediatric disability or medical complexity. For example, complex care clinics, family advocacy organizations, and a private social media group for pediatric rehabilitation medicine physicians. Potential participants did not have a previous relationship with the study team and volunteered by completing a brief online screening questionnaire to provide contact information, experience with disability, and other potentially marginalizing identities or circumstances. We asked specifically about race, ethnicity, religion, sexuality, gender identity, immigration status, medical complexity, accommodation needs, and justice system involvement and asked participants to self-describe "other factors" that could lead to unfair treatment.

Study staff then used purposive, expert sampling to minimize sampling bias and maximize variation, choosing participants with a range of disability experiences and intersectional identities from many different recruitment sources.[19,20] To broaden accessibility, the study team communicated using the participant's method of choice and provided information in advance about procedures, expectations, flexibility in virtual platform, and choice of individual or focus group format, and used closed captioning, both voicing and displaying questions, and live ASL interpretation as needed. Disability was self-identified, and no disability type was excluded.

The interview guide, developed through an iterative process that included research team members with lived expertise, asked questions about programs and services that were supportive, fair, and easy to navigate and about how existing services could be changed to better support the health and well-being of multiply marginalized children with disabilities. Individual interviews were conducted by a single facilitator (VS or KF) and focus group interviews by a pair of facilitators (VS, DH, DC, and JR). Both used the same interview guide (Supplemental Materials) and lasted 90–120 min via Zoom. Individual interviews were conducted concurrently when a participant was unable to attend a focus group or requested an interview. The sessions were recorded and transcribed verbatim with identifying information removed. Participants completed a demographic survey via Qualtrics and were compensated with a $100 gift card.

Codebook development, the coding process, and data analysis used an initial deductive approach combined with ongoing inductive thematic analysis.[21] Deductive codes were written in advance based on the research question and interview guide, both of which were grounded in the team's lived experience and knowledge of relevant literature, and additional codes were added by consensus as new ideas emerged from the data. Each transcript was dual coded by two of five study team members (VS, KF, DC, JR, ZH) using Dedoose version 9.2.7. Spanish transcripts were coded in Spanish by bilingual, bicultural team members (VS, JR) who then collaboratively translated representative excerpts into English. Transcripts were re-examined as new codes were added. Consensus meetings were held to review and resolve discrepancies. Coded data were sorted and combined to create themes that represent coherent patterns in the data. Themes were further refined, defined, and named in a collaborative, iterative process that included peer debriefing with a collective of research colleagues (see Acknowledgments). Presented here are the themes most relevant to the health

Table 1. Participant Demographics

	Frequency	%
Caregiver participants	26	79%
Aged 32–60 years (average: 45.84, median: 47)		
Female/woman	25	96%
Minoritized race	13	50%
Hispanic or Latino ethnicity	7	27%
Participated in English	19	73%
Participated in Spanish	6	23%
Participated using American Sign Language interpretation	1	4%
Geographic region of the United States		
Pacific	5	19%
Mountain West	4	15%
Central	10	38%
Eastern, including Puerto Rico	7	27%
Young adult participants	7	21%
Aged 19–23 years (average: 21.57, median: 22)		
Female/woman	6	86%
Minoritized race	3	43%
Hispanic or Latino ethnicity	1	14%
Participated in English	6	86%
Participated using American Sign Language interpretation	1	14%
Geographic region of the United States		
Pacific	0	0%
Mountain West	1	14%
Central	1	14%
Eastern, including Puerto Rico	5	71%
Total participants	33	

care experiences and health outcomes of multiply marginalized children with disabilities.

The consolidated criteria for reporting qualitative research checklist[22] was used to guide study design and reporting, and the University of Pittsburgh Institutional Review Board determined the study to be of minimal risk and therefore exempt. No sensitive information was collected. All relevant study materials were translated into Spanish by a professional service.

RESULTS

Five focus groups and four individual interviews were conducted over a seven-month period in 2023 with a total of 33 diverse participants: seven young adults and twenty-six caregivers (Table 1). Nine transcripts resulted, six in English and three in Spanish. Forty-four multiply marginalized individuals with a wide array of disabilities and marginalizing circumstances are represented here either by themselves or by their caregivers, some of whom discussed experiences with multiple children (Table 2). No participants withdrew.

To improve health care and outcomes for multiply marginalized children with disabilities, participants described a wide range of influential factors. Although not specifically asked to share negative experiences, these were discussed extensively to frame the problems and contextualize the proposed solutions. Thus, the resulting seven themes are divided into two groups: Negative health care experiences that impact care and lived experience-based solutions for improving health care and outcomes. Negative experience themes include (1) biased and discriminatory HCP behavior, (2) access barriers that are compounded by marginalization, and (3) the necessity and burden of advocacy. Participants proposed solutions they believed would alleviate the impact of these negative experiences and promote health equity. These include (4) develop reflective, teachable, and empathic practices and systems, (5) include mental health and well-being in care, (6) practice disability-centered design, and (7) foster lived experience leadership and collaboration (Table S1). Unifying and underlying all themes is the desire for multiply marginalized children with disabilities to be seen and treated as humans with inherent value and dignity: "*It's*

Table 2. Multiply Marginalizing Identities and Circumstances of the 44* Children and Young Adults Represented

	Frequency	%
Disability type		
Physical *(For example, being weak, having trouble moving around)*	17	39%
Cognitive/thinking *(For example, an attention, memory, or problem-solving disability)*	24	55%
Sensory *(For example, a vision or hearing related disability)*	22	50%
Mental or behavioral health *(For example, depression, bipolar disorder, anxiety, etc.)*	14	32%
Intellectual or developmental *(A disability you were born with that is diagnosed before age 18)*	28	64%
Other	6	14%
Other marginalizing identity or circumstance		
Minoritized race	26	59%
Household poverty†	22	50%
Single parent household	15	34%
Hispanic or Latino ethnicity	10	23%
LGBTQ+	10	23%
Immigrant	6	14%
Foster care involvement	6	14%
Religious beliefs outside of Christianity	2	5%
Juvenile justice system involvement	1	2%
Total represented individuals	44*	

* Certain caregiver participants discussed experiences with multiple children, bringing the n from 33 to 44

† Experiencing at least one poverty metric such as not being able to pay utility or mortgage bills, food insecurity, or qualifying for certain government assistance programs

Table 3. Negative Health Care Experiences that Impact Care (themes 1–3), Representative Excerpts*

Theme 1: Biased and Discriminatory Health Care Provider Behavior	
1.0	I think having a single mom really impacted it because they didn't really take either of our opinions into account when treating me. It was just kind of, "Oh, you're a female, you're always at work, how do you know what's really going on with your daughter?" And then when they'd ask me, it was, "Oh, well, you're a little kid. How do you actually know what's going on with yourself?" But I think a third factor that really played into it would be, I've been plus-sized my entire life and having every single doctor, even though I have a brain abnormality, having every doctor tell me, "Oh, it's related to your weight." […] I don't think a seizure is related to my weight. (Young adult, FG6–3)
1.1	We're [already] not getting the best services just because we have kiddos and adults and family members who have disabilities. But if you add race into it, […] when it comes to accessing services for my son, when I was accessing services along the way, one of the challenges was stigma. (Caregiver FG3–5)
1.2	Was it my behavior, my family's behavior, my color? I would not know how to answer you that, but I can tell you one thing: it was the lack of respect, the ignorance of that person, […] of the two medical providers who had that behavior. I will tell you if it was because of my color, my size, […] I do not know. I can communicate very well in English. I do not know if it was because he did not like my accent. I could not answer you, but I could tell you that that happened to me. (Caregiver FG4–2, translated from Spanish)
	¿Fue mi comportamiento, el comportamiento de mi familia, mi color? No te sabría contestar eso, pero sí te puedo decir una cosa, que fue la falta de respeto, la ignorancia de esa persona […] de los dos proveedores médicos que tuvieron ese comportamiento. Yo contestarte si fue por mi color, por mi tamaño, […] Yo no sé. Yo me puedo comunicar muy bien en inglés. Yo no sé si fue que no le gustó mi acento. No te podría contestar, pero sí te podría decir de que eso me sucedió. (Cuidadora FG4–2)
1.3	If I've been treated this way in this space, or I've experienced medical gaslighting and things like that, […] I don't really want to go back and kind of see if that's going to happen again with another provider. So that's another thing too, to take into account, […] it can affect continuance of care. And that can be really dangerous. (Young adult FG6–7)
1.4	I try to be more passing [as a cis woman] because I want to […] receive better care. […] So I try to be more passing so I can have better quality care as a passing, [or] looking like a cis woman, as compared to having a trans identity. (Young adult, II8–2)
Theme 2: Access barriers are compounded by multiple marginalization	
2.0	My God, I spend hours on the phone and the biggest thing that I hear in my area is, "We're not accepting new patients," or, "We're not accepting insurance." […] I swear, there comes a point when you are so tired of fighting for your kid. And it never stops. It's every single day. […] It's just this patchwork hell to get through [this system]. […] There's days I sit down and I'm just like, there's a 12-month wait list. I feel like 10% of his childhood is gone before I can get an appointment for appropriate care. And that's common. (Caregiver FG3–11)
2.1	But a lot of parents, like multiple people have said […] don't have time to spend 12 hours a day on the phone. And it's exhausting. It's exhausting to make all the phone calls and to schedule all the appointments, and then on top of that, you have to work your work schedule around your appointment schedule and your therapy schedule. (Caregiver FG3–10)
Theme 3: The necessity and burden of advocacy	
3.0	My son has the rights he has, for the simple fact of being alive. Just because he's alive, my son has the same rights you have, the same rights I have, the same rights everyone has. […] You do not have to love him, you do not have to like me, but give me what my son is entitled to for the simple fact of being alive. […] Because we all need the same things. […] The same needs, the same rights, because he is alive, because he is a human being like you and like me. (Caregiver II9–2, translated from Spanish)
	Mi hijo tiene los derechos que tiene, por el simple hecho de estar vivo. Solamente porque está vivo, mi hijo tiene los mismos derechos que tienes tú, que tengo yo y que tenemos todos […] No tienes que quererlo, no tienes que gustarme, pero dame lo que mi hijo tiene derecho por el simple hecho de estar vivo. […] Porque todos necesitamos lo mismo […] Las mismas necesidades, los mismos derechos, porque está vivo, porque es un ser humano como tú y como yo. (Cuidadora II9–2)
3.1	Advocacy really gets tiring. And, well, you can find yourself with security near. […] I think that, especially if you come packaged in a certain way, that if you tell a doctor, "It's not going to be that way. It's going to…" suddenly there's a threat. […] What I'm getting at is that there are some people that walk more of a tightrope, and it's something that is just part of reality. […] It's not written that way or anything, but it was written that way at one time, and so it has a lingering effect. (Caregiver FG3–6)

* Additional supporting excerpts are provided in Supplemental Table 2

human rights. We're human and we want to be treated like humans. We want equal rights and we deserve that" (Caregiver FG2-6). Representative excerpts are referenced below and reported in Tables 3 and 4 and S2.

Negative Health Care Experiences that Impact Care

Negative experiences impact relationships with HCPs, create preventable barriers to care, contribute to poor outcomes, and provide context and justification for proposed solutions. Participants discussed these experiences as common and compounding. These themes are thus interconnected and interrelated, with one experience building on another to create magnified impacts.

Theme 1: Biased and Discriminatory HCP Behavior

Patient-HCP interactions were the most frequently discussed examples of negative health care experiences. Participants described how the behavior, attitude, and beliefs of a HCP negatively impacted their access to care, the timeliness of care, whether they sought or avoided care, and the overall experience of receiving care. HCP behavior was described as uncollaborative, disrespectful, uninformed, biased, judgmental, and unaccepting. Participants report that HCPs failed to understand their lives and circumstances and made inappropriate value judgements and assumptions. One caregiver described this as a "*shame layer"* that is added to their child's care (Table S2:1.0).

Table 4. Lived Experience-based Solutions for Improving Health Care and Outcomes (Themes 4–7), Representative Excerpts*

Theme 4: Develop Reflective, Teachable, and Empathic Practices and Systems	
4.0	One of the things that bothers me most is the discrimination against others based on their race, color, or economic status. Therefore, I would say that these are some of the fundamental issues the system must change in order to work with children with special needs. (Caregiver II5–2, translated from Spanish) Una de las cosas que más me molestan, que discriminen al otro por su raza, su color, su estatus económico. Entonces, yo diría que esas son unas de las cosas primordiales que tiene el sistema que cambiar para poder trabajar con los niños con necesidades especiales. (Cuidadora II5–2)
4.1	The unconscious bias that walks in the room with [a] provider. […] It's that unspoken curriculum that we, you know, feel more than anything. And then to address it, there may at times be hostility or, "No, I'm not that way," or, "No, I took this DEI training so I have it on the chart that I have a certificate." But when it comes to the actual in-practice piece, what you're bringing into the room is all of your generational history, as well as your education and your privilege. And being able to check it, whether you're aware of it or not, right? I mean, that's maturity, and that's real wisdom." (Caregiver FG1–9)
4.2	You were talking about this kind of societal factors that go into care for people that can't just be fixed in just a clinical pamphlet, right? […] I mean, obviously, we are in an age now where there are more bias trainings and […] different trainings on how to talk to people who maybe don't look like you or aren't from the same background as you, and I think that that's important. But I think it's also a willingness to learn and remaining teachable, and that can be difficult to instill in people. (Young adult FG6–7)
Theme 5: Include mental health and well-being as part of care	
5.0	I do think it's all interconnected. I think the being treated as a whole person has a stronger effect on the emotional and mental well-being, which then impacts the physical and all of the others. (Caregiver FG2–5)
5.1	And I say "Wait, wait, wait, wait. Has anyone talked to Mom?" "No, with mom no." Forget about the baby, forget about physical therapy, occupational therapy, latching, or WIC. Talk to Mom. How is Mom feeling? What is happening with Mom? Mom may be depressed, mom may be sad, mom may not be sleeping. Maybe mom does not have money for gas. Maybe mom does not have money to pay for parking. […] Or if she has to go to therapy, she has to be in therapy all morning and she does not have money to bring food for therapy. […] Ask her, but do not assume, and adapt to the family's needs. (Caregiver II9–2, translated from Spanish) Y yo digo "Espérate, espérate, espérate, espérate. ¿Alguien ha hablado con mamá?". "No, con mamá no". Olvídate del nene, olvídate del physical therapy, occupational therapy, del agarre o el WIC. Habla con mamá. ¿Cómo se siente mamá? ¿Qué está pasando con mamá? Mamá puede estar deprimida, mamá puede estar triste, mamá puede que no esté durmiendo. A lo mejor mamá no tiene dinero para la gasolina. A lo mejor mamá no tiene dinero para pagar el parking. […] O si tiene que ir a terapia, tiene que estar toda la mañana en terapia y no tiene dinero para llevar comida para la terapia. […] Pregúntenle, pero no asumamos, y adáptate a las necesidades de la familia. (Cuidadora II9–2)
Theme 6: Practice disability-centered design	
6.0	Well, I will say, in some cases, being treated differently […] is necessary and a good thing. […] Because if you just treat them [children with disabilities] like everyone else, I think that may be, in some cases, bad, if they need accommodations. So in some way, treating them differently is important, as long as it's not in a bad or discriminatory way. (Young adult II7–2)
6.1	Getting people who need those resources to be a part of the conversation is also incredibly important. […] A lot of the resources that they offer feel inaccessible as well and feel disconnected from my experience. […] So I just think having those things that may seem small to someone could be the difference between […] life and death for other people. Having telehealth services, […] having support groups that are telehealth or Zoom, whatever, things like that. (Young adult FG6–7)
Theme 7: Foster lived experience leadership and collaboration	
7.0	Include families in the decision-making. Include them in the entire process, listen to them, give them the opportunity to speak. […] At a table we have to have people with different points of view. […] If everyone at the table, we all see the same or talk the same or think the same, something is wrong at that table. At that table, there should be different colors, races, opinions, and ways of thinking. […] There has to be a mix, and we have to listen to all the points of view, even if we do not like them. Include us all, listen to us, and give us the opportunity, because we have a lot to say and a lot to contribute. (Caregiver II9–2, translated from Spanish) Eso, incluyan a las familias en la toma de decisiones. Inclúyanlos en todo el proceso, escúchenlos hablar, denles la oportunidad de hablar. […] En una mesa tenemos que haber personas con diferentes puntos de vista. […] Si todos en la mesa nos vemos igual o hablamos igual o pensamos igual, algo está mal en esa mesa. En esa mesa deben haber diferentes colores, razas, opiniones, formas de pensar. […] Tiene que haber una mezcla, y tenemos que escuchar todos los puntos de vista, aunque no nos gusten. Inclúyannos a todos, escúchenos, y dennos la oportunidad, porque tenemos mucho que decir y mucho que aportar. (Cuidadora II9–2)
7.1	When decisions are made, when work plans are made, everything. That families are included, because services are for families, so include them. (Caregiver II9–2, translated from Spanish) Cuando se toman decisiones, cuando se hacen planes de trabajo, todo. Que estén las familias incluidas, porque los servicios son para las familias, pues inclúyelos. (Cuidadora II9–2)
7.2	I would just want to feel more included in the decisions that would have to do with my health. And typically, when they [patients] are kids, they'll just go directly to the parent and say, "What do you think if we do this?" Well, it's not mom and dad living through the disability. It's me. I'm the one that has to wake up in the morning with back spasms and pain and have to figure out how to function. So I think finding that right balance of being able to connect with the kid, but also, since he is a kid, include the parents. So I think there has to be an equal balance of that because at the end of the day, it's not my parents that are going to be living with the disability for the rest of their life. It's me. (Young adult FG6–6)

* Additional supporting excerpts are provided in Supplemental Table 2

For some participants, negative interactions with HCPs felt clearly related to specific identity factors such as gender, race, socioeconomic status, or body size (Table 3:0.1–1.1, S2:1.1). For many others, the bias was obvious, but the identity factor that bias stemmed from was unclear and compounded by multiple possibilities

(Table 3:1.2). These negative experiences contribute to delays in care as participants sought to avoid repeated negative experiences (Table 3:1.3, S2:1.2) in a system where they do not see HCPs held accountable (Table S2:1.3–1.4).

Notably, participants recognized that certain more privileged circumstances alleviated these experiences (Table S2:1.5) while disadvantaged ones led to greater challenges. This created the additional burden of obscuring marginalized identities or creating the illusion of privileged identity in the hope of encountering less bias, getting better care (Table 3:1.4, S2:1.6), and avoiding blame for system failures (Table S2:1.7).

Theme 2: Access Barriers are Compounded by Multiple Marginalization

The health care system was repeatedly described as extremely difficult to navigate and not designed for the level of access that multiply marginalized children with disabilities often need. Participants described issues with physical access to services, interpretation, accessible transportation, long wait times, cost, and services available "only on paper" (Table S2:2.0). Inadequate care coordination support, limited or inflexible scheduling, gaps in insurance coverage, limited funding for needed programs, and few professionals with the expertise or demeanor to work with their children were also cited as barriers (Table 3:2.0, Table S2:2.1–2.3). Participants did not claim these things as unique to multiply marginalized children with disabilities, but rather as experiences related to the elevated utilization needs of childhood disability and compounded by additional marginalizing factors such as the need for translation or existence of provider and systemic bias. These negative experiences add up and the result, participants report, is that they *"spend a lot of time"* (Table S2:2.3) seeking appropriate care and are exhausted from the effort of addressing the sheer number of barriers they encounter (Table 3:2.1).

Theme 3: The Necessity and Burden of Advocacy

One caregiver shared that the medical system feels "*very much stacked against"* their multiply marginalized children and that it is "*very hard to cut a path for a child"* (Table S2:3.0). Another caregiver reported the many sources of bias and inequities experienced by multiply marginalized children meant that *"we had to learn to advocate very quickly"* (Table S2:3.1) to receive necessary care and services. Participants shared that they are endlessly advocating for equal treatment and recognition of the humanity of themselves and their children and that this advocacy is both burdensome and necessary (Table S2:3.1–3.2). They want HCPs to respect their children for the simple fact that they are human (Table 3:3.0).

When considering the intersection of oppressed identities, participants described what one caregiver called having to *"walk more of a tightrope"* (Table 3:3.1) in their disability-related advocacy because of their other identities. Advocacy efforts must be tailored to the situation because what might increase acceptance for one person could harm it for another. For example, participants acknowledged that the type and amount of speaking up for themselves or their children that they can do differs by marginalized factors such as gender, skin color, or socioeconomic status (Table S2:3.3–3.4). "Ev*erybody kind of lives by a different set of rules. It's just kind of the way it is"* (Table S2:3.5).

Lived Experience-based Solutions for Improving Health Care and Outcomes

Mitigating negative health care experiences and their impacts was discussed as foundational to improving health outcomes for multiply marginalized children with disabilities, and participants described solutions they believed would improve the health and well-being of multiply marginalized children with disabilities.

Theme 4: Develop Reflective, Teachable, and Empathic Practices and Systems

Solutions described by participants included obtaining relevant knowledge, self-reflection to examine biases that impact care, and growth of professional practice to integrate knowledge with interpersonal characteristics like humility and empathy. Participants discussed that they do not need HCPs to learn everything about every identity or disability. Rather, HCPs should obtain basic background knowledge about disability and other marginalizations and then listen to patients and families to learn about their experience (Table S2:4.0–4.3).

Participants told us that listening and the development of empathy is essential to delivering high quality care to multiply marginalized patients, and HCPs should learn how to approach individuals with experiences that differ from their own (Table 4:4.0–4.2, S2:4.2–4.4). Participants believe this requires active reflection on beliefs and behavior and maintenance of a growth mindset. They shared that they need HCPs who recognize that diversity trainings alone are not sufficient (Table 4:4.1–4.2), who are willing to consider errors in their practice, and who come with "*a willingness to learn and remaining teachable"* (Table 4:4.2). While there was wide agreement that this sort of socioemotional growth is an ongoing process and commitment and therefore not adequately addressed by training alone, one caregiver summed up what is needed as *"Give them get-it classes. Everywhere. Just education on how to approach a patient who is not from the same socioeconomic [background]. And what are your assumptions?"* (Table S2:4.5).

Theme 5: Include Mental Health and Well-being as Part of Care

As described by participants, the amplified effect of negative experiences and disparities for multiply marginalized populations contributes to a heavy emotional and mental load that impacts physical health. Both young adults and caregivers identified mental health as an important, interconnected health domain that is commonly absent or minimized in physical health care, particularly

for caregivers and siblings (Table 4:5.0–5.1, S2:5.0–5.1). They discussed that given this interconnection, HCP attention to their mental health impacts their overall health (Table S2:5.2–5.3) and, in the case of caregivers, also the health of their children (Table S2:5.4–5.6). Including mental health as part of care was described as asking specifically about the mental health and well-being of children and caregivers, validation of the emotional experience of disability and caregiving, and making appropriate referrals (Table 4:5.1, S2:5.0, 5.5–5.6).

Theme 6: Practice Disability-centered Design

The concept of disability-centered design was discussed as a means of improving care access via preemptive accommodations (Table 4:6.0–6.1). "*I think that accessibility should be considered the default, taking a disability-centered framework to make sure that accessibility is not an afterthought, but rather something that is built in from the beginning*" (Table S2:6.0). Accommodations are normalized, *"status quo,"* (Table S2:6.1) and the Americans with Disabilities Act, [the 1990 law prohibiting discrimination against people with disabilities], is *"not the ceiling, but it's actually just the floor. It's the minimum of what we should be asking for"* (Table S2:6.2). Examples of helpful, disability-centered design described by participants included availability of knowledgeable care coordinators (Table S2:3.0, 5.5, 6.3), proactive sharing of information on resources (Table S2:6.4), flexibility in service modality and scheduling (Table 4:6.1, S2:6.5–6.6), consideration of invisible disabilities (Table S2:6.7), and reduction of paperwork or procedural barriers (Table 3:2.1, S2:3.0, 3.6).

Theme 7: Foster Lived Experience Leadership and Collaboration

Participants recognized that experiential knowledge is important to improving systems for multiply marginalized children with disabilities and that being included in the decisions that impact them would improve outcomes. Leadership by or collaboration with individuals with lived experience is considered critical both in patient care and on committees, advisory boards, and other relevant decision-making bodies (Table 4:7.0–7.2, S2:7.0–7.1). *"At that table there should be different colors, races, opinions, ways of thinking. […] Listen to us, […] because we have a lot to say and a lot to contribute"* (Table 4:7.0). This was particularly relevant for multiply marginalized individuals who bring a unique perspective not commonly understood or represented. Participants believe HCPs have a role in creating a culture that invites and respects patient and caregiver input (Table S2:7.2) and inclusion of the child in shared decision-making during treatment was important from both the young adult and caregiver perspectives (Table 4:7.2, S2:7.1).

Discussion

This study contributes the voices of both multiply marginalized young adults with disabilities and of caregivers of multiply marginalized children with disabilities to existing literature on health disparities. These voices, often underrepresented in disability and health care research, described how the compounded effect of negative experiences adversely impacted their care and proposed solutions to alleviate these impacts. Biased and discriminatory HCP behavior was the most discussed source of negative health care experiences followed by the compounding of access barriers and the necessity of advocacy in obtaining care. Solutions proposed are actionable at individual HCP and systems levels. These include addressing personal biases and developing reflective and empathic practices, including child and family mental health and well-being in care, implementing disability-centered design, and fostering lived experience leadership and collaboration. Underscoring all these themes is the desire to be treated as human and the centering of human dignity for multiply marginalized children with disabilities and their families.

As framing and context for the proposed solutions, participants described many examples of inequitable treatment and disrespectful interactions with HCPs, which aligns with previous research.[23,24] Although any individual may have negative health care experiences, the frequency, intensity, and compounded accumulation of negative experiences like bias, discrimination, and inequity is likely unique to multiply marginalized individuals.[4,9–12,25] The interaction of disability with culture, stereotypes, or biased treatment results in a distinct experience for multiply marginalized individuals with disabilities.[2,4,25] Participants repeatedly discussed how their other oppressed identities negatively affected their health care experiences. From whether they received recommendations appropriate to their intersectional needs, whether they could advocate without fear of negative consequences, to whether they were viewed as a trustworthy informant. Participants reported experiences that led to delays in care in part due to patient and caregiver reticence to have another negative experience, and this connection between HCP behavior and health care access is reported in other studies.[2,24]

The type of HCP education and changes to practice that participants proposed as solutions to address biased HCP behavior are actionable at individual and systems levels. Participants recommended HCP training that increases knowledge of oppressed populations and encourages socioemotional growth, self-awareness of biases, and humility to adapt one's practice. The training components participants described align with adult learning theories and are applicable to existing health care education.[26] Given the limitations of a single training to change biases,[27,28] alternatives include training facilitators who can provide reflective, equity-related programming[28] and including multiple marginalization representation in existing programs. Options such as narrative medicine,[29] reflective practice in medical school curriculum,[30] and Schwartz Rounds[31] are promising methods for increasing compassion, reflecting upon biases, and considering alternative perspectives. Participants noted how certain

identities afford more or less privilege resulting in differing interactions with HCPs, thus training related to intersectionality remains important.[2–4,12]

As in other studies, mental health, especially caregiver mental health, was an important topic often missing from discussions with HCPs.[32,33] The strength of the connection described by participants between mental health and physical health suggests that physical health care is incomplete without consideration of mental health. Mental health screening is inconsistent in pediatric complex care,[34] and children with disabilities and their caregivers experience higher rates of mental health difficulties and barriers to accessing supports.[32,33] Due to the sensitivity of mental health information, integration with the other themes can guide implementation of mental health and well-being in care. For example, patient and family collaboration to develop mental health screening processes or HCP self-reflection to examine potential bias that may affect appraisal of mental health reporting.

LIMITATIONS

This study was designed to gather a broad array of ideas from a set number of participants with a wide variety of perspectives rather than exhaustive recommendations specific to identity intersections. Therefore, we did not expect data saturation[35] and are limited in what we can conclude regarding any specific intersectional identity. We did not collect insurance status and therefore did not capture concerns specific to those without health insurance. Our sample is majority female, which mirrors the population of caregivers for children with disabilities, but does not represent the male perspective. Finally, we did not collect rurality data and cannot draw conclusions about that important intersection. This project did not utilize and therefore cannot report on field notes, transcript return, participant checking, or data triangulation.

CONCLUSION

This study gathered information about the health care experiences of multiply marginalized children with disabilities and offered lived experience-based solutions for improving health care and outcomes. Participants described negative health care experiences that interact and build on each other, contributing to health disparities. They identified actionable solutions at individual and systems levels. These include addressing personal biases and developing reflective and empathic practices and systems, integration of child and family mental health and well-being into care, and use of disability-centered design to proactively and flexibly address access barriers. These findings both align well with existing literature on health disparities and also extend that knowledge to explicitly include multiply marginalized children with disabilities. They also suggest that solutions do not have to be novel or designed specifically for individual groups, but rather that targeted workforce development and disability-centered design can be impactful. Importantly, the adoption of new initiatives should occur in collaboration with those with lived experience as leaders in these endeavors.

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SUPPORTING INFORMATION

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